



EASA Center for Excellence

Session 2: Creating an Effective Community Response to Early Psychosis

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What we will cover today



- Brief overview of the Coordinated Specialty Care model
- How the early psychosis field has evolved
- Quick overview of psychosis
- Common challenges and what works
- Steps in getting a specialty program going
- Resources





Early Psychosis Coordinated Specialty Care: A National Movement

- Strong support for Coordinated Specialty Care from NIMH, SAMHSA and national organizations
- Existing programs with significant experience in U.S.
- Concrete steps taken toward national coordination
- “Learning healthcare system” concept



Coordinated Specialty Care



- Rapid response team
- Embedded in larger system/community
- Proactive; seeks out people needing support; facilitates service for those screened out
- Intensive, integrated approach with multiple disciplines
- Learning healthcare approach:
 - Services based on evidence
 - Participatory decision making
 - Focus on outcomes



CSC Components



- Team Leadership
- Case Management & Psychotherapy
- Supported Education and Employment
- Family Education and Support
- Pharmacotherapy
- Primary Care Coordination

<http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml>

Early Psychosis Timeline

EPPIC, AU	Int'l: TIPS/OPUS, Commonwealth dissemination NAPLS →	PIER	EASA	CA Prop 63/ IRIS (UK)	OR statewide EDIPPP	RAISE began	5% Set-Aside
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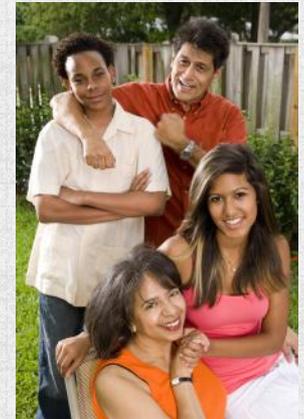
The Big Picture: A Growing Movement

- 1988 Early Psychosis Prevention and Intervention Center (EPPIC) created in **Melbourne, Australia**
- Late 90s/early 2000s:
 - OPUS, TIPS studies in **Scandinavia; German, British, Australian, Canadian** research
 - Growing number of **U.S. and Canadian universities** focused on prodrome starting in 1990s- turned into **North American Prodrome Longitudinal Study (NAPLS)**
 - National initiatives in **Australia, New Zealand, Canada**
 - Zucker Hillside Hospital program
- 2000: **Portland Intervention and Early Referral Service** created in **Maine**; research program **focused on prodrome**
- 2001: **Early Assessment and Support Team (later Alliance)** formed in **Oregon** integrated into public mental health system in five counties; early focus on **first episode**
- 2004: IRIS (Initiative to Reduce the Incidence of Schizophrenia) national initiative in **Great Britain**
- 2004: **California** Proposition 63 passes; establishes flexible funding source in CA (local programs created gradually over time)
- 2007: Oregon funds **statewide EASA initiative**
- 2007: Early Detection and Intervention for the Prevention of Psychosis Program (**EDIPPP**) study sponsored by The Robert Wood Johnson Foundation. Included **very early first episode and psychosis risk**; Oregon original five counties UC Davis, RAPP clinic in Long Island, Washtenaw County, Michigan, University of New Mexico.
- 2010: RAISE (Recovery After and Initial Schizophrenia Episode) study. 2 arms- Randomized Early Treatment Program (17 sites nationally in experimental condition) and RAISE Connections designed to prepare implementation support materials (OnTrack **New York**)
- Last couple of years: Rapidly growing interest and program development nationally
- 2014: **Congressional mandate** to begin funding in all states & territories; added to Mental Health Block Grant requirements



Changing Understanding

- Most people will be successful with the right support
- Underlying cognitive changes can be accommodated
- Relationships are central
- Engagement in normal activities and areas of strength
- Importance of addressing stigma





Recognizing and Mobilizing Around a Problem

- What is the experience today in your community when young people develop psychosis?
- Is it easy to get help? Do people know what to watch for and who to call? Do they and their families get effective help when they look for it?
- Are they staying in community relationships, school and work? What is the impact?
- What does your data show?





Common Challenges in Responding

- People don't know what to look for
- Not providing opportunities to learn from people in recovery
- Under-reaction and over-reaction
- Delays and barriers
- Negative assumptions or impatience
- Assuming speaking well is the same as doing well
- Lack of effective tools
- Lack of intensity of response
- Lack of continuity and follow-through

Build on What You Know

- A successful effort to change something important?
 - What led to accomplishing the change?

- What needs to happen for teenagers to become successful young adults?
 - What supports that process?



Re-writing our own stories...





Ingredients

- ✓ Recognition of problem and advocacy
- ✓ Leadership and program development
- ✓ Recognition
- ✓ Referral
- ✓ Engagement
- ✓ Assessment
- ✓ Treatment & support
- ✓ Long-term supports

Creating a Vision

- How will people find their way to effective services?
- What will those services look like and how will they be coordinated, trained, & supported?
- How will the community work together to
 - identify young people quickly
 - get them the help they need
 - Improve services available





No One Can Do this Alone

- Young people
- Families
- Mental health programs
- Schools
- Employers
- Justice system
- Child welfare
- Churches

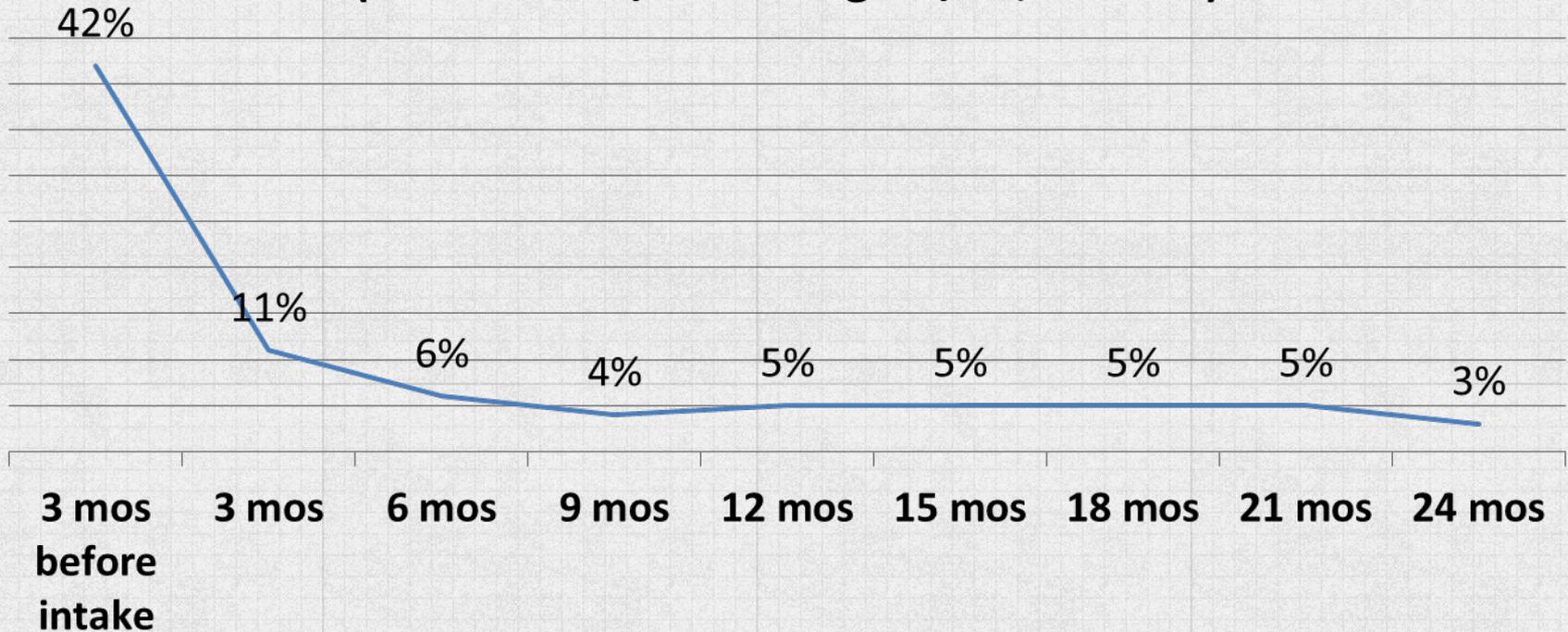


Tying Early Psychosis to Core Motivations

- Young Adults and Families: Trauma and loss vs. empowerment and hope
 - Rights! (Olmstead Decision, parity)
- Community:
 - Care about our kids!
 - Finishing school
 - Public safety
 - Economic well-being
 - Health and mortality
- Funders: Paying for what works

EASA Results

**Percent of EASA Participants Hospitalized
(Data from 1/08 through 9/13, n = 943)**



Time in EASA



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Outcomes of Effective Intervention

- Large majority in remission or with minimal negative impact
- 60-80% (more than the general population for their age) in school or work
- Social supports preserved
- Progressing developmentally
- Educated and empowered
- Safety net/ongoing care established
- Relapse plan in place



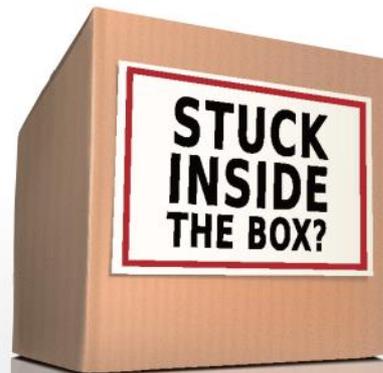
Philosophical Underpinnings



- Strengths focus
- Rapid response: there when people need us, in the way they need
- Partnership with individuals and families
 - Build on the wisdom of lived experience
- Holistic and focused on functional outcomes, long-term well-being
- Evidence-supported
- Supporting person to gain mastery
- Everyone can develop psychosis; there are ways to increase and decrease vulnerability

Advocating for System Improvements

- Recognize we all play a role
- Encourage expertise development
- Challenge barriers
- Challenge and celebrate media portrayals
- Come to table to problem solve



Recognition

- People are educated

- Early symptoms
- How common it is
- Likelihood of positive outcome with early help
- How to reach program and what to expect



- Resources are visible, accessible and responsive

Symptoms of Acute Psychosis

- Hallucinations
- Delusions
- Speech & movement problems
- Cognitive & sensory problems
- Inability to tell what is real from what is not real

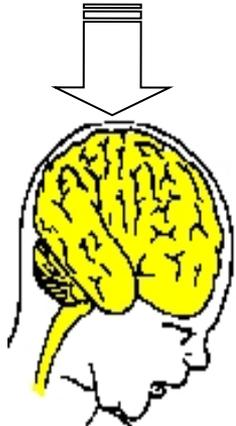


What can cause psychosis?

- Genetic vulnerability
- Thyroid
- Frontal lobe epilepsy
- Cushings Disease
- Wilsons
- LOTS of medical conditions
- Schizophrenia
- Bipolar disorder
- Depression
- Anxiety disorder
- Steroids
- Stimulants
- Methamphetamine
- Brain tumors
- Sleep deprivation
- Severe stress
- Sensory deprivation
- And others....

Early Insults
(e.g. Disease
Genes,
Possibly Viral Infections,
Environmental Toxins)

Social and
Environmental
Triggers



Brain
Abnormalities

Biological Vulnerability: CASIS

- Cognitive Deficits
- Affective Sx: Depression
- Social Isolation
- School Failure

Structural
Biochemical
Functional

Increasing Positive symptoms



Disability

After Cornblatt, et al., 2005

Performance Changes to Watch for



- New trouble with:
 - reading or understanding complex sentences
 - Speaking or understanding what others are saying
 - Coordination in sports (passing ball, etc.)
 - Attendance or grades



Behavior Changes

- Extreme fear for no apparent reason
- Uncharacteristic, bizarre actions, statements or beliefs
- Incoherent or bizarre writing
- Extreme social withdrawal
- Decline in appearance and hygiene
- Sleep (sleep reversal, sleeping all the time, not sleeping)
- Dramatic changes in eating



Perceptual Changes



- Fear others are trying to hurt them
- Heightened sensitivity to sights, sounds, smells or touch
- Statements like, “I think I’m going crazy” or “My brain is playing tricks on me”
- Hearing voices or sounds others don’t
- Visual changes (wavy lines, distorted faces, colors more intense)
- Feeling like someone else is putting thoughts in your brain or taking them out

The Special Challenges of Identity and Individuation

- Often ignored by mental health systems
- Identity forming while struggling, receiving negative messages
- Internalized stigma is a huge issue
- Going on medicine, applying for disability funding, trauma of psychosis and coercive care interact with identity formation
 - Perceptions of being broken, assumptions about what the label means, frustration that things are harder
- Need powerful antidotes and role models

Learning from People in Recovery

- “Going through something traumatic like this makes you stronger; it’s not a sign of weakness.”
- “Provide a safe space.”
- “Even if the person is not talking the beginning, keep coming consistently. Caring is motivational.”
- “Consistency made a difference in my life. Eventually you’re going to get through to that person.”
- “I was at a low point and seeing others who had been through it and were doing well was a turning point for me.”

Under-reacting and Over-reacting

- Hallucinations are more common than we realize
- Don't jump to a diagnosis.
- Language matters.
- Eliminate the words "There's nothing we can do".



Changing Our Assumptions and Messages

- Common condition that many people have dealt with successfully
- There is a lot of knowledge about what helps
- May take some time but you can get your life back
- The person has a lot to offer

Effective Tools

- Engagement and outreach
- Person-centered planning
- Mentoring and role models
- Medicine where indicated
- Family psychoeducation
- Supported employment and education (IPS)
- Developmentally tailored responses
- Recovery skills
- Relapse prevention

Talking to Someone Experiencing Psychosis

- Sit or stand side-by-side
- Know the person- strengths, motivations- and focus on these
- Use short sentences and simple language
- Listen and give them plenty of time to speak (information processing speed may be slowed)
- Hallucinations and delusions are real to the person
- Reflect on the feelings
- LEAP (Amador): Listen, Empathize, Agree, Partner
- Don't ignore safety concerns

Creating a Specialty Team

- Local expertise so there is an effective place to turn
- Services based on what people need



Getting Started Checklist:

	Activity
<input checked="" type="checkbox"/>	Identify program structure and services
<input checked="" type="checkbox"/>	Determine geographic boundaries
<input checked="" type="checkbox"/>	Define clinic population and eligibility criteria
<input checked="" type="checkbox"/>	Connect with state and surrounding partners
<input checked="" type="checkbox"/>	Establish funding / operating budget
<input checked="" type="checkbox"/>	Establish a referral network
<input checked="" type="checkbox"/>	Apply clinic procedures to the team
<input checked="" type="checkbox"/>	Establish programmatic oversight rules
<input checked="" type="checkbox"/>	Assess staffing requirements
<input checked="" type="checkbox"/>	Develop standards for team functioning
<input checked="" type="checkbox"/>	Develop training plan

Source: RAISE Coordinated Specialty Care for
Early Psychosis Manual II: Implementation



Population and Eligibility

- How many do you expect to serve? (Projected annual incidence based on population)
- Who will you serve?
 - Diagnostic spectrum: schizophreniform/ bipolar spectrum/ other psychoses/ psychosis risk syndrome
 - Diagnostic uncertainty hallmark
 - Age (EASA minimum 15-25; can go beyond)
 - Funding restrictions?

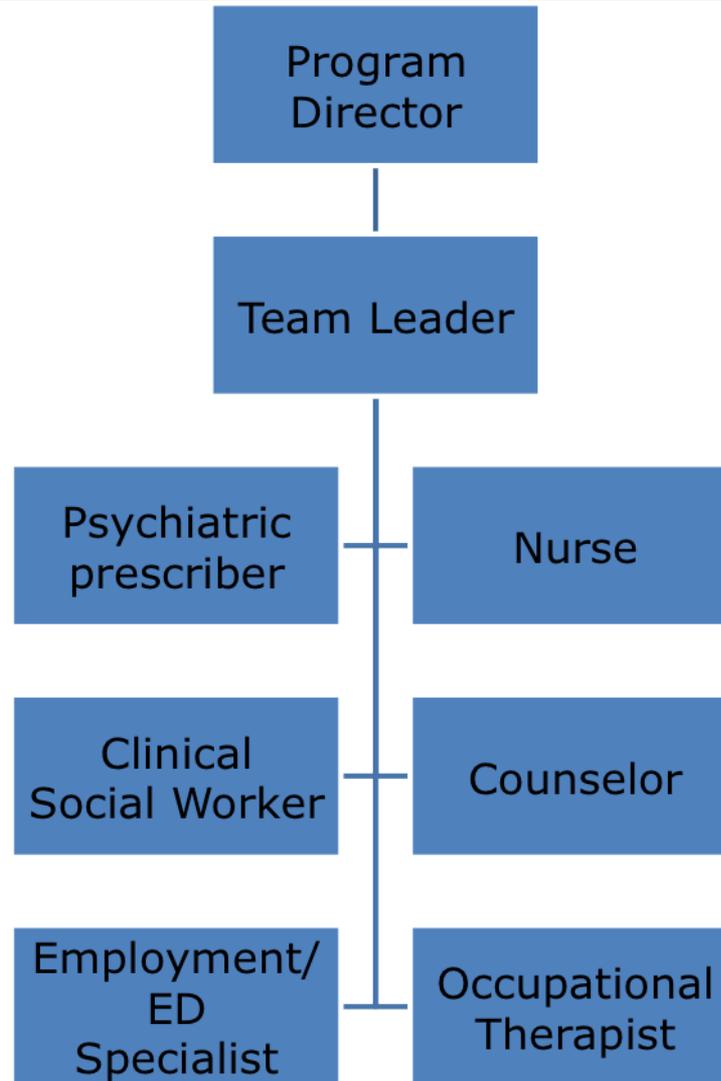


Program Structure and Services

- Compatibility with program mission and needs
 - Tie-in to organizational mission/ leadership
 - Linkage to crisis systems, referral structures
 - Staffing intensity, coordination and flexibility



Trans-Disciplinary Treatment Team



Services

- Shoot for 1:10 fte (total fte, not per clinician)
- Need is more intensive in early stages
- Lead clinician caseload needs to be limited (1:20-25)
- Minimum weekly review of all individuals in service; close coordination
- Whole team serves above and below 18
- Team and strategies reflect local culture



Duration

- How long will program last?
 - EASA started 3-5 years, moved to 2, and is now working toward “aftercare” or “alumni”
 - Graduates are exceptional resource
 - Issues:
 - Permanent connection to public mental health system and impact on identity development
 - Management of new influx
- Transition
 - Planned, gradual, with ability to do longer-term check-ins & problem solve with graduates



Core Element: Referral

- Streamline processes!! Needs to be fast.
 - Rapid path to specialty team; no intermediate intake process
 - Focus is on engagement from beginning
- Attend to relationships
 - Don't just screen out; offer resources and advocacy
- Be available to coach the family and referents
- Once people get to you, revisit their pathway to look for missed opportunities

Core Element: Engagement

- Pay attention to language and entry barriers.
 - Modify if needed
- Each engagement is different
 - Get to know them, their strengths & and motivation
 - Allow time and trust-building
 - Persistence, flexibility
- Families may engage more quickly and that's ok

Core Element: Assessment

- Comprehensive risk assessment:
 - Don't assume the person's safe until you get to know them well
 - High risk of suicide and accidental harm
 - Low risk of violence generally but content of delusions is important

Core Element: Assessment

- Engagement & educational process
- Strengths discovery key
- Social network
- Progression and developmental history
- Current functioning and resources (individual and family)
- Symptoms and impact
- Their explanatory model

Core Element: Treatment

- Team
 - Lead clinician- social worker/counselor/psychologist)
 - Psychiatrist/ Psychiatric Nurse Practitioner
 - Supported Employment/Education
 - Peer Support
 - RN
 - Occupational therapist

Core Element: Treatment

- Goals are theirs and in their words
 - How do symptoms interfere?
- Medical
 - Low dose antipsychotics generally recommended with persistent psychosis
 - Participatory decision making
 - Close attention to side effects and metabolic disorder
 - Persistent engagement by medical team
 - Attention to nutrition, exercise, sexual behaviors

Core Element: Treatment

- Clinical interventions
 - Case management, psychoed, CBT, dual diagnosis treatment/MI, attention to trauma, feedback-informed treatment
 - Family psychoed and support (single or multi-family)
- Coordination
 - Weekly team meeting reviewing everyone in program
 - Shared plan and shared decision making

Core Element: Long-Term Supports

- Gradual transition out of program
- Consideration: What is your transition-to-adult system? Do you have one?
- What is available and is it consistent with what they experienced initially?

Staffing Considerations

- There by choice
- In their job description!
- Supervisory support
 - Productivity
 - Flexibility
 - Training needs





Financing

- Program builds to plateau
- Adequate utilization (not below 1:10!)
- Diversified funding
 - Private insurance: aggressive pursuit and staff licensure
 - Projection of need for subsidy (insurance mix, % cost reimbursed)
- Exploration of alternative eligibility & billing methods/strategies:
 - Expanded Medicaid eligibility
 - Case rate/Bundled service

Training & Accountability

- Ongoing training, consultation & coaching
 - Philosophy, why and what you are doing, how team operates
 - Differential diagnosis
 - Clinical interventions
 - Other identified needs (role-specific, developmental psych, working with schools, etc.)
- Fidelity review
- Outcome measures

Resources

- EASA
 - Website www.easacommunity.org
 - Sections for young people and families
 - Practice guidelines include large amount of material and fidelity tool
 - Some consultation/training available but generally strategize/ work with other partners to customize & ensure long-term support

The NAVIGATE Team: Each has a manual and a training package

- Director and Family Clinician (combined role)
- Prescriber
- Supported Employment and Education (SEE) specialist
- Individual Resiliency Training (IRT) clinicians
- Sometimes a peer specialist and/or separate case manager

CONTACT: For more information, contact Susan Gingerich at navigate.info@gmail.com

WEBSITE: www.navigateconsultants.org

Resources

- NIMH/OnTrackUSA:
<http://practiceinnovations.org/OnTrackUSA/tabid/253/Default.aspx> &
- <http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml>
- University of North Carolina OASIS:
<http://www.med.unc.edu/psych/cecmh/patient-client-information/oasis>
- University of California San Francisco/Felton Institute:
<http://prepwellness.org/> & <http://felton.org/>
- PIER Training Institute: <http://www.piertraining.com/>
- Commonwealth programs: EPPIC <http://eppic.org.au/> , IRIS <http://www.iris-initiative.org.uk/> , Canadian programs



One Last Thought

- We all play a role
 - The problems we face have often been solved by someone, or will be soon!
 - Synergy increases speed of change

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