Journeys Through and Beyond Psychosis: Our Experience in Oregon

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First early psychosis roll-out in U.S. public mental health system: 5 counties 2001; statewide 2007-present

EASA Center for Excellence created at Portland State University in 2013; connected to Pathways RTC and National Training and Technical Assistance Center
Our messages today

Early psychosis intervention matters!

There is something we can each do.

We are creating a thriving community and revolution of hope. Please join us.
• Michael’s journey
• EASA’s birth and evolution
• A national movement
• The Young Adult Leadership Council
• Call to action
Psychosis

• 100,000 new individuals each year
• Common onset teens and young adult
• Multiple causes but most early psychosis programs target schizophrenia
• Typical delay to treatment - 1-2 years
Psychosis symptoms

- Delusions
- Hallucinations
- Thought/language disorder
- “Negative” and cognitive symptoms
- Loss of ability to reality test
- Learn more: http://www.easacommunity.org/what-is-psychosis
Symptoms evolve over time

- **COGNITIVE**
  - Normal things are harder to do

- **AFFECTIVE/PERCEPTUAL**
  - Visual distortions
  - Voices
  - Things seem different/weird

- **BEHAVIOR CHANGE**
  - Social withdrawal
  - Strange actions and statements

- **PSYCHOSIS**
  - Acute symptoms
  - Loss of contact with reality
Common experience before EASA

- Obstacles, delays, trauma, isolation
- Involuntary entry, lack of evidence-based care
- High doses of medicine
- Institutionalized poverty

*But also...*

Resilient emerging leaders & role models (Deegan, Armstrong, Fisher, etc.)
Goals

- Engage early: proactive, voluntary, strengths-based
- Provide what helps
- Empower and partner to keep people in control
- Provide support for career, family, moving forward
- Learning and improvement
EASA’s evolution

• 2001-2004 5 counties; Australians (EPPIC)
  – Funded by Oregon Health Plan and private foundations (The Robert Wood Johnson Foundation, Paul G Allen, local)

• 2004
  – Adopted guidelines
    • Began with Australian guidelines
    • Adapted & expanded based on experience & SAMHSA toolkit (Individual Placement and Support, Multi-Family Psychoeducation, Illness Management & Recovery, dual diagnosis)
Coordinated Specialty Care

- Team focused on person-centered strengths, goals & outcomes (teens & adults)
- Counseling/illness education
- Medical and wellness; Low-dose prescribing
- Community education, outreach & engagement
- Family & individual partnership and education
- Supported employment & education
- Occupational therapy
- Peer support

EASA Center for Excellence
EASA’s evolution

• 2007: Oregon legislature began funding statewide dissemination

• 2007: Early Detection and Intervention for the Prevention of Psychosis Program (EDIPPPP)
  – Sponsored by RWJF & led by PIER; original 5 counties integrated psychosis risk syndrome
EASA’s evolution

• 2013: Young Adult Leadership Council
• 2013: Center for Excellence at Portland State University
• To date: Over 2000 served; over 400 people/year
EASA’s evolution

• Impact:
  – Family involvement (over 90% engagement)
  – Maintaining vocational path (majority in school or work)
  – Majority (over 60%) not seeking disability
  – Reduced hospitalizations after entry (25-40% at entry, reduced to 10 and then steady drop)
  – Growing community awareness
  – Young adults becoming leaders
Growing U.S. Momentum

“These early findings [from RAISE], combined with the already reviewed evidence supporting early intervention in psychosis, are so compelling that the question to ask is not whether early intervention works for FEP, but how specialty care programs can be implemented in community settings throughout the United States.”

National evolution

- 2010 RAISE studies (NAVIGATE, Connections)
- 2014 National prioritization
  - 2014 Congress: 5% set-aside
  - 2015 Congress: 10% set-aside
EASA Young Adult Leadership Council

Uniting the strengths and voices of young adults and their allies to create a thriving community and revolution of hope.

Early psychosis intervention matters! There is something we can all do.
EASA’s Young Adult Leadership Council

• A safe place for learning from our own experiences

• A professional board experience which values the diverse experience and capacity of each individual
Our greatest passion as a group is reaching out to others who are new to journeys like ours to let them know: You are not alone. There is hope. You deserve respect. You have many strengths and they will serve you well. It matters what you think, even when others disagree.
EASA’s Young Adult Leadership Council

• Helping to educate professionals, the community

• Using our own experiences and the experiences of others to help improve and create change within Oregon

• Partnering to achieve our goals
Early Psychosis Learning Collaborative

- Funded by National Training and Technical Assistance Center; provided by EASA Center for Excellence in collaboration with PEPPNET/Stanford
- Multiple ways to connect with others (calls, webinars, learning exchange bulletins, affinity groups)
- Networking and learning opportunities
- Technical assistance resources (monthly meetings)
- Small implementation learning group, April-December 2016
- To learn more or apply: tsale@pdx.edu (application can be found at http://www.pathwaysrtc.pdx.edu/proj2-easa-connections)
Unprecedented opportunities for connection and learning


- International Early Psychosis Association: [www.iepa.org.au](http://www.iepa.org.au)

- National Association of State Mental Health Program Directors portal: [http://www.nasmhpd.org/content/early-intervention-psychosis-eip](http://www.nasmhpd.org/content/early-intervention-psychosis-eip)

- NAMI National: https://www.nami.org/Learn-More/Mental-Health-Conditions/Related-Conditions/Psychosis/First-Episode-Psychosis


Some Technical Assistance Resources

  - Navigate (RAISE Early Tx Program manuals & consultation): www.navigateconsultants.org
  - RAISE Connections/ OnTrack USA (implementation and treatment manuals & consultation): http://practiceinnovations.org/OnTrackUSA/tabid/253/Default.aspx
- EASA (practice guidelines, training materials, psychoeducation resources, consultation): www.easacommunity.org
- PIER Training Institute (EDIPPP lead): http://www.piertraining.com/
Steps you can take today (in the next 2 minutes)

• Wifi code: CMHConference 2016
• Join PEPPNET!
  – www.med.stanford.edu/peppnet.html
• Sign up with Partners4StrongMinds (conversation starters)!
  – www.partners4strongminds.org
• Learn more about the early signs:
  http://www.easacommunity.org/what-is-psychosis
What can we do?

- Talk openly and optimistically about psychosis as a common condition

- Use person-first language and avoid us-and-them thinking

- Work for real insurance parity and access to vocational supports so teens and young adults are not pushed onto lifelong disability
I alone am young
I alone have a voice
I alone need my freedom
I alone fight my battles
I alone stand up tall
I alone fight for reality
I alone fight for sanity
I alone have an independence
I alone have an identity
I alone have a journey - a long journey
I alone am afraid
I alone struggle
EVERYONE UNDER 30:
• Together we are young
• Together we have a voice
• Together we need our freedom

ALL:
• Together we fight battles
• Together we stand United
• Together we fight for reality
• Together we fight for sanity
• Together we are a Community
• Together we are friends
• Together we have a long journey
• Together we have no fear
• Together we succeed
• Together we create a Revolution of Hope.
Join us on line!

- Like us on Facebook: [https://www.facebook.com/easacommunity/](https://www.facebook.com/easacommunity/)
- Visit our website: [www.easacommunity.org](http://www.easacommunity.org)
- Also: [http://www.pathwaysrtc.pdx.edu](http://www.pathwaysrtc.pdx.edu)
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