# Steps and Decision Points in Starting an Early Psychosis Program

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INTRODUCTION

An increasing number of sites throughout the United States are beginning the process of implementing early psychosis intervention. This guide walks through the steps involved in establishing a new early psychosis program, including an explicit articulation of the decisions involved. The guide describes core elements of Coordinated Specialty Care, which is considered the current standard of practice for early psychosis intervention. Replication of an existing program model can help simplify the process considerably, but many of the decisions listed in this document are not explicitly addressed by the research. Within Coordinated Specialty Care there remains variation, because early psychosis intervention is multi-dimensional and evolving. It is important to understand the strengths and weaknesses of the model being implemented and to give thought to how the program can be most beneficial, sustainable and effective.

New early psychosis programs are joining a thriving international movement with many available resources. Within the United States there is active national collaboration to help organize and disseminate the resources that new sites need. In addition to identifying the steps involved, this guide will also provide introductory information about some of those resources.

Why implement an early psychosis program?

Worldwide duration of untreated psychosis has been reported to last an average of two years[2] and the recent Recovery After an Initial Schizophrenia Episode (RAISE) study in the United States found that the median time from the onset of psychosis to the time a person received treatment was over a year.[1,2] Even with short durations, psychosis can rapidly lead to justice system involvement, involuntary hospitalization, loss of social support and normal roles, and loss of ability to function.[3,4,5,6] Since the onset of psychosis is commonly during adolescence and young adult years, it can greatly disrupt the normal developmental processes of individuation, adopting adult roles and responsibilities and forming an adult identity. Although the U.S. spends billions of dollars per year responding to psychosis, the service delivery system does not effectively address the needs of young people who develop this condition.[7,8,9,10] Early psychosis intervention provides a viable, non-coercive, and more effective alternative to individuals who have recently developed psychosis.

THE BROADER CONTEXT

Early psychosis intervention is well-established in numerous locations internationally, including a growing network inside of the United States. ("Step 2" in this document directs readers to where they can find additional information about the programs described here). Outside of the United States, early psychosis intervention was well-established throughout most Commonwealth countries and in parts of Scandinavia by the early 2000's. The Early Psychosis Prevention and Intervention Center (EPPIC) at the University of Melbourne collected, tested and developed methods related to early psychosis intervention, and became an international training ground.[11] Australia, New Zealand and Great Britain were the first countries to adopt national early psychosis strategies. Other countries such as Canada developed widespread early psychosis intervention without a single national strategy or guidelines. The International Early Psychosis Association (www.iepa.org.au) provides a vibrant and growing forum for programs throughout the world to share their growing knowledge and experience.[12]

In the United States, Zucker Hillside Hospital was a forerunner in early psychosis intervention, providing early psychosis services within a hospital setting and later playing an important role in the first national study of community-based implementation (RAISE).[13] Numerous universities within the U.S. began researching the onset of schizophrenia in the 1990's and developed interventions in support of that research, leading to the North American Prodromal Longitudinal Study (NAPLS), a network of U.S. and Canadian universities which have shared their data and findings in order to move the knowledge base forward faster (http://campuspress.yale.edu/napls/). Some, such as the University of North Carolina's OASIS Program, Yale, and the numerous University of California programs (UC Davis- EDAPT program, UC San Francisco/Felton Institute's PREP Program, UCLA, and UC San Diego), continue to play important roles in dissemination and ongoing research.

In 2001, two early adopters, the Oregon Early Assessment and Support Alliance (EASA and the Portland Identification and Early Referral Service (PIER) in Portland, Maine, began to provide community-level early psychosis intervention.[14,15] Oregon's EASA Initiative was created by Mid-Valley Behavioral Care Network, a five-county intergovernmental mental health managed care organization responsible for publicly funded mental health services under the Oregon Health Plan. EASA was the first systematic integration of population-wide early psychosis intervention into the public mental health system in the U.S. Statewide implementation of EASA using a state-level set of practice guidelines and a fidelity/evaluation process began in 2007. PIER in Portland, Maine, was research-funded and took a population-level approach to trying to identify early symptoms prior to the development of psychosis. In 2007, The Robert Wood Johnson Foundation funded a six-site replication of PIER's Family-Assisted Community Treatment (FACT) model called the Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPP).[16] Oregon's original five counties were part of this study. Due to the EDIPPP study criteria, PIER began providing first episode services and EASA began providing services to the psychosis risk syndrome population.

In 2010, the National Institute of Mental Health sponsored a national study of early psychosis intervention in the public mental health system called Recovery After an Initial Schizophrenia Episode, or RAISE.[13] RAISE had two arms- RAISE Early Treatment Program (www.navigateconsultants.org), which randomized sites into a manualized process of treatment versus "treatment as usual," and RAISE Connections/OnTrack New York (http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml), which implemented early psychosis teams in New York and Maryland and provided documentation in support of program implementation nationally. Both programs developed high-quality detailed written guidance for new sites that are available on the internet, and offer in-person technical assistance. RAISE also helped to launch a regional effort in Ohio through Northeast Ohio Medical University called BeST (Best Practices in Schizophrenia Treatment).

In April 2014, Congress allocated new funding and directed all states and territories to begin the process of developing early intervention efforts for individuals experiencing a first episode of serious mental illness, including psychosis.[1] As a result of this and additional federal grant moneys, a large amount of new activity began to focus on early psychosis intervention in the U.S. In September 2014, the Substance Abuse and Mental Health Services Administration, the National Institute of Mental Health and The Robert Wood Johnson Foundation co-sponsored the first ever organizational meeting for the creation of a formalized national early psychosis network in the U.S., called the "Prodromal and Early Psychosis Prevention Network (PEPPNET)".[17] PEPPNET has developed a steering council, several subcommittees, and a national mailing list in addition to coordinating national efforts.

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[1] Set-aside funding within the Substance Abuse and Mental Health Services Administration's Community Mental Health Services Block Grant is specifically for the purpose of addressing first episodes of serious mental illness, and not to provide services for persons at high risk for developing such disorders.

UNDERSTANDING THE CORE ELEMENTS OF EARLY PSYCHOSIS INTERVENTION.

Early psychosis intervention works to systematically identify individuals in the early stages of psychosis, reduce barriers to access, and successfully engage the person and family in a way that fosters their positive identity and resilience. Early psychosis programs provide education, treatment and support, and they transition the person into long-term resources. [7,11,14,15,16,18] Early psychosis intervention can be understood as a set of interventions tailored to the unique needs of adolescents and young adults who have experienced symptoms of psychosis. Many of the interventions included in early psychosis programs were developed primarily with individuals with long-term illness, and the process of adapting these approaches is still relatively new. There is broad consensus about the elements of early psychosis intervention. [1,13] The following are core elements of early psychosis programs:

- Early psychosis programs aspire to engage with young people and families as partners in decision making at all levels.

- Community education facilitates rapid identification, referral, successful engagement, and positive ongoing supports within the community.

- Programs aspire to minimize barriers to entry which often prevent successful engagement, such as requirements around motivation, recognition of illness, and logistical challenges such as funding and transportation.

- Family support and education help to maintain a sense of hope, equip families to provide the type of support young people with psychosis need, and reduce trauma, conflict and illness-related stress.

- Illness and resiliency education for the individual builds on the young person's sense of and connection to personal strengths and ability, provides basic information about psychosis and how it can be managed, and partners with the young person to develop personal understanding, skills, attitudes and relationships which support developmental progress over time.

- Counseling approaches are used that: facilitate the young person's: informed decision making; finding meaning in experience; successful achievement of personal goals; and mastery of symptoms.

- Medical services include: low-dose prescribing; careful attention to side effects; and wellness strategies in support of symptom reduction and positive health outcomes with a strong emphasis on shared decision making.

- Supported employment and education encourage and support the young person to continue on, or return to a school/career trajectory.

- Substance abuse treatment provided directly by the team reduces unnecessary consequences and supports a higher level of recovery.

- Assessment and treatment are designed to be sensitive to trauma and to reduce new trauma associated with psychosis and resultant legal involvement and acute care.

- Services are closely coordinated with a shared plan and approach by the team, including weekly review of every individual being served in order to align all services to a common approach and set of goals based on the young person's and family's perspectives.

- Clinical supervision and attention to human resources issues help build clinical skills and provide an environment which is supportive of team members' roles and needs.

- Attention to sustainability and evaluation are also of central importance.

- It is helpful to replicate existing models to implement programs more quickly, but most programs will need to make adaptations based on missing or weaker elements in the model they are following and local cultural or programmatic considerations. In addition, early intervention programs must remain attuned to ongoing research, feedback and experience and recognize that programs must actively work to improve and develop with time. Individuals with first-person experience of psychosis are also an extremely important ongoing source of knowledge and direction for these programs.

Most early psychosis programs are primarily if not entirely outpatient in focus. However, early psychosis understanding and best practices also have significant implications for acute care providers, medical providers, funders and for other supporting systems such as educational and vocational programs. A comprehensive approach which addresses practices systemically at multiple levels increases the consistency of experience and reduces the chances of negative experiences leading to trauma and disengagement.

STEPS IN BEGINNING A PROGRAM

Regardless of the current implementation status, the following steps are ultimately needed to successfully implement a program. The steps do not always occur in this order.

STEP 1. Identify and coordinate with other parallel and related efforts.

If there are multiple early psychosis efforts within the same state, network, or region, it is helpful to have a program leader/champion at the state level, and to establish a collaborative cross-site planning process which facilitates one consistent approach while recognizing local variation. Inconsistencies across sites can lead to confusion, ethical concerns (i.e., an individual being eligible for one early psychosis program but not another in the same state or region), and inability to set standards, coordinate or advocate in a consistent way at the state level. It is helpful to have consistency and coordination of programs within the same state or network with regard to:

- Program name, to facilitate social marketing and visibility across a broader geographic area;

- Logo and marketing materials;

- Eligibility criteria;

- Program guidelines and basic structure;

- Training and oversight processes;

- Data collection and reporting; and

- Cross-community problem solving and sharing.

Since program implementation involves numerous decisions, it is helpful to clarify how those decisions will be made and how disagreements will be managed.

In addition to other programs or entities with similar interests in early psychosis, related efforts may provide early synergy and may even make sense to combine in some way. For example, programs may find significant benefit in combining efforts with community education efforts such as Mental Health First Aid, treatment programs such as Assertive Community Treatment, Transition Age Youth programs, and efforts to divert people from hospitalizations.[19,20,21] Likewise, funders who have access to data about emergency room visits and emergency rooms may want to integrate broader system data into quality benchmarking, as well as to develop cross-system procedures focused on referral, linkages and appropriate care.
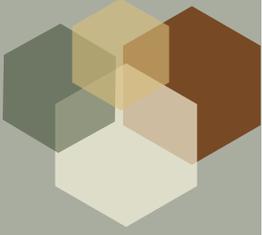
STEP 2. Become familiar with core documents and available resources.

As described above, there are numerous excellent resources focused on early psychosis intervention. A few of these are listed below to help get started.

Overview Information
The International Early Psychosis Association: A national organization which brings together researchers, practitioners, and individuals with lived experience to share knowledge and collaborate across nations. The IEPA has an international conference every two years: www.iepa.or.au
The National Institute of Mental Health: Created a central page with links to and a useful summary article about "Coordinated Specialty Care" as a standard for early psychosis and materials developed through RAISE, including an Implementation Manual: http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml
The Substance Abuse and Mental Health Services Administration (SAMHSA): Supported the development of a web-based environmental scan of early psychosis programs from throughout the world including multiple programs in the United States which offer technical assistance: http://www.nasmhpd.org/sites/default/files/Environmental%20Scan%20%202.10.2015_1%285%29.pdf
Other National Organizations and Agencies: The National Council on and NAMI have early psychosis resource information on their national websites, and NIMH is also developing a centralized location for early psychosis information. Numerous webinars have been archived and are available for viewing. The National Association of State Mental Health Program Directors (NASMHPD) recently launched a comprehensive Early Intervention in Psychosis virtual resource center that can be accessed at: http://www.nasmhpd.org/content/early-intervention-psychosis-eip
PEPPNET: The following document provides an overview of the new U.S. early psychosis network, PEPPNET: https://ncc.expoplanner.com/files/13/SessionFilesHandouts/D24_Adelsheim_1.pdf
England's IRIS initiative and Australia's Early Psychosis Prevention and Intervention Center: Developed usable and relevant resource materials: http://www.iris-initiative.org.uk/

ARE THERE PROGRAMS NEAR YOU?

The National Psychosis Prevention Council maintains a web-based listing of early psychosis programs and technical assistance resources nationally (http://psychosisprevention.org/), and EASA and the Foundation for Excellence in Mental Health also have developed a directory which is updated periodically (http://www.eaSacommunity.org/home/ec1/smartlist_123/national_resources.html).

Program-specific information. The SAMHSA environmental scan listed above provides a large amount of detail and links to programs around the world.
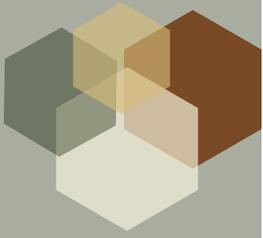
STEP 3. Identify and enlist an oversight/leadership group.

Successful implementation of early psychosis intervention requires significant leadership.[22,23] Formal leadership groups which meet on a routine basis increase the chances of success and help build personal investment and understanding among stakeholders.

The structure and function of leadership groups is likely to change based on the stage of implementation and the level of jurisdiction. It is essential at all stages to include strong voice and ownership by people with lived experience, family members, and key decision makers involved with implementation. A separate advisory group consisting of young adults with lived experience of psychosis can play a particularly powerful role. If one or a small number of young people is asked to serve on a larger group, their voices may be overwhelmed by the agendas and interests of other stakeholders.

CORE ROLES IN THE EARLY STAGES INCLUDE:

- Establishing a shared understanding of the underlying purpose, goals and methods of the program;

- Anticipating the future development of the program beyond its initial stages and to ensure that key decisions reflect the long-term needs;

- Ensuring the successful implementation of the program;

- Including key stakeholder perspectives in the planning and implementation process;

- Linking to other related processes to facilitate the new program's ability to succeed in its goals; and

- Establishing program performance benchmarks.

Oversight and advisory groups require staff support and coordination, so depending on the needs and developmental stage of the program, groups may not necessarily be permanent, and may evolve with time. As implementation progresses, oversight groups may play an important roles such as:

- Helping to facilitate and improve linkages to professional and community networks;

- Tracking outcomes and continuing to work toward improvement;

- Identifying gaps, needs and opportunities for improving the program's sustainability, comprehensiveness, and continuity of care; and

- Carrying the program's philosophy, goals and knowledge into partner organizations, such as medical organizations, schools, hospitals, etc.

SOME CONSIDERATIONS IN ESTABLISHING A LEADERSHIP STRUCTURE INCLUDE:

- How does the group relate back to existing decision making processes? For example, if there is a board or other decision making body, can the leadership group be established as a committee or initiative of the decision-making body rather than as an independent group? Tying the leadership group into a more formally supported and empowered decision-making body: (a) provides a higher level of sanction for the group's activities; (b) increases the level of coherence between the group's strategies and the overall system structure; and (c) provides ongoing opportunities for those who have ultimate responsibility at a system level to officially embrace the vision, goals and decisions of the early psychosis leadership group.

- How will the group be staffed? The process of recruiting, orienting and facilitating the group will require a skilled and knowledgeable individual, who may or may not be the same person charged with program implementation.

- How will participation by individuals with lived experience of psychosis, young adults, and family members be sought out and supported? Support may take the form of orientation, mentoring and role clarification, payment, logistical support (such as transportation and childcare), and interpretation.

- In some cases, a two-tiered structure of an operational oversight group and a strategic advisory board may make the most sense, since some members of the group will have different levels of involvement, but broader partnerships are also needed. The operational group could be a committee of the broader group rather than a separate structure.

- Likewise, there may be advantages to having both a state-level group which is able to address policy, regulatory, financing and state-level activities, and a local group which can build on partnerships to facilitate local linkages and outreach.

PERSPECTIVES WHICH ARE ESSENTIAL TO INCLUDE ON THE LEADERSHIP GROUP INCLUDE:

- Individuals with lived experience of psychosis and/or representation by key consumer organizations;

- Family members of individuals with lived experience of psychosis;

- Local program directors and managers for programs being implemented; and

- Representation of state and regional regulatory and funding organizations likely to impact implementation and sustainability.

Other key champions or partners who are in a position to facilitate successful implementation may also be helpful, on either the leadership team or an advisory group, or as less formal partners. These could include:

Representation of tribal leadership or key cultural groups reflective of the community

Mental health treatment provider organizations

Advocacy organizations

K-12 school system representation

Community and four-year college/university representation

Local crisis and hospital systems

Medical community

Vocational Rehabilitation and other workforce-related stakeholders

Public health representation

Law enforcement

Juvenile court/ forensics

Housing programs

Insurance companies

STEP 4. Orient the leadership group and other key partners to early psychosis intervention and how it relates to existing missions, initiatives, and priorities.

It is helpful to draw on outside expertise and resources. If a position charged with implementation has already been established, that individual may take the lead on orientation, or do so in combination with outside experts.

It is important early on for leaders to understand the transformative nature of early psychosis intervention. It is not simply an add-on to existing services, but requires a profound shift in how organizations think about and approach providing supports for young adults.

There are a variety of ways of articulating the organizing goal of the early psychosis effort; and how that goal or "problem" is defined will affect the vision and range of options considered, as well as the perceived relevance of the program. Goals such as reducing the duration of untreated psychosis and preventing relapse, while important, are more a means to an end than the end itself. So, for example, an overarching goal (such as keeping young people with early signs of psychosis on their normal developmental path and reducing long-term disability) provides a broader framework in which to incorporate the energy and vision of young people, families and other community partners.

Early psychosis intervention can also be framed as systemic work with the goal of more rapidly transforming the mental health system and its allies toward a coherent and agreed-upon long-term vision. Articulating early psychosis goals within a longer-term developmental context reduces the likelihood of complacency with an inadequate or incomplete effort, and provides a long-term framework for ongoing partner engagement.

AT A MINIMUM, THE INITIAL LEADERSHIP OVERVIEW SHOULD INCLUDE:

- Issues which early psychosis programs are trying to remedy and a vision for how the system will be different once early psychosis intervention is fully implemented

  - The early creation of a mission statement for the leadership group can help to rally partners and create a shared sense of direction.

- Philosophical underpinnings of early psychosis such as the stress-vulnerability model, developmental focus, and the importance of an evidence-based approach

- Core components of early psychosis intervention

- Team functions and intensity/flexibility requirements

- What is needed from leadership in the ongoing effort, including:

  - Addressing policy, regulatory and procedural barriers to developmentally appropriate, proactive care; and

  - Identifying and facilitating linkages to systems, organizations or individuals whose participation is needed or potentially helpful. For example, if the program does not have easy access to community/agency partners such as schools or adult crisis response, facilitated introductions may resolve these challenges. Likewise, issues of eligibility and intake procedures, human resources (i.e., interpretation of billing codes, productivity, flexible time, billing infrastructure and requirements), and sustainability (ability to fund all individuals and elements of the program) may require facilitation and advocacy by individuals at a senior level of authority.

- Finally, specific parameters from funders and regulators.

THE OVERVIEW MIGHT ALSO INCLUDE:

- Local data and first person accounts focused on service utilization and what currently happens when someone experiences psychosis; and

- Existing mandates and priorities which tie well to this effort (i.e., Olmstead Supreme Court decision/ other court decisions associated with the right to non-restrictive care, other state-level priorities associated with recovery, employment, etc.).

STEP 5. Identify one individual or a small team who will have the primary responsibility for facilitating successful implementation.

This individual or small group should have strong support and authority within decision making structures, and the ability to reach out to decision makers in a range of hierarchical positions to accomplish goals. Optimally, the early psychosis effort should be one individual's primary or sole responsibility, with a job description that reflects this. The individual can and should rely on consultation from outside experts as needed, but a local facilitator/advocate embedded in the decision making infrastructure of the state cannot be successfully replaced by individuals outside of the state.

ATTRIBUTES WHICH ARE HELPFUL IN THIS POSITION INCLUDE:

- A strong orientation toward person-centered approaches;

- Versatility in navigating and facilitating system development needs from multiple perspectives: analysis and translation of clinical and research knowledge, lived experience of people with psychosis and families, data and research, planning and implementation, financing, and operational concerns, as well as social marketing to a variety of audiences from policy makers to parents;

- Understanding of and commitment to the importance of this work;

- Ability to articulate and facilitate broad ownership over a coherent vision, set of principles, and action plan; and

- Problem solving ability, flexibility, and persistence.

STEP 6. Articulate long-term and short-term goals, roles and timelines.

IT IS USEFUL TO IDENTIFY SPECIFIC GOALS ASSOCIATED WITH THE EARLY PSYCHOSIS EFFORT, INCLUDING:

- What is the early psychosis effort trying to accomplish/change?

  - A before/after document is useful in providing a visual illustration of the change the early psychosis implementation is attempting to implement, and providing a framework for tying long-term vision to specific strategies and actions

- What implementation steps will be completed by whom and in what time frame?

- What changes are hoped for as a result, and how will those changes be measured?
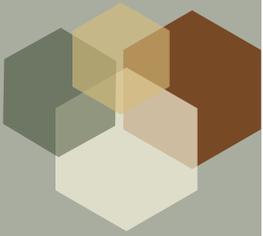
STEP 7. Identify initial resource availability and resource development needs, and resource development strategies.

Early psychosis services combine a range of activities, some of which are not ordinarily billable under health insurance. In addition, individuals served by early psychosis services frequently change insurance status. Limitations in service access based on insurance can create discontinuity and delays in care, force people out of the private insurance market and into publicly funded care, and create a situation where effective care is available only to publicly funded individuals and not to people who are privately insured. Thus, a proactive and intentional approach to diversified revenue is necessary for program efforts to succeed in the long run.

A FEW STRATEGIES WHICH EXISTING SITES HAVE FOUND HELPFUL, AND/OR WHICH HOLD PROMISE INCLUDE:

Maximizing Existing Billing	Within the existing environment, this may require staff licensure. In some cases, hourly billing can be increased to incorporate additional related functions such as outreach and team coordination.
Exploring Alternative Payment Methods	Adequately funded case rates or service bundling agreements may be preferable to fee-for-service, although funders need strong buy-in for this to occur
Re-aligning Existing Funding.	Federal Block Grant dollars have already been allocated. Additional potential resources include hospital diversion for individuals who have a legal right to services in the community, and partnerships with workforce and vocational rehabilitation organizations.
Extending Coverage	Since young adults are among the most likely to be uninsured and also tend to be very low income, the extension of Medicaid can have a major impact on their access to coverage. (Oregon's EASA outcome review data showed a decline from over 30% uninsured to under 10% in June 2014 almost entirely as a result of Medicaid expansion).
Utilizing Short-term Strategies	Private foundation grants and other short-term strategies may be effective in building the support for long-term financing.

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AS PROGRAMS BEGIN, AN INVENTORY OF PROJECTED RESOURCES, GAPS AND STRATEGIES IS IMPORTANT. QUESTIONS INCLUDE:

- What resources are already allocated to this purpose (Federal Block Grant, other sources)? Are there restrictions on the use of the funds?

- What financing sources could be available for this purpose and how would they be accessed (Medicaid and private insurance billing, funds targeting hospital diversion, jail diversion and indigent care, Vocational Rehabilitation, housing funds, private foundation funds, etc.?

- What gaps are anticipated?

- How might partnerships contribute?

- What early strategies will be pursued to maximize available revenue (i.e., grant writing, documenting gaps, advocacy, etc.)?
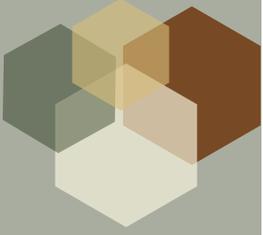
STEP 8. Identify the initial geographic catchment area and agency provider for the early psychosis program(s).

Where pilot sites are being identified, geographic factors, local leadership and infrastructure, and pragmatic considerations may contribute to the choice of catchment area. Factors affecting these decisions may include:

- Required procurement processes.

- Population size and density. There is not a specific requirement around needed population size to support a program, but the structure and expectations of the program will vary based on these factors. Also, it is easier to gain a "critical mass" of participants in areas with larger populations.

- Some attributes which are important for the choice of "early adopters" which will lay the groundwork for statewide efforts include:

  - Strong organizational and clinical leadership;

  - Commitment to and experience with adapting evidence-based practice;

  - Consistency with organizational mission;

  - Strong orientation to strengths-focused and person-centered approaches;

  - Strong relationships across the catchment area and commitment to access by underserved, rural and remote populations;

  - Engagement by people with lived experience and families in organizational decision making; and

  - Organizational practices which support outreach, flexibility in personnel practices and schedules, integration of data into decision making,and problem solving.
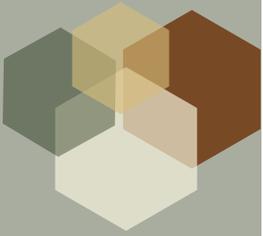
STEP 9. Define the program's initial eligibility criteria or guidelines.

While the primary focus of most early psychosis intervention programs is on identifying individuals in the early stages of schizophrenia and related conditions, symptoms in the early stages may be harder to differentiate, and it is important not to diagnose prematurely. Many programs internationally focus on a broader spectrum of psychosis. It is common for community-based criteria to be modified over time based on experience and ongoing discussion.

IN THE EARLY STAGES IT IS IMPORTANT TO CONSIDER THE FOLLOWING PROCEDURAL QUESTIONS:

- How will the eligibility criteria/guidelines be determined? What is the process for future modifications?

- How will the program facilitate rapid response and eligibility decision making? It is important to assume that individuals referred may end up rapidly in a life threatening situation and in need of proactive support, even when the referent does not describe behavior of imminent concern. Therefore initial eligibility decision making and engagement must allow for rapid early triage and response.

- Are the eligibility standards considered hard-and-fast criteria, or is there flexibility for exception? If there is flexibility for exception, who has the authority to make an exception?

- If an individual or referent disagrees with a decision, what is the appeal process? How is the decision and the appeal process communicated to referents and/or referred individuals? Who makes the final determination?

- No matter what eligibility criteria are established, the program will always receive numerous referrals which are not appropriate for the program. It is not uncommon for half to two-thirds of referrals to be outside of the program guidelines, with some referent groups much more likely to refer individuals not experiencing early signs of psychosis. Diagnostic clarification and a brief educational process for the referent is an important community service, and often it is considered good news that the person is not experiencing psychosis. This phenomenon leads to three important questions which programs must answer:

  - For individuals not accepted into the program, what is the process for facilitating entry into appropriate care, staying engaged until an appropriate connection has been made, and tracking the relative success in doing so?

  - What support is available for the team in facilitating access to appropriate care for those who are screened out of the program?

  - How will the program be described to the community in order to create accurate expectations? Program descriptions may explain the program as a community consultation service, as well as a treatment program, and explain the program's role in problem solving and facilitating appropriate care.

Each program faces specific decisions associated with eligibility:

WHAT WILL BE THE AGE RANGE AT ENTRY?

Generally age criteria only apply at the point of entry; if a person reaches the upper end of the age range during the program they are generally not discharged due to "aging out" of the program.

It is recommended that programs serve ages 15 to 25 at the minimum. This age range aligns programs with transition-age youth efforts and the typical age of onset, particularly for males. However, since the median onset for females is older, a younger cut-off leads to fewer females being identified. Programs have set their upper age cut-off as high as 40, but developmentally and programmatically it may be more difficult to maintain a coherent approach with a wider age span. Onset younger than 12 is very unusual and more diagnostically complex.

WHAT DIAGNOSTIC SPECTRUM IS ELIGIBLE FOR THE PROGRAM?

Since early psychosis intervention involves early detection of symptoms, those symptoms will not normally be diagnosed prior to entry into the program. The primary focus of many early psychosis programs is schizophrenia and related conditions, since this is the primary research base, and schizophrenia and related conditions have a history of poor outcomes and large public expense.[8,9,24] Some programs also include bipolar spectrum with psychosis. Diagnostic ambiguity and uncertainty is normal in the early stages. Many individuals will enter with a diagnosis of Psychosis NOS.

Some programs have chosen to accept everyone with psychosis. The benefit of this approach is that it simplifies screening and makes the program much more broadly accessible. The downside of this approach is that it opens the program up to a much larger group of individuals, such as those with depression, substance use disorders, and Post-Traumatic Stress Disorder, and it requires careful attention to the range of appropriate responses based on underlying diagnosis.

Most programs screen individuals out if their psychosis is due to a head injury or medical condition, since the needed approach is likely to be different. Appropriate medical examination and laboratory testing are important to rule out a range of potential medical conditions. Also, most programs screen out individuals whose psychosis is clearly caused by substances, although it can be expected that substance use will be common among those accepted and will create complexity in the differential diagnosis and treatment process.

Programs will need to determine whether they will accept individuals with intellectual disabilities. Many early psychosis programs do not accept individuals with intellectual disabilities because differential diagnosis can be complex, and early psychosis interventions may be unable meet the long-term and specialized needs of these individuals.

New early psychosis programs can anticipate that they will receive referrals of individuals with both undiagnosed and previously diagnosed autism who have recently developed psychotic symptoms. Referral guidelines should be clear in determining whether individuals with autism may accepted by the program, and if team members are serving autism spectrum they may need additional training in differential diagnosis and the unique needs of individuals with autism.

The diagnostic uncertainty of the early stages means that it is common for diagnosis to change with time. Once a person is accepted into the program, it is important to maintain ongoing responsibility until a successful transition has occurred. Changes in diagnosis should not automatically lead to the discharge of the individual. Each person's specific needs for treatment and support should be evaluated, with a gradual process of transition into ongoing care.

WHAT WILL BE THE CUT-OFF RELATED TO DURATION OF UNTREATED PSYCHOSIS?

The goal of early psychosis intervention is to identify and engage the individual as soon as possible once symptoms develop in order to prevent severe impact on functioning. Thus, earlier is better. The hope is that as the program continues with time there will be fewer people who have gone for long periods without treatment.

The program will need to determine whether there is a cut-off related to duration. This is not mandatory; programs could choose to use age and symptoms alone, but longer duration of symptoms means that individuals are likely to be more disabled and require higher amounts of care. Since early psychosis practices are consistent with evidence-based care for individuals with longer-term illness, integrating similar practices across the system is a good strategy for ensuring that people with longer-term needs are able to get those met.

Duration cut-offs in early psychosis programs range from 6 months to 2 years[26] or even longer. This is from the onset of acute psychotic symptoms, not including psychosis risk syndrome (prodromal) symptoms which may extend back considerably longer.

HOW WILL THE PROGRAM ADDRESS PSYCHOSIS RISK SYNDROME?

The "psychosis risk syndrome" refers to the period of onset before the individual's symptoms pass the threshold of clinically diagnosable psychosis. The dividing line between "psychosis risk syndrome" and "psychosis" as measured by standardized tools such as the Structured Interview for Psychosis Risk Syndrome (SIPS) involves the person's lack of ability to reality test, degree of conviction in delusional beliefs, and the degree to which the person rearranges life activities around the psychotic symptoms.[25] Once psychosis occurs, the onset period is referred to as the "prodrome". Early symptoms prior to diagnosis should not be referred to as prodromal because the prodrome is a retrospective concept and the majority of people who develop symptoms consistent with the psychosis risk syndrome will not develop psychosis. Incorporation of prodromal/psychosis risk syndrome symptoms into community education and clinical assessment facilitates more rapid referral and provides information helpful to anticipate the person's relapse process.[25]

First episode programs will receive referrals of individuals who may be experiencing hallucinations, paranoia, bizarre behavior, emerging delusional thoughts and significant declines in functioning but whose symptoms fall into the "psychosis risk syndrome". Once a person has lost insight, consequences such as legal charges, involuntary commitment and severe loss to roles and social network are common and can be rapid. Accepted practices for individuals identified as "psychosis risk syndrome" are also different, particularly in the area of medication use. It is important that local teams understand the difference and that they have an intentional strategy for responding to individuals whose symptoms are below the clinical threshold for psychosis. One potential strategy is to recommend services elsewhere but provide brief education about the symptoms or changes that would warrant a re-referral. Another strategy would be to begin to incorporate psychosis risk syndrome intentionally. The current national expansion of early psychosis services is focused primarily on first episode services so there may be prioritization and restrictions in funding which discourage integration of the psychosis risk syndrome. *[Note: Because the SAMHSA Mental Health Block Grant dollars can only be used to serve persons who already have a serious mental disorder, states might opt to use other funding sources to support care for persons at risk for psychosis.]* Furthermore, clinical and ethical considerations include addressing medication use and labeling.

Clinical services for psychosis risk syndrome must address a broad spectrum of potential etiologies, and medication use is much less frequent and more potentially problematic. Also, the confusion of "risk syndrome" versus "prodrome" can lead to over-labeling and treating the person as if they have a condition they do not have.

WILL THERE BE RESTRICTIONS ON INSURER/FUNDER?

Perhaps the most challenging aspect of implementing early psychosis intervention in the U.S. is the fragmentation of the delivery system.[8,24] Successful implementation of an effective program typically requires diversification and realignment of funding. Many public systems do not accept private insurance payments, although a large percentage of young people develop the early stages of illness when they are either privately insured or uninsured. Accepting only Medicaid or other forms of public insurance may result in significant delays; young people often enter the public system after an extended period of receiving inappropriate or no care, resulting in more advanced illness and the resultant consequences. Leadership and supplemental funding are needed in order to take a population-based approach in which funding is not a determinant of eligibility. At a community level, this kind of coherent and coordinated approach has the most benefit and does not perpetuate a multi-tiered system in which young people are encouraged to opt out of private insurance in order to access the care they need. This particular area is one where significant work is needed at policy and systems level to ensure that individuals with private insurance, Medicare and no insurance are able to access care appropriate for their condition.
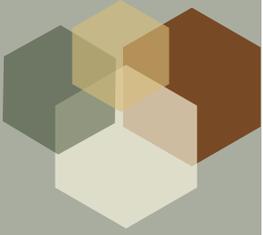
STEP 10. Develop initial incidence projections.

Incidence is the number of new individuals developing a condition during a time period, whereas prevalence is the estimated number of individuals having the condition during a specified period of time.[27] An initial projection of annual incidence will provide an important part of determining the team capacity needed. Estimates of incidence for program planning are based on a combination of diagnostic spectrum and age range, epidemiological research, and experience in the field. There is some evidence that urban areas may have a slightly higher level of incidence than less urban areas.[28,29] Epidemiological research studies offer a range of incidence figures, so ultimately there is some level of arbitrariness in initial estimates. The number of new people entering the program will also be impacted by the fact that even in the best of ascertainment systems there is some inaccuracy, and the programs will intentionally accept individuals at earlier stages where there is less diagnostic certainty.

In addition to the anticipated incidence, programs should factor in the fact that for every appropriate referral they can expect one to two referrals which will not be appropriate. Despite being screened out from the program, these referrals can take a significant amount of time in assessment, debriefing, problem solving and assisting with linkages in the community. The EASA program assumes approximately an average of three hours of time per referral, whether the person is accepted into the program or not.
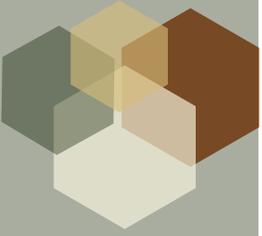
STEP 11. Identify expected staffing levels and positions.

There is broad consensus that the best approach to care for individuals who are in the early stages of psychosis is through a closely coordinated team with multiple disciplines. Given the level of acuity and the multi-dimensional needs of individuals who experience psychosis, early psychosis teams often adopt intensity and coordination standards similar to Assertive Community Treatment, recommending that programs plan for a level of intensity of about one full-time equivalent team member for every ten program participants.[20]

A FEW CONSIDERATIONS WHEN CONSTRUCTING POSITIONS:

- All roles operate as part of a single team and should have the capacity to serve both under and over 18 without having to transition to a different clinician. This often requires additional training and supervision to help team members gain comfort with an age spectrum they may not have previously served.

- Early psychosis teams require close coordination, flexible response and a steep learning curve. Consolidating into fewer positions which are full-time or closer to full-time increases efficiency and flexibility.

- While each team member brings special knowledge, functions are sometimes shared across positions depending on the specific needs of the participant.

- Although the team as a whole may try to maintain a 1:10 ratio, individual positions typically serve more than that ratio. Planners may choose to set a limit to the caseload for specific positions, or standards about access, minimum frequency and duration of contact.

- If some positions are not mobile and others are, the individuals in mobile positions often engage more rapidly with participants. More strongly engaged team members may need to facilitate the connection to others who have not established that engagement. Enabling all roles to do outreach and cross-training in core skills increases the overall level of engagement and team effectiveness.

- All positions will have some level of contact with family members, and all will offer some level of psychoeducation.

- It is common for more than one staff person to participate in a meeting with the person. For example, counselors often join meetings with the psychiatrist.

- Job descriptions should be specific to early psychosis functions rather than using standardized language from the agency.

- Attention to cross-training and backup is important in order to maintain consistent performance during holidays and when there is staff turnover.

THE EXACT ROLES AMONG CLINICIANS VARY ACROSS TEAMS, BUT COVER THE FOLLOWING FUNCTIONS:

Clinical supervision. Consistent, proactive and frequent clinical supervision is extremely important for supporting skill development, problem solving, and modifying and buffering competing demands and expectations. It is common for early psychosis teams to have multiple supervisors (medical and supported employment are often separate units). Where this occurs, it will be important to ensure that all supervisors have basic training and agreement about what practices are expected, and that they meet regularly to address any conflicts or concerns.

Community education. The frequency and persistence of community education is one of the most important determinants of whether individuals are developed at an early stage and whether the program receives appropriate referrals. One person should have primary responsibility to community education planning and coordination. All individuals providing community education should be trained in effective messaging.

Community consultation, screening, intake and engagement. For every person accepted into the program, a significant number (as high as half to two-thirds) of referrals are not a good fit for the program. To maintain the program's positive reputation to ensure consistent high quality, referents and the individuals being referred will need meaningful guidance in finding appropriate care. In addition, many people who have psychosis will not recognize they are ill and will require effort to engage. Thus, a member of the team who is skilled in differential diagnosis and engagement needs to set aside significant time for this set of functions.

Acute care. Psychosis can be life-threatening, so early psychosis programs need to pay close attention to risk assessment and to linking with acute care systems. Twenty-four hour response availability is needed. Some early psychosis teams include on-call duties, while others link to local crisis systems. Acute care practices can cause trauma and negative perceptions of coercion. In addition, many acute care settings turn rapidly to high-doses of medicines with negative metabolic syndrome profiles or other significant side effects. Since early psychosis programs typically start with low doses and emphasize careful attention to prevent side effects, early psychosis programs often try to switch individuals who start out with high doses of side-effect-inducing medicine. The switching process may be complicated and the initial experience of medication may impact the participant's long-term perceptions.

Lead clinician. This role may go by various titles and may be filled by a range of disciplines such as a counselor, therapist, social worker or psychologist. The lead clinician is generally a masters-level or more advanced clinician who takes a lead in assessment and clinical interventions. This position uses a range of clinical approaches, which can include cognitive behavioral therapy, psychoeducation, motivational interviewing, feedback-informed treatment, trauma reduction, in vivo strategies and other strategies such as mindfulness training. Traditional therapist and care management roles are sometimes blended, since the process of engagement requires significant outreach and the translation of knowledge is sometimes easiest in "real-life" settings. Generally caseloads need to be carefully managed based on acuity and clinical intensity. It is recommended that these positions never have more than 25 participants per full-time position.

Peer support. Individuals with lived experience of psychosis who have navigated that experience successfully can play a crucial role in supporting the early recovery process, as well informing other team members. While professional peer support roles are common throughout the mental health system, their emergence in early psychosis programs is relatively recent. Although there is not yet a strong evidence base around peer support in early psychosis, there is growing recognition of the importance and impact of this role.[30] Successful implementation will require clear job duties, significant leadership and team training to ensure a supportive climate.

Care management[2] and skills training. The team works with the participant and family as needed in goal-directed activities based on the person's needs and interests, such as helping the person utilize public transportation, engage in community recreation, access insurance and learn to live independently. Some programs utilize staff with bachelor's degrees or less to assist with these types of tasks.

Psychiatry. Psychiatry is a crucial part of the team. In some states and locales psychiatric nurse practitioners are utilized in conjunction with, or sometimes in lieu of, psychiatrists. It is essential for the medical professional to attend all team meetings, and to ensure rapid access and frequent contact, including seeing individuals when they choose not to take medicine. Like all team members, psychiatrists or psychiatric nurse practitioners need to have the ability to serve both under and over age 18, along with in-depth knowledge about psychosis, adolescent physiology and developmental context. Medication algorithms are available to support prescribing practices. Early psychosis programs will want to address whether an algorithm will be used, and if so, how.

Nursing. Registered nurses are key players in coordination of care across medical settings, monitoring for symptoms and side effects, and nutritional and wellness-related programming within the team. They are not included on all early psychosis teams and there are not identified standards for levels of nursing, but given the significant health concerns (such as early mortality and metabolic disorder), nursing functions should be carefully attended to.

Family support. Families are critically important partners in early psychosis programs, for individuals under and over eighteen. They are often the primary catalysts and facilitators helping the person find the way to the team. Partnership with families and use of evidence-based individual family and multi-family group psychoeducation both supports families and can have a significant impact on the participant's functioning and symptoms.

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[2] Care management is used here instead of the term case management. Although the term case management is still popular, it is often perceived as a negative term suggesting that they are dehumanized "cases" in need of "management". Careful attention to language connotation is a key element of early intervention.

Supported employment and education. [31,32] Supported employment and education is a near-universal expectation within early psychosis programs. Without a strong supported employment and education focus, there is significant iatrogenic potential for programs to facilitate young people's exit from a career path and entry into long-term disability as a primary focus. The Individual Placement and Support (IPS) model is the most comprehensively researched approach and is currently widely viewed as offering the most effective evidence-based approach.[31] However, IPS was developed with individuals who were older and already on disability benefits, so the approach has to be adapted to transition age young adults who are entering a career path. Specific areas which are central for early psychosis teams include career planning, supporting participants in completing or returning to school, and supporting unpaid career development activities. Some early psychosis programs incorporate a hybrid supported employment and education role, whereas others have a wholly distinct supported employment role and delegate supported education to other team members. Although many individuals with psychosis do extremely well in school, the evidence base for supported education is much less extensive than for supported employment.

Occupational therapy. Some national and international early psychosis programs utilize occupational therapy as a core element of their programs. As the understanding of schizophrenia and psychosis evolves, occupational therapy skill sets are becoming particularly relevant. They play key roles in identifying and ameliorating underlying cognitive and sensory issues which have significant impacts on functioning and often go unrecognized. In addition, they are skilled in helping to improve people's ability to function by breaking down tasks, identifying accommodations, and helping to build routines. Occupational therapists are often particularly adept at group development and implementation, as well as brain-body strategies for enhancing learning, activation and stress management. Occupational therapists also sometimes work with occupational therapy assistants, who require significantly less schooling and are able to carry out many occupational-therapy related activities at a lesser cost.

Substance abuse. Early psychosis programs normally provide substance abuse treatment using a harm reduction model. The optimal approach is for substance abuse services to be provided within the team, and for the team to integrate dual diagnosis best practices.[33]

Cultural adaptations. Team members will need to actively seek to understand the culture of their community and the individuals they work with, as well as biases and preconceptions endemic in their own cultures. Cultural information should be actively sought from the point of first contact, and integrated into the conceptualization of community education strategies, explanatory models and treatment approaches.

Housing/independent living. A portion of individuals referred to early psychosis programs are homeless or at risk of becoming homeless. Depending on their stage of individuation, most participants are actively working toward higher levels of independent living in the community. Teams should be prepared to help with housing and independent living skills development, and to link with local community resources.

STEP 12. Determine how long the program will be.

Early psychosis intervention programs are almost always viewed as transitional, and where they are time-limited they should always incorporate a systematic and gradual transition into longer-term supports. Many, if not most, individuals in early psychosis programs will require ongoing support to maintain the gains that they make during the program.

One of the core concepts of early psychosis intervention is the "critical window" construct, which identifies the first three to five years as a core period during which the long-term level of disability is often established.[34,35] Although many early psychosis programs currently have durations of two years, in a recent review of standards for early psychosis programs, a three to five year duration was identified as optimal.[18]

No matter how long the program, rapid access for new referrals as they emerge is a core feature of early psychosis intervention. Thus, if the program will be longer, it will be important to ensure the ability to manage the ongoing projected volume of the program.

One of the challenges in a longer program is the difficulty of maintaining a transitional focus. One method of providing longer-term supports while also maintaining a strong transitional focus and access is to create a series of demarcations of progress within the program which will allow acknowledgement of the accomplishments of participants and change the nature of the relationship between the individual, family and the program gradually as they transition. For example, some programs provide long-term access to certain services such as multi-family psychoeducation, vocational support, and advocacy and problem solving. Graduates of early psychosis programs become important resources as they act as natural role models, share feedback and knowledge gained from their lived experience, take more of a role in leadership and advocacy, and provide better understanding about the long-term needs of program participants.
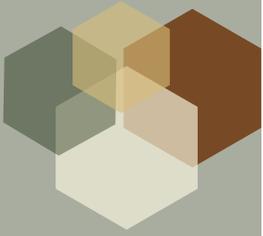
STEP 13. Develop caseload projections.

The actual level of staffing will be determined by projected incidence in combination with duration, assumptions about how many individuals will be retained over time, and maximum caseload requirements. A spreadsheet format such as the one developed by RAISE Connections may be helpful (http://practiceinnovations.org/OnTrackUSA/tabid/253/Default.aspx). It is important to note the underlying assumptions in order be able to track their accuracy as the program develops. A few areas requiring assumptions:

How quickly will individuals enter the program? This is impacted by the eligibility criteria, consistency of the screening process, population size, demand and visibility of the program. Often in the beginning there are a significant number of referrals of individuals who have been experiencing psychosis for lengthy periods without appropriate care, and in some cases those individuals are accepted into early psychosis programs. The advantage of accepting individuals (often by exception) who have had longer duration of psychosis is that it offers them evidence-based care and it allows the program to gain relevance in the community. The disadvantage is that the people who have been experiencing psychosis for longer may have greater and longer-term needs. Also, if the community is not adequately serving individuals with long-term support needs, this issue will need to be addressed at a community level in order to ensure the long-term success of early psychosis program graduates.

- *How many will continue over time?* Generally there will be some attrition, even with proactive engagement, as individuals move, choose not to continue, or connect to care elsewhere.

- *Will the anticipated intensity shift with time?* In the early stages the lead clinician may need to maintain a 1:10 ratio temporarily if the entire caseload is made up of people who are newer and have higher acuity, but the ratio may shift as high as 1:25 for longer-term less intensive needs. Likewise, the overall level of care may not need to be as much after the first year. It is important to maintain intensity in order to respond to acuity and help participants maintain developmental momentum, but simultaneously the program must balance the need to maintain access.

- *At what point will the team become fully staffed for its long-term projected capacity?* Since referrals to the program occur gradually, it can take as long as two years or more before the program has reached its anticipated capacity. There is a great deal of need for community education in the beginning stages, so having extra staff during that time can help speed up getting the word out and generating referrals. However, community education activities are not billable and excess capacity is not sustainable without start-up funding.
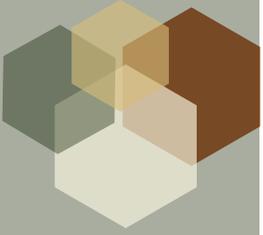
STEP 14. Develop a projected team budget.

The simplest short-term method for developing a budget is to identify projected staff costs and projected revenue. This step cannot be entirely completed without clarity about where the program will be housed, since there are significant variations in salary levels.

Typically Medicaid funding will reimburse a much higher percentage of the costs than private insurance, although a case rate is generally preferred if the funder is willing to negotiate an alternative funding methodology.

It may be helpful to establish a sustainability committee early on including key government and funding representatives who can review which elements of the program are currently funded and which are requiring subsidization. By enlisting funders in problem solving early on they may be able to identify opportunities such as hospital diversion, work force or other funds which can help provide diversified funding for local and statewide efforts. Engaging funders in the sustainability dialogue also helps to build program champions who may ultimately support solutions such as legislative appropriations.

Most early psychosis programs will require ongoing subsidization given the current financing system in the U.S., so careful attention to financing and collaboration across sites to build a long-term strategy is important. As insurance parity requirements become better articulated as they relate to team-based services for individuals with serious mental illness and preventive services, and as fewer individuals remain uninsured, early psychosis programs will likely become easier to fund. Meanwhile, early psychosis programs play an important role in identifying and advocating for long-term financing strategies.
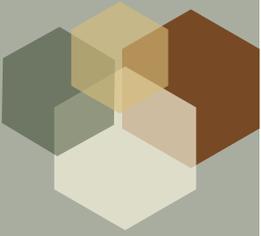
STEP 15. Establish a strong internal management/ support infrastructure at the agency level.

Once the provider agency is selected, it will be important to repeat or review the orientation and initial planning process with senior management staff, including agency director, clinical supervisors, and key operational staff together to review implications of the new program for functions such as human resources, quality improvement, and finance. Ongoing communication and problem solving with funders and regulators should be established from the beginning, and if there are multiple providers within the state, it is optimal to create a forum for shared decision making and problem solving.

At the earliest stage, key managers need to understand the intent and core parameters of the program, early systemic infrastructure needs, opportunities for linkages to efforts beyond the program, and common challenges to anticipate and plan for, such as issues with productivity standards, youth-friendly communications, flexible work schedules and the need to modify forms. It is important early on to map how communication about the early psychosis program, referrals, intake, data collection, assessment and treatment planning, and discharge planning will occur within the agency's normal service flow, and what needs to be different to accommodate the program's needs.

OVERSIGHT

How will the early psychosis effort connect formally to local governance and quality improvement structures? Since the program relies on partnerships and requires philosophical and practice realignment and redesign in multiple activities throughout the organization, it is important to tie efforts into formal governance or local oversight processes. If the effort is primarily local, this oversight group could be combined with the state level, but local governance should not be overlooked.

WHERE IN THE ORGANIZATIONAL CHART WILL THE EARLY PSYCHOSIS PROGRAM STAFF BE PLACED?

For programs which are not stand-alone, it is particularly important to attend to the consistency between the early psychosis functions and other responsibilities of team members. The following factors may affect the decision about where to place the early psychosis program:

- Strong clinical supervision is a key element of early psychosis intervention. Clinical supervision focuses both on supporting clinical development and decision making, as well as advocating and linking within the larger system.

- Since early psychosis programs involve rapid, sustained and intensive response to the needs of individuals identified, it is important that the environment support this type of response. When agencies attempt to combine early psychosis work as part of a person's job with large caseloads in the other part, it frequently becomes highly problematic.

- Most mental health centers currently have separate youth and adult services. Early psychosis services combine these and can help move the agency toward a teenage/young adult focus. It is important to recognize that services housed in the child and adolescent part of the organization will often lack basic knowledge about psychosis and adult resources, whereas on the adult side there is often more knowledge about psychosis and less about developmental psychology and schools.

- In addition, it is important to attend to the culture surrounding the program. Early psychosis teams thrive best in an environment which has lower turnover, a strong and consistent orientation toward strengths, person-centered planning and outreach, and a strong support for flexibility and creativity.

Physical location. Physical location is a very important element because it can facilitate or work against the teams' goals, and it has a strong impact on the perceptions of individuals coming into the program. Some considerations in planning the physical location include:

- What will the space feel like to young adults? What is the waiting area like? If there are a large number of much older individuals who have long-term illness or small children this can work against engagement. It is helpful to engage young adults early on in giving feedback about the physical and emotional climate they experience entering the program.

- How will the staff achieve physical proximity? Co-location is optimal. Team members will need the ability to confer with each other routinely, and having the team in the same physical location makes communication much easier as well as building a visible sense of identity.

- How will the program address medical space needs? This includes appropriate secure and climate-controlled storage of medication samples, lab testing if this is being done on site, equipment for measuring height and weight, a sink, and other needs identified by medical staff. It is important to have a private space for physical examinations and medication injections where appropriate.

PROGRAM NAME AND VISIBILITY.

- The program should have its own name and look, which may include a logo. It is optimal for the name to be the same across sites if there are multiple programs beginning in a state. Naming the program can be an important early role for young adults and the new team. It is important to think about the connotations of the name and how individuals referring and being referred may react to it. For example, a team named the "Early Psychosis Initiative" may encounter immediate resistance by individuals being referred in response to negative assumptions about the term psychosis.

- Signage within the physical location indicating the presence of the early psychosis team helps to facilitate a sense of identity both within the agency and within the community.

Human resources considerations. It is critical to identify staff who are motivated to learn and to do the work, as well as to adapt human resources processes to ensure they are appropriately supported.

- **Hiring.** While this may seem obvious, it is important to develop job descriptions which explicitly describe early psychosis functions and expectations, and to recruit for the individuals who are suitable for the job. If team members are selected through a reassignment process, it is important to make sure that they want to be doing the work and are a good fit. There are advantages to using staff who are well-established in the agency and community, since (assuming they are motivated and the right fit) they may be less likely to leave the agency and better prepared to navigate systems. Staff attributes which are particularly important for early psychosis programs are noted below:

  - Preferably, staff should reflect the cultural, linguistic and ethnic diversity of their community.

  - Early psychosis programs need staff who are flexible, proactive, persistent, believe in the capacity of individuals with psychosis, love learning, and enjoy working with teenagers and young adults.

  - Highly skilled clinicians with experience in psychosis are preferable, although mindset may be more important.

  - It is highly recommended that hiring committees routinely involve individuals with lived experience and family members throughout the process.

- **Productivity standards.** Early psychosis professionals often fall short of agency productivity standards because they are involved in team-related activities, outreach, community education, coordination and training. Agencies often either reduce the productivity standard for members of the early psychosis team, or count additional activities toward the standard.

Communications and technology infrastructure. Access to cell phones and internet are essential for this program. In addition, a few things to consider early on:

- **Direct phone line to the program.** The program will need its own phone number for referrals. It is very important to ensure that this phone number remains the same over time because it will be widely distributed in brochures and other community education formats, and if the phone number changes people may not find the program.

- **Texting and email policy.** Many individuals, particularly young adults, no longer communicate directly by telephone. Texting may be the only way to reach a young person, and family members often want to use email to communicate. While this will require its own procedures to obtain required permissions and there are appropriate limits on content, agencies will need to address how emails and texting can occur where it is the only way to communicate with an individual or family.

- **Health records systems.** How will existing health records systems be modified to include required elements of the early psychosis program? Typical areas needing modification include:

  - **Referral tracking.** Information about referrals and the reason for acceptance or non-acceptance needs to be tracked over time, even for those who are not accepted into care. Re-referrals are common, so it is important to know the outcome of the prior referral. Also, referral data provides important information about the impact of community education, sources of referrals, demographics of individuals being referred, accuracy of referent sources, and other important information for quality improvement such as timing between the referral and intake and frequency of repeat referrals.

  - **Assessment.** Early psychosis assessment is relatively more comprehensive than some agency assessments, and so forms may need to be modified. Examples of this include: comprehensive strengths assessment, areas of risk assessment going beyond criteria for imminent threat, more detailed information about premorbid functioning, onset process and explanatory models. The program may also elect to add clinical assessment tools which need to be integrated into charts.

  - **Treatment plans.** Treatments plans should be easy to customize and modify and should be readable and easily accessible for printing in order to share with the individual and team.

  - **Crisis plans, relapse plans and/or advanced directives.** Early psychosis programs typically develop proactive plans which identify early and late signs and a plan of action which has been agreed to by to the young person and family. If the person presents through the crisis system it is important to have access to these documents.

- **Website.** It is optimal for the program to have its own web page, and preferably, website.

- **Brochures.** The program will need its own brochures and informational material, preferably of high quality, with color. Brochures should include basic information about early signs and symptoms of psychosis, who the program accepts, and how to make a referral. Materials should facilitate a positive and hopeful outlook on the likely success of young people facing these conditions. Brochures and other educational materials should be translated into common local languages, and may need to be modified based on cultural differences.

Linkages across the agency and systems*.* The team has numerous responsibilities which will require support and modified procedures from other parts of the agency and system:

- **Orientation of internal stakeholders.** How will internal stakeholders be oriented to the program and how will they facilitate referrals to the program? How will new staff be oriented to the program? Specific stakeholder groups to consider include reception, intake, adult and children's crisis team(s), outpatient mental health and substance abuse.

- **Community education.** Do others in the agency or the community have pre-existing community education efforts which the team could connect to? Are there relationships with hospitals, high schools, colleges, public officials or media?

- **Referral and intake processes.** How will normal referral and intake processes be modified in order to allow rapid, direct access to the team?

- **Fee policies.** Since services are intensive, people paying out-of-pocket may end up with a large bill which results in them choosing to limit necessary care. It is important to develop methods for minimizing the financial burden on families which cannot afford the cost of the program.

- **24-hour crisis support.** How will the program link to and provide 24-hour crisis services? If a person is referred through the crisis team, how will a rapid linkage to the team occur?

- **Sustainability planning and billing.** Proactive billing and revenue maximization strategies are important for the sustainability of these intensive programs. Some specific strategies related to financing and billing functions which may be useful include:

  - Educating and monitoring staff to ensure they use billing codes which are appropriate;

  - Setting rates to better incorporate the program's real costs (i.e., higher level of travel time, etc.);

  - Pursuing private insurance panel participation and staff professional licensure;

  - Negotiating alternative payment methods with funders such as case rates and service bundle arrangements; and

  - Pursuing alternative financing (e.g., vocational, crisis diversion, housing related, private foundations, legislative appropriations, etc.)

- **Interpretation, translation, cultural consultations.** Programs will interact with a variety of cultural groups, and will need rapid access to trained interpreters and translation services, as well as cultural consultation.
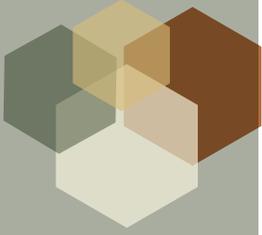
STEP 16. Identify clinical strategies and standards.

It is useful to replicate an existing model which offers a foundational template. Existing models are continuing to evolve and have particular strengths as well as less developed areas. Programs should determine how each of the following elements will be provided, trained for and monitored. Since all of these practices have relevance beyond early psychosis intervention, integration of these practices at a broader scale will facilitate the success of the early psychosis program. The more consistent early psychosis practices are with broader practices in the agency and broader system, the less the program will be working at odds with its environment, and the more graduates of the early psychosis program will experience continuity of support.

Outreach and engagement. Programs need to integrate proactive, flexible, strengths-oriented engagement methods in order to make the program relevant and accessible.

COMPREHENSIVE RISK ASSESSMENT AND SAFETY PLANNING.

Individuals experiencing psychosis, or even in the stages leading up to psychosis, are at significantly greater risk of suicide, as well as accidental harm.[36] From the first conversation, clinicians will need to be assessing for potential risk to the individual or, although far less common, to others. This assessment goes significantly beyond risk assessments traditionally done in mental health centers where the focus is often assessing for involuntary commitment criteria. Specific areas which should be included in the assessment are:

- History of self-harm or aggression;

- Suicide and aggression toward others;

- Content of delusions and how the person is thinking about responding;

- Conflict in the environment;

- Impulsivity and access to car keys;

- Access to weapons, medications that are lethal if taken in excess, including over-the-counter medications, or other potentially lethal means; and

- Self-neglect and potential for victimization.

Strengths assessment. A comprehensive strengths assessment and ongoing focus on strengths discovery is a core element of all effective early psychosis programs. Organizations often have a small "strengths" section in their assessment, but in early psychosis programs, comprehensive strengths addressing multiple life domains and social relationships form the scaffolding for the interventions. It is through these strengths that individuals are able to construct meaning, purpose, daily structure, social supports and career paths. See the University of Kansas website for a good resource: http://mentalhealth.socwel.ku.edu/principles-strengths.

Person-centered planning. The goals which provide the direction for treatment activities come from the individual's perspective and with input from the family; clinical strategies are viewed as a method to build the person's capacity and remediate symptoms which prevent the person from moving forward with these goals. This provides a common understanding between the clinical team, the person and family of what the group is working to accomplish together.

Comprehensive clinical assessment. The elements of clinical assessment incorporate standard mental health assessment, but also delve more intensively into areas such as the progression of symptoms over time, premorbid functioning, family impact, and explanatory models.

Shared decision making processes. Transparency and shared decision making with the individual being served and family members are core values for most early psychosis programs. Thus, programs will need explicit and robust methods for facilitating decision making partnerships and for integrating feedback into program design and quality improvement.

Team coordination. Early psychosis services rely on close collaboration among team members, working off of a single plan of care. In order to accomplish this, team members meet and discuss every person who they are serving at least weekly, in addition to routine coordinated treatment planning and review, shared training and planning. Many early psychosis programs have adopted methods similar to Assertive Community Treatment standards.[20]

Clinical supervision and clinical management. Team members routinely work with individuals who may be dealing with acute and potentially life-threatening symptoms, as well as a range of complex needs related to their stage of development and relationships. Skilled, frequent and easily accessible clinical supervision is critical for problem solving, clinical skill development, and ensuring that the work is well-supported within the agency structure.

Family psychoeducation. Family psychoeducation has a strong evidence base and effective family psychoeducation can have as much impact on outcomes as any other mode of treatment.[37] It is optimal to offer family psychoeducation in both group and individual family settings. Core elements include joining (spending time engaging with, listening to and providing initial education to family members), providing core knowledge about the illness, symptoms, gradual onset and relationship to relapse planning, impact on family members (changed expectations, conflict, grief, etc.), needed skills of communication with someone experiencing psychosis, healthy limit setting, and other guidelines related to family support. Ongoing sessions typically include a focus on social interaction, check-in about what is working and challenges, structured problem solving and follow-up. To implement family psychoeducation effectively, clinicians should receive training and ongoing consultation.

Peer support. There are multiple models of peer support and not a clear consensus on a single model most relevant to early psychosis. It is important for individuals who have recently begun to experience symptoms of psychosis to meet others who can share knowledge gained from both direct experience and training. It is important that the functions of peer support positions be well-articulated and structured, and that leadership recognizes the staff training, cultural shifts and clinical supervision needed to fully embrace peer support.

Cognitive Behavioral Therapy. Cognitive behavioral therapy (CBT) for psychosis, depression and anxiety have a well-established evidence base.[38,39] Basic CBT skills can be useful for all team members, and a more extensive skill set within the team is desirable, with at least one team member trained to competency in formulation-based CBT for psychosis.

Substance use disorder treatment. A substantial subgroup of individuals in the early stages of psychosis will use alcohol or other drugs, and early psychosis teams should be competent in assessing the impact of this use and whether it is at a level of misuse or abuse, and intervening. Generally harm reduction strategies and integration of motivational interviewing are the standard approaches within early psychosis teams, where the level of substance abuse is not advanced enough to need more intensive care (e.g., detox or residential treatment).[33]

Supported employment. The best-researched model of supported employment for this population is Individual Placement and Support (IPS), which focuses on rapid access to support for job search and retention of competitive employment.[31] Employment specialists focus heavily on employer relationships and employment-related activities. Within an early psychosis setting, supported employment specialists have to be able to work with young people who often have no work history and who often are as focused on educational progression as on work. Young people may also be ambivalent or lack confidence in their ability to work, and the supported employment specialist may play the role of introducing them to the workforce for the first time. In addition to employment experience in the short term, early psychosis programs should consider how long-term career exploration and planning can be facilitated, and how early psychosis services can link to long-term employment and educational supports after individuals have completed the program.

Supported education. The IPS principles of supported employment are also widely used in early psychosis programs' efforts to support individuals in high school, college, apprenticeships and other post-high school educational settings.[32] Blended supported employment-supported education roles are common in early psychosis programs, although the degree to which these roles can and should be blended is still under debate. The experience of psychosis symptoms does not prevent the ability of individuals to complete these programs and do well. Team members should become familiar with the types of supports available on campus, including 504 plans, Individualized Educational Plans (IEPs), and how to work with higher education Disability Services. Both for school and for work, the ability to assess for and identify accommodations for cognitive, sensory, and symptom-related issues including anxiety are important supports for young people who are continuing in school.

Trauma reduction. Differential diagnosis for post-traumatic stress disorder is an important part of the diagnostic process, as the treatment for PTSD may differ substantially from the recommended treatment for schizophrenia. Also, the experience of psychosis itself, along with the experience of law enforcement intervention, involuntary commitment and other frightening and dangerous experiences may create trauma.[40] Intentional debriefing and trauma-informed practices are an important part of treatment.

Cognition. Many individuals with early psychosis experience difficulties with slowed information processing speed, working memory, attention and other cognitive functions. These changes can be accommodated, and perhaps even remediated. Understanding how to identify and accommodate cognitive challenges is a core competence of early psychosis teams. Cognitive remediation or enhancement models have achieved a significant evidence base and are increasingly being integrated into early psychosis programs.[41]

Psychiatric care and prescribing. Care by a psychiatrist or psychiatric nurse practitioner is a critical part of early psychosis intervention. A formal or informal algorithm which encourages low dosing with gradual tapering, careful attention to and avoidance of side effects, and avoidance of polypharmacy are all central components of early psychosis services. In addition, there are other important standards for medical services, including rapid access to psychiatry at entry into the program, completion of early and follow-up physical examinations and lab testing, ongoing contact (even if the person chooses not to take medicine), and frequent contact (weekly in the beginning, and most programs recommend at least monthly throughout the course of treatment, with a minimum of half hour visits).

Relapse prevention. Another core element of early psychosis intervention is the development and ongoing refinement of a relapse prevention plan shared by the individual, family and informal supporters, as well as professional team members.

Health and wellness strategies. Nutrition, exercise, sexual health, and tobacco use prevention and cessation are all important in early psychosis programs. Careful attention to metabolic disorder and diabetes are particularly critical.

Occupational therapy. Occupational therapists can provide insight and practical assistance in areas which have a significant impact on functioning but which usually go unaddressed, particularly in the areas of cognitive challenges, sensory preferences, and breaking down functional tasks in order to develop accommodation strategies where individuals are getting stuck.

Cultural adaptations. Early psychosis programs serve individuals from many cultures, and need to be culturally humble and adept at working with families with different or even no concept of mental illness, widely varying explanatory models and methods of seeking healing, and varying relationships with dominant cultures. Migration may even be a risk factor for the development of psychosis.[28] Ongoing efforts to increase cultural understanding and awareness, access to interpretation and cultural consultation, as well as staffing patterns which reflect the community's diversity are all important elements of early psychosis programs.

STEP 17. Identify resources and methods to establish staff core competencies.

Given the range of competencies needed by early psychosis teams, staff learning is an important function for all early psychosis programs. Early psychosis team members will need training and ongoing consultation from experts, and an ongoing process of training needs to be set in place as new staff come on board. Periodic consultation with managers is also important in order to address system issues and gaps as they are identified. Program planners need to address:

- Which practices will the agency integrate? What expertise is needed and available to help establish these practices?

- How will existing organizational processes and structures be modified to facilitate adaptation of these practices?

- What training, consultation and clinical practice review will be required? How will staff receive training? How will training be repeated over time for new staff?

- How will ongoing consultation be provided?

- Can existing state resources or staff be developed to provide ongoing training and consultation? How can that capacity be developed?

- How will core staff competencies not included in minimum training be developed and recognized?
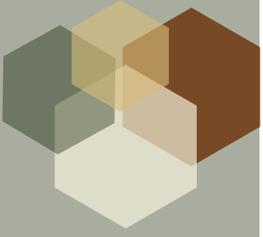
STEP 18. Develop and implement a community education strategy.

The success of early psychosis intervention is greatly determined by early symptom identification and referrals. Social marketing aims to encourage identification and referral, while fostering a sense of the likely positive impact of such a referral and encouraging community partners to play a supportive role.

The program and its partners will need to develop and implement an ongoing community education strategy which addresses each of the following steps:

- Set aside routine time for community education and engage partners who may help.

- Identify and prioritize key internal and external audiences:

  - Since they may be the first to take calls, start with internal audiences: (e.g., reception, crisis, intake, or other mental health practitioners)

  - The second layer of prioritization is crisis and referral systems: ER, 24-hour crisis, hospitals, and 211

  - Then explore other external entities: mental health professionals, doctors, youth-serving organizations, schools, community groups

  - Targeted media stories can be helpful in reaching out to family members and friends. However it is important to pitch the story carefully with a positive, personal hook since there is a danger that the media may want to tie the story to violence, and a bad story can be worse than not having one. Opinion pieces give the most control. Be sure to include specific symptom descriptions based on who you want referred.

- Measure and evaluate the community education, with measures such as: level of effort, resultant referrals, referral accuracy, and duration of untreated psychosis/early hospitalizations and legal involvement.
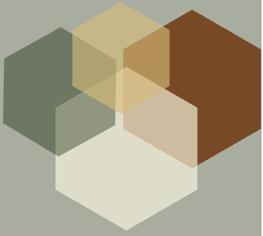
STEP 19. Establish an outcome measurement process.

In order to document the impact and ensure program improvement over time, it is important to track, review and respond to outcomes and implementation fidelity (see step 20). In designing and implementing data collection and evaluation, individuals who are skilled in survey design, databases and statistical analysis will be needed. Early psychosis programs must answer the following questions:

- What outcome data will be collected, by whom? How will quality improvement and evaluation occur?

- Will standardized measures be included? How will they be integrated into the clinical treatment and clinical review process?

- How will the experience of program participants, families and other advocates with lived experience of psychosis be included in defining and interpreting outcome measures?

- Where will data results be shared? How will the information be used?

- Will the results be tied to money or other formal expectations? How will data be used to aid ongoing quality improvement and service development?

- How will programs revise and improve evaluation processes with time?

Several active processes are occurring nationally to establish agreement on the optimal data set for early psychosis programs. Considerations in that process include clinical and administrative usefulness, as well as burden.
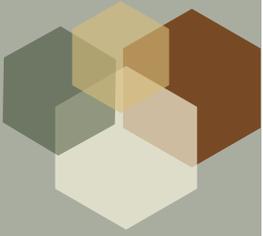
STEP 20. Establish evaluation and fidelity measurement processes.

Fidelity review processes help to evaluate whether the program is operating in the way the program is intended and can provide important feedback about areas of improvement. Generally, fidelity review occurs periodically and in an ongoing manner. There is not current consensus internationally about a single fidelity tool, and development of a fidelity process can be intensive. A recent review by Donald Addington, *et al* went through the process of identifying areas of expert agreement and developing a simple fidelity tool with the hope of creating a framework for early psychosis programs internationally. The document identifies core areas of measurement and a measurement scale, but does not identify a method for weighting how well programs score or identifying which items are essential. Other programs have developed fidelity tools, such as On Track New York and Oregon EASA. A few considerations in adopting and developing a fidelity tool:

- How does it relate back to program guidelines? Fidelity tools presume an articulated set of expectations or standards to which programs are held. In order to develop or even adopt a fidelity tool, it will be important to make sure that the tool is a good reflection of the program's training and written performance expectations.

- If there are fidelity scales associated with specific evidence-based practices the program is implementing, will those scales be integrated, and how? Are there inconsistencies between the program guidelines/intent and the available scales? How will those inconsistencies be managed?

Who will take the lead on the fidelity process? Responsibility for fidelity measurement must be linked to training and performance expectations, so responsibility for adoption and implementation of fidelity tools should be closely tied. For example, Oregon EASA has written practice guidelines which are periodically updated and form the foundation of both training and the fidelity measurement document. Changes to the fidelity document occur through a consensus process and are directly tied to the practice guidelines.

- How are the items within the tool ranked and weighted? Are there certain items which are so central to practice that without them the program cannot pass?

- What is required to "pass" the fidelity process, and what does it mean not to "pass"? Does it impact funding? Is there a process for technical assistance and re-review?

- Will the review process occur on-site or remotely, and under what circumstances? On-site reviews can very effectively use multiple sources of information to highlight local strengths and developmental needs. On-site processes may be particularly important for newly established programs, programs with significant turnover, and programs which have difficulty passing the review process. However, on-site processes are also time intensive and require significant preparation by local programs. A combination of on-site reviews with self-assessments and use of remote data may be optimal. On-site reviews can be designed to use both experts and peers from sister programs.

- How will fidelity connect to outcomes and clinical training? Use of outcome reporting to supplement fidelity review keeps the focus on the "why" of what programs are trying to accomplish, versus the "how" of how they get there. Clinical training and credentialing can include a clinical supervision component which may address fidelity to clinical practices, and therefore may replace elements of a broader fidelity process.

Conclusion

Collectively, the **20 Steps** delineated in this document are intended to provide a helpful framework for decision-making and associated action steps to be taken when embarking on the important process of establishing an early psychosis initiative. This Guide may be updated in the future to reflect newly emerging lessons-learned in this growing field of programming.

Please feel free to offer your feedback/input by sending an e-mail to

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