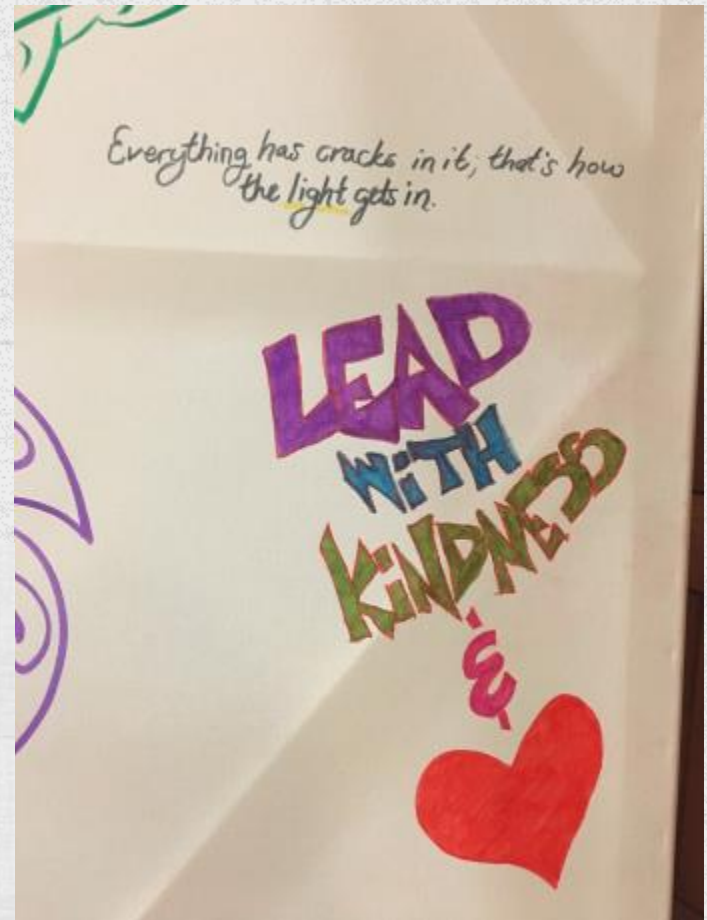
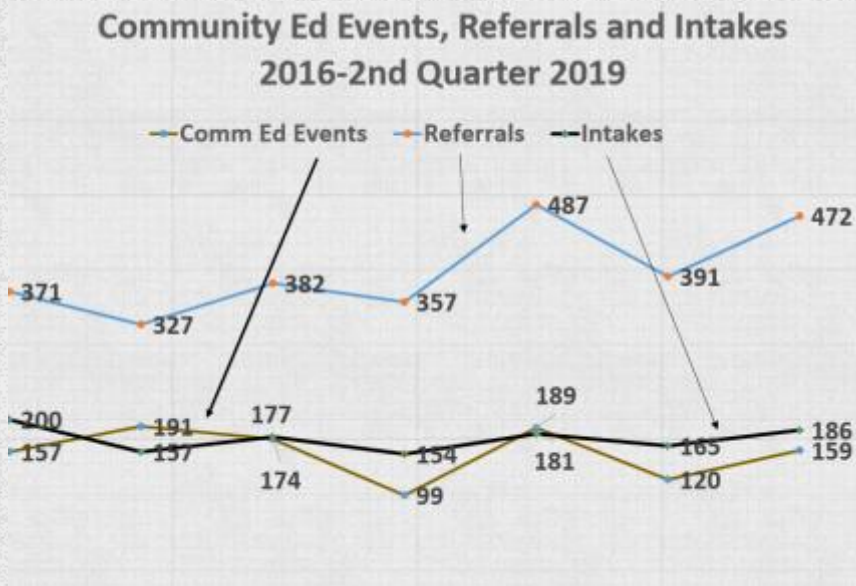


# *Transforming Our Culture...*



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# Embracing Lived Experience and Evidence



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# *Introducing Ourselves*

- Nybelle Caruso
- Nicholas Buekea
- Tamara Sale



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# ***EASA Origins***

- Created 2001 from Oregon Health Plan / Mid-Valley Behavioral Care Network
- Combined anticipatory decision making, evidence based practice/prevention focus
- Iterative 2001-present
  - University of Melbourne Early Psychosis Prevention and Intervention Center (EPIC)
  - SAMHSA Toolkits
  - Practice guidelines/fidelity/training, statewide dissemination (2008 forward) [www.easacommunity.org](http://www.easacommunity.org)
- 2013 Center for Excellence/Young Adult Council
- 2014 huge national expansion of CSC



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# *Discussion Today*

What is the context and history of the early psychosis field?

What is the current state of the early psychosis field?

How do lived experience and evidence-based practice relate to each other?

What will an outcome-driven, equitable and person-centered system look like?



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# *Core Messages*

- We are in an unprecedented position to RE-DESIGN our systems based on the strengths, needs and voices of people as well as evidence
- Importance of including and amplifying voices of lived experience
- Multiple forms of knowledge are needed





# *How did the early psychosis field get to where it is now?*

- Systems not aligned to people's diverse strengths and needs
  - Negative experiences with the system & resulting lived experience advocacy
- New research & scientific advocacy
- Intense commitment at multiple levels





# *Historical Barriers and Challenges*

- Not knowing what to look for, where to go
- Mental health center inflexibility (insurance, unwillingness to talk to family, requirement to be “motivated for treatment” or “imminent threat”, lack of outreach)
- Negative assumptions and little focus person’s strengths, developmental stage or culture



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# *Effects of involuntary hospitalization or legal involvement*

- Trauma
- Adversarial relationship
- Higher doses/side effects
- Negative self-image
- Disrupted life
- Criminal record



# *Where we came from*

- Crisis and deficit focus
- Treating symptoms but not supporting independence and growth
- Medication without partnership
- Rates of unemployment around 90%
- Mortality 10-25 years earlier than the rest of the population





# *To be a mental patient, Rae Unziker 1984 © (Photo: When Women Pursue Justice, Brooklyn)*

To be a mental patient is to be stigmatized, ostracized, socialized, patronized, psychiatrized.

To be a mental patient is to have everyone controlling your life but you. You're watched by your shrink, your social worker, your friends, your family. And then you're diagnosed as paranoid.

To be a mental patient is to live with the constant threat and possibility of being locked up at any time, for almost any reason.

To be a mental patient is to live on \$82 a month in food stamps, which won't let you buy Kleenex to dry your tears. And to watch your shrink come back to his office from lunch, driving a Mercedes Benz.

To be a mental patient  
and then you take medicine

To be a mental patient  
the hospital, and then  
is not to matter.

To be a mental patient

To be a mental patient  
and hungry and bored and broke as you are.



nses, make you jitter and drool

s or years, because you've been in  
al patient. To be a mental patient

mental patients who are as scared

# *Changing the system and culture*

- Proactive engagement: both individual and family/supporters
  - Rapid accessibility
  - Strengths and resilience focus vs. disability
  - Persistence and trust building
  - Grounded in the person's culture
  - Shared decision making
- Focus on evidence
- Developmental focus, support for school, work
- Doing what works for the person & family
- Long-term relationships and leadership
- Continuity





# ***Brief History***

- Consumer/survivor movement
- Deinstitutionalization, Community Support Systems Movement
- Family movement
- Finance reform (Managed Care/Oregon Health Plan; ACA; Federal Block Grant allocation)



# Brief History

- Research

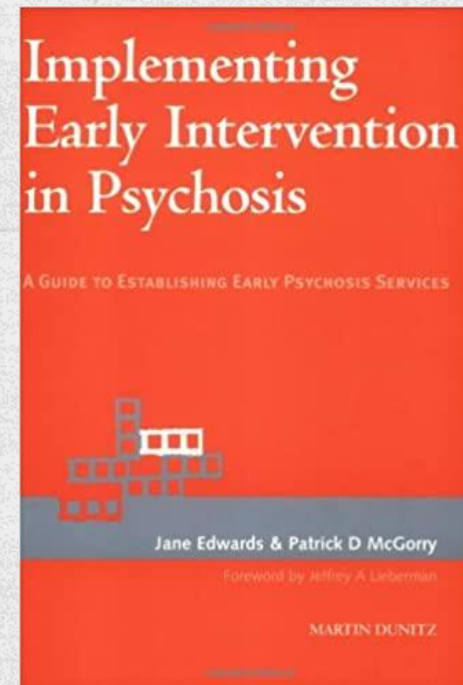
- Duration of Untreated Psychosis

- Clinical High Risk/Onset

- North American Longitudinal Study
    - EDIPPP
    - SAMHSA grants

- Treatments

- Evidence-Based Treatments (CBT, family psychoed, ACT, Individual Placement and Support, etc.)
  - Emergence of Early Psychosis Programs (Scandinavia, Australia, UK, U.S., etc.)
  - RAISE (ETP/Navigate; Connections/OnTrack New York)



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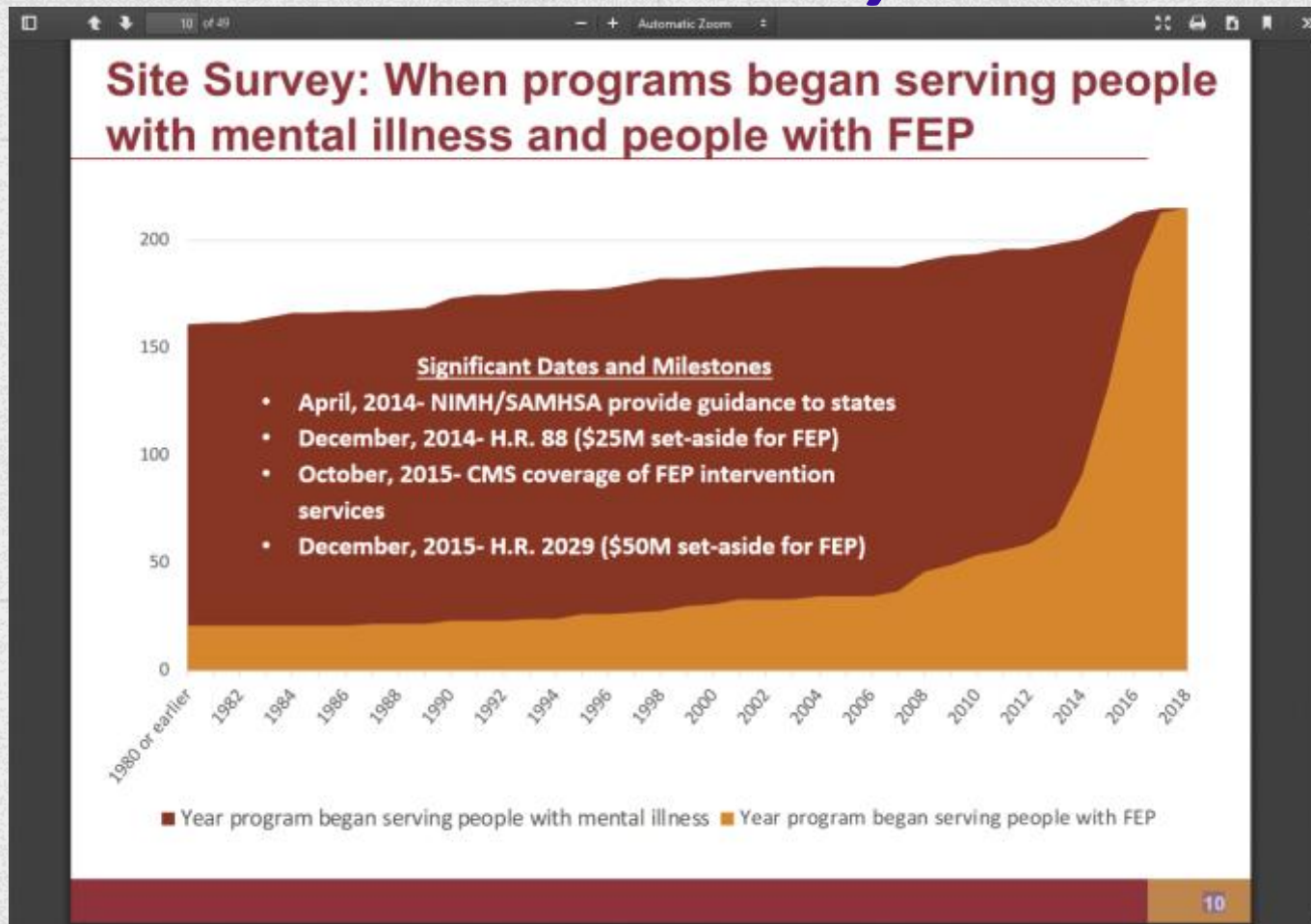


# *The Concept of “Coordinated Specialty Care”*

- Term introduced after RAISE (NIMH)
- Early versions of the “team” were less robust
- Supported employment & education central feature
- Peer support not included originally but most programs have it
- Some models include nursing, occupational therapy, supported housing, other disciplines



# Growth in CSC (Westat MHBG Evaluation)





# *Interesting Findings*

- Extensive use of peer support
- Large number of rural/frontier sites
- Relationship between outcome and fidelity
- Challenges:
  - Staff turnover
  - Transition/discharge planning



# Useful Networks

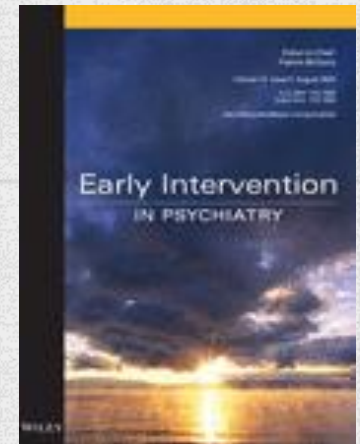
- PEPPNET:

<http://med.stanford.edu/peppnet.html>

- List servs & collaboration
- Annual conference (SMI Advisors/APA)

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

- Biannual conference
- Free journal (Early Intervention in Psychiatry)

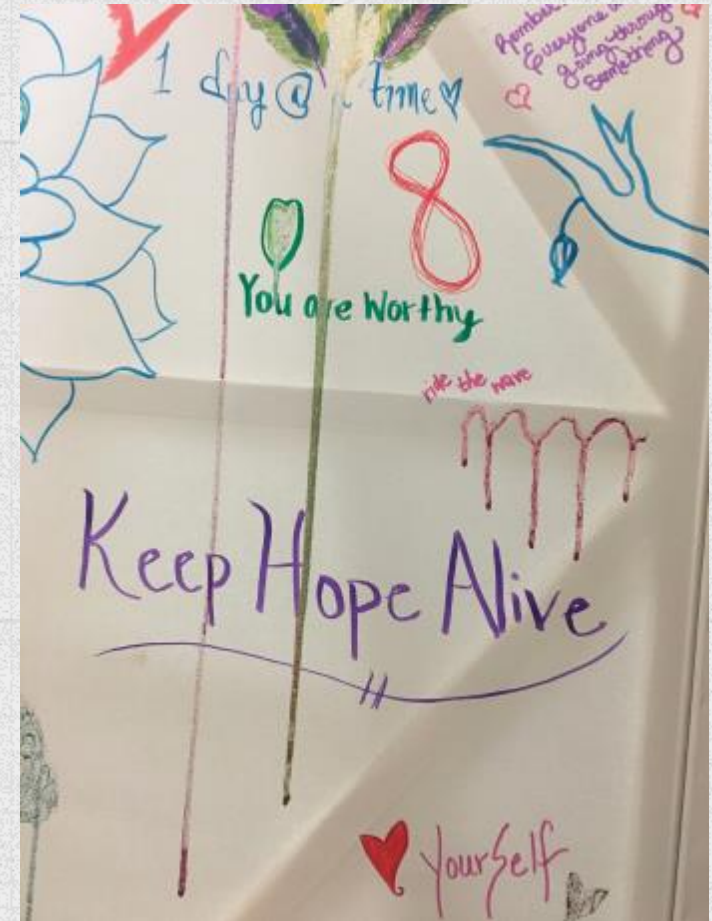


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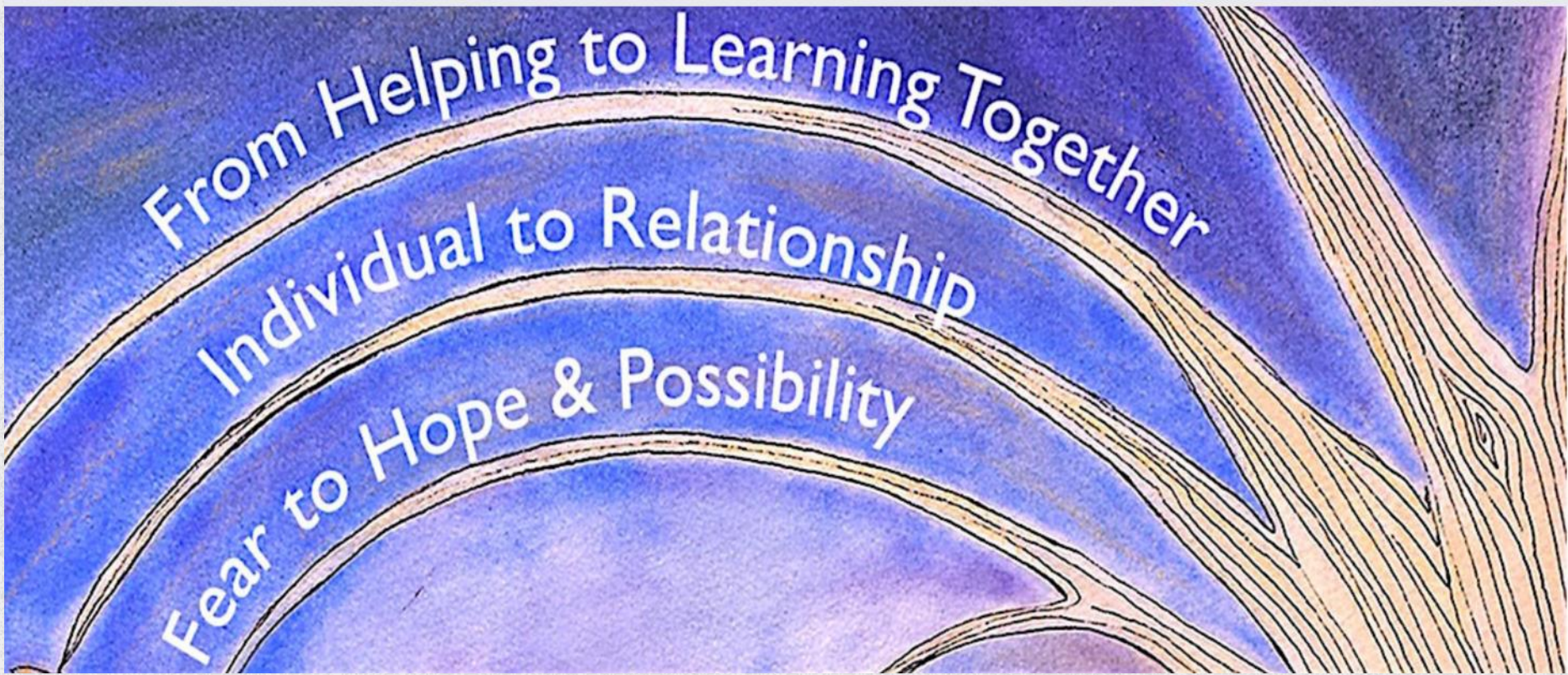


# Changing our culture: Some guiding principles

- Intentional re-design to change results
- Systems built on listening, shared decision making
- Each person and discipline is unique and essential
- Learning from diverse expertise and perspectives (peer support example)







<https://www.intentionalpeersupport.org/coreflection/?v=b8a74b2fbcbb>



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# ***PURPOSE: Why we're here***

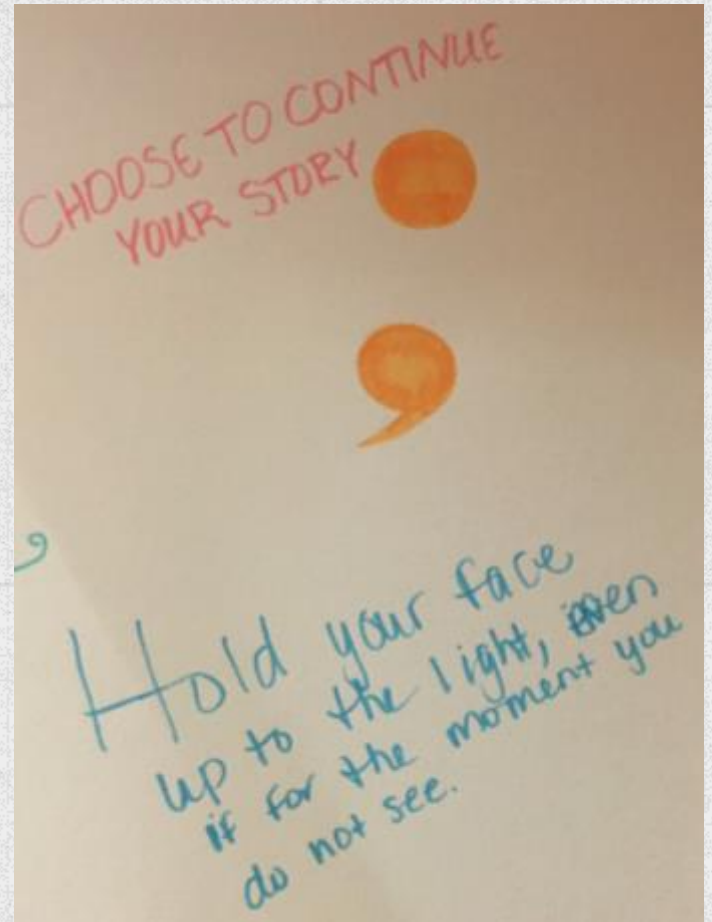
- Lived experience perspectives and advocacy



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# *Institutional Equity*

- Ground services in the perspectives of the individuals we wish to serve
- Significant differences in access, relevance of services
- Need to understand how patterns of historical oppression continue to play out
- Confront injustices & build new practices together





# *The Opportunities before Us*

- Huge traction, expertise and tremendous resources nationally & internationally
- Significant gaps (justice system and hospital diversion, school support, long-term supports)
- Design for results
  - Inclusive leadership
  - Learning health systems
  - Community-engaged research



# ***Early Psychosis Information Network (EPINET)***

- National learning health system
  - Aligned measures (community and research centers)
  - Centralized data system
  - Ability to focus on less populous groups
  - Goal: Rapid cycle of research and practice advances





# *Lived Experience Interfacing with EBP*

- How did this study come about? Who designed the study? Who was included and excluded from the study? How did it define success?
- What are its strengths and limitations? How can we remain true to the EBP while making it relevant and accessible in our community?
- How can we add to knowledge: Engaging people with lived experience in defining questions, outcomes, evaluating research methods, doing research (Participatory Research)



# *How do we define purpose and measures of success (and who are “we”)?*

- Important not to be too narrow symptoms and “relapse”
  - Distress and/or impact on functioning
  - Side effects
- Equipped for life & self-advocacy
- Preserving and encouraging family and community relationships
- Sense of well-being, self esteem, self-determination
- Developmental progression (identity, decision making, relationships, school/work)





# ***EASA Young Adult Leadership Council***

- Young adults who have graduated or are near graduation from EASA
- Combine program results and lived experience
- Self-directed prioritization
- Iterative feedback on statewide EASA activities
- Ongoing effort to expand participatory opportunities statewide

# The EASA Young Adult Leadership Council: Our Experiences and Vision

**W**e are the EASA Young Adult Leadership Council. We are from different cultures and we range in age. All of us have been affected socially, emotionally, and mentally by the break from our previous perceptions of reality, called "psychosis." We have felt alone, afraid, and misunderstood. We have also felt stronger in the end for having had those experiences. Our group includes a high school student, college graduates, and individuals pursuing professional paths such as peer support, occupational therapy, music, and law. We offer mirrors of hope and inspiration to each other. We have a common vision: "Uniting the voices and strengths of young adults and their allies in order to create a thriving community and revolution of hope." EASA teams work to be welcoming, respectful, and honest. They listen and keep you in the lead. They give the message: "This is a normal experience and we are here to help you." EASA includes mental health professionals, supported employment and education specialists, peer support specialists, occupational therapists, psychiatrists, and nurses. Shared decision making is at the core, and recognizes the diverse needs and perspectives of each person:

*"It's your battle but others are there to support you."*

*"I needed a place to live and someone to work with my family."*

*"The information I needed as a high school freshman was different than what I would have needed if I were a pre-med student."*

*"I wanted to read and explore the research articles. I understood them."*

Navigating our way from fear to hope, self-acceptance, independence and wellness takes trust, patience, and persistence:



Photo: Some members of the EASA Young Adult Leadership Council

*"Experiencing a mental illness is a really scary thing. You think you are alone and the path is dark. Even the recovery path can be scary because there's the potential for relapse. You have to trust yourself and you have to trust what other people are telling you."*

*"Helping me to understand what I was experiencing made a huge difference."*

*"They were there for me when I went to the hospital, and didn't let me forget that I wanted to go to college."*

*"There's this idea that we're the microwave generation so that we expect everything to happen fast...It really takes patience and determination to...walk through recovery."*

We have struggled with our relationship with medicine. "Medication can be very empowering if the decision is truly made by the individual. Pressure can be subtle. The information can be stacked to make it look like the only option. If one option isn't working it's important to explore others that might."

We will make decisions that others disagree with, and it is important for us to be able to be honest and discuss our decisions without feeling shamed, blamed, or threatened.

EASA is not perfect. Some of us struggled with the early signs of psychosis for a long time before we found EASA. EASA teams vary and can be improved. We have struggled finding long-term support after leaving EASA's two-year program. We have at times been denied critically important care when leaving EASA because we had private insurance. We have found a larger system of care focused largely on maintenance and not much on career development, independence, and shared decision making.

Many of us have experienced ignorance and discrimination in school, employment, and housing. Some of us have experienced homelessness, involuntary hospitalizations, and criminalization. At times we have felt marginalized, reduced to the role of "pill swallower" and not having our full humanity recognized and honored. We have struggled to find our voices and to stand up for our rights. We are beginning to use our experience to develop policy recommendations and to help create a more educated and accepting community.

In spite of these obstacles, we have experienced graduations, new jobs and career paths, finding our ways back from relapses, new independence, new relationships, marriage, and becoming new parents. We have appreciated the opportunity to be on a professional leadership board which is both safe for self-disclosure and serious in its mission.

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.

We believe that the early psychosis field has the potential to radically change people's experiences for the better. "It is the difference between thriving and surviving." It is important for us all to come together in order to really create a revolution of hope. That revolution will involve more than just offering a service package for a couple of years. It will mean a different attitude and sense of ownership, confronting discrimination and injustice, valuing the importance of lived experience, and working in support of each other to change attitudes and practices in all the settings we encounter.

## AUTHORS

*Nicholas Buekea* is a Policy Research Assistant and member of the EASA Young Adult Leadership Council.

*Nybelles Caruso* is a student pursuing her BS, a peer support mental health professional, and member of the EASA Young Adult Leadership Council.

*Nicholas and Nybelles helped to weave the voices of EASA's Young Adult Leadership Council into a "united voice."*



**“It's your battle but others are there to support you.”**





Browser address bar: [https://easaconnections.org/index.php?mod\\_id=0](https://easaconnections.org/index.php?mod_id=0)





Browser tabs: early psychosis images - Go..., lord of the rings images fre..., free images castle and moa..., inaccessible castle free imag..., Female Participants In Obst..., When Women Pursue Justic..., Introduction



Navigation bar:  **EASA**  **EASA Connections**

Menu: Modules: ▾ Introduction ▾

Links: Download Contacts About

**Select a topic in Introduction to jump to it.**

-  Welcome to EASA  
expand section ↓↑
-  What is EASA?  
expand section ↓↑
-  What is psychosis?  
expand section ↓↑
-  What is self-determination  
expand section ↓↑

 **Welcome from Other EASA Participants**


Greetings!

Welcome new EASA participant! We are the *Young Adult Leadership Council*. We understand your situation and have



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EASA Connections

Modules: ▾

Shared Decision-making ▾

Download Contacts About

Select a topic in Shared Decision-making to jump to it.



Shared Decision-Making

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Medicine

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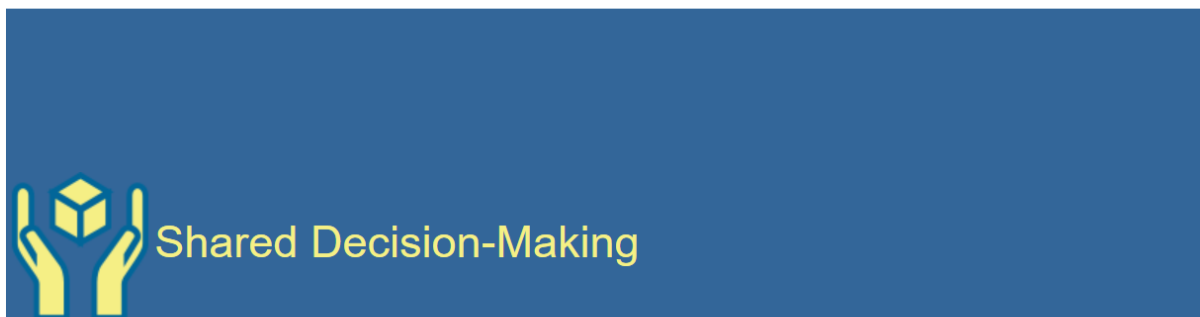


Other Types of Treatment

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Relapse Planning



What is shared decision-making?

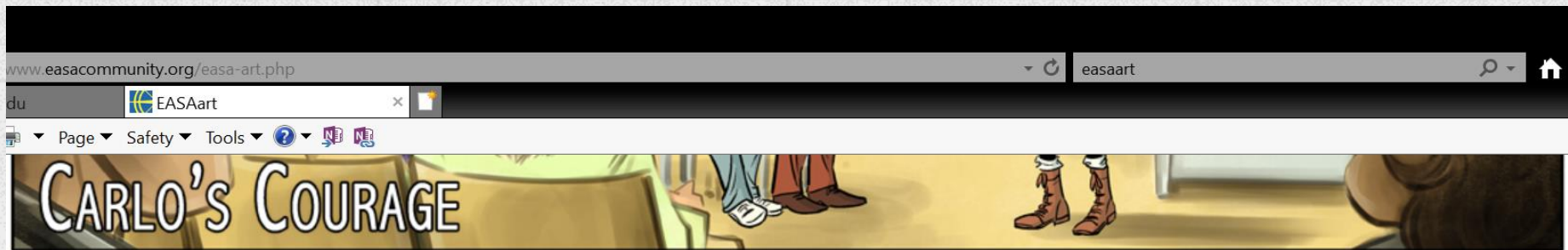
Shared decision-making is a way of making choices about healthcare and services. Shared decision-making is part of an approach to



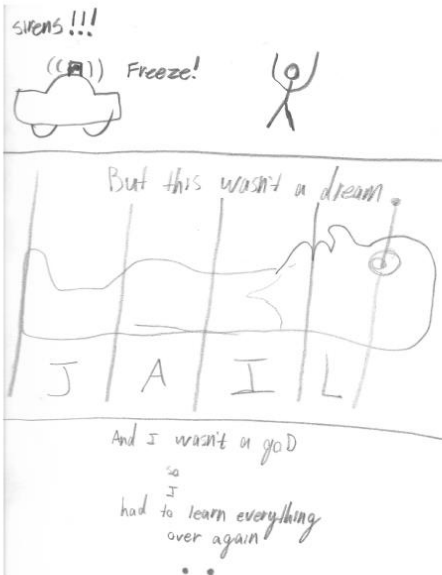
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# How do we make our messages relevant/digestable? (EASA Art)



# Buekea (in development)



I'm really worried  am I a psychopath?

No. what you went through is common. Most people who've experienced first-episode-psychosis, are usually around your age, early twenties for guys and a little later for gals. Regardless of gender, psychosis affects anyone from any culture, religion, class, creed, race, or hegemony. And that's just direct experience. Many people are family or friends with someone who's been through psychosis



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# *Reflections on what's been working & where we're headed*



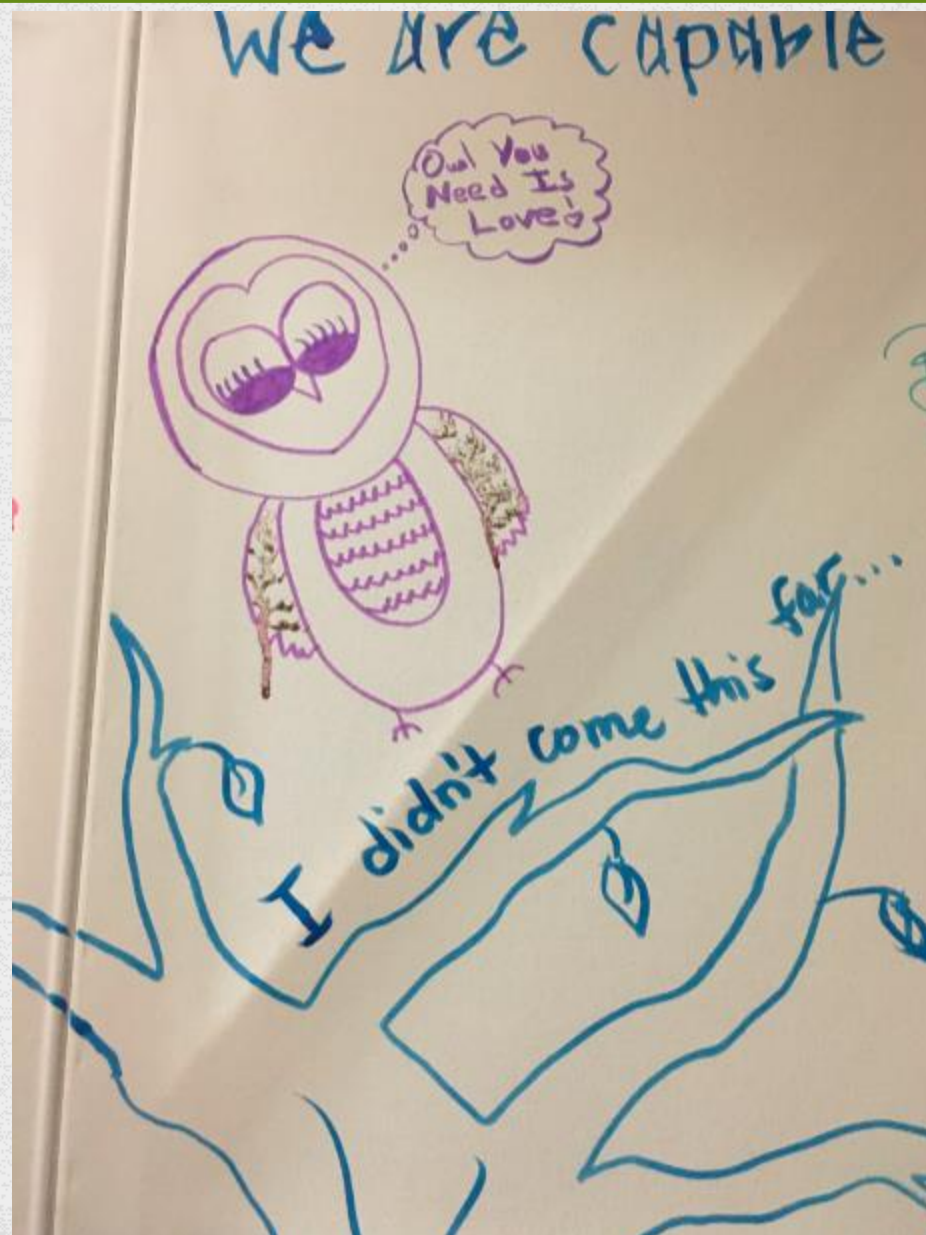
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## EASA Young Adult Leadership Council National Policy Platform

The EASA Young Adult Leadership Council is the outgrowth of Oregon's Early Assessment and Support Alliance, the first statewide effort to make early psychosis intervention universally available in the United States. Our group, which was created in April 2013, consists entirely of young adults who have graduated from EASA, as well as representatives from Youth Move. The Leadership Council works to unite the voices and strengths of young adults and their allies in order to help create a thriving community and a revolution of hope. Having directly experienced psychosis, we deeply appreciate how profoundly important these programs are. In reflecting on our experiences and the great momentum toward early psychosis intervention, our group has made the following recommendations for national policy development:

- ✓ The EASA Young Adult Leadership Council is interested in any attempts currently going on to reduce





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... anyone is  
going through  
something

m  
ve

self



I didn't come this far...

to only come this far.

Be gentle  
with yourself

Every





# Resources

- National Association of State Mental Health Program Directors trainings and products (including EDIPPP):  
<https://www.nasmhpd.org/content/early-intervention-psychosis-eip>
- National Council on Behavioral Health:  
<https://www.thenationalcouncil.org/topics/first-episode-psychosis/>
- NAMI resources: [www.nami.org](http://www.nami.org)
- RAISE:  
<https://www.nimh.nih.gov/health/topics/schizophrenia/raise/what-is-raise.shtml>
- Navigate: [www.navigateconsultants.org](http://www.navigateconsultants.org)
- OnTrack: [www.ontrackny.org/Resources](http://www.ontrackny.org/Resources)
- EASA: [www.easacommunity.org](http://www.easacommunity.org)



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# *The dialogue continues!*

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