

Building Upon Existing Programs and Services to Meet the Needs of Persons Experiencing a First Episode of Psychosis

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Many individuals experiencing a first episode of a psychotic illness (FEP), often wait months to years before seeking a diagnosis and initiating treatment. There is mounting evidence that the coordinated specialty care programs for early identification and treatment of psychosis can promote a faster, more complete recovery and improve the long-term course of psychotic illness.

This fact sheet offers strategies to increase access to recovery-oriented, evidence-based, integrated care services for individuals experiencing a first episode of a psychotic illness (FEP) and practical suggestions for starting FEP programs or building on existing programs to enhance the quality of life for individuals affected by early-course psychotic illness.

State Support and Policy Considerations

Taking clinical, financial and operational aspects related to establishing a FEP coordinated specialty care program into account and addressing them simultaneously is the best strategy for establishing and sustaining a FEP program.

Clinical Considerations: Determine treatment service components, eligibility criteria and outcome measures

Consider establishing a statewide stakeholder work group to determine the treatment service components, eligibility criteria and outcome measures for FEP programs.

Treatment Service Components

FEP programs are team-based and include evidence-based practices. Most FEP programs include: psychiatric care, individual counseling, supported employment/education and family psychoeducation. Some FEP program models include additional components, such as case management, cognitive remediation therapies and peer support services. *An Inventory & Environmental Scan of Evidence-Based Practices for Treating Persons in Early Stages of Serious Mental Disorders* (Developed for SAMHSA by NASMHPD and NRI, Feb. 10, 2015) is a helpful resource for determining FEP program models and treatment services.

Begin by taking inventory: Are there services that may already be available but are not offered in combination? Are there existing team-based care models that could be modified to incorporate additional services or approaches that would help individuals experiencing a first episode of a psychotic illness? Build upon existing strengths.

Practical tip: While high fidelity to an evidence-based model is the gold standard, all of the elements of an evidence-based practice do not need to be in place before FEP initiatives begin. Initiatives that follow principles vs. practices are places to begin building momentum.

Also consider engaging a FEP technical assistance purveyor to help with training and other aspects of program development.

Eligibility Criteria

Eligibility considerations for FPE programs generally include age range, duration of untreated psychosis, diagnoses and previous treatment experience.

Outcome Measures

Establishing a simple set of outcome measures, including measures such as employment/school participation, self-reported recovery measures and utilization of inpatient and FEP services. Whenever possible, use existing data sets.

Outcome data should be collected at baseline and at prescribed intervals for the duration of the individual's participation in the program.

Financial Considerations: Establish Multiple Payer Sources and Funding Partnerships

Program Start-up

FEP programs can also potentially lead to significant long-term savings for the public mental health system by reducing inpatient stays.

FEP programs start slowly; it takes time to identify and engage individuals experiencing FEP in treatment. Initially, most FEP programs will not require full-time staffing and team members will have responsibilities in addition to the FEP program for a significant phase-up period.

Pulling together diverse services that may be available in the community, but that are not offered in an integrated way by a treatment team, can be a very helpful and cost-effective way to start a FEP program. Agencies can contract with other providers for specific treatment services, such as psychiatric care or peer support services, and/or share personnel or other resources with other providers. For example, a vocational services agency could provide a mental health agency with the services of a supported employment specialist and the vocational agency could receive the mental health assessment services in exchange for supported employment.

In some cases, services can be also be braided. State Medicaid plans vary widely. If a state's Medicaid plan will not cover supported employment services, it may pay for medically necessary case management services that can assist an individual with addressing symptoms (such as paranoia or disorganized speech) that may interfere with job performance. Depending on the structure of the mental health system and payer sources, the case manager can assist

the individual with supported employment/education services, such as helping with employment or educational applications. It is advisable to connect with representatives from the payer sources (including the state Medicaid office) early on, to have a clear sense from the onset of what services can be covered via different funding mechanisms.

FEP programs also require modest investments in training and program start-up, which could be funded by matching funds from a state and local partnership or a private foundation.

Diverse Payer Mix

Medicaid, private insurance and funds for indigent care are all used to pay for services for individuals enrolled in FEP programs. The Medicaid rehabilitation option will cover many FEP services, but the specifics vary by state. States are urged not to seek Medicaid funding that is contingent upon Social Security disability determinations for FEP services. Individuals with FEP are actively encouraged to pursue educational and employment goals that allow them to live independently in the community rather than to apply for disability benefits.

Individuals may have private insurance, either their parents' or their own, to cover FEP services. Most insurance companies do not cover the case management or supported employment/education services that are often part of a FEP treatment. States can advocate with insurance companies to pay for these services for individuals with FEP by making the case that emerging evidence indicates that individuals enrolled in FEP programs are less likely to require hospitalization.

Operational Considerations: Getting Started with Pilot FEP Programs

Consider issuing a competitive statewide Request for Partners for agency partners to implement pilot FEP programs. When selecting partners, keep in mind that FEP programs are most easily and successfully implemented and sustained in communities and agencies with the following characteristics:

Community

- Multiple community stakeholders, including mental health and recovery authorities, funders and others, have a vested interest in individuals' and program's success;
- Housing supports are available. Many individuals who experience FEP are transitional age youth;
- Sufficient volume of individuals with FEP in the service area. To determine the potential number of individuals with FEP in a specific area, estimate 30-50 individuals per year per 100,000 population. However, most FEP programs recruit about 20 percent of the individuals with FEP during the initial 12-18 months of the program.

Agency

- Recovery-focused philosophy;
- Leadership support and philosophy that is consistent with and supports the program;
- Familiarity with evidence-based or best practices implementation;
- Strength in a key FEP treatment service area;
- Identification of an executive-level staff member with the ability to facilitate implementation and modify/change barriers to the implementation process to serve as the administrative lead for the FEP team;
- Identification of a clinical leader to serve as the FEP team leader;
- Duties of FEP program are allowed to take precedence rather than adding FEP team duties to an already overextended staff;
- Willingness to set aside time for initial weekly meetings to coordinate training and implementation;
- FEP team members elect to be part of the FEP team;
- Good morale and communication within the agency; flexible, progressive and innovative culture and low staff turnover;
- Updated electronic medical records (integration of the FEP program information into current treatment plans and notes, ability to monitor individuals enrolled in the program, extract data, maintain databases);
- Ability to provide medication;
- Ability and resources to undertake assertive public education and community outreach to identify and engage individuals with FEP in treatment;
- Financial stability and multiple public and private payer sources;
- Quality Improvement process: understand the need to collect outcomes and evaluate programs and existing methods for monitoring outcomes;
- Sustainability plan (e.g., long-range financial planning, plans for turnover/method for training new FEP team members);
- Willingness to be part of an FEP learning community and to share successes and lessons learned with others implementing FEP programs.

Tips for Agencies Implementing FEP Programs

Critical elements and capacities for agencies implementing FEP programs include:

- A recovery-oriented treatment philosophy;
- A treatment team that prioritizes FEP individuals and services;
- Treatment services tailored to needs of individuals experiencing FEP;
- A capacity for rapid response;
- Strategies for engaging individuals with FEP in treatment; and
- Strategies for developing a referral network for the program.

A Recovery-Oriented Treatment Philosophy

FEP programs focus on assisting individuals to achieve the goals that are most important to them and that allow them to function independently in the community. Treatment team members promote recovery and resiliency, and work to reduce the symptoms of a psychotic illness, prevent relapse and improve the long-term course of the illness.

Shared decision making is at the core of FEP treatment. Shared decision making is based on the premise that the individual has a primary voice in treatment, is involved in establishing his/her own treatment goals, and that he or she has the ability to pursue and attain individual goals. The FEP team's role is to educate the individual about psychotic illness and to describe the landscape of treatment services so that he or she can make informed decisions.

A Treatment Team That Prioritizes Individuals with FEP and Services

While it is common to have multiple health care professionals providing care to the same individual or family, services are not always offered in a team-based or integrated manner. An interprofessional team that is able to prioritize the needs of individuals enrolled in the FEP program is essential to successful program implementation.

FEP teams include: the individual and his or her identified support persons, a team leader, a psychiatrist, therapists, a supported employment/education specialist and a case manager. They can also include others such as peer support specialists, nurses and cognitive remediation clinicians. Ideally, FEP team members are individuals who are interested and willing to learn new tools and methods to meet the needs of individuals with FEP and who volunteer to be part of the FEP team.

While each team member has a specific role and set of responsibilities, it is crucial that every member of the team be knowledgeable about others' roles, responsibilities and strengths. Team members can also be cross-trained to offer a variety of services. For example, in most situations, the case manager can offer traditional case management and assist with educational services.

Team Leader

The FEP team leader is an experienced clinician with a solid foundation of knowledge about psychotic disorders. He or she manages the treatment team meetings, coordinates services within the team, monitors overall care coordination, provides supervision to the therapists, case manager and supported employment/education specialist, maintains a continuous flow of communication among the team members and offers family psychoeducation. The team leader is also the first point of contact and conducts initial screening to determine if the FEP program is the most appropriate treatment option for an individual.

Team Meetings

FEP treatment team members should meet weekly for one hour to discuss treatment planning, progress and care coordination. Team meeting time needs to be protected, and every team member needs to be present for the meeting or to provide updates to the team leader in advance of the meeting if he or she cannot attend.

Treatment Services Tailored to Needs of Individuals Experiencing FEP

Intervening early and with a comprehensive, recovery-oriented treatment package can potentially alter the course of schizophrenia for individuals with FEP in significant and positive ways. Because brain plasticity is greater in individuals who are in the early stages of psychotic illness, early interventions may lead to both better immediate and long-term outcomes.

All FEP treatment services can be tailored to address the specific needs of individuals experiencing FEP in ways that help them to lead personally meaningful, independent lives in the community. For example, many individuals with FEP may experience significant symptom relief by taking lower doses of medications than those prescribed for individuals with multi-episode psychotic illness. FEP team therapists can integrate Cognitive Behavioral Therapy for psychosis (CBT-p) into sessions to assist individuals with understanding symptoms and developing strategies to manage them.

FEP often occurs when an individual is entering a developmental phase when their peers are making educational and employment choices. The individual may not have experienced failures related to these pursuits, but is struggling with psychotic illness symptoms that are interfering with work or school performance. As a result, Supported Employment/Education services can focus on the specific symptoms of psychotic illness, such as memory problems, sequencing or making plans, and ways to manage these symptoms.

The chances of engaging family in family psychoeducation and their loved one's care during the early course of the illness is greater because the long-term effects of mental illness that can create separation and disruption in families have not yet occurred.

Psychiatric Care

The FEP team psychiatrist places a strong emphasis on shared decision-making and consults with the individual to provide appropriate medication to treat psychotic or other symptoms, based on the most up-to-date research regarding the safest medications proven to be efficacious with individuals with early psychosis.

Individual Therapy

Licensed providers help individuals with FEP set goals, learn more about their illness, develop the ability to bounce back, deal with negative feelings, cope with symptoms, prevent relapse, address issues related to substance abuse, encourage healthy lifestyles and maintain and develop relationships. It is helpful if there are two therapists, a male and a female, on the FEP team.

Supported Employment/Education Services

FEP programs place strong emphasis on encouraging individuals to use the supported employment/educational services that will help them to achieve independence. Ideally, FEP Supported Employment/Education (SEE) services are modeled after the established evidence-based practice of supported employment and include an additional emphasis on education. SEE specialists help individuals achieve rapid return to or initiation of competitive employment. Individual needs and preferences drive treatment services, and, to the extent possible, services are provided at community sites.

Family Psychoeducation

Research has shown that family members and significant others play a vital role in recovery from psychosis. As part of the FEP family psychoeducation program, family members and support persons learn about the illness and how to improve communication and solve problems together. Family psychoeducation can be offered to individual or multiple families. If multi-family services are not available, families can be referred to a National Alliance on Mental Illness (NAMI) Family-to-Family group.

Case Management

The FEP team case manager assists the individual with accessing available resources, advocates for him or her in the community and provides crisis/distress intervention as needed. To the greatest extent possible, these FEP case management services are provided in the community. Initially the case manager helps the individual with FEP to rapidly engage with appropriate services, but then moves as quickly as is appropriate to help the individual to reduce reliance on services and to develop the skills to live independently.

Capacity for Rapid Response

The capacity for rapid response is a central FEP program component. It is helpful to have a dedicated phone line specifically for referrals to the FEP treatment program and for the FEP team leader to respond to initial calls and complete screening and initial intake quickly. If an individual appears to be appropriate for services, it is beneficial to expedite scheduling appointments with the psychiatric provider and other team members.

Strategies for Engaging Individuals with FEP in treatment

Engaging individuals experiencing a FEP in treatment can be difficult, especially with individuals who lack insight into the illness or who do not want treatment. Teamwork, Motivational Interviewing and structured sessions are ways to engage individuals in their treatment.

Teamwork

FEP team members can work together in creative ways to engage individuals. Teams are encouraged to help Individuals enrolled in the FEP program to get to know as many members of the treatment team as possible, even if it is just an introduction. When struggling with

engagement, the team member who has the best rapport with the individual can reach out to him or her.

The team's goal is to work with the individual to establish personal goals and to address the psychotic illness symptoms that interfere with achieving these goals. For example, many individuals are interested in pursuing employment. The supported employment/education specialist can work with the individual to seek employment while developing rapport and trust.

Ideally, the team leader continues to stay in contact with individuals and families who have discontinued participation in FEP treatment. The team is encouraged to reach out to the individual for at least six months after he or she has stopped engaging in treatment before closing the case.

Motivational Interviewing

Motivational Interviewing is a helpful way of interacting with the individual to enhance motivation to pursue goals and focus on recovery.

Structure of Sessions

It is very helpful if all FEP team members use the same structure for their sessions with individuals enrolled in the program, and many FEP programs use the structure developed for Cognitive Behavioral Therapy for Psychosis sessions with individuals with FEP. A set structure allows for consistency across sessions and providers, focuses on goals that are important to the individual and encourages collaboration and feedback.

Strategies for developing an FEP program referral network

Assertive, community-based outreach is essential for raising awareness of the importance of early identification and treatment of psychosis and building a referral network for the FEP program.

Developing FEP outreach tools, including brochures, fliers, social media messages, PowerPoint presentations, press releases and newsletter stories, is an important part of an outreach strategy. All outreach tools need to emphasize the benefits of early identification and treatment of psychosis through specialized FEP treatment and include the FEP dedicated phone number and locations for treatment services. It is also helpful to describe the signs and symptoms of psychotic illness and how FEP services can promote recovery.

The FEP team can build a referral network by identifying local individuals and organizations that are likely to come into contact with individuals who are eligible for FEP services, including inpatient psychiatry units, crisis centers, specialized law enforcement officers (Crisis Intervention Teams, jails and courts, including specialty mental health and veterans courts) other community mental health agencies, primary care clinics, primary care practices, colleges and high schools, mental health and recovery authorities, advocacy groups, clergy and others.

The team leader or administrative lead can coordinate outreach efforts, but all FEP team members can assist with outreach by providing contacts for referral sources, making visits and presentations about the FEP program and distributing materials. All outreach should be tracked and referral network contact information kept up to date to allow for ongoing communication and follow-up with referral sources.

Case Example: Treatment Services for Individuals with FEP

James is the executive director of Hope, a community mental health agency. He is interested in implementing a FEP program, but he is concerned about available services, costs and program fidelity. He and his agency leadership met with a technical assistance provider for FEP implementation. During the meeting, agency leadership realized that, with some creativity and flexibility related to job roles, they could acquire the resources necessary to implement a FEP program.

Before implementing the FEP program, agency leadership needed to address how to provide both psychiatric care and supported employment services for individuals with FEP. They turned to the community to do so. The agency contracted with a local psychiatrist to provide psychiatric care for individuals with FEP two half days per week. Hope also contracted with a nearby agency providing vocational services for the services of a supported employment specialist two days per week.

Hope's leadership team identified individuals within the agency who expressed interest in being part of a team that would provide integrated FEP treatment services. In the end, the team consisted of a team leader who coordinated services and provided family psychoeducation, a case manager who supplemented supported employment and education services as needed, a therapist, and the contracted psychiatrist and supported employment specialist. The team met weekly and maintained ongoing communication throughout the week. If team members were unable to attend a team meeting, they updated the FEP team leader on progress related to the individuals with FEP with whom they were working so that the information could inform treatment planning and integrated care coordination.

In time, the FEP program reached its capacity, and an additional case manager and therapist were added to the team.

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