



Engaging individuals, families, and a community in early intervention of psychosis in rural Maine

SARAH LYNCH, LCSW SEPTEMBER 30, 2024



Vermont Coordinated Specialty Care Conference Hotel Champlain, Burlington, VT September 30, 2024 JOINTLY ACCREDITED PROVIDER
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Workshop #: 5 of 7 Engaging Individuals, Families, and a Community in Early Intervention of

Psychosis in Rural Maine

Planners: Vermont Department of Mental Health Staff

Speaker: Sarah Lynch, LCSW

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Vermont Coordinated Specialty Care Conference Hotel Champlain, Burlington, VT September 30, 2024



In support of improving patient care, this activity has been planned and implemented by The Robert Larner College of Medicine at the University of Vermont is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME) and the American Nurses Credentialing Center (ANCC), to provide continuing education for the healthcare team.

The University of Vermont designates this live activity for a maximum of 5.5 *AMA PRA Category 1 Credit*(s)TM. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This program has been reviewed and is acceptable for up to 5.5 Nursing Contact Hours.

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This activity was planned by and for the healthcare team, and learners will receive 5.5 Interprofessional Continuing Education (IPCE) credit for learning and change.

My "why" over 20 years

- Our current mental health system waits for people to prove a level of disability before offering more assertive, comprehensive treatment.
- Stigma influences funding and access.
- Key components of CSC model are not billable or available.
- We know how to provide good care that is coordinated, communitybased, and responsive to the feedback of young people and families.
- I'm inspired by all the young people and families I have worked with over many years that have used their voices to help with access for others.



PIER and Resilience First Episode Psychosis CSC Teams Funding: MHBG/Case Rate Pending

Sarah Lynch, LCSW, Program Dir Jennifer Wienckowski, Coord Jess McKenzie, Referral Spec

Barbara Bowman, LCSW Graham Botto, LCSW Benji Cashin, LMSW-CC Joyce Nadeau, LCSW

Eric Dodge, MHRTC, CM Mary Ross, MHRTC, Lead CM

Liisa Sloat, MA, CRC, ES/ES Sup Erick Schadler, PhD, ES/ES

Robert Kysela, MD Amy Mayhew, MD, MPH Elsie Moshimer, RN

Renee Stachmus, Family Peer Elias Peirce, Peer Supervisor Sameena Flinner, Peer Support PIER Community Hope and Resources for Psychosis (CHRP)

Stepped Care Model
Funding: 4 Year SAMHSA
Grant

Rebecca Jaynes, LCPC, Prog Supervisor Jennifer Collins, LCSW Su'di A Abdirahman, LMSW-CC Joyce Nadeau, LCSW Sarah Lynch, LCSW, Prog Dir

Daniel Semukanya, MHRTC, CM Liisa Sloat, MA, CRC, ES/ES Sup

Amy Mayhew, MD, MPH Elsie Moshimer, RN

Renee Stachmus, Family Peer Elias Peirce, Peer Supervisor TBD, Peer Support

Statewide Training and Technical Assistance Funding: MHBG

Sarah Lynch, LCSW, Program Dir Rebecca Jaynes, Prog Sup Kristen Woodberry, PhD, LCSW Amy Mayhew, MD, MPH Jennifer Wienckowski, Coord Jess McKenzie, Referral Spec

Mary Ross, MHRTC, Lead CM Liisa Sloat, MA, CRC, ES/ES Sup Elias Peirce, Peer Supervisor

> Early Psychosis Research Team (MHIR) Funding: Research and Philanthropy

Kristen Woodberry, PhD, LCSW, Research Scientist

Eb Bernier, RA Pete Rosencrans, PhD, PostDoc Merelise Ametti, PhD, PostDoc

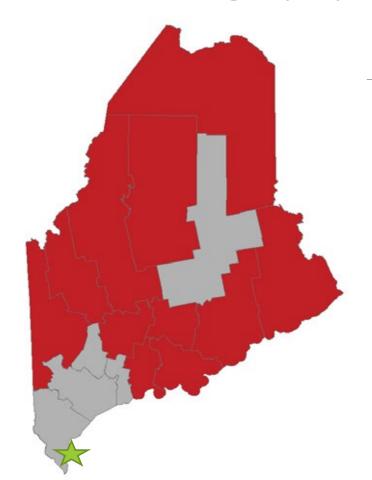


Today's Agenda

- 1) Rural state/regional collaboration. Sharing resources and experience.
- 2) Leveraging youth and parent lived experience to engage rural youth and families.
- 3) Hybrid in person/telehealth model to engage a broad geographic region and different preferences for engagement.
- 4) Power of CBTp and Multifamily Group model.
- 5) Describe trainings offered statewide.



Maine Geography and Demographics



50% of Maine's land area is almost completely uninhabited.

Maine has an estimated pop of 1,340,825.

40.8% live in one of Maine's 11 rural counties.

The poverty rate in rural Maine is 12.2% (9.6% in urban).

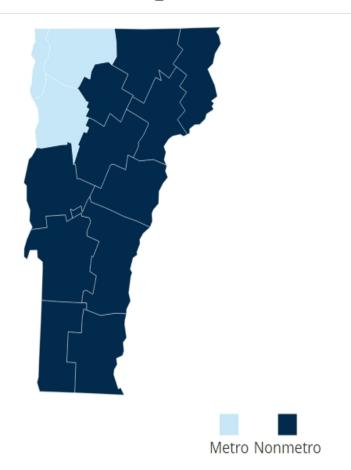
7.2 % of the rural population has not completed high school.

■ RURAL COUNTIES ■ URBAN COUNTIES



Vermont Geography and Demographics – half the population of Maine

Vermont Nonmetro Population



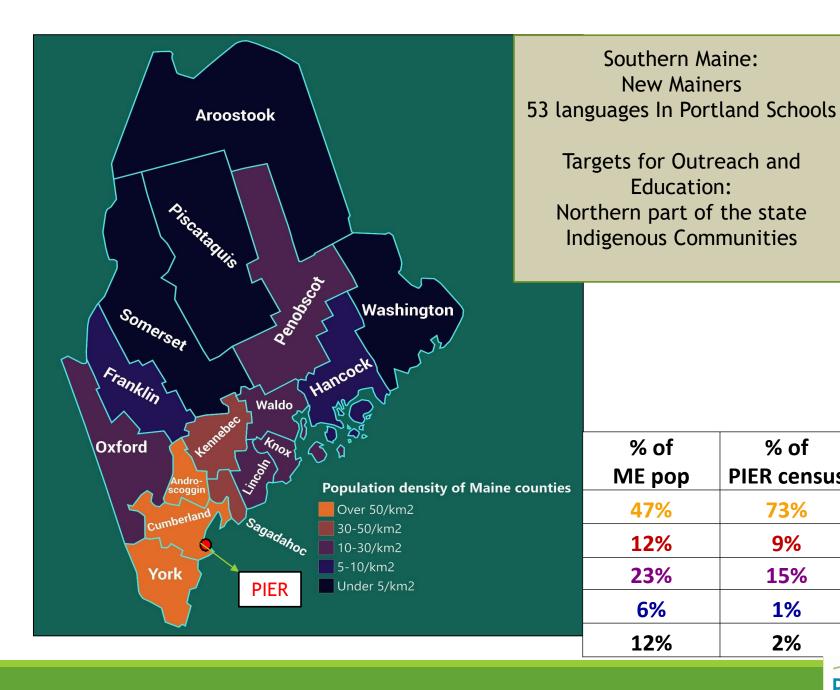
643,816

Estimated population

418,071 (64.9%)

People living in nonmetro areas







% of

PIER census

73%

9%

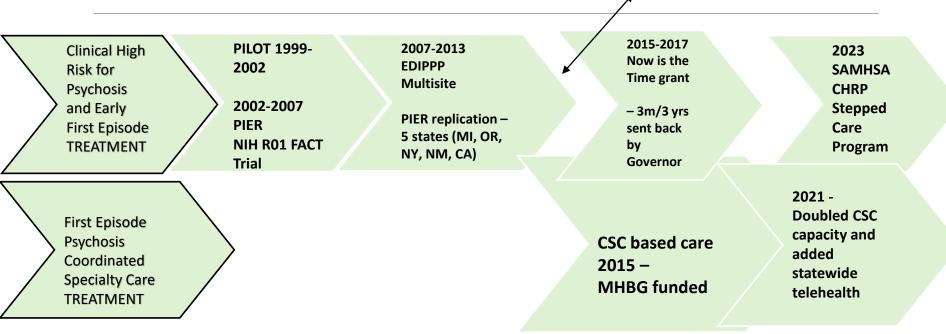
15%

1%

2%

20 Years of Treatment and Research in Maine

Funding GAP in SERVICES Program closed and needed to be rebuilt.



Politics influence funding and sustainability. Partnership with the state has been key.

Case rate slated for 2025 expected to support additional sites statewide that PIER will train.

Efforts toward sustainable funding

2018-Present

- PIER has worked closely with DHHS toward sustainable funding for CSC.
- LD 1461 (2019) and LD 674 (2021) received unanimous support from HHS Committee.
- Clients and family members testified along with partner agencies statewide interested in offering FEP services.

2021

Governor Mills' Behavioral Health Initiative prioritized the case rate role out to Coordinated
 Specialty Care (CSC) by implementing a MaineCare bundled reimbursement rate and providing training and technical assistance to providers to adopt this model."

2022 - 2025

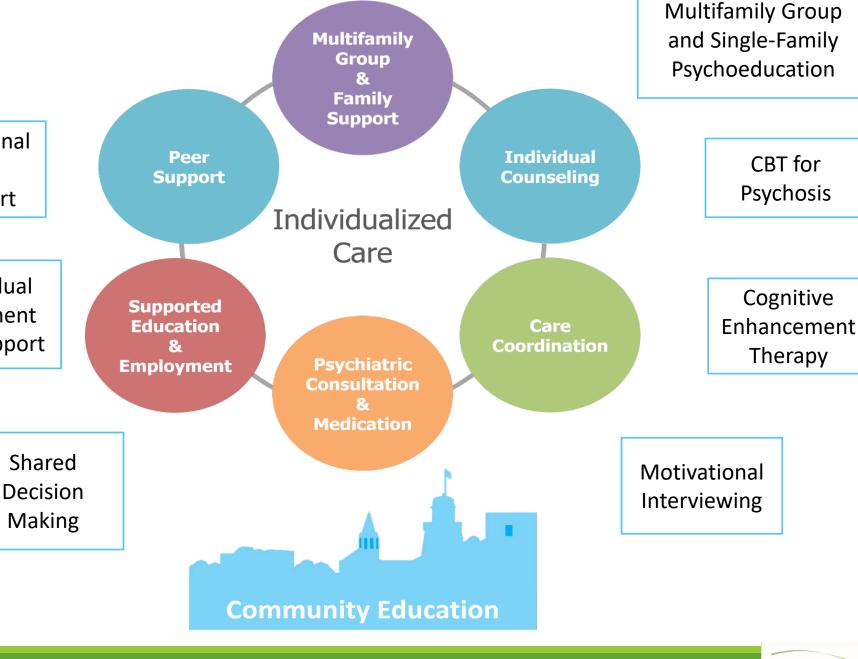
- The Medicaid dollars were allocated for CSC to begin in 2022 but the state plan amendment to make the case rate possible has not been completed.
- The PIER Program was funded through MHBG and COVID emergency funds to double the numbers treated (since the case rate not yet available) and continue to build a workforce to offer statewide CSC model.



PIER/Resilience Coordinated Specialty Care







Intentional

Peer

Support

Individual

Placement

and Support



Inclusion criteria

PIER and RESILIENCE – Both First Episode Psychosis Programs

- Coordinated care for those ages 14-35 within 2 years of a first episode of psychosis
- Affective psychosis and schizophrenia spectrum psychosis included.
- IQ > 70

We have a 4 year SAMHSA grant for those at **Clinical High Risk for Psychosis** (called Community Hope and Resources for Psychosis (CHRp) Program) for to test a stepped model of care (ages 12-26)



Added a NEW CHRP team – Expanding Services in Early Psychosis

Community Hope and Resources for Psychosis (CHRp) Program (age 12-25)

Stepped Levels of Care (LOC):

- a. Targeted outreach
- b. Assessment of CHRP symptoms (SIPS)
- Maintain current community providers with free consultation over time
- d. Adding some components of specialty care, or
- e. Transferring to CSC if converted to psychosis

York, Cumberland, Androscoggin, Oxford, Sagadahoc Counties ONLY

First Episode Psychosis (FEP) Programs (age 14-35)

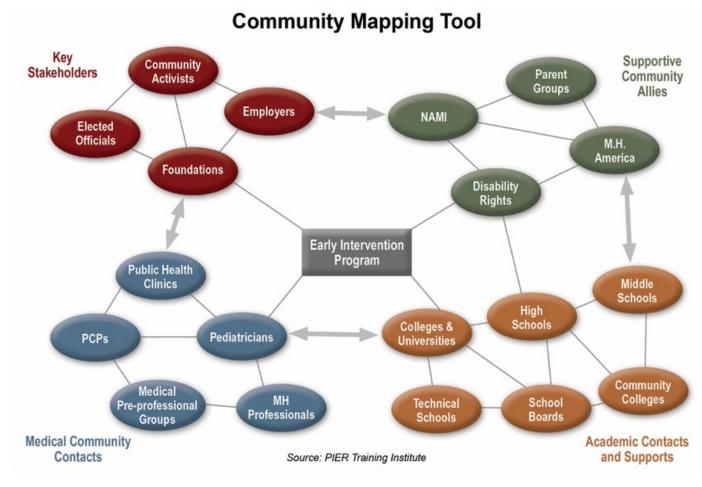
Full-Team CSC:

- Community Outreach/Engagement
- Psychiatry
- Employment/Education Support
- Counseling
- Case Management
- Multi-Family Groups
- Peer Support

Statewide Services



COMMUNITY MAPPING FOR POTENTIAL AUDIENCES



- Intentional, targeted
- Based on Community Map
- Prioritizes
 primary care,
 community and
 school settings

Guidance Manual: Educating Communities to Identify and Engage Youth in the Early Phases of an Initial Psychosis: A Manual for Specialty Programs

EDIPPP: 6 PIER Model Replication Sites

Early Detection, Intervention and Prevention of Psychosis Program: Community Outreach and Early Identification at Six U.S. Sites

- All 6 sites yielded a representative sample with racial and ethnic characteristics similar to those of the 2010 U.S. population data
- EDIPPP's outreach and education model demonstrated effectiveness following a protocol-defined outreach strategy that allowed for flexibility to target demographic and regional diversity and unique challenges.
- All EDIPPP sites yielded appropriate referrals of youths at risk of psychosis.

Lynch, S et al (2016)



Maine Rural Healthcare

16

Critical Access Hospitals

37

Rural Health Clinics

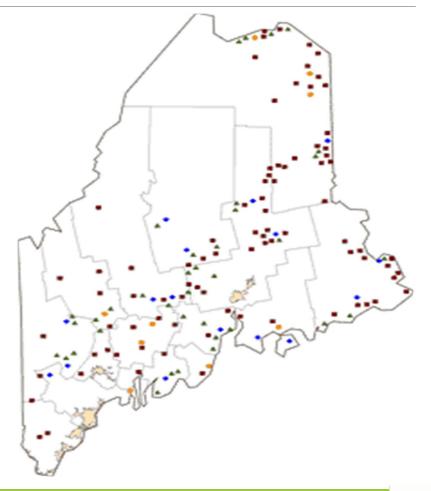
85

Federally Qualified Health Centers

9

Short term hospitals

*Sites according to data.HRSA.gov (January 2023), showing only locations outside of U.S Census Bureau Urban Areas with a population of 50,000 or more





Vermont Rural Healthcare

8

Critical Access Hospitals

10

Rural Health Clinics

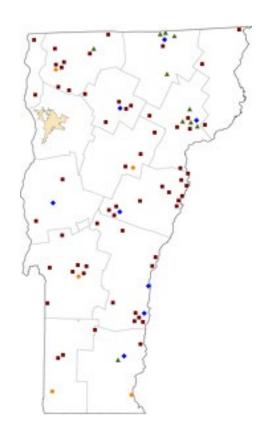
61

Federally Qualified Health Centers*

5

Short Term/PPS Hospitals*

*Sites according to data.HRSA.gov (April 2024), showing only locations outside of U.S. Census Bureau Urban Areas with a population of 50,000 or more <a href="mailto:Length:





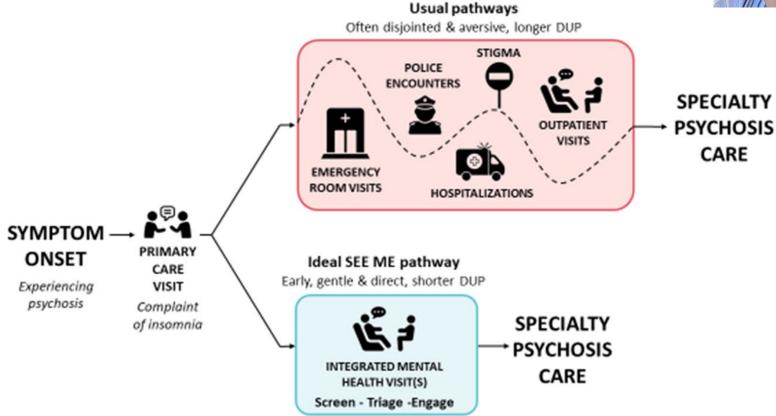
How does Maine rank in access to care as a rural state?

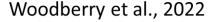
- Maine ranks **8th** in the U.S. for the number of **psychiatrists** practicing in rural counties. Maine has 6.2 per 100,000 residents. The U.S. rural average is 3.4.
- Maine ranks **2nd** in the U.S. for the number of **primary care physicians practicing in rural counties** (99.5 per 100,000). The national average for rural counties is 54.5 per 100,000.
- Maine was an early adopter of integrated primary and behavioral healthcare.



Earlier Intervention = Shorter duration of untreated psychosis with earlier, gentler, direct pathway









Critical window: 3-6 months after psychosis onset

Adolescence /Early Adulthood is a critical period for:

- Brain development
- Identity formation
- Increased social intimacy
- Transition to independence



Months right before and after psychosis onset:

- Peak risk for hospitalizations
- Peak risk for suicide (Nielssen et al., 2012)

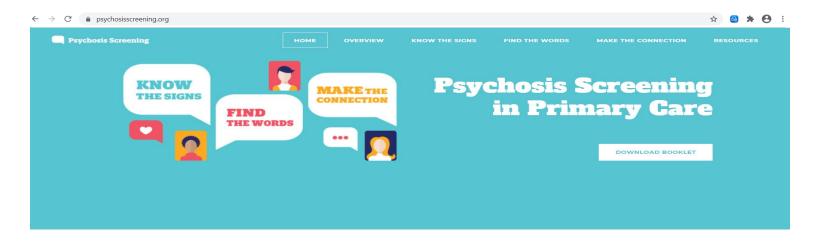
Timing impacts: (Marshall et al., 2005; Pentillä et al., 2014)

Clinical outcomes, Functional outcomes, Costs





Online Resource: <u>Psychosisscreening.org</u>



This website was designed to help providers working with teenagers & young adults to:





PIER: Approach To Engagement with Young People and Families

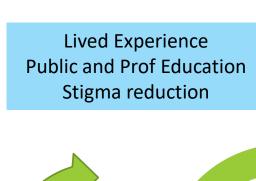
Participants:

- 1:1 Peer Connection offered in person prior to intake
- Monthly Education workshop
- Peer Support groups offered (after found eligible)
- Share your story presentation from Program Graduates

Families/Supports:

- 1:1 family mentoring—pair graduate families with prospective families
- Family to Family Weekly Zoom Call for prospective and current families
- Monthly Community/ Family Education Workshop
- Graduate Family Panel— monthly zoom





Outreach Education

Program Participation

Multi-Disc. Team
MFG groups
Individ Therapy
Peer Support
Employment/Ed
Care Mngmt
Medication

Speakers Bureau
Peer Support
Advisory Council
Research
Participation

Peer Advocacy



Lynch, S. Jaynes, R. Nnguany, N. (2019) Engaging Families and Individuals in Care: *Intervening Early in Psychosis: A Team Approach*: Hardy, Ballon, Noordsy, Adelsheim, Eds. APA Publishing, Washington, DC.



Lived Experience over decades (video)



2018 PIER Program Participant Panel Bangor, ME



Research on Early Intervention in Psychosis Teams (EIT) in rural areas

- Inclusion of 5 studies evaluating clinical outcomes and 4 studies evaluating adherence to EIT model.
- Positive clinical outcomes using "hub and spoke" model.
 Managerial and geographical flexibility to enable early access to care.
- Partnership networks with local existing services critical.
- Full stand-alone team faced financial challenges, broad geographic coverage areas and workforce shortage.

Pipkin A. Evidence base for early intervention in psychosis services in rural areas: A critical review. Early Interv Psychiatry. 2021 Aug;15(4):762-774. doi: 10.1111/eip.13019. Epub 2020 Jul 13. PMID: 32657522.



Rural adherence to CSC model

- Adherence to EBPs low including CBT, involvement of families, physical health monitoring and use of outcome measures - ranging from 16% to 50% usage across a number of teams.
- Lack of funding and administrative support to effectively evaluate services.
- Challenges for rural providers distances to travel, workload and lack of post-training support.

Pipkin A. Evidence base for early intervention in psychosis services in rural areas: A critical review. Early Interv Psychiatry. 2021 Aug;15(4):762-774. doi: 10.1111/eip.13019. Epub 2020 Jul 13. PMID: 32657522.



State of Maine and CSC

Currently, PIER is a statewide service without capacity to do the local engagement and relationship building to be most effective in rural areas.

With case rate, northern part of the state will be able to provide CSC team-based care.

Advantage of centralized training, supervision, and oversight:

- Long history of this expertise in Maine
- Strong partnership with state of Maine
- EBP adherence
- Outcomes measures consistent across the state
- Statewide provider and lived experience network
- Combination of hub and local providers to meet CSC components



How do we teach symptoms of psychosis on a spectrum?

NORMALIZE!

- ✓ Builds rapport and trust
- ✓ Increases dialogue about difficult experiences
- ✓ Destigmatizes experience
- ✓ Depathologizes mental health



Early symptoms of psychosis do not imply a specific diagnosis

Psychotic experiences are part of the human experience

- Up to 17% of children and teenagers have had psychotic-like experiences
- 1 in 10 people report they have "heard voices"
- Psychotic experience occur across cultures



Most people wait 1-2 (or more!) years with distressing symptoms before asking for help



Psychosis is more than an individual experience = a societal issue



Systemic issues and socioeconomic factors reflect:

- Social and racial/ethnic inequities
- Political/cultural norms
- Trauma experience (abuse, bullying)



Symptom experiences that clinically define psychosis

Positive Symptoms (new/altered)

- Changes in Perceptions (5 senses)
- Changes in Thinking
- Changes in Mental Processing



Negative Symptoms (lessened)

- Reduced motivation/energy
- Reduced emotional & social experiences





Psychosis Continuum

Mild

Noticeable, but not bothersome

Reality testing intact

Moderate

Bothersome and affects daily life.

Able to induce doubt

High

Significantly interferes with daily life

100% Conviction



"I'm not sure why but I feel a bit unreal around my friends." "I don't want to hang out. My friends seem like cartoon characters."

"I can't go to school. Everyone has been watching my life online."



Psychosis Spectrum

Changes in Perceptions









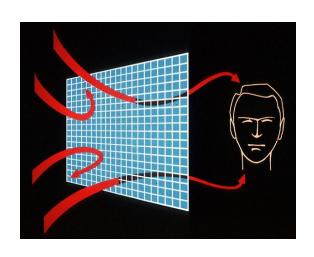
Psychosis Spectrum

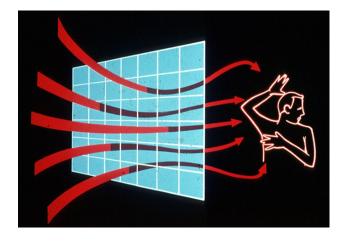
Changes in Mental Organization





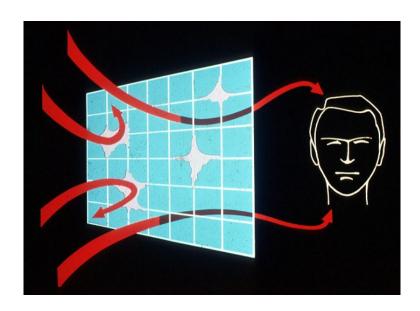
The Brain's Filtering System







Goal: Build back a healthy filter





Stress-Vulnerability Model

Positive Events (e.g. graduation, new job)

Family history (e.g. genetics)

Negative Events (e.g. accident, job loss)

Traumatic experiences

Health Issues

Substance Use

Acute Stress (e.g. grief/loss, work stress)

Chronic Stress (e.g. racism, economic strain, limited resources, pandemic)

Stress

Psychosis is a result of stress overflow



Self Care-Resiliency Model





Multifamily Groups and Cognitive Behavioral Therapy for Psychosis

- Both are Evidence-Based
- Structure of each model complements each other (formulation-based, structured agenda setting, etc.)
- MFG Problem-solving process enhances cognitive flexibility—seeing things from multiple perspectives



Why Cognitive Behavioral Therapy for psychosis?

- People with psychosis want to and can play an active role in their treatment
- Many people with psychotic disorders continue to have psychotic symptoms and specific interventions to target these symptoms are warranted
- CBTp improves psychotic symptoms and decreases distress
- Managing distress allows for more meaning and functional improvement in lives



Curiosity and Socratic Questions

What is the EXPERIENCE?

- •Tell me more about that experience.
- •What do you make of that?
- •Why do you think this is happening?
- •How so?

Is it IMPACTING them?

- •What do you do when that happens?
- •Do you ever do anything differently because of it?
- •Does it bother you? How so?

Is it RECURRING or PROGRESSING?

- •Has this changed at all over time? (for instance, becoming more intense or harder to dismiss)
- •Has it been happening more frequently or bothering you more than it used to?



Research supports CBTp

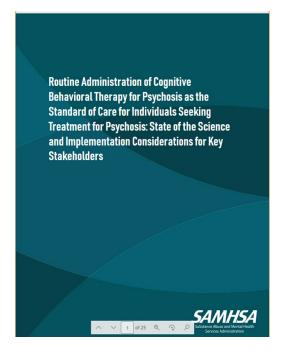
- CBTp is the most well-researched psychotherapeutic intervention for psychotic disorders, with 30 years of efficacy, effectiveness, and—more recently—implementation trials, meta-analyses, and systematic reviews.
- CBTp effect sizes for both positive and negative symptoms tend to be comparable to most antipsychotic medications, and prevailing guidance is to offer CBTp alongside medications and preferably within the context of multidisciplinary care teams.



Why CBTp-Informed Care?

CBTp is recommended as standard of care in U.S. psychosis practice guidelines, yet, remarkably, fewer than one percent of Americans with a diagnosed psychotic disorder have access to this treatment.

As one of the leading causes of disability worldwide, one would be hard-pressed to find another condition for which the health and economic effects are so profound, yet for which well-researched efficacious treatment is so inaccessible. This must change.





Outcomes in early psychosis and across the spectrum of psychosis

Early Psychosis (CHR)

Reduction of conversion to psychosis for CHRP.

Psychosis – across the spectrum (FEP and beyond)

 Reduction in positive symptoms of psychosis, mood symptoms, hospitalizations, improved medication adherence, and maintenance of treatment gains

*>50 published studies, including meta-analyses and RCTs

https://doi.org/10.1017/S003329172100341X

https://doi.org/10.3389/fpsyt.2020.00402

https://doi.org/10.1016/j.schres.2020.03.041



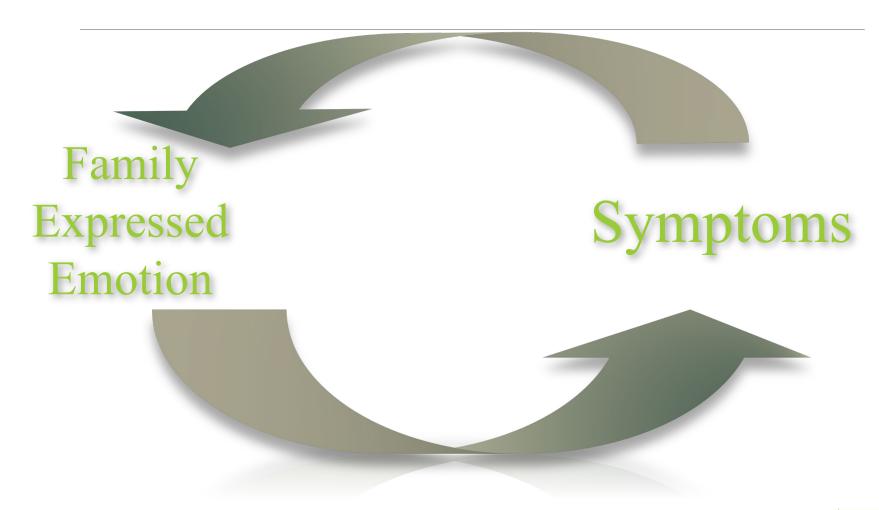
PIER: Approach To Engagement with families/loved ones

Family Treatments offered

- Multifamily groups (co-led by ES, CM, Clinician, Peer Support)
- Single family therapy
- Family Peer Support Group
- Family-Supported CBTp, medication management, supported education/employment, care management



Interaction of Biological and Social Factors



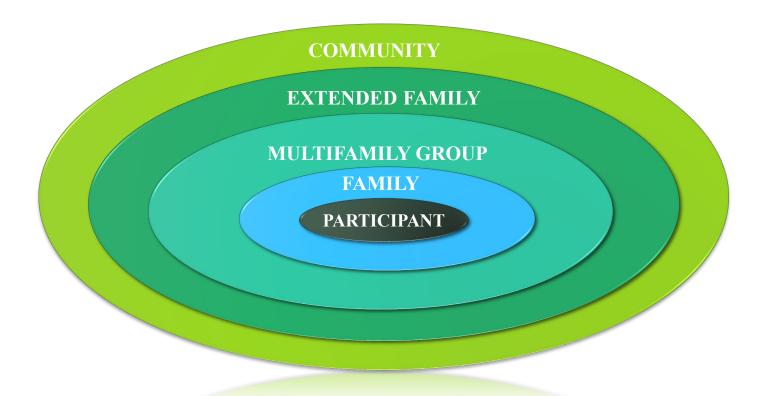


Interaction of Biological and Social Factors





Social Networks and Multifamily Groups – Practice ground for re-engagement





Multifamily Groups and Coordinated Specialty Care (CSC)

- MFG as the 'hub' of treatment
- All team members 'join' with clients for group
- Reflects the spirit of team-based coordination
- Values everyone's input and perspective
- Joint problem-solving
- Enhances team communication



Multifamily Groups (MFGs)

An effective way to deliver treatment:

- Helps people hear things differently
- Promotes different learning styles
- Holds people accountable for small steps toward progress
- Allows people to experience being helpers not just a person in need of help.
- Offers opportunities for cross-parenting
- Creates community and reduces stigma



MFG and other CSC models

- Other models provides family psychoeducation in single family format.
- PIER has trained both Navigate and OnTrackNY teams in other states who want to add Multifamily Group model.
- May enable more group learning spaces, increased support, less stigma, and combats social isolation.



Workforce Development Statewide

www.pierprogram.org

Network of Referrers and Community Clinicians—Invite to workshops/trainings.

Psychosis Informed Care and CBT for Psychosis training— Online trainings and on demand training 2x year.

Family and Community Education Workshop – Monthly

Consultation and Referral Group — Monthly



Building Skilled Community Workforce

UMaine Collaboration:

 HRSA grant: training rural and statewide integrated behavioral health clinicians and trainees

SAMHSA CHRP

- Grant Trainings:
 - 22 Integrated Behavioral Health Clinicians, 18 clinics
 - SEE ME "light" 2 3-hour "screen-triage-engage" trainings
 - Monthly drop-in consultation

Stepped Care Model

 Case-based consultation to community providers re: psychosisinformed care for mild CHR



Services Provided Statewide since 2015

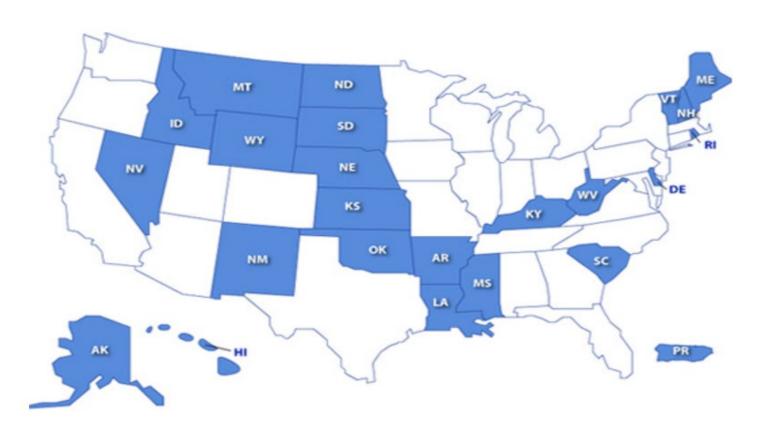
- At present, the PIER Program has treated **380 people** with first episode psychosis or acute clinical high-risk symptoms of psychosis since re-opening its doors in 2015.
- The average stay in the program is 405 days.
- The PIER staff has completed **200 educational presentations** about early psychosis to reach **5,073 people**.
- Cognitive Behavioral Therapy for Psychosis training to 300
 professionals statewide and Multifamily Group training to 80
 professionals.



IDeA-eligible states

Building research capacity in states with historically low levels of NIH funding

IDeA-eligible states are shaded on the map below:









Thank you! Questions? sarah.lynch@mainehealth.org

