Integrating the Evidence into an Evolving System of Care: Oregon’s Experience

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Unprecedented opportunity

• We have the potential to achieve a series of major breakthroughs in care throughout the west coast (and across the country and world).

• Well-aligned efforts building on lived experience and community perspectives, and carefully considered research will get us there faster.

• Oregon, California and New York are well-positioned to be catalysts.

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• Quick introduction to how Oregon has evolved
• How Oregon has used a shared context and framework to move forward more rapidly toward a new standard of care
• Reflections on integration of research into community implementation: cautions and opportunities
• Opportunities for share for action
Integrating the Evidence into an Evolving System of Care

- Oregon is not California but we both care about young people and families!
- How Oregon created a shared context and framework a new standard of care
- How EASA is informed by research and how a community-based perspective changes the way we think about research
- Where we are going from here: common opportunities and challenges
A Quick comparison

- 4 million people
- 40 people/square mile
- 22.6% under 18
- 12.7% Hispanic/Latino
- 4.4% Asian
- 2.1 Black/African American
- 9.9% born in foreign country
- Suicide rate 15.9/100,000

- 38.8 million people
- 237 people/square mile
- 23.3% under 18
- 38.8% Hispanic/Latino
- 14.7% Asian
- 6.5% Black/African American
- 38% “White alone”/not Hispanic
- 27% born in foreign country
- Suicide rate 9.4/100,000
Something we Share
(the proposed state of Jefferson)
Other things we share

- The wine industry
- Our property tax limit measure
- Legalized marijuana
- “West coast politics”
EASA Timeline

• 1997  Oregon Health Plan
• 1999  Researcher hired (Australia)
• 2001  5-county program
• 2006  Iterative development
• 2007  Entered research: EDIPPP
• 2007  Statewide dissemination
• 2010  RAISE Early Treatment Program (Lane County)
• 2013  EASA Center for Excellence
• 2014  PEPPNET; Congressional action
How Oregon has Conceptualized Early Psychosis Services

Goal: Early universal access and most effective and empowering care

Early psychosis programs as agents of change

Alignment of leadership, funding

Developmental framework (system, clinician, individual)

Facilitation of rapid adoption of effective practices

Individuals and families as owners

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Leveraging change in Oregon

- Common name, branding, eligibility (with flex), structure
- Common practices and learning process
  - Guidelines & fidelity
  - Ongoing training & forums
  - Data system
  - Website www.easacommunity.org
- Forums for problem solving & program development
- Shared decision making

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EASA

• Guided by lived experience and core philosophy
• Goal is long-term system change
• Integration of research and evidence-based practice
  • DUP research
  • SAMHSA “Toolkit”:
    • Individualized Placement and Support
    • ACT
    • Dual diagnosis
    • IMR (relationship to IRT)
• Low-dose prescribing; shared decision making
• CBT
• MI
• Feedback-informed treatment
• Occupational therapy
• Peer support
• Nursing
• Family psychoeducation (group and individual)

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**Lived Experience:** Philosophy; goal refinement; feedback; language; direction

**Research:** Goal refinement (qualitative, DUP, etc.); relative efficacy (RCT); emerging research, consensus (Delphi)

**Organizational:** Developmental goals; process evaluation; quality improvement

**CBPR**
Research translation: what we look for changes how we see the evidence

- Symptom remission
- Duration of “untreated” psychosis
- “Preventing” schizophrenia
- “Functioning”
- Developmental progression, locus of control and identity
- Participatory decision making and empowerment
- Social determinants:
  - Social network
  - Income level and income security: safety net, education, vocation
  - Access to basic needs: housing, transportation, nutrition, safety
  - Belonging and social participation
Integrating the Evidence

• “Coordinated specialty care” is hybrid of multiple practices & fields

• Significant problems need work: metabolic disorder, developmental progression, sustainability

• Need to build our own evidence and consensus
On the verge of multiple breakthroughs

• Earlier and more accurate engagement
• Understanding cognitive and sensory underlays
• Better understanding of the phenomenology of psychosis (biological, experiential)
• Systematic workforce development
• Multiple emerging treatment methods
• System of care approaches focused on developmental progression and multiple life domains
• Vocational and career support approaches

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Evidence-based practices: challenges

- RCT standard often means older data and practices
- Requires multiple RCTs with large enough numbers
- Researchers usually define questions
- Evidence base developed with older populations in long-term services
- Multiple fidelity requirements (IPS, ACT, CSC, etc.)
- Key disciplines and practices missing (engagement, peer support, nursing)
Limitations of research findings

• Controlled conditions
• Eligibility restrictions
• Timing driven by funding
• Years to come to publication
• Negative results often go unpublished; data is sometimes presented in its most “favorable” light
• Statistical significance does not always translate to individual
• Lack of bridge between experiment and implementation
The line between research/evaluation and advocacy

- Potential for over-interpretation and over-statement
  - Community members are easily misled by downward graphs
- Lack of guidance on adaptation (age, cultural, variation in presentation)
- “Proving the case” versus continual learning
  - Proving the case is easy when things are as bad as they have been!!
  - Can’t be complacent with what we’ve learned so far

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Implementation dangers in early psychosis

- Population vs. clinic-based framework
  - Who is left out? Who is not engaged?
- Unintended consequences of cliffs”:
  - Prodrome vs. FEP,
  - Two-year vs. long-term support
The power of numbers: EPINET

- Rapid learning process
- Defining common data set and practices
- PhenX measures first step
Creating the field!

• Lots of California examples (university-local connections)
• Social media strategies, reducing metabolic disorder (Orygen, UC Davis, New South Wales)
• Clinical high risk national meeting
• Data sharing: NAPLS and EDIPPP (Risk Calculator)
• Beginnings of Community-Based Participatory Research: EASA Connections example (Lived experience and our movement toward community-based participatory research)*

* funded by National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), through Portland State University's Pathways program

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EASA Connections Logic Model

**Inputs**
- Online psycho-educational content on EASA, psychosis, self-determination, shared decision-making, discrimination and stigma, community and social engagement
- Online forms and worksheets for shared decision-making and self-understanding
- Peer navigator

**Activities**
- Use Modules
  - Browse psycho-educational content
  - Use forms and worksheets
  - View EASA Graduate stories
- Interact with Peer
  - Module introduction
  - Monthly check-in

**Outputs**
- **Intervention Fidelity**
  - % clients completing
  - % of modules viewed-monthly checkin / server metrics
  - % of worksheets used
  - # peer contacts
  - Fidelity checklists from RA/peer/others?
- **Intervention Acceptability**
  - Client satisfaction with online resources (evaluation/qual)
  - Client satisfaction with peer navigator (evaluation/qual)
  - Peer navigator / clinical team satisfaction (qual)

**Outcomes**
- **Immediate**
  - knowledge of psychosis, self-determination, treatment, goal-setting (confidence meas.)
  - attitudes about psychosis (ISMI), treatment, self-efficacy (GESES-6), hopefulness (LOT-R), desire to connect (EASA items)
  - skills with communication, goal-setting, self-advocacy (confidence meas.)
- **Short-term**
  - retention / increase of social support (MOS-SS)
  - Increased self-esteem (Rosenberg)
  - Decreased internalized stigma (ISMI)
  - Increased engagement in treatment that is in alignment with client's self-determined goals (confidence meas.)
  - Retention/engagement in existing important activities (activities item)

**Impact**
- Achievement of self-determined (Basic Needs in General) goals (e.g., school, employment, relationships)
Getting Back to Life

2 Stages of Adjustment

Getting back to life after experiencing psychosis isn't easy for most people. Some have to re-learn everyday things, like talking or making a sandwich. Some are afraid of bad experiences happening again, or are embarrassed by who saw them when weren't acting like themselves. Getting back to life is a process. For a lot of people, that process happens in the stages described below. The stages may come in small steps, and some may happen at the same time or more than once.
How We Might Learn from Each Other

- Articulate common goals across programs
- Work on clear measurements to facilitate comparability
- Challenge our field’s assumptions (i.e. is short DUP always good?)
- Participate in research and peer review
- Work toward Community-Based Participatory Research approaches and practice-based evidence
- Recognize and facilitate sharing of diverse expertise
“Crowd-sourcing” research
(Large-scale peer review??)

• What does research teach us; what other data is available?
• How can this help us?
• What conclusions should we NOT draw?
• Are we asking the right questions?
Integrating the Evidence into an Evolving System of Care

• Oregon is not California but we both care about young people and families!
• Creating a shared context and framework can help us move more rapidly toward a new standard of care
• We need to integrate research but learn from lived experience and how a community-based perspective
• We will all play a role in an exciting time of important break-throughs.

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Join PEPPNET!

To join, please submit this brief enrollment form: [https://www.surveymonkey.com/r/3RD6DN7](https://www.surveymonkey.com/r/3RD6DN7)

There is no cost to join and membership grants you access to the national PEPPNET listserv and notification of resources, training opportunities, and events.

For other questions, please contact Program Manager, Vicki Harrison at vickih@stanford.edu or complete the form below.

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Working in California? You can also join the CA-PEPPNET listserv. This is a Google Group for providers and interested colleagues across California working with programs that focus on early identification and intervention for young people and their families. To join, please...
To contact us...

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