

*We Can't Wait!*  
The Public Health  
Imperative for Early  
Psychosis Programs

Michael Haines  
Tamara Sale



# Our agenda

- Introduction
- The goals of Early Psychosis Intervention/  
Coordinated Specialty Care
- Contrasting stories: Tamara and Michael
- What CSC teams do
- History and implementation of CSC in the U.S.
- Implications for the future
- What we can all do: leveraging our actions today  
toward a new future



# Who we are: strengths and roles we play

- Michael Haines



- Tamara Sale



- Our audience today



# Oregon Early Assessment and Support Alliance (EASA)



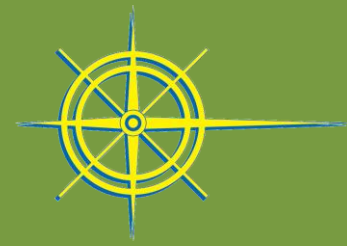
First early psychosis roll-out in U.S. public mental health system: 5 counties 2001; statewide 2007-present



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



# Oregon Early Assessment and Support Alliance



- Created **2001** by Oregon Health Plan managed care entity:
  - 5 counties Mid-Valley Behavioral Care Network
- Based on EPPIC in Australia
- Oregon legislature funded statewide dissemination starting 2007; goal is universal access in Oregon by end of next year
- 2010 (after EDIPPP study participation) expanded statewide to psychosis risk syndrome
- Approx. 500 people/year currently served
- 2013 legislature funded Center for Excellence and 4 young adult hubs to extend services to more transition-age youth

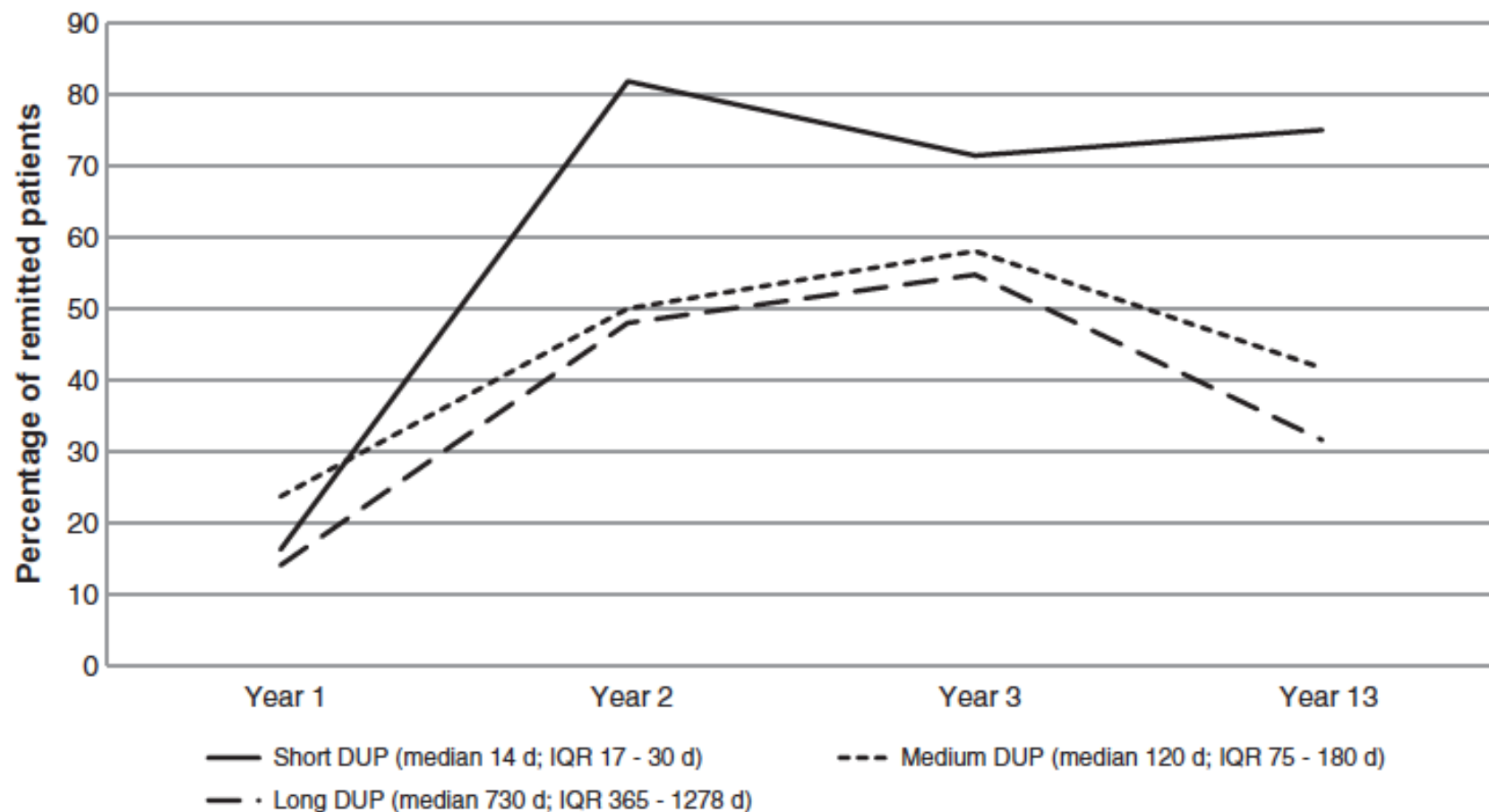


# Our most important messages

- Early psychosis intervention is desperately needed.
- It is a cultural and program shift which NAMI has been working toward from its beginning.
- Every NAMI member plays a part.



# Prospective relationship between duration of untreated psychosis and 13-year clinical outcome: A first-episode psychosis study: Percentage of patients in remission over the course of the illness, grouped by short, medium and long DUP.



Jennifer Yee-Man Tang et al Schizophrenia Research, Volume 153, Issues 1-3, 2014, 1-8



# Common experience without early psychosis intervention

- Obstacles, delays, trauma, isolation
  - RAISE ETP delay: 74 weeks
- Involuntary entry, lack of evidence-based care
- Families isolated
- Lack of supported employment or education
- High doses of medicine
- Negative messages and discrimination
- Institutionalized poverty
- Billions of dollars spent annually with poor outcomes

***But also...***

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





# Early psychosis goals

- Identify people as early as possible
- Engage in a positive and strengths-focused way
- Support the person and family to adapt and continue on developmental path
  - Evidence based treatment
  - Illness education and support
  - Supported employment and education
  - Person-centered approaches
  - Reinforcing social network
  - Transitioning gradually into ongoing supports



# Tamara's family story



# Putting CSC in context: Tamara's story

- No clear path to care: private-public disconnect
  - Ignorant and potentially harmful messages
- Escalating crisis & involuntary, traumatizing entry
- High doses of medicine and inattention to side effects
- Very limited support for school or work
- Lack of attention to the person's goals, family education & support, illness management skill development or normal developmental progression
- Dependency and adversarial relationships
- Years of ineffective, highly expensive care with poor outcomes
- Recovering from treatment effects as well as illness



# How Early Psychosis Intervention is Different: Cycle of Recovery & Wellness



Michael's story: still work to do,  
but headed in the right direction!



# 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

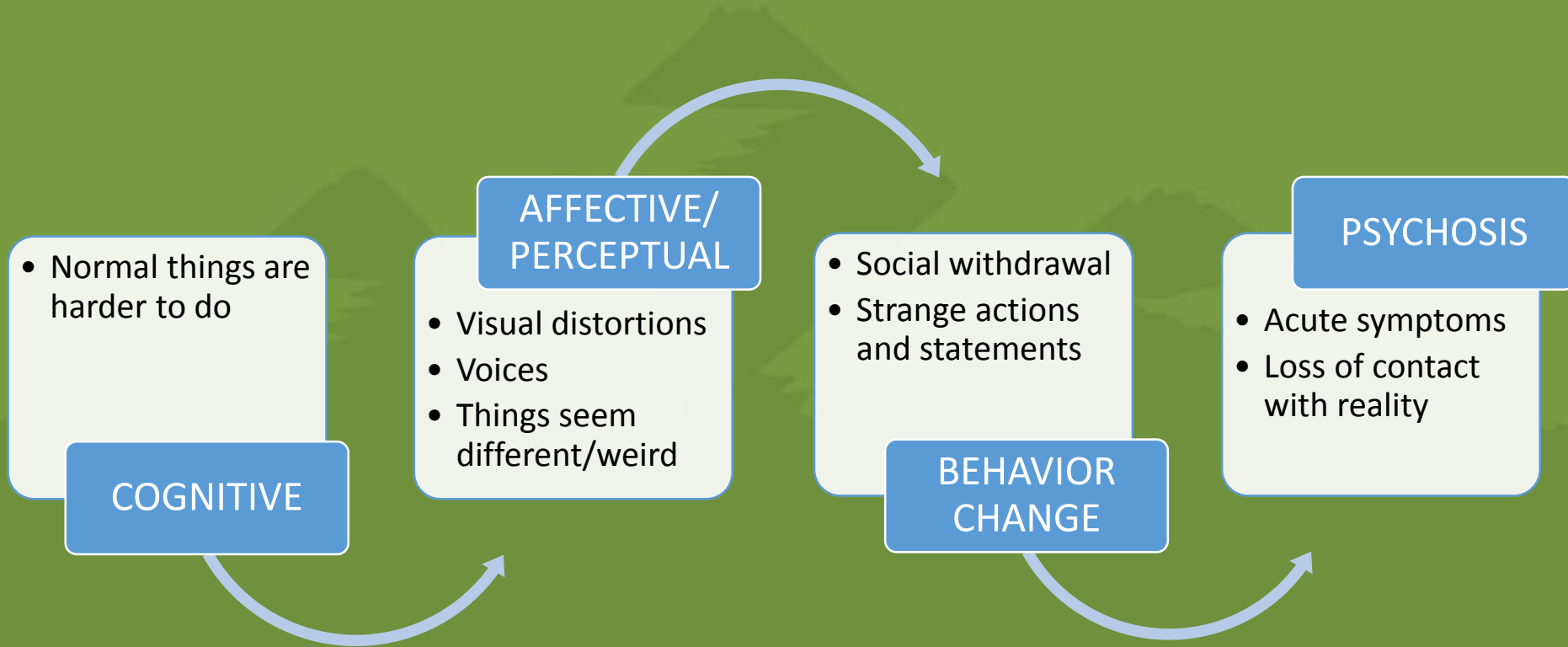


# Psychosis symptoms

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

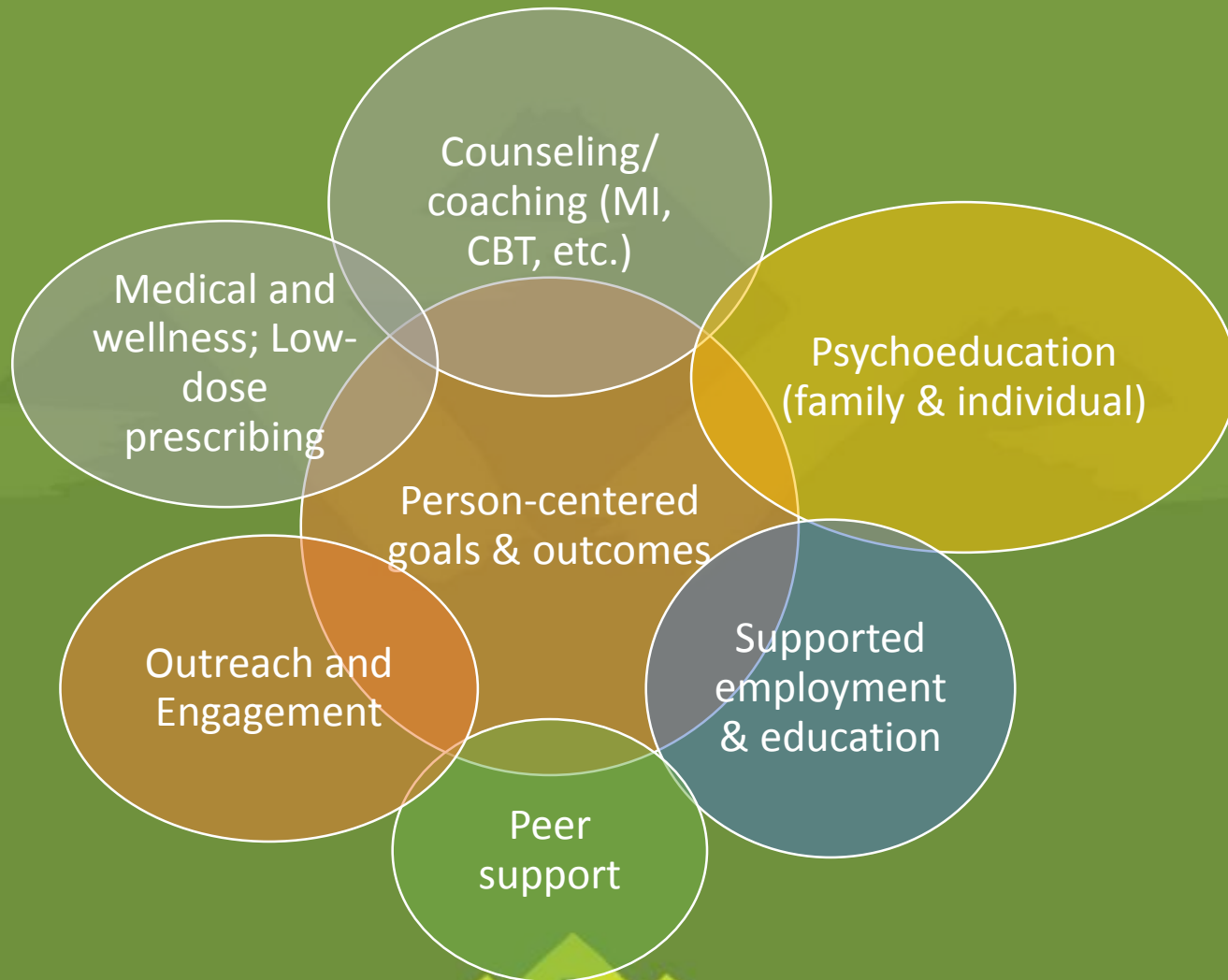


# Symptoms evolve over time





# CSC Strategies



# Coordinated Specialty Care Team

- Systematic integration of evidence base
  - Evolving!
- Intensity similar to Assertive Community Treatment (ACT): generally around 1 fte:10-15 participants
- Majority of care including substance abuse managed within team



# 1980s-1990s

- The end of the schizophrenogenic era
- NAMI created in 1979
- Advocacy and Community Support Systems movement
- Systems still driven by crisis and disability
- Clozaril
- Huge human rights issues



# More recent evolution

- Evidence-based practice
- Person-centered planning
- Supported employment
- Parity & health care reform
- Systems driven by recovery and functioning



# International research and implementation

- 1990s Early Psychosis Prevention and Intervention Center (EPPIC), Australia
- Scandinavia: TIPS/OPUS
- Growing international network coordinated through International Early Psychosis Association ([www.iepa.org.au](http://www.iepa.org.au))
- National dissemination in late 90s/early 2000s: Australia, New Zealand, England, Canada





# U.S. Research & Implementation

- Much university research has not made it to community
- North American Prodromal Longitudinal Study (NAPLS)- ongoing
- Hillside Hospital, UNC OASIS, UCLA/University of CA programs, Yale PRIME clinic, EASA 2001 (first episode; expanded statewide to psychosis risk 2010); PIER (Psychosis Risk, 2001)
- Early Detection and Intervention for the Prevention of Psychosis Program, 2007 (funded by The Robert Wood Johnson Foundation; psychosis risk and very early first episode using multi-family psychoeducation, ACT components, supported employment & education)
- RAISE Early Treatment Program & Connections (funded by NIMH), 2010; basis for most of current roll-out





National Institute  
of Mental Health

Transforming the understanding  
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# RAISE

Recovery After an Initial  
Schizophrenia Episode

A Research Project of the NIMH

Home > Health & Education > Mental Health Information > Schizophrenia

*The “Recovery After an Initial Schizophrenia Episode” initiative seeks to fundamentally alter the trajectory and prognosis of schizophrenia through coordinated and aggressive treatment in the earliest stages of illness.*



# NIMH RAISE Projects

## ■ Randomized clinical trial

- John Kane
- Nina Schooler
- Delbert Robinson



## ■ Implementation study

- Lisa Dixon
- Susan Essock
- Jeffery Lieberman
- Howard Goldman





# Recent Congressional Action



- Congressional action 2014, 2015 increased & set aside 5% of Mental Health Block Grant
- *Consolidated Appropriations Act, 2016 increases Mental Health Block Grant by \$50,000,000 and increases requirement to 10%*
- *2016 Act directs SAMHSA to continue its collaboration with NIMH to ensure that funds from the set-aside are only used for programs showing strong evidence of effectiveness and targets the first episode of psychosis.*

(See <http://docs.house.gov/billssthisweek/20151214/CPRT-114-HPRT-RU00-SAHR2029-AMNT1final.pdf>. The section on SAMHSA begins on page 907; information about the Mental Health Block Grant set-aside for FEP is found on pages 908-909.)



# 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.***”

–Heinssen, Goldstein & Azrin. *Evidence-Based Treatments for First Episode Psychosis: Components of Coordinated Specialty Care*. April 2014. Downloadable at [http://www.nimh.nih.gov/health/topics/schizophrenia/raise/nimh-white-paper-csc-for-fep\\_147096.pdf](http://www.nimh.nih.gov/health/topics/schizophrenia/raise/nimh-white-paper-csc-for-fep_147096.pdf)

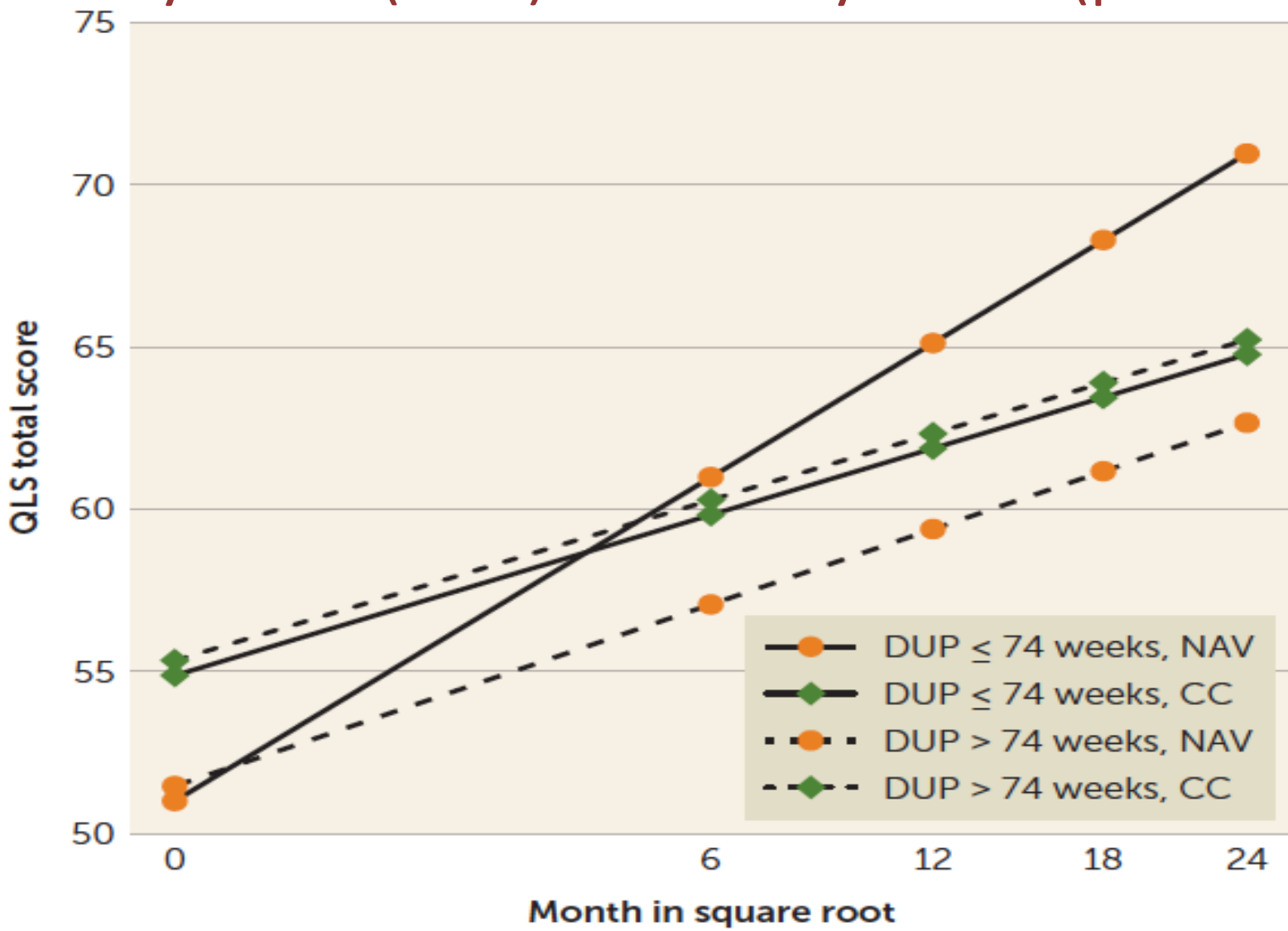


# RAISE Early Treatment Program Study

- Cluster Randomized Trial comparing clients (N= 223) at 17 sites randomized to Navigate vs at 17 sites randomized to usual care (N=181) for two years
- Navigate clients significantly more likely to remain in treatment, experienced significantly greater improvements in quality of life, were more likely to be in work or school, and had fewer symptoms

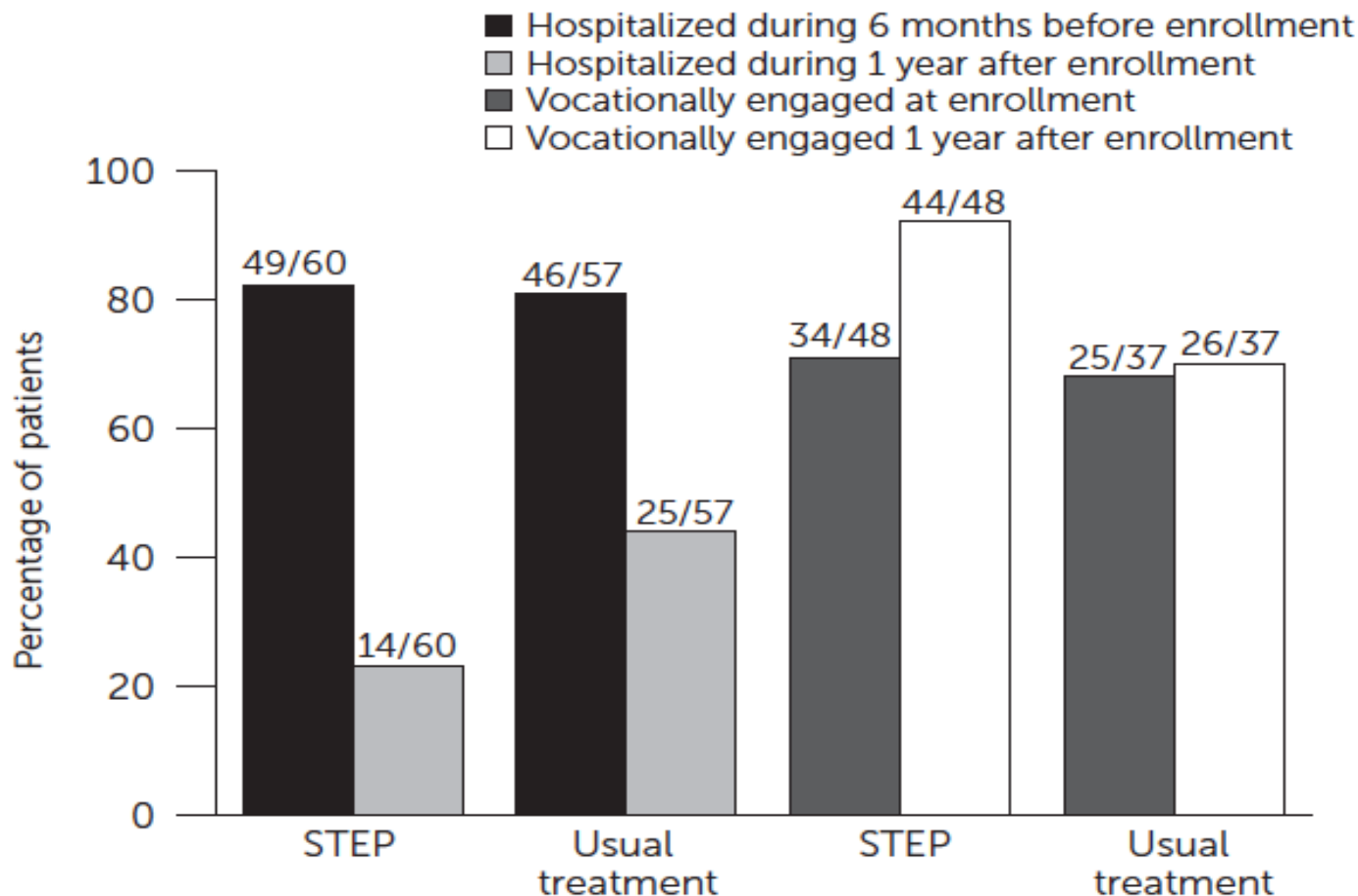


# Shorter vs. Longer Duration of Untreated Psychosis (DUP) on Quality of Life ( $p < 0.03$ )



Kane et al. [Am J Psychiatry](#). 2015 Oct 20:appiajp201515050632. [Epub ahead of print]

**FIGURE 1. One-year hospitalization and vocational engagement outcomes among STEP participants and those in usual treatment<sup>a</sup>**



<sup>a</sup>STEP, Specialized Treatment Early in Psychosis. Between-groups comparisons: for hospitalization rates (adjusted for pretreatment hospitalization), omnibus  $\chi^2=5.60$ ,  $df=1$ ,  $p=.018$ ; for vocational engagement (adjusted for pretreatment vocational engagement), omnibus  $\chi^2=9.56$ ,  $df=1$ ,  $p=.002$

# A Systematic Review of the Effect of Early Interventions for Psychosis on the Usage of Inpatient Services

Jason R. Randall<sup>1,2</sup>, Sherri Vokey<sup>3</sup>, Hal Loewen<sup>3</sup>, Patricia J. Martens<sup>1,2</sup>, Marni Brownell<sup>1,2</sup>, Alan Katz<sup>1,2</sup>, Nathan C. Nickel<sup>1,2</sup>, Elaine Burland<sup>2</sup>, and Dan Chateau<sup>\*,1,2</sup>

## Schizophrenia Bulletin Advance Access published July 29, 2015

Table 1. Summary of Included Studies

Study	Country	Design	Outcomes	Program
Agius 2010	UK	Cohort	Both	
Bertelson 2008	Denmark	RCT	Both	OPUS
Boden 2010	Sweden	Historical control	Both	
Chen 2011	Hong Kong	Matched historical control	Both	EASY
Cocchi 2011	Italy	Cohort	Bed days	Programma 2000
Craig 2004	UK	RCT	Both	LEO
Cullberg 2002	Sweden	Cohort and Historical control	Hospitalization	Parachute
Dodgson 2008	UK	Historical control	Bed days	
Fowler 2009	UK	Historical control	Both	
Goldberg 2006	Canada	Historical control	Both	PEPP
Grawe 2006	Norway	RCT	Hospitalization	
McGorry 1996	Australia	Matched historical control	Both	EPPIC
Petrakis 2012	Australia	Historical control	Both	EPP
Sandbrook 2006	Australia	Historical control	Hospitalization	
Singh 2007	UK	Cohort	Hospitalization	ETHOS



# Implications:

- People regularly learn to manage their condition and progress with their lives
- Support and community around recovery
- Reason for hope vs. hopelessness
- Expectation of ongoing developmental progression vs. permanent dependency



# 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.”





# 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



# What can we do?

- Join PEPPNET
  - [www.med.stanford.edu/peppnet.html](http://www.med.stanford.edu/peppnet.html)
- Learn more
  - [www.nami.org/earlypsychosis](http://www.nami.org/earlypsychosis)
- Sign up with Partners4StrongMinds
  - [www.partners4strongminds.org](http://www.partners4strongminds.org)



# What can we do?

- Talk openly and optimistically about psychosis as a common condition
- Use person-first language and avoid us-and-them thinking
- Continue to expand NAMI's support, education and advocacy agenda for young adults
- Listen to what people want and advocate
- Work for real insurance parity and access to vocational supports so teens and young adults are not pushed onto lifelong disability



# Unprecedented opportunities for connection and learning

- NAMI: [www.nami.org/earlypsychosis](http://www.nami.org/earlypsychosis)
- Prodrome and Early Psychosis Network (PEPNET): <http://med.stanford.edu/peppnet/howeare.html>
- 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>
- National Council on Behavioral Health: <http://www.thenationalcouncil.org/topics/first-episode-psychosis/>
- Partners 4 Strong Minds (national education effort): <http://partners4strongminds.org/>



# Keep learning! Some Technical Assistance Resources

- RAISE study resources:  
<http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml>
  - Navigate (RAISE Early Tx Program manuals & consultation):  
[www.navigateconsultants.org](http://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](http://www.easacommunity.org)
- Commonwealth programs: Orygen (formerly EPPIC) <https://orygen.org.au/Campus>, IRIS <http://www.iris-initiative.org.uk/>
- PIER Training Institute (EDIPPP lead): <http://www.piertraining.com/>



# Join us on line!

- Like us on Facebook: <https://www.facebook.com/easacommunity/>
- Visit our website: [www.easacommunity.org](http://www.easacommunity.org)
- Also: <http://www.pathwaysrtc.pdx.edu>
- Questions or follow-up: Tamara Sale, [tsale@pdx.edu](mailto:tsale@pdx.edu)



# Adapted from We are EASA (Jess S.)

- 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.**

