

# 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*



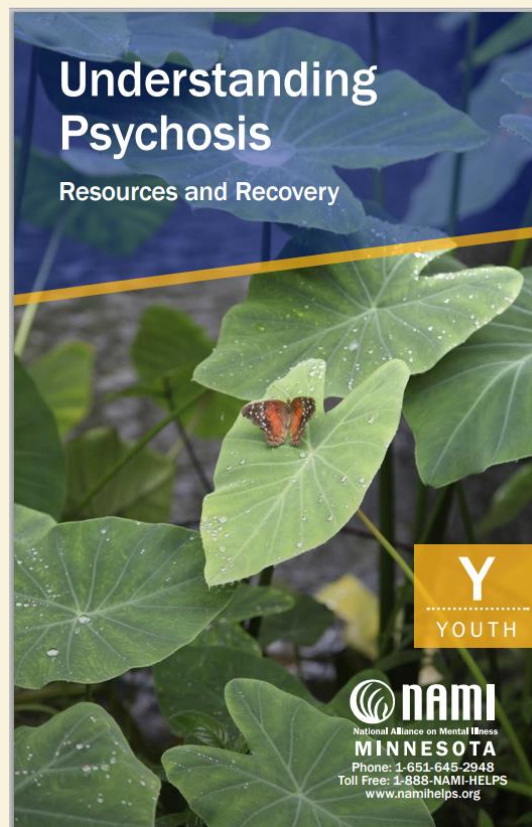
# Sue Abderholden, Executive Director

**NAMI Minnesota**



# NAMI Minnesota's Efforts

- **Understanding Psychosis Booklet**
  - *Psychosis/Mental Illnesses*
  - *Recovery*
  - *Engaging Young People in Treatment*

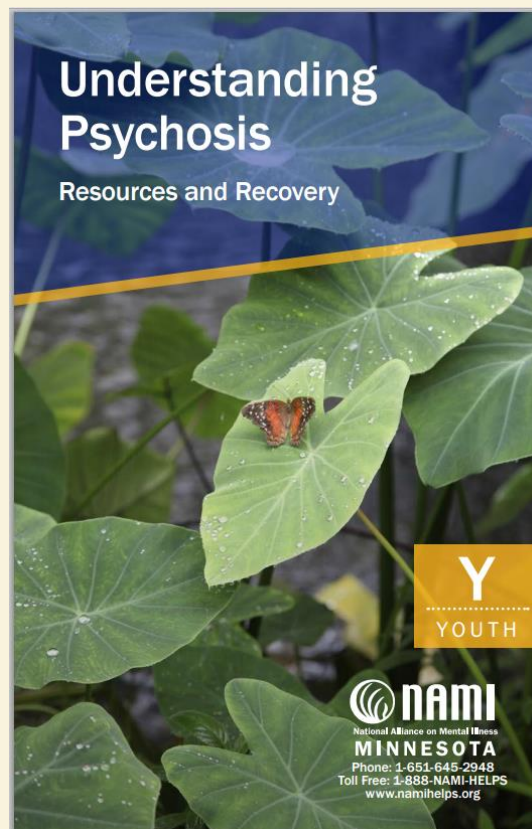




# NAMI Minnesota's Efforts

- **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.**

# NAMI's FEP Learning Community

- 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.*

# NAMI's FEP Learning Community

- **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](http://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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