Behavioral Health is Essential To Health

Prevention Works

Treatment is Effective

People Recover
Gaining Momentum in Early Psychosis

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EASA Center for Excellence
Lessons from Oregon’s Early Assessment and Support Alliance
Oregon Early Assessment and Support Alliance (EASA)

- 2001 *managed mental healthcare initiative* in 5 counties (Mid-Valley Behavioral Care Network)
  - *Roots: Early Psychosis Prevention and Intervention Center (EPPIC)* in Australia

- 2007 legislature began *statewide* effort; Oregon Health Authority position created
  - *Subsidy to ensure access regardless of funding*

- *EASA Center for Excellence* partners to provide coordination, training, consultation, coaching, practice guideline and fidelity review development, planning and program development support
Gaining Momentum

- Understanding and articulating the importance ("call to action")
- Understanding what is needed & where we’re headed (before/after/how to get there)
- Gaining leadership & champions
- Learning from other places about what can be done
- Learning from our own experience
- Ongoing collaboration
Understanding and articulating the importance
“Deep History”

- Institutionalization; early recovery movement
- Schizophrenogenic constructs
- “De-institutionalization”
- NAMI movement
- Case management (holistic needs)
- “Priority population” laws
- Decade of the brain
- New medicines & approaches
“Deep History”

- Still within our lifetimes
- Challenges with priority population construct
  - Prioritizes by illness but also by severity/chronicity
  - Didn’t address front door & access, particularly for privately insured
  - Disability track pushes people out of developmental path
How Things Have Changed with Schizophrenia Since the 1970s

- More awareness
- Recovery is more expected
- Growing movement of individuals in recovery & families
- Array of services developed (new medications, case management, supported employment, family psychoeducation, etc.)
- Olmstead Supreme Court decision
- Parity law
How Things Have Not Changed

- Hard to get help in most places when illness first begins
- First entry into the system often traumatizing & through involuntary means
  - *People still hear, “There’s nothing we can do”*
- People have to turn to public system to get appropriate care
- Appropriate care often unavailable
- Unemployment & poverty
- Families often not engaged
Common Experience of Individuals and Families

- Multiple layers of injustice & discrimination
- Blame
- Experiences & perceptions of isolation and abandonment: “There’s nothing we can do”.
- Not being heard or understood
- Not being able to access what helps
- Communication of hopelessness
Analogy

- Wheelchair: What if there were a center for people in wheelchairs that was located on the second floor and had no ramps or elevators, and no outreach?
  - Who would make it into service?
Analogy

• Heart attacks: What if the care available for heart attacks consisted of
  • Requiring multiple episodes becoming more imminent each time
  • Not talking to their family
  • Waiting until the person is near death
    • Taking away their rights
    • Putting them in handcuffs
    • Treating them, involuntarily, based on knowledge 20 years old
Understanding What’s Needed
Oregon’s Experience: Lessons in Building Momentum
Oregon Health Plan

- Medicaid reform, late 90s
- Creation of Managed Mental Healthcare Organizations (MHOs), 1997
- Has evolved into Coordinated Care Organizations (2013)
  - Organizations integrating or replacing MHOs
Mid-Valley Behavioral Care Network

• Focus on bringing person-centered prevention & evidence based practices
• Strong consensus governance including people with lived experience
• Investment to change outcomes for long term versus “nickel and diming”
• Interview with founders Jim Russell & Kathy Savicki: https://www.youtube.com/watch?v=LAiK7R5E6W4
Mid-Valley Behavioral Care Network

- While people with serious mental illness are a small percentage they were costing the most.
- Easy to embrace hopefulness of early psychosis intervention vs. “throwing people away at great public expense”
- “Help people live the life they can live, not entertain them or give them a diversion from smoking cigarettes.”
What Individuals & Families Need

• Rapid, helpful response
• Someone to listen, care, communicate and persist
• Education, support
• Problem solving
• Access to current and holistic care
• Partnership with mental health
• Support for developmental progress
• Hope
Early Psychosis as a System Intervention

• Easy to find (community education)
• Accessible based on symptom presentation (outreach, attention to barriers, all payors)
• Service mix based on current evidence
• Participatory decision making
• Training, accountability
Core Elements of Early Psychosis Services Which Should be More Broadly Available

- Outreach and engagement
- Strengths focus
- Support for school and work (Individual Placement & Support)
- Medicine - Start low, go slow, targeting specific symptoms, with close attention to side effects
- Counseling targeting shared explanatory model,
Key Ingredients

- Top leadership - lead genuine clinical change & clear away barriers, make sure financing is there
  - Need to care about this no matter, when money’s tight and when there’s resistance
- Put in the hands of the right program manager who has a vision and is persistent
- Unwavering commitment will attract resources
Key Ingredients

• Don’t make it up; build on evidence & experience.
  • “Make your pie from known ingredients.”

• Public health approach- don’t wait for people to become and stay severely ill for a long time before they can access care.
  • Need to integrate private insurance & non-Medicaid funds.
Key Ingredients

• Services are guided by what the person and family want for their lives
  • “It upsets a traditional mental health paradigm where the mental health professional is the expert.”
  • Not plugging them into a program; putting them in the driver’s seat.
  • Disability not the ticket to receiving services.
How Oregon Gained Traction

- Brought together advisory group; everyone clear they wanted to do it
- Planning process
- Brought clinicians together to figure it out
  - Saw themselves as allies & problem solvers
  - Leadership support to allow them to act differently
- Kept staying with it and evolving it
Lessons Learned

• State dissemination - took several legislative sessions, made it further each time
  • Gained strong support from state mental health director over time
  • Told stories; talked about it over and over again
  • Written materials with graph; individuals in program testified
  • Tied to Olmstead and rebuilding state hospital
NAMI Minnesota’s Efforts

• Understanding Psychosis Booklet
  • Psychosis/Mental Illnesses
  • Recovery
  • Engaging Young People in Treatment
NAMI Minnesota’s Efforts

- Understanding Psychosis Booklet
  - Treatment: Medications, Psychosocial, Intensive Supports
  - Physical Health Concerns
  - Education and Employment
  - Resources
NAMI Minnesota’s Efforts

- Workshop for Young People & Families
- Partnership with Blue Cross Blue Shield of MN & U of MN Medical Center First Episode program to provide one-on-one support to families
The Growing Momentum in First Episode Programs

Darcy Gruttadaro, J.D.
Director, NAMI Child & Adolescent Action Center
NAMI’s Work on First Episode

- NAMI was extremely pleased to see that early and first episode psychosis programs include peer support and family support and education.
- NAMI has long recognized the key role that peers and families play in the recovery of their loved ones.
- This is especially true for youth and young adults.
In early 2015, NAMI created an FEP Learning Community to educate and inform the grassroots about early and first episode psychosis programs. The level of interest and involvement is tremendous with about 40 grassroots leaders involved in this work.
NAMI’s FEP Learning Community

What are we doing with the learning community?

- Connecting NAMI with leading researchers and program directors.
- Hearing from NAMI grassroots leaders about their work on early and first episode psychosis.
- Brainstorming on how NAMI can help to bring these programs into more communities.
What is NAMI doing to spread the word about early and first episode psychosis?

- Developing outreach resources.
- Adapting NAMI programs like Say it out Loud, Ending the Silence, Parents & Teachers as Allies and others that reach children, youth, young adults and families.
- Creating toolkits to educate and inform community leaders about these programs.
NAMI’s FEP Learning Community

- We recently launched a new web-section for resources – a work in progress: www.nami.org/feplearningcommunity.
- We recognize the importance of collaboration and partnership in the broader dissemination and implementation of these programs.
- We look forward to the work ahead.
NAMI’s FEP Learning Community

Contact me to join our FEP learning community or to learn more

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Questions?
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