COORDINATED SPECIALTY CARE FOR EARLY EPISODE PSYCHOSIS

7/31/2024

Road Map to Implementation in Vermont

This report provides an overview of Coordinated Specialty Care for Early Episode Psychosis (CSC-EEP). It is intended to provide a road map for implementing CSC-EEP in the State of Vermont.

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EXECUTIVE SUMMARY

Background

In May 2023, the Substance Abuse and Mental Health Services Administration (SAMHSA) directed the State of Vermont to allocate 10 percent of its federal Mental Health Block Grant to evidence-based programs focused on first episode psychosis. Coordinated Specialty Care for first or early episode psychosis (CSC-EEP) is the only evidence-based program for first or early episode psychosis recognized by SAMHSA. Vermont is the only state in the country that has not implemented Coordinated Specialty Care for first or early episode psychosis.

In February 2022, the Department of Mental Health retained Wilda L. White Consulting to assist in the development of CSC-EEP in Vermont. This report marks the inaugural phase in the development and implementation of CSC-EEP in Vermont.

The objective of this report is not only to inform the Department of Mental Health about CSC-EEP but also to educate stakeholders about CSC-EEP, to allow stakeholders to participate in the design, development, and implementation of CSC-EEP in Vermont.

This report aims to serve as a guiding roadmap rather than an exhaustive treatment, offering an overview of CSC-EEP and direction for implementing CSC-EEP in Vermont.

This report is based on literature reviews, informational interviews, stakeholder surveys, internet searches, visits to CSC-EEP programs outside Vermont, attendance at conferences and webinars, and discussions with staff at the Department of Mental Health.

What is First or Early Episode Psychosis

Psychosis, sometimes referred to as an “extreme state,” is a medical term used to describe an individual’s experience of perceiving things through any of the five senses (seeing, smelling, hearing, feeling, and tasting) that are outside consensus reality. Such experiences are also called visual, olfactory, auditory, tactile, and gustatory hallucinations, respectively. The term “psychosis” also encompasses delusions – believing things that are outside the consensus reality – and confused thinking.

These symptoms exist on a continuum, ranging from minor, fleeting experiences to severe, fully developed psychosis affecting behavior and functioning. Factors like stress, trauma, sleep deprivation, and substance use can increase the risk of developing full psychosis.

The specific definition of early or first episode psychosis varies across medical and research settings. In the context of coordinated specialty care, early episode psychosis is generally considered the period up to five years after the onset of psychotic symptoms due to a serious mental illness and unrelated to substance use, brain injury or other medical issues (e.g., dementia).

What is Coordinated Specialty Care for Early Episode Psychosis (CSC)

Coordinated Specialty Care for early episode psychosis (CSC-EEP) is an evidence-based, multi-disciplinary, team-based approach to providing early intervention for psychosis related to mental illness. CSC-EEP is intended primarily for adolescents and young adults between the ages of 15 and 30. CSC services are typically offered over a two-to-three-year period following the onset of first episode psychosis. After three years, individuals typically step down to a lower level of specialized care, and then transition to regular services at a mental health center. The *American Psychiatric Association Practice Guideline for the Treatment of Patients with Schizophrenia* recommends that individuals diagnosed with schizophrenia who are experiencing a first episode psychosis be treated in a coordinated specialty care program.

CSC-EEP emphasizes shared decision making and collaboration between program participants, the treatment team, and family members. The multidisciplinary team provides services such as case management, medication management, psychotherapy, supported employment and education, family education and support, and primary care coordination.

While no research has identified what coordinated specialty care interventions are associated with positive outcomes, the National Institute of Mental Health recommends that CSC-EEP include five core activities:

(1) Cognitive or behavioral psychotherapy;
(2) Medication management;
(3) Family education and support;
(4) Service coordination and case management; and
(5) Supported employment and education.

CSC programs vary across states and within states. Variation between CSC programs involve differences in caseloads, team structure, services provided, and family involvement. A 2022 survey of CSC programs found most programs include the following:

(1) Team lead,
(2) Cognitive-behavior-oriented psychotherapy,
(3) Case management, medication management,
(4) Family education and support,
(5) Supported employment and education services,
(6) Peer support services,
(7) Crisis intervention services,
(8) Primary care coordination, and
(9) Co-occurring substance use services.

History of CSC

During the late 20th century, research began to highlight the importance of early intervention in psychosis. Studies showed that early treatment could improve long-term outcomes for individuals experiencing their first episode of psychosis.

The first early psychosis intervention programs were developed in Australia, the United Kingdom, and Scandinavia. These programs emphasized comprehensive, multi-disciplinary approaches to treatment.

Between 1990 and 2000, programs like the Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia, and the Early Assessment and Support Alliance (EASA) in Oregon, became models for early intervention in psychosis. These programs provided integrated services, including medication management, psychotherapy, family education, and vocational support.

Coordinated Specialty Care for early episode psychosis expanded in the United States following the Recovery After an Initial Schizophrenia Episode (RAISE) research project. Initiated by the National Institute of Mental Health (NIMH), the RAISE study developed and evaluated a particular model of early episode psychosis called Navigate. Navigate was a standardized, team-based program that was designed to be implemented by existing staff in community mental health centers serving persons experiencing first episode psychosis. Navigate included four interventions:

(1) Individual resilience training;
(2) Family education and support;
(3) Supported education and employment; and
(4) Individualized medication management.

The RAISE Navigate study showed that participants in the Navigate program had significantly greater reductions in overall psychiatric symptoms and depression and greater improvement in quality of life, social relationships, and involvement in work and school compared to those who received customary community treatment.

In 2014, the U.S. Congress mandated that States "expend at least five percent of [their Mental Health Block Grant] …to support evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders, regardless of the age of the individual at onset."

The Mental Health Block Grant (MHBG) program is a formula-based, state grant program in which federal funds are distributed to states and territories. The amount each state receives varies based on specified economic and demographic factors.

In 2016, the 21st Century Cures Act increased the mandatory, MHBG set-aside to 10 percent and included a supplemental grant.[1] The appropriation bill specifically required the 10 percent set-aside to fund only those evidence-based programs that target first episode psychosis.

As of 2022, there were an estimated 381 programs in the United States offering coordinated specialty care services to individuals in every state except Vermont.

CSC Program Models

CSC programs vary widely in structure and services across the United States. The following table summarizes commonly reported CSC models and programs and identifies their different components.

	PIER	**EASA**	**OASIS**	**STEP**	**NAVIGATE**	**EDAPT**	**EPICENTER**	**ONTRACK-NY**	**FIRST**
Locations	**ME**	**OR**	**NC**	**CT**	*[1]	**CA**	**AZ; OH**	**NY**	**OH**
Services									
Case Management/Care Coordination	X			X	X	X		X	X
Cognitive Behavior Therapy	X	X					X	X	X
Cognitive Health/Remediation								X	X
Community Outreach/Assertive Outreach	X	X					X		
Comprehensive Assessment and Evaluation			X	X		X	X		
Digital Interventions[2]			X						
Family Advocates/Family Peer Support	X					X			
Family Education and Support				X	X	X	X	X	X
Family Therapy			X			X			
Group Psychotherapy			X						
Group Sessions								X	
Health and Wellness Services			X					X	
Individual Psychotherapy		X	X	X		X			X
Individual Resilience Training					X				

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[1] The NAVIGATE model is used in multiple locations across the United States. According to a report of the Early Psychosis Intervention Network (EPINET), it is the most reported CSC model in the United States (25.7%).

[2] Digital interventions include remote therapy sessions and consultations; digital cognitive behavioral therapy; mobile health apps designed to assist with medication management, symptom tracking, and providing psychoeducation resources; and online peer support groups.

	PIER	EASA	OASIS	STEP	NAVIGATE	EDAPT	EPICENTER	ONTRACK-NY	FIRST
Locations	**ME**	**OR**	**NC**	**CT**	*[1]	**CA**	**AZ; OH**	**NY**	**OH**
Services									
Integrated Primary and Mental Health Care									X
Medical Assessment and Treatment		X		X					
Medication Management	X	X	X	X	X	X	X	X	X
Metacognition Remediation Therapy							X		
Multifamily Psychoeducation	X	X		X		X	X		
Occupational Therapy	X	X							
Peer Support	X	X	X			X		X	
Recreational/Social Activity Rehabilitation			X						
Social Skills Training			X						
Substance Use Treatment		X	X			X			
Support with Concrete Needs[3]								X	
Supported Education and Employment	X	X	X	X	X	X	X	X	X
Supported Housing		X							

CSC Program Admission Criteria

CSC programs across the United States tend to have different program admission criteria. Typically, program admission criteria include (1) age; (2) psychiatric diagnosis; (3) duration of psychosis; (4) treatment history; and (5) co-occurring diagnoses.

For example, eligible participants in the original RAISE Navigate research study included individuals 15 to 40 years old with a first episode of schizophrenia, schizoaffective disorder, schizophreniform disorder, psychotic disorder not otherwise specified, or brief psychotic disorder according to DSM-IV and no more than six months

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[3] OnTrackNY teams offer support with life essentials and everyday needs, such as finding housing, getting financial support, applying for community services or health insurance, etc.

of treatment with antipsychotic medications. Diagnoses of affective psychosis, substance-induced psychotic disorder, psychosis due to general medical conditions, clinically significant head trauma, or other serious medical conditions were excluded.

Delivery of Coordinated Specialty Care

CSC is typically delivered by four to six clinicians who are trained for a specific component of coordinated specialty care. The team typically maintains a shared caseload of 30 to 35 clients. However, in practice, team sizes can be as low as two members.

Key roles on a CSC team include (1) overall team leadership; (2) case management; (3) psychotherapy; (4) supported employment and education; (5) family education and support; and (5) medication management/primary care coordination. Key roles may be combined, provided the provider has achieved competency in each assigned CSC function.

In addition to the clinical components of CSC, CSC teams must also offer (1) access to clinical providers with specialized training in EEP care; (2) easy access to the CSC program through active outreach and engagement; (3) provision of services in home, community, and clinic settings, as needed; (4) acute care during or following a psychiatric crisis; (5) transition to step-down services with the CSC team or discharge to regular care after two to three years, and (6) program quality assurance through continuous monitoring of treatment fidelity.

Experienced clinicians paid competitive wages are the ideal candidates for CSC programs. In addition to experience, ideal candidates embrace the challenge of working with adolescents and young adults experiencing psychosis, are flexible regarding intervention approaches to engage clients and family members and are tolerant of uncertainty regarding a client's preferred recovery strategies.

The exact configuration of staffing will depend on the program model.

Funding and Costs of CSC

CSC programs are funded through a mix of federal block grants, Medicaid, commercial insurance, and state and local funds.

The costs associated with CSC-EEP can be significant. Randomized controlled trials have demonstrated that the total treatment costs for those assigned to CSC-EEP do not significantly differ from those receiving standard care. The primary source of savings in CSC-EEP typically comes from reduced hospitalization, emergency room visits, and other healthcare costs. Thus, while the costs for CSC-EEP services may be comparable to standard care, the Substance Abuse and Mental Health Services Administration (SAMHSA) has concluded, based on a systematic literature review, that CSC-EEP is more cost-effective due to decreases in high-cost adverse outcomes.

Start-Up Costs

Start-up costs for establishing a CSC-EEP program are substantial. The most recent estimates range from $300,000 per year for two years to $995,686 over two years. CSC teams are highly specialized and require extensive training to deliver an evidence-based model of coordinated specialty care. Recruitment for new teams generally requires at least six months, during which no individuals are enrolled.

Outreach requires a significant effort by the team throughout the first year to educate community stakeholders about recognizing early psychosis and the availability and evidence base for CSC-EEP. Because recruitment, training, and outreach are conducted before any clients are recruited, third-party reimbursement is unavailable. Therefore, start-up costs are typically covered by federal grants and state revenues.

Operating Costs

The cost of implementing CSC for early episode psychosis depends on the number of teams required and the composition of those teams.

The number of teams a state needs will vary based on assumptions regarding several unknown variables, including the incidence of early episode psychosis in a population, the percentage of individuals experiencing early episode psychosis who are identified, the percentage of identified individuals who agree to participate in the program, the number of individuals served by a team, and the average duration of time an individual is served.

Based on four studies published between 2013 and 2023, SAMHSA concluded that when adjusted for 2023 inflation, the per-client per-month cost of providing CSC-EEP ranged from $1,054 to $1,653.

In 2013, the New York State Office of Mental Health developed an interactive modeling tool to input various estimates for relevant variables and estimate the number of teams needed and their costs. This tool, adapted for Vermont by Wilda L. White Consulting, provides an estimate of the number of teams Vermont would need and the costs of providing the team(s). The interactive tool estimated a per-client per-month costs for CSC-EEP in Vermont similar to the per-client per-month costs identified in the 2023 SAMHSA analysis.

State Case Studies

The report includes an overview of CSC programs from selected states to guide Vermont in developing and implementing its own CSC program. These case studies highlight various approaches, challenges, and successes that can inform Vermont's efforts.

Project ARROW - Atlanta, Georgia

OVERVIEW:
Project ARROW combines Open Dialogue (OD) and CSC treatment to serve individuals aged 18-30 who have experienced psychotic symptoms within the past 24 months. Exclusion criteria include intellectual disability, substance-induced psychosis, or psychosis due to a medical condition.

KEY COMPONENTS:
Team-based approach with roles such as psychotherapy, case management, supported employment, peer support, family education, pharmacotherapy, and nursing.

Integration of Open Dialogue principles, which emphasize involving the patient's social network, fostering dialogue, and maintaining flexibility and minimal medication use.

LESSONS LEARNED:
Implementing OD within CSC structures can provide financial sustainability and enhance family involvement.

Training and supporting staff in OD principles require patience and ongoing mentorship.

Combining OD with CSC offers a structured approach that benefits from both models' strengths.

PIER - Maine

OVERVIEW:
Maine's PIER program focuses on early intervention for youth aged 14-26 experiencing early psychosis. The program emphasizes community outreach, family involvement, and education.

KEY COMPONENTS:
Multifamily group model for family psychoeducation.

Assertive outreach and support services, including cognitive behavior therapy, medication management, supported education/employment, and peer support.

Expansion into rural areas using a hub and spoke model.

LESSONS LEARNED:
Engaging families and communities through structured support and education can improve outcomes and reduce stigma.

Expanding services to rural areas requires flexibility and partnerships with local organizations.

Mass-STEP - Massachusetts

OVERVIEW:
Massachusetts developed a strategic plan for early intervention in psychosis, focusing on creating a high-quality system of care through community and stakeholder engagement.

KEY COMPONENTS:
Six primary goals, including support for individuals and families, early identification, specialized support for healthcare professionals, and reducing stigma.

Socio-ecological model of health that considers community, organizational, and systemic influences on mental health.

LESSONS LEARNED:
Comprehensive planning and stakeholder engagement are critical for developing an effective CSC program.

Addressing social determinants of health and systemic barriers can enhance care delivery.

OnTrackNY - New York

OVERVIEW:
OnTrackNY, an evolving CSC program, focuses on rapid access, cultural competence, and continuous quality improvement.

KEY COMPONENTS:
Team-based approach with roles such as licensed clinicians, supported education/employment specialists, peer support, and medication management.

Emphasis on equity, inclusion, and participant self-determination.

LESSONS LEARNED:
Continuous learning and adaptation based on feedback and data can enhance program effectiveness.

Focusing on equity and cultural competence can improve engagement and outcomes for diverse populations.

New Journeys - Washington State

OVERVIEW:
Washington State's New Journeys program adapts the Navigate CSC model to meet the needs of rural and tribal communities, emphasizing rapid referral, integrated care, and addressing racial disparities.

KEY COMPONENTS:

Team-based approach with roles such as program director, psychiatric care provider, resiliency training therapist, supported employment/education specialist, peer support, and case management.

Community and tribally based participatory research to adapt services for specific populations.

LESSONS LEARNED:

Addressing racial disparities and adapting services to meet the needs of specific communities can improve access and outcomes.

Integrating research and data-driven decision-making supports continuous program improvement.

Vermont's Context

Vermont does not currently offer CSC for first episode psychosis, but the Howard Center in Chittenden County participated in the RAISE research initiative, which randomized community mental health agencies to deliver either the NAVIGATE Early Treatment Program or standard care. The Howard Center, delivering NAVIGATE, enrolled 14 participants assessed over two years, and demonstrated high fidelity to the NAVIGATE model. Despite the successful implementation, the Howard Center did not continue the program post-study.

Historically, Vermont has used its Mental Health Block Grant (MHBG) set-aside funds to support the development of Vermont's version of Open Dialogue, known as the Collaborative Network Approach. SAMHSA does not consider Collaborative Network Approach or Open Dialogue an evidence-based intervention for early episode psychosis.

Current Vermont Services and Supports

Current services and supports for early episode psychosis in Vermont include Soteria House and Hilltop Recovery Residence. Soteria House offers a supportive environment for individuals experiencing early psychosis, emphasizing minimal medication use and fostering recovery through peer support. Hilltop Recovery Residence provides similar services focused on community integration and recovery. Other resources include the Brattleboro Retreat, the Vermont Child Psychiatry Access Program, and the Vermont Child Health Improvement Program (VCHIP).

Young people experiencing early episode psychosis (EEP) in Vermont receive treatment from private providers or through designated agencies serving their counties. The current treatment interventions at designated agencies include:

> General Mental Health Services: Young people are provided with general mental health services that are not specifically tailored to early episode psychosis. These services often cater to a broader population and may not address the unique needs of EEP.
>
> Crisis Intervention: Agencies may provide crisis intervention services, but these are typically short-term and not specialized for early episode psychosis.
>
> Case Management: Limited case management services are available, often influenced by insurance coverage, leading to inconsistent support for young people with EEP.

Housing Assistance: There is a lack of stable and safe housing options specifically for young people with EEP, making it difficult to address their housing needs effectively.

Coordination with Outside Agencies: There are significant challenges in collaborating and coordinating with outside agencies, including hospitals, which impacts the continuity and comprehensiveness of care.

Engagement Strategies: Traditional service models are used to engage clients, but these may not be effective for young people with EEP, who often require a softer touch and more family involvement.

Substance Use Treatment: While substance use treatment is recognized as a need, it is not adequately integrated into the services provided by designated agencies to young people experiencing early episode psychosis.

Barriers, Gaps in Services, and Unmet Needs in Vermont

Interviewees and survey respondents, including clinical staff at designated agencies, individuals with lived experience of early episode psychosis, caregivers, and mental health providers, uniformly expressed dissatisfaction with Vermont's current interventions for young people experiencing early episode psychosis. The responses highlighted significant barriers, gaps in services, and unmet needs for both young people and their families.

Designated agency respondents identified several barriers:

- Safety Concerns: Issues around living conditions for youth and families.
- Lack of Trained Clinicians: Shortage of clinicians trained to work specifically with young people.
- Skilled Staff Shortage: Inadequate number of skilled staff with relevant experience.
- Inadequate Housing Options: Lack of stable, safe housing.
- Need for Case Management: Services needed regardless of insurance coverage, with many patients having private insurance.
- Coordination Challenges: Difficulty collaborating with outside agencies, including hospitals.
- Insurance Limitations: Insurance constraints preventing coordinated specialty care.
- Engagement Difficulties: Challenges in engaging clients and families, requiring a different approach than traditional models.

Survey respondents highlighted several unmet needs:

- Housing: Stable, safe housing options.
- Substance Use Treatment: Services for co-occurring substance use disorders.
- Family Support: Guidance and support for parents and families.
- Peer Support: Lack of peer support for individuals under 18.
- Care Coordination: Effective care coordination needed, unhampered by insurance constraints.

Respondents identified several areas for improvement:

- Improved Housing Access: Options for youth with safety concerns who have exhausted available community resources.
- Training Opportunities: Enhanced training for clinicians.

- Case Management: Urgent care case management grants to support eligible individuals regardless of insurance.
- Continuity of Care: Multidisciplinary teams providing continuous, strengths-based support from adolescence to early adulthood.
- Flexible Funding: Grant-funded urgent care coordinators to provide non-insurance-based services.

It should also be noted that impressions of mental health services for young people experiencing early episode psychosis have not changed significantly in the eight-year period since the Dartmouth Institute for Health Policy and Clinical Practice conducted interviews to examine the perspectives and experiences of individuals with lived experience of early episode psychosis, their family members, and services providers using survey and in-depth qualitative interviews.

Respondents in 2016 and in 2024 consistently reported significant delays and barriers in accessing mental health services. Both sets of respondents reported negative experiences with mental health professionals who were dismissive of their concerns. Issues related to psychotropic medications, such as over-medication and polypharmacy, were repeatedly mentioned. Both sets of respondents emphasized the need for more inclusive and supportive family involvement in treatment plans.

CSC and Needs Specific to Vermont

Most of the unmet needs identified by respondents (e.g., peer support; family support; care/case management; well-trained clinicians) would be fulfilled by the effective implementation of coordinated specialty care in Vermont. However, respondents also identified unmet needs that are not typically included in coordinated specialty care but must be included in Vermont for the program to be successful.

Housing

Housing is a significant need for young people experiencing early episode psychosis (EEP) in Vermont. Caregivers frequently face challenges when their children experience episodes of psychosis at home, and some individuals with lived experience of EEP report ending up homeless. The shortage of housing is acute in Vermont, affecting everyone, but particularly young people without rental histories, credit ratings, and stable employment. This finding underscores the importance of including a housing specialist on CSC teams and developing specific housing options for young people with EEP.

Financial Support

Financial support is another critical need. Young people experiencing EEP often face intense financial struggles, compounded by poverty. Dr. Nev Jones highlighted the lack of attention to anti-poverty interventions in recent decades. Historically, there were interventions aimed at promoting socioeconomic mobility, but these have been neglected in the U.S. for over 15 years. Caregivers and individuals with lived experience of psychosis emphasized the need for comprehensive financial support to help young people achieve true socioeconomic mobility rather than just subsisting on low-wage jobs or Social Security benefits.

Substance Use Treatment

Substance use treatment is a vital component of care for young people with EEP. A significant percentage of individuals experiencing their first episode of psychosis also have a co-occurring substance use challenge. Vermont has some of the highest rates of substance use in the country, which complicates treatment. Research suggests that treatment for co-occurring disorders is rarely effective when provided by clinicians unconnected to CSC. There is a high dropout rate from traditional substance use treatment programs due to poor coordination and follow-through. Caregivers, clinicians and research advocate for integrated, seamless treatment for co-occurring disorders within CSC programs.

Cultural Competence

Implementing CSC-EEP in Vermont requires addressing cultural competence. The state must ensure that care is appropriate and effective for diverse populations, considering factors such as ethnicity, language, and cultural beliefs. This involves training clinicians and staff to understand and respect different cultural backgrounds and to provide care that is sensitive to these differences.

Equity

Equity in access to mental health services is a significant challenge. There are disparities in the availability and quality of care across different populations and regions. Survey respondents and interviewees stressed the importance of creating equitable access to CSC-EEP services, ensuring that all young people, regardless of their background or location, can receive the services they want and need.

Rural Access

Providing CSC-EEP in rural areas is particularly challenging. Rural communities typically have fewer resources, including mental health services, and lack public transportation options. Individuals in rural areas often experience longer periods of untreated psychosis compared to those in urban areas. While some states have developed hybrid models of telehealth and in-person care to address this issue, telehealth may not be viable in Vermont due to the reluctance of some individuals with lived experience to receive treatment through “screens,” which they feel exacerbate their symptoms. Vermont may wish to explore models like Maine's hub and spoke system for rural expansion.

Disengagement

Disengagement from treatment is a common issue in CSC programs. Newer programs tend to have higher rates of disengagement than more established ones. Recent research funded by the National Institute of Mental Health (NIMH) focuses on increasing engagement and reducing the duration of untreated psychosis. Strategies include greater family involvement, utilizing family members as change agents, reducing self-stigma, and increasing shared decision-making around antipsychotic medication. Vermont may wish to monitor these research developments and adopt evidence-based practices to improve engagement in its CSC program.

Vermont’s ability to address the foregoing issues will be crucial in developing an effective and sustainable CSC program.

Implementation Checklist

- ☐ Conduct a needs assessment to identify gaps and resources.
- ☐ Develop a multidisciplinary team and provide comprehensive training.
- ☐ Implement outreach strategies to raise awareness and reduce stigma/discrimination.

☐ Establish a streamlined referral process for timely access to services.
☐ Engage clients and their families in treatment planning and decision-making.
☐ Monitor program fidelity and outcomes to ensure high-quality care.
☐ Secure sustainable funding through a combination of federal, state, and private sources.

Conclusion

To implement CSC effectively, Vermont will need to consider the local context, establish comprehensive training programs, and secure sustainable funding sources. Collaboration with community stakeholders and continuous quality improvement will be crucial for the success and sustainability of CSC programs.

COORDINATED SPECIALTY CARE FOR EARLY EPISODE PSYCHOSIS

ROAD MAP TO IMPLEMENTATION IN VERMONT

BACKGROUND 1 | ONE

In May 2023, the Substance Abuse and Mental Health Services Administration (SAMHSA) directed the State of Vermont to allocate 10 percent of its federal, Mental Health Block Grant to evidence-based programs focused on first episode psychosis. Coordinated Specialty Care for First Episode Psychosis (CSC-FEP) is the only evidence-based program for first episode psychosis recognized by SAMHSA. Vermont is the only state in the United States that has not implemented Coordinated Specialty Care for first episode psychosis.

Vermont is the only state in the United States that has not implemented Coordinated Specialty Care for first episode psychosis.

Coordinated Specialty Care for first episode psychosis (CSC-FEP) is a team-based approach to providing early intervention for psychosis related to mental illness. Collectively, the team offers a variety of services including, but not limited to, case management, family education and support, individual resilience training, medication management, and supported employment and education. CSC-FEP is intended primarily for adolescents and young adults between the ages of 15 and 30. CSC services are typically offered over a two-to-three-year period following the onset of first episode psychosis, after which individuals typically step down to a lower level of specialized care, and then transition to regular services at a mental health center.

In February 2024, the Vermont Department of Mental Health engaged Wilda L. White to assist in the development and implementation of CSC-FEP in the State of Vermont. The first phase of the engagement was to create a report that would serve as a road map for developing and implementing CSC-FEP in the State of Vermont.

The target audience for this report includes the Department of Mental Health and stakeholders, ranging from young people experiencing early episode psychosis and their families to healthcare practitioners, education administrators, legislators, mental health advocates, peer-run organizations, family organizations, social service agencies, and social justice organizations—essentially, anyone invested in the welfare of young Vermonters.

The objective of this report is not only to inform the Department of Mental Health about CSC-FEP but also to educate stakeholders about CSC-FEP, to allow stakeholders to participate in the design, development, and implementation of CSC-FEP in Vermont.

The report is a guiding roadmap rather than an exhaustive treatment, offering an overview of CSC-FEP and direction for implementing CSC-FEP in Vermont.

Following the publication of the report, Wilda L. White Consulting will convene meetings for stakeholders to engage in discussions, answer questions, and deliberate on a CSC-FEP model that meets the needs of young Vermonters and their families and fits within the State's resources.

A Note about Terminology

Going forward, this report uses the term "early episode psychosis" (EEP) instead of "first episode psychosis" (FEP).

HOW THE REPORT WAS CREATED 2 | TWO

This report is based on literature reviews, informational interviews, stakeholder surveys, internet searches, visits to CSC-EEP programs outside Vermont, attendance at conferences and webinars, and discussions with staff at the Department of Mental Health.

Interviews

The following individuals and organizations were interviewed either in person, over the telephone or via teleconference.

Full Name	Affiliation
Zelda Alpern	Coordinator, Collaborative Network Approach
Megan Becker	Director of Inpatient Social Work Brattleboro Retreat
Robert O. Cotes, M.D.	Associate Professor Department of Psychiatry and Behavioral Sciences Emory University School of Medicine
Joscelyn Cura	Supported Employment and Education Specialist – STEP Program Pittsburg, PA
Emily Gagen, Ph.D.	Director M-Path The Brookline Center for Community Mental Health
Graham Heavener	Residential Specialist Hilltop Recovery Residence – HCRS Brattleboro, VT
Stacy Karpowitz	Brattleboro Retreat Brattleboro, Vermont
Karl Jeffries, M.D.	Chief Medical Director Brattleboro Retreat
Christie Kelley	Program Supervisor – STEP Program Pittsburg, PA
Alexa Licata	Clinical Care Coordinator Hilltop Recovery Residence – HCRS Brattleboro, VT
Monica Luke	Mental Health Advocate Commonwealth of Massachusetts
Hilary Melton	Executive Director, Pathways Vermont

Full Name	Affiliation
Oladunni Oluwoye, Ph.D.	Assistant Professor Elson S Flloyd College of Medicine, Washington State University
Justin M. Palanci, M.D.	Assistant Professor, Medical Director, Assertive Community Treatment Program, Grady System Department of Psychiatry and Behavioral Sciences Emory University School of Medicine
Gary Scannevin	Trainer, Supported Employment, OnTrackNY
Margaret (Greta) Spottswood, M.D., MPH	Vermont Child Psychiatry Access Program Medical Program Director
Jessica Stern, MD	Medical Director The Brookline Center - CEDAR
Joelle van Lent, Psy.D.	Private Practice Clinician
George (Bud) Vana, M.D.	Triple Board-Certified Vermont Adult and Child Psychiatrist and Pediatrician
Akansha Vaswani-Bye, Ph.D.	Acting Assistant Professor University of Washington Psychiatry & Behavioral Sciences, School of Medicine
Amanda Weber, Ph.D.	Director The Brookline Center - CEDAR
Helen Wood, DClinPsy	Clinical Associate Professor Department of Psychological Science University of Vermont
Bay Area Clinical Associates	Bay Area Clinical Associates Coordinated Specialty Care Program Berkeley, California
Child, Adolescent, and Family Standing Committee	Vermont State Program Standing Committee
Felton BEAM UP	Felton BEAM UP Coordinated Specialty Care Program San Francisco, California

Surveys

Survey for Families of Children, Adolescents, and Young Adults Experiencing First Episode Psychosis

Survey for Designated Agencies

Survey for Pediatricians, Naturopaths, and Family Practitioners Regarding Early Episode Psychosis Treatment in Vermont

Survey for College and University Health Center Regarding Early Episode Psychosis

Webinars

Breitborde, Nicholas, PH.D., ABPP, “How Can We Improve upon Coordinated Specialty Care for Individuals with First-Episode Psychosis?” Department of Psychiatry and Behavioral Health, EPICENTER Psychosis Speaker Series, April 5, 2024

Shah, Jai, MD, MSc, FRCPC, “Pathways to Psychosis (and what they can tell us about the future of youth mental health),” Department of Psychiatry and Behavioral Health, EPICENTER Psychosis Speaker Series, May 3, 2024

Coordinated Specialty Care for Early Psychosis: Financing and Fidelity, TPN.health, May 10, 2024

McDermott, Glen, “How to Increase Public Awareness of FEP State Programs and Reduce Duration of Untreated Psychosis,” June 11, 2024

HeadsUp Grand Rounds 2024, “Bringing the Two Worlds Together: Schools and Coordinated Specialty Care Programs as Allies for Youth with Psychosis,” July 18, 2024

Brady, Roscoe, MD, PhD, New England Mental Health Technology Transfer Center, “Navigating the Overlap: Psychosis and Bipolar Disorder,” July 26, 2024

Conferences

PEPPNET National Early Psychosis Mini-Conference: Broadening the Reach: Ensuring equitable access to early psychosis care for all, September 28 - 29, 2023

DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, “Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis,” Nev Jones, Killington Grand Hotel, Killington, VT, October 19, 2023

4th Annual 2023 Mass-Step Meeting Scaling Up: Access & Equity for Psychosis, Bentley University Conference Center, Waltham, MA and Via Zoom, November 6 -7, 2023

Psychosis CARE 2024 Virtual Conference, Elson S. Floyd College of Medicine, New Journeys, Washington State Center of Excellence in Early Psychosis, SPIRIT, April 30 – May 1, 2024

South Southwest MHTTC First Episode Psychosis Virtual Conference 2024, “Pausing with Purpose: Guiding FEP Care with Human Connection,” June 5 – June 6, 2024

Work Group

Mental Health Technology Transfer Center (MHTTC) Rural Early Psychosis Sub-Working Group, April 16, 2024; May 14, 2024; and July 9, 2024

OVERVIEW OF COORDINATED SPECIALTY CARE FOR EARLY EPISODE PSYCHOSIS 3 | THREE

Early Episode Psychosis

Psychosis, sometimes referred to as an “extreme state,” is a medical term used to describe an individual’s experience of perceiving things through any of the five senses (seeing, smelling, hearing, feeling, and tasting) that are outside consensus reality. Such experiences are also called visual, olfactory, auditory, tactile, and gustatory hallucinations, respectively. The term “psychosis” also encompasses delusions – believing things that are outside the consensus reality – and confused thinking.

In the research literature, psychosis is thought to exist on a continuum.[2] The continuum ranges from an absence of any psychotic-like experiences through to what mental health practitioners consider to be fully psychotic symptoms that affect behavior and functioning. In between no psychotic symptoms and fully psychotic symptoms are psychotic-like experiences common in the general population including magical thinking (making links between two seemingly unrelated events), low level perceptual irregularities (hearing one’s name called when no one is around), and suspiciousness and paranoia, such as unfounded negative beliefs about close associates. These experiences are typically fleeting and easily dismissed by the individual. Further along the continuum, such experiences may become more meaningful to the individual and they may begin to experience them with an increased frequency, higher distress, and find them harder to dismiss. At this point, the individual may be experiencing what mental health practitioners call ‘attenuated psychotic symptoms.’ Individuals experiencing ‘attenuated psychotic symptoms’ may be at risk for developing full psychosis. Factors associated with an increased risk of full psychosis include stress, trauma, sleep deprivation, substance use, and changes in brain anatomy.

Attenuated symptoms are deemed to have reached the threshold for ‘full psychosis’ when they negatively affect an individual’s functioning, and the individual has full belief as to the reality of their experience.

The continuum approach to psychosis allows:

- Normalization of psychotic symptoms, which helps individuals understand that full psychosis is an extreme state of normal human psychological functioning
- Earlier identification of individuals who may be at risk for developing full psychosis
- Provision of interventions to individuals at risk of developing psychosis to prevent or delay transition to full psychosis
- Implementation of recovery-oriented interventions to address factors that may trigger progression along the continuum

The specific definition of early or first episode psychosis varies across clinical and research settings. In the context of coordinated specialty care, early episode psychosis is generally considered the period up to five years after the onset of psychotic symptoms due to a serious mental illness and unrelated to substance use, brain injury or other medical issues (e.g., dementia).[3]

People usually first experience early episode psychosis when they are in their teens to mid-20.[4] Research studies indicate that people experiencing early episode psychosis often go untreated for a year or longer. Untreated symptoms increase the risk of substance misuse, self-injury, homelessness, justice-system involvement, and unemployment.[5] A longer duration of untreated psychosis is also associated with poorer clinical, social and functional outcomes.[6]

Each year in the United States, approximately 100,000 people experience early episode psychosis. Research indicates that early intervention services for psychosis can improve symptoms and restore adaptive functioning in a manner superior to traditional care.[7]

History of Coordinated Specialty Care for Early Episode Psychosis

Coordinated Specialty Care is an Americanized name for what is more commonly referred to outside of the United States as Specialized Early Intervention and Psychosis Services (EIP). Australia and the United Kingdom are considered pioneers in implementing specialized services for individuals experiencing psychosis, with Australia implementing specialized, early psychosis services in Melbourne in the late 1980s.

In 1996, the Early Psychosis Prevention and Intervention Centre study in Australia first reported that comprehensive early interventions significantly reduced duration of untreated psychosis in young people.[8] These study results led to efforts in European countries to investigate the effectiveness of early, comprehensive interventions in reducing the long-term chronicity of psychosis.

Following research trials conducted in the United Kingdom in the early 2000s, which validated the effectiveness of early intervention services for psychosis when compared to standard care, the United Kingdom mandated national coverage of first episode psychosis services and programs.[9] In 2005 and 2006, Denmark and Norway, respectively, conducted large scale trials to examine the effectiveness of first episode psychosis programs in their countries. The results of those trials also demonstrated the effectiveness of specialized first episode psychosis care over standard care.[10]

Around the same time, programs and trials of specialized psychosis care were being designed and implemented in the United States. In 2000, in Portland, Maine, the Center for Psychiatric Research at Maine Medical Center and Dr. William McFarlane started the Portland Identification and Early Referral and Resilience Program (PIER).[11] The next year, in 2001, Oregon community mental health clinicians in five counties started the Early Assessment and Support Alliance (EASA).[12]

The first trial of first episode psychosis services in the United States was the Outreach and Support Intervention Services trial in North Carolina which began in 2005 and was published in 2012.[13]

In 2008, the National Institute of Mental Health undertook the Recovery After an Initial Schizophrenia Episode (RAISE) initiative.

The RAISE initiative led to two research studies: the RAISE Implementation and Evaluation study (RAISE Connection) and the RAISE Early Treatment Program study (RAISE Navigate).

The RAISE Navigate study was the first, multisite, control trial and feasibility study of first episode psychosis programs across the United States. The term “Coordinated Specialty Care for First Episode Psychosis” was coined during the RAISE initiative.

The RAISE initiative developed and evaluated a particular model of early episode psychosis care called Navigate. The name was chosen to convey the goal of helping study participants and their family members find their way to recovery through the complexities of psychosis and the mental health system.

The RAISE initiative included individuals 15 to 40 years old with a first episode of schizophrenia, schizoaffective disorder, schizophreniform disorder, psychotic disorder not otherwise specified, or brief psychotic disorder according to DSM-IV and no more than six months of treatment with antipsychotic medications. Diagnoses of affective psychosis, substance-induced psychotic disorder, psychosis due to general medical conditions, clinically significant head trauma, or other serious medical conditions were excluded.[14]

Navigate was a standardized, team-based program that was designed to be implemented by existing staff in community mental health centers serving persons experiencing first episode psychosis. Navigate included four interventions:

(1) Individual resilience training;
(2) Family education and support;
(3) Supported education and employment; and
(4) Individualized medication management.

The program was compared to standard community treatment in a randomized controlled trial across 34 community mental health centers in 21 states with a two-year treatment and follow-up. Results showed that participants in Navigate had significantly greater reductions in overall psychiatric symptoms and depression, and greater improvement in quality of life, social relationships, and involvement in work and school compared to those who received customary community treatment.[15] There were not significant differences between the control group and the Navigate group in rehospitalization rates, changes in positive and negative symptoms or changes in cognitive functioning[16], but those in the Navigate program remained in treatment longer and had more involvement in work and school.[17]

Dr. Nev Jones spoke about CSC in October 2023 at a conference convened by the Vermont Department of Mental Health. Dr. Jones is an assistant professor in the School of Social Work at the University of Pittsburgh, and an interdisciplinary mental health services researcher focused on serious mental illness (SMI). Dr. Jones' work is grounded in her personal and family experiences of schizophrenia and associated experiences with public sector mental health services. She has been a steadfast champion of participatory research methods and the integration and co-leadership of individuals and families directly impacted by psychiatric disability in research, policy, and implementation. She currently leads studies focused on early psychosis, community-based SMI services, civil commitment, and poverty and unemployment.

Dr. Jones' work is grounded in her personal and family experiences of schizophrenia and associated experiences with public sector mental health services.

During her remarks, Dr. Jones shared that a recent re-analysis of RAISE data found that clients in the lower, three socioeconomic quartiles did not benefit from Navigate on a single, primary outcome. According to Dr. Jones:

> "When you look at employment and education outcomes of RAISE, they are extremely underwhelming. In fact, it was not until the 24-month mark – end of the program – that the two groups were actually the same in their outcomes. However, the Navigate group improved more so the baseline that they started from was a bit lower. But the outcomes, the hard outcomes, the raw outcomes were not different between groups. Keeping that in mind, there were significant effectiveness findings overall; clearly, real limitations to this model, clearly significant socioeconomic stratification, unaddressed and potentially even reinforced."[18]

Dr. Jones also described Navigate as an "ultra-manualized" approach. Speaking about the Navigate manuals in use today, Dr. Jones said:

> "They are very really technically, biopsychosocial, but that means that psychoeducation consists of telling clients and their families that they have a biological brain disease in that language, literally that language, and that medications are the first line and most essential component of early intervention."[19]

In contrast to the RAISE Navigate study, the RAISE Implementation and Evaluation study (RAISE Connection) was a feasibility study. There was no control group. The study reported on the implementation tools, process and the overall feasibility of implementing coordinated specialty care in a real-world setting. The RAISE Connection program involved two sites (Baltimore and New York City). The program enrolled 65 enrollees in a program that provided medication, supported employment and education, family support and education, psychoeducation, skills training, substance abuse treatment, and suicide prevention.

In the RAISE Connection study, participants had high rates of engagement, and overall, participants showed significant improvements in symptoms and functions outcomes.[20]

According to Dr. Jones, RAISE Connection did not follow Navigate's "hyper-manualized" approach. According to Dr. Jones, "it was a very different kind of model in which the manuals are really guides, toolkits, and guides to practice and it's not to say that it's perfect."[21]

In 2014, the U.S. Congress mandated that States "expend at least five percent of [their Mental Health Block Grant] …to support evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders, regardless of the age of the individual at onset."

The Mental Health Block Grant (MHBG) program is a formula-based, state grant program in which federal funds are distributed to states and territories. The amount each state receives varies based on specified economic and demographic factors.

In 2016, the 21st Century Cures Act increased the mandatory, MHBG set-aside to 10 percent and included a supplemental grant.[22] The 2016 federal guidance noted:

> "States can implement models which have demonstrated efficacy, including the range of services and principles identified by NIMH via its Recovery After an Initial Schizophrenia Episode (RAISE) initiative."

Although Federal guidance encouraged states to implement the range of services and principles outlined in RAISE they were not required to do so. States were also given freedom to select which CSC model to implement, what types of services and training activities to fund, and what program admission criteria to require. However, the appropriation bill specifically required the 10 percent set-aside to fund only those evidence-based programs that target first episode psychosis. By law,

> "… the funds from set-aside are only used for programs showing strong evidence of effectiveness and targets the first episode psychosis. SAMHSA shall not expand the use of the set-aside to programs outside of those that address first episode psychosis."[23]

As of 2022, there were an estimated 381 programs in the United States offering coordinated specialty care services to individuals in every state except Vermont. The programs do not follow a uniform model. One CSC researcher noted that there are likely as many models of coordinated specialty care as there are programs.[24]

Description of Coordinated Specialty Care for Early Episode Psychosis

Coordinated Specialty Care for early episode psychosis (CSC-EEP) is an evidence-based, multi-disciplinary, team-based approach to providing early intervention for psychosis related to mental illness. CSC-EEP is intended primarily for adolescents and young adults between the ages of 15 and 30. CSC services are typically offered over a two-to-three-year period following the onset of first episode psychosis. After three years, individuals typically step down to a lower level of specialized care, and then transition to regular services at a mental health center.

The American Psychiatric Association (APA) has identified coordinated specialty care as standard of care in the treatment of individuals diagnosed with schizophrenia who are experiencing a first episode psychosis.[25]

CSC is a recovery-oriented approach that emphasizes shared decision making and collaboration between program participants, the treatment team, and family members. CSC uses a multidisciplinary team to provide services such as case management, medication management, psychotherapy, supported employment and education, family education and support, and primary care coordination.

While no research has identified what coordinated specialty care interventions are associated with positive outcomes, the National Institute of Mental Health recommends that CSC-EEP include five core activities:

(1) Cognitive or behavioral psychotherapy;
(2) Medication management;
(3) Family education and support;
(4) Service coordination and case management; and
(5) Supported employment and education.[26]

CSC programs vary across states and within states. Variation between CSC programs involve differences in caseloads, team structure, services provided, and family involvement. A 2022 survey of CSC programs found most programs include the following:

(1) Team lead,
(2) Cognitive-behavior-oriented psychotherapy,
(3) Case management, medication management,
(4) Family education and support,
(5) Supported employment and education services,
(6) Peer support services,
(7) Crisis intervention services,
(8) Primary care coordination, and
(9) Co-occurring substance use services.[27]

Dr. Jones has opined that what is consistent across CSC programs is rapid access and eliminating limitations on eligibility in terms of insurance status. Dr. Jones also observed that an underlying premise of CSC models is that medication and therapy are not enough.

> **"The most central components of CSC are the supported education and employment specialist, the peer support specialist, and a focus on physical health and wellbeing."**
> **Nev Jones, Ph.D.**

According to Dr. Jones, the most central components of CSC are the supported education and employment specialist, the peer support specialist, and a focus on physical health and wellbeing. Dr. Jones continued:

> "You may be aware of this, maybe not as aware that mortality of a young adult within 10 years of first episode [psychosis], basically before most people would even reach the age of

> 30 is staggeringly high, and only a portion of that is suicide. So, the physical health integration as much as it might sound medical, is really, really important."

Dr. Jones contributed the high mortality rate to side effects of medications, social isolation, and loss of social relationships: "So somebody who might be a star soccer player is suddenly no longer out on the field at all, totally isolated, not exercising, not getting out."

> **"… the mortality of a young adult within 10 years of first episode [psychosis], basically before most people would even reach the age of 30, is staggeringly high, and only a portion of that is suicide. … physical health integration … is really important."**
>
> **Nev Jones, Ph.D.**

Dr. Jones also shared that some CSC programs have dedicated housing specialists. "It's really care navigation and care management," according to Dr. Jones.

Ultimately, Dr. Jones said, the downside of evidence-based practice discourse is that it deemphasizes often what matters most, which is the human beings involved and not the model.

Despite the variation in CSC programs, there are commonly reported CSC models found across the United States.

Commonly Reported CSC Models and Programs

Name	Location	Start Date	Program Description
Portland Identification and Early Referral Program (PIER)	Maine, California, Utah	2000	Designed to treat the earliest signs of psychosis. Program emphasizes community outreach, assessment and treatment. Treatment components include multifamily group therapy; cognitive behavior therapy for psychosis; peer support; care management; supported employment and education; and psychiatric consultation and medication management

Commonly Reported CSC Models and Programs			
Name	**Location**	**Start Date**	**Program Description**
Early Assessment and Support Alliance (EASA)	Oregon and other states	2001	Provide information and care for those experiencing psychosis for the first time or having early symptoms of psychosis in the last 12 months. The program is two years long. Treatment components include community education and engagement, cognitive behavioral therapy, occupational therapy, Individual Placement and Support supported employment, Multi-Family and Individual Psychoeducation, intensive community coordination much like Assertive Community Treatment, medical assessment and treatment, peer support, supported housing, participatory decision making, co-occurring substance use treatment, and transition planning
Outreach and Support Intervention Services Program (OASIS)	North Carolina	2005	Teams include psychologists, social workers and psychiatrists. Treatment components include medication management, individual therapy, family therapy, co-occurring substance use treatment, supported employment and education, recreational/social activity rehabilitation, social skills training, and peer support
Specialized Treatment Early in Psychosis (STEP)	Connecticut	2006	Joint program between Yale School of Medicine and the Connecticut Mental Health center. It is a research- based clinic that provides treatment to those with early psychosis. Treatment components include comprehensive assessment and evaluation, medication management, cognitive behavioral therapy, family focused therapy, Multi-Family Group Psychoeducation, supported employment, and Social Cognition Interactive Training

Commonly Reported CSC Models and Programs			
Name	**Location**	**Start Date**	**Program Description**
NAVIGATE	Multiple sites across US and Canada	2008	Provides family care and individual treatment to those who have experienced a first episode of psychosis. Treatment components include supported employment, supported education, medication management, Individual Family Therapy and Individual Resilience Training (IRT)
Early Diagnosis and Preventative Treatment Program (EDAPT)	UC Davis (California)	2004	Provides medication management, employment and education supports, family education and support and individual counseling; substance misuse groups and peer support
Early Psychosis Intervention Center (EPICENTER)	AZ; OH	2010	Specialized services and supports for youth and young adults with psychosis or at – risk for developing psychosis. Treatment components include medication management, cognitive behavioral therapy, family psychoeducation, Metacognitive Remediation Therapy, Community education, family education and support and clinical evaluation and assessment
OnTrack and OnTrackNY	NY and other states	2013	The services include case management, psychopharmacology and medication management, cognitive- behavioral therapy and supports, family education and support, and supported education and employment
FIRST	OH and other states	2009	An outpatient early identification and treatment of psychotic illness programs, focused on rapid access to services; helping people with schizophrenia spectrum disorders set and achieve goals for the future; and involving loved ones in the recovery process. Treatment services are provided in an integrated manner by a six-person team and include: psychiatric care; individual counseling, family education and support; supported employment/education; case management

According to a report of the Early Psychosis Intervention Network (EPINET)[28], the most reported CSC model in the United States was NAVIGATE (25.7%), followed by EASA (25.1%), OnTrack (20.3%), and FIRST (13.4%).

CSC Model by Number of States and Programs		
CSC Model	**Number of States with Model**	**Number of Programs**
NAVIGATE	16	48
OnTrack	11	38
EASA	6	47
PIER	3	10
FIRST	2	25
EDAPT	1	3

Some states have adopted a single CSC model for the state. For example, EASA is used throughout the State of Oregon; OnTrackNY is used throughout New York; and New Journeys is used across Washington State. There are also states where CSC program models vary within the State. For example, researchers found that across 58 California counties, five counties offered more than one version of CSC. In Ohio, some programs employ the FIRST model while others employ the EASA model.

Eligibility for CSC-EEP

Eligibility for CSC programs varies by the program. Typically, eligibility criteria include (1) age; (2) psychiatric diagnosis; (3) duration of psychosis; (4) treatment history; and (5) co-occurring diagnoses.

Traditionally, many programs excluded individuals experiencing a first episode of affective psychosis (e.g., bipolar mania with psychotic features) because the original RAISE Navigate research study included only individuals experiencing nonaffective psychosis (e.g., schizophrenia and related diagnoses). However, a Navigate team based in Colorado recently reported that it has developed a CSC program for bipolar disorder called Stride.

The Stride program is an adaptation of the Navigate program for early episode psychosis but focused specifically on bipolar disorder. The Stride program aims to provide a coordinated specialty care approach for young people with bipolar disorder, including bipolar disorder-specific education for patients and families; medication management tailored to bipolar disorder; and psychosocial interventions like individual therapy and support for employment/education.

In a late July 2024 webinar, proponents of the program expressed excitement about the potential of the Stride program to provide a more comprehensive and coordinated approach to treating bipolar disorder, compared to the patchwork of services that is often available.

The program is currently being tested for feasibility and usability in Colorado. Reportedly, there are plans to implement the Stride program in Washington State and Florida.[29]

DELIVERY OF COORDINATED SPECIALTY CARE 4 | FOUR

CSC Team Composition

CSC is typically delivered by four to six clinicians who are trained for a specific component of coordinated specialty care. The team typically maintains a shared caseload of 30 to 35 clients. However, in practice, team sizes can be as low as two members.

Key CSC Roles on Teams

The successful implementation of CSC relies on ensuring adequate coverage of key roles. Essential functions encompass overall team leadership and management, as well as delivery of core clinical services, including case management, psychotherapy, supported employment and education, family education and support, and pharmacotherapy/primary care coordination.

The number of providers required to fulfill key roles varies based on factors such as the size of the EEP cohort served, the availability of providers, and the level of effort each provider dedicates to the CSC program. In programs with smaller caseloads, key roles may be combined, provided the provider has achieved competency in each assigned CSC function.

For instance, the Team Leader might deliver clinical interventions such as primary care management or family education and support while also providing overall administrative and supervisory oversight to the team. Alternatively, the roles of individual psychotherapist and care manager might be merged. The only exception to this practice is the supported employment/education role, which demands highly specialized skills and entails a significant amount of time spent in the community assisting job seekers with finding employment or helping students secure accommodations that allow them to complete their education.

The table below summarizes critical roles and clinical services provided in CSC programs and a description of the skills, education, and training required to hold the role.

CSC Role	Description	Required Skills, Credentials, Experience
Team Leadership	The CSC Team Leader is an experienced clinician with a clear commitment to recovery- oriented care and strong communication, management, and program development skills. The Leader provides ongoing consultation to team members regarding the principles of early psychosis intervention and coordinates key services such as screening potential clients for admission into the program, leading weekly team meetings, overseeing treatment planning and case review conferences, and cultivating referral pathways to and from the CSC program.	Licensed clinicians (e.g., psychologists, social workers, mental health counselors, and rehabilitation counselors)

CSC Role	Description	Required Skills, Credentials, Experience
Case Management	Case management assists clients with problem solving, offering solutions to address practical problems, and coordinating social services across multiple areas of need. Case management involves frequent in-person contact between the clinician and the young person and their family, with sessions occurring in clinic, community, and home settings, as required.	Licensed clinicians (e.g., psychologists, social workers, mental health counselors, and rehabilitation counselors)
Supported Employment and Education (SEE)	SEE services facilitate the recovering person's return to work or school, as well as attainment of expected vocational and educational milestones. SEE emphasizes rapid placement in the individual's desired work or school setting and provides active and sustained coaching and support to ensure the individual's success. The SEE Specialist strives to integrate vocational and mental health services, is the CSC team liaison with outside educators and employers, and frequently works with the client in the community to enhance school or job performance.	SEE specialists should be trained to provide employment services within the Individual Placement and Support model. A SEE trainer who was interviewed for this report suggested that the best background for a SEE specialist was in marketing, sales, and customer service[30] Occupational therapists can also fill this role.
Psychotherapy	Psychotherapy for EEP is based upon cognitive and behavioral treatment principles and emphasizes resilience training, illness and wellness management, and general coping skills. Treatment consists of core and supplemental modules and is tailored to each client's needs. Clients and psychotherapists work one-on-one or in groups, meeting weekly or bi-weekly, with the duration and frequency of sessions personalized for each individual.	Licensed clinicians (e.g., psychologists, social workers, mental health counselors, and rehabilitation counselors)
Family Education and Support	Family education and support teaches relatives or other individuals providing support about psychosis and its treatment and strengthens their capacity to aide in the client's recovery. To the greatest extent possible, and consistent with the client's preferences, supportive individuals are included in all phases of treatment planning and decision making. For individuals less than 18 years of age, participation of a family or guardian is generally required. Depending on the number of clients served at any given time, family therapy may be offered on an individual basis, or through multi-family workshops and support groups.	Licensed clinicians (e.g., psychologists, social workers, mental health counselors, and rehabilitation counselors)

CSC Role	Description	Required Skills, Credentials, Experience
Pharmacotherapy and Primary Care Coordination	Evidence-based pharmacologic approaches guide medication selection and dosing for persons with EEP. Pharmacotherapy typically begins with a low dose of a single antipsychotic medication and involves monitoring for psychopathology, side effects, and attitudes towards medication at every visit. Special emphasis should be given to cardiometabolic risk factors such as smoking, weight gain, hypertension, dyslipidemia, and pre-diabetes. Prescribers maintain close contact with primary care providers to assure optimal medical treatment for risk factors related to cardiovascular disease and diabetes.	Licensed physicians and nurses
Peer Support Provider	Peer support providers focus on building relationships with participants, enhancing outreach efforts to help participants stay connected to the program, connecting participants to resources in the community and empowering participants to advocate for themselves and effectively use CSC services.	Certified peer support provider

Core Functions of CSC

In addition to the clinical components of CSC, CSC teams must also offer (1) access to clinical providers with specialized training in EEP care; (2) easy access to the CSC program through active outreach and engagement; (3) provision of services in home, community, and clinic settings, as needed; (4) acute care during or following a psychiatric crisis; (5) transition to step-down services with the CSC team or discharge to regular care after two to three years, and (6) program quality assurance through continuous monitoring of treatment fidelity.

Specialized Training in CSC-EEP Care

Training in evidence-based treatment for CSC-EEP occurs at two distinct levels within CSC. First, team members must understand the overarching philosophy of team-based care. Second, they must master specialized services designed to bolster clients' recovery. It is imperative for each team member to understand the theoretical framework of CSC treatment. This includes understanding the potential for recovery, navigating the unique developmental challenges faced by adolescents and young adults experiencing first episode psychosis, embracing the principles of shared decision making and person-centered care, and consistently maintaining an optimistic therapeutic outlook. Additionally, CSC staff members must be adept at addressing common challenges spanning all service categories. These challenges may include difficulties in engaging clients and their families, the heightened susceptibility of clients to substance use problems, and the increased risk of suicide during the initial phases of treatment.

To maintain fidelity to the CSC model, continuous workforce development is key. This involves ongoing supervision and educational initiatives for all staff engaged in the treatment program. Supervision occurs at various levels, including face-to-face sessions with the CSC Team Leader for case managers and supported employment specialists. Additionally, staff may engage in consultations with EEP subject matter experts through methods such as conference calls, webinars, or distance learning programs tailored for medical professionals, psychotherapists, and family therapists. Regular case reviews during team meetings serve as a valuable tool for reinforcing CSC treatment principles and ensuring high-quality clinical care for individuals experiencing EEP. Furthermore, soliciting feedback from current and former clients is an effective strategy to ensure the program remains accessible and relevant to young people in recovery from EEP.

Community Outreach

Early intervention programs are designed to shorten the duration of untreated psychosis by enhancing the early detection of EEP within the community and ensuring swift access to CSC services. Effective community outreach typically requires a designated provider tasked with eliminating obstacles to CSC access and expediting entry into EEP services. This outreach specialist dedicates time to establishing referral pathways with various institutions, including inpatient facilities, emergency departments, crisis intervention services, and the criminal justice system. Building rapport with personnel from these agencies through regular visits, calls, emails, and prompt evaluation of potential EEP cases is crucial. Additionally, the outreach specialist maintains communication with administrators of child and youth mental health programs to identify individuals who could benefit from CSC treatment. Moreover, the specialist monitors referrals and intakes within the parent agency to ensure seamless connections for potential CSC candidates.

Experts in the field recommend deferring outreach to schools, primary care physicians, and social services agencies until the program is firmly established.

Client and Family Engagement

Engaging individuals experiencing EEP and their family members in treatment requires a thoughtful approach from the outset. Assertive outreach, efficient enrollment procedures, and messages filled with hope are crucial during intake. It is critical that informational materials avoid stigmatizing language and clinical jargon, instead emphasizing the program's aim to help individuals achieve their own goals.

Initial interactions with clients and their families need to be supportive and focused on understanding how symptoms impact daily life and affect loved ones. The CSC team uses this information to tailor their description of the program, highlighting services most relevant to the individual and their family. Since initial uncertainty is common, ongoing education and support are essential, with providers being open to negotiating changes in treatment goals and strategies.

Establishing a welcoming environment is crucial for fostering engagement in mental health programs. Some initiatives across the country are situated in storefronts or youth centers, with one program in Philadelphia even featuring a café within its facilities. It's essential that the ambiance, including posters, brochures, artwork, and furnishings, is youth-friendly and radiates hope and optimism. Brochures and advertisements related to medications or how to apply for public entitlement programs are incongruent with CSC principles and may deter young individuals experiencing early episodes of psychosis.

"… what 18-year-old on the planet wants to be labeled with schizophrenia and walk into an environment like that … what healthy 18-year-old would not reject that. It's like something is almost wrong if you're not rejecting it."

Father of a son experiencing EEP

An interaction Dr. Nev Jones shared at DMH's October 2023 conference underscores this point. Dr. Jones was conducting research on individuals who drop out of treatment programs. During the research study, Dr. Jones interviewed the father of a son who had dropped out of a CSC program. The son was subsequently placed in an Assisted Outpatient Treatment program, which the father was not happy about. Dr. Jones asked the father, "where did the problems start ?" The interview was conducted in the waiting room of the agency where the son had received treatment. According to Dr. Jones, the father responded: "Let me show you what went wrong."

> "And he just started going around and he picked up our pamphlets and he said, 'What is the language there, schizophrenia? What's that research advertisement from Stanford on the wall right? "Participants with schizophrenia wanted."' He's like what 18-year-old on the planet wants to be labeled with schizophrenia and walk into an environment like that. And you can say you have your peer team and all that which we did, that's not going to compensate for the damage that you're doing to somebody's identity; and 'what healthy 18-year-old would not reject that. It's like something is almost wrong if you're not rejecting it.'"

Receptionists and office staff, accustomed to serving adults with long-standing psychotic disorders, may require additional training on the recovery model and the needs of young individuals experiencing EEP.

Ideally, the CSC care manager contacts referred individuals promptly within 24 hours, to explain the services offered and screen for program eligibility. Offering appointments during evenings and weekends accommodates the schedules of youth and their families with school or work commitments. If individuals are in the hospital, connecting with the inpatient unit is optimal.

During eligibility screening, the care manager gathers relevant information in a supportive, person-centered, and youth-friendly manner. Eligible individuals should be offered an admission interview with the CSC team within seven days of the screening interview.

For admitted individuals, setting personalized, recovery-oriented goals focusing on normal developmental milestones, like returning to school or work, helps sustain motivation for treatment beyond the initial phase of care.

Mobile Outreach and Crisis Intervention Services

Mobile outreach services are offered to young individuals who face challenges in engaging with clinic-based services or have complex needs requiring intensive support, such as legal issues, homelessness, or managing comorbid physical conditions. The CSC team adopts a multidisciplinary approach to mobile case management, providing supportive interventions in clinic, community, and home settings as necessary. For example, case managers may accompany clients to community appointments and facilitate access to essential social services. Supported employment and education specialists offer active coaching and support within school and work environments. Similarly, family clinicians may offer support in the homes of clients to providing practical assistance to both clients and their families during times of upheaval or instability.

Transition of Care

Transition planning is a critical component of CSC treatment programs. Research indicates that abruptly transitioning to regular care after two years can compromise the immediate benefits of early intervention. This evidence suggests that short-term gains from early psychosis intervention do not necessarily translate into long-term benefits. Therefore, CSC programs should consider maintaining continuity of care for up to five years after the onset of psychosis.

Studies have demonstrated that clients who transitioned to a lower intensity of specialized intervention after two years maintained their early treatment gains at a five-year follow-up. This step down in care involved ongoing connection with a member of the CSC team, such as a case manager or psychiatrist, for an additional one to two years before transitioning to regular services at a mental health center.

Deciding when a client is ready for transition to a less intensive level of care should be a collaborative process involving the client, their family, significant others, and members of the CSC team. Together, they assess the client's progress in achieving treatment goals across various domains, such as school and work functioning, relationships with peers and family, symptom relief, substance use, and health management.

An important aspect of planning the transition from CSC is considering the client's personal vision of stability, success in community functioning, and autonomy. By focusing on these issues, the CSC team can effectively collaborate with the client to strike a balance between professionally delivered treatment, community-based therapeutic activities and support, and the client's self-directed recovery goals.

Fidelity to CSC Model

Fidelity and outcome measures play a crucial role in assessing the implementation of CSC programs. Fidelity and outcome measures should allow planners and administrators to answer questions such as: (1) are CSC team members delivering interventions as intended?; (2) are providers meeting the commitments outlined in the service contract?; and (3) have CSC services achieved the desired clinical and functional outcomes for individuals experiencing EEP?

Monitoring fidelity also meets the needs of clients and their families, who seek assurance that the services provided are of high quality and will lead to positive outcomes in areas like education, employment, social connections, and health.

Efficient fidelity monitoring requires a practical approach, utilizing measures derived from readily available information in routine clinical operations. Effective fidelity measures serve as proxies for key components of CSC. For instance, since antipsychotic medications are a fundamental aspect of EEP specialty care, medication records and associated laboratory orders offer valuable insights into the quality of psychopharmacology interventions, including medication type, dosage, and metabolic monitoring over time.

A program's fidelity to pharmacotherapy guidelines can be assessed by determining the proportion of clients who received recommended antipsychotic medication, underwent a trial of recommended medication within the recommended dosage range for a minimum duration, and received the required metabolic monitoring. The RAISE Early Treatment Program has developed a decision support system for prescribers to enhance evidence-based pharmacotherapy implementation and monitor the quality and fidelity of medical interventions.

Many programs with CSC teams utilize electronic health records (EHRs) to document service contacts and clinical data, facilitating access to fidelity and outcome information through electronic claims data or automated reports. In the absence of an EHR, routine service logs can inform fidelity measures if they record client and staff involvement, family presence, and service location (e.g., office or community). If electronic claims data abstraction is not feasible, implementing a chart abstraction system offers a practical alternative.

Configuring and Staffing CSC Programs

Continuity of care is a critical in CSC-EEP programs. This was noted by several respondents during interviews for this report. Of note, a prominent EEP researcher recently observed during an EEP conference that inexperienced clinicians will often seek positions in CSC-like programs to accumulate required credentialing hours, subsequently transitioning to more financially rewarding roles. Consequently, careful consideration in staffing is crucial to mitigate high turnover rates resulting from inadequate compensation or demanding work environments.

Experienced clinicians paid competitive wages are the ideal candidates for these programs. In addition to experience, ideal candidates embrace the challenge of working with adolescents and young adults experiencing psychosis, are flexible regarding intervention approaches to engage clients and family members and are tolerant of uncertainty regarding a client's preferred recovery strategies.

The exact configuration of staffing will depend on the program model. In the RAISE Connection program, each team consisted of four staff members (2.7 full-time equivalent employees) for a target caseload of 25 clients. A licensed clinician served as full-time team leader. The team leader provided administrative oversight of the program and supervised other team members to assure fidelity to the CSC model. The team leader also served as the primary care manager for most clients. A full-time supported employment/education specialist provided services based on the IPS model. A half-time recovery coach provided individual and group cognitive and behavioral psychotherapy interventions for clients experiencing EEP and psychoeducation sessions for clients' family members. The total FTE for the program psychiatrist was 0.2. Of note, the team members were not responsible for conducting evaluations for program eligibility; this was done by a separate outreach and enrollment specialist who worked with the team.

The staffing configuration in the RAISE Navigate study varied by the 17 experimental sites. The table below illustrates different staffing configurations for three of the sites.

	Urban	**Suburban**	**Rural**
Caseload	25 – 30	20 – 25	12 -15
Staff Headcount	6	4	5
Team Leader	.3 FTE	1 FTE Team Leader and Therapist Role Combined	1 FTE Team Leader and Therapist Role Combined
Family Therapist	.25 FTE		
SEE	.5 FTE	.5 FTE	.25 FTE
Psychiatrist	.2 FTE	.2 FTE	.1 FTE
Psychologist	.5 FTE	1.0 FTE	.25 FTE

	Urban	**Suburban**	**Rural**
Case Manager	Two clinicians filled the combined role of psychotherapist/case manager	Psychologist and case manager role combined	.3 FTE

Additional information on staffing configurations is available in the State Case Studies section of the report.

COSTS OF COORDINATED SPECIALTY CARE 5 |FIVE

The costs associated with CSC-EEP can be significant. Randomized controlled trials have shown that total treatment costs for those assigned to CSC-EEP did not significantly differ from those in standard care.

The primary source of savings with CSC-EEP is typically associated with reduced hospitalization and emergency room visits, and other health care costs. Thus, while the costs of providing CSC-EEP services may be comparable to standard care, SAMHSA has concluded based on a systematic literature review that CSC-EEP is more cost-effective than standard care based on decreases in high cost of adverse outcomes.[31]

Start Up Costs

The most recent estimates of start-up costs for establishing a CSC-EEP program range from $300,000[32] a year for two years to $995,686 over two years.[33]

CSC teams are highly specialized and require extensive training to deliver an evidence-based model of coordinated specialty care. Recruitment for new teams is reported to require at least six months during which individuals are not enrolled. In addition, CSC-EEP requires a strong referral network to identify individuals experiencing early episode psychosis.

Outreach must be intentional and targeted. Effective outreach includes key stakeholders; supportive community allies; medical community contacts; and academic contacts and supports.[34]

Key Stakeholders	**Medical Community**	**Academic Community**	**Supportive Community Allies**
▪ Elected officials ▪ Community activists ▪ Foundations ▪ Employers	▪ Primary care providers ▪ Medical pre-professional groups ▪ Public health clinics ▪ Pediatricians ▪ Mental health professionals	▪ Colleges and universities ▪ Technical schools ▪ School boards ▪ Community colleges ▪ Middle Schools ▪ High Schools	▪ Disability Rights ▪ Parent groups ▪ Mental health advocacy groups ▪ NAMI

In Vermont, outreach must also necessarily include hospital emergency departments, psychiatric hospitals, law enforcement agencies, embedded clinicians in police barracks, EMS personnel, youth and family service organizations (e.g., Spectrum[35]), Street Outreach, Mobile Crisis Response Teams, school resource officers, and designated agencies. According to survey respondents, these are the current entry points for young Vermonters experiencing early episode psychosis.

Outreach requires a significant effort by the team throughout the first year to educate community stakeholders to recognize early psychosis and the availability of and evidence base for CSC-EEP.

Because recruitment, training, and outreach are conducted before any clients are recruited, third-party reimbursement is unavailable. Thus, start-up costs are typically covered by federal grants and state revenues.

At least 10 percent of the total Mental Health Block Grant funds a state or territory receives must be used for evidence-based services for individuals experiencing early episode psychosis or early serious mental illness. The funds may be used for any component of CSC services as well as training and overhead costs.

In 2023, Vermont's Mental Health Block Grant final allotment totaled $1,672, 361[36], 10 percent of which amounts to $167, 236.10, which leaves a shortfall between $132,764 and $330,607 a year for start-up costs.

Operating Costs

The cost of implementing Coordinated Specialty Care for early episode psychosis depends on the number of teams required and the composition of those teams.

In 2013, the New York State Office of Mental Health developed an interactive modeling tool that allows users to input various estimates for relevant variables and estimate the number of teams needed and the costs of those teams.[37] The New York State Office of Mental Health was a partner in RAISE Connection, an initiative of the National Institute of Mental Health that established the evidence base for CSC-EEP.

Wilda L White Consulting adapted the interactive modeling tool for Vermont to provide an estimate of the number of teams Vermont would need and the costs of providing the team(s). The tool allows policy makers to compare costs and treatment team sizes by varying assumptions.

The number of teams a state will need will vary based on assumptions regarding several unknown variables, including:

(1) The incidence of early episode psychosis in a population;
(2) The percentage of individuals experiencing early episode psychosis who are identified;
(3) The percentage of identified individuals who agree to participate in the program; and
(4) The number of individuals served by a team; and
(5) The average duration of time an individual is served.

The interactive tool provides four estimates of operating costs and number of required teams based on a set of assumptions characterized by the interactive tool as a low, medium#1, medium #2, and high.

The table below lists the interactive tool's variables and corresponding assumptions.

Line	Variable	Low Estimate	High Estimate	Medium Estimate #1	Medium Estimate #2
1	EEP incidence per year	0.0003	0.0003	0.00025	0.0002
2	% incident cases approached	0.2	0.5	0.333	0.25
3	% agreeing to participate	0.5	0.75	0.5	0.6

Line	Variable	Low Estimate	High Estimate	Medium Estimate #1	Medium Estimate #2
4	# of active individuals served by a team	30	35	35	30
5	# months in the program	18	24	18	22

Line 1, the EEP incidence per year is based on published incidence rates of 20 to 30 cases per 100,000 population. The State of Vermont is currently conducting an analysis to estimate the incidence of psychosis in Vermont.

The State of Vermont is currently conducting an analysis to estimate the incidence of psychosis in Vermont.

Line 2, the percent of cases approached, assumes that outreach efforts are unlikely to reach all incident cases. Therefore, line 2 estimates the percentage of cases likely reached each year.

Line 3, the percent of individuals who agree to participate, assumes that not everyone contacted will agree to participate. Therefore, line 3 estimates the percent of individuals who agree to participate.

These variables combine to estimate the total number of new individuals enrolled per year in the service area.

Line 5, the number of months in the program, is used to calculate the number of slots opening on a team each month. That number is derived by dividing the number of active cases per team by the average number of months in treatment.

Line 4, the number of active individuals served by a team, is used to calculate the number of teams needed in the geographic region. That number is derived by dividing the total number of active clients by the number of new individuals each team can take per year.

The tool then calculates the population size needed to support one team by dividing the geographic area's population size (647,464, according to 2024 US Census for Vermont) by the number of teams required.

The tool also estimates the total annual costs per year based on estimated salary levels entered by the user.

The salary estimates used in the interactive tool adapted by Wilda L. White Consulting are generally based on current, average salaries in Vermont as reported by salary.com, ZipRecruiter.com, or job ads, except for the salary level for the team's psychiatrist. The salary level for the team psychiatrist is based on the salary level that a Vermont, child psychiatrist estimated would be required to attract and retain a qualified candidate.

The following table illustrates the salary estimates used in the interactive tool.

Team Member	**Percent Time**	**Annual Salary**	**Hourly Salary**
Team Leader	100%	$85,000	$41
SEE Specialist	100%	$68,011	$33
Psychotherapist	100%	$73,364	$35
Psychiatrist	30%	$468,000	$225
Peer Support Specialist	100%	$43,680	$21
Case Manager	100%	$56,160	$27

Based on the foregoing salary estimates and low, medium and high assumptions for each variable, the interactive tool estimated that Vermont would need 1 to 4.4 teams, at an annual cost ranging from $708,765 to $3,037,565 or from $1,737.58 to $2,027.17, per client per month.

Below is an excerpt of the interactive tool in use. A printout of the Excel-based interactive tool in its entirety can be found at Appendix F. You may also download the adapted, Excel-based interactive tool at this link[38].

		Low Estimate	**High Estimate**
1	Population size (2023 Census)	647,464	647,464
2	EEP incidence per year (V)	0.0003	0.0003
3	# of incident cases per year (Population size*Incidence)	194	194
4	Fraction of incident cases approached (V)	0.2	0.5
5	# of incident cases approached	39	97
6	Fraction agreeing to enter services (V)	0.5	0.75
7	# total active individuals	19	73
8	# active individuals per team (V)	30	35
9	# months in treatment (V)	18	24
10	# new individuals each team can take/month (active cases per team/months in treatment)	1.667	1.458
11	# new individuals each team can take/year (new individuals per month*12)	20	18
12	**# teams needed statewide** **(# active individuals/new individuals each team can take per year)**	**1.0**	**4.2**

		Low Estimate	High Estimate
	# clients taken per week in start-up	**1**	**1**
	# weeks to full capacity	**30**	**35**
	# months to full capacity	**7.5**	**8.75**
13	**Population size to support 1 team (population size/number of teams)**	**666,667**	**155,556**
14	**Salary costs per EEP team per year[1]**	**466,615**	**466,615**
15	**Total Costs per EEP team per year (including 36% fringe and 15% indirect)**	**729,786**	**729,786**
16	Cost per client (Total salary costs/clients served per team)	24,326	20,851
17	Cost per team per initial year (As calculated on cost worksheet)[39]	$531,122	$493,474
18	Staffing cost per team per year - at capacity (Cost per client per year)x(N clients per team)	$729,786	$729,786
19	**Total cost per year (# teams*cost per team at capacity)**	**$708,765**	**$3,037,565**

Relying on four studies published between 2013 and 2023, SAMHSA concluded that when adjusted for 2023 inflation, the per client per month cost of providing CSC-EEP ranged from $1,054 to $1,653.[40]

The table below summarizes the cost estimates from the research studies and the interactive tool.

Per Client Per Month Estimated Cost of Providing CSC-EEP Services			
Study Year	**Service and State**	**Cost estimate components**	**Cost adjusted for 2023 inflation[41]**
2015	EPICENTER, Arizona	Salary and benefits for clinical staff, indirect costs for the hospital in which the program was located	$1,309.13
2019	ePEP, Texas	Provision of all CSC services	$1,053.74

Per Client Per Month Estimated Cost of Providing CSC-EEP Services			
Study Year	**Service and State**	**Cost estimate components**	**Cost adjusted for 2023 inflation[41]**
2016	RAISE (NAVIGATE), clinics across 21 states	Inpatient and outpatient care, medication, and staff training	$1,653.38
2019	OnTrackNY, NY	All clinic activities provided to 75 Medicaid patients during a two-week period and staff time spent on each activity	$1,634.24
2024	Excel interactive tool – low estimate for Vermont[42]	Salary, benefits, and indirect costs	$1,865.22
2024	Excel interactive tool – medium estimate #1 for Vermont	Salary, benefits, and indirect costs	$1,598.79
2024	Excel interactive tool – medium estimate #2 for Vermont	Salary, benefits, and indirect costs	$1,865.22
2024	Excel interactive tool – high estimate for Vermont[43]	Salary, benefits, and indirect costs	$1,598.79

After adjusting for inflation, the interactive tool appears to be a fairly accurate tool for estimating costs of staffing a CSC-EEP or at least somewhat approximates the cost estimates of the four research studies.

FUNDING AND FINANCING COORDINATED SPECIALITY CARE 6 |SIX

Funding Sources

States have typically used a combination of four, principal sources of funds to pay for coordinated specialty care for early episode psychosis: (1) Mental Health Block Grant; (2) Medicaid; (3) Commercial Insurance; and (4) State and Local Funds.

None of these funds are individually sufficient to cover the costs of providing CSC services.

Mental Health Block Grant

The Mental Health Block Grant is a noncompetitive grant awarded via a formula mandated by the U.S. Congress and administered by SAMHSA through the Community Mental Health Services Block Grant (MHBG) program. The funds are provided to all U.S. states and territories to provide community mental health services.

In FY2016, Congress directed SAMHSA to set aside 10 percent of the Mental Health Block Grant allocation for each state to support evidence -based programs that provide treatment for those experiencing early serious mental illness (ESMI) and a first episode of psychosis. The appropriation bill specifically requires the 10 percent set-aside to fund only those evidence-based programs that target EEP. By law,

> "… the funds from set-aside are only used for programs showing strong evidence of effectiveness and targets the first episode psychosis. SAMHSA shall not expand the use of the set-aside to programs outside of those that address first episode psychosis."[44]

The MHBG funds may not be used for primary prevention or preventive intervention for those at high risk for psychosis.

MHBG funds may be used for any component of CSC-EEP services as well as training and overhead costs.

In 2023, Vermont's MHBG was $$1,672, 361.

In short, MHBG funds are insufficient to support a CSC-EEP program.

Medicaid

Medicaid can potentially fund most components of CSC services through mechanisms such as a State Plan amendment, Managed Care Organization, SMI/Serious Emotional Disturbance (SED) 1115 waivers, In Lieu of Services (ILOS) in Medicaid managed care, and Certified Community Behavioral Health Clinics (CCBHCs).[45]

Medicaid's Early Periodic Screening, Diagnostic and Treatment (EPSDT) benefit is available to cover all costs of CSC services for individuals under age 21 experiencing EEP, except the cost of the premium.[46] CHIP can also potentially cover CSC services for Medicaid-eligible individuals under age 19 (nationally, about five percent of individuals experiencing EEP).

Several states have successfully amended their Medicaid state plans or SMI/SED 1115 waivers to provide CSC services. In these states, Medicaid is available to pay for all CSC services, including activities to integrate medical services, rehabilitation service coordination with other Medicaid-services, therapy, and counseling. It will also cover care coordination to assist those eligible for Medicaid to access medical, social, educational, and other services. There are, however, some elements of supported employment and outreach and engagement services that are not covered under regular Medicaid state plan authority.[47]

Effective October 1, 2023, the Centers for Medicare & Medicaid Services established two new billing codes for Coordinated Specialty Care for First Episode Psychosis.

1. H2040, "Coordinated specialty care, team-based, for first episode psychosis, per month; and
2. H2041, "Coordinated specialty care, team-based, for first episode psychosis, per encounter.[48]

The new codes are expected to open a pathway to reimbursement for non-clinical services offered by CSC teams such as education and employment support, assertive outreach in the community, and treatment team meetings. They will also allow for the development of case rates for CSC services.

However, to use the codes, each state must prepare a State Plan Amendment to incorporate the new billing codes into the State's Medicaid plan, after conducting an economic analysis to set appropriate reimbursement rates.

Commercial Insurance

Commercial insurance rarely funds all the required components of CSC-EEP. Typically, commercial insurance covers traditional services such as psychotherapy, physicians, and laboratory costs.

As the table below illustrates, in general, neither public nor private insurance programs typically cover most CSC-EEP team services that are essential for (1) assertive outreach to referral networks; (2) facilitating participants' access to EEP care; (3) engaging and retaining participants in treatment; (4) coordinating services in team meetings; (5) clinical supervision; and/or (6) assuring the quality of services through fidelity monitoring.

Traditional Coverage of CSC Components Under Commercial Insurance

CSC Service/Role	Description of Service	Traditional Coverage Status
Team Leadership	Cultivate referral networks; facilitate access to care; outreach to program participants and family members; coordinate clinical services among team members; provide ongoing clinical supervision	Not covered

Traditional Coverage of CSC Components Under Commercial Insurance

CSC Service/Role	Description of Service	Traditional Coverage Status
Psychotherapy	Provide individual and group psychotherapy sessions, including integrated substance misuse sessions, when needed	Billable via CPT 90832; 90834; 90853
Case Management	Perform assertive case management functions in clinic and community settings	Inconsistently covered
Family Education and Support	Provide psychoeducation, relapse prevention counseling, and crisis intervention services	Billable via CPT 90846; 90847; 90849
Supported Education and Employment	Implement IPS model of supported employment and supported education; provide ongoing client support following job or education placement	Inconsistently covered
Medication Management and Primary Care Coordination	Medication management and coordination with primary medical care	Billable via CPT 99214
CSC Team Activities	Team meetings, coordination of services among team members, CSC training, clinical supervision, 24-hour phone coverage for crisis intervention	Not covered

In addition, some CSC-EEP programs do not bill commercial insurers because of the difficulty of receiving payment, when, for example, a CSC team is not a member of an insurer's network.[49]

State and Local Funding

Many CSC programs are partially funded through grants, philanthropy, and state general revenue. State and local funding is typically used to fill in coverage gaps from billing Medicaid or commercial insurers or to support individuals without insurance. State and local funding varies by jurisdiction.

CSC Financing Strategies

There are three primary strategies for financing the cost of CSC-EEP services: (1) Fee-for-service; (2) a team-based rate; and (3) braided funding.

Fee-for-Service

Fee-for-Service is a payment method that pays healthcare providers for each service they perform. Several components of CSC-EEP are typically not paid by commercial insurance when fee-for-service is the only payment source.

Increasingly, Medicaid programs are covering all services offered by CSC-EEP programs. However, services such as assertive community outreach and supported employment and education are not generally covered through fee-for-service billing in Medicaid because billing fee schedules seldom cover the costs of delivering community-based care for a small caseload of individuals with intensive needs, which is a necessary element of an evidence-based CSC-EEP program.

Fee-for-service billing typically does not cover CSC program overhead, outreach, training, and costs to support certification and CSC-EEP model fidelity.

Team-Based Rate

A team-based rate is payment for a pre-defined set of services for an evidence-based practice, typically provided by a team of healthcare practitioners. Team-based rates recognize the needs of the individual receiving services rather than the volume of services provided.

Because CSC-EEP programs are team-based, this financing strategy can provide coverage for CSC team activities that fee-for-service payment models typically do not cover.

A team-based rate can be daily or monthly for all approved services provided through the team for eligible individuals.

Braided Funding

Braided funding combines two or more funding sources to support the total cost of service. Medicaid, commercial insurance, the MHBG, and state funds may all be sued to fund CSC-EEP program services. Braided funding gives the provider access to more funds to support an array of services that any one source provides alone.

Braided funding can be challenging for providers to use because each of the funding sources may have different rules for providing services and different reporting requirements, which may increase the provider’s administrative burden.

Examples of State Financing Strategies

A recent SAMHSA report highlighted a variety of financing strategies undertaken by different states.[50] The information in this section is taken largely from that report.

New York – Fee-for-Service Billing for Medicaid and Commercial Insurance

New York uses fee-for-service billing to obtain reimbursement for CSC services from both Medicaid and commercial insurance. New York is also in the process of developing a Medicaid team-based rate based on a cost-based rate developed from all OnTrackNY sites. The plan is to have the case rate approved in a state plan amendment.

Illinois – Mandated Commercial Insurance Reimbursement

Illinois has passed legislation[51] mandating that commercial insurers cover CSC services at a bundled payment rate (also known as a team-based rate). The law requires that treatment planning, medication management and monitoring, crisis intervention services, peer support, case management, family psychoeducation, resiliency training, substance use treatment support, care coordination, public outreach and education, and individual and group psychotherapy be reimbursable through a bundled rate. However, CSC-EEP services related to education and employment are not mandated in the rate. The State of Illinois plans to finance the cost of these services through other sources.

At least one commercial insurer in Illinois has agreed to provide a bundled rate for services mandated by the law. The payments will be a per diem rate based on a bundle of existing billing codes.

Washington State – Mandated Medicaid team-based rate

The State of Washington has mandated a Medicaid team-based rate for CSC. Washington State has estimated that adoption of the Medicaid team-based rate will offset start-up costs for CSC-EEP by $329,004, thereby reducing start-up costs to approximately $666,682 over two years.[52]

Billing through the team-based rate for Medicaid eligible individuals is projected to result in reimbursements of $415, 584 per team annually, which would cover an estimated 76 percent of CSC-EEP program costs.

Washington State's Medicaid team-based rate is determined through actuarial analysis of service utilization data and unique CSC team-based costs such as small caseloads, specialized training, team meetings, and team leader wages. It is reimbursed monthly through MCOs and includes a per member per month case rate that is not a directed payment. Services paid through the team-based rate include clinical services, family therapy, case management, and peer support. Services not reimbursed by the Medicaid program are paid for with state Managed Care Organization Wrap Contracts.

State Managed Care Organization (MCO) Wrap Contracts are agreements between state Medicaid agencies and managed care organizations (MCOs) that provide additional services or benefits to Medicaid beneficiaries beyond what is typically covered under the state's Medicaid managed care program. Wrap contracts are designed to complement the services offered by traditional Medicaid managed care plans and address specific needs or gaps in care for Medicaid beneficiaries.

Many states contract with MCOs to administer their Medicaid managed care programs. These MCOs are responsible for coordinating and delivering healthcare services to Medicaid beneficiaries, including medical, mental health, and long-term care services.

State Medicaid agencies may enter into wrap contracts with MCOs to provide additional services or benefits that are not covered under the standard Medicaid managed care plan. These additional services may include specialized treatments, care coordination, case management, transportation assistance, interpreter services, and other non-medical support services.

Wrap contracts may target specific populations with unique healthcare needs, such as individuals with chronic conditions, mental health conditions, developmental disabilities, or complex care needs. The additional services provided through wrap contracts aim to improve access to care, enhance care coordination, and address social determinants of health.

MCOs that hold wrap contracts work in coordination with the primary Medicaid managed care plans to ensure seamless delivery of services and coordination of care for beneficiaries. Wrap contracts may specify the roles and responsibilities of each party in delivering the additional services and integrating them with the overall care plan.

Wrap contracts between state Medicaid agencies and MCOs outline the terms, conditions, and payment arrangements for the additional services provided. These contracts may specify performance metrics, quality standards, reporting requirements, and reimbursement rates for the services rendered.

State Medicaid agencies monitor the performance of MCOs holding wrap contracts to ensure compliance with contractual obligations, quality standards, and regulatory requirements. Oversight mechanisms may include performance evaluations, audits, site visits, and beneficiary feedback mechanisms.

Texas – Medicaid “In Lieu of Services” Provision

As of late 2022, Texas provides CSC-EEP services for Medicaid clients as a cost-effective and medically appropriate alternative to other treatment under the Medicaid “in lieu of service” (ILOS) provision.

The Medicaid “In Lieu of Services" provision allows states to provide benefits or services to certain eligible individuals through Medicaid instead of receiving traditional Medicaid-covered services. This provision gives states flexibility in how they allocate Medicaid funds and provide services to their Medicaid beneficiaries.

To utilize the “In Lieu of Service” provision, States first identify certain populations or individuals who may benefit from receiving services through Medicaid in lieu of traditional Medicaid-covered services. These populations may include individuals with specific healthcare needs or those who require specialized services not typically covered by Medicaid.

States then develop a service plan outlining the types of benefits or services that will be provided to eligible individuals through Medicaid. This plan may include a range of services tailored to meet the needs of the target population, such as case management, home and community-based services, personal care assistance, or other non-traditional healthcare services.

States must seek federal approval from the Centers for Medicare & Medicaid Services (CMS) for their Medicaid in Lieu of Services plan. This approval ensures that the proposed services meet federal Medicaid requirements and are consistent with the goals of the Medicaid program.

Once approved, states can implement their Medicaid in Lieu of Services program and begin providing benefits or services to eligible individuals. States may contract with managed care organizations, healthcare providers, or community-based organizations to deliver the services outlined in the plan.

States are responsible for monitoring the effectiveness and outcomes of their Medicaid in Lieu of Services program. This may involve tracking utilization, assessing health outcomes, and soliciting feedback from beneficiaries to ensure that the program is meeting its objectives and addressing the needs of the target population.

Examples of services that states may provide through Medicaid in lieu of traditional Medicaid-covered services include supportive housing, supportive employment programs, peer support services, transportation assistance, and mental health or substance use disorder treatment programs tailored to specific populations.

Medicaid in Lieu of Services provision allows states to tailor their Medicaid programs to better meet the needs of their Medicaid beneficiaries, particularly those with complex healthcare needs or who may benefit from non-traditional services and supports.

Conclusion

To finance CSC-EEP programs, Vermont will likely need to rely on a variety of funding sources and financing strategies. CMS's recent issuance of billing codes for CSC services portends a greater reliance on team-based billing and a greater likelihood of commercial insurance reimbursement, particularly if Vermont legislators are willing to mandate commercial insurance coverage for CSC-EEP program services.

Outreach to legislators and increasing their knowledge of the program and cost benefits of CSC-EEP is critical to the expansion and sustainability of CSC-EEP programs.

COORDINATED SPECIALTY CARE IN SELECTED STATES 7| SEVEN

This section of the report offers an overview of CSC programs in other states that might offer guidance to Vermont during the development and implementation of a CSC program in Vermont. The case studies are not meant to be exhaustive. Rather, they are intended to provide sufficient information for stakeholders and the Department of Mental Health to determine whether there is interest in a more in-depth review of a program or a particular aspect of a program, including site visits.

Atlanta, Georgia – Project ARROW (Grady Health System)

This report includes an overview of Project ARROW as an example of a CSC program that implemented a combined Open Dialogue and CSC treatment program and for which there is a forthcoming qualitative study of clinicians' perspectives about the implementation.

Overview of Project ARROW

Project ARROW (Achieving Recovery through Resilience, Optimism and Wellness) serves individuals between the ages of 18 and 30 who have experienced an onset of psychotic symptoms within 24 months before admission interview. Eligible primary diagnoses for the program include primary psychotic disorder and affective disorders with psychotic features. Exclusion criteria for the program are a diagnosis of intellectual disability, a diagnosis of substance-induced psychosis or psychotic disorder due to a general medical condition or clinically significant head trauma affective diagnosis or prognosis.

Project ARROW is situated in the mental health department of Grady Health System, a public safety-net hospital that serves the Atlanta metropolitan area. Within the mental health department, various services are available, including a 24-bed inpatient unit, three assertive community treatment teams, a clozapine clinic, a clinic for medication-assisted therapy for opioid misuse, vocational rehabilitation, peer support, case management, integrated primary care, and a large general outpatient clinic offering medication management, group therapy, and individual therapy. Annually, the outpatient program serves more than 6,000 unique clients, a majority of whom lack insurance coverage.

Key roles and functions in the model include:

(1) Team lead/psychotherapy;
(2) Transition coach/case management;
(3) Supported employment/education specialist;
(4) Certified peer specialist;
(5) Certified per specialist – parent/family education and support;
(6) Prescriber/pharmacotherapy and primary care coordination; and
(7) Nursing.

Introduction to Open Dialogue

Open Dialogue originated in Finland in the 1980s. It is both a form of therapy and a method of organizing a mental health system. Open Dialogue operates on seven key principles aimed at organizing services and therapeutic interventions.

At its core, Open Dialogue focuses on involving the individual experiencing distress, along with their social network, in the treatment process right from the start. This means that instead of relying solely on professional expertise, Open Dialogue values the perspectives and experiences of everyone involved, including family members, friends, and other support systems. Open Dialogue focuses on creating meaning, highlighting self-determination and personhood, and moving away from the hierarchical structure of traditional medicine.

One of the key principles of Open Dialogue is to foster dialogue among all parties. This involves active listening, respectful communication, and a willingness to explore different viewpoints. Clinicians are trained to avoid jumping to conclusions and actively seek out differing viewpoints. Rather than imposing a single treatment plan, clinicians in Open Dialogue engage in open-ended discussions, allowing for collaborative decision-making.

Another important aspect of Open Dialogue is its emphasis on polyphony, which means acknowledging and valuing multiple voices and perspectives. Instead of seeing mental health issues as solely individual problems, Open Dialogue recognizes the interconnectedness of people's lives and the importance of addressing social and relational factors in the healing process.

Open Dialogue also embraces uncertainty as a natural part of the therapeutic journey. Instead of rushing to conclusions or diagnoses, clinicians in Open Dialogue approach each situation with curiosity and openness, exploring possibilities and adapting the treatment plan as needed.

Overall, Open Dialogue offers a more human-centered and holistic approach to mental health care, emphasizing the importance of relationships, dialogue, and collaboration in promoting healing and recovery.

Implementing Open Dialogue can be challenging because it relies heavily on skills that are hard to measure, such as promoting diverse perspectives and accepting uncertainty. Additionally, in the US healthcare system, the dominant fee-for-service model poses a significant implementation hurdle. Clinicians also face barriers like rigid organizational cultures and extensive training requirements. However, previous studies have shown that despite these challenges, clinicians appreciate the value of this approach.

Open Dialogue and CSC share some important features. Both models focus on teamwork, community-based services, using language that doesn't stigmatize, using minimal medication doses when possible, maintaining a high ratio of staff to patients, involving patients in decisions about their care, and offering individual therapy if needed.

However, there are also notable differences in their goals. CSC aims for easy access to care and reducing the time between the onset of psychosis and receiving treatment. Open Dialogue, on the other hand, prioritizes providing immediate help within 24 hours of a crisis and involving the patient's social network throughout treatment. Additionally, the Open Dialogue tends to be more neutral towards antipsychotic medication compared to CSC.

Both models allow for the use of antipsychotics, however Open Dialogue places more emphasis on patient and family autonomy in deciding whether to use them. A unique goal of the Open Dialogue is to minimize the need for ongoing psychiatric services once they are no longer needed, while CSC focuses more on long-term follow-up and staying connected to services. Finally, CSC includes goals related to supporting employment and education, which are not as explicitly stated in the OD approach.

Rationale for Combining Open Dialogue and CSC

An Open Dialogue-informed approach for individuals experiencing early psychosis had already been implemented in outpatient mental health services at Grady Health System from 2016 to 2019. The Open Dialogue-only approach proved difficult to sustain because after grant funding expired, the team could not bill for a second clinician (which Open Dialogue requires) in the fee-for-service model. By adding Open Dialogue to the CSC delivery structure, the program was able to overcome some of the challenges of the Open Dialogue-Only approach while still including Open Dialogue’s specific engagement strategies.

For example, by combining Open Dialogue with CSC, the Open Dialogue-inspired approach was able to use the CSC program’s financial reimbursement structure along with CSC’s other established clinical processes. In addition, the CSC program’s community-based, multidisciplinary model high staff to patient ratio allows for the intensive work in which Open Dialogue aspires to engage.

Project ARROW staff members believe that Open Dialogue brings valuable enhancements to CSC. For instance, Open Dialogue's unique approach to engagement places greater emphasis on involving patients in decision-making and prioritizes patient autonomy in a more direct manner.

In addition, according to Project ARROW staff, the Open Dialogue approach allows for deeper exploration and understanding of experiences related to psychosis, which is not explicitly emphasized in the CSC framework. For instance, in Open Dialogue sessions, clinicians openly reflect on their thoughts and experiences, fostering mutual understanding among patients, clinicians, and family members. This emphasis on understanding can strengthen relationships, promote self-discovery, and increase transparency in treatment. By focusing on the whole individual rather than just symptoms, Open Dialogue offers valuable insights into complex psychiatric experiences. Additionally, Open Dialogue involves families more extensively in care compared to traditional approaches like CSC, which often prioritize psychoeducation. This shift could address racial disparities in family involvement, which research has documented in CSC programs[53], and create a more inclusive treatment environment.

Adding Open Dialogue to CSC, was expected to give Open Dialogue more structure, improve incorporation of multidisciplinary team components, and allow for a more accommodating payment model. The addition of Open Dialogue to CSC was expected to give families a greater voice in the CSC treatment process.

Implementation of Project ARROW

Project ARROW began implementation during the Coronavirus Pandemic.

All team members received training in two different approaches: Coordinated Specialty Care (CSC) and Dialogic Practice. The CSC training lasted two days and was led by the state's early psychosis coordinator. Another training, lasting four days, was conducted by an outside expert in Dialogic Practice. Four team members already had experience with Dialogic Practice. Initially, the team held weekly supervision meetings focused on Dialogic Practice. However, due to the COVID pandemic, these meetings merged with census review meetings to form one virtual weekly team meeting for Project ARROW. The team adopted the seven guiding principles of Dialogic Practice as the program's own. At first, network meetings were just one service among others, like supported employment or case management. Team members without experience in

Dialogic Practice were paired with those who had it. By the second year, network meetings became the standard approach for engaging clients and their families, planning treatment, addressing crises, and responding to requests from the individuals receiving care or their support networks.

Lessons Learned from Project ARROW's Combined Open Dialogue/CSC

In a soon to be published qualitative study of clinician's perspectives of the integration of Open Dialogue with Project ARROW CSC, the report's authors share a few lessons learned:

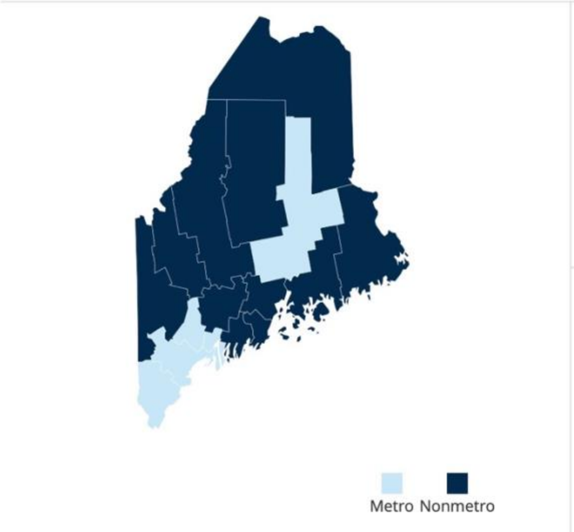
- Learning Open Dialogue takes time and patience. Compared to CSC, the learning curve for Open Dialogue is steeper and more prolonged. This is partly because Open Dialogue is not strictly manualized, and mastering the model relies heavily on hands-on experience rather than following a set protocol. Given the high turnover rates in community mental health settings, offering brief training sessions in Open Dialogue could be beneficial, with opportunities for more extensive training for interested staff.
- Working in the Open Dialogue way requires a different support system. Healthcare professionals are accustomed to using diagnoses and measurable outcomes to gauge treatment progress. However, Open Dialogue does not prioritize diagnoses or conventional outcome measurements. As a result, progress may not always be visible through traditional metrics, potentially leading to frustrations among team members. Supervisory and mentorship support should acknowledge this and find ways to validate progress in ways that are more familiar to team members.
- In a combined approach like Open Dialogue/CSC, team members may naturally gravitate toward one model over the other, potentially causing divisions within the team. It is essential for leadership to be aware of these dynamics and make efforts to promote team cohesion.
- Consideration of organizational change models could be beneficial for future implementations. For example, the Addressing Problems Through Organizational Change (APTOC) model was employed during the initial implementation of Open Dialogue at Grady Hospital. However, in the Open Dialogue/CSC team, which entailed the recruitment of numerous new team members, a formal implementation model was not utilized. Utilizing an implementation framework might enhance the sustainability of cultural change efforts.

Maine (PIER)

Maine's CSC program is included as a case study because of the program's success in incorporating lived experience, involving families, and educating the community through outreach. Maine is also in the process of expanding its CSC program to rural Maine, which may provide lessons for Vermont.

Maine Background

With an estimated population of 1,340,825, Maine is the most rural state in the United States. Fifty percent of the state's land area is almost completely uninhabited. Forty percent of Mainers live in one of Maine's 11 rural counties. In rural Maine, there is a higher poverty rate (12.2 percent vs 9.6% in urban Maine) and a lower, high school completion rate; 7.2 percent of rural Mainers have not completed high school. Maine ranks eighth in the number of psychiatrists practicing in rural counties, and second, in the number of primary care physicians practicing in rural counties.



Maine launched one of the earliest, clinical high risk for psychosis programs in the country, and was a participant in the Early Detection, Intervention and Prevention of Psychosis Program (EDIPPP), a national, multisite study in six states ((MI, OR, NY, NM, CA, ME). The study ran from May 2007 to May 2010.

EDIPPP's model was designed to generate rapid referrals of youths at clinical high risk of psychosis by creating a network of professionals and community members trained to identify signs of early psychosis. The study demonstrated the effectiveness of EDIPPP's outreach and education model of following a protocol-defined outreach strategy combined with flexibility to reach culturally diverse audiences or initially inaccessible systems.

Maine recently amended its State Plan to implement a bundled per member per month rate covering all core services of CSC through state Medicaid (MaineCare).

Overview of Maine's CSC Program

Launched in 2000, Maine's CSC program was created by Maine psychiatrist, William R. McFarlane, in collaboration with colleagues and community partners. Named Portland Identification and Early Referral (PIER) program, the program is an evidence-based, team model designed to treat the earliest symptoms of mental illness.

The program is based in Portland, Maine. Its catchment area includes 25 towns surrounding and including the city of Portland.

The program is funded through Maine's Department of Health and Human Services and the Office of Child and Family Services.

PROGRAM PHILOSOPHY

The PIER model relies on community outreach to teach others the early signs of psychosis. The PIER model considers those who interact frequently with young people in the best position to notice early changes in a young person's functioning and behavior. Such individuals include educators, therapists, and physicians.

ELIGIBILITY

Maine's PIER program is for transition-age youth between the ages of 14 and 26, experiencing symptoms of early episode psychosis (EEP) or early serious mental illness (ESMI).

PROGRAM COMPONENTS

The program is delivered within the first three years from psychosis onset, and typically lasts two to three years before transition to usual care.

The PIER model includes assertive outreach, care coordination, cognitive behavior therapy, medication management, supported education and employment, peer support, and family education and support.

Family education and support (also known as family psychoeducation) is an essential element in the PIER model. Family psychoeducation is an evidence-based model of practice in which clients, clinicians/facilitators and family members work together in a highly structured, problem-solving format on life issues that affect symptoms.

PIER uses a multifamily group (MFG) model, which involves working with several families together in a group setting rather than in a single, family-to-therapist setting. The model allows families to work along with mental health care professionals while connecting with other families. The model allows participants to gain insight from listening to and interacting with other families with similar challenges, and to derive support and motivation from participating in a network of family members who are similarly affected by early episode psychosis.

Community outreach is also a vital component of the PIER model. Community outreach in the PIER model:

- Educates key audience about the importance of early detection and intervention
- Empowers family and community members with the information and tools to recognize the early signs of psychosis
- Establishes a community network of "early identifiers"

- Develops and maintains relationships with community agencies, which are critical for the identification and treatment of psychosis in adolescents and young adults

The PIER model uses the Structured Interview for Psychosis-Risk Syndromes (SIPS) in its assessments. SIPS is used internationally to assess potential CSC clients.

The Assessment component of the PIER model is conducted in the following phases:

- Screenings: Potential clients are identified via anonymous phone screenings
- SIPS Assessment: During an office visit, a trained SIPS interviewer asks questions about the onset, frequency, duration, and intensity of symptoms to determine severity and function
- Follow-up: A clinician conducts a follow-up SIPS at six to 12 months to monitor symptoms.

PROGRAM STAFFING

To serve a shared caseload of 30 to 35 clients in a community of 300,000 to 450,000, the PIER model recommends a team of five people, serving in the following roles.

- Master's Level Social Worker (Full-Time)
- Full-time Nurse of Additional Master's Level Social Worker (Full-Time)
- Psychiatrist or Nurse Practitioner (Half-time)
- Occupational Therapist (Half-time)
- Education/Employment Specialist (Half-Time)
- Case Manager/Peer Counselor (Half- or Full-time)

For larger populations, staff sizes increase proportionally. A service area with a population of one million, requires a minimum of three to four full-time social workers, 1.5 full-time equivalent Psychiatrists or Nurse Practitioners, one occupational therapist, 1.5 full-time equivalent education/employment specialist, and one full-time case manager/peer counselor.

TRAINING

The PIER model training consists of a five-day in-person training from the PIER Training Institute in each of the PIER model components: Assessments; Treatment and Family Psychoeducation; three, two-hour webinars in Community Outreach; a four-hour teleconference in Supported Education/Supported Employment and extensive supervision for 24 months.

The PIER Training Institute faculty works closely with agencies that adopt the PIER model by providing ongoing training, consultation, and assistance to monitor fidelity and adherence to the model to maximize the treatment effectiveness and impact.

The PIER Training Institute offers comprehensive training and certification programs on the PIER model and Family Psychoeducation.

PIER MODEL TRAINED AND CERTIFIED PROGRAMS

The PIER Model is used through the world. The following is a list of PIER Model trained and certified programs in the United States:

- Contra Costa County Mental Health Services, First Hope Program – Concord, CA*
- Kickstart – San Diego, CA

- Maine Medical Center – Portland, ME
- Mid-Valley Behavioral Care Network – Salem, OR
- Momentum for Mental Health – Santa Clara County, CA
- Santa Clara County REACH (Starlight and Momentum) Programs – San Jose, CA*
- University of California – San Francisco, CA
- University of California Davis – Sacramento, CA
- University of New Mexico – Albuquerque, NM
- Ventura Early Intervention Prevention Services (VIPS), Telecare Corporation – Ventura, CA*
- Ventura County Mental Health- Ventura, CA
- Washtenaw Community Health Organization – Ypsilanti, MI
- Zucker Hillside Hospital – Glen Oaks, NY
- Imperial County Behavioral Health Services – El Centro, CA
- Prevention and Recovery in Early Psychosis (PREP)/Felton Institute – various agencies in the SF Bay area, CA
- Weber Human Services Program – Ogden, UT
- Beckman Mental Health Services, South Carolina (multiple sites)

Maine's PIER Model in Action

The following is an example of how Maine's PIER model works in practice. This is an account from a graduate of Maine's PIER program, shared in 2018 at a conference hosted by Maine's PIER program.

> You think about someone going off to college. It's a very exciting time, a positive stressor. And so that kind of made me more vulnerable to what was going to happen right after I started college. And I also have genetic vulnerabilities. So my father has schizophrenia. So anyways, with all of these different things kind of coming to a head at age 17, I started having some serious and concerning symptoms. My aunt from the reservation was like, 'oh, you should go see a counselor,' and I'm like, okay, you know, and I was at that time. I was actually open to seeing a counselor because I'd seen one when I was younger, so that barrier wasn't there as much as I see now with my clients because I'm a provider now.
>
> The counselor right off, she kind of knew that something was off and she's like, I'm actually going to refer you to the nurse practitioner who is on campus at the time. So I didn't have to leave my dorm or go that far because the health clinic was literally right in the same dorm. So, when I saw the nurse practitioner, she thought my symptoms were pretty severe. So, the nurse practitioner who was just recently trained by PIER at the time, so this was back in 2005. Fortunately, she had had this training was like, 'oh, you know, I'm suspecting that a student of mine is having some really concerning symptoms. Could you please just come and assess them.' And what's amazing in thinking back is how … the social worker at the time … came to see me at my dorm; so she came on campus. She met me right in the counselor's office. I don't think I would have been able to go see her in Portland. I wouldn't have been able to make that appointment. So, the flexibility and just her being able to come see me where I was at is crucial.

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-Graduate of Maine's PIER program

I think, you know, just having that appointment, very quickly, I got engaged into the PIER program. And that's kind of like how everything started and it began for me. So that was back in fall 2005 and I ended the program in fall of 2009. So, I was in the program for a good four years. During that period of time, I saw a psychiatrist who did med management. I saw [the social worker] who was my counselor. You know, the psychosocial piece of it is because I was so far away from home and my reservation and my culture, making sure that I had people in places to go to that made me feel safe and happy and normal.

So, I started being engaged in the Multicultural Center on campus. …[To my providers] it wasn't just about decreasing symptoms. It was like wow, you know, she's more engaged. She's exercising, she's taking tennis, she's joining a sorority; like these are all things that were very typical of me before I went to college, so I started to feel more of myself probably a good year later. I make this sound so easy like it was just, you know, 1-2-3. I wasn't the perfect patient. You know, I didn't adhere to my medications. I missed appointments. So, it was a long process, and it took a big team. It took [the social worker], took my psychiatrist. It took my outside therapist. It took family and friends, especially because I was away from home.

School was one of the biggest things. I needed to stay in school. That was so, so important to me. And so, my psychiatrists [and the social worker] all worked with me so that I can get accommodations, that I can work with my teachers to make sure that I did stay in school. I did not want to go back home, and I was like, I'm going to make this work no matter what.

So I guess when you think about where I was when they kind of intervened, I was in the prodrome period, and I'm very thankful that the PIER Program was available to me at that time because if it wasn't there, I would have just continued on that continuum. And God knows where I would be at this point in my life.

So anyways, fast forward. I did my bachelor's and I now work as a psychiatric nurse practitioner. I've been doing it for almost four years now. And I love my job and I'm in this really unique position where I've been a participant and I've "been there, done that," and I'm also on the other side now trying to help patients manage what they're going through.[54]

Program Strengths

ALUMNI INVOLVEMENT

The PIER model, as implemented in Portland, Maine, has been very successful in having young people stay involved through a Peer Advisory Council, and having parents stay involved through a Parent Advisory Council, long after they have left the program. Because families are part of the multi-family group, they appreciate the benefit of what they have received from other people further along in the program, and they want to give back.

CREATIVE APPROACHES TO ENGAGEMENT

Maine's PIER program has a speaker's bureau and family and peer advisory councils that participate in community outreach along with PIER facilitators and clinicians. People with lived experience participate in all outreach efforts, education presentations, and research.

In addition, before joining the PIER program, individuals experiencing early psychosis and their families are offered the opportunity to connect with individuals and families in the program, and graduates of the program. Maine's PIER program offers weekly Zoom groups for prospective and current clients and families.

The program also offers monthly community education workshops, which includes a panel presentation from graduates of the program (individuals with lived experience and families).

WORKFORCE DEVELOPMENT

Maine's PIER program has a training and technical assistance component. The program offers trainings to therapists in psychosis inquiry, and CBTp. The program has trained approximately 350 clinicians across the state, which benefits the program by building a workforce that will have the interest and the capacity to work with the new PIER programs that Maine is expected to introduce.

RURAL EXPANSION

Maine's PIER program has thoughtfully about expansion into Maine's rural counties. It undertook a literature review that revealed five studies in the United Kingdom that evaluated clinical outcomes, and four studies that evaluated adherence to a CSC model in rural areas.

The research reveals that positive clinical outcomes have been shown using a hub and spoke model that allows for managerial and geographically flexibility to enable early access to care and the use of partnership networks throughout a state.

The research also reveals that adherence to evidence-based practices is low in rural areas, including CBTp, family psychoeducation, physical health monitoring, and the use of outcome measures. In the UK studies, usage of evidence-based practices ranged from 16 to 50 percent across teams, attributable to a lack of funding and administrative support to effectively evaluate services, and travel distance and its impact on managing caseloads.

Maine PIER expects to expand into the state's rural counties using a hub and spoke model.

Massachusetts (Mass-STEP)

Massachusetts is included as a state case study because of its work to develop a strategic plan to create a high-quality system of care for people experiencing psychosis in Massachusetts. The process of developing the plan and the plan itself may provide guidance for Vermont.

Overview of Massachusetts CSC Programs

With an estimated population of 7,001,399 as of July 1, 2023, Massachusetts has approximately 20 specialty clinics for early episode psychosis, including 12, Coordinated Specialty Care – Early Episode Psychosis programs, which according to the Commonwealth of Massachusetts is less than one-third of the minimum number required. Although technically required by the Commonwealth of Massachusetts to offer the same CSC model (Navigate), the programs do not use the same model. For example, McClean Hospital uses the OnTrack CSC model. The programs also do not offer the same services nor do the programs have the same eligibility criteria. They also operate in a variety of settings, including hospitals, clinics, and standalone programs.

Strategic Planning Process

Driven by evidence that early intervention for psychosis results in better outcomes, the Massachusetts Department of Mental Health decided to partner with community stakeholders to develop a strategic plan to support early intervention in psychosis. The goal of the plan is to identify priorities for future state-funded early intervention initiatives and provide an evidence-based rationale for investing in early intervention.

In fall 2020, Massachusetts disseminated a survey to assess the experiences of individuals with lived experience of EEP and their caregivers with treatment services and resources, as well as gather suggestions for activities to improve or expand early psychosis programming in the state. Results of the survey informed the content of focus groups and individual interviews with a subset of survey respondents to gain a deeper understanding of needs and challenges, and to gather input in the strategic plan.

In November 2020, the Massachusetts Department of Mental Health, the Laboratory for Early Psychosis (LEAP) Center, and the Massachusetts Psychosis Network for Early Treatment (MAPNET) jointly sponsored a symposium to develop a strategic plan for Massachusetts. More than 200 people registered for the conference, representing policy makers, clinicians, researchers, community advocates, and individuals and family members with lived experience of EEP. Eighty-four percent of registered attendees indicated that they lived, worked, or received mental health services in the Commonwealth of Massachusetts.

The conference brought together a broad set of stakeholders, including individuals with lived experience of psychosis, family members, clinicians, and others directly involved in Massachusetts's mental health system.

Presenters addressed the following topics: (1) Global, national and local frameworks; (2) Pathways and barriers to care; (3) Building capacity and workforce; (4) Paying for services; and (5) Lived experience and clinician experience.

Because the context and background of the Massachusetts Stategic Plan is important to a consideration of the plan's applicability to Vermont, a summary of each presentation is included below.[55]

GLOBAL, NATIONAL AND LOCAL FRAMEWORK

The opening talk was led by Professor Patrick McGorry (University of Melbourne) to provide a global perspective on early intervention in psychosis. Prof. McGorry described the need to “bend the curve” in improving outcomes in early psychosis, identifying key evidence-based interventions that are gaining traction worldwide. He identified a steady uptake in the incorporation of early intervention models into global healthcare services, noting several meta-analyses showing superiority of targeted treatment in early and emerging psychosis (Correll et al., 2018; Devoe et al., 2019). Finally, Professor McGorry highlighted the significant differences in diagnosis outcomes among various mental health conditions within the psychosis spectrum. He suggested using a trans-diagnostic staging approach in early intervention, which means considering the stage of illness rather than specific diagnoses to provide better support and treatment early on.

Dr. Robert Heinssen (National Institutes of Mental Health) then provided an overview of national trends in care for early course psychosis. Dr. Heinssen reviewed foundational studies showing that early intervention improves both symptomology and quality of life (Kane et al., 2016). With backing from the 21st Century Cures Act (H.R. Report No. 34, 2016), government funding has led to a dramatic expansion of the number of coordinated specialty care (CSC) programs across the US — at least 330 as of 2020. Dr. Heinssen described the Early Psychosis Intervention Network (EPINET), which will fund multiple regional hubs across the US to create a learning healthcare system for early intervention.

Dr. Dost Ongur (McLean Hospital, Harvard Medical School) linked national progress with local innovations in Massachusetts. His talk introduced the LEAP Center, which seeks to develop collaborations between national stakeholders at EPINET and researchers in Massachusetts.

Dr. Margaret Guyer (Massachusetts DMH) spoke specifically on the Commonwealth of Massachusetts’ development of a strategic plan. Dr. Guyer outlined current goals to expand early intervention services to enhance awareness, access, and availability for all young people showing early signs of psychosis and encouraged attendees to reflect on promising directions for the future of early intervention.

PATHWAYS AND BARRIERS TO CARE

Dr. Emily Kline (Beth Israel Deaconess Medical Center, Harvard Medical School) presented on barriers to engagement in early intervention programs in Massachusetts. Dr. Kline noted the significant gap between research-demonstrated efficacy and real-world implementation of early intervention treatment services and presented evidence suggesting that many who need treatment do not receive it (Schoenbaum et al., 2017). Barriers to care and attrition in staying connected to healthcare are closely tied to differences in income and race. Additionally, being too strict in how we apply proven methods could make the gap between what works in theory and what works in real life even wider. Dr. Kline identified strategic areas for improvement including treatment accessibility, com- munity awareness, and enhancing equity both in staffing and patient engagement.

Dr. Vinod Srihari (Yale University School of Medicine) presented a recently completed project demonstrating the ability of population- level interventions to reduce treatment delays for psychosis, building upon prior Scandinavian initiatives to demonstrate how delays might be reduced in the United States (Johannessen et al., 2000; Srihari et al., 2020). This project consisted of a media campaign, professional out-reach to community referral targets (e.g., schools, healthcare providers), and efforts to provide treatment in a CSC clinic within a week of contact. Compared to a demographically similar control site, preliminary results suggest that increasing awareness and providing rapid access to care can reduce treatment delays, thereby improving treatment outcomes.

BUILDING CAPACITY AND WORKFORCE

Dr. Lisa Dixon (Columbia University Medical Center, New York State Psychiatric Institute) led a discussion on implementation strategies to scale up evidence-based interventions for psychotic illnesses, drawing from her experience at the Center for Practice Innovations (CPI). Dr. Dixon highlighted the importance of intermediate organizations that offer outside help with training, making sure programs stay true to their goals, and helping them grow stronger. Sharing the perspective developed at the CPI, she identified a strategy to build a synergetic system of care and outlined approaches to organize clinical data to inform improvements in both individual services and statewide mental health systems.

Drs. Margaret Guyer (DMH) and Michelle Friedman-Yakoobian (Beth Israel Deaconess Medical Center, Harvard Medical School) reviewed workforce development efforts in Massachusetts. They described a three-tiered approach, including educational resources to facilitate recognition and response to signs of psychosis in the community, targeted outreach to staff likely to encounter youth experiencing psychosis, and intensive training for students to build the future workforce. Ongoing challenges were discussed, including turnover, limited training on psychosis in graduate programs, and a need for increased racial diversity in the workforce.

PAYING FOR SERVICES

Dr. Ken Duckworth (Blue Cross Blue Shield Association, National Alliance on Mental Illness) proposed a strategy to enhance financial sustainability of early intervention. He compared the financing of early intervention to similar services that are reimbursed using a bundled “day rate” rather than a fee-for- service model. He proposed a similar approach for CSC programs, in which a program-level day rate would replace or augment current billing code-based reimbursement. Dr. Duckworth offered evidence that early intervention reduces downstream costs related to emergency care as an industry rationale for favoring this model (Dixon et al., 2015; Murphy et al., 2018). He advocated for establishing a nationally recognized certification and licensure model for CSC, which payers could rely upon to ensure high-quality clinical services.

LIVED EXPERIENCE AND CLINICIAN EXPERIENCE

Three panel discussions were held, one led by clients, another by parents, and a third by frontline clinicians. A common theme across panels was to identify the strengths of CSC, including the team-based approach, autonomy in choosing services, and access to peer support. The ability to participate in a shared decision-making model was viewed as critical by the client panel; one panelist described feeling as if they had been presented a “menu” of treatment options, from which they could build a treatment plan that worked for them. However, both clients and family members pointed to serious flaws in the mental health system. Hospitalizations and interactions with first responders were described as stressful and potentially harmful. Parents described obvious disparities between the physical facilities, staffing, and overall dignity of care provided in psychiatric facilities relative to other medical services. Such disparities are particularly salient for families with financial limitations and undermine confidence in the system. Amidst these challenges, parents identified family support groups as a lifesaving resource provided by CSC programs.

Clinician stakeholders described the gratifying experience of following a client's recovery, noting that strengths- and resilience-based approaches are critical. Clinicians identified roadblocks including issues with transportation, technological barriers in telehealth, and limitations in a fee-for-service reimbursement system. Suggestions for the strategic plan included increasing the availability of peer support, enhancing services offered to families, and engaging with community partners in education and hospital settings.

In addition to the surveys, focus groups, and the conference, which Massachusetts has convened on a different topic every year since 2020, Massachusetts also incorporated into its strategic plan the results of a self-assessment Massachusetts undertook in 2015 as it began to expand its CSC programs following the MHBG set-aside.

Mass Strategic Plan for Early Psychosis (Mass-STEP)

STRATEGIC PLAN FRAMEWORK

The Mass STEP program looks at mental health and illness broadly, by considering how different parts of our lives affect our well-being. Massachusetts calls its framework a socio-ecological model of health. The main goal of the framework is to help people with mental health issues, like psychosis, feel better and live healthier lives. But to achieve this, Massachusetts policymakers recognize that mental health problems do not happen in a vacuum—they're influenced by the communities we live in, the organizations we interact with, and the larger systems that shape our lives.

Massachusetts offered the following example of its socio-ecological model of health: There’s a young person who starts hearing things in school that distract them a lot. They might tell a teacher they trust (that's the community part), who could suggest they see a doctor. Then, the doctor might refer them to a special program that helps with psychosis (that's the organization part). This program offers good treatment because it works with other experts and gets support from insurance (that's the systems part). But if any part of this process doesn't work well—for example, if the teacher ignores the signs or the insurance doesn't cover the treatment—the person might not get the help they need.

Massachusetts uses this example to illustrate how policymakers can look at mental health issues by considering the bigger picture. Community connections, such as support groups, can help with treatment. But sometimes, barriers to getting help, like inequalities based on race or income, happen because of bigger systems in place. The Mass STEP program wants to make sure the Commonwealth of Massachusetts is helping at every level—whether it's in communities, organizations, or larger systems—to improve how society aids young people experiencing EEP.

Stigma is one issue the Mass STEP is committed to addressing. Stigma can happen on an individual level, when, for example, when a person feels bad about themselves—or on a larger scale, when laws make it harder for people with mental health issues to find jobs or homes. The Mass STEP program is committed to challenging stigma at every level, from how individuals see themselves to how society treats them.

CONTENT OF MASS-STEP (STRATEGIC PLAN)

The Mass-STEP includes an evidence-based rationale for investing in early intervention for psychosis and outlines a set of priorities for the next 10-plus years for funding and program development through the Massachusetts Department of Mental Health.

Using Massachusetts’s socio-ecological model of health, the plan identified the following six primary goals:

1. Assure support for **individuals who experience psychosis and their families** through individual advocacy opportunities, community-building, and specialized early psychosis services.
2. Promote early identification and intervention for psychosis through community education and awareness efforts across the **diverse communities of Massachusetts**, particularly among underserved groups who face multiple barriers in accessing mental healthcare.
3. Promote early identification and intervention for psychosis through specialized supports for **community members who are likely to interact with those experiencing psychosis** (e.g. schools, faith leaders, law enforcement, EMTs).
4. Provide specialized support to **medical and behavioral healthcare professionals** in competencies related to early psychosis.
5. Support **specialized early psychosis treatment teams** in delivering high-quality, evidence-based care in a stepped framework that is culturally and linguistically appropriate, person centered, trauma informed, and recovery focused for people experiencing psychosis and their families.
6. Support and develop the **statewide system of services for early psychosis** by fostering communication across programs and integrating systemic supports for early intervention and prevention.

For each primary goal, the Strategic Plan provides examples of possible actions to take to reach the goal. The possible actions were identified at the 2020 conference and in focus groups. Each goal included a specific, possible action to challenge stigma.

A copy of the Massachusetts Strategic Plan for Early Psychosis (Mass-STEP) is included in Appendix D.

New York

This report includes an overview of New York's OnTrackNY CSC program as an example of an evolutionary model, which by design, that is constantly being revised to meet the needs of participants. The model places a lot of emphasis on ethnic and racial disparities and cultural competence.

Overview of OnTrackNY

OnTrackNY began in 2013 as an initiative of the New York State Office of Mental Health (OMH). According to community-engaged mental health services researcher Nev Jones, the State of New York "massively invested" in the model, using non-federal funds. The Center for Social Innovation was retained to help brand the program. The OnTrack name was chosen to reflect the programs positive and hopeful mission. The Center for Practice Innovations (CPI), an OMH-funded training and technical assistance center at the New York State Psychiatric Institute, was charged with program development, implementation, training, and monitoring.

OnTrackNY grew out of the successful implementation of the RAISE Connection program. The RAISE Connection program was implemented in Washington Heights, NYC and in Baltimore, Maryland as part of the RAISE research initiative. When the research study ended, in view of the program's success, OMH started OnTrackNY with four programs in the downstate area: Washington Heights (Manhattan), Zucker Hillside (Queens), Kings County (Brooklyn), and MHA Westchester (Yonkers).

Over the last 10 years, OnTrackNY has grown from the initial four teams to include 28 teams statewide. The ONTrackNY program nearest to Vermont is in Albany, Vermont.

The program is for adolescents and young adults between the ages of 16 and 30 who have recently begun experiencing psychotic symptoms, for more than a week but less than two years.

OnTrackNY is always learning and improving. More than 20 peer-reviewed research studies based on quality improvement have been conducted in the OnTrackNY program. Since its inception, OnTrackNY has enrolled 3,200 individuals. Program evaluation information shows that participation in school and work increases from 44 percent at the time of enrollment to 70 percent at six months following enrollment, and rates of hospitalization decrease from 72 percent at enrollment to 10 percent at one year. OnTrackNY also has lower disengagement rates compared to comparable programs.

According to OnTrackNY, equity, inclusion, rapid access, and self-determination are at the core of everything it does.

OnTrackNY Team Composition

Position	Role	Headcount	Full-Time Equivalent
Licensed Clinician	Primary clinician, outreach and recruitment coordinator, and team leader	2	2.0

Position	Role	Headcount	Full-Time Equivalent
Supported education and employment specialist	Supported education and employment	1	1.0
Peer specialist	Peer support	1	.5
Prescriber and Nurse	Medication management	2	.5

Each team serves between 35 and 45 individuals, depending on staffing, and provides a range of evidence-based treatments.

OnTrackNY Treatment Approach and Practices

- Peer Services | focuses on building relationships with participants and empowering them to advocate for themselves
- Family Services | Provides family support and education and encourages family involvement in treatment
- Case Management | Helps individuals and families meet concrete needs, like health insurance and housing
- Medication | Given at the lowest effective doses with the fewest side effects
- Shared Decision Making | Treatment delivered is person-centered, recovery-focused, and culturally competent, and driven by participant goals
- Health & Wellness | Education on nutrition and exercise and assessing health with routine lab work
- Therapy | Flexible and collaborative, focusing on personal goals, illness and wellness management, and coping skills

OnTrackNY treatment is delivered in a person-centered, recovery-focused, culturally competent fashion and uses a shared decision-making (SDM) framework, which sets out specific steps for clients and providers to make health care decisions together. Patricia Deegan, Ph.D., helped create the program's SDM materials.

Training and Implementation

Training is delivered by a centralized team. A three-day, in-person training introduces providers to the model. Technical assistance continues through individual and collaborative role-based calls, care consultation calls, and special topics requested by trainees. Team members use the CPI's online learning management system (LMS). The system provides access to training modules, event registration, and resource libraries and allows tracking of participants' module completion, training attendance, and training evaluations. Several levels of evaluation are collected: satisfaction with and usefulness of training, knowledge mastery, self-efficacy, and reports of practice change as a result of training. The LMS also allows team leaders to assign training and obtain real-time reports of staff completion.

Teams identify special topics for additional training. For topics of interest, the training team develops enhanced activities and materials that allowed for more in-depth discussion, extensive use of case examples, and identification of validated assessment tools and consulted the scientific literature to inform service delivery. Outside experts in each area of interest deliver technical assistance to the teams. Cultural competency and gender and sexuality experts were enlisted to develop training materials. With team input, in 2018, OnTrackNY developed a guide on culture and EEP, entitled Delivering Culturally Competent Care in FEP. The guide identifies six themes (religion and spirituality, family culture, language barriers, gender and sexuality, youth culture, and organizational culture) for practitioners to attend to when working with individuals and families.

OnTrackNY also created a set of Web-based modules to provide psychoeducation about LGBTQ individuals and strategies for working with related issues among young people experiencing EEP.

OnTrackNY also utilizes the American Psychiatric Associations' Cultural Formulation Interview to assist in understanding an individual's cultural perspective of their distress and symptoms.

Fidelity Data

As a condition of funding, teams submit client- and team-level data regarding key service components and client outcomes as measures of fidelity monthly to OMH and receive monthly continuous quality improvement–focused reports from the CPI training team. The program has established basic performance expectations, which are being developed into a full fidelity protocol.

A notable feature of OnTrackNY it the program took all of the learnings from RAISE Connection and then built into their own program a system for collecting data in a systematic way to provide treatment teams performance feedback that is delivered continuously around fidelity to the model and areas of improvement.

Manuals and Other Web-Based Resources

OnTrackNY provides consultant and training, as well as web-based resources to programs and State agencies that would like to implement CSC teams for people experience EEP.

OnTrackNY has a very informative website that is easy to navigate. A list of and links to manuals and other web-based resources is included in Appendix C.

Washington State

Washington State is included as a state case study because of its efforts to adapt its CSC model to meet the needs of rural and Tribal communities, its commitment to investigating and addressing racial disparities in its CSC program, and its innovative Medicaid case rate. Vermont has similar needs for its ethnic and racial minority residents, and its rural and indigenous communities. Washington state has also demonstrated vigorous engagement at using research to understand the capacity and limitations of CSC-EEP, and pioneering ways to overcome the limitations and improve its CSC programs. A national trend in CSC-EEP programming is applying a learning healthcare model to provide the best evidence-based care possible. Washington state's efforts may provide a model or inspiration for Vermont to do similarly.

Overview of Washington State's CSC Program

With set-aside funding received from SAMHSA, in 2015, Washington state initiated a pilot of the evidence-based, early identification and intervention program for early episode psychosis. Following the establishment of additional pilot sites, Washington State named its CSC-EEP program New Journeys. New Journeys was developed through a partnership between the Washington State Division of Behavioral Health and Recovery, the University of Washington, and Washington State University.

In 2019, the Washington State Legislature passed Senate Bill 5903, which called for the creation of a Statewide Implementation Plan for evidence-based recovery supports, development of a financing strategy for Medicaid, and statewide expansion based on the incidence of early episode psychosis in Washington state.

Today, Washington State has 15 teams statewide. The state is also in the process of adapting the model to fit the needs of rural and Tribal communities; there are 29 registered tribes and numerous unregistered tribes.

Washington State has determined that in the immediate term, it needs to add at least six additional teams to meet a minimum threshold across Regional Service Areas. To meet population health needs statewide, Washington projects it will need an increase of 36 teams from current levels to address EEP based on a population needs basis.

New Journeys is an adaptation of NAVIGATE. New Journeys promotes rapid referral and treatment of symptoms of psychosis soon after they appear. The mission of New Journeys is to (1) make screening for early psychosis among youth and young adults a universal health practice; (2) to decrease the duration of untreated psychosis; and (3) to improve the quality of life for individuals experiencing early psychosis and their families.

The primary focus of the model is strategic community outreach and education about EEP as well as targeted program recruitment to decrease the duration of untreated psychosis (DUP). Each New Journeys team serves no more than 30 individuals, at any given time, and teams are expected to provide services wherever an individual is most comfortable, including in home, community, and clinic settings.

Current funding, through a Teams Based Rate, allows individuals to receive treatment from New Journeys for a maximum of 24 months. In 2022, the average length of participation was 22 months. However, if teams determine that treatment beyond 24 months is clinically appropriate, the team may continue to provide services using standard outpatient billing codes if the individual is no longer eligible for the Team Based Rate.

The Washington New Journeys program is required to serve eligible individuals regardless of payer type, including those who are Medicaid-enrolled, those enrolled in private insurance, and those without insurance.

Team members include:

- Program Director/Family Education Provider (1.0 FTE)
- Psychiatric Care Provider (0.25 FTE)
- Individual Resiliency Training (IRT) Therapist (1.0 FTE)
- Supported Employment and Education (SEE) Specialist (1.0 FTE)
- Peer Support Specialist (0.5 FTE)
- Case Manager and/or Registered Nurse Care Manager (0.5 FTE)

New Journeys Eligibility Criteria	
Age	15 – 40 years old
Diagnosis	Schizophrenia Schizoaffective disorder Schizophreniform disorder Brief psychotic disorder Delusional disorder Other specified psychotic disorder
Duration of illness/onset of illness	Greater than or equal to one week Less than or equal to two years
Exclusions	Documented IQ of less than 70 Psychosis known to be caused by: ▪ Mood disorder with psychotic features ▪ Pervasive developmental disorder and/or Autism Spectrum Disorder ▪ Psychotic disorder due to another medical condition including medication induced psychotic disorder ▪ The temporary effects of substance use or withdrawal

Washington State also has a research division within its Department of Social and Health Services. The mission of the Research and Data Analysis (RDA) division is to provide data, analytics, and decision support tools to improve the delivery of services that transform lives.

Investigation of Racial Disparities

Between 2018 and 2023, Washington state has published nine research studies related to its implementation of CSC. In 2018, Washington state data indicated that black families were scheduled for psychoeducation less often than white families despite significantly higher telephone outreach. There were no noted racial disparities in outcome but terms of access to a key component of CSC, there was a noticeable difference. Another data analysis revealed that when family members of black individuals enrolled in the CSC program met with a provider before admission, participants had better outcomes. They then conducted two, systematic analyses of the research literature to investigate factors that impede family members from seeking help for relatives experiencing EEP and pathways to care for black individuals. One study consulted suggested links between trauma and substance misuse before CSC that will impact both the duration of untreated psychosis and the initiation of treatment. They used these research results to inform how they constituted their CSC programs.

The data also revealed that the rate of disengagement in their CSC programs was 29 percent. After hypothesizing that the level of outreach and engagement were insufficient, the programs increased the level of outreach, particularly to black families. A second study found that the State achieved its goal of increasing engagement. In fact, outreach was significantly higher for black families than for white families.

After data revealed that fewer black families were scheduled for psychoeducation and enrolled in family treatment, Washington launched new research to investigate.

As a result of its research, Washington is developing a new approach that would augment the traditional family therapy that’s offered in CSC to improve the experiences of black families seeking CSC. The State will also evaluate the effectiveness of the new approach.

Washington state’s approach highlights the value and perhaps the necessity of systematically gathering data about the delivery of CSC care and applying the most promising evidence to improve care for all.

Adapting New Journeys for Rural and Tribal Communities

Washington State utilizes an approach formerly known as community or tribally based participatory research, to determine whether New Journeys CSC can be adapted for and implemented in tribal communities.

Community or tribally based participatory research is a collaboration between an academic institution and the community from the outset. Together, the institution and the tribe identify and address community concerns, identify community strengths and resources, identify any interventions and cultural adaptations and how to implement them, how to evaluate them, how to interpret any results, and how to fund them. In the model, the experience and expertise of all partners are acknowledged and integrated. The institution and the tribe are learning from each other. Everyone is an expert. The values and practices that are essential are transparency throughout the process, being humble, ongoing communication, respect, flexibility, patience, and mutual learning. Washington state is using this model currently to adapt New Journeys to a tribal community.

COORDINATED SPECIALTY CARE IN VERMONT 8| EIGHT

History of CSC in Vermont

Although Vermont does not currently offer Coordinated Specialty Care for First Episode Psychosis, the Howard Center, a community mental health agency in Chittenden County, was one of the 34 sites that participated in the RAISE research initiative. In the RAISE research initiative, 34 community mental health agencies across 21 states were randomized to deliver either NAVIGATE Early Treatment Program or standard care.

The Howard Center was randomly selected to deliver NAVIGATE. Sandy Steingard, M.D., who served as the Howard Center's Medical Director, participated in the study.[56] The Howard Center enrolled 14 study participants who were assessed at baseline and every six months for two years by clinical interviewers who were blind to whether participants were receiving NAVIGATE services or standard care.

The NAVIGATE study developed specific methods for evaluating fidelity to the NAVIGATE model. The NAVIGATE study findings indicated that the Howard Center demonstrated high levels of fidelity to the model, based on scores on the NAVIGATE Fidelity Index.[57]

NAVIGATE Fidelity Scale	Howard Center Score	Overall Mean Score
Supported Employment and Education	3.63	3.25
Team Fidelity	3.65	3.54
Overall Fidelity	2.60	2.51

The NAVIGATE study concluded that the NAVIGATE Early Treatment Program can be implemented with good fidelity to the model in a diverse array of community mental health care settings serving individuals experiencing first episode psychosis.

The Howard Center ultimately did not continue NAVIGATE beyond the study period. While Dr. Steingard is no longer the Howard Center's Medical Director, she is still involved in Vermont's mental health community and may be a resource as Vermont embarks on fulfilling its mandate to offer coordinated specialty care for first episode psychosis.

History of MHBG Set-Aside in Vermont

In 2014, the State of Vermont received an increase in its annual Mental Health Block Grant to support "evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders."[58] The Vermont Department of Mental Health decided to use the additional funds to support a multi-year initiative to adopt evidence-based interventions and treatment approaches for adolescents and young adults experiencing and struggling with early episode and first episode psychosis.

The first year of funding was dedicated to planning, training, and infrastructure development. Th second year focused on program implementation and workforce development. The Vermont Department of Mental Health contracted with consultants, including a team at the Dartmouth Institute for Health Policy and Clinical Practice and the Vermont Collaborative for Practice Improvement and Innovation (VCPI) to assist with the endeavor.

The consultants worked with a group of stakeholders, including young adults, family members, mental health and peer support providers, and other state partners serving both youth and adults.

The stakeholders began the process of identifying and prioritizing the target population and, reviewing several current evidence-based and promising practices for the target population.

The Dartmouth Psychiatric Research team completed an ethnographic study and those findings together with reviews of other research and in consultation with national experts, the Department of Mental Health, with the advice of the Early Episode Psychosis Advisory Committee, invested most of the Mental Health Block Grant ten-percent set-aside funds to support the continued development and implementation of Collaborative Network Approach, Vermont's version of Open Dialogue. (A copy of the ethnographic study is included in Appendix E.)

Collaborative Network Approach (Open Dialogue)

Developed in Finland in the 1980s, Open Dialogue is both a therapeutic approach and a way of organizing a system of mental healthcare.[59]

Open Dialogue emerged from the Needs Adapted Treatment model in the 1960s-1970s. It revolves around family meetings held preferably at the family's home. These meetings employ various techniques to gather different perspectives on a problem, aiming to understand mental health crises and extreme psychological distress. A notable aspect is having two therapists present, who engage in reflection by sharing their thoughts and interpretations during sessions.

Described as a rights-based approach to mental health, Open Dialogue aligns with the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It provides both organizational and clinical tools rooted in principles such as eliminating coercion, respecting legal capacity, promoting community inclusion, and focusing on person-centered care.

Open Dialogue has garnered global interest and has been adapted in various places worldwide, including several locations in the United States such as Massachusetts, Atlanta, New York City, and Vermont.[60]

Open Dialogue is grounded in seven principles:

1. Immediate help;
2. Social network perspective;
3. Flexibility;
4. Responsibility;
5. Psychological continuity;
6. Tolerating uncertainty; and
7. Dialogism.

According to a study of Open Dialogue's effectiveness conducted in 2011, new cases of schizophrenia in Western Lapland decreased from 35 cases per 100,000 individuals to two cases per 100,000 individuals. In addition, the duration of the untreated psychosis declined from 2 to 3 years in Finland's traditional psychiatric system to 3 weeks in Western Lapland; and 84% of individuals served had returned to full employment. The study replicated earlier results for the period from 1992 to 1997 in which only 35 percent were treated with antipsychotic medication, 81percent experienced complete remission of symptoms, and 81percent had achieved full employment. A follow-up study documented greatly reduced hospitalizations, use of antipsychotic medication, and utilization of disability benefits. In a 19-year follow-up study, the study's authors noted that indices of hospital days, use of antipsychotics, and reliance on disability benefits continued to remain lower with people who were engaged in the practice of Open Dialogue.[61]

The State of Vermont initially invested in Open Dialogue in 2012, following the Vermont General Assembly's passage of Act 79, which redirected funds towards enhanced community-based responses to mental health crises with the goal of keeping people out of the hospital. The impetus for Act 79 was the flooding and subsequent closure of Vermont's lone, public psychiatric hospital during Tropical Storm Irene.

Psychiatric survivors and leaders within several community mental health agencies successfully advocated for funding to support training in dialogic practice that would be open to staff in the Vermont system of care. The training was conducted by the Institute for Dialogic Practice. Leaders at three community mental health agencies (Howard Center, the Counseling Service of Addison County, and United Counseling Service), the Vermont Psychiatric Care Hospital, and the Department of Mental Health went on to create a statewide training program that would be viable within the context of Vermont's community mental health system.

Participants in the training include psychiatrists, case managers, peer support workers, social workers, residential staff, psychologists, nurses, mental health technicians, and mental health counselors working primarily in mental health but in youth and family development as well. These practitioners serve both people experiencing first time crises and people who have had long-term involvement with the public mental health system. At the outset, the intent was to to offer dialogic responses to people experiencing a wide range of difficult situations, and not exclusively to those experiencing early or first episode psychosis.

In Vermont, the practice informed by Open Dialogue is referred to as the Collaborative Network Approach (CNA) in recognition that Vermont's mental health system is not designed to embody the principles of Open Dialogue. While the Vermont Department of Mental Health and the leadership of early adopter mental health agencies and hospital have been supportive of CNA training and practice, there has not been a complete, systemic commitment to the principles of Open Dialogue or a restructuring of the system of care to conform to align with the principles of Open Dialogue.

In May 2023, SAMHSA informed the State of Vermont that the Open Dialogue-informed Collaborative Network Approach is not an evidence-based practice for first episode psychosis, and thus, cannot be funded with the 10-percent MHBG set-aside. There have been no studies conducted to evaluate the effectiveness of Vermont's Collaborative Network Approach.

The Department of Mental Health has said it remains committed to Collaborative Network Approach and plans to find another source of funds to support.

During a recent interview, with Collaborative Network Approach Coordinator Zelda Alpern, she shared some of what has been learned from Vermont's practice of Open Dialogue-inspired Collaborative Network Approach.

Lessons learn include:

(1) The importance of reducing barriers to participation by minimizing paperwork and avoiding the use of technology (screens) to communicate;
(2) The importance of emphasizing flexibility in meeting locations and frequency to accommodate individuals' needs and the intensity of their experiences.
(3) The importance of continuity of care with consistent team members to foster trust and relational continuity, which is vital for building resilience and supporting at-risk relationships.
(4) The importance of collaboration between outpatient and inpatient settings, coupled with shared training and values, which enhances teamwork and ensures a cohesive approach to care.
(5) The importance of normalizing experiences of psychosis and offering services without overly emphasizing diagnoses to help alleviate fear and facilitate access to support without over-reliance on medication.
(6) The importance of staff flexibility and the ability to engage individuals wherever they are in their journey.
(7) the importance of personalized, holistic approaches to supporting individuals experiencing psychosis and their loved ones.

Current Services and Supports for EEP

Soteria House Vermont

Soteria House Vermont is a five-bed Therapeutic Community Residence for the prevention of hospitalization for individuals experiencing first episode psychosis based on the Soteria model, a milieu-therapeutic approach developed originally to treat individuals diagnosed with schizophrenia.

Soteria House is funded by the Vermont Department of Mental Health and operated by Pathways Vermont.

SOTERIA MODEL

The Soteria model is an innovative approach to mental health treatment that originated in the United States in the 1970s. It was developed as an alternative to traditional psychiatric hospitals for individuals experiencing acute psychotic episodes, particularly those diagnosed with schizophrenia.

At its core, the Soteria model emphasizes a non-medical, community-based model of care that focuses on creating a supportive and homelike environment for individuals in distress. The word "Soteria" is Greek for "salvation" or "deliverance," reflecting the underlying philosophy of the approach, which prioritizes compassion, respect, and empowerment.

The model operates on the principle of non-coercion, meaning that individuals are not subjected to involuntary treatment, seclusion, or restraint. Instead, the emphasis is on building trust, fostering autonomy, and empowering individuals to make their own decisions about their treatment and recovery.

The model is designed as a therapeutic community where individuals experiencing psychosis can feel safe, supported, and understood.

The Soteria model places less reliance on medication as the primary treatment for psychosis. Instead, the focus is on creating a nurturing and non-stigmatizing and non-discriminatory environment where individuals can explore their experiences, build relationships, and engage in meaningful activities.

The model takes a holistic approach to treatment, addressing the physical, emotional, social, and spiritual needs of individuals in distress. Supportive services may include individual and group therapy, peer support, nutritional counseling, mindfulness practices, and access to community resources.

The model also encourages community integration and participation, recognizing the importance of social connections and meaningful engagement in the recovery process. Individuals are encouraged to explore their interests, pursue hobbies, and reconnect with their families and communities.

SOTERIA HOUSE VERMONT

Founded in April 2015, and based on the Soteria model, Soteria House Vermont is a home-like environment providing alternatives to hospitalization for individuals experiencing first episode psychosis. Soteria House Vermont is staffed around the clock by individuals with lived experience of mental health challenges. Soteria House Vermont is located in Burlington, Vermont, and is open to all Vermonters.

Soteria House Vermont residents, many of whom are young adults, may stay for three to six months or longer. Soteria House Vermont offers a less restrictive setting than inpatient hospitalization and promotes self-expression and community as primary sources of healing.

Antipsychotic medications are de-emphasized, although available through an on-staff psychiatrist.

According to Soteria House Vermont, short-term outcomes are comparable to inpatient hospitalization, and long-term outcomes are much better.

The daily cost of treatment at Soteria House Vermont in 2020 was $547, nearly one-fifth the $2,625 per day cost of inpatient, psychiatric hospitalization.

According to Pathways Vermont, in the last two years, Soteria House Vermont has turned away approximately 45 referrals statewide because of lack of space.

Recently, Pathways Vermont secured funding to purchase and renovate a permanent home for Soteria House Vermont. The property, located at 141 Maple Street in Burlington Vermont, is owned by the Champlain Housing Trust. The purchase will allow Pathways Vermont to increase its capacity from five beds to nine beds and expand its ADA-accessible capacity from one bed to two beds.

Pathways Vermont also recently hired a new on-site psychiatrist. Dr. George (Bud) Vana will replace Pathways Vermont's long-time psychiatrist who recently retired from practice.

Dr. Vana is a board-certified general pediatrician, adult psychiatrist, and child psychiatrist. He grew up in the Northeast Kingdom and attended medical school at the University of Vermont. He completed his residency and fellowship training at Brown University in Providence, Rhode Island. He has previously developed telehealth infrastructure with the Lumbee Tribal Health Center in Bellingham, Washington, as well as early psychosis programming in tribal communities. He currently operates a telemedicine bridge clinic serving children needing short term intensive treatment in Vermont. His other professional interests include family-based psychiatry, Acceptance and Commitment Therapy, treatment of co-occurring disorders, and treatment of developmental disabilities in integrated medical and mental health care.

In a recent interview with Dr. Vana, he observed:

> "Pathways is really probably the best situated agency in the state to be able to do CSC. They already have an understanding of psychosis from the Soteria House work that they're doing. They have the teams around the state. … What's necessary for a CSC team and the way that the state [of Vermont] works, I think, so much of it is really developing the CSC team to bridge that patient back to their home agencies, to their natural supports, and having a mobile, telemedicine-hybrid, based team that really can meet the patients, where they're at, which could be in their homes, could be in school could be, any number of places early on and with really non-threatening supports early -- those peers, the sort of non-white coated Doctor approach is what could really work well in the state.
>
> I think we have a great opportunity in the state to do this. And again, it fits with, I think, the philosophy in Vermont, which is, that hospitalization is not the desired outcome. We want to meet people where they're at, keep them out of the hospital, provide a non-pathologizing approach. If it requires other supports, provide those supports in the community, intensively."

Pathways is really probably the best situated agency in the state to be able to do CSC. They already have an understanding of psychosis from the Soteria House work that they're doing. They have the teams around the state. …

Dr. George (Bud) Vana

Dr. Vana's reference to Pathways teams around the state refers to Pathways' Assertive Community Treatment (ACT) teams. Pathways ACT teams utilize a multidisciplinary team to serve a combined caseload of clients and communicate with community partners. Team member skills include employment services, wellness/life skills, peer substance use support, benefits coordination, and art therapy.

ABOUT PATHWAYS VERMONT

Based in Burlington, Vermont, Pathways Vermont is a nonprofit organization that provides supportive housing and wraparound services to individuals experiencing homelessness, mental health challenges, and other co-occurring challenges.

Founded in 2009, Pathways Vermont operates on the Housing First model, which prioritizes providing stable housing as a first step in addressing an individual's needs. The organization believes that having a safe and stable place to live is essential for individuals to address other challenges they may be facing, such as mental illness, substance use, or chronic health conditions.

Pathways Vermont provides permanent supportive housing to individuals experiencing homelessness, including those with mental health and substance use disorders.

Pathways Vermont offers wraparound services tailored to the individual needs of each client. This may include case management, mental health counseling, substance use treatment, peer support, vocational support, and assistance with accessing healthcare and community resources.

Pathways Vermont embraces a harm reduction approach, which focuses on reducing the negative consequences of substance use and other risky behaviors without requiring abstinence as a precondition for receiving services. The organization provides non-judgmental support and resources to help individuals make informed choices.

Peer support is an integral part of Pathways Vermont. The organization employs individuals with lived experience of homelessness and mental health challenges as peer support specialists.

Pathways Vermont emphasizes community integration and social inclusion as key components of recovery. The organization helps clients reconnect with their communities, build social networks, and pursue meaningful activities and goals.

In addition to its Housing First and Soteria House programs, Pathways Vermont operates a peer-run community center in Burlington. It also operates a 24/7 Support Line for Vermonters 18 years and up. The Support Line is staffed by individuals who acknowledge that they have experienced a broad range of struggle of their own and who are willing to be open about them. Pathways Vermont also offers peer-assisted vocational exploration, with special assistance offered to individuals between the ages of 18 and 30 who identify as an individual with a disability.

Hilltop Recovery Residence

Hilltop Recovery Residence is an eight-bed, staff supported residence originally intended for young adults experiencing early episodes of psychosis. The program is operated by Health Care & Rehabilitation Services (HCRS), a designated community mental health agency serving Windham County, Vermont.

The following information about the program was obtained during interviews with Graham Heavener, a Hilltop residential specialist, and Alexa Licata, the program's clinical coordinator.

ELIGIBILITY CRITERIA

The program's original target population was young adults of all genders between the ages of 18 to 26 years old. Recently, the program expanded its eligibility criteria to include individuals up to 35 years of age because the program found it was not getting many referrals in the 18 to 26 age range. Expanding the age range did increase the number of referrals. The program typically admits individuals experiencing first episode psychosis; however, it also admits individuals with other mental health diagnoses such as anxiety or depression.

EXCLUSIONS

The program does not accept individuals with primary substance use or developmental diagnoses because of limited resources to support these needs effectively.

ADMISSION PROCESS

Residents typically transition to Hilltop from involuntary inpatient stays or step-down programs, with community referrals being a lower priority. The program aims to support individuals who may not require the same level of supervision as those in hospital settings but still benefit from transitional support.

Referrals are accepted from both the community and hospitals, with a priority given to individuals in the hospital, particularly those in the care and custody of the Commissioner of Mental Health (involuntary status).

Typically, referrals come from hospitals where individuals have been receiving inpatient care for about a month, although community referrals are accepted when bed availability permits.

The program prioritizes individuals based on criteria such as readiness for discharge and involvement with the Department of Mental Health (DMH). Individuals who are on involuntary in inpatient stays are often pushed to the top of the waitlist in collaboration with DMH.

Referrals undergo a screening process, including a review of recent assessments and meetings with program staff to discuss the program's expectations and requirements. The program operates on a voluntary basis, and individuals must express a willingness to engage in treatment and adhere to program guidelines.

COSTS AND FINANCIAL CONSIDERATIONS

The program is funded by the Department of Mental Health.

Residents with income are charged monthly rent on a sliding scale basis, with a maximum rent of $640 per month. Residents must pay in rent the amount that will allow them to have $80 remaining each month. For example, if a resident’s monthly income is $720, their monthly rent will be set at $640. The program prioritizes skill-building around budgeting and financial responsibility, with the goal of fostering independence and self-sufficiency.

SERVICES AND PROGRAMS

Hilltop offers daily therapeutic groups, nursing services, psychiatry, individual therapy, case management, executive functioning skill development, community integration, and connection to community resources. Hilltop operates in a harm reduction and person-centered approach that promotes doing with not doing for.

LENGTH OF STAY

The program offers a maximum stay of two years, with recent data indicating an average length of stay ranging from six to seven months. This timeframe allows individuals to receive the support they need while also encouraging progress towards independent living.

AFTERCARE AND TRANSITION PLANNING

Prior to the COVID-19 pandemic, most residents discharged to family homes. However, during and after COVID-19, there has been a significant decrease in the percentage of residents returning to family homes, with most individuals now transitioning to step-down programs for continued support. These step-down programs offer a reduced level of staff support while still providing essential residential support services.

One common destination for discharges is 72 Winooski, a program associated with the Howard Center.

During the height of the COVID-19 pandemic, some individuals discharged to homelessness due to stringent quarantine regulations and discomfort with the quarantine process. While rare, there has been at least one instance of discharge to homelessness because of inability to finding housing for a resident. The resident had a history of criminal justice involvement that ultimately made it impossible to find housing that would accept the resident.

STAFFING AND EXPERTISE

The program employs residential specialists and community integration specialists, one of whom is focused on housing and social security, and the other, focused on employment and school. If additional support for clients is needed, the program tends to refer clients to community providers, such as vocational rehabilitation services.

FACILITY AND ENVIRONMENT

Hilltop sits on a large property, which allows Hilltop to offer work experience on the property itself. For example, the property contains a maple sugar shack.

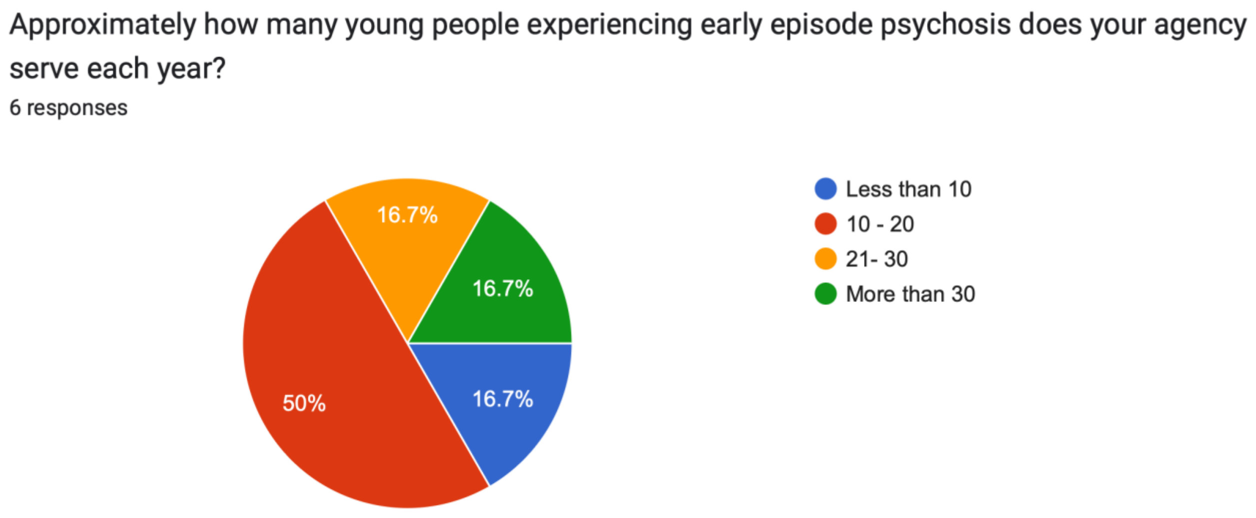
Community Mental Health Agencies (Designated Agencies)

Young people experiencing early episode psychosis currently receive treatment from private providers or through the designated agency serving their counties.

None of the designated agencies offers specialty programs for early episode psychosis.

Surveys of clinicians at designated agencies revealed that current treatment interventions at designated agencies for young people experiencing early episode psychosis are general, and lack specialization, comprehensive case management, effective coordination, and tailored engagement strategies.

DESIGNATED AGENCY SURVEY RESULTS – CURRENT INTERVENTIONS

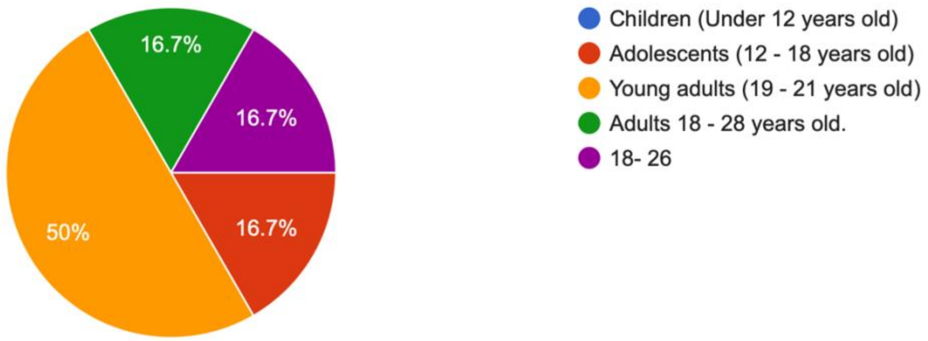


Approximately how many young people experiencing early episode psychosis does your agency serve each year?

6 responses

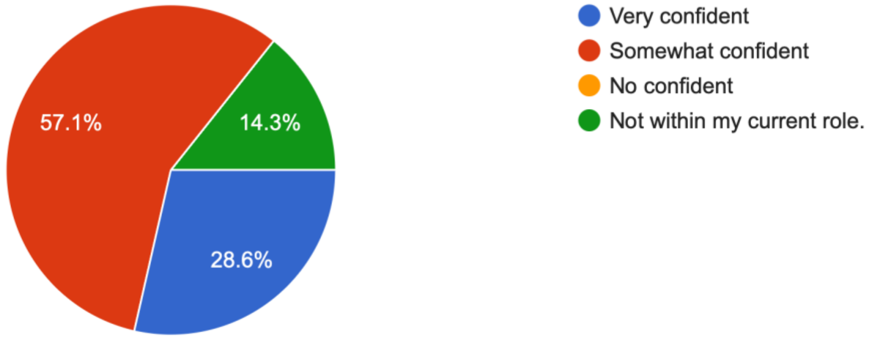
What age range do these young people typically fall into?

6 responses



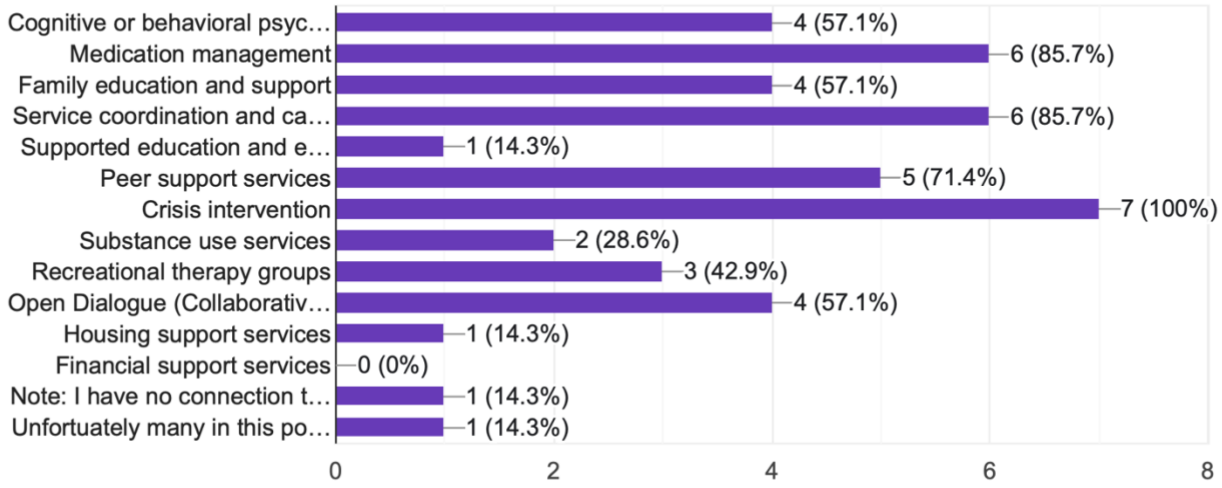
How confident do you feel in identifying early signs and symptoms of psychosis in children, adolescents and young adults?

7 responses



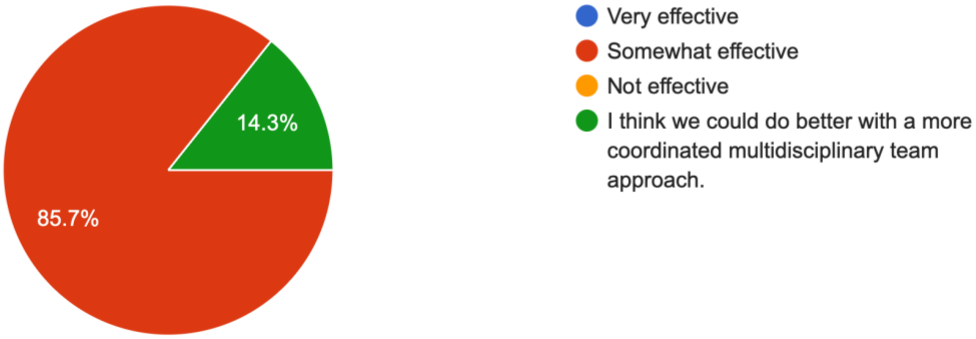
What services have young people experiencing early episode psychosis received or are currently receiving?

7 responses



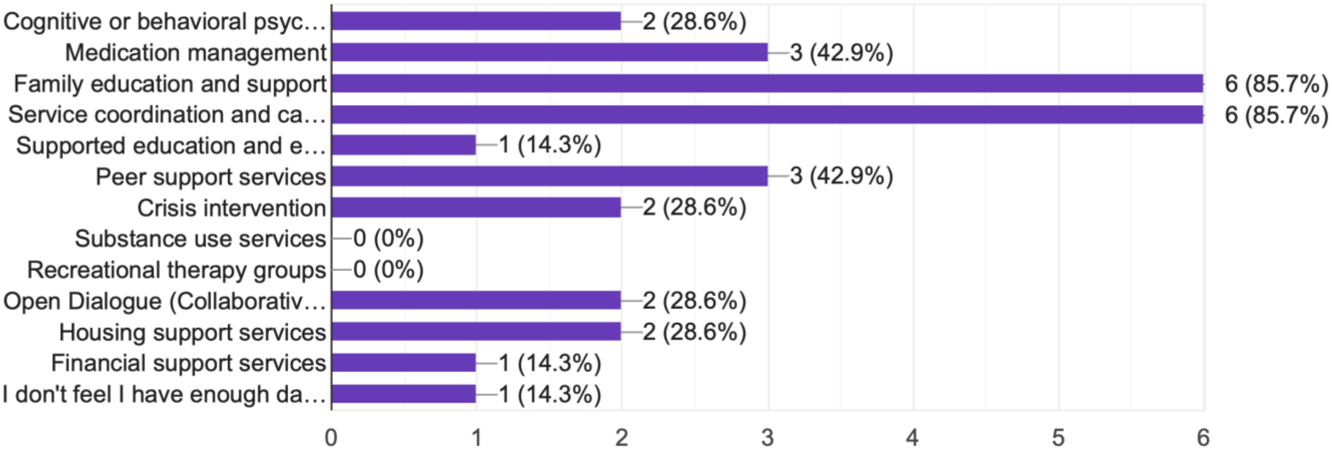
How effective do you perceive these support or intervention measures to be in addressing the needs of young people with early episode psychosis?

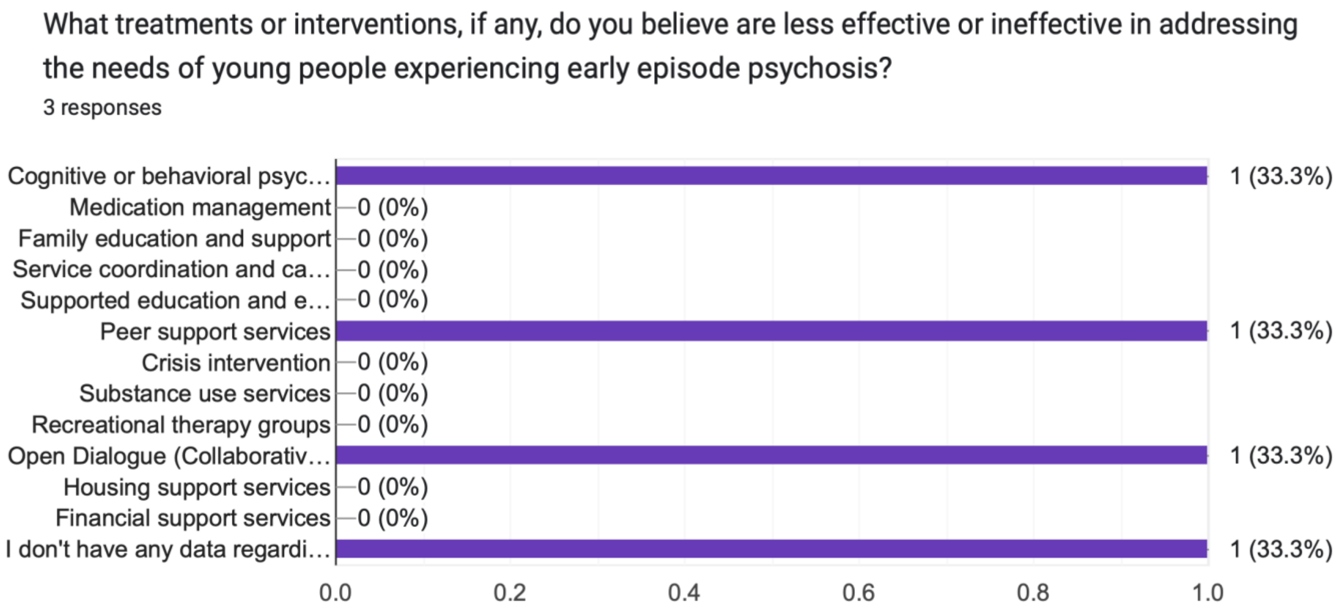
7 responses



Which specific treatments or interventions have shown the most effectiveness in supporting young people with early episode psychosis?

7 responses





What treatments or interventions, if any, do you believe are less effective or ineffective in addressing the needs of young people experiencing early episode psychosis?

3 responses

What barriers, if any, do you encounter in providing support or intervention to young people experiencing early episode psychosis?

7 responses

- Barriers are usually around meeting the needs of youth/families who may be presenting with concerns about being able to live in the home safely
- Lack of trained clinicians supporting young people. The majority of clinicians trained in this area work with adults.
- Skilled staff who have experience
- Lack of stable, safe housing options
- Need for case management specific to this population regardless of insurance. Many have private insurance.
- No way to collaborate/coordinate with outside agencies including hospitals.
- Insurance- we are unable to provide coordinated specialty care b/c most the services are not covered by private insurance, which most this population has; another barrier is engagement of clients, often a softer touch/outreach/family engagement is required, which is different from traditional- [client] signing onto services, providing insurance, financial info for billing, signing consents, engaging in treatment planning

In your experience, what needs do young people experiencing early episode psychosis and/or their families have that are not adequately addressed by your agency?

6 responses

- Housing, financial support
- Substance use treatment
- Housing
- How to support the parents/family
- There is no peer support for individuals under the age of 18
- Family support, outreach, care coordination (due to insurance)

Are there any specific resources or services you believe would significantly improve the care and outcomes for young people experiencing early episode psychosis?

6 responses

- Improved access to housing, options for youth who are presenting with safety concerns, who may have exhausted all available community resources
- More training opportunities
- Housing options appropriate for this demographic
- Urgent Care Case manager grant supported this population well regardless of insurance
- Provide continuity of care throughout a person's experience. Eliminate barriers on funding sources. Increase recovery oriented, strengths-based options for individuals along the continuum of young adulthood. Create multidisciplinary teams that can work with individuals as they age into early adulthood.
- It was a step in the right direction when we had our grant funded urgent care coordinator, who was able to be more flexible and did not have bill insurance

Brattleboro Retreat

The Brattleboro Retreat is a private, not-for-profit, psychiatric hospital offering a range of services intended to meet the mental health needs of children, adolescents, and adults. It is Vermont's only psychiatric hospital for children.

According to its website, the Brattleboro Retreat's Adolescent Inpatient Program offers crisis stabilization, specialized treatment, and aftercare planning for young people ages 12 to 18. The program utilizes a treatment philosophy based on Dialectical Behavior Therapy (DBT).

The Adolescent Inpatient Program employs a multidisciplinary team approach that is intended to be short-term, strengths-based, and skills oriented. According to the Brattleboro Retreat's website, the Adolescent Inpatient Program offers:

- Psychiatric assessment and treatment

- Individual and family meetings with a Social Worker and Psychiatric Provider
- DBT Skills Groups to learn effective ways of coping with difficult emotions and problems
- Group Psychotherapy
- Milieu Support from nursing staff to coach and practice positive coping skills as challenges arise
- Ongoing case management toward coordinating services with the providers in your community.

The Retreat's Adolescent Inpatient Unit will soon have 23 licensed beds for young people ages 12 – 18 who need short-term, inpatient care to help manage and overcome serious psychiatric diagnoses.

Parents and clinicians complained that the Brattleboro Retreat does not provide adequate aftercare support. They said the Retreat gives parents a piece of paper with instructions but does not follow up to ensure the parents can execute the aftercare plan. Clinicians and private providers in the community also felt they could not easily get information or coordinate with the Retreat on aftercare planning for patients. One interviewee said when they asked the Retreat for more support in setting up aftercare, the Retreat replied that it was beyond their capabilities.

Representatives from the Brattleboro Retreat said the Retreat starts aftercare planning as soon as the patient enters the hospital, and patients leave with an aftercare plan that includes a mental health appointment scheduled within seven days of discharge. Representatives acknowledged there may be a communication issue, where the Retreat is providing this aftercare planning, but families are not aware of it. Retreat representatives said they work to coordinate with outpatient providers and agencies to ensure patients can remain connected to their community supports. Retreat representatives also mentioned they hold reentry meetings with schools when patients are transitioning back, to help coordinate the patient's return.

Other Relevant Vermont Resources

The Vermont Child Psychiatry Access Program

The Vermont Child Psychiatry Access Program ("VT-CPAP") is a telephone consultation service that supports primary care providers (PCPs) to address and treat pediatric mental health concerns within their practice.

VT-CPAP is funded by a Pediatric Mental Health Care Access (PMHCA) New Area Expansion grant from the American Rescue Plan Act through the Health Resources and Services Administration (HRSA) supporting an agreement between the Vermont Department of Mental Health and Community Health Centers of Burlington as host of the Vermont Child Psychiatry Access Program ("VT-CPAP").

The intent of the VT-CPAP program is to support primary care providers (PCPs) in Vermont who are managing patients with mental health problems so that those patients can continue to be treated within the practice. This patient group includes children, adolescents, and young adults through age 21.

VT-CPAP psychiatrists support primary care providers through telephone consultations to answer questions related to diagnosis, medication management, and psychotherapy recommendations. VT-CPAP providers are available by phone Monday through Friday from 9am to 3pm, excluding holidays.

The program's Medical Director described the program as follows:

> Instead of the PCP needing a consultation with a psychiatrist and immediately filling out a referral form, and the patient has to get all the way to the psychiatrist where there's usually a two year long wait. Instead of that, we're able to help the PCPs sort through their questions. So, they're only referring the higher level question. The questions that to us are very straightforward, but might not be to a PCP, we're able to answer that day on the phone. And we work really closely with a liaison coordination team, which is a licensed independent clinical social worker. So, it's always one social worker and one child psychiatrist on the phone. The primary care provider, sees the patient, has a question instead of just filling out the referral form and off you go. They give us a call, we help them think about what screeners might be helpful, what next medications or next therapies might be helpful and instead of just saying, 'Oh, go find this,' our social workers actually have really good relationships and we're constantly working on this with different levels of care and providers and a lot of community therapists and so instead of just saying, 'oh, this is this is academically what you should do,' we're saying this is the gold standard of care, this is academically what you should do and let's see how close we can get in terms of actual availability, and then we'll call around and we'll send them a list of maybe three available options for the family to call instead of, 'here's our general list, and have a family call these 20 options.'[62]

The Vermont Child Psychiatry Access Program has registered 100 percent of pediatric practices in Vermont, 50 percent of family practices, and 44 percent of naturopathic clinics. The program could potentially be a referral source and a valuable partner in outreach to and education of pediatricians and family practitioners about the CSC-EEP program and recognizing the signs and symptoms of early episode psychosis.

In an interview with the program's medical director, Dr. Margaret "Greta" Spottswood saw a role for VT-CPAP in helping to make appropriate referrals to a CSC-EEP program.

Vermont Child Health Improvement Program (VCHIP)

The Vermont Child Health Improvement Program (VCHIP) is a population-based child and family health services research and quality improvement program at the University of Vermont. In collaboration with various public health, clinical, policy, community, and academic partners, it aims to optimize the health of Vermont's children and families by initiating and supporting measurement-based efforts aimed at enhancing both private and public child health practice, while also informing policy decisions.

With its extensive experience in improvement science, public health, academic medicine, and health policy, VCHIP utilizes its expertise to engage in quality improvement initiatives with its clinical partners, support state policy leaders in making informed decisions, and contribute to national organizations seeking system-wide transformation. The core principles guiding VCHIP's work include collaboration, measurement, and the utilization of best practices, all aimed at fostering a children's healthcare system that is accessible, equitable, family-centered, comprehensive, and well-coordinated.

Vermont Collaborative for Practice Improvement & Innovation (VCPI)

The Vermont Collaborative for Practice Improvement & Innovation (VCPI) is a statewide membership collaborative, representing, among others, mental health and substance abuse providers, state agencies, hospitals, professional associations, peers, families, to support practice improvement and workforce development in the Vermont system of care.

VCPI provides technical assistance, coaching and consulting, clinical resources, learning communities, data and evaluation, and project management services.

VCPI administered funding provided by the Department of Mental Health to pilot the application of Open Dialogue in Vermont. In collaboration with the Open Dialogue work group, VCPI developed a proposal for continuation of the Open Dialogue model as well as a statewide survey to assess interest and readiness for people who have been involved with Open Dialogue in Vermont.

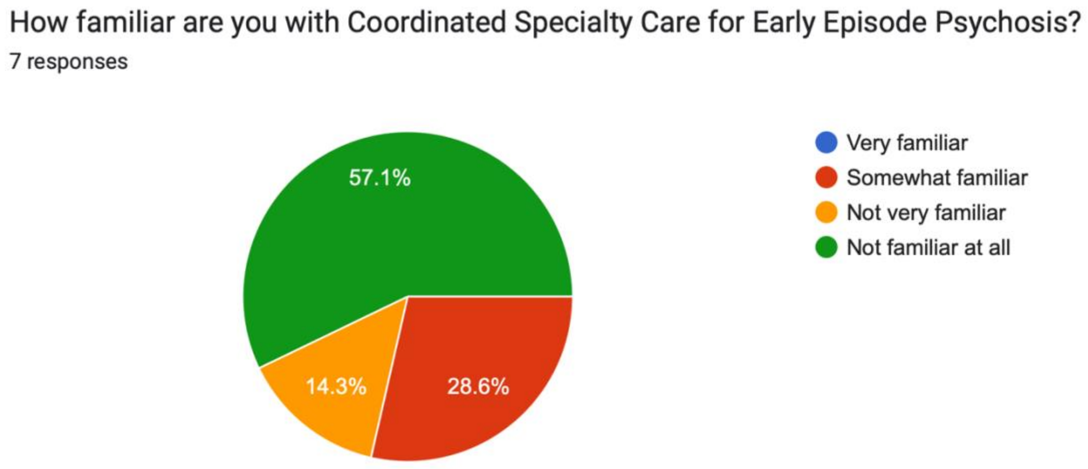
VCPI also partnered with the Department of Mental Health and other consultants to launch a multi-year initiative to adopt evidence-based interventions and treatment approaches for young adults experiencing first episode psychosis. That project culminated in the investment of the MGHB 10-percent aside in Vermont's Open Dialogue-inspired Collaborative Network Approach (CNA).

EARLY EPISODE PSYCHOSIS AND CRITICAL VERMONT NEEDS 9 | NINE

Interviewees and survey respondents, including clinical staff at designated agencies, individuals with lived experience of early psychosis, caregivers, and mental health providers, uniformly expressed dissatisfaction with Vermont's current interventions for young people experiencing early episode psychosis (EEP). The responses highlighted significant barriers, gaps in services, and unmet needs for both young people and their families.

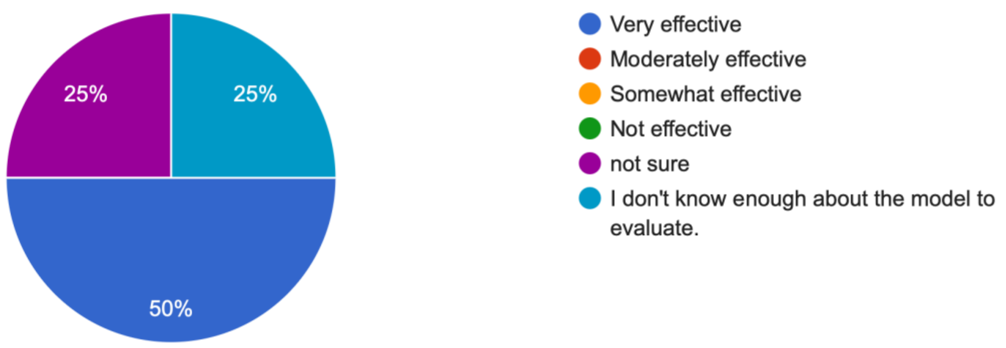
Clinical Staff at Designated Agencies Survey Results

When asked about Coordinated Specialty Care for early episode psychosis, respondents responded as follows:



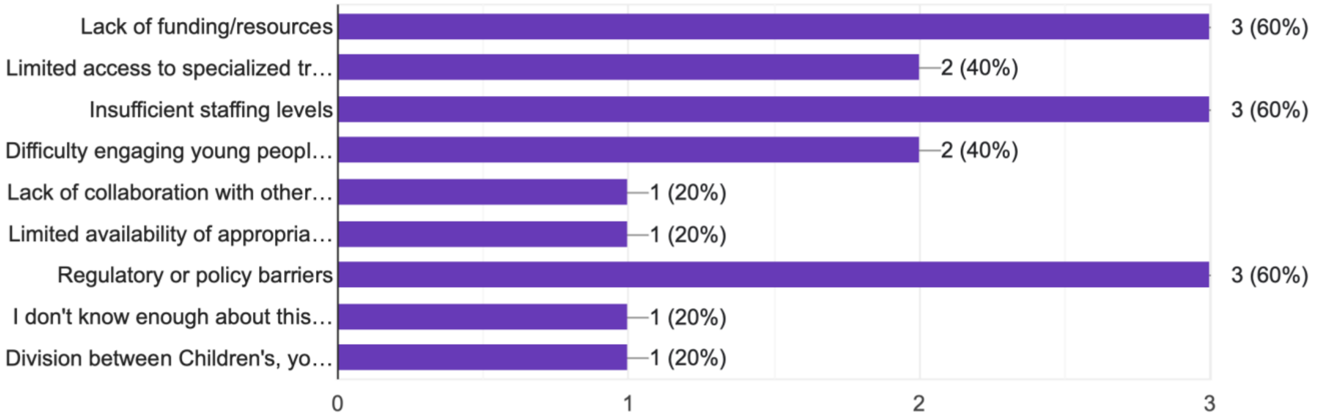
Based on your knowledge or experience, how effective do you perceive Coordinated Specialty Care to be in supporting young people with early episode psychosis?

4 responses



What would be the primary barriers or challenges to implementing Coordinated Specialty Care for Early Episode Psychosis at your agency. Please check all that apply

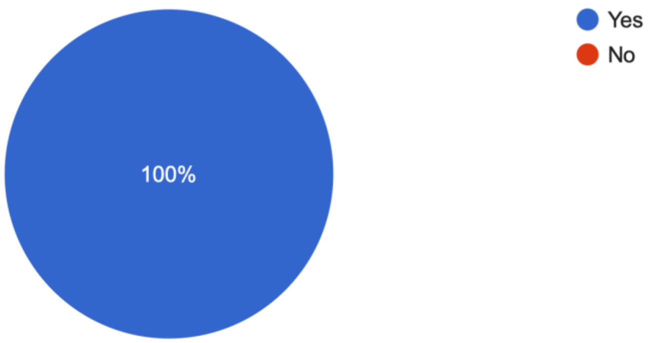
5 responses



Parent and Caregiver Survey Results

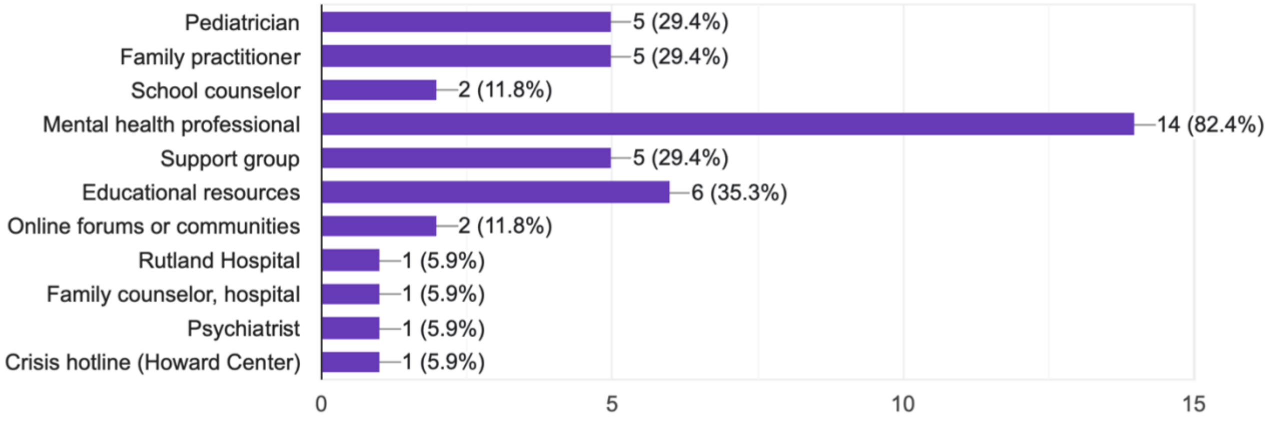
Did you seek treatment for the child, adolescent or young adult when they first experienced psychosis?

17 responses



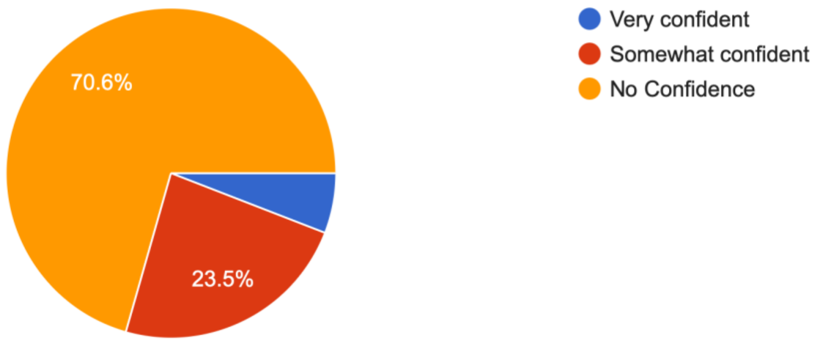
What support services or resources did you seek out initially? (Check all that apply)

17 responses



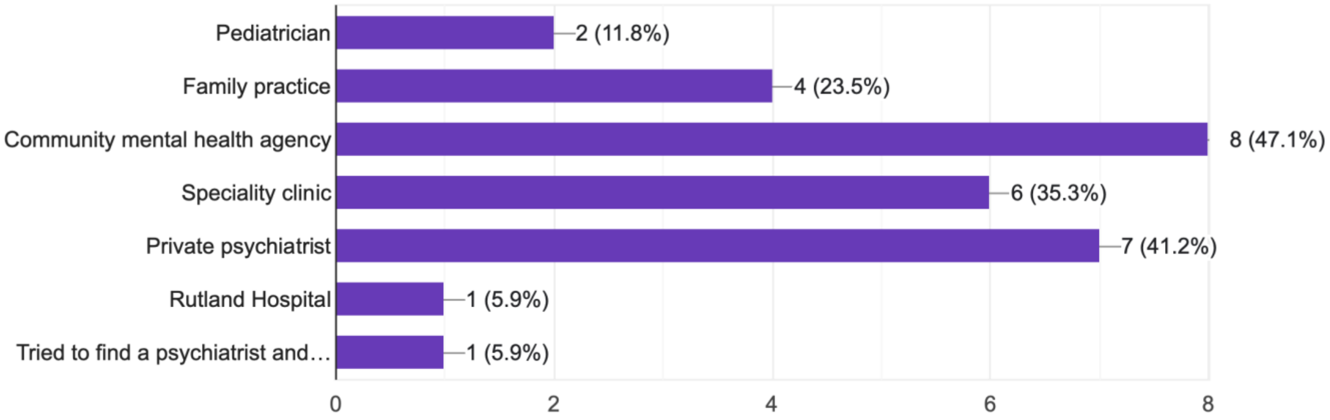
How confident did you feel in seeking treatment for the child, adolescent or young adult experiencing a first episode of psychosis?

17 responses



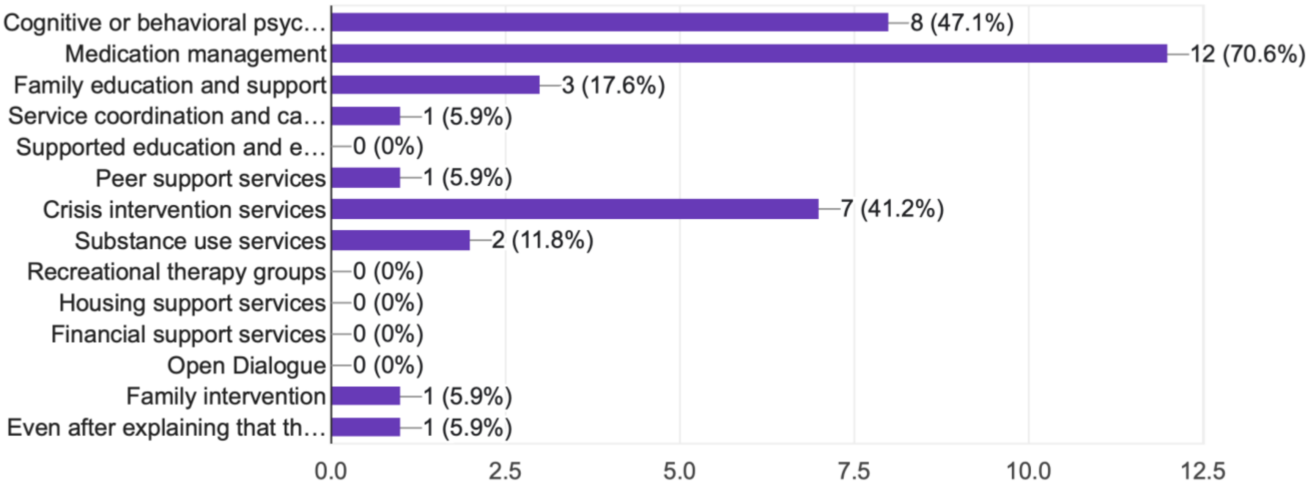
If you sought treatment for a child, adolescent or young adult experiencing a first episode of psychosis, from whom did you seek treatment?

17 responses



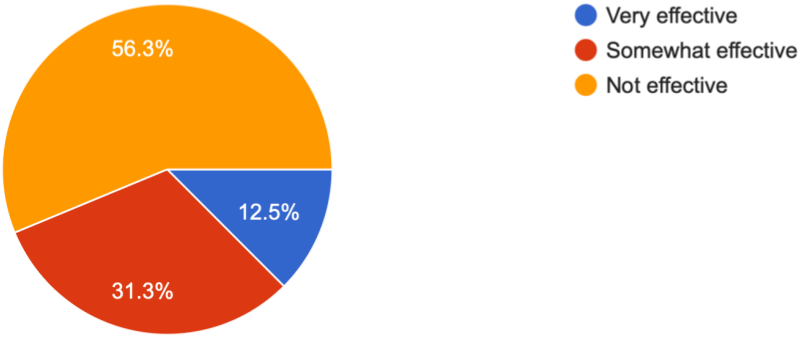
Which of the following treatments, if any, did the child, adolescent or young adult receive following the first episode of psychosis?

17 responses



How effective were the services in addressing the needs of the child, adolescent or young adult experiencing first episode psychosis?

16 responses



What barriers, if any, did you encounter in seeking support or treatment for the child, adolescent or young adult experiencing first episode psychosis?

15 responses

- Clara Martin refused to treat my daughter due to her comorbid diagnosis of autism and intellectual disability
- We had no idea what to do or where to go… defaulted to the hospital.
- He was resistant to all conventional treatment because of PTSD around past treatment for major depression and anxiety which was ineffective.
- It was nearly impossible to access services for our son because he was a legal adult when he began experiencing psychosis. Therefore it was left up to him to request services and he doesn't think he has psychosis. He refuses to take anti-psychotic medication and refuses to include us in his therapy program to work to improve his relationship with us; so that he can remain in our home peacefully.
- We had zero support in our community. We were forced by lack of a bed to travel from Newport VT to Rutland VT Having zero education on what was happening to my child I was told by the staff to join a NAMI group for support. The NEKHS has no supports or respect for the clients or families of those that are suffering from mental health issues that they developed through NO fault of their own. We must do better.
- There were not many options for care. There were no local (closer than a few hours away) inpatient care facilities designed to meet the specific needs of young adults. Also, the choices for partial hospitalization were very limited as well. We actually withdrew our son from the UVM program due to lack of communication between the program's providers and our son's current therapist and psychiatrist. We even went as far as to file a formal complaint to the head of UVM psychiatry about the lack of professionalism.

- Initially insurance did not pay for psychological therapy provided by hospital, but did when I went to state regulatory agency to complain.
- Very small number of psychiatrists available in the community.
- There were missteps at the facility where our son was housed, with his untimely release resulting in grave danger. Our inexperience and lack of understanding contributed to this situation.
- Knowledge base, access
- Difficulty finding therapist with experience, difficulty finding a psychiatrist, medication management was a mess
- As explained above. We (my husband and myself) felt like we were being dismissed by the crisis interventionalist
- I didn't know or understand the process we had to go through by starting at the Emergency Dept of at UVM Medical and waiting many hours to get any services. It was extremely difficult to keep my son from walking out of the ED during that long waiting time. I did not realize we couldn't walk into a mental health facility and get evaluated on our own volition. Lack of psychiatrists: it was very difficult to find a psychiatrist who would take on a new patient. We ended up using an out of network video-only (not in person) psychiatrist.
- Because they were a young adult, we had no authority to make decisions or talk to anyone. They were initially in LA, so we had to learn their system. When they returned to VT, it was an entirely new system to learn how to navigate. Also, in VT, the "designated agency" system is confusing. If they changed counties, we would have had to learn a whole new system.
- No functioning systems in place to deal with the issues.

What barriers, if any, did you encounter in seeking support to help you care for and support your child, adolescent or young adult experiencing first episode psychosis?

14 responses

- No local inpatient short term treatment
- We were not equipped to support him with his issues at home. We were lucky enough to be referred to Soteria House by an emergency room nurse when he admitted himself. After a month in Rutland, he got a bed at Soteria.
- Constantly being told to hospitalize, and that meds were the only effective means of treatment.
- It feels that no one was supportive to our needs at all, other than to say that we are in a very difficult situation. Our son has been destructive to our home, and verbally abusive to us, and has even had one physical assault toward his father. We were left with no choice but to call the police on multiple occasions, and finally pressed charges when he got physical. The court case lasted 2.5+ years, and was eventually dismissed. He now is mandated to go to the local mental health agency, but they have not returned our calls. We wanted to work with them regarding his needs for housing and financial counseling; as his ongoing behavior has made our home so stressful that we can no longer allow him to live with us. We are forced to choose to evict him which means he will be unhoused, or continue living in an environment that is unhealthy for all of us. We now have high blood pressure and tachycardia ourselves, most likely due to the stress in our home environment. And he isn't getting any better! And even if we muster the courage to try to have him removed from our home, in an effort to get help for him, there has been no support in figuring out HOW to do that! And we don't feel confident at all that there will be services to support him; or even housing for him when/if we get him removed from our home! We have been living like this for 4.5 years now!
- No one to answer questions. No bed available in our community. No funds available to support the caregiver that must devote 100% of their time keeping everyone safe. And traveling daily up to 6 hours away to family meetings and just visits with our child. Jobs outside of this for caregivers is impossible. Not being heard by the system and included in planning. The list is just too long. Did I mention the over-medication and lack of oversight of the doctors prescribing the meds? We need to do better.
- I was lucky enough to have found NAMI VT which I still participate in.
- Very difficult to get a diagnosis. There was a long prodromal period when intervention would have been effective, in my opinion.
- School administrators blaming us as parents for the problems the mental health issues were causing. Lack of education for the support structure around our loved one. High cost of related testing which was not covered by insurance
- There seemed to be few resources other than NAMI-VT and our private physician and his therapist wife. We did not know how to navigate our local DA's system well.
- Resources
- If the person is not an obvious danger to themself or other you are pretty much left alone
- It's difficult to find a quick-start guide. I appreciate the existence of NAMI but I needed something that helped me in a crisis because I had zero experience and didn't know where to go or what to do. I was glad the Howard Center could take my calls and they helped some, but I could have used caregiver specific support, like an information line I could call. Also, because my son is an adult, not having a HIPAA consent in place in advance (since I never anticipated this situation).

- Knowing where to turn.
- Privacy Policies

In your experience, what needs do children, adolescents or young adults experiencing first episode psychosis have that are not adequately addressed by current health care systems or interventions?

17 responses

- Psychotherapy (~18%)
- Psychosocial education (~18%)
- Housing services (~18%)
- Supported education and/or employment (~18%)
- Family education (~12%)
- Competency, higher treatment standards, better communication (~6%)
- Structured follow-up after acute treatment (hospitalization)
- Psychiatrists (~6 %)
- Follow up from a team of providers working together to make sure the individual is receiving the care that they need (~6 %)
- Quick access to quality care (~6 %)
- Peer support for families and individuals experiencing psychosis (~12 %)

Are there any specific resources or services you believe would significantly improve the care and outcomes for children, adolescents or young adults experiencing first episode psychosis?

14 responses

- Access to mass general early psychosis treatment
- I would include HVN support groups for voice hearers and HVN support groups for family members as well. Tapering groups through Mad in America, Wildflower Alliance, Angie Peacock, Will Hall, Olga Runciman (and more) as excellent resources. There's too many others to list!
- First better outpatient services and educational support for individual with symptoms and families responsible for their care. Second, more non institutional residential care with peer support services.
- I'm not sure what specific services are needed but families need to be included in the services for their children, even if the child has now become an adult! And families who are trying to continue to care for their loved one, need more support too! I think mediation services would help our family to begin to work together to heal. We set up open dialogue sessions, but stopped after three sessions because our son wouldn't join us. I think that our son should be mandated to work with us if he is to remain in our home.
- An agency in our communities that are staffed, educated and experienced to deal with the mental health issues that come with the first break.
- NAMI
- More mental health counselors, to reduce wait times and increase frequency of appointments, more leniency about clients arriving late to appointments.

- Shortened waiting times in ER's waiting for a bed or placement. Shortened intake procedure and paperwork to the Designated Agencies
- Greater public awareness of places like Alyssum and Soteria, as well as greater public knowledge of the role of DAs continue to help families weather the challenges of onset of psychosis.
- A case manager to help coordinate all the resources and act as mediator between the young adult and the family and support team
- I think that there needs to be a direct referral to psychiatrist even if they won't be the one that will provide continuous care
- Options for intake that are NOT via the Emergency Department. More psychiatrists available for after crisis care (even if it's remote telehealth!). Peer support resources (someone who is near their age and understands them from first-hand experience). Post acute level care (hospitalization) follow-up from social worker and/or others.
- Residential treatment centers that are not private pay or government operated; sober living options for aftercare. Case management that's available not just after the 3rd hospitalization, but from the start. All the care that's available seems to need to wait until things progress to a certain point. It would seem that more preemptive care would make sense.
- A proven process for identifying and treating psychosis related mental health issues.

In your experience, what needs do families of children, adolescents or young adults experiencing early psychosis have that are not adequately addressed by current healthcare systems or interventions?

15 responses

- Better support, better coordination of care, better access to services
- Peer support individually and in groups, up to date information regarding short and long-term effects of meds, access to alternative approaches and ability to choose course of action that best serves the needs of the individual in distress.
- Available resources for education and group / peer support, provided by hospitals and mental health care workers.
- We are trying to help and support our son but no one is supporting us!
- We need education, support and compensation in an environment that respects our input during one of the most heartbreaking confusing and scary times any parent can experience. Our children during first break have no concept of reality. And you have idea what is happened to your child. Put yourself in that parent's place for a minute. Your so scared and your literally on your own.
- In school mentoring to allow the individual to remain with peers. Also, the reluctance to diagnose children makes it impossible to get the right treatment. Family support is lacking.
- Information concerning resources available to them from the state or Federal government; Advocates to represent them in school IEP meetings;
- They cannot know what they have not learned, and part of the answer is the continued educational efforts of DAs, medical facilities, psychotherapists, etc. and letting the public know of their services. Normalizing these needs in the way the therapy has become accepted is part of our shared mission.
- Financial resources
- Having a point person to help like a case manager would be very helpful

Please feel free to share any additional insights, experiences, or suggestions regarding the care, support and treatment for young people experiencing first episode psychosis.
11 responses

- More self-love, more self-acceptance of personal experience, less self-judgment and fear... willingness to hold one another in highest personal regard... willingness to validate others experience, offer compassion, be willing to be vulnerable about one's own struggles, offer connection even when we don't understand and don't know what to do... offer to help find others who have experienced this for support.
- If you have any info that might help, please send it to us! CSC-EEP sounds like it is what we need, but this kind of system has not been our experience!
- If your planning on making real and proven changes to our system of care I suggest to talk to the people on the front lines. The parents and the CIS workers. Anyone else is just pushing paper.
- I was in a unique position as a psychiatric nurse. My colleagues were incredibly helpful in getting treatment for my son. The school system is totally inadequate to handle these issues.
- When our daughter first entered the [Brattleboro] Retreat we were left standing in the entry after she was ushered inside. No one gave us any idea of what would happen next or what we might need to do. She was getting help however we, the family and friends were left adrift, unable to effectively take part in her care
- We have no one to blame and anything that I have said about missteps and inadequacies are part of the necessary steps, I fear, unless we destigmatize MH crises in a Utopian way. Having a larger corps of believers and those of us with experience speaking up about what works is necessary and important. Thank you for collecting data; I hope that it continues to move the needle of public awareness of resources and of access to those resources.
- Another contributing factor to our equation was that our son was over 18-[year-old] so HIPPA was a huge factor even though he was living in our household
- Outside of a crisis, there are high expectations of families to be able to provide support for a loved one. Families can do a lot to keep the person well if they are equipped with tools and information to enable that, which can keep loved ones out of busy facilities. Please don't forget about families and friends who could use more guidance on what to expect. I took the 8-week NAMI Family-to-Family course, but many folks need support much quicker than that.
- Vermont has good people and good programs in the mental health field. But our experience has been that residential and aftercare facilities are severely lacking unless you can afford private pay. I would like to see more insurance-based or Medicaid-based options.
- Suggestions: Help families recognize early symptoms, develop pre-psychosis interventions, eliminate stigma associated with a diagnosis, provide for effective, long-lasting medications. Prioritize mental health issues from policy, financial allocation, research, and community well-being perspectives. Establish treatment plans that integrate various specialists, family, and stable environment to help those with mental health issues. Our child died at the age of 29, largely as a result of eliminating family from the process of care through HIPPA regulations, a system that sustains incompetence in managing medications, and counter-productive psychotherapy. Insurance companies do not support the costs of mental health care, and those afflicted suffer devasting stigma related issues.

Mental Health Provider Survey Results

Demographic Information

There were six respondents to the mental health provider survey, four of whom were pediatricians, one of whom was a psychiatrist, and one of whom was a Licensed Clinical Mental Health Counselor. Half of the respondents reported that they occasionally encountered patients experiencing early episode psychosis in their practices. Most of the patients encountered were between the ages of 12 and 18.

Experience with Early Episode Psychosis

Two-thirds of the respondents reported that they felt “somewhat confident,” in identifying early signs and symptoms of psychosis in children, adolescents and young adults. The remaining respondents were evenly divided between “very confident” and “no confidence.”

Referrals to Specialty Care

If you have referred patients experiencing early episode psychosis to specialty care in the last 12 months, to whom did you refer?

3 responses

- Nobody because it’s not actually available for patients in my area. I would have loved to refer the patient who bought a gun to protect her family from a voice, or the patient who was saving his urine in pans, or the patient who ended up involved in drugs and prostitution due to unchecked mania, but none of them met the criteria for Howard Center’s ACT team.
- I work in a child and adolescent psychiatry practice and referral options for further subspecialty care are hard to come by.
- Psychiatrist through community phone referral/consult service

If you referred patients experiencing early episode psychosis to specialty care within the last 12 months, what was the primary reason for the referral?

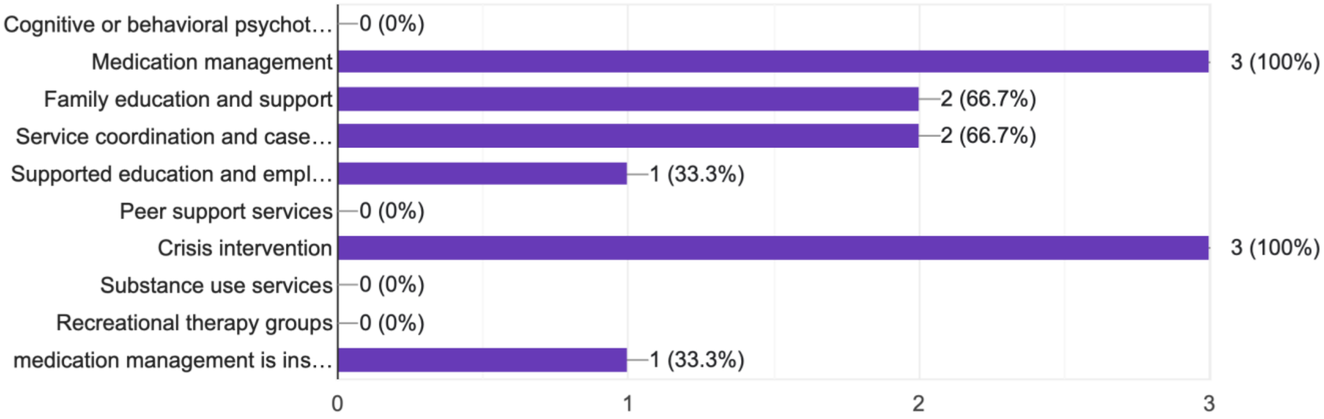
3 responses

- I was not able to refer, the above reasons due to psychotic experiences would have been great opportunities to refer, unfortunately all of them had to experience worse outcomes from their psychosis (hospitalizations, increased drugs and sex work, law enforcement involvement) prior to being eligible for specialty care like the ACT team--the criteria are too specific to prevent bad outcomes
- Severe decline in function and ‘personality change’ noted by home and school

Current Support and Interventions for Early Episode Psychosis

What services have your patients experiencing early episode psychosis received or are currently receiving?

3 responses



How effective do you perceive these support or intervention measures to be in addressing the needs of patients with early episode psychosis?

4 responses

What barriers, if any, do you encounter in providing support or intervention to patients experiencing early episode psychosis?

5 responses

- No coordinated care for them, high barriers to accessing community treatment necessitating extremely poor outcomes prior to accessing community treatment.
- lack of access to psychiatric care
- Access to services
- Oppositional behavior, poor access to outpatient psychiatric care and severe shortage of safe spaces like residential options for patients.
- lack of access to specialty care

Early Episode Psychosis Unmet Treatment Needs

In your experience, what needs do young people experiencing early episode psychosis and/or their families have that are not adequately addressed by current healthcare systems or interventions?

5 responses

- Low barriers for engaging in preventive early psychosis care, not waiting until there are bad outcomes to meet eligibility criteria. Coordinated case management, medication management, psychotherapy, supported employment and supported education, and family education and support. All the services should happen within the same local agency to simplify the challenges present around engagement in care when people experience psychosis. The agency should have very well paid, experienced people delivering the services. Too often DAs financially incentivize talented and experienced clinicians moving from direct care to middle management roles because those providing direct care are poorly compensated. Those with psychosis need stable relationships with those providing care.
- supervision / respite needs for caregivers
- Coordinated care, family and individual support, broader psychosocial interventions and recreational/occupational opportunities.
- alternative schooling, in person therapy, enough time to build trust, then delve into the what, the why etc.
- access to wrap around psychiatric and psychologic care

Are there any specific resources or services you believe would significantly improve the care and outcomes for young people experiencing early episode psychosis?

5 responses

- Earlier access to psychiatric care
- Better emergency care. More residential treatment, juvenile justice and health care collaboration.
- More access to professionals

How do you think collaboration between pediatricians/ general practitioners and mental health specialists could be improved to better support young people experiencing early episode psychosis?

5 responses

- Those experiencing early psychosis need a dedicated psychiatrist prescriber. PCPs should not be expected to be that prescriber. PCPs should be able to easily refer to early psychosis wraparound teams, potentially using VTCPAP to first vet the symptoms and think about possible differential diagnoses (e.g. trauma, OCD, drug use) to make sure care is provided targeting the underlying cause of the symptoms.
- I think VT CPAP is a priceless resource for this now
- Greater communication/collaboration.
- VT CPAP is great for things like this. We need ongoing support for VT CPAP and a UVM plus independent provider network of available clinicians who can maintain patients over time.

Additional Comments

Please feel free to share any additional insights, experiences, or suggestions regarding the care of young people experiencing early episode psychosis.

1 response

- These are the individuals who deserve intensive resources to prevent bad outcomes. There are few of them but by sorting through the needs with VTCPAP, the few young Vermonters experiencing these early psychosis symptoms can access excellent supports if Vermont invests in this type of needed and intensive mental health care. The workers on the ground must be paid really well or this program will not be effective.

Summary of Interview and Survey Responses

Interviewees and survey respondents were uniform in their responses that Vermont needs CSC-EEP. No one felt that Vermont was meeting the needs of young people experiencing early psychosis or their families. When asked what current services and treatment were most helpful, caregiver respondents mentioned Soteria House, Alyssum, a peer-run respite in Rochester, Vermont, and NAMI-VT.

Many of the services and resources identified by respondents as needs of young people experiencing EEP are typically included in CSC-EEP programs. Respondents mentioned a desire for less reliance on medication or alternatives to medication; easy access to care and a transparent referral process; case management and coordination; continuity of care; recovery-oriented, strengths-based options; and peer support.

Overview of Critical Vermont Needs

Survey findings and interviews highlight significant barriers and gaps in services, as well as the needs of both young people and their families that are not adequately addressed by the current healthcare system, and these conditions have endured over time.

It should also be noted that impressions of mental health services for young people experiencing early episode psychosis have not changed significantly in the eight-year period since the Dartmouth Institute for Health Policy and Clinical Practice conducted interviews to examine the perspectives and experiences of individuals with lived experience of early episode psychosis, their family members, and services providers using survey and in-depth qualitative interviews.

Respondents in 2016 and respondents in 2024 both consistently highlighted significant delays and barriers in accessing mental health services. Families and individuals reported long wait times and difficulties navigating the mental health system. The shortage of mental health professionals, especially in rural areas, remained a persistent issue.

Respondents in both years reported negative experiences with mental health professionals who were dismissive of their concerns. The lack of seriousness in addressing the severity of symptoms was a common theme.

Issues related to psychotropic medications, such as overmedication and polypharmacy, were repeatedly mentioned. Respondents expressed frustration with the trial-and-error approach to medication.

Respondents in both years underscored the importance of strong family support and peer networks in the recovery process. Respondents emphasized the need for more inclusive and supportive family involvement in treatment plans.

There was also a consistent call for a more holistic approach to treatment that includes psychosocial interventions, education, employment support, and alternative therapies.

Housing was identified as a critical gap in 2016, however, in 2024, there was a stronger emphasis on the acute need for stable housing for young people experiencing early episode psychosis.

A need for comprehensive financial support was a more prominent issue among 2024 respondents, as were issues of equity in access to mental health treatment, and the need for substance use treatment.

Open Dialogue and NAMI Family-to-Family were mentioned in 2016 as helpful resources. Open Dialogue was not mentioned in 2024. However, NAMI was mentioned along with Alyssum Peer Respite and Soteria House as helpful resources in 2024.

Housing

Housing was cited by clinicians, individuals with lived experience of EEP and caregivers as a need for young people experiencing EEP. Many caregivers described how difficult it is for them to live with their children when they are experiencing episodes of psychosis. A few individuals with lived experience of EEP reported ending up homeless.

As most know, obtaining housing is challenging in Vermont for everyone. It is especially difficult for young people without rental histories, credit ratings, and gainful employment.

This underscores a need to staff a CSC team with a housing specialist, and to develop housing options specifically for young people experiencing EEP.

Financial Support

Financial support was also cited by clinicians and caregivers as needs of young people experiencing EEP. Dr. Nev Jones also suggested that poverty is an issue for young people experiencing EEP. According to Dr. Jones,

> "Poverty really matters. It really, really does matter. And it's something that in a way, maybe none of the [CSC-EEP] models we're talking about have paid enough attention to and the field in general even psych rehab. It's incredible. If you look back to the 70s and the 80s there were actual anti-poverty interventions in the psych rehab space. In the last 15 years there have been none; we have just did a systematic review on this. So, the inattention to what would it actually take to move people out of poverty, not onto SSI not into a low wage job, but actual socioeconomic mobility -- such interventions used to exist in other parts of the world and not in the United States. So, it's not just a CSC thing. And I think so much of what we hear and increasingly with the economy is it is just intense struggles of youth and young adults around poverty and not seeing a way out and certainly not perceiving that services are helping them find a path out of poverty."

Substance Use Treatment

Substance use treatment was cited by caregivers and clinicians as a need for young people experiencing EEP. According to a 2019 SAMHSA publication, 13 to 51 percent of young people who experience first episode psychosis have a co-occurring substance use disorder at the start of treatment of psychosis.[63]

According to the Vermont Department of Health, Vermont has some of the highest rates of substance use in the country, including higher drinking rates, higher cannabis use rates, and among the highest heroin use rates for people aged 18 to 25.[64]

Research has demonstrated that treatment of substance misuse or substance use disorders by clinicians unconnected to CSC is rarely effective. Poor follow-through on referrals to other agencies for treatment and lack of coordination between treatment providers contribute to high rates of dropout from traditional substance use treatment for people diagnosed with psychotic illnesses. Research indicates that treatment for co-occurring disorders should be provided in an integrated and seamless way. [65]

Equitable Access to Treatment

Equitable access to treatment was also cited by respondents as a need in Vermont. Respondents want care in their community, they want access to care without regard to family resources, and they want care for their children with comorbid diagnoses such as autism and intellectual disabilities. Many respondents described Vermont's current system of mental health as inequitable.

Issues of equity will require Vermont to consider where to locate CSC-EEP programs, what funding strategies to use, as well as eligibility criteria.

> **"Our children during first break have no concept of reality. And you have no idea what is happened to your child. Put yourself in that parent's place for a minute. You're so scared and you're literally on your own."**
>
> **Caregiver survey respondent**

Family Support

Caregivers uniformly reported needing support for their own needs, separate and apart from learning how to support their children.

While family education and support are core components of CSC programs, it is essential to highlight their significance, given the suffering and distress expressed by many caregiver respondents in their survey responses. A family peer support provider will perhaps be a necessary and critical member of a CSC-EEP program in Vermont.

IMPLEMENTATON CHALLENGES FOR VERMONT 10 | TEN

All CSC-EEP programs face implementation challenges. These challenges include the stigma related to psychosis; a lack of cultural competence; client disengagement; measurement and evaluation; workforce development; implementation in rural areas; and financial sustainability. While these challenges are not unique to Vermont, some of these challenges and others will be heightened because of conditions unique to Vermont.

This section provides a brief overview of these heightened challenges and offers possibilities for overcoming them.

Cultural Competence

Cultural competence in health care is defined as "the ability of systems to provide care to patients with diverse values, beliefs and behaviors, including tailoring delivery to meet patients' social, cultural, and linguistic needs." [66] A lack of cultural competence can lead to misdiagnosis, client disengagement, and poor prognosis. [67]

There are several pending research studies investigating addressing racial disparities in CSC. As Vermont nears implementation, it should review the literature and incorporate any evidence-based practices into its program.

Equity

Issues of equity were a consistent theme among survey and interview respondents. Equity issues revolved around inequitable geographic access to care, with individuals being forced to travel at great expense and loss of time to receive care. A caregiver respondent wrote:

> "We had zero support in our community. We were forced by lack of a bed to travel from Newport VT to Rutland VT.

Another caregiver respondent reported:

> "There were not many options for care. There were no local (closer than a few hours away) inpatient care facilities designed to meet the specific needs of young adults."

A third caregiver respondent shared:

> "No funds available to support the caregiver that must devote 100% of their time keeping everyone safe. And traveling daily up to 6 hours away to family meetings and just visits with our child. Jobs outside of this for caregivers is impossible."

Issues of equity were also raised based on the varying abilities of parents to provide for and advocate for their children. For example, respondents observed that a child with four parents by virtue of remarriages, who are well-educated and affluent, is treated the same as a parent who is unhoused in terms of their capacity to track down resources for their children or implement a list of aftercare recommendations.

CSC programs may be better able to address the disparities in parent's capacities to care for their children by adhering to principles of CSC that call for meeting clients and their families where they are and providing individualized treatment plans.

The geographic inequities in Vermont will likely need to be addressed before the CSC program implemented. For example, Vermont may want to take care in siting its CSC program and should be very transparent about how it selects a location. Perhaps analysis of Vermont-specific data will reveal disparities in the incidence of psychosis by geography. Rather than siting the CSC program based on population density, it may be more equitable to site the program where there is a greater need for specialty psychosis care and also taking into consideration the different abilities of caregivers to travel great distances to support their children.

Caregivers also cited inequity in providing appropriate treatment for children with developmental disabilities and mental health challenges.

Rural

CSC can be challenging to implement in rural communities. Rural communities typically have fewer resources compared to cities and lack public transportation to access mental health services. Individuals in rural communities are more likely to have longer periods of untreated psychosis compared to individuals in urban cities.[68] A few states have expanded coverage to rural communities through the development of teams offering a hybrid of telehealth and in-person care.

Telehealth may not be a viable option in Vermont. Individuals with lived experience EEP expressed an aversion to receiving treatment through "screens." Some said it exacerbated their symptoms.

As discussed, in the State Studies, Maine is embarking on an expansion of its program into rural Maine using a hub and spoke system. That may also be a viable option for Vermont.

Disengagement

Disengagement has been challenging for CSC programs. Recent research has demonstrated that newer programs have higher rates of disengagement than more established programs.

Since 2019, NIMH is funding 10 new research project grants that are focused on increasing engagement or reducing the duration of untreated psychosis, i.e., getting to people early or getting them into services before the negative experiences accrue that make it harder for them to respond to treatment or how to engage people already in the program more fully.

A variety of strategies are being employed including greater attention to family involvement, utilizing family members as change agents and supporters of the treatment program, and giving families more tools to be effective in that role, reducing self-stigma, and increasing shared decision making around anti-psychotic medication.

Vermont should monitor the research and adopt any evidence-based practices when it implements its CSC program.

This section is not intended to offer a tailored implementation plan for CSC in Vermont. Rather, it is included here to illustrate what Vermont must consider during its development and implementation of a CSC-EEP program.

Needs Assessment

☐ Conduct a comprehensive needs assessment to identify gaps and resources in the community related to early psychosis intervention and treatment.

To develop and implement a CSC program, a program needs to understand the people who are going to receive care, the people who are going to deliver the care, and the environment in which the care is going to be delivered. The program is then built around these realities. Thus, a comprehensive assessment is critical.

States also analyze hospital data, insurance claims data, and any other relevant and available data to estimate incidences of early episode psychosis in the state, perhaps at the county level.

Washington State estimated the incidence of psychosis in Washington State by looking at its eligible Medicaid population under the age of 65. It found an incidence rate of early episode psychosis of 235 per 100,000 of just Medicaid eligible individuals. The data revealed that individuals dually enrolled in Medicaid and Medicare were five times more likely to be diagnosed with a psychotic illness during the year under study (2021). Washington state conducted its analysis at the county level, which revealed that different counties had different incidence rates. It then determined how many of the individuals would have met the age eligibility requirement for its CSC program. An analysis of the incidence of psychosis in Washington states revealed geographical disparities in the distribution of CSC programs across the state.

An analysis of the incidence of psychosis in Washington states revealed geographical disparities in the distribution of CSC programs across the state.

☐ Gather input from stakeholders, including individuals with lived experience, family members, healthcare providers, community organizations, and policymakers.

Program Development

☐ Identify program structure and services
☐ Determine location(s)
☐ Define target population and eligibility criteria
☐ Design a multidisciplinary team comprising psychiatrists, psychologists, social workers, nurses, peer support specialists, substance use specialists, and vocational/educational specialists.
☐ Establish partnerships with local mental health agencies, primary care providers, schools, employers, and housing providers to facilitate coordinated care.

Training and Capacity Building

- ☐ Provide comprehensive training for CSC team members on evidence-based practices, including early intervention strategies, cognitive-behavioral therapy for psychosis, family psychoeducation, and supported employment/education.
- ☐ Offer ongoing professional development opportunities to ensure staff competency and adherence to best practices in early psychosis treatment.

Outreach and Engagement

- ☐ Implement outreach strategies to raise awareness about the CSC program and reduce stigma and discrimination surrounding early psychosis.
- ☐ Develop educational materials and presentations for schools, primary care clinics, community centers, and other relevant venues.
- ☐ Engage with community leaders and organizations to promote collaboration and referrals to the CSC program.

Access and Referral Process

- ☐ Establish a streamlined referral process for individuals experiencing early psychosis, including pathways for self-referral, referrals from primary care providers, emergency departments, and community agencies.
- ☐ Ensure timely access to CSC services, with an emphasis on reducing wait times and barriers to entry.

Assessment and Treatment Planning

- ☐ Conduct comprehensive assessments of individuals referred to the CSC program, including psychiatric evaluation, psychosocial assessment, and assessment of vocational/educational needs.
- ☐ Collaborate with clients and their families to develop individualized treatment plans based on their strengths, preferences, and goals.

Treatment Delivery

- ☐ Provide evidence-based interventions within the CSC framework, including medication management, individual and group therapy, family psychoeducation, supported education/employment, and case management.
- ☐ Foster a recovery-oriented approach that emphasizes empowerment, hope, and resilience.
- ☐ Monitor progress regularly and adjust treatment plans as needed in collaboration with clients and their support networks.

Quality Assurance and Evaluation

- ☐ Implement mechanisms for ongoing quality assurance and program evaluation to monitor fidelity to the CSC model and outcomes of care.
- ☐ Collect data on key performance indicators, including engagement rates, symptom reduction, functional outcomes, and client satisfaction.
- ☐ Use feedback from clients, families, and staff to identify areas for improvement and inform program enhancements.

Sustainability and Expansion

☐ Develop a sustainable funding model for the CSC program, leveraging a combination of public and private funding sources.
☐ Advocate for policy changes and funding allocation to support the expansion of early psychosis intervention programs at the state, and national levels.
☐ Explore opportunities for collaboration with research institutions to contribute to the evidence base for early psychosis treatment and inform future program development. It is also important in CSC to include the voices of individuals with lived experience of EEP in all research efforts to help define the problem, determine what to study, what to improve, and how to interpret the results.

EPINET, a national learning health care system for early psychosis, recently created a web-based platform that allows programs outside of EPINET to contribute their own data and get a readout of their program's performance to help with quality improvement.

EPINET links early psychosis clinics through standard clinical measures, uniform data collection methods, data sharing agreements, and integration of client-level data across service users and clinics. Clients and their families, clinicians, health care administrators, and scientific experts partner with EPINET to improve early psychosis care and conduct large-scale, practice-based research.

Initiated in 2019 and sponsored by the National Institute of Mental Health (NIMH), the EPINET initiative includes eight Regional Hubs, more than 100 early psychosis clinics across 17 states, and the EPINET National Data Coordinating Center (ENDCC). The LEAP Center in Boston is a Regional Hub.

EPINET has developed a core assessment battery and collected data on more than 5,000 individuals enrolled in programs across the United States from member clinics.

The Commonwealth of Virginia has enrolled all 12 of its coordinated specialty care programs in this web-based program to assess fidelity, improve quality, and identify where the Commonwealth might shift programs within the state to better meet the needs of its residents.

The program is not without controversy. Critics contend that the core assessment battery is cumbersome to use for clinicians and clients and is not particularly useful because it primarily tracks symptom outcomes. A Massachusetts clinician, speaking about EPINET's core assessment battery, observed the following:

“We're not tracking the things that matter [to our clients]. We're not tracking do they graduate? How long have they been in a relationship with their provider? What does that relationship look like? What does their relationship with the clinic look like. Those are the things that keep you engaged and those are the things that keep you motivated. I have so many thoughts about it, and I will never sign on to that thing [EPINET Core Assessment Battery].”

-Massachusetts CSC-EEP Clinician

Community Integration and Collaboration

☐ Foster partnerships with community stakeholders to promote seamless transitions between CSC and other mental health services, primary care, housing, education, and employment supports.
☐ Advocate for the needs of individuals experiencing early episode psychosis and promote system-level changes.

APPENDIX A | ACRONYMS AND ABBREVIATIONS

Acronym/Abbreviation	Full Form
APA	American Psychiatric Association
BPRS	Brief Psychiatric Rating Scale
CAB	Core Assessment Battery
CBT	Cognitive Behavioral Therapy
CBTp	Cognitive-Behavioral Therapy for Psychosis
CHIP	Children's Health Insurance Program
CHRP	Clinical High Risk (for Psychosis)
CMS	Centers for Medicare & Medicaid
CNA	Collaborative Network Approach
CPAP	Child Psychiatry Access Program
CPCC	Child Psychiatry Consultation Clinic
CPI	Center for Practice Innovations (located at the New York State Psychiatric Institute)
CRPD	Convention on the Rights of Persons with Disabilities
CSC	Coordinated Specialty Care
CSC-EEP	Coordinated Specialty Care for Early Episode Psychosis
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
DUP	Duration of Untreated Psychosis
EASA	Early Assessment and Support Alliance
EBP	Evidence-based practice
ECHO	Extension for Community Healthcare Outcomes
EDAPT	Early Diagnosis and Preventative Treatment Program
EDIPPP	Early Detection, Intervention and Prevention of Psychosis Program
EEP	Early Episode Psychosis
EIP	Early Intervention and Psychosis Services
EMS	Emergency Medical Services
ENDCC	EPINET National Data Coordinating Center
EPICENTER	Early Psychosis Intervention Center
EPINET	Early Psychosis Intervention Network
EPSDT	Early Periodic Screening, Diagnostic and Treatment
ESMI	Early Serious Mental Illness
FEP	First Episode Psychosis

Acronym/Abbreviation	**Full Form**
FIRST	Family Involvement; Individualized Treatment; Recovery Focused; Supportive Services; Team-Based Approach
FTE	Full-time Equivalent
HCPCS	Healthcare Common Procedure Coding System
IEPA	International Early Psychosis Association
ILOS	In Lieu of Services
LEAP	Laboratory for Early Psychosis Center
LMS	Learning Management System
MAPNET	Massachusetts Psychosis Network for Early Treatment
Mass-STEP	Massachusetts Strategic Plan for Early Psychosis
MCO	Managed Care Organization
MFG	Multi-Family Group Therapy
MHBG	Community Mental Health Block Grant
MHTTC	Mental Health Technology Transfer Center
NIMH	National Institute of Mental Health
OASIS	Outreach and Support Intervention Services Program
OD	Open Dialogue
OMH	New York State Office of Mental Health
PCP	Primary Care Physician
PEPPNET	Psychosis-Risk and Early Psychosis Program Network
PIER	Portland Identification and Early Referral Program
PMHCA	Pediatric Mental Health Care Access
Project ARROW	Achieving Recovery through Resilience, Optimism and Wellness
RAISE	Recovery After Initial Schizophrenia Episode
RDA	Research and Data Analysis
SAMHSA	Substance Abuse Mental Health Services Administration
SDM	Shared Decision-Making
SED	Serious Emotional Disturbance
SEE	Supported Employment and Education
SIPS	Structured Interview for Psychosis Risk Syndromes
SMI	Serious Mental Illness
STEP	Specialized Treatment Early in Psychosis program

Acronym/Abbreviation	Full Form
UK	United Kingdom
VCHIP	Vermont Child Health Improvement Program
VCPI	Vermont Collaborative for Practice Improvement and Innovation
VT-CPAP	Vermont Child Psychiatry Access Program

APPENDIX B | GLOSSARY

Term	Definition
Affective psychosis	Affective psychosis, also known as mood disorder with psychotic features or psychotic depression, is a mental health condition characterized by a combination of mood disturbance, such as depression or mania, and psychotic symptoms, such as hallucinations or delusions. In affective psychosis, individuals experience symptoms of a mood disorder, such as major depressive disorder or bipolar disorder, along with features of psychosis.
Cognitive-Behavioral Therapy for Psychosis (CBTp)	Cognitive-Behavioral Therapy for Psychosis (CBTp) is a therapeutic approach designed to help individuals experiencing psychosis to manage their symptoms and improve their overall well-being. Unlike traditional psychotherapeutic approaches that may focus solely on insight-oriented exploration or symptom reduction through medication, CBTp integrates cognitive and behavioral techniques to address the specific challenges associated with psychosis. In CBTp, therapists work collaboratively with clients to identify and challenge thoughts and beliefs that contribute to their psychotic experiences. This process involves helping clients develop insight into the nature of their symptoms and recognizing when their thoughts may be inaccurate or unhelpful. Additionally, behavioral techniques are employed to assist individuals in testing the validity of their beliefs and learning coping strategies to manage distressing symptoms. CBTp typically involves several key components, including: Psychoeducation: Providing information about psychosis, its causes, and its potential triggers can help individuals better understand their experiences and reduce anxiety or fear associated with them. Cognitive restructuring: This involves identifying and challenging irrational or unhelpful thoughts and replacing them with more accurate and adaptive beliefs. By examining evidence and considering alternative explanations, individuals can develop a more balanced perspective on their experiences. Reality testing: Clients learn to assess the validity of their perceptions and beliefs by examining evidence and seeking alternative explanations for their experiences. This helps reduce the intensity of hallucinations or delusions and promotes a greater sense of control. Coping skills training: Clients are taught practical strategies to manage distressing symptoms, such as relaxation techniques, problem-solving skills, and mindfulness exercises. These skills empower individuals to cope effectively with stressors and minimize the impact of psychotic episodes on their daily functioning. CBTp is often delivered in individual or group settings by mental health professionals trained in CBTp techniques.
Community-defined evidence practices	**Community-defined evidence practices** (CDEPs) are practices that communities have shown to yield positive results as determined by community consensus over time, and which may or may not have been measured empirically but have reached a level of acceptance by the community.

Term	Definition
Coordinated Specialty Care (CSC)	Coordinated specialty care is a recovery-oriented, team approach to treating early psychosis that promotes easy access to care and shared decision-making among clinicians and specialist team members, the person experiencing psychosis, and family members. Specifically, coordinated specialty care involves multiple components: • Individual or group psychotherapy is tailored to a person's recovery goals. Cognitive and behavioral therapy focuses on developing the knowledge and skills necessary to build resilience and cope with aspects of psychosis while maintaining and achieving personal goals. • Family support and education programs teach family members about psychosis as well as coping, communication, and problem-solving skills. • Medication management involves health care providers tailoring medication to a person's specific needs by selecting the appropriate type and dose to help reduce psychosis symptoms. • Supported employment and education services aim to help individuals return to work or school, using the support of a coach to help people achieve their goals. • Case management allows people with psychosis to work with a case manager to address practical problems and improve access to needed support services. Coordinated specialty care is considered the standard of care for treating early psychosis caused by a diagnosis of schizophrenia, according to "The American Psychiatric Association Practice Guideline for the Treatment of Patients With Schizophrenia .
Culturally adapted practice	A culturally adapted practice refers to the systematic modification of an evidence-based practice (EBP) that considers language, culture, and context in a way that is compatible with the clients' cultural patterns, meaning, and values.
DSM-IV	Released in 1994, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, is a publication by the American Psychiatric Association (APA) that provides standardized criteria for the classification and diagnosis of mental health disorders. It served as a critical reference for mental health professionals for diagnosing mental disorders. The latest version of the DSM is the DSM-5-TR, which stands for the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision. It was released in March 2022 by the American Psychiatric Association. The DSM-5-TR includes updated criteria for diagnosing mental health disorders, new and revised disorders, and new diagnostic guidelines.

Term	Definition
Duration of Untreated Psychosis (DUP)	The duration of untreated psychosis (DUP) refers to the period between the onset of psychotic symptoms and the initiation of appropriate treatment or intervention. DUP is an important concept in the field of mental health because research suggests that delaying the initiation of effective treatment for psychosis can have significant negative consequences for individuals, including (1) increased symptom severity; poorer long-term outcomes; neurobiological changes in the brain, potentially impacting treatment response and recovery; and increased risk of self-harm, suicide, substance abuse, and involvement in risky or dangerous behaviors. Assessing the duration of untreated psychosis is important for identifying individuals who may benefit from early intervention and treatment. Early detection and intervention have been shown to improve outcomes for individuals experiencing psychosis, including reducing symptom severity, improving functioning, and increasing the likelihood of recovery. Measuring DUP typically involves gathering information about the onset of psychotic symptoms and the timing of initial treatment or intervention. This information can help clinicians and researchers better understand the impact of untreated psychosis and develop strategies for early detection and intervention to improve outcomes for individuals experiencing psychosis.

Term	Definition
International Early Psychosis Association (IEPA)	International Early Psychosis Association (IEPA) is an international organization dedicated to promoting early detection, intervention, and treatment of mental health disorders, particularly psychosis and related conditions. IEPA focuses on addressing the needs of individuals experiencing the early stages of psychosis, with the goal of improving outcomes and promoting recovery. IEPA advocates for early detection of mental health disorders, including psychosis, through screening, assessment, and identification of symptoms and risk factors. Early detection allows for prompt intervention and treatment, which can lead to better outcomes for individuals. IEPA promotes the implementation of evidence-based early intervention strategies for psychosis tailored to the needs of individuals in the early stages of illness. IEPA supports research efforts to improve understanding of the early stages of mental illness, identify effective intervention strategies, and evaluate outcomes. The organization also provides education and training for healthcare professionals, researchers, policymakers, and the public to increase awareness of early intervention approaches and their importance in mental health care. IEPA advocates for policies and initiatives that support early intervention in mental health care, including funding for research, development of specialized treatment programs, implementation of early detection and intervention strategies, and integration of mental health services into primary care settings. IEPA facilitates collaboration and networking among professionals, organizations, and stakeholders involved in early intervention in mental health. The organization hosts conferences, workshops, and forums where experts can share knowledge, best practices, and innovative approaches to early intervention.

Term	**Definition**
Early Psychosis Intervention Network (EPINET)	Initiated in 2019 and sponsored by the National Institute of Mental Health (NIMH), the Early Psychosis Intervention Network (EPINET) is a national learning healthcare system that focuses on early psychosis. EPINET is designed to support practice-based research to improve early identification, clinical assessment, diagnosis, intervention effectiveness, service delivery, and health outcomes in clinics offering evidence-based care to persons who are experiencing their first episode of psychosis or are identified as clinical high risk for psychotic illness. EPINET includes Scientific Regional Hubs (Hubs), first episode psychosis clinics, and the EPINET National Data Coordinating Center (ENDCC). EPINET links clinics that work with individuals with early psychosis through • Standardized clinical measures, • Uniform data collection methods, • Data sharing agreements, and • Integration of client-level data across service users and clinics. Early Psychosis Intervention Network (EPINET) funded awards to establish regional scientific hubs connected to multiple coordinated specialty care programs that provide early psychosis treatment and a national data coordinating center. The initiative has expanded to eight regional hubs in 17 states with more than 100 clinics that provide coordinated specialty care.
Evidence-based practice (EBP)	An **evidence-based practice** (EBP) is a practice that has been documented with research data to show its effectiveness.

Term	Definition
Extension for Community Healthcare Outcomes (ECHO)	In 2003, the Extension for Community Healthcare Outcomes (ECHO) model was developed by a physician at the University of New Mexico to increase rural clinicians' ability to treat hepatitis C. In 2017, the Northwest Portland Area Indian Health Board established its first ECHO program under the name Indian Country ECHO. The aim of this ECHO program was to create a welcoming learning environment where clinicians and staff serving American Indian and Alaska Native people could receive guidance and mentorship from clinical experts on treating and preventing hepatitis C. What staff and participants quickly observed was that providers who regularly participated in the hepatitis C ECHO program grew their knowledge such that they were able to treat patients with this condition in house. Bringing specialty care directly to patients not only reduced costs, it reduced patients' need to travel outside of their community for services. Furthermore, clinicians and staff felt supported by their ECHO community, whom they could turn to for professional guidance, accurate expert advice, and case consultation. Today, Indian Country ECHO continues to expand American Indian and Alaska Native peoples' access to high-quality specialized care through offering providers ECHO programs on a variety of topics including mental health.: In addition to offering providers a variety of ECHO programs, Indian Country ECHO provides no cost trainings, as well as technical assistance and capacity building services. It also facilitates the Indian Country ECHO Collective – a community of predominantly Indigenous organizations that provide ECHO services across the globe.
Leap Center	The LEAP Center is one of the National Institute of Mental Health's Advanced Laboratories for Accelerating the Reach and Impact of Treatments for Youth and Adults With Mental Illness (ALACRITY) Research Centers. LEAP was funded by the National Institute of Mental Health (NIMH) in May 2019.
Navigate	NAVIGATE is a comprehensive program designed to provide early and effective treatment to individuals who have experienced a first episode of psychosis. It was developed with support from NIMH and has been implemented at over 60 sites throughout the U.S. as well as in China, Canada, and Israel. NAVIGATE teams have served urban, suburban, and rural populations, and have provided treatment to people from diverse ethnic and cultural backgrounds. NAVIGATE is one of the options for implementing Coordinated Specialty Care (CSC) for early psychosis, as described on SAMHSA's website. The program is named "NAVIGATE" to convey the mission of helping individuals with a first episode of psychosis and their families to successfully find their way to psychological and functional well-being, and to access the services they need in the mental health system. Directory of NAVIGATE and other CSC teams: https://www.samhsa.gov/esmi-treatment-locator

Term	Definition
New England Mental Health Technology Transfer Center	The New England MHTTC is one of 10 regional Centers funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). Its mission is to support the dissemination of evidence-based mental health practices across Health and Human Services (HHS) Region 1, which includes the states of Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The New England MHTTC team is led by the Yale Program for Recovery and Community Health, in partnership with the Harvard Department of Psychiatry, and C4 Innovations. Its activities are guided by a robust advisory team consisting of people with lived experience, direct care practitioners, family advocates, and organizational and state leaders. The New England MHTTC offers training and technical assistance and develops and disseminate tools to promote the adoption of recovery-oriented practices across the mental health workforce. It also curates resources to meet the needs of a broader audience of critical partners including educators and school leaders, individuals and families, people with lived experience, community-based organizations, nonprofits, governmental agencies, and faith-based institutions. The content and process of its work is grounded in its Guiding Principles on Resilience and Recovery. Consistent with these principles, it takes an equity-minded approach to recovery-oriented care which recognizes that even the most progressive treatment systems exist within a social context where people of color and other historically marginalized groups often experience—both individually and collectively—an additional layer of trauma that has devastating consequences on their health and well-being.
Nonaffective psychosis	Nonaffective psychosis, also known as primary psychotic disorders, refers to a group of mental health conditions characterized by the presence of psychotic symptoms, such as hallucinations, delusions, disorganized thinking, or disorganized behavior, without a significant mood component. Unlike affective psychosis, which involves mood disorders with psychotic features, nonaffective psychosis primarily involves psychotic disorders that are not primarily mood-related. Some common examples of nonaffective psychotic illnesses include schizophrenia; schizophreniform disorder; brief psychotic disorder; delusional disorder; and schizoaffective disorder (with psychotic features).
OnTrackNY	OnTrack NY is a Coordinated Specialty Care (CSC) program in New York State that provides treatment to individuals ages 16 to 30 who have experienced nonaffective psychosis for less than two years. The program is intended to help young people achieve their goals for school, work, and social relationships. The OnTrackNY model of CSC evolved from the Recovery After an Initial Schizophrenia Episode (RAISE) projects, funded by the National Institute of Mental Health (NIMH). The RAISE Connection program included a research site in New York.

Term	Definition
Psychosis-Risk and Early Psychosis Program Network (PEPPNET)	With initial support from the Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institute of Mental Health (NIMH), and the Robert Wood Johnson Foundation (RWJF), the Psychosis-Risk and Early Psychosis Program Network (PEPPNET) started in September 2014 with a kick-off meeting of approximately 30 advocates, government agencies, researchers, and clinician experts engaged in the field of clinical high risk and early psychosis intervention, research, and service development. Out of this initial meeting came the consensus that there would be great value in formalizing this network of experts on an ongoing basis to organize thinking around clinical best practices, training approaches and metrics, and to provide leadership to communities nationwide who are implementing early high risk and psychosis programs. Through a one-year grant from RWJF in 2015, Stanford's Department of Psychiatry and Behavioral Sciences began organizing the development of an infrastructure to support PEPPNET in expanding clinical high risk and first episode psychosis program training, coordination, and awareness. PEPPNET has convened a national steering committee of clinicians, educators, policy leaders, government agencies and researchers who are leading community implementation efforts for early psychosis and psychosis risk programs. Through regular meetings, multiple subgroups, a national listserv and website, PEPPNET supports the development and dissemination of evidence-based best practices and evaluation standards. PEPPNET offers various working groups (lived experience, financing, training, and technical assistance) to support national coordination of early psychosis care. PEPPNET also offers an annual conference (typically in March) in collaboration with other partners.
Recovery After Initial Schizophrenia Episode (RAISE)	Launched in 2008, the Recovery After an Initial Schizophrenia Episode (RAISE) was a large-scale research initiative testing coordinated specialty care treatments. RAISE aimed to determine the best ways to help people recover from a psychotic episode and to reduce the likelihood of future episodes and long-term disability. The results of RAISE demonstrated that people who received CSC services had a better quality of life, more social and occupational success, and better ratings on symptoms. The success of this intervention has led to a growth of CSC clinics throughout this country.

Term	Definition
Specialized Treatment Early in Psychosis (STEP) program	The Specialized Treatment Early in Psychosis (STEP) program is an evidence-based treatment approach designed to provide specialized care for individuals experiencing first episode of psychosis. The program aims to intervene early to improve outcomes, promote recovery, and prevent long-term disability. STEP programs typically include: Early Detection and Intervention: The STEP program emphasizes early detection of psychosis and prompt initiation of treatment. It focuses on identifying individuals who are experiencing their first episode of psychosis and providing specialized care as soon as possible to prevent further deterioration and improve outcomes. Comprehensive Assessment: The STEP program conducts comprehensive assessments to evaluate the individual's symptoms, functioning, and treatment needs. This may involve psychiatric evaluation, psychological assessment, medical evaluation, and screening for co-occurring disorders. Multidisciplinary Team Approach: The STEP program utilizes a multidisciplinary team of healthcare professionals with expertise in psychiatry, psychology, social work, nursing, and other relevant disciplines. The team collaborates to develop individualized treatment plans based on the unique needs and preferences of each client. Evidence-Based Treatment Modalities: The STEP program incorporates evidence-based treatment modalities for psychosis, such as medication management, cognitive-behavioral therapy for psychosis (CBTp), family psychoeducation, supported employment/education, and case management. These interventions are tailored to address the specific needs of individuals experiencing early psychosis. Psychosocial Support: The STEP program provides psychosocial support and practical assistance to help individuals navigate the challenges associated with psychosis, such as managing symptoms, coping with stress, improving social skills, and enhancing functioning in daily life. Recovery-Oriented Care: The STEP program adopts a recovery-oriented approach that emphasizes hope, empowerment, and person-centered care. It focuses on promoting resilience, supporting individuals in achieving their goals, and fostering independence and self-determination.
Stride Program	The Stride program is an adaptation of the Navigate program for early episode psychosis but focused specifically on bipolar disorder. The Stride program aims to provide a coordinated specialty care approach for young people with bipolar disorder, including bipolar disorder-specific education for patients and families; medication management tailored to bipolar disorder; and psychosocial interventions like individual therapy and support for employment/education. The goal of the Stride program is to provide a more comprehensive and coordinated approach to treating bipolar disorder, compared to the patchwork of services that is often available. The program is currently being tested for feasibility and usability in Colorado. Reportedly, there are plans to implement the Stride program in Washington State and Florida.

Term	Definition
The RAISE Connection Program	The RAISE (Recovery After an Initial Schizophrenia Episode) Connection Program is an example of a “Coordinated Specialty Care” (CSC) program, which is a team-based, multi-element intervention that includes evidence-based components for the care of individuals experiencing early non-affective psychosis. The RAISE Implementation Evaluation Study (RAISE-IES) was a two-site study, funded by NIMH in partnership with New York and Maryland. It intended to assess feasibility of implementation and evaluate the Raise Connection Program's impact on overall functioning, as well as to assess its capacity to promote engagement and adherence to treatment, foster recovery and reduce or prevent disability in persons experiencing a first episode of psychosis. The program had a positive impact on primary outcomes including social and occupational functioning and symptom severity.
The Reach Institute	The Resource for Advancing Children’s Mental Health (REACH) is a tax-exempt, non-profit organization whose mission is to ensure that the most effective, scientifically proven mental health care reaches all children and families. REACH provides thousands of primary care providers, therapists, and health care institutions with training in the best evidence-based therapies to better diagnose, treat and manage child and adult mental health issues.

APPENDIX C | ONTRACKNY RESOURCES

OnTrack Manuals

https://www.ontrackny.org/for-providers/provider-resources

OnTrackNY Team Manuals

- Team Manual
- Medical Manual
- Primary Clinician's Manual
- Supported Employment and Supported Education Manual
- Recovery Coaching Manual
- Outreach and Recruitment Manual
- Voices of Recovery Manual
- Peer Specialist Manual
- Family Treatment and Resources Manual
- Delivering Culturally Competent Care in FEP
- Treating Cognitive Health Manual
- Windows of Opportunity in Early Psychosis Care: A Companion Guide for Navigating Cultural Dilemmas

APPENDIX D | MASS-STEP

JANUARY 13, 2022

Mass-STEP

Massachusetts Strategic Plan for Early Psychosis

ACKNOWLEDGEMENTS

In this document, we use the term “early-course psychosis” to encompass a range of populations and experiences, including individuals with a recent onset of psychosis, those at clinical high risk to develop psychosis, and the families that support these individuals and are themselves impacted by their loved ones’ experience of psychosis. Although early intervention is the priority and focus of this plan, we recognize that a lifespan approach is necessary to support lifelong wellbeing among those experiencing psychosis and their families. We also refer to the BIPOC (black, indigenous, and other people of color) and LGBTQ (lesbian, gay, bisexual, transgender, nonbinary and queer or questioning) communities as key intersecting groups for whom unique considerations may be needed. Our goal in this document (as clinicians, researchers, public health professionals, and government stakeholders) is to partner with these communities to define priorities for improving statewide resources and services for early-course psychosis.

I. INTRODUCTION

The prevention and early intervention of psychotic disorders has emerged as a key public health mandate for local, national, and global mental health authorities. Early intervention in psychosis is both effective and necessary. The World Health Organization recommends a delay of no more than 90 days between symptom presentation and specialized early-course psychosis treatment (Bertolote & McGorry, 2005); however, estimates across the US place the average delay in accessing treatment between one to three years (Marshall et al., 2005; Srihari et al., 2009). The first two years of a psychotic illness in particular are a critical period for intervention, in which cognitive declines, grey matter loss, and suicide risk are highest. Rapid identification and access to specialized early psychosis services are associated with improved quality of life, cognitive functioning, participation in work and school, and treatment engagement, as well as reduced symptom severity, substance use, and downstream healthcare costs and involvement among individuals served (Breitborde et al., 2015; Correll et al., 2018; Kane et al., 2015, Randall et al., 2015; Goldberg et al., 2006). Simply put, intervention in this critical window is not only life-changing, but life-saving.

Epidemiological research has established a stark need for wide-spread easy access to evidence based early-course psychosis services. Each year, roughly 100,000 people across the US will experience a first episode of a psychotic disorder, with peak onset between the ages of 15 and 25 (Heinssen, Goldstein, & Azrin, 2014). In Massachusetts alone, this amounts to approximately 2,000 new cases annually. If each early intervention program can meet the ambitious goal of admitting one patient per week, or 52 patients per year, then we will need 39 programs minimally to meet this need. Currently, Massachusetts has approximately 20 specialty clinics for early-course psychosis including 12 Coordinated Specialty Care (CSC) programs for first-episode psychosis (FEP)— less than one third of the minimum number required ("First Episode Psychosis Programs", n.d.). Even these available clinics vary in their ability to deliver the standard of care for treatment in early-course psychosis, as essential elements of CSC are not currently supported through 3rd party reimbursement payment models.

In addition to the scarcity of clinics and clinicians specializing in early psychosis treatment, many individuals face barriers in accessing specialized mental health services. Factors including out of pocket costs, transportation, protected time to attend appointments, stable housing, affordable childcare, stigma, and more contribute to disparities in access to mental health care. These factors are compounded by a lack of public knowledge about the early signs of psychosis and resources available to youth and families. While stigma is a powerful factor known to deter individuals from understanding and identifying their symptoms, managing symptoms, connecting with others in the community, and seeking formal care, those experiencing stigma and discrimination associated with intersecting aspects of their identity such as race, sexual and gender minority status, or immigration status may be even more hesitant to seek help for emerging mental illness. One study conducted by Schoenbaum et al. (2017) found that, of individuals aged 16 to 30 in the US who received an index diagnosis of a psychotic disorder, 61% did not fill an antipsychotic prescription and 41% did not receive individual therapy in the year following this diagnosis. Further research suggests that access to care is particularly limited for Black and Hispanic individuals, for whom there are significant reductions in outpatient mental health service use within a year of diagnosis compared to non-Hispanic white individuals (van der Ven et al. 2020).

With the clear evidence that early intervention is critical to the health and wellbeing of people living with psychosis and their families, the well-established evidence-based standards of care for early intervention, and the mental health parity laws, now is the time to address the challenges necessary to assure wide-spread availability of specialized services for individuals in the early course of psychosis. Insufficient numbers of programs, limited geographic availability, insufficient funding, and other access barriers to early-course psychosis services constitute an issue of equity both for individuals affected by psychosis who themselves represent an underserved subset of the community living with mental illness, and for intersecting BIPOC, LGBTQ, and low-income communities who shoulder a disproportionate burden of serious mental illness while simultaneously experiencing disparities in access to and quality of care.

With guidance from community members who have first-hand experience with psychosis and other expert stakeholders, the Massachusetts DMH has partnered with the Laboratory for Early Psychosis (LEAP) Center, the Massachusetts Psychosis Network for Early Treatment (MAPNET), and the Northeastern University Institute for Health Equity and Social Justice Research (IHESJR) to develop the Massachusetts Strategic Plan for Early Psychosis (Mass STEP). The Mass STEP outlines priorities for mobilizing actions centered around prevention efforts, treatment services, and the system-level coordination needed to build up an adequate system of care for individuals living with psychosis in Massachusetts. Mass STEP acknowledges the difficult history of psychiatry and the racialization of psychotic disorders which continues to serve as a barrier to trust and engagement with some BIPOC communities. Mass STEP includes attention to diversity in religion and spirituality, familial culture, language barriers, gender and sexuality, and youth culture. It also prioritizes attention to the needs of BIPOC communities experiencing and managing discrimination, racially motivated violence, marginalization, and exclusion. All of these factors impact mental health and well-being, including experiences of psychotic symptoms and disorders. Mass STEP advocates for the development and implementation of early-course psychosis services informed by the principles of cultural sensitivity and humility.

The following sections of this report describe the mixed-methods approach used to identify priorities for the Mass STEP (Section II), the framework used to conceptualize these priorities (Section III), and a list of overarching goals and recommendations to promote and advance early intervention in psychosis across Massachusetts (Section IV).

II. A COMMUNITY-ENGAGED STRATEGIC PLANNING PROCESS

A. Feedback and Recommendations from People with Early-Course Psychosis and their Families

A mixed methods approach was used to gather information from people receiving services from early psychosis programs in Massachusetts and their family members. First, in the summer and fall of 2020, a survey was disseminated to assess patients' and caregivers' experiences with treatment services and resources, as well as suggestions for activities to improve or expand early psychosis programming across the state. Results from the survey informed the content of focus groups and individual interviews with a subset of survey respondents in order to gain a deeper understanding of consumers' needs and challenges, and to gather their input on the strategic plan. A detailed description of this mixed-methods data collection process is included in Appendix A.

B. Feedback and Recommendations from Expert Stakeholders in Early-Course Psychosis

Following the consumer and caregiver survey, a conference was held on November 5th, 2020 to further develop priorities for the strategic plan with experts in the field, titled "Early Intervention in Psychosis: A Strategic Roadmap for Massachusetts." Sessions included presentations from national and international experts in early intervention for psychosis, as well as panel discussions with clients, families, and clinicians involved with early psychosis treatment programs across Massachusetts. Discussion and brainstorming sessions were held using Zoom breakout groups to solicit feedback from all attendees. Over 200 participants registered for the conference, representing policy makers, clinicians, researchers, community advocates, and individuals and family members with lived experience of psychosis. Eighty-four perecent of registered attendees indicated that they lived, worked, or received mental health services in the state of Massachusetts. A full summary of proceedings from this symposium was published in March 2021 through Schizophrenia Research (Johnson et al., 2021).

III. FRAMEWORK (THE SOCIO-ECOLOGICAL FRAMEWORK)

The Mass STEP understands mental health and illness through the lens of a socio-ecological model of health. The overarching goal of early intervention and prevention in psychosis is to reduce suffering caused by these disorders and promote the overall health and wellbeing of individuals and their families; however, the actions taken to achieve this goal must acknowledge the context within which psychosis occurs. This framework identifies *Communities*, *Organizations*, and *Systems* as important contributors to an *Individual's* health and wellbeing. The model allows for a comprehensive look at mental health, providing insight into the specific challenges and needs of clients experiencing early-course psychosis.

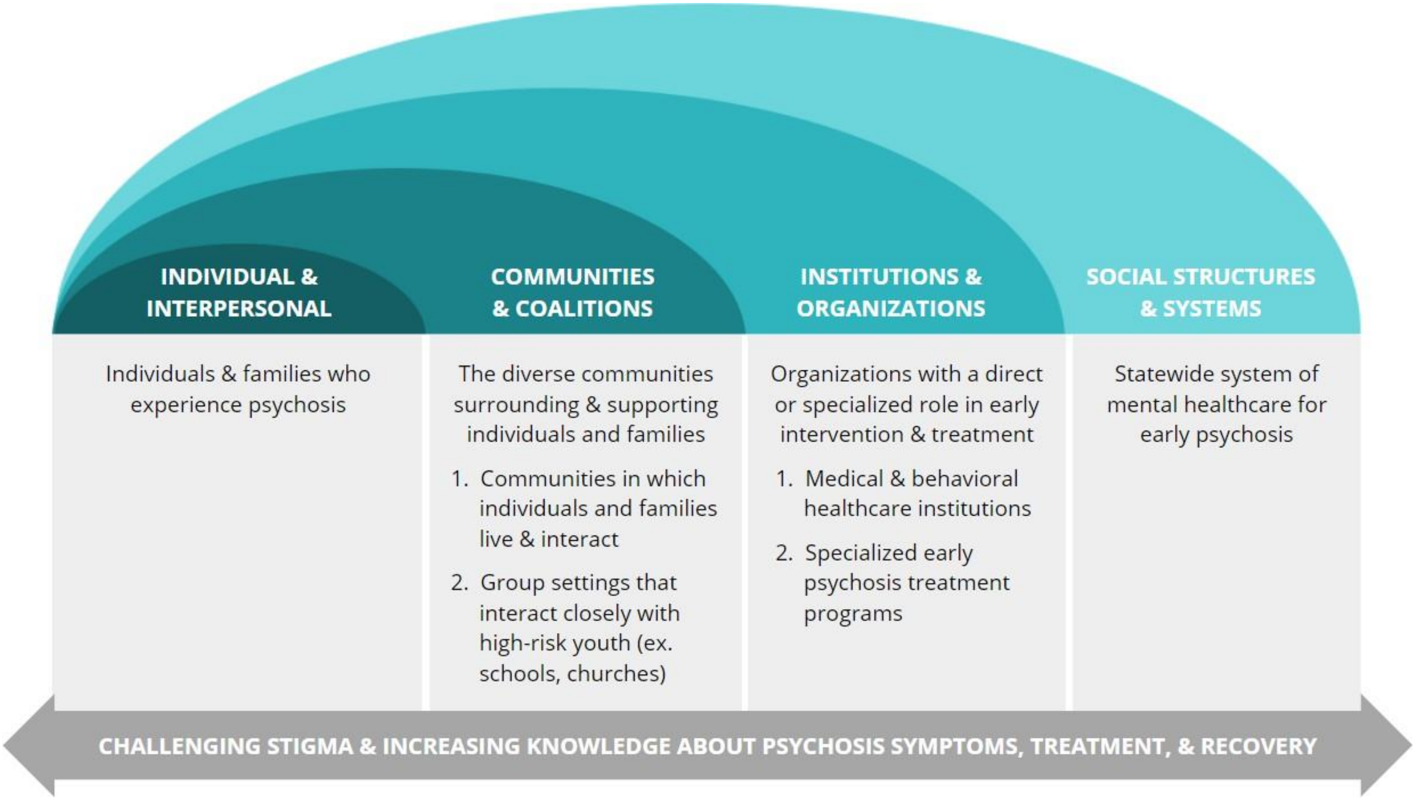
As an example, consider a young person who begins to experience auditory hallucinations in school, which impede greatly on their ability to focus. They may disclose this to a trusted teacher in their school's network (*Communities*), who might suggest the need for further assessment. The student may then talk to their primary care clinician, who could refer them to a specialty psychosis program (*Organizations*). This program would provide high-quality evidence-based treatment thanks to collaborations with other specialists across the state and support from insurance (*Systems*). If any piece of this pathway were to be interrupted— for example, a teacher ignoring warning signs, a provider unsure of available treatment options, or insurance unable to cover the student's treatment needs— the end result would likely be the same. All levels of intervention must receive adequate support to make a difference for the individual seeking care.

This is just one situation in which the socio-ecological model may be applied to examine early intervention and prevention strategies. *Community* connections such as peer and social groups are known to enhance treatment and recovery outcomes in psychosis. In contrast, barriers to care are frequently contextualized on the *Systems* level through structural inequalities by race, ethnicity, gender, sexuality, and socio-economic status. With this knowledge, the Mass STEP aims to intervene at each level of the socio-ecological model to improve early psychosis services.

Lastly, the Mass STEP recognizes a need to create environments that minimize suffering and promote wellbeing by addressing stigma at every level of the model. Stigma, a devaluation of individuals resulting from negative beliefs and attitudes, can have a devastating impact on those with mental illness and is particularly salient for individuals experiencing psychosis. Internalized stigma (*Individual*) and *Community*-wide beliefs often deter people from disclosing symptoms and seeking support for psychosis. When individuals do choose to access services, medical and behavioral healthcare *Organizations* can perpetuate stigma by communicating in a paternalistic, demeaning, or pessimistic manner. At the *Systems* level, laws and policies can hinder pathways to recovery by restricting access to employment, education, and housing. To acknowledge the critical impact of stigma in psychosis— from internalized stigma to institutional bias— "Challenging Stigma" is noted as a core overarching theme that must be acted upon at every level.

The following figure illustrates the priority populations identified through this model and the six primary goals resulting from these categories. In Section IV, we provide a detailed assessment of each goal and their potential action items, which are all informed by the stakeholder discussions described in Section II.

Socio-Ecological Model of Priority Populations for Early Intervention in Psychosis
Adapted from the Massachusetts Strategic Plan for Suicide Prevention



INDIVIDUAL & INTERPERSONAL	COMMUNITIES & COALITIONS	INSTITUTIONS & ORGANIZATIONS	SOCIAL STRUCTURES & SYSTEMS
Individuals & families who experience psychosis	The diverse communities surrounding & supporting individuals and families 1. Communities in which individuals and families live & interact 2. Group settings that interact closely with high-risk youth (ex. schools, churches)	Organizations with a direct or specialized role in early intervention & treatment 1. Medical & behavioral healthcare institutions 2. Specialized early psychosis treatment programs	Statewide system of mental healthcare for early psychosis

CHALLENGING STIGMA & INCREASING KNOWLEDGE ABOUT PSYCHOSIS SYMPTOMS, TREATMENT, & RECOVERY

Following this framework, the six primary goals of this plan are as follows:

1. Assure support for **<u>individuals who experience psychosis and their families</u>** through individual advocacy opportunities, community-building, and specialized early psychosis services.
2. Promote early identification and intervention for psychosis through community education and awareness efforts across the **diverse communities of Massachusetts**, particularly among underserved groups who face multiple barriers in accessing mental healthcare.
3. Promote early identification and intervention for psychosis through specialized supports for **community members who are likely to interact with those experiencing psychosis** (e.g. schools, faith leaders, law enforcement, EMTs).
4. Provide specialized support to **medical and behavioral healthcare professionals** in competencies related to early psychosis.
5. Support **specialized early psychosis treatment teams** in delivering high-quality, evidence-based care in a stepped framework that is culturally and linguistically appropriate, person centered, trauma informed, and recovery focused for people experiencing psychosis and their families.
6. Support and develop the **statewide system of services for early psychosis** by fostering communication across programs and integrating systemic supports for early intervention and prevention.

IV. STRATEGIC PLAN GOALS

Goal & Population	Examples of Possible Actions *(as identified in Symposium and Interviews/Focus Groups)*
1. Assure support for **<u>individuals who experience psychosis and their families</u>** through individual advocacy opportunities, community-building, and specialized early psychosis services.	1.1 Include stakeholders who experience psychosis on committees that make decisions about early psychosis resources, services and research (ex. DMH IRB, DMH, research advisory boards) 1.2 Increase resources for peer specialist roles on early psychosis teams; provide avenues for peer specialists to collaborate across programs and to advocate for needs in these roles. 1.3 Expand the reach of early psychosis support groups for individuals and families; for example, developing peer- and clinician-led support groups available regardless of program enrollment (see Wellspace groups at McLean, McFarlane multi-family groups, Australia's Headspace model), or utilizing virtual spaces for community-building and outreach (ex. apps & social media) 1.4 Provide specialized services to support individuals in achieving goals related to education and employment 1.5 Develop and strengthen supports for families & caregivers of individuals experiencing psychosis (Examples: In-Reach approach to teach motivational interviewing for caregivers) 1.6 Provide assistance with housing and food insecurity for individuals experiencing psychosis **CHALLENGING STIGMA**: Expand informational resources and programs for individuals and families who experience psychosis; Promote avenues for peer-led interpersonal support for individuals and families (ex. Hearing Voices groups); Implement evidence-based treatment approaches to address internalized stigma within the context of early-course psychosis treatment programs.
2. Promote early identification and intervention for psychosis through community education and awareness efforts across the **<u>diverse communities of Massachusetts</u>**, particularly among underserved groups who face multiple barriers in accessing mental healthcare.	2.1 Identify communities that are underserved by existing treatment programs and develop specialized approaches to outreach and support in these communities (ex. through churches or tribal governments) 2.2 Implement a public awareness campaign regarding signs and symptoms of psychosis, screening tools, etc. (see Yale MindMap campaign, https://mindmapct.org/about/) 2.3 Increase visibility of available resources and improve online information; for example, funding a marketing & media coordinator for early psychosis services or reassessing resources on the DMH website **CHALLENGING STIGMA**: Implement evidence-based anti-stigma programs to reduce community-level stigma associated with psychotic symptoms and increase hope for recovery.
3. Promote early identification and intervention for psychosis through specialized supports for **<u>community members who are likely to interact with those experiencing psychosis</u>** (e.g. schools, faith leaders, law enforcement, EMTs).	3.1 Develop a statewide centralized triage and navigation service to provide quick access to consultation & support in early psychosis and facilitate rapid connection of individuals and their families with care (ie. "MCPAP for psychosis" model) 3.2 Train community leaders & programs in the early signs, symptoms, and referral options for early psychosis (ex. schools, religious communities, youth programs, law enforcement/forensic programs, EMTs) 3.3 Create collaborative relationships between community organizations (emergency service providers, schools, etc.) and early psychosis assessment and treatment resources 3.4 Support local law enforcement in developing organizational procedures and culture that promote safe and compassionate interactions with people in crisis, including the provision of Mental Health First Aid and Crisis Intervention trainings (see IACP One Mind Campaign & Police-Mental Health Collaboration Toolkit). **CHALLENGING STIGMA**: Integrate anti-stigma and recovery-oriented content into trainings for community programs

4. Provide specialized support to **<u>medical and behavioral healthcare professionals</u>** in competencies related to early psychosis.	4.1 Improve psychosis-specific resources in psychiatric inpatient units & strengthen connections to community programs; for example, developing a FEP-specific inpatient unit, supporting structure and psychosis competency in existing units, promoting continuity of care and discharge planning for transitions between inpatient and outpatient settings, and developing peer support/peer navigator programs within hospitals 4.2 Assist family members and practitioners in acute care settings in connecting to early psychosis treatment services (See description of centralized triage and navigation service in goal 3.1) 4.3 Create collaborative/integrated relationships between medical/behavioral health providers and specialized early psychosis teams 4.4 Educate behavioral health providers to, at a minimum, screen, detect, and refer to specialized services for psychotic symptoms (inpatient, ESP, and outpatient services) 4.5 Increase psychosis competency among community and private practice mental health providers for those who are being discharged from an early psychosis program or who may not need the level of support offered by specialty programs
	CHALLENGING STIGMA: Implement anti-stigma training for medical and behavioral healthcare professionals
5. Support **<u>specialized early psychosis treatment teams</u>** in delivering high-quality, evidence-based care in a stepped framework that is culturally and linguistically appropriate, person centered, trauma informed, and recovery focused for people experiencing psychosis and their families.	5.1 Promote the development of new early psychosis coordinated specialty care (CSC) treatment programs in underserved areas across the state and support high-quality, whole-person, and recovery-oriented care initiatives across new and existing programs. Using a stepped-care framework, these programs should have capacity to adjust the intensity of the intervention based on the fluctuating needs of individuals and families over time 5.2 Maintain capacity to provide intensive outpatient service for those needing a higher level of care (ex. PREP) 5.3 Maintain the infrastructure necessary to provide expert training and consultation in the implementation of evidence-based practices to providers in early psychosis programs (ex. MAPNET) 5.4 Address issues of accessibility for telehealth and in-person services among clients & families; for example, using telehealth and mobile teams to increase access in communities far from urban academic medical centers, providing laptops/broadband for clients & families to address accessibility needs related to telehealth, and supporting access to in-person treatment through transportation programs and geographic flexibility 5.5 Support community programs within treatment settings such as cooking classes, exercise/sports groups, special interest groups, etc. that help clients to live healthy and active lives 5.6 Adapt engagement and treatment models to best meet the needs of culturally and linguistically diverse communities; for example, building a diverse workforce and increasing access to interpreter services 5.7 Invest in building a racially, linguistically and culturally diverse early psychosis workforce by providing paid mentorship and training opportunties for students, clinical trainees and residents from under-represented minority groups to learn to specialize in treating early psychosis 5.8 Support CSC programs in addressing comorbid substance use in treatment
	CHALLENGING STIGMA: Survey knowledge & beliefs about recovery among early psychosis treatment providers; Standardize the inclusion of recovery orientation in the training process for early psychosis treatment providers

6. Support and develop the **<u>statewide system of services for early psychosis</u>** by fostering communication across programs and integrating systemic supports for early intervention and prevention.	6.1 Assess and address issues related to capacity in the early psychosis care system; for example, addressing clinician burnout and turnover, utilizing community-level interventions (ex. Horyzons platform in Australia), and assuring that graduate programs and training sites are training future behavioral workforce members in recognizing the signs of early & emerging psychosis 6.2 Expand and diversify the workforce of trained staff across early psychosis services; for example, providing intensive training in psychosis for graduate & undergraduate students, developing incentives to reduce staff turnover, and increasing racial diversity in the mental health workforce (see 5.7) 6.3 Implement evidence-based strategies to monitor and address the mental health impact of marijuana legislation; for example, promoting evidence-based legal regulations for THC content and labelling of cannabis products, developing a community education campaign, or considering a “sin tax” wherein tax dollars generated by marijuana sales are allocated to support early psychosis services 6.4 Enhance sustainability in billing practices by creating a standardized program-level day-rate for early psychosis treatment reimbursable by third-party insurance payers. Formalize billing structures for services that are not currently 3rd party billable, e.g. peer support, psychoeducation, employment/education support, team meetings, coordination of care between acute & outpatient services, community education and outreach. Ensure that treatment is available in some form to everyone regardless of insurance coverage. 6.5 Evaluate implementation strategies that support the translation of innovative evidence-based practices in non-research settings 6.6 Utilize data to monitor needs in early psychosis services, capacity of the behavioral health system to address service needs, quality of services provided, and to evaluate impact of services received (via standardized systems for outcome evaluations & regular assessments of fidelity across teams implementing CSC or other EBPs)
	CHALLENGING STIGMA: Identify employer practices and policies that exemplify best practices in inclusion and stigma reduction for psychosis, and promote the use of these practices in new and existing systems/policies

References

Bertolote, J., & McGorry, P. (2005). Early intervention and recovery for young people with early psychosis: Consensus statement. *British Journal of Psychiatry Supplement*, 48, s116–119

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa

Breitborde, N. J. K., Bell, E. K., Dawley, D., Woolverton, C., Ceaser, A., Waters, A. C., … & Harrison-Monroe, P. (2015). The Early Pschosis Intervention Center (EPICENTER): Development and six-month outcomes of an American first-episode psychosis clinical service. *BMC Psychiatry, 15*, 266. doi:10.1186/s12888-015-0650-3

Charlson, F. J., Ferrari, A. J., Santomauro, D. F., Diminic, S., Stockings, E., Scott, J. G., … & Whiteford, H. A. (2018). Global epidemiology and burden of schizophrenia: Findings from the Global Burden of Disease Study 2016. *Schizophrenia Bulletin*, *44*(6), 1195-1203. doi.org/10.1093/schbul/sby058

Correll, C. U., Galling, B., Pawar, A., Krivko, A., Bonetto, C., Ruggeri, M., … & Kane, J. M. (2018). Comparison of early intervention services vs treatment as usual for early-phase psychosis: A systematic review, meta-analysis, and meta-regression. *75*(6), 555-565. doi: 10.1001/jamapsychiatry.2018.0623

Falcone, T., Mishra, L., Carlton, E., Lee, C., Butler, R. S, Janigro, D., … & Franco, K. (2010). Suicidal behavior in adolescents with first-episode psychosis, *Clinical Schizophrenia & Related Psychoses, 4*(1), 34-40. doi:10.3371/CSRP.4.1.2

First Episode Psychosis Programs in Massachusetts. Massachusetts Psychosis Network for Early Treatment. (n.d.). Retrieved September 16, 2021, from www.mapnet.online/program-directory.

Friedman-Yakoobian, M., West, M. L., Woodberry, K. A., O'Donovan, K. E., Zimmet, S., ... & Seidman, L. J. (2018). Development of a Boston treatment program for youth at clinical high risk for psychosis: Center for early detection, assessment, and response to risk (CEDAR). *Harvard Review of Psychiatry*, *26*(5), 274-286. doi:10.1097/HRP.0000000000000181

Fusar-Poli, P., McGorry, P. D., & Kane, J. M. (2017). Improving outcomes of first-episode psychosis: an overview. *World Psychiatry*, *16*(3), 251-265. doi:10.1002/wps.20446

Goldberg, K., Norman, R., Hoch, J., Schmitz, N., Windell, D., Brown, N., & Malla, A. (2006). Impact of a Specialized Early Intervention Service for Psychotic Disorders on Patient Characteristics, Service Use, and Hospital Costs in a Defined Catchment Area. *The Canadian Journal of Psychiatry*, 51(14), 895–903. doi.org/10.1177/070674370605101405

Heinssen, R. K., Goldstein, A. B., & Azrin, S. T. (2014). Evidence-based treatments for first episode psychosis: Components of coordinated specialty care. National Institute of Mental Health White Paper. www.nimh.nih.gov/health/topics/schizophrenia/raise/nimh-white-paper-csc-for-fep_147096.pdf

IBM Corp. (2017). IBM SPSS Statistics for Windows, Version, 25.0. Armonk, NY: IBM Corp.

Johnson, K. A., Guyer, M., Öngür, D., Friedman-Yakoobian, M., Kline, E., Carol, E., Davis, B., & Keshavan, M. (2021). Early intervention in psychosis: Building a strategic roadmap for Massachusetts. *Schizophrenia research*, 229, 43–45. doi.org/10.1016/j.schres.2021.01.026

Kane, J. M., Schooler, N. R., Marcy, P., Correll, C. U., Brunette, M. F., Mueser, K. T., …& Robinson, D. G. *(2015).* The RAISE early treatment program for first-episode psychosis: Background, rationale, and study design. *Journal of Clinical Psychiatry, 76*(3), 240-246. doi: 10.4088/JCP.14m09289

Kelleher, I., Connor, D., Clarke, M. C., Devlin, N., Harley, M., & Cannon, M. (2012). Prevalence of psychotic symptoms in childhood and adolescence: a systematic review and meta-analysis of population-based studies. *Psychological Medicine, 42*(9), 1857-1863. doi:10.1017/s0033291711002960

Kelleher, I., Keeley, H., Corcoran, P., Lynch, F., Fitzpatrick, C., Devlin, N, … & Cannon, M. (2012). Clinicopathological significance of psychotic experiences in non-psychotic young people: Evidence from four population-based studies. *British Journal of Psychiatry, 201*(1), 26-32. doi:10.1192/bjp.bp.111.101543

Lake, J., & Turner, M. (2017). Urgent need for improved mental health care and a more collaborative model of care. *Permanente Journal, 21*. doi:10.7812/TPP/17-024

Malla, A., & McGorry, P. (2019). Early intervention in psychosis in young people: A population and public health perspective. *American Journal of Public Health*, *109*(S3), 181-184. doi: 10.2105/AJPH.2019.305018

Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: A systematic review. *Archives of General Psychiatry*, 62(9), 975–983. doi:10.1001/archpsyc.62.9.975

National Alliance on Mental Illness (n.d.). *Psychosis*. Retrieved from https://www.nami.org/About-Mental-Illness/Mental-Health-Conditions/Psychosis

Perärä, J., Suvisaari, J., Saarni, S., Kuoppasalmi, K., Isometsä, E., Pikola, S., Partonen, T., … & Lönnqvist, J. (2007). Lifetime prevalence of psychotic and bipolar I disorders in a general population. *Archives of General Psychiatry 64*(1), 19-28. doi:10.1001/archpsyc.64.1.19

Randall, J. R., Vokey, S., Loewen, H., Martens, P., Brownell, M., Katz, A., … & Chateau, D. (2015). A systematic review of the effect of early interventions for psychosis on the usage of inpatient services. *Schizophrenia Bulletin, 41*(6), 1379-1386. doi:10.1093/schbul/sbv016

Schoenbaum, M., Sutherland, J. M., Chappel, A., Azrin, S., Goldstein, A. B., Rupp, A., & Heinssen, R. K. (2017). Twelve-month health care use and mortality in commercially insured young people with incident psychosis in the United States. *Schizophrenia Bulletin, 43*(6), 1262-1272. doi:10.1093/schbul/sbx009

Srihari, V. H., Breitborde, N. J., Pollard, J., Tek, C., Hyman, L., Frisman, L. K., … Woods, S. W. (2009). Public-academic partnerships: Early intervention for psychotic disorders in a community mental health center. *Psychiatric Services*, 60(11), 1426–1428.

Turnbull, F. M. (2003). Historical note: Preventing mental illness, 1882. *Journal of Nervous and Mental Disease, 191*(2), 121. doi:10.1097/01.NMD.0000051549.79407.DA

Van der Ven, E., Susser, E., Dixon, L. B., Olfson, M., & Gilmer, T. P. (2020). Racial-ethnic differences in service use patterns among young, commercially insured individuals with recent-onset psychosis. *Psychiatric Services, 71*(5), 433-439. doi:10.1176/appi.ps.201900301

Appendix A
Data Collection Methods for Client & Family Stakeholder Feedback

Three phases of data collection were used to gather input from people experiencing early psychosis and their caregivers. First, in the Fall of 2020, a survey was disseminated to young adults and their caregivers through Massachusetts's network of early psychosis programs. The survey was developed by the research team at Northeastern University Institute for Health Equity and Social Justice Research in collaboration with the Massachusetts Department of Mental Health. In our survey, both people impacted by psychosis and caregivers were asked demographic questions concerning race, ethnicity, gender, sexual orientation, place of living, education, and employment status. Questions were developed to understand the experiences individuals and their caregivers had with treatment services, and to gain a deeper understanding of the lived experiences of those involved with early psychosis services. The data from the survey were analyzed using Statistical Package for the Social Sciences (IBM Corp, 2017) and open ended responses were approached as a thematic analysis to identify themes for focus groups and interviews (Braun & Clarke, 2007).

Following the completion of this survey participants were asked whether they were interested in participating in a follow-up focus group or interview concerning early psychosis services. In December 2020, we carried out two focus group interviews and four individual interviews over HIPAA-compliant Zoom calls. The two focus groups each consisted of three and four caregivers for an individual receiving early psychosis services. Individual interviews were conducted with those who were unable to participate in the focus groups. These included two additional caregivers, and two young adults receiving early psychosis services.

During the focus groups, we asked a series of questions to both individuals and caregivers. These questions were developed using information gathered from our patient survey and included questions to gage what would improve services (lists of questions asked for young adults and caregivers are included in the following pages). Questions encouraged participants to discuss their experiences receiving early psychosis services, and potential concerns where treatment could be improved. Audio recordings of all focus groups and interviews were transcribed and anonymized prior to analysis.

Interview Questions with Young Adults

1. When did you come in contact with treatment or services?
    a. How did you find out about services or how was your first contact with services?

2. Is there something that could have been done differently for you to better find out about services, treatment, and/or resources?
    a. What were some barriers to you getting into services?
    b. What were some things that helped you to access services?

3. What type of information was provided to you when entering into services?
    a. What would you have liked provided in terms of information when you first started services?

4. What types of services, treatment, resources were offered to you and your family?
    a. What did you like about what was available to you and your family?
    b. What do you wish was available to you and your family that wasn't?
    c. What would you have liked to be done differently for you and for your family?
    d. What types of resources, services, treatment would you like offered that weren't?

5. Now, I would like you to think about the current services, treatment, resources you receive.
    a. What services, treatment, resources that are available to you and your family now that are different than when you first came into services?
    b. What services, treatment, resources, do you wish were available to you and your family now that are different than when you first started using services?

6. I have one final question before we wrap up. What else would you like us to know as the Department of Mental Health (DMH) plans services, treatment, resources for youth who are experiencing psychosis. What do you want DMH to know?

Focus Group Interview Guide For Individuals and Caregivers

1. Would you share with us what has worked well or has been helpful for your child/family member?

2. What has been challenging in accessing support needed for your child/family?

3. We would like to share some pieces and goals of the draft on the roadmap:

   Increase the competence of first responders who are more likely to encounter people at high risk and recent onset of psychosis. (such as law enforcement, forensic services; EMT'S and schools)
   - Training in early signs, symptoms, screening
   - Increased collaboration between emergency service providers, early psychosis assessment, and treatment resources
   - Quick access to phone consultation/support regarding recognizing and responding to concerns for emerging symptoms

   Partner with the diverse communities of Massachusetts to increase awareness and ability to identify individuals experiencing recent onset of psychosis
   - Conduct public awareness campaigns regarding signs and symptoms, screening tools, etc.
   - Reduce stigma associated with psychotic symptoms and increase hope for recovery
   - Consider use of telehealth and mobile teams for increasing access to care for communities far from urban academic medical centers
   - Adapt engagement and treatment models to best meet the needs of culturally and linguistically diverse communities

   Would you share your reactions?

   Would you like to add anything that you think might be important and helpful that we might have missed?

4. We value your experience as a caregiver/parent. We believe that you as a caregiver/parent have experiences that inform you to think about what could be helpful for your child/family member and other young people with psychosis. We ask you to imagine a world without any constraints such as funding. What would you like to add to the roadmap?

5. Is there anything else that you would like us to communicate with the Department of Mental Health as they plan for the roadmap?

APPENDIX E | VERMONT FIRST-EPISODE PSYCHIATRIC EVALUATION FINAL REPORT

Vermont First-Episode Psychosis Evaluation
Final Report

Elizabeth Carpenter-Song, John Torrey, David Strickler, Robert E. Drake

v. 9.25.18 (DRAFT)

Introduction

Onset of psychosis often occurs in late adolescence and early adulthood, with some studies reporting a median age of onset in the early 20s (Kessler et al., 2007; McGorry et al., 2011). Schizophrenia spectrum disorders, which account for two-thirds of psychotic disorders, usually begin between the ages of 15 and 35 (Kessler et al., 2007). A recent study of the incidence of first-episode psychosis found estimated true incidence rates of 86 per 100,000 per year among people aged 15-29 and 46 per 100,000 among people aged 30-59 (Simon et al., 2017).

Early treatment of first-episode psychosis is considered important to improving outcomes and reducing duration of untreated psychosis (McGorry et al., 2007; Marshall et al., 2005; Perkins et al., 2005). Yet many young people experience substantial delays in receiving treatment and pathways to care that are complex and typically characterized by multiple help-seeking contacts including primary care providers, emergency services, mental health professionals, and family/relatives (MacDonald et al., 2018). A meta-analysis on help seeking in early psychosis concluded that, “Treatment delay is a feature common to all the help-seeking studies we reviewed.” (Boydell et al., 2006 p. 19). Treatment delays can result from an individual or family member not being educated about psychosis, difficulty accessing services, and stigma (Boydell et al., 2006; Gronholm et al., 2017). The literature on first-episode psychosis highlights the role that parents and other individuals within a person’s social network can play in facilitating identification of psychosis and help seeking. (Boydell et al., 2006). General practitioners and school social workers are frequently crucial in connecting people experiencing psychosis to mental health services. (Addington, et al., 2002; Boydell et al., 2006; MacDonald et al., 2018).

Counseling, medication, and psychosocial interventions following a first-episode psychosis can substantially contribute to recovery (McGorry et al., 2007). Early identification and treatment, with clozapine and cognitive-behavioral therapies, have been shown to make a positive difference in prognosis (Edwards et al., 2005). Psychosocial factors, including employment, education, self-care, recreation, and social participation have been found to contribute to desirable health outcomes after FEP (Boydell et al., 2006). Psychoeducation that helps patients make sense of psychotic experiences has also been shown to be important in recovery following first-episode psychosis (Boydell et al., 2006). Larsen’s ethnographic work found that people experiencing psychosis develop a “system of explanation” to make sense of their illnesses (Larsen, 2004). Explanatory systems can draw from multiple means of cultural understanding at the same time, for example both medical and spiritual interpretations (Larsen, 2004).

Rural areas in the U.S. face specific mental health challenges, notably, higher rates of suicide (Eberhardt & Pamuk, 2008; Hirsch & Cukrowicz, 2014), depression (Hauenstein & Peddada, 2007), and opioid use-related deaths (Paulozzi, et al. 2012) compared to urban areas. Despite the high burden of mental health challenges, rural residents are less likely than their urban counterparts to receive mental health treatment (Wang et al., 2005) and receive less in terms of amount of treatment and effective treatment (Adams, et al. 2006; Hauenstein, et al. 2007). Access to mental health treatment in rural areas is difficult given shortages of mental health providers, long distances to treatment centers, and barriers including lack of infrastructure, poverty, and substance abuse (Thomas et al., 2012). Other barriers include a lack of culturally competent providers in rural areas (Hastings & Cohn, 2013). Researchers have also suggested that characteristics of rural areas, including low population density and a consequent lack of anonymity, may be barriers to seeking professional services (Flaskerud & Kviz, 1983; Fuller et al., 2000; Hill, 1986; Hill & Fraser, 1995). Individuals may be reluctant to be seen attending mental health services (Bachrach, 1983; Hill & Fraser, 1995; Johnson et al., 1997; Lambert & Hartley, 1998) and cultural values of stoicism and resilience may impede professional help-seeking as individuals feel that they should deal with problems on their own (Fuller et al., 2000). Overall, social stigma associated with mental illness may be higher in rural areas (Hoyt et al., 1997) and rural people may be reluctant to talk about 'sensitive' topics (Zanjani & Rowles, 2012).

Yet rural areas may also present unique opportunities as some evidence suggests that rural areas have greater social cohesion and stronger care-system connections because small-town residents are more likely to know each other (Welch & Welch, 2007, p. 486). Because specialty mental health services are less accessible in rural contexts, general practitioners, community organizations, schools, and other social resources are often vital in educating and caring for those suffering early psychosis.

With such challenges and opportunities in rural areas as a backdrop, there is a specific need to examine experiences of early psychosis, pathways to care, and experiences of services in rural areas. Research into first-episode psychosis care networks and systems has largely been undertaken in urban areas (Welch & Welch, 2007). In their systematic review of literature on early psychosis care provision in rural areas, Welch and Welch conclude that "overall rural mental health, and [early psychosis] in particular, is underserved and underresearched" (Welch & Welch, 2007, p. 489). Further, they note that: "there is no rigorous body of evidence to indicate best practice in the delivery of early psychosis services in rural areas, their needs and characteristics" (Welch & Welch, 2007, p. 490). The collaborative project between mental health researchers at Dartmouth College/ The Dartmouth Institute for Health Policy and Clinical Practice and the Vermont Department of Mental Health aimed to provide insight into the experiences and perspectives of multiple stakeholders – individuals with lived experience, family members, clinicians, peer specialists, and community leaders – related to early episode psychosis in the State of Vermont.

Project Summary

In 2014, the Vermont Department of Mental Health (DMH) received an increase in its annual Federal Mental Health Block Grant (MHBG) allocation to support "evidence-based programs that address the needs of individuals with early serious mental illness, including psychotic disorders." The Congressional language supporting this increase in funding states that, "The majority of individuals with severe mental illness experience their first symptoms during adolescence or early adulthood, and despite the existence of effective treatments, there are often long delays – years and sometimes decades – between the first onset of symptoms and when people receive help." The Vermont DMH plans to use the increased funding to support a multi-year initiative to adopt evidence-based interventions and treatment approaches for adolescents and young adults who are in the early stages of experiencing and struggling with psychosis (Early Episode Psychosis).

The Vermont DMH contracted with a team at the Dartmouth Institute for Health Policy and Clinical Practice to examine the perspectives and experiences of individuals with lived experience of Early Episode Psychosis, their family members, and service providers using survey and in-depth qualitative interviews. The insights gained from this project were used to develop recommendations for the State of Vermont to optimize resources in the provision of services for Early Episode Psychosis.

Methods

The project used qualitative interviews and a web-based survey to inquire into first-person perspectives regarding experiences of services, supports, and resources in the context of early episode psychosis. The project was submitted to the Dartmouth Committee for the Protection of Human Subjects and was determined to be a Quality Activity without a research component on March 25, 2016.

We conducted qualitative interviews with individuals with lived experience of early psychosis (n=3) and parents of individuals who had experienced early psychosis (n=2). We recruited participants using a variety of strategies. The project Advisory Board helped to identify community-based organizations with which we could partner for recruitment. In some cases, members of the Advisory Board liaised between the organization and the researchers to facilitate recruitment. In other cases, researchers led informational sessions at community organizations to build awareness of, and interest in, the project. Information posters were also created and made available to community organizations via the project Advisory Board so that interested individuals could self-refer to the project.

We also interviewed key informants (n=3) who had expertise and experience in social services, community psychiatry, and peer-led mental health services. We recruited key informants via local informal networks.

Interviews were 45-60 minutes long and were conducted in-person or by telephone/Skype depending on the preference of the participant. Interviews were audio-recorded and transcribed. A qualitative mental health researcher led interviews with participants with lived experience and parents using a semi-structured interview guide tailored for each stakeholder group. We used semi-structured interviews because they are useful for gaining perspectives on a set of similar topics across participants while also allowing for flexibility and probing to elicit rich narratives of experience. We created the interview guides through a collaborative process with the project Advisory Board involving mental health researchers, clinicians, and individuals with lived experience. We revised the interview guides multiple times in response to Advisory Board feedback. Key informant interviews were less structured and focused on the participant's relevant professional experience in relation to early psychosis. Detailed notes were taken to document key informant interviews.

We analyzed qualitative data using an inductive approach to identify prominent and salient themes within the data (Braun & Clarke, 2006). Transcripts and notes were reviewed by the qualitative researcher to develop a code book. Qualitative coding is a systematic process of reducing large volumes of text-based data into meaningful units by labeling portions of text with relevant categories and concepts (Charmaz, 2006). We developed codes based on the domains and questions in the interview guides as well as codes that emerged through our review of the data. A research assistant coded the data using the code book with supervision and quality checks by the qualitative researcher. The qualitative researcher then reviewed the coded data to develop memos, which synthesize and summarize key ideas, concepts, and patterns across the dataset to distill the core themes reported.

We also administered an anonymous web-based survey (N=38) that was open to individuals with lived experience and family members. The survey was programmed into the survey software program, Qualtrics, and was accessible on either computers or smart phones to mitigate access barriers. Two versions of the survey were developed: one for individuals with lived experience and one for family members/caregivers. Members of the Advisory Board sent emails to community organizations to invite individuals to participate in the survey. Analysis of the survey data is preliminary and we will report frequencies for key items.

Results

Delays and Difficulty Accessing Mental Health Services:

Families reported challenges accessing mental health services during times of crisis. Mental health workforce shortages in rural areas may exacerbate barriers to access. One family member reported a long wait time for an initial take evaluation for her young adult child:

> And I tried to make an appointment to have him see a psychiatrist at our designated agency. And I was going to have to wait for 3 months. But in their defense, I was trying to [accommodate my work schedule.] So that made the wait longer. But that was just to see an intake worker. (Family 01)

Accessing needed services was sometimes made more challenging because of issues of confidentiality with adult child, parents, and health care providers:

> So he was terribly ill. And I couldn't get him treatment. He was a legal adult. And so the huge huge issue with psychiatry refusing to speak to parents, and that's a theme. The story goes on and on. But a recurrent theme is, many psychiatrists without given consent [won't speak to parents.] (Family 01)

Small, rural social networks also posed a barrier to accessing mental health providers:

> And after something like a month, [the receptionist] got back to me and says, "He won't see your son. It's against his policy to see family members of area physicians." So then I lost time. (Family 01)

As the quote above illustrates, the challenge of having fewer mental health professionals in rural areas may be compounded when providers maintain rigid boundaries in a social context characterized by a lack of anonymity.

Challenges with Current Mental Health Services

Some participants described negative experiences with mental health professionals who were dismissive of their concerns:

> And one [psychiatrist] was utterly dismissive of me… Part of the problem was a child psychiatrist refusing to take a mother seriously. I think they were in denial. Thinking "Oh this beautiful looking child from a good home."… He had schizophrenia. I still don't understand why they were so inept. (Family 01)

Similarly, this participant with lived experience felt that mental health professionals did not provide services that reflected the severity of the person's experience:

> I don't feel like I was taken very seriously. Just referred to a med management when I was released, counseling. I think that I was very, very close to a full psychotic break. (Lived Exp 03)

The inexact nature of identification and diagnosis in psychiatric care was another source of frustration among participants:

> there's not one test to find out or to diagnose mental illness. There's not one test. As much as they say you have a chemical imbalance in the brain, I have never seen one test to corroborate that. You take this drug. Now do a test and do blood work and tell me what changed and what you corrected. There is absolutely nothing. It really gets under my skin. (Family 02)

In some cases, diagnostic ambiguity led to psychiatrists "missing" or "avoiding" a diagnosis of schizophrenia:

> When I asked the different psychiatrists if they thought it was childhood-onset schizophrenia, they were like politicians and somehow managed to avoid answering that question. (Family 01)

Many participants identified challenges related to psychotropic medications. Echoing frustrations with the uncertainty of psychiatric diagnosis, participants noted similar challenges related to inexact pharmaceutical treatment in psychiatry. One family member imagined a similar "trial and error" process playing out with other chronic conditions to underscore his view that inexact treatment with medication is "wrong":

> "You have diabetes? Well, let me give you this heart medication and see if that works. That didn't work. Let me try arthritic medicine. That didn't work either. Maybe insulin will do it. Here you go." That's what we're doing with our kids and it's wrong. (Family 02)

A participant with lived experience also critiqued the broad application of antipsychotic medication across conditions:

> The chemists, they need to continue working on more targeted psychiatric meds. This whole cure-all, give everyone who's slightly delusional or psychotic or borderline an antipsychotic, might not necessarily be the right thing. (Lived exp 03)

Polypharmacy – the use of multiple psychotropic medications – was also identified as a problem in current mental health services:

> They wanted to give him four drugs right away. And that's then I went into my diatribe and said, "You might see a thousand people. This is my one son. You got a lot of nerve just throwing out here four drugs because he might get diabetes…. That's what was done. Overlapping time when the Risperdal was still in his system and he was taking Zyprexa. And boy, there was a time when he was drooling. I was really upset. (Family 02)

Similarly, participants were critical of what they viewed as a tendency toward overmedication within psychiatric practice:

> Yeah, I feel like the tendency towards medicating and sometimes overmedicating is raging headline. I not only have my own experience, but, I mean, a lot of my peers have been through the mental health system, various diagnoses and areas of medication issues. (Lived exp 03)

Participants' often negative experiences with medications led some to develop strategies to minimize medication:

> It's been a lot of work really to navigate my mental illness with a minimal of drugs. Just some of the logic behind the whole medication culture just doesn't sit well with me. Some of the medications themselves are more potent than I need. So, I'm trying to get by on the minimal amount of outside influence as possible. (Lived exp 03)

Some participants expressed a desire for treatments beyond medication:

> I just really wish that there was a little more variety in the options for therapy. (Lived exp 03)

More broadly, negative experiences in the mental health system led to a fierce desire for autonomy among some participants:

> Basically, told them what they wanted to hear. That's sort of the way I dealt with psychiatric hospital staff from then on out. Just tell them what they want to hear, get out, you're back into the world. I'll deal with my own shit my own way. (Lived exp 03)

Other Challenges in the Context of Early Episode Psychosis

Stakeholder interviews revealed additional challenges within the context of early episode psychosis. Educators were challenged by disruptive behaviors and often did not how to respond appropriately:

> the educators and they have a guidance counselor but she didn't know what to do with him, so they just kept suspending him, because of the disruption… So he spent about 20% of high school at home, not in school, suspension, and we had to go to work! And he'd kind of isolate and play computer games and do math. And the problems all escalated, sort of escalated. (Family 01)

Several stakeholders also spoke to the problematic interface between the spheres of mental health services and the criminal justice system. This family member recounted the frustrations of navigating complex criminal justice processes while trying to get her son needed services:

> [My son] had this whole series of criminal proceedings. The prosecutor charged him, back and forth, drive back and forth, in shackles. Just sick, sick sick sick. These court proceedings. And finally, after two or three months, I finally after many attempts got a lawyer who got the charges dropped to insanity. … Then, there's going to be more court proceedings. I'm confused: Why? I thought he was clear, the insanity defense, why can't you treat him now? …Then he had to go to the hearing for involuntary [treatment]… I tried to talk him in to taking medications and he wouldn't. And so finally after another couple months, I finally get [him] voluntarily treated. And now he's on his 19th admission and it's just more and more and more. (Family 01)

Positive Experiences in Current Mental Health Services

Interviews across stakeholder groups also provided insight into positive dimensions of care within current mental health services. Having a mental health provider who respected autonomy over treatment decisions was important:

> [Our psychiatrist] is absolutely phenomenal. She always backed off. Always. But consistently brought up things that she would like to see [my son] do. She always brought them up and it was up to [him] to take it or leave it. And she respected that. That really I think made an impression on [him]. That he would be able to say things freely, even if it wasn't what she wanted to hear. In the long run, he would determine his own outcome. … She handled him very well. Never confrontational. Only gave him all the options and all the alternatives and just kept on presenting those things. And when the time is right, hopefully he'll pick one. (Family 02)

Similarly, this individual with lived experience described positive experiences with psychiatrists who worked collaboratively to address medication concerns:

> I've had some good psychiatrists. Who were pretty understanding of my issues with medication side effects and they were open to getting, taking little, at my request. If something wasn't working or the side effects were too heavy for me, they were pretty open to changing things up a little. (Lived exp 03)

Beyond the patient-provider dyad, positive experiences were also facilitated by broader systems. In particular, participants spoke to the need for coordinated care and communication between systems:

> We've got a whole team there. People that wrote up the admission thing for when [name] started to attack us, back on September 11th. That's when things really went to hell in a handcart. And they did all the write up. And they took care of all the contacting the police about picking him up and getting the court order and all of that. All in one day. Because they already had the information at that point. They'd been working with us. (Family 01)

Several individuals also spoke specifically to a perceived shift in the culture of mental health treatment toward greater involvement of the family. Open Dialogue and NAMI family psychoeducation were both mentioned specifically as positive experiences:

> After our Open Dialogue with some people that [the psychiatrist] facilitated, which was very interesting. And [our son] didn't participate, at least not verbally, but he was there to listen. And suddenly, he did improve. It was really interesting. He started to communicate a little bit more. Not in the meetings, but outside the meetings. Which just shows the importance of just having a social network. (Family 02)

> One of the biggest things was the NAMI Family to Family, the 12 week course. That was huge. Especially for schizophrenia, to have empathy for that illness. (Family 02)

Supports and "Key Ingredients" for Recovery Outside of the Mental Health System

Participants' narratives also spoke to broader social and structural supports that were key to supporting mental health and facilitating recovery. Strong, unconditional family support was one such element:

> We've been through what a lot of people, parents, have been through. We always said to him, "No matter what, we're not going to lie to you and we'll always have your back. No matter what happens." That doesn't mean we agree with him, but we just reinforce the idea that we're always going to be your friend and that will never change. Those are just words, but if you stick with that through all your crises, it just starts to ... You plant that seeds and then you see it through to fruition. I think he's at a place where he knows that he can trust us. (Family 02)

Similarly, a network of supportive friends and educational supports was key to wellbeing:

> Well, definitely advocacy was really key for me… close ties with teachers at my high school, having a very good, supportive small group of friends. (Lived exp 04)

Other participants expressed the importance of structural supports, including employment and housing:

> Well, I recently got a really good job and that tends to ground me when I'm working, keep me busy. It helps with the depressant side of things. It helps my self-worth and that tends to help the depressed side of things. I'm doing reasonably well. I pretty much quit drinking all together. So, I'm not triggering episodes with alcohol. (Lived exp 03)
>
> It hit me very very young like how important housing is and being able to secure that (Lived exp 04)

Finally, faith and complementary/alternative healing practices were viewed by some as important facilitators of recovery:

> Well, I think that maybe, actually practicing my religion like I used to would be helpful. Thinking of more meditation, helpful. I mean, I do genuinely believe that the mind can do a great deal to heal itself. I've had a lot of success in the past when I was younger with managing my symptoms through alternative medicine, or meditative states, and keeping dream journals, things like that. (Lived exp 03)

Recommendations: Summary

1. Change the culture of mental health services

Stakeholders expressed the need for significant changes within the culture of mental health services to better meet the needs of young people experiencing early psychosis. Currently, mental health services are too often experienced as haphazard and unhelpful (at best) or dehumanizing. Distilling views from across the interviews, a collective vision emerged of mental health services that would promote: (1) accepting/non-judgmental interactions; (2) humility among healthcare providers; (3) a team-based/coordinated approach to care; (4) trauma-informed care; (5) meaningful involvement of family members, especially early in the experience; (6) access to psychosocial treatments; (7) shared decision making around medications and avoidance of polypharmacy and overmedication; and (8) respect for autonomy of young person.

2. Create more intentional and humane connections between the mental health and criminal justice systems

It was clear that some of the most dehumanizing and distressing experiences among stakeholders occurred at the interface between the mental health and criminal justice systems. There is a clear need to support innovative strategies, including mental health courts, to promote more humane and effective social responses when young people are experiencing a crisis.

3. Improve access to a range of supports for young people

The diverse experiences of young people who may be experiencing early psychosis call for a range of supports that can be easily accessed and address a full spectrum of needs. The types of services/supports recommended by stakeholders included: housing, employment, and education; wellness (e.g., exercise and nutrition); mental health services; and peer services. The interviews underscored the importance of recognizing the need for supports for those who may not identify as having a mental illness. In this vein, one key informant noted the need for "neutral points of entry" within communities to provide a gateway into consistent, available supports (housing, community spaces) that meet young people "where they are" and do not presume a medicalized viewpoint on experiences.

4. Provide education and support for families and communities

Supporting young people and families impacted by early psychosis in meaningful ways occurs within a broader social context. Stakeholders expressed the need for schools and communities to have greater awareness of mental health and young people with the goals of promoting more humane and supportive responses to complex experiences, reducing stigma, and creating bridges for young people to needed supports/services.

References:

Adams, S.J., et al. (2006) Differential effectiveness of depression disease management for rural and urban primary care patients. *The Journal of Rural Health,* 22(4):343-350.

Addington, J., van Mastrigt, S., Hutchinson, J., Addington, D. (2002) Pathways to care: help seeking behavior in first episode psychosis. *Acta Psychiatrica Scandinavica,* 106:358-364.

Boydell, K. M. Gladstone, B.M., Volpe, T. (2006) Understanding help seeking delay in the prodrome to first episode psychosis: A secondary analysis of the perspectives of young people. *Psychiatric Rehabilitation Journal*, 30(1): 54-60.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3 (2). pp. 77-101.

Charmaz K. (2006) *Constructing Grounded Theory*, 2nd Edition. Thousand Oaks, Sage Publications.

Eberhardt, M.S., and Pamuk, E.R. (2004) The importance of place of residence: examining health in rural and nonrural areas. *American Journal of Public Health,* 94(10):1682-1686.

Edwards, J., Harris, M.E., and Bapat, S. (2005) Developing services for first-episode psychosis and the critical period. *British Journal of Psychiatry,* 187 (suppl. 48):s91-s97.

Flaskerud, J. H., & Kviz, F. J. (1983). Rural attitudes toward and knowledge of mental illness and treatment resources. *Psychiatric Services*, *34*(3), 229-233.

Fuller, J., Edwards, J., Procter, N., & Moss, J. (2000). How definition of mental health problems can influence help seeking in rural and remote communities. *Australian Journal of Rural Health*, *8*(3), 148-153.

Hastings, S. L., & Cohn, T. J. (2013). Challenges and opportunities associated with rural mental health practice. *Journal of Rural Mental Health*, *37*(1), 37.

Hauenstein E. J. & Peddada, S. D. (2007). Prevalence of major depressive episodes in rural women using primary care. *Journal of health care for the poor and underserved*, *18*(1), 185-202.

Hauenstein, E.J., et al. (2007) Rurality and mental health treatment. *Administration and Policy in Mental Health and Mental Health Services Research*, 34(3):255-267.

Hill, C.E. (1986). Folk beliefs and practices. In L.R. Jones and R.R. Parlour, (Eds.). *Psychiatric Services for Underserved Rural Populations*, 27–36. New York, NY: Brunner/Mazel Publishers.

Hill, C. E., & Fraser, G. J. (1995). Local knowledge and rural mental health reform. *Community mental health journal*, *31*(6), 553-568.

Hirsch, J. K., & Cukrowicz, K. C. (2014). Suicide in rural areas: An updated review of the literature. *Journal of Rural Mental Health*, *38*(2), 65-78.

Hoyt, D. R., Conger, R. D., Valde, J. G., & Weihs, K. (1997). Psychological distress and help seeking in rural America. *American Journal of Community Psychology*, *25*(4), 449-470.

Johnsen, M. C., Morrissey, J. P., Calloway, M. O., Fried, B. J., Blank, M., & Starrett, B. E. (1997). Rural mental health leaders' perceptions of stigma and community issues. *The Journal of Rural Health*, *13*(1), 59-70.

Kessler, R.C., Amminger, G.P., Aguilar-Gaxiola, S. et al. (2007) Age of onset of mental disorders: a review of recent literature. *Current Opinion Psychiatry*, 20:359-364.

Lambert, D., & Hartley, D. (1998). Linking primary care and rural psychiatry: where have we been and where are we going? *Papers on Rural Psychiatry*,*49*(7).

MacDonald, K., Fainman-Adelman, N., Anderson, K.K. and Iyer, S.N. (2018) Pathways to mental health services for young people: a systematic review. *Social Psychiatry and Psychiatric Epidemiology*, DOI: 10.1007/s00127-018-1578-y

McGorry, P.D., Killackey, E., and Yung, A.R. (2007) Early intervention in psychotic disorders: detection and treatment of the first episode and the critical early stages. *Medical Journal of Australia*, 187(7):S8-S10.

Marshall, M., Lewis, S., Lockwood, A., et al. (2005) Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review. *Archives of General Psychiatry*, 62:975-983.

Paulozzi, L.J., et al. (2012) CDC grand rounds: prescription drug overdoses-a US epidemic. MMWR. *Morbidity and Mortality Weekly Report* 61(1):10.

Perkins, D.O., Gu, H., Boteva, K., Lieberman, J.A. (2005) Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: a critical review and meta-analysis. *American Journal of Psychiatry*, 162:1785-1804.

Simon, G.E., Coleman, K.J., Yarborough, B.J., Operskalski, B., Hunkeler, E., Lynch, F.L., Carrell, D., Beck., A. (2017) Incidence and presentation of first-episode psychosis in a population-based sample. *Psychiatric Services*, 68(5):456-461.

Thomas, D., Macdowell, M. and Glasser, M. (2012) Rural mental health workforce needs assessment–a national survey. *Rural Remote Health*, 12(4):2176-2176.

Wang, P. S., Lane, M., Olfson, M., Pincus, H. A., Wells, K.B., Kessler, R. C. (2005). Twelve-month use of mental health services in the united states: Results from the national comorbidity survey replication. *Archives of General Psychiatry, 62*(6), 629-640.

Zanjani, F., & Rowles, G. D. (2012). “We don't want to talk about that”: Overcoming barriers to rural aging research and interventions on sensitive topics. *Journal of rural studies*, *28*(4), 398-405.

APPENDIX F | INTERACTIVE COST TOOL RESULTS

Estimates of Number of First Episode Psychosis (FEP) Teams Needed and Associated Costs, in Vermont

		Low Estimate	High Estimate	Medium Estimate #1	Medium Estimate #2
1	Population size (2023 Census)	647,464	647,464	647,464	647,464
2	FEP incidence per year (V)	0.0003	0.0003	0.00025	0.0002
3	# of incident cases per year (Population size*Incidence)	194	194	162	129
4	Fraction of incident cases approached (V)	0.2	0.5	0.333	0.25
5	# of incident cases approached	39	97	54	32
6	Fraction agreeing to enter services (V)	0.5	0.75	0.5	0.6
7	# total active individuals	19	73	27	19
8	# active individuals per team (V)	30	35	35	30
9	# months in treatment (V)	18	24	18	22
10	# new individuals each team can take/month (active cases per team/months in treatment)	1.667	1.458	1.944	1.364
11	# new individuals each team can take/year (new individuals per month*12)	20	18	23	16
12	**# teams needed statewide (# active individuals/new individuals each team can take per year)**	**1.0**	**4.2**	**1.2**	**1.2**
	# clients taken per week in start-up	**1**	**1**	**1**	**1**
	# weeks to full capacity	**30**	**35**	**35**	**30**
	# months to full capacity	**7.5**	**8.75**	**8.75**	**7.5**
13	**Population size to support 1 team (population size/number of teams)**	**666,667**	**155,556**	**560,561**	**545,455**
14	**Salary costs per FEP team per year**[1]	**466,615**	**466,615**	**466,615**	**466,615**
15	**Total Costs per FEP team per year (including 36% fringe and 15% indirect)**	**729,786**	**729,786**	**729,786**	**729,786**
16	Cost per client (Total salary costs/clients servded per team)	24,326	20,851	20,851	24,326
17	Cost per team per initial year (As calculated on cost worksheet)	$531,122	$493,474	$493,474	$531,122
18	Staffing cost per team per year - at capacity (Cost per client per year)x(N clients per team)	$729,786	$729,786	$729,786	$729,786
19	**Total cost per year (# teams*cost per team at capacity)**	**$708,765**	**$3,037,565**	**$842,924**	**$866,268**
20	**Note: Source of Population Data - 2023 Census**				
21	**Note: (V) indicates variable to be estimated; altering the variables changes the number of estimated teams needed and associated costs per year**				
22	[1] Staffing estimates assume FEP team leader (1FTE at $85,000 annual salary), SEE specialist (1FTE at $68,011), Psychotherapist (1FTE at $73,364), Psychiatrist (.3FTE at $140,400), Peer Suport Provider (1FTE at $43,680) , Case Manager (1FTE at $56,160)				

Adapted from JL Humensky, LB Dixon, SM Essock, Center for Practice Innovations, New York State Psychiatric Institute, 1051 Riverside Dr, New York, NY 10032

Annual cost of each team				
	Role	**% Time**	**Annual Salary Rate**	**Cost**
1	FEP Team Leader	100%	85,000	$85,000
2	SEE Specialist	100%	68,011	$68,011
3	Psychotherapist	100%	73,364	$73,364
4	Psychiatrist	30%	468,000	$140,400
5	Peer Support Specialist	100%	43,680	$43,680
6	Case Manager	100%	56,160	$56,160
7	Total salary for team			$466,615
8	Fringe			36%
9	Total + Fringe			$634,596
10	Indirect			15%
11	Total Cost			$729,786
12	Cost per Client (30 client team)			24,326
13	Cost per client (35 client team)			$20,851
14	**Cost per initial year (based on estimate of 30 total active clients per team and 4 new clients per month in start-up)**			
15	**Month**	**#new clients per month**	**Cumulative clients**	**Annual cost of new clients**
16	1	4	4	$97,305
17	2	4	8	$89,196
18	3	4	12	$81,087
19	4	4	16	$72,979
20	5	4	20	$64,870
21	6	4	24	$56,761
22	7	4	28	$48,652
23	8	2	30	$20,272
24	9	0	30	$0
25	10	0	30	$0
26	11	0	30	$0
27	12	0	30	$0
28	Total cost of initial year			$531,122
28	**Cost per initial year (based on estimate of 35 total active clients per team and 4 new clients per month in start-up)**			
29	Month	#new clients per month	Cumulative clients	Annual cost of new clients
30	1	4	4	$83,404
31	2	4	8	$76,454
32	3	4	12	$69,503
33	4	4	16	$62,553
34	5	4	20	$55,603
35	6	4	24	$48,652
36	7	4	28	$41,702
37	8	4	32	$34,752
38	9	3	35	$20,851
39	10	0	35	$0
40	11	0	35	$0
41	12	0	35	$0
42	Total cost of initial year			$493,474

Adapted from JL Humensky, LB Dixon, SM Essock, Center for Practice Innovations, New York State Psychiatric Institute, New York, NY 10032

ENDNOTES

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[1] *Guidance for Revision of the FY2016–2017 Block Grant Application for the New 10 Percent Set-Aside* Substance Abuse and Mental Health Services Administration, Rockville, MD, 2016. https://www.samhsa.gov/sites/default/files/mhbg-5-percent-set-aside-guidance.pdf

[2] This explanation of the continuum theory of psychosis borrows heavily from Stanford Medicine PEPPNET. See https://med.stanford.edu/peppnet/whoweare/earlypsychosis.html.

[3] Breitborde NJ, Srihari VH, Woods SW. Review of operational definition for first-episode psychosis. *Early Interv Psychiatry*. 2009;3:2590265. Accessed March 3, 2023. https://doi.org/10.1111/j.1751-7893.2009.00148.x; Substance Abuse and Mental Health Services Administration. First-Episode Psychosis and Co-Occurring Substance Use Disorders. Publication No. PEP19-PL-Guide-3: National Mental Health and Substance Use Policy Laboratory. SAMHSA.gov; 2019. Accessed February 14, 2024. https://store.samhsa.gov/sites/default/files/pep19-pl-guide-3.pdf

[4] Heinssen R, Goldstein A, Azrin, S. Evidence-based treatments for first episode psychosis: components of coordinated specialty care. National Institute on Mental Health; 2014. Accessed February 14, 2024. https://www.nimh.nih.gov/sites/default/files/documents/health/topics/schizophrenia/raise/evidence-based-treatments-for-first-episode-psychosis.pdf

[5] National Institute on Mental Health. Recovery after an Initial Schizophrenia Episode (RAISE). National Institute on Mental Health; 2022. Accessed February 14, 2024. https://www.nimh.nih.gov/research/research-funded-by-nimh/research-initiatives/recovery-after-an-initial-schizophrenia-episode-raise

[6] Anderson, K. K., Norman, R., MacDougall, A., Edwards, J., Palaniyappan, L., Lau, C., & Kurdyak, P. (2018). Effectiveness of Early Psychosis Intervention: Comparison of Service Users and Nonusersin Population-Based Health Administrative Data. The American Journal of Psychiatry, 175(5), 443–452. https:// doi. org/ 10. 1176/ appi. ajp. 2017. 17050 480; Csillag, C., Nordentoft, M., Mizuno, M., Jones, P. B., Killackey, E., Taylor, M., Chen, E., Kane, J., & McDaid, D. (2016). Early intervention services in psychosis: From evidence to wide implementation. Early Intervention in Psychiatry, 10(6), 540–546. https:// doi. org/ 10. 1111/ eip. 12279

[7] Bird, V., Premkumar, P., Kendall, T., Whittington, C., Mitchell, J. & Kuipers, E. (2010). Early intervention services, cognitive-behavior therapy and family intervention in early psychosis: systematic review. British Journal of Psychiatry, 197, 350-356.

[8] McGorry, P. D., Edwards, J., Mihalopoulos, C., Harrigan, S. M., & Jackson, H. J. (1996). EPPIC: An evolving system of early detection and optimal management. Schizophrenia Bulletin, 22(2), 305–326. https://doi.org/10.1093/schbul/22.2.305

[9] Radhakrishnan, M., McCrone, P., Lafortune, L., Everard, L., Fowler, D., Amos, T., Freemantle, N., Singh, S. P., Marshall, M., Sharma, V., Lavis, A., Jones, P. B., & Birchwood, M. (2018). Cost-effectiveness of early intervention services for psychosis and fidelity to national policy implementation guidance. Early Intervention in Psychiatry, 12(4), 747–756. https://onlinelibrary.wiley.com/doi/10.1111/eip.12481

[10] Breitborde, N. J. K., & Moe, A. M. (2017). Early Intervention in Psychosis in the United States: From Science to Policy Reform. *Policy Insights from the Behavioral and Brain Sciences, 4*(1), 79–87. https://doi.org/10.1177/2372732216683965

[11] Lynch, S., McFarlane, W. R., Joly, B., Adelsheim, S., Auther, A., Corn- blatt, B. A., Migliorati, M., Ragland, J. D., Sale, T., Spring, E., Calkins, R., Carter, C. S., Jaynes, R., Taylor, S. F., & Downing, D. (2016). Early detection,

---

intervention, and prevention of psychosis program: Community outreach and early identification at six US sites. *Psychiatric Services, 67*(5), 510–516. https://doi.org/10. 1176/appi.ps.201300236

[12] Sage, M. G. (Ed.). (2019). *EASA team manual*. Portland

[13] Uzenoff, S. R., Penn, D. L., Graham, K. A., Saade, S., Smith, B. B., & Perkins, D. O. (2012). Evaluation of a multi-element treatment center for early psychosis in the United States. *Social Psychiatry and Psychiatric Epidemiology, 47*(10), 1607–1615. https://doi. org/10.1007/s00127-011-0467-4

[14] Kane, J. M., Robinson, D. G., Schooler, N. R., Mueser, K. T., Penn, D. L., Rosenheck, R. A., Addington, J., Brunette, M. F., Correll, C. U., Estroff, S. E., Marcy, P., Robinson, J., Meyer-Kalos, P. S., Gottlieb, J. D., Glynn, S. M., Lynde, D. W., Pipes, R., Kurian, B. T., Miller, A. L., … Heinssen, R. K. (2016). Comprehensive versus usual community care for first-episode psychosis: 2-year outcomes from the NIMH RAISE early treatment program. *American Journal of Psychiatry, 173*(4), 362–372. https://doi.org/10.1176/appi. ajp.2015.15050632

[15] Kane, J. M., Robinson, D. G., Schooler, N. R., Mueser, K. T., Penn, D. L., Rosenheck, R. A., Addington, J., Brunette, M. F., Correll, C. U., Estroff, S. E., Marcy, P., Robinson, J., Meyer-Kalos, P. S., Gottlieb, J. D., Glynn, S. M., Lynde, D. W., Pipes, R., Kurian, B. T., Miller, A. L., … Heinssen, R. K. (2016). Comprehensive versus usual community care for first-episode psychosis: 2-year outcomes from the NIMH RAISE early treatment program. *American Journal of Psychiatry, 173*(4), 362–372. https://doi.org/10.1176/appi. ajp.2015.15050632

[16] Kane, J. M., Robinson, D. G., Schooler, N. R., Mueser, K. T., Penn, D. L., Rosenheck, R. A., Addington, J., Brunette, M. F., Correll, C. U., Estroff, S. E., Marcy, P., Robinson, J., Meyer-Kalos, P. S., Gottlieb, J. D., Glynn, S. M., Lynde, D. W., Pipes, R., Kurian, B. T., Miller, A. L., … Heinssen, R. K. (2016). Comprehensive versus usual community care for first-episode psychosis: 2-year outcomes from the NIMH RAISE early treatment program. *American Journal of Psychiatry, 173*(4), 362–372. https://doi.org/10.1176/appi. ajp.2015.15050632

[17] Rosenheck, R., Leslie, D., Sint, K., Lin, H., Robinson, D. G., Schooler, N. R., Mueser, K. T., Penn, D. L., Addington, J., Brunette, M. F., Correll, C. U., Estroff, S. E., Marcy, P., Robinson, J., Severe, J., Rupp, A., Schoenbaum, M., & Kane, J. M. (2016). Cost-effective- ness of comprehensive, integrated care for first episode psychosis in the NIMH RAISE Early Treatment Program. *Schizophrenia Bulletin, 42*(4), 896–906. https://doi.org/10.1093/schbul/sbv224

[18] DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, "Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis," Nev Jones, Killington Grand Hotel, Killington, VT, October 19, 2023

[19] DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, "Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis," Nev Jones, Killington Grand Hotel, Killington, VT, October 19, 2023

[20] Dixon LB, Goldman HH, Bennett ME, et al: Implementing coordinated specialty care for early psychosis: the RAISE Connection Program. Psychiatric Services 66:691-698, 2015. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5637730/pdf/nihms692509.pdf

[21] DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, "Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis," Nev Jones, Killington Grand Hotel, Killington, VT, October 19, 2023

[22] *Guidance for Revision of the FY2016–2017 Block Grant Application for the New 10 Percent Set-Aside* Substance Abuse and Mental Health Services Administration, Rockville, MD, 2016. https://www.samhsa.gov/sites/default/files/mhbg-5-percent-set-aside-guidance.pdf

[23] Guidance for Revision of the FY2016-2017 Block Grant Application for the new 10 percent set-aside, February 8, 2016, Substance Abuse and Mental Health Services Administration.

---

[24] DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, "Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis," Nev Jones, Killington Grand Hotel, Killington, VT, October 19, 2023

[25] *American Psychiatric Association. (2020). **The American Psychiatric Association Practice Guideline for the Treatment of Patients with Schizophrenia** (3rd ed.). American Psychiatric Association Publishing. https://doi.org/10.1176/appi.books.9780890424841*

[26] Heinssen R, Goldstein A, Azrin, S. *Evidence-based treatments for first episode psychosis: components of coordinated specialty care*. National Institute of Mental Health; 2014. Accessed October 7, 2023. https://www.nimh.nih.gov/sites/default/files/documents/health/topics/schizophrenia/raise/evidence-based-treatments-for-first-episode-psychosis.pdf; Substance Abuse and Mental Health Services Administration. *First-episode Psychosis and Co-Occurring Substance Use Disorders*. Publication No. PEP19-PL-Guide-3: National Mental Health and Substance Use Policy Laboratory. SAMHSA.gov; 2019. Accessed October 7, 2023. https://store.samhsa.gov/product/First-Episode-Psychosis-and-Co-Occurring-Substance-use-Disorders/PEP19-PL-Guide-3; National Institute on Mental Health. *Recovery after an Initial Schizophrenia Episode (RAISE)*. National Institute of Mental Health; 2022. Accessed October 7, 2023. https://www.nimh.nih.gov/research/research-funded-by-nimh/research-initiatives/recovery-after-an-initial-schizophrenia-episode-raise

[27] George P, Ghose SS, Goldman HH, O'Brien J, Daley TC, Dixon LB, Rosenblatt A. Growth of Coordinated Specialty Care in the United States With Changes in Federal Funding Policies: 2014-2018. Psychiatr Serv. 2022 Dec 1;73(12):1346-1351. doi: 10.1176/appi.ps.202100600. Epub 2022 Jun 16. Erratum in: Psychiatr Serv. 2022 Oct 1;73(10):1189. PMID: 35707858; PMCID: PMC9722492. Accessed February 20, 2023. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9722492/

[28] Kazandjian, M, Neylon K., Ghose S, George P, Masiakowski NP, Lutterman T, Rosenblatt A. State Snapshot 2021-2022: Early Psychosis Programming across the United States. Published November 2022. Accessed February 16, 2024. https://nationalepinet.org/wp-content/uploads/2022/12/EPINET_State_Snapshot_FINAL_508_COMPLIANT.pdf

[29] Henderson, M.D., Susan and Rizzo, M.D., Katherine (attendees), New England Mental Health Technology Transfer Center, "Navigating the Overlap: Psychosis and Bipolar Disorder," July 26, 2024

[30] March 6, 2023 Interview with Gary Scannevin, Supported Employment Trainer, OnTrackNY.

[31] Substance Abuse and Mental Health Services Administration: Coordinated Specialty Care for First Episode Psychosis: Costs and Financing Strategies. HHS Publication No. PEP23-01-00-003 Rockville, MD: Substance Abuse and Mental Health Services Administration, 2023.

[32] March 11, 2024, interview with George (Bud) Vana, M.D. Dr. Vana is a general pediatrician, adult psychiatrist, and child psychiatrist. He is a graduate of Harvard University. He completed medical school at the University of Vermont, and his residency and fellowship training at Brown University in Providence, Rhode Island. He has previously developed telehealth infrastructure with the Lumbee Tribal Health Center in Bellingham, Washington, as well as early psychosis programming in tribal communities. He currently operates a telemedicine bridge clinic serving children needing short term intensive treatment in Vermont. His other professional interests include family-based psychiatry, Acceptance and Commitment Therapy, treatment of co-occurring disorders, and treatment of developmental disabilities in integrated medical and mental health care.

[33] State of Washington, New Journeys: Coordinated Specialty Care for first episode psychosis, January 28, 2020, at p. 8.

---

[34] Lynch, S. et al (2014). Early Detection, Intervention and Prevention of Psychosis Program: Community Outreach and Early Identification at Six U.S. Sites.

[35] Spectrum Youth and Family Services is a 54-yearold, tax-exempt, non-profit agency serving youth and their families in the Burlington and St. Albans areas.

[36] Substance Abuse and Mental Health Services Administration, FY23 Mental Health Block Grant Final Allotments, by State, https://www.samhsa.gov/grants/block-grants/mhbg-final-allotments, last accessed March 10, 2024.
[37] Humensky JL, Dixon LB, Essock SM. State mental health policy: an interactive tool to estimate costs and resources for a first-episode psychosis initiative in New York State. Psychiatr Serv. 2013 Sep 1;64(9):832-4. doi: 10.1176/appi.ps.201300186. PMID: 24026833.

[38] https://tinyurl.com/y42xr2vk

[39] The cost worksheet is included in Appendix F.

[40] Substance Abuse and Mental Health Services Administration: Coordinated Specialty Care for First Episode Psychosis: Costs and Financing Strategies. HHS Publication No. PEP23-01-00-003 Rockville, MD: Substance Abuse and Mental Health Services Administration, 2023, at p. 9.

[41] The inflation adjusted cost for the Excel interactive tool was calculated using the Consumer Price Index for All Urban Consumers (CPI-U), which according to the U.S. Bureau of Labor Statistics was 284.668 in January 2023 and was 309.498 in March 2024.

[42] The “Low Estimate” refers to assumptions of the number of incident cases approached (20%), the number of individuals agreeing to participate (50%), the number of active individuals on a team (30), and the number of months in treatment (18).

[43] The “High Estimate” refers to the assumptions of the number of incident cases approached (50%), the number of individuals agreeing to participate (75%), the number of active individuals on a team (35), and the number of months in treatment (24).

[44] Guidance for Revision of the FY2016-2017 Block Grant Application for the new 10 percent set-aside, February 8, 2016, Substance Abuse and Mental Health Services Administration.

[45] Shern, D. Financing Coordinated Specialty Care for First Episode Psychosis: A Clinician/Advocate’s Guide. SMI Advisor. American Psychiatric Association; 2020. Accessed March 1, 2024. https://smiadviser.org/knowledge_post/financing-coordinated-specialty-care-for-first-episode-psychosis-a-clinician-advocates-guide

[46] Centers for Medicare & Medicaid Services. *Early and Periodic Screening, Diagnostic, and Treatment*. Medicaid.gov. Accessed November 20, 2023. https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html

[47] Center for Medicaid & CHIP Services, National Institute of Mental Health, and Substance Abuse and Mental Health Services Administration. *Joint Informational Bulletin: Coverage of Early Intervention Services for First Episode Psychosis*. Medicaid.gov; October 2015. Accessed November 20, 2023. https://www.medicaid.gov/sites/default/files/Federal-Policy-Guidance/Downloads/cib-10-16-2015.pdf; Centers for Medicare & Medicaid Services. *Opportunities to Design Innovative Service Delivery Systems for Adults with a Serious Emotional Disturbance*. Medicaid.gov; November 2018. Accessed November 20, 2023. https://www.medicaid.gov/sites/default/files/federal-policy-guidance/downloads/smd18011.pdf
[48] Centers for Medicare & Medicaid Services’ (CMS’) Healthcare Common Procedure Coding System (HCPCS) Level II Final Coding, Benefit Category and Payment Determinations. *First Biannual (B1), 2023 HCPCS Coding Cycle,* at

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p. 9. Accessed March 1, 2024. https://www.cms.gov/files/document/2023-hcpcs-application-summary-biannual-1-2023-non-drug-and-non-biological-items-and-services.pdf

[49]Shern, D. Financing Coordinated Specialty Care for First Episode Psychosis: A Clinician/Advocate's Guide. SMI Advisor. American Psychiatric Association; 2020. Accessed March 1, 2024. https://smiadviser.org/knowledge_post/financing-coordinated-specialty-care-for-first-episode-psychosis-a-clinician-advocates-guide

[50] Substance Abuse and Mental Health Services Administration: Coordinated Specialty Care for First Episode Psychosis: Costs and Financing Strategies. HHS Publication No. PEP23-01-00-003 Rockville, MD: Substance Abuse and Mental Health Services Administration, 2023, at pp. 21 – 30.

[51] Child and Young Adult Mental Health Crisis Act (PA 101-0461, Sec. 30), 2019.

[52] State of Washington, New Journeys: Coordinated Specialty Care for first episode psychosis, January 28, 2020, at p. 8.

[53] Oluwoye O, Stiles B, Monroe-DeVita M, Chwastiak L, McClellan JM, Dyck D, Cabassa LJ, McDonell MG. Racial-Ethnic Disparities in First-Episode Psychosis Treatment Outcomes From the RAISE-ETP Study. Psychiatr Serv. 2018 Nov 1;69(11):1138-1145. doi: 10.1176/appi.ps.201800067. Epub 2018 Aug 28. PMID: 30152275; PMCID: PMC6395511. https://pubmed.ncbi.nlm.nih.gov/30152275/

[54] Tiffany Martinez, 2018 PIER Program Participant Panel, Bangor, Maine.

[55] Johnson KA, Guyer M, Öngür D, Friedman-Yakoobian M, Kline E, Carol E, Davis B, Keshavan M. Early intervention in psychosis: Building a strategic roadmap for Massachusetts. Schizophr Res. 2021 Mar;229:43-45. doi: 10.1016/j.schres.2021.01.026. Epub 2021 Feb 19. PMID: 33611222.

[56] DMH Conference 2023: Reshaping Mental Health Systems Through Integration -- A Statewide Symposium on Advancing the Mental Health System, "Coordinated Specialty Care and Other Best Practices for Early Episode Psychosis," Sandy Steingard, Killington Grand Hotel, Killington, VT, October 19, 2023

[57] Mueser KT, Meyer-Kalos PS, Glynn SM, Lynde DW, Robinson DG, Gingerich S, Penn DL, Cather C, Gottlieb JD, Marcy P, Wiseman JL, Potretzke S, Brunette MF, Schooler NR, Addington J, Rosenheck RA, Estroff SE, Kane JM. Implementation and fidelity assessment of the NAVIGATE treatment program for first episode psychosis in a multi-site study. Schizophr Res. 2019 Feb;204:271-281. doi: 10.1016/j.schres.2018.08.015. Epub 2018 Aug 20. PMID: 30139553; PMCID: PMC6382606.

[58] Carpenter-Song, Elizabeth, Torrey, John, Strickler, David, Drake, Robert E., "Vermont First-Episode Psychosis Evaluation Final Report, e.9.25.18 (DRAFT) at p. 2, which can be found in Appendix E.

[59] Alpern Z, Binshadler S, Oakley A. Anticipation dialogs in Vermont's system of mental healthcare: Sustaining the growth of a dialogic practice culture. Front Psychol. 2023 Mar 20;14:1084788. doi: 10.3389/fpsyg.2023.1084788. PMID: 37020919; PMCID: PMC10067615.

[60] Florence AC, Jordan G, Yasui S, Cabrini DR, Davidson L. "It Makes us Realize that We Have Been Heard": Experiences with Open Dialogue in Vermont. Psychiatr Q. 2021 Dec;92(4):1771-1783. doi: 10.1007/s11126-021-09948-1. Epub 2021 Aug 27. PMID: 34453270. https://pubmed.ncbi.nlm.nih.gov/34453270/

[61] Alpern Z, Binshadler S, Oakley A. Anticipation dialogs in Vermont's system of mental healthcare: Sustaining the growth of a dialogic practice culture. Front Psychol. 2023 Mar 20;14:1084788. doi: 10.3389/fpsyg.2023.1084788. PMID: 37020919; PMCID: PMC10067615.

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[62] March 7, 2023 Interview with Margaret (Greta) Spottswood, M.D., MPH. Dr. Spottswood is a board certified child and adult psychiatrist and VTCPAP Medical Program Director. She also works at a federally qualified health center supporting PCPs in their work with their younger patients. She graduated from University of Vermont College of Medicine and completed her Psychiatry Residency and Child and Adolescent Psychiatry Fellowship at the Cambridge Health Alliance.

[63] Substance Abuse and Mental Health Services Administration: First-Episode Psychosis and Co-Occurring Substance Use Disorders. Publication No. PEP19-PL-Guide-3 Rockville, MD: National Mental Health and Substance Use Policy Laboratory. Substance Abuse and Mental Health Services Administration, 2019.

[64] https://www.healthvermont.gov/alcohol-drugs/alcohol-drugs

[65] Mueser, K.T. & Gingerich, S. (2013). Treatment of co-occurring psychotic and substance use disorders. *Social Work and Public Health*, 28, 424-439. Ridgely, M.S., Goldman, H.H., & Willenbring, M. (1990). Barriers to the care of persons with dual diagnoses: organizational and financing issues, 16, 123-132.

[66] Betancourt, J.R., Green, A.R., & Carrillo, J.E. (2002). *Cultural competence in health care: Emerging frameworks and practical approaches* (Vol. 576). New York, NY: Commonwealth Fund, Quality of Care for Underserved Populations.

[67] Cheung, F.K., & Snowden, L.R. (1990).Community mental health and ethnic minority populations. Community Mental Health Journal, 26, 277-291. https://doi.org/10.1007/BF00752778

[68] Kelly, M, Howard, O, Smith, J (2007). Early intervention in psychosis: A rural perspective. *Journal of Psychiatric and Mental Health Nursing,* 14, 203 – 208. https://doi.org/10.1111/j.1365-2850.2007.01064.x