

Early Psychosis Project

Powered by Hope

First Episode Psychosis Programs

A Guide to State Expansion





National Alliance on Mental Illness

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ABOUT NAMI

NAMI, the National Alliance on Mental Illness, is the nation's largest grassroots mental health organization dedicated to building better lives for the millions of Americans affected by mental illness.

What started as a small group of families gathered around a kitchen table in 1979 has blossomed into the nation's leading voice on mental health. Today, we are an association of thousands of state organizations, local affiliates and volunteers who raise awareness and provide advocacy, education and support in communities across the United States.

ACKNOWLEDGEMENTS

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FACEBOOK: NAMI

TWITTER: NAMICommunicate

INSTAGRAM: NAMICommunicate

TUMBLR: notalone.nami.org ■ ok2talk.org

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INTRODUCTION

Welcome to NAMI's guide to expanding First Episode Psychosis (FEP) programs. NAMI believes that the roughly 100,000 youth and young adults who first experience psychosis each year deserve to realize the promise of hope and recovery.

Fortunately, research conducted by the National Institute of Mental Health (NIMH) shows that, compared to typical care, people with early psychosis who receive Coordinated Specialty Care in FEP programs (CSC-FEP) experience greater improvement in their symptoms, relationships and quality of life, are more involved in work or school and stay in treatment longer. Research also shows that the sooner people get CSC-FEP, the greater the improvements.

The NIMH-funded research on Coordinated Specialty Care set a new standard for treating first episode psychosis. Congress recognized the importance of this early intervention and now requires states to set aside federal Mental Health Block Grant (MHBG) funds to help expand FEP programs.

While FEP programs are growing, your advocacy is needed to speed the spread of programs in every state. NAMI created this guide to help NAMI State Organizations lead the charge. No group has more invested in the future of mental health care and this toolkit is designed to **equip you to ensure that every young person experiencing psychosis in your state receives quality FEP care.**

CSC-FEP programs



CSC-FEP is a team-based approach using shared decision-making and an array of person-centered services that help young people reach their recovery goals. Hope is at the heart of this work.

While not part of the NIMH-funded research on CSC-FEP, peer support services contribute to recovery and should be available in FEP programs.

The Research Base for First Episode Psychosis Programs

Early Psychosis

First Episode Psychosis (FEP) programs treat psychosis, which affects about 3 out of 100 people at some point in their lives.¹ 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.

With early treatment, some people never have another psychotic episode. For others, psychosis may be a recurring symptom of schizophrenia or another mental illness. However, even if they continue to experience symptoms, early treatment provides a foundation for recovery and a full life.

¹ McGrath, J et al. (2008, May 14). Schizophrenia: a concise overview of incidence, prevalence, and mortality. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/18480098>.

Recovery After an Initial Schizophrenia Episode (RAISE) project

The National Institute of Mental Health (NIMH) funded the Recovery After an Initial Schizophrenia Episode (RAISE) project to study coordinated specialty care (CSC) for youth and young adults with early psychosis. The research found that young people in CSC-FEP programs had greater improvement in their symptoms, stayed in treatment longer and were more likely to stay in school or working and connected socially than those who received standard mental health care.

The RAISE study and other research also showed that, like cancer, schizophrenia develops in stages.² Providing care at the earliest possible stage produces the best results. Too often, though, crises occur before people receive care. In the U.S., there is an average delay of 74 weeks from the time a person first experiences psychosis to when he or she receives treatment. Other countries have cut that delay to just 2 to 7 weeks. In order to achieve the promise of early intervention, it is vital to expand CSC-FEP programs and reduce the time from first psychosis to effective care.

The Business Case for First Episode Psychosis Programs

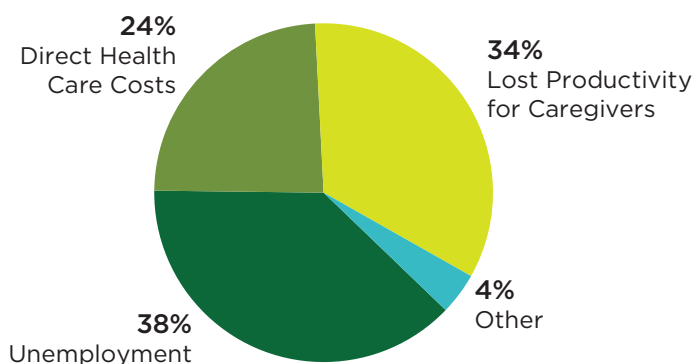
The High Cost of Schizophrenia

Schizophrenia, which is characterized by psychosis, usually begins between the ages of 16 and 30. People can and do experience recovery, yet many people get too little treatment, too

late. Inadequate and delayed treatment takes a heavy toll on individuals and families. It costs our economy an estimated \$155.7 billion a year in direct health care costs, unemployment and lost productivity for caregivers.³

Without CSC-FEP, treatment for psychosis often starts only after crises—frequently, long after the first episode and after disability has taken hold. At that stage, treatment is often limited to managing symptoms rather than promoting full recovery.⁴ Early intervention with

Cost of Schizophrenia



² Power point presentation by Robert Heinssen, Ph.D., Director of the Division of Services and Intervention Research, NIMH. Congressional briefing, October 2015.

³ Cloutier, et. al, The Economic Burden of Schizophrenia in the United States in 2013. *J. Clin. Psychiatry*, 2016 June: 77(6): 764-71. Doi: 10.4088/JCP.15m10278.

⁴ Power point presentation by Robert Heinssen, Ph.D., Director of the Division of Services and Intervention Research, NIMH. Congressional briefing, October 2015.



CSC-FEP is essential to move away from a costly, crisis-driven model to delivering effective recovery-oriented care that improves young lives and strengthens families.

CSC-FEP

Program Costs

In contrast to the high cost of delayed and inadequate treatment, well-established CSC-FEP programs estimate that it costs about \$1,200 per person per month, or \$14,400 per year, to provide coordinated specialty care.¹⁰ The cost of serving 35 young adults, a recommended program size, is \$42,000 per month, or about \$504,000 per year.

The RAISE study showed that while the cost for CSC-FEP was about 27% higher than the comparison treatment, it produced better clinical and quality of life outcomes, making it a better value. Importantly, the average annual cost of CSC-FEP care was lower than typical care for young people who received treatment earlier.¹¹

The costs of crisis-driven care for people with serious mental illness, including schizophrenia:

- Strained and high-conflict relationships
- Families left out of treatment planning
- High rates of school drop-out⁵
- High unemployment rates⁶
- High rates of homelessness (**26%**)⁷
- High rates of incarceration (**20%**)⁸
- High rates of suicide and early death (**10%**)⁹

The benefits of coordinated specialty care for first-episode psychosis (CSC-FEP):

- Reduced symptoms
- Improved quality of life
- Active engagement of family members
- Improved social and family relationships
- Higher rates of school completion
- Higher rates of employment

⁵ U.S. Department of Education. (2014). 35th Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2013. Washington, DC: U.S. Department of Education.

⁶ Luciano, A. & Meara, E. Psychiatr Serv. 2014 Oct 1; 65(10): 1201–1209. doi: 10.1176/appi.ps.201300335.

⁷ U.S. Department of Housing and Urban Development, Office of Community Planning and Development. (2011). The 2010 Annual Homeless Assessment Report to Congress.

⁸ Glaze, L.E. & James, D.J. (2006). Mental Health Problems of Prison and Jail Inmates. Bureau of Justice Statistics Special Report. U.S. Department of Justice, Office of Justice Programs Washington, D.C.

⁹ Hor, K et al. (2010). Suicide and schizophrenia: a systematic review of rates and risk factors. Journal of Psychopharmacology, 24 (4). Retrieved from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2951591/>.

¹⁰ Gonzalez, Goplerud, Shern. Coordinated Specialty Care – First Episode Psychosis Programs: Why specialty early intervention programs are a smart investment. Accessed online at http://www.nasmhpd.org/sites/default/files/Policy%20Brief%20Coordinated%20Specialty%20Care%20First%20Episode%20Psychosis%20Programs_0.pdf

¹¹ Rosenheck, R., et. al. Cost-Effectiveness of Comprehensive, Integrated Care for First Episode Psychosis in the NIMH RAISE Early Treatment Program. Schizophr Bull. 2016 Jul;42(4):896-906. doi: 10.1093/schbul/sbv224. Epub 2016 Jan 31.

Funding for First Episode Psychosis Programs

Despite the strong research and business cases for CSC-FEP programs, funding remains a challenge. Key components of coordinated specialty care, like supported education and employment and outreach and engagement, are not typically covered by commercial health insurance or Medicaid plans. Federal funding for CSC-FEP has increased, but falls short of meeting program funding needs.

Community Mental Health Block Grant Funds

Congress provides funds to state mental health programs through the Community Mental Health Block Grant (MHBG) program. In 2015 and 2016, Congress doubled its funding for CSC-FEP programs. NAMI advocated for this significant increase in a joint Congressional briefing with NIMH.

Congress also put into law a requirement that states “set-aside” 10% of their MHBG funds for early psychosis programs. States also have the option to spend 20% of their MHBG funds on CSC-FEP by the end of two fiscal years in lieu of spending 10% each year. This federal funding provides important “seed money” to help states begin to develop CSC-FEP programs, but is not enough to sustain programs.

Medicaid and Commercial Health Insurance

For young people who are enrolled in Medicaid, CSC-FEP programs can bill for services such as psychotherapy, case management, family support and education, medication and, in some states, supported employment and education or peer support services. Medicaid does not, however, cover community outreach, the full cost of supported employment and education services and some other program costs.

For young people covered by commercial health insurance or Medicaid, CSC-FEP programs can typically only bill for psychotherapy, case management and medication, leaving other important CSC-FEP services and program costs unreimbursed.

State and Local General Funds

Because Medicaid, commercial health insurance and MHBG funds only cover a portion of CSC-FEP program costs, states with strong CSC-FEP program implementation—like Oregon, New York, Virginia, California and Ohio—rely on additional funding sources.

Typically, they use state general funds to support program costs and to cover young people who are uninsured.

- **Oregon:** statewide expansion using an annual allocation of state funds, SAMHSA funding, commercial insurance and Medicaid coverage and foundation funding.
- **New York:** statewide expansion using a state allocation of \$6.75 million, SAMHSA funding, commercial insurance and Medicaid coverage.
- **Virginia:** broad expansion with a state allocation of \$4 million.
- **California:** broad expansion with state funding provided through the Mental Health Services Act, SAMHSA funding and commercial insurance and Medicaid coverage.
- **Ohio:** broad expansion with funding provided by SAMHSA, foundations and earmarked local tax levy funding.

Flexible funding to cover the full cost of supported education and employment services is vital. These services motivate young people to stay engaged in treatment because they support their life goals, such as staying in school or having a job or career.

Funding for outreach and engagement is also critical to getting young people into services earlier, before their psychosis worsens and becomes harder to treat.

To help address funding challenges, NAMI is working with the Centers for Medicare & Medicaid Services (CMS) and national health insurance organizations to build support for coverage of CSC-FEP programs, including alternative payment models that will better cover costs.¹² This is an important long-term strategy for program sustainability. In the meantime, **advocacy for state or local resources is vital to realize NAMI's goal that every young person experiencing psychosis receives quality FEP care.**

¹² Id.

FIRST EPISODE PSYCHOSIS ADVOCACY NUTS AND BOLTS

This portion of the FEP state expansion guide is designed to support your advocacy at state and local levels. It covers three important components of advocacy:

- Gathering information,
- Building support & cultivating allies, and
- Implementing a strategy.

Depending on your circumstances, you may start with a different component, work in a different order or work on two or more components at the same time.

Gathering Information

Explore what is happening in your state around FEP programs. The information you gather will be invaluable in informing your advocacy strategy and building support for program expansion.

1. Connect with FEP programs

Find out if there are any FEP programs in your state at Partners4StrongMinds.org. If there are, set up a visit or call with the program manager of each. Some sample questions to ask:

- What is the program's greatest success?
- How is the program helping youth and families?
- How is the program funded?
- What challenges is the program experiencing?
- Have you served a young person or family member whose story might illustrate the value of FEP programs?
- Do you have program outcomes data you can share?
- Are you working with individuals or organizations that are supportive of FEP programs?

2. Explore neighboring states' FEP programs

Find out if there are FEP programs in other states in your region at Partners4StrongMinds.org or Snapshot of State Plans. This will be helpful information because legislators like to know what other states are doing.

3. Discover others involved in FEP programs

Other groups may be working on or involved with FEP programs. Besides contacts identified by any local FEP programs, consider reaching out to the following to see what role, if any, they are playing in FEP program adoption:

- State community mental health program association,
- State mental health coalition(s), if any, and
- Universities that conduct mental health services research.

4. Estimate number of FEP programs needed

Estimate the number of FEP programs your state may need using a simple modeling tool (included in the [Advocacy Tools](#)) developed by leading RAISE researchers and colleagues.¹³

¹³ Jennifer L. Humensky, Ph.D., Lisa B. Dixon, M.D., M.P.H., and Susan M. Essock, Ph.D., *State Mental Health Policy: An Interactive Tool to Estimate Costs and Resources for a First-Episode Psychosis Initiative in New York State*. Accessed online at <http://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201300186>

5. Meet with your state mental health authority

Schedule a meeting with your state mental health authority (mental health division or administration) to discuss development of FEP programs.

Before you meet, **do your homework.**

Your state is required to use 10% of its Community Mental Health Block Grant (MHBG) funds (or 20% by the end of two years) to support FEP programs or other early intervention programs for serious mental illness.

FEP programs often use one of the RAISE research models—OnTrack or NAVI-GATE. Other states have adopted other CSC models.

Find out what model your state is adopting and what it is doing with its FEP block grant funding [here](#).

Let your state mental health officials know that you are interested in working with them to expand FEP programs and would like to learn more about their efforts and how NAMI might help. Consider using some or all of the following talking points and questions in your meeting(s):

- NAMI knows that FEP program expansion is a priority for SAMHSA and the National Association of State Mental Health Program Directors (NASMHPD). NAMI shares this goal and would like to be a helpful partner on efforts in our state.
- At the national level, NAMI co-hosted a Congressional briefing in 2015 with NIMH and SAMHSA to highlight research results on FEP programs.
- NAMI also called on—and got—Congress to double the “set-aside” requirement for early psychosis programs to 10% of MHBG funds, which resulted in an additional \$25 million to cover the increased set-aside.
- We are interested in learning about (or confirming what we’ve read or heard):
 - Our state’s plan for expanding FEP programs,
 - How our state is using its MHBG set-aside to help,
 - How many FEP programs will be needed in the long-term (you may choose to refer to the modeling tool mentioned above),
 - What CSC model our state is adopting and what are its advantages, and
 - FEP program successes to date and any program outcome and performance data.
- We know that funding and developing FEP programs can be challenging, so we would like to discuss what barriers our state faces.

- NAMI would like to know what might help support successes and overcome barriers, such as:
 - Educating lawmakers about the value of FEP programs,
 - Advocating with the state legislature for FEP program funding, and
 - Facilitating partnerships.
- NAMI would like to keep in regular contact to support FEP expansion. Who is the appropriate point-of-contact, and what would be the best way to establish an ongoing and helpful dialogue?

Building Support & Cultivating Allies

Build strong internal support and cultivate diverse allies to help you make the case for FEP program expansion. Remember that you can often partner effectively on FEP expansion even if your organizations do not agree on other issues.

Get Board buy-in. Provide your board of directors information about First Episode Psychosis (FEP) programs. The fact sheet in the Advocacy Tools section, *Paying for what works*, is a helpful summary. Share additional information about the status of FEP programs locally and seek support for program expansion.

Once you have the support of your board, reach out to potential allies (see suggestions below) and seek their support.

- **Existing FEP programs:** Existing programs can offer outcomes data and compelling stories of recovery. This powerful combination plays an important role in educating policymakers.
- **Advocacy organizations:** Mental Health America, state disability rights organizations and mental health coalitions or advocacy organizations can amplify advocacy efforts with policymakers.

State uses of MHBG set-aside funds

The 10% MHBG set-aside funds for FEP—and how they are used—vary widely from state to state. Regardless of how funds are used, they should play a strategic role in FEP program expansion. Examples of state use of the MHBG set-aside funds include:

- Issuing Request for Proposals (RFPs) to develop FEP programs
- Training Coordinated Specialty Care (CSC) teams
- Paying for CSC costs not covered by insurance or Medicaid
- Supporting FEP program community outreach and engagement
- Educating providers, service recipients, families, academics and policymakers
- Staffing positions to coordinate FEP programs

- **State Mental Health Planning Council:** State planning councils offer an excellent opportunity to work with state agencies and colleague organizations to influence the use of mental health block grant (MHBG) funding for FEP program development.
- **Mental health provider groups:** Community mental health program associations and other provider groups, such as state psychological associations, psychiatric associations and social workers' associations, usually have lobbyists, useful contacts and members who can be activated to contact policymakers.
- **Primary care provider groups:** Pediatric associations, associations of primary care clinics or school-based health clinics, and nursing associations may have lobbyists and members who can contact policymakers.

NOTE: Primary care providers (and mental health providers) may see young people who experience psychosis and not know about FEP programs and how they can help. They may be interested in learning more and supporting FEP expansion to better serve young people with psychosis.

- **Hospitals:** Local hospitals and state hospital associations often have lobbyists and major influence with state and local policymakers.

NOTE: People with untreated psychosis have high rates of emergency department visits and hospitalizations, which often strain hospitals and their staff. Let hospitals know about FEP programs and how they can reduce the burden on inpatient facilities by helping young people successfully manage early psychosis.

- **Law enforcement and justice organizations:** Sheriff's associations, state associations of chiefs of police, juvenile justice departments and other justice-related organizations often have significant influence with state and local policymakers.

NOTE: People with untreated psychosis have high rates of arrests and incarceration. In jail or juvenile detention, their conditions often worsen and cause significant challenges and costs. Let your partners know how FEP programs can help by engaging young people in effective treatment and supports for managing psychosis.

- **Elected officials:** State legislators or local officials who have an interest in mental health issues can be valuable champions.

NOTE: Elected officials who are supportive of mental health may not know about the high cost of untreated serious mental illness and how FEP programs can keep young lives on track and reduce future disability and the high cost of failure.

Implementing a Strategy

Plan and implement a thoughtful advocacy strategy for FEP program expansion based on your state's needs and circumstances. Loop in your allies to assist.

The guidance below is based on the objective of securing state general funds to support FEP programs, which is the objective many states are likely to pursue. If your objective is different, such as obtaining Medicaid coverage of FEP services, pursuing a federal grant or securing local funds, modify the approach or targets as needed.

- 1. Know your objective.** Craft a clear ask for state funding to support FEP programs. Seek assistance from your State Mental Health Authority and your state association of community mental health programs in determining the amount requested. Clarify how many programs will be supported, in what regions and how many people are expected to be served.
- 2. Identify opportunities.** Work with your state mental health authority and key partners to identify opportunities to increase state funding and strategies. Here are some examples of common vehicles:
 - State mental health agency budget request
 - Governor's budget line item or agency budgets
 - House and Senate mental health agency budgets
 - Legislation in support of FEP programs
- 3. Make a plan.** Develop a plan based on the opportunities you intend to pursue.
 - Identify legislative committees and key subcommittees that will act on FEP legislation and/or budget requests.
 - Map out a calendar based on the timing of your budget and legislative processes. Note relevant dates, such as when a budget is released, dates the legislature is in session, breaks, committee meeting days and related activity.
 - Identify key legislators, such as Committee Chairs and leadership, whose support is important to achieving your objective.
 - List allies who have strong relationships or influence with target legislators.
 - Note media that is influential with target legislators.
- 4. Form a working group.** Convene about five people (including, if applicable, people from several organizations) who will coordinate and lead advocacy efforts. The working group should prepare to implement the steps that follow.

5. Gather stories and facts. Cultivate spokespersons, especially young people or family members, who can share real stories about how FEP programs help. If there are no programs in your state, consider sharing stories from another state's program or bringing in a program expert.

Use the Paying for what works fact sheet to provide a brief overview on early psychosis. Develop talking points and materials that highlight any state-specific data or successes. Be prepared to share information on RAISE research, program costs, how your state is spending its block grant set-aside and what is needed to expand FEP programs.

6. Educate policymakers. Schedule meetings with your Governor's office and key legislators.

- Provide an overview on FEP, including the research base and business case.
- Share a story (preferably told by a young person or family member) that illustrates the power of FEP programs to change lives.
- Let policymakers know that there is strong bipartisan support in Congress for FEP programs because they produce better outcomes and keep young lives on track. Congress committed to FEP by including a 10% set-aside in the Community Mental Health Block Grant for early psychosis programs.

Your meetings should let you know who will support FEP program expansion and may allow you to identify one or more potential champions.

7. Raise visibility. Build support for legislative action by raising visibility about FEP programs. Work with your allies. United voices create a more compelling argument for public support.

- Pitch an op-ed on the importance of FEP programs that features a positive personal story to a major newspaper in your state, or one that serves the local region represented by a target legislator.
- Work with local television programs to highlight a local FEP program and a personal story.

Advocacy Tools included to help you expand FEP programs:

- ✓ Funding sources for FEP programs
- ✓ Modeling tool for determining # of needed FEP programs
- ✓ Sample legislation
- ✓ Talking points
- ✓ Sample advocacy alert
- ✓ Sample advocacy alert email
- ✓ Sample social media posts
- ✓ Paying for what works fact sheet

- Share Facebook and Twitter posts widely, targeting legislators.
- Invite legislators to visit a local FEP program.
- Distribute stories or information about FEP programs in newsletters and listservs.

8. Prepare testimony. Develop both written and oral testimony in advance. Draft a lineup of people who would provide compelling oral testimony and help prepare them. It is helpful to have people who can share compelling stories, as well as people who can provide a strong case for FEP program funding, especially influential individuals such as police chiefs and hospital administrators.

9. Activate advocates. Advocacy by your members and allies is vital to helping move legislators. Activate their power to influence legislators:

- Send advocacy alerts prior to significant legislative actions, such as committee hearings or votes.
- Encourage advocates to ask for support of FEP programs at local events with their legislators, such as town hall meetings.

Passing legislation or a budget request may take more than one legislative session. Keep taking steps to educate and promote awareness of the need for FEP programs. Continue your advocacy to reach NAMI's goal **that every young person experiencing early psychosis receives research-based coordinated specialty care.**

ADVOCACY TOOLS

Most common funding sources for FEP programs and coordinated specialty care (CSC)

Funding Sources	Infrastructure Development (Not CSC)	Community Outreach (Not CSC)	Psychotherapy (CSC)	Case Management (CSC)	Family support & education (CSC)	Supported Employment & Education (CSC)	Medication (CSC)	Peer support (CSC)
Commercial Insurance			✓	✓			✓	
Medicaid			✓	✓	✓	* (with waivers or state plan amendments)	✓	✓
MHBG	✓	✓			✓	✓		✓
State and local General Funds	✓	✓			✓	✓		✓
Other sources (foundation)	✓	✓						

NOTE: CMS, NIMH and SAMHSA issued a joint informational bulletin providing states with guidance on funding CSC in FEP programs.¹⁴ The bulletin recommends using coverage and reimbursement strategies like those used to fund Assertive Community Treatment (ACT) programs. The bulletin informs states about the opportunity to use Medicaid 1115 waiver authority and 1915(i) state plan amendments to cover CSC.

¹⁴ CMS, NIMH and SAMHSA Joint Informational Bulletin: Coverage of Early Intervention Services for First Episode Psychosis. October 16, 2015. Available online: <https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-10-16-2015.pdf>

Modeling tool to determine the number of FEP programs needed¹⁵

Estimated state population (include your state's population here— VA is used as an example)	8,300,000
Estimated incidence of FEP each year (this is a national estimate)	.03%
# of FEP cases each year (8,300,000 \times .0003)	2,490
Percentage of individuals with FEP approached (this % is a high estimate of the % of young adults that a program will reach)	50%
# of individuals experiencing FEP approached (2,490 \times 50%)	1,245
Percentage of individuals likely to engage in FEP program	75%
# of individuals willing to engage in FEP program (1,245 \times 75%)	934
# of individuals served by 1 FEP program	35*
# of FEP programs needed statewide (934 \div 35)	27

*The CSC model of care provided in FEP programs keeps the individual to provider ratio low at about 30 to 40 program participants.

¹⁵ Jennifer L. Humensky, Ph.D., Lisa B. Dixon, M.D., M.P.H., and Susan M. Essock, Ph.D., State Mental Health Policy: An Interactive Tool to Estimate Costs and Resources for a First-Episode Psychosis Initiative in New York State. Accessed online at <http://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201300186>

Sample Legislation

A bill relating to mental health; appropriating funds for identification of early psychosis, intensive treatment, first episode psychosis (FEP) program development and operation, and supports.

[SECTION #]

\$ _____ (insert funding amount requested) in fiscal year 2018 is appropriated from the general fund to the [commissioner/secretary of health and human services] to fund grant proposals which provide intensive treatment and supports through first episode psychosis programs to adolescents and young adults experiencing early psychosis or psychotic symptoms. Intensive treatment and supports shall use the coordinated specialty care model. The intensive treatment and supports may also include crisis planning, stress management and supportive housing components. The [commissioner/secretary] shall track the data on programs awarded funds, and submit a report with outcomes reported to the legislature no later than November 1, 2019.

\$ _____ (insert funding amount requested) in fiscal year 2018 is appropriated from the general fund to the [commissioner/secretary of health and human services] to provide specialized training and guidance to community mental health centers and health care professionals on early psychosis in adolescents and young adults, reducing the duration of untreated psychosis, research data and best practices.

Talking points for calling state legislators

- My name is [your name] and I'm a constituent from [your town or city].
- I'm calling to ask for support for funding for First Episode Psychosis, or FEP, programs in our state.
- FEP programs help young people with symptoms of serious mental illness get the treatment they need to get better, get their lives on track and pursue their life goals.
- Getting the right care at the right time can reduce costly outcomes, like arrests and hospital stays.
- FEP programs can help by providing research-based care.
- We know it's important to spend taxpayer resources wisely. Research shows that FEP programs are cost-effective and improve lives.
- Can we count on [legislator's name] to support funding for FEP programs?

Sample advocacy alert

Keep young lives on track



Mental illness often strikes in youth—75% of serious conditions begin by age 24.

Psychosis (for example, seeing or hearing things that others do not) can be a symptom of serious mental illness. Fortunately, research shows that early intervention with First Episode Psychosis (FEP) programs changes the course of young lives. FEP programs help young people get the treatment they need to get better, get their lives on track and pursue their life goals.

Every young person who experiences psychosis deserves access to quality FEP care.

You can help make that happen in our state.

Ask your [insert target elected official(s)] to **support funding for life-changing First Episode Psychosis (FEP) programs.**

Call or e-mail today

Forward this email to a fellow mental health warrior.

Sample advocacy alert email to legislator

Dear [Legislator]:

Mental illness strikes in youth—75% of serious conditions begin by age 24.

Psychosis (for example, seeing or hearing things that others do not) can be a symptom of serious mental illness. Fortunately, research shows that early intervention with First Episode Psychosis (FEP) programs changes the course of young lives. FEP programs help young people get the treatment they need to get better, get their lives on track and pursue their life goals.

I am asking you, as my elected official, to support funding for FEP programs in our state. Without effective early intervention for serious mental illness, we pay a high price:

- People with serious mental illness are booked into custody at 4 x the rate of other individuals.
- People hospitalized with schizophrenia are readmitted at 4 x the rate of people without a mental illness.
- Suicide is the second leading cause of death for youth ages 15-24, a time when symptoms of psychosis are most likely to first appear.

Arrests, hospitalizations—and even suicides—are avoidable when people get the right care at the right time. You can help. Fund life-changing, cost-effective FEP programs to keep young lives on track and in recovery.

Sincerely,

[Insert Supporter Name]

[Insert Supporter Address/Phone Number]

Sample Social Media Posts

Twitter

Keep young lives on track. Support #FirstEpisodePsychosis programs in [insert state]. [Insert Governor's or State Legislator's Twitter handle].

100,000 young Americans experience psychosis each year. #FirstEpisodePsychosis programs provide hope for recovery @[Governor or State Legislator's Twitter handle]

75% of lifetime mental health conditions occur by age 24. Getting care early makes a difference. Invest in #FEP programs @[Governor or State Legislator's Twitter handle]

#FirstEpisodePsychosis affects thousands of Americans. Early intervention helps. Learn more: nami.org/earlypsychosis

#FEP programs could mean the difference between graduating school and ending up in jail. Learn more: nami.org/earlypsychosis

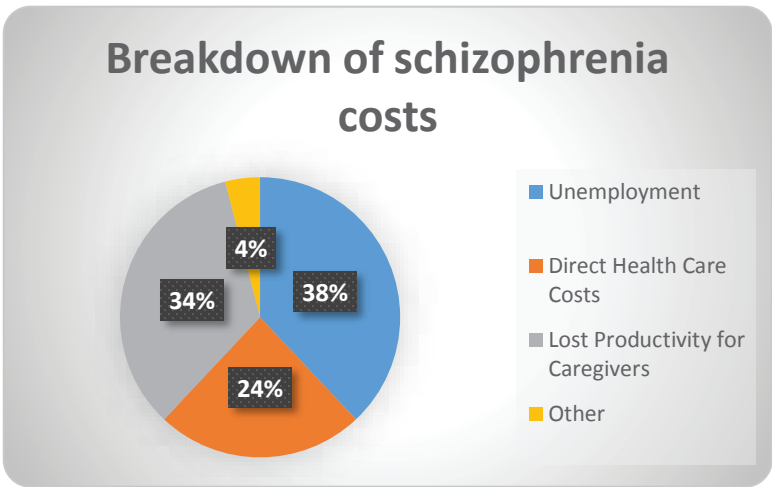
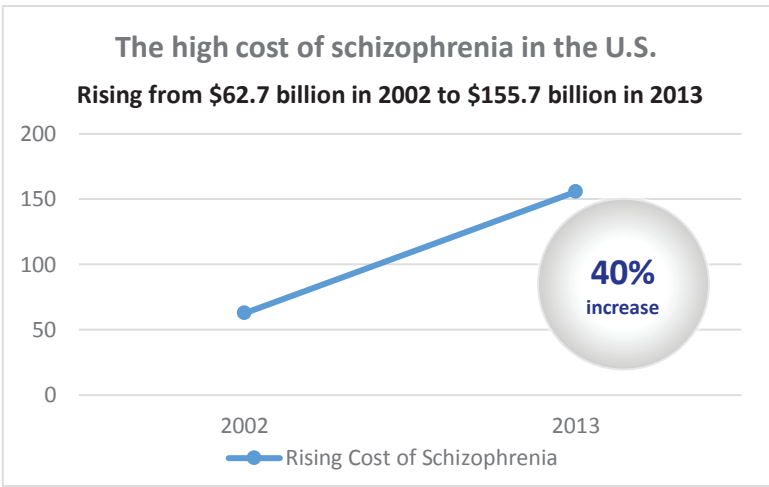
Facebook

About 100,000 young Americans experience psychosis each year. Three in 100 will have an episode during their lives. Identifying psychosis early and connecting youth and young adults with First Episode Psychosis (FEP) programs provides hope for recovery. FEP programs help youth and young adults stay in school, continue working and lead productive lives. Learn more at nami.org/earlypsychosis

Help us advocate for expanding First Episode Psychosis (FEP) programs. On [insert date], the legislature will vote on a funding bill to expand these innovative programs. Call your state legislator TODAY to request a YES vote for keeping young lives on track. Give young adults in [state name] with early psychosis the opportunity to lead independent, healthy lives.


Paying for what works

Early care for psychosis associated with schizophrenia significantly improves young lives. Failing to do so is costly.¹



Too often, young people experience crises before they receive care for early psychosis. Typically, there is a 1 to 3 year delay from the start of psychosis to intervention. That delay must be shortened. A federally funded NIMH study² showed that by intervening early with coordinated specialty care (CSC), young adults with early psychosis get better.

Components of Coordinated Specialty Care (CSC)



Medication Management

Peer Support

Psychotherapy

Person-Centered Care

Case Management

Family Education & Support

Supported Education & Employment

CSC allows young people with psychosis to:

- Stay in school
- Continue working
- Experience improved symptoms

Every young person experiencing early psychosis deserves access to CSC programs.

Paying for what works improves outcomes

Crisis-driven systems

- High rates of dropping out of school
- High unemployment rates (**80-90%**)
- Strained and high-conflict relationships
- High rates of homelessness (**20%**)
- Families not involved with the treatment team
- High rates of incarceration (**17%**)
- Increased rates of suicide and early death (**10%**)

Coordinated Specialty Care (CSC)

- Staying in school
- Securing and staying in jobs
- Building healthy social and family relationships
- Improved quality of life
- Families are valued and involved in care
- More productive members of society

Federal Funding Supporting CSC

Congress recognizes the value and importance of CSC programs by funding FEP program expansion through a set-aside added to state Mental Health Block Grants (MHBG). This funding is vital for developing these effective programs.



State Funding is Essential

NAMI calls on states to support sustainable funding for coordinated specialty care (CSC) programs. Components of CSC often not covered by commercial insurance or Medicaid include supported education and employment and community outreach. Without state support for CSC programs, the operation and sustainability of these programs are at high risk.

States and local communities use scarce resources to continue to operate crisis-driven systems for individuals experiencing early psychosis rather than paying for what works. Let's start paying for care in all of the right places. The time for action is now.

¹ Cloutier, et.al, *The Economic Burden of Schizophrenia in the United States in 2013*. J. Clin. Psychiatry, 2016 June: 77(6): 764-71. Doi: 10.4088/JCP.15m10278.

² Information about the NIMH funded *Recovery After an Initial Episode of Schizophrenia* (RAISE) study is available at www.nimh.nih.gov/raise.

RESOURCES

■ NAMI

<http://www.nami.org/earlypsychosis>

Tip Sheets:

What's going on and what can you do?

What is early and first episode psychosis?

Tips for school staff and coaches

Encouraging people to seek help

■ National Institute of Mental Health

RAISE online information

<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/index.shtml>

■ National Association of State Mental Health Program Directors

online technical assistance information on early intervention in psychosis

<http://www.nasmhpd.org/content/early-intervention-psychosis-eip>

■ OnTrack NY

an early treatment program for people with first episode psychosis

<http://ontrackny.org/>

■ NAVIGATE

an early treatment program for people with first episode psychosis

<http://navigateconsultants.org/>

■ Early Assessment & Support Alliance (EASA)

<http://www.easacommunity.org/>

■ Partners for Strong Minds

<http://partners4strongminds.org/>

■ Coverage of Early Intervention Services for First Episode Psychosis

A Joint Informational Bulletin from CMS, NIMH and SAMSHA

<https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-10-16-2015.pdf>



www.nami.org

3803 N. Fairfax Drive, Suite 100
Arlington, VA 22203

MAIN PHONE: 703-524-7600
NAMI HELPLINE: 800-950-6264

FACEBOOK: NAMI
TWITTER: NAMICommunicate
INSTAGRAM: NAMICommunicate
TUMBLR: notalone.nami.org ■ ok2talk.org