

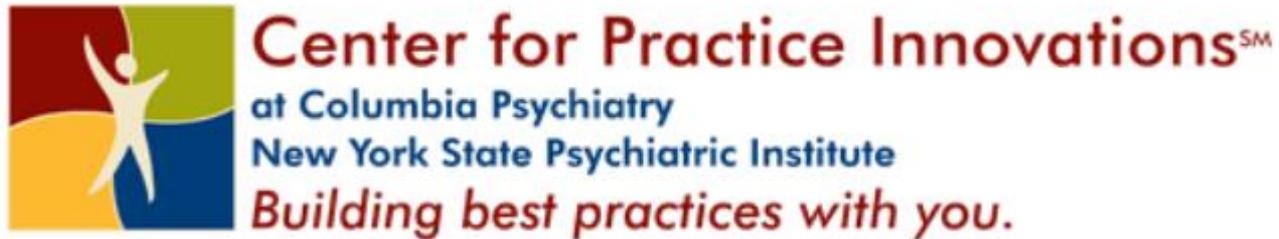
# Treating First Episode Psychosis

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Director, OnTrackNY



# Presentation Created by



On Track  NY

*My health. My choices. My future.*

# Overview

- Introductions
- What is psychosis
- Background & context for services
- Coordinated Specialty Care
- Tips for Working with Individuals with FEP
- Resources

# What is psychosis?

- Psychosis occurs when a person loses contact with reality. The word “psychosis” scares some people, but it actually describes an experience that many people have.
- Three out of every 100 people experience psychosis at some time in their lives, and most of them recover.
- FEP: refers to the first episode of psychosis

# The Basics: Psychotic Symptoms

- Delusions: False personal beliefs not subject to reason or contradictory evidence and not explained by culture and religion.
- Hallucination: Perception of visual, auditory, tactile, olfactory, or gustatory experiences without an external stimulus and with a compelling sense of their reality
- Disordered speech and behavior

# Schizophrenia (DSM-5)

- Symptoms: Delusions; Hallucinations; Disorganized speech; Grossly disorganized or catatonic behavior; Negative symptoms (two or more for a month)
- Level of functioning declines
- Lasts at least six months

# Schizophrenia: Big Picture

- Occurs worldwide (~0.5-1.5%): annual incidence 15.2 per 100,000; Male/female: 1.4-1.6
- Usually develops age 16 to 25; men younger than women
- Accounts for 25% of all hospital bed days
- Accounts for 40% of all long-term care days
- Accounts for 20% of all Social Security benefit days
- Costs the nation up to \$65 Billion per year

Cloutier, M, Aigbogun, MS, Guerin, A, Nitulescu R, Ramanakumar, AV, et al. (2016). The economic burden of schizophrenia in the United States in 2013. *Journal of Clinical Psychiatry*, 77(6):764-771.

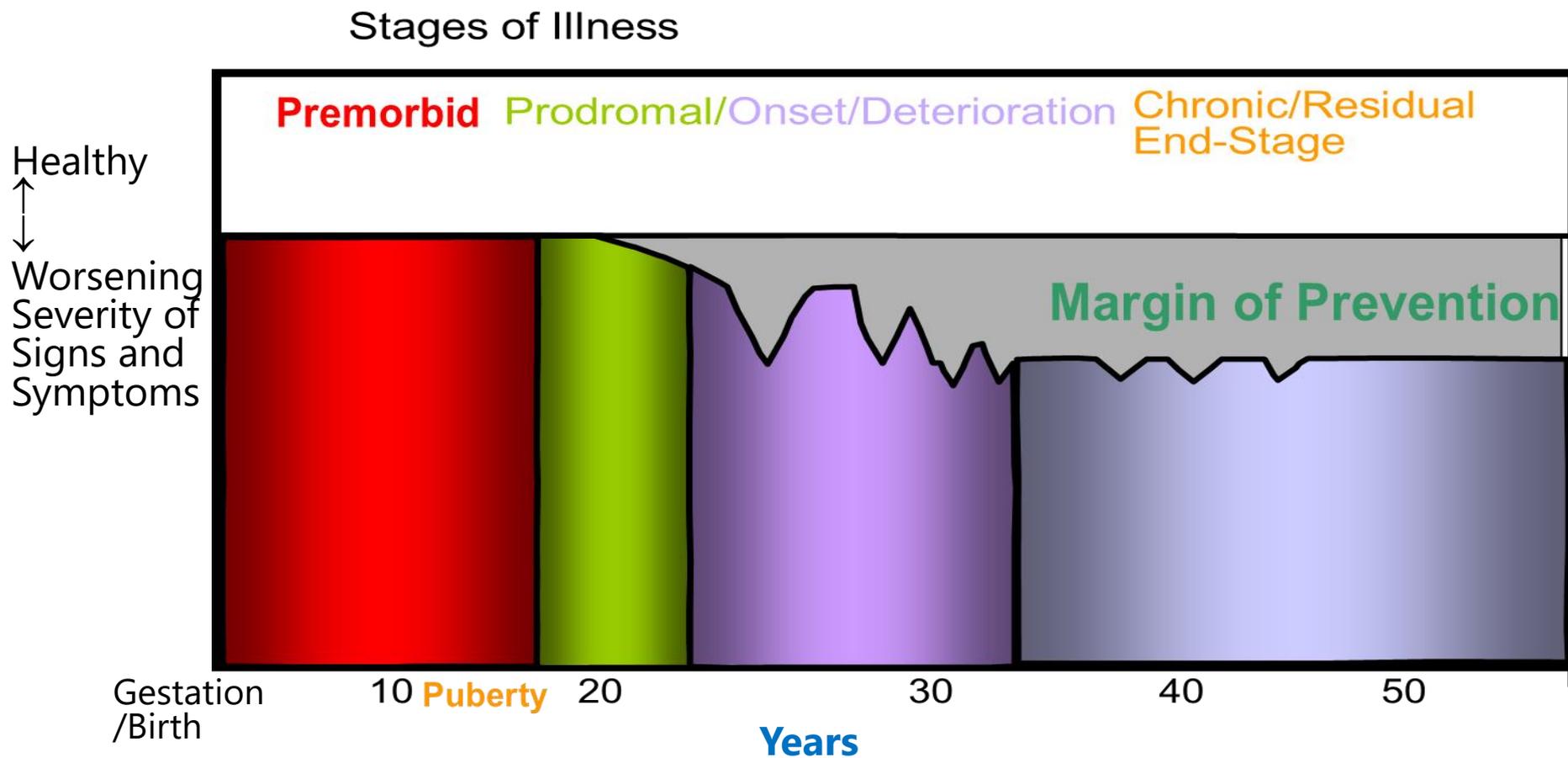
# Schizophrenia in youth

- Compared to adult-onset schizophrenia, childhood onset is rare (1 in 10,000 children)
- Incidence in adolescence is not well established
- 20% of adults with a diagnosis report onset before age 18.

Maloney, AE, Yakutis, LJ, Frazier, JA. Empirical evidence for psychopharmacologic treatment in early onset psychosis and schizophrenia. *Child Adolesc Psychiatr Clin N Am.* 2012; 21(4): 885-909.

# Natural History of Schizophrenia

## Rationale for Early Detection and Intervention



# How to Explain Psychosis to Youth and Families



# Educating Youth/Family: Describing Psychosis

- What is Psychosis?
  - Psychosis involves difficulty telling the difference between what is real and what is not.
  - Psychosis can affect the way a person thinks, feels, and acts.
  - Symptoms of psychosis are different from person to person and may even be different over time.
  - The first episode of psychosis typically occurs in a person's late teens or early twenties. Symptoms may start suddenly or develop gradually over time.
- You are not alone.
  - Experienced by approximately 3 out of every 100 people at some point in their lives.
  - Both men and women of every race, ethnicity, culture, and socioeconomic group have these experiences.
- Now what?
  - Psychosis is treatable and most people recover. Discuss the young person's experience in greater depth here.

# Educating Youth/Family: Explaining Hallucinations

- Hallucinations cause people to hear, see, taste, or feel things that are not there.
- Hallucinations can seem very real. For that reason, people who experience hallucinations often have difficulty believing that they are not real.
- Examples of hallucinations include:
  - Hearing noises or voices that others don't hear
  - Seeing things that other don't see
  - Having unusual sensations in one's body

# Educating Youth/Family: Explaining Delusions

- Delusions are beliefs that a person holds despite evidence that those beliefs are not true or accurate.
- Examples include:
  - Believing that one is being watched or followed
  - Believing that someone else is controlling one's thoughts
  - Believing that others want to harm you
  - Believing that things in the environment have a special meaning just for you

# Educating Youth/Family: Explaining Confused Thinking

- Confused thinking. One's thoughts, and the expression of those thoughts, don't connect together in a way that makes sense.
- Examples include:
  - Thoughts can seem unclear
  - Thoughts are jumbled together
  - Thoughts are racing too fast or are coming too slow

# Educating Youth/Family: Explaining Changes in Behavior

- Spending more time alone.
- Having less interest in socializing with friends and family, going to work or school, or otherwise engaging in activities one used to enjoy.
- Not taking care of oneself as well as one used to (e.g., not bathing or dressing, may appear disheveled).
- Behaving in a way that doesn't seem to fit with the situation, such as laughing when talking about something sad or upsetting, or for no apparent reason.

# Educating Youth/Family: Causes of Psychosis

- Psychosis could have a number of different causes, and many researchers are working to understand why psychosis occurs. Some popular ideas are:
  - Biological: Some people are more likely to develop psychosis because of their biology or their heredity. Many cases of psychosis have been linked to problems with neurotransmitters, or the chemical messengers that transmit impulses throughout a person's brain and central nervous system. In addition, the relatives of people who experience psychosis are more likely to experience psychosis themselves.
  - Other factors: A person's first episode of psychosis can be triggered by stressful events or by drug use (especially use of marijuana, speed, or LSD).

# Setting the Stage: Background and Context for Services



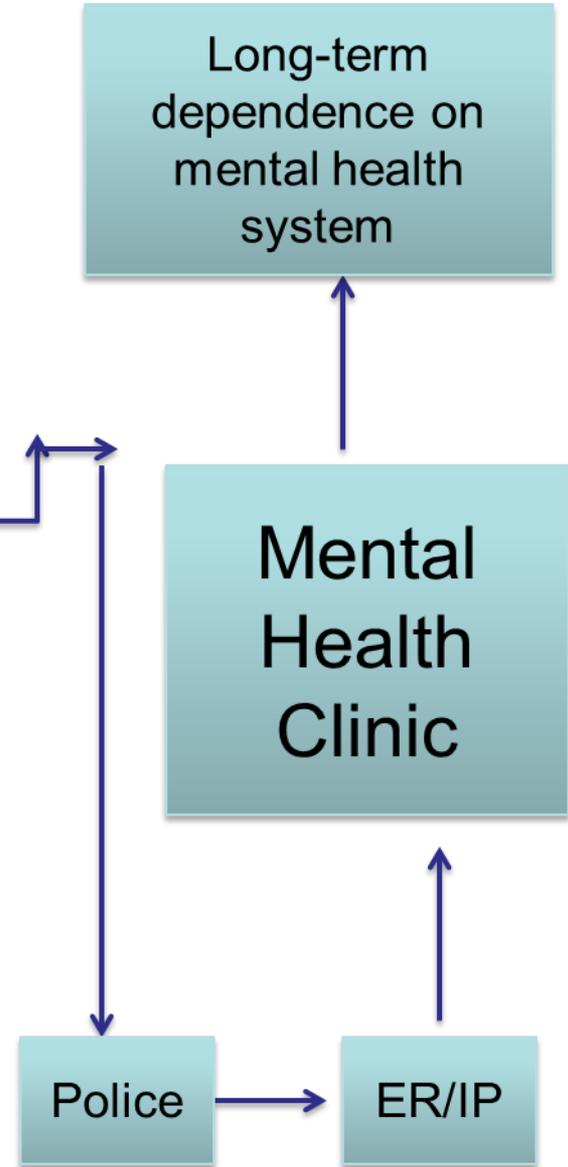
# Barriers in Current System



Stigma  
Lack of Knowledge  
Distrust  
Insidious Onset

Help seeking

Referral from GP  
Lack of Access  
Unaffordability  
and Inefficiency of  
health care



\*GP- General Practitioner

Compton M, Broussard B: *Current Psych Reviews* 2011, 7, 1-11

## Two Key Scientific Findings

- Longer **duration of untreated psychosis (DUP)** is associated with *poorer* short term and long term outcome
  - DUP is the time between onset of psychosis and specified treatment (e.g., antipsychotics or CSC)
- Treatment with **coordinated specialty care (CSC)** is associated with better outcomes

# Duration of untreated psychosis (DUP) and the course of schizophrenia in a 20-year follow-up study<sup>☆</sup>

Andrzej Cechnicki<sup>\*</sup>, Łukasz Cichocki, Aneta Kalisz, Piotr Błądziński, Przemysław Adamczyk, Joanna Franczyk-Glita

*Department of Community Psychiatry, Chair of Psychiatry, Collegium Medicum, Jagiellonian University in Cracow, Pl. Sikorskiego 2/8, 31-115 Krakow, Poland*

Shorter DUP associated with:

- reduced symptoms and relapses
- higher GAF scores
- Improved social functioning indicated by employment and social contacts

Results show efficacy of early therapeutic intervention

# Association Between Duration of Untreated Psychosis and Outcome in Cohorts of First-Episode Patients: A Systematic Review

*Marshall et al. Arch Gen Psychiatry. 2005;62(9):975-983.*

- Examined the relationship between DUP and outcomes at 6, 12 and 24 months
  - At baseline there as no significant relationships between DUP and outcomes
  - By 6 months longer DUP was significantly associated with positive symptoms, negative symptoms, depression, anxiety, quality of life, social functioning
  - By 12 months longer DUP was significantly associated with all outcomes
  - People did worse the longer the illness went untreated

# The Benefits of Early Intervention Services

- Improvements in hospital re-admission rates, symptom severity, and relapse rates
- Specific treatment components and approaches
  - Low-dose antipsychotic medications
  - Cognitive and behavioral psychotherapy
  - Family education and support
  - Educational and vocational rehabilitation
- Meta-analyses of 4 RCTs (N~800 FEP Ss) support the early treatment model (Bird, 2010)



# 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

- RCT to compare the effectiveness of a phase-specific intervention vs. usual community care for FEP
  - Symptomatic recovery and relapse
  - Social, academic, and vocational functioning
  - Cost effectiveness of treatment
- Implementation study to identify and surmount barriers to rapid adoption of early psychosis interventions
  - Referral and case finding strategies
  - Training and supervision of existing clinical staff
  - Financing models to support FEP treatment programs

# RAISE Results

## RAISE ETP Study

- Participants stayed in specialized treatment longer
- Fewer psychotic symptoms
- Experienced significantly greater improvement in quality of life (QOL)
  - Only participants with shorter DUP demonstrated a significant improvement in QOL when receiving specialized services.
- More likely to be in work or school

## RAISE Connection

- High engagement and retention rates
- Significant reduction of psychotic symptoms
- Significant improvement of social and occupational functioning
- Rates of engagement in competitive work or school doubled

# The Big Picture: Rationale

**Goal is to reduce DUP and provide early intervention services to promote long term recovery and reduce disability**

# Roadmap for Pathway to Care

Onset of  
Symptoms



Help  
Seeking

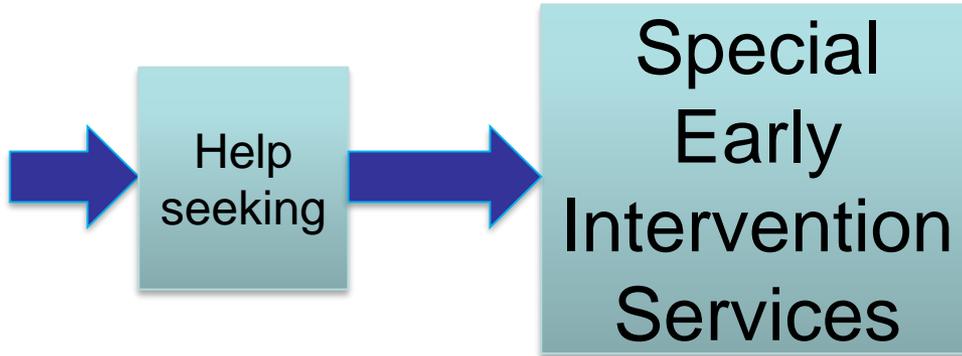


Referral to  
Mental Health  
Services  
(Could  
receive  
criterion  
treatment in  
MHS)



Referral to  
Early  
Intervention  
Services

# Vision for Treatment: Rapid Connection



# Coordinated Specialty Care

## Clinical Services

- Case management, Supported Employment/Education, Psychotherapy, Family Education and Support, Pharmacotherapy and Primary Care Coordination

## Core Functions/Processes

- Team based approach, Specialized training, Community outreach, Client and family engagement, Mobile outreach and Crisis intervention services, shared decision making

<http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml>



*My health. My choices. My future.*

OnTrackNY is an innovative treatment program for adolescents and young adults who recently have had unusual thoughts and behaviors or who have started hearing or seeing things that others don't. OnTrackNY helps people achieve their goals for school, work, and relationships.

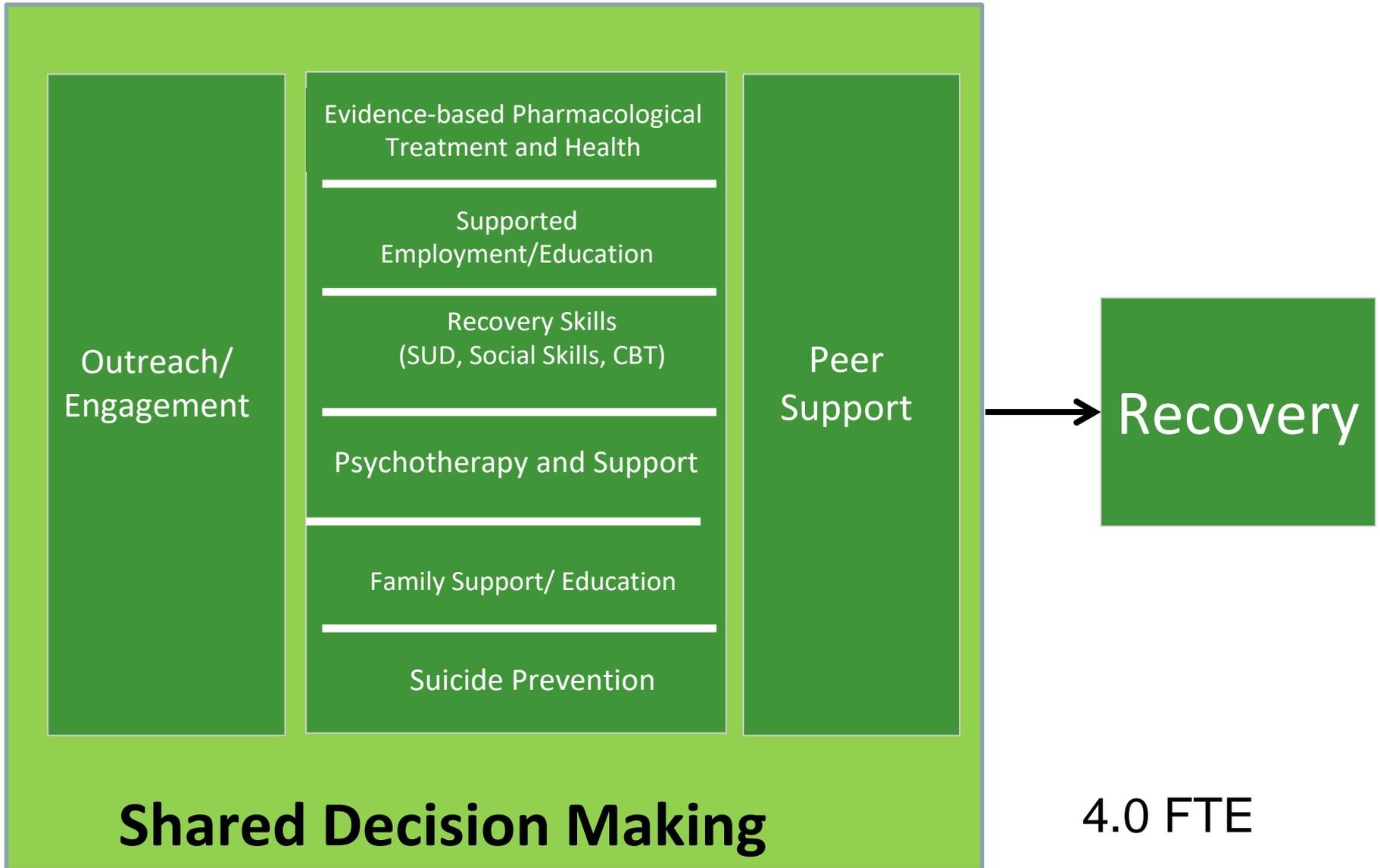
# What does OnTrackNY Offer?

- The goal of OnTrackNY is to provide hope and effective treatment so that young adults with psychosis can achieve their goals in life.
- Rather than working with just one mental health professional, we offer a collaborative team approach that relies on everyone's strengths and energy.
- The young adult with psychosis is a member of the team, along with the family and other mental health professionals.
- A team leader helps to keep everyone on the team working together toward the young adult's recovery.
- We use a "shared decision making" approach. That means that the young adult and the team work together to decide on the best treatment options.

# Treatment offered by OnTrackNY

- A comprehensive assessment of the young adult's personal recovery goals to inform and guide treatment.
- Treatment and support from team members including a doctor, mental health professionals, and vocational specialists who have worked with people recovering from psychosis.
- Counseling for family members focused on providing information about psychosis and teaching family members how to assist young people in their recovery.
- Coaching from a vocational specialist with expertise in helping young people identify and reach their school and work goals.
- Assistance with strategies for building healthy relationships and coping with problems in positive ways.
- Treatment and support for drug or alcohol problems.

# OnTrackNY Team Intervention



# Eligibility Criteria

- Age: 16-30
- Diagnosis: Primary psychotic disorder. Diagnoses include: Schizophrenia, Schizoaffective disorder, Schizophreniform disorder, Other specified schizophrenia spectrum and other psychotic disorder, Unspecified schizophrenia spectrum and other psychotic disorder, or Delusional disorder
- Duration of illness: Onset of psychosis must be  $\geq 1$  week and  $\leq 2$  years
- New York State Resident

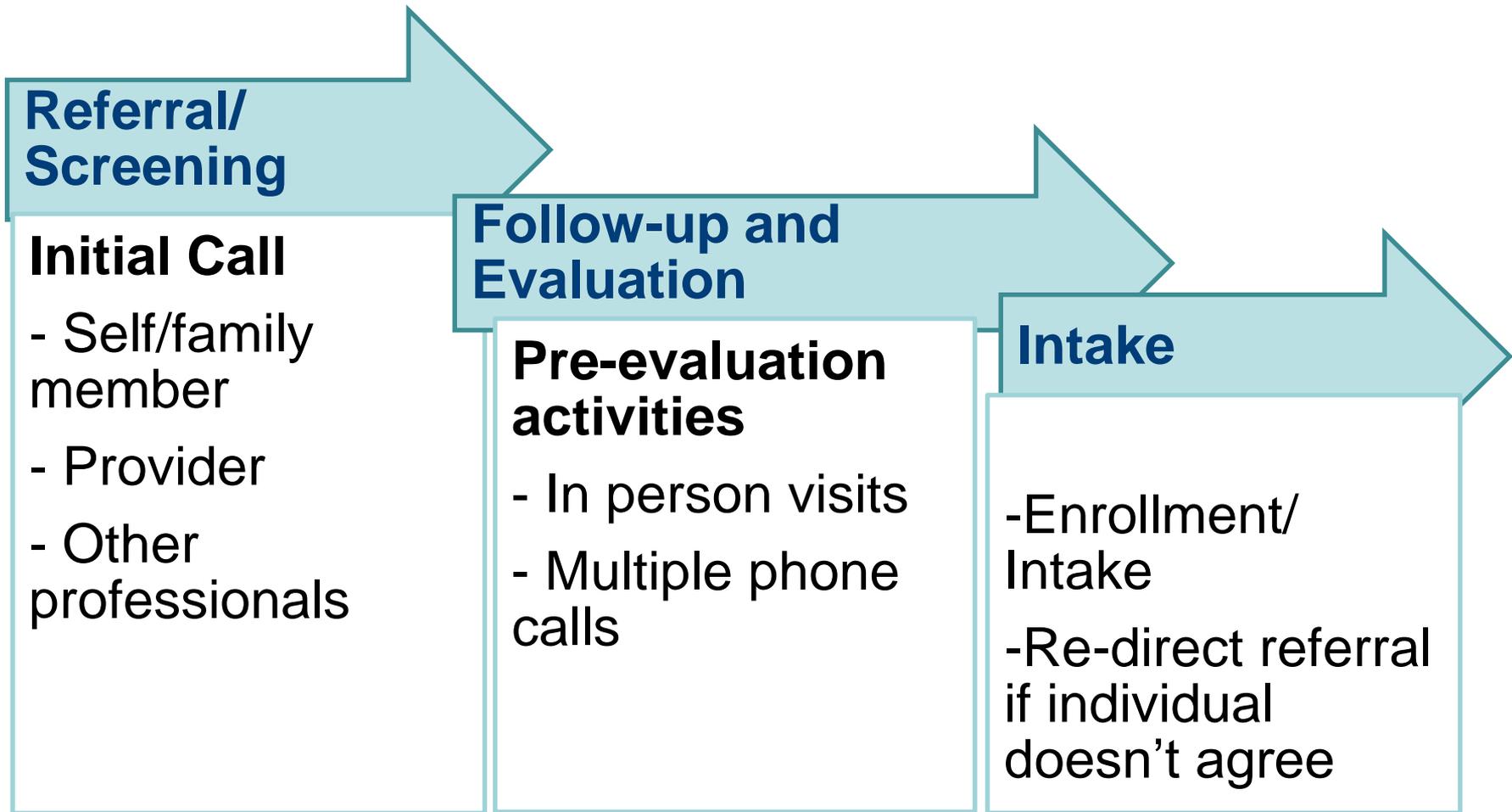
# Eligibility Criteria: Exclusionary Factors

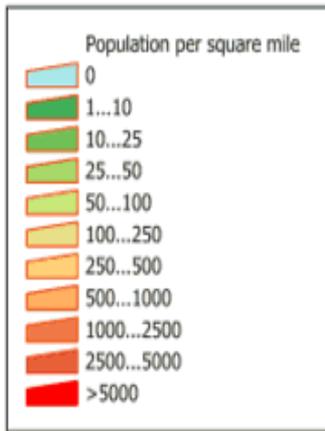
- Intellectual Disability (IQ < 70) or Autism Spectrum Disorder
- Primary diagnosis of substance-induced psychosis, mood disorder with psychotic features, or psychosis secondary to a general medical condition
- Serious or chronic medical illness significantly impairing function independent of psychosis

# Eligibility Criteria

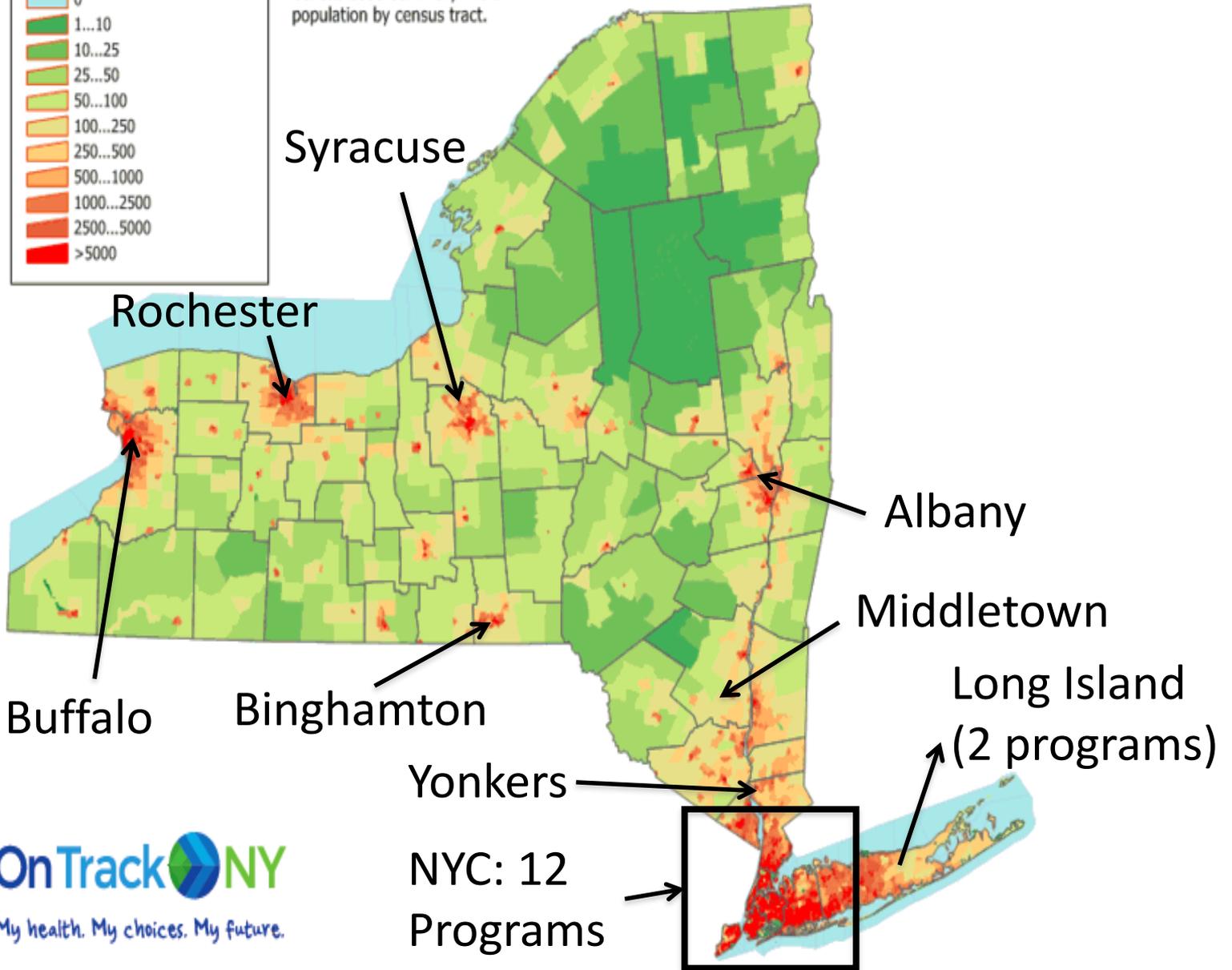
OnTrackNY teams provide services to all referred individuals meeting clinical admission criteria, without wait lists and regardless of their insurance status or ability to pay

# Referral Process





Source: U.S. Census Bureau  
Census 2000 Summary File 1  
population by census tract.



# NYC START

## **Supportive Transition and Recovery Team**

- Goal: improve the connection to community based care among New Yorkers experiencing a first episode of psychotic illness; works with all hospitals that provide in-patient psychiatric services in NYC
- Serves: young adults (ages 18-30) who have been hospitalized for the first time due to psychosis
- Offers: care coordination, psycho-education and support services to ensure linkage to care, services, and support their transition back to the community.

## How It Works

- Hospital alerts DOHMH when an individual is admitted with first-episode psychosis
- A specialized DOHMH team makes contact and provides information
- If individual agrees, the DOHMH team engages him/her and family to link to treatment and follows up to assure continuous care
- All identifiable information deleted from reporting system after 30 days

# General Tips for Working with Individuals with FEP



# Tips for Engagement

- Understand what they are seeking by learning what is going on for them at this time.
- What programs/kinds of treatment have they already (recently) tried connecting with? What were the challenges?
- Provide information about services based on the above
- Connect such exploration with detailed examples about services might be able to help (e.g., getting a job, making friends, etc.)

**Common traps:** Talking about the program too mechanically; asking too many detailed questions in order to begin determining eligibility.

## Tips for talking to youth and family

- During these early stages of engagement, it is especially important to be mindful of the young person's experience of what may be happening and to adopt his/her language in the conversation.
- Important to do this with family also
- Understand cultural context and incorporate as much as possible

## Persons says "I am not psychotic" how should you respond?

- Ask them what they think is the problem and what might be helpful. Then try to communicate how services can help given their understanding of the problem. Do not try to convince a person that he/she is psychotic. Instead, try to find common ground.

# Factors that Contribute to Recovery

- Clinicians play a vital role in early detection of first episode psychosis, connecting people to the right care and conveying hope for recovery.
- Specialized early intervention services improve clinical and functional outcomes by focusing on the individual's goals to guide treatment decisions. Clinicians follow a shared decision making framework to make decisions about treatment, encourage family involvement, and help the individual develop skills to manage symptoms and prevent relapse.

# Importance of Family Collaboration

- First Episode Psychosis often affects young people who are living in the family home.
- Families are often the first to notice the changes associated with symptoms of psychosis and can be key players in seeking help.
- Family members may not understand why the changes they see in their loved ones are occurring, or how to help. Recognizing that families can be a valuable resource in getting individuals to appropriate care and supporting treatment engagement is key.
- Coordinated Specialty Care programs provide families with the education and support they need.

# Resources

- [www.ontrackny.org](http://www.ontrackny.org)

## For young adults and family members

***Links to Mental Health Resources***

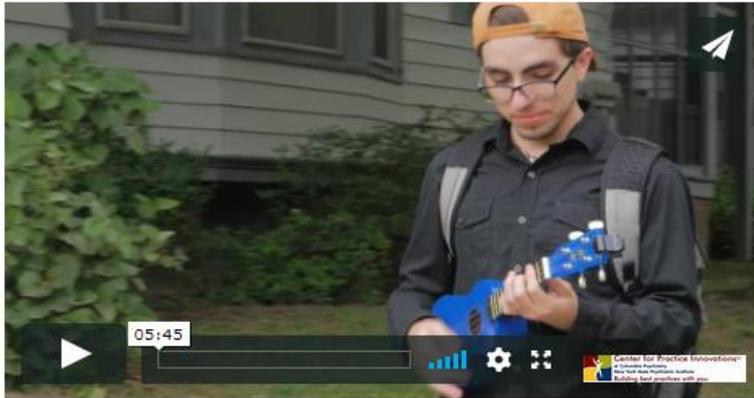
Center for Practice Innovations	SBIRT & Screening App
National Alliance on Mental Illness National	Employment Resource Book
National Alliance on Mental Illness NYC Chapter	Voices of Recovery Videos
First Episode Psychosis Recovery Stories	NASMHPD Information for Providers

## For providers and organizations

<b><i>OnTrackNY Team Manuals</i></b>	<b><i>Links</i></b>
Team Manual	Voices of Recovery Videos
Medical Manual	First Episode Psychosis Recovery Stories
Primary Clinician's Manual	Center for Practice Innovations
Supported Employment and Supported Education Manual	Learning Management System
Recovery Coaching Manual	New York State Psychiatric Institute
Outreach and Recruitment Manual	New York State Office of Mental Health
Voices of Recovery Manual	Data Collection Forms
Peer Specialist Manual	Nathan Kline Institute for Psychiatric Research
Family Manual	LGBT Module 1: LGBT 101
Delivering Culturally Competent Care in FEP	LGBT Module 2: Identity Development
Treating Cognitive Health Manual	LGBT Module 3: Affirmative Health for LGBT Individuals with Psychosis

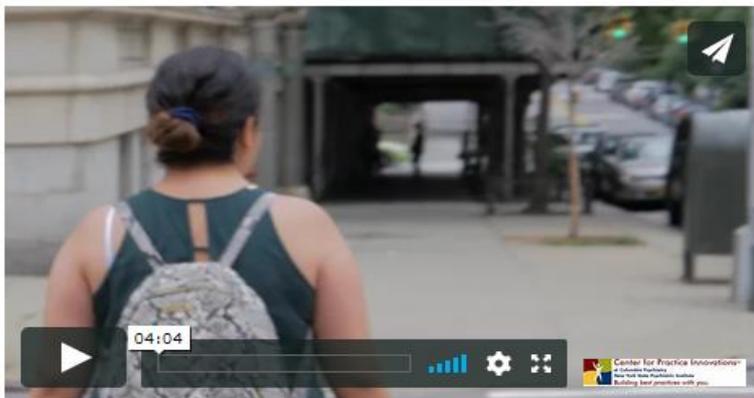
# www.OnTrackNY.org/videos

Sebastian - Finding Harmony through Music

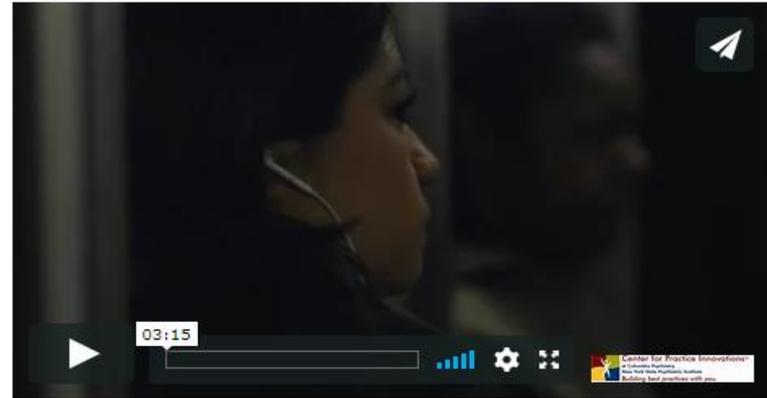


Just before starting college, Sebastian began having unusual auditory and visual experiences. With the support from OnTrackNY and using music to cope, Sebastian gained the confidence to share his story to help others. Sebastian's mother also shares her perspective on recovery and being part of OnTrackNY.

"D" - Learning to Prioritize Your Mental Health



Skittles - Laying the Foundation for Recovery



In this video, Skittles speaks about hearing voices and how her passion for makeup has helped her cope and express herself. Skittles also talks about her initial apprehension to open up about her psychosis and the role OnTrackNY played in her openness to receive help.

Anna - Drawing the Path to Recovery



# Other Resources

- NYC Start
  - <https://www1.nyc.gov/site/doh/health/health-topics/crisis-emergency-services-nyc-start.page>
- Outpatient programs/clinics
  - Lenox Hill Early Treatment Program & Long Island Jewish Hospital Early Treatment Program
  - <https://www.northwell.edu/behavioral-health/programs-services/early-treatment-program>
- Mount Sinai clinical and research program for youths 12-30
  - [www.icanfeelbetter.org](http://www.icanfeelbetter.org)
- Center for Prevention and Evaluation Cope
  - <https://www.columbiapsychiatry.org/research-clinics/prodromal-clinic-center-prevention-and-evaluation-cope>

# Appendix: Results of the RAISE studies



# Duration of Untreated Psychosis in Community Treatment Settings in the United States

Jean Addington, Ph.D., Robert K. Heinssen, Ph.D., Delbert G. Robinson, M.D., Nina R. Schooler, Ph.D., Patricia Marcy, B.S.N., Mary F. Brunette, M.D., Christoph U. Correll, M.D., Sue Estroff, Ph.D., Kim T. Mueser, Ph.D., David Penn, Ph.D., James A. Robinson, M.Ed., Robert A. Rosenheck, M.D., Susan T. Azrin, Ph.D., Amy B. Goldstein, Ph.D., Joanne Severe, M.S., John M. Kane, M.D.

- Methods: Participants were 404 individuals (ages 15-40) who presented for treatment for FEP at 34 nonacademic clinics in 21 states. DUP and individual- and site-level variables were measured.
- DUP was defined as the period between onset of psychotic symptoms and initial treatment with antipsychotic medications

## Results: DUP in RAISE ETP Study

- Mean DUP 196 (262) weeks
- Median 74 (1-1456)
- 268 (68%) had DUP of > 6 months

# Engagement Service Utilization

- Participants remained patients of the Teams for **91.0%** (SD 21.4) of the total possible time they could have received services (constrained by time of enrollment and study completion)
- The median time was 100%.
- Only 6/65 participants remained patients of the Team for less than 50% of the possible time they could be engaged.

Dixon, et al., Implementing Coordinated Specialty Care for Early Psychosis: The RAISE Connection Program, Psychiatric Services (in press)

# Highlights of Outcomes: Significantly Improved

- MIRECC GAF Occupational Functioning Scores (neuropsych/negative symptoms negative predictor)
- MIRECC GAF Social Functioning Scores (greater number of family meetings and fidelity regarding recovery coach mediators)
- PANSS Total and Subscale Scores
- Participation in competitive work or degree granting school program (40% to 80%)
- Rates of remission (25% to 75-80%)
- CGI scores (Moderately III to Borderline Mentally III)

Dixon, et al., Implementing Coordinated Specialty Care for Early Psychosis: The RAISE Connection Program, Psychiatric Services (in press)

# RAISE Early Treatment Program Study

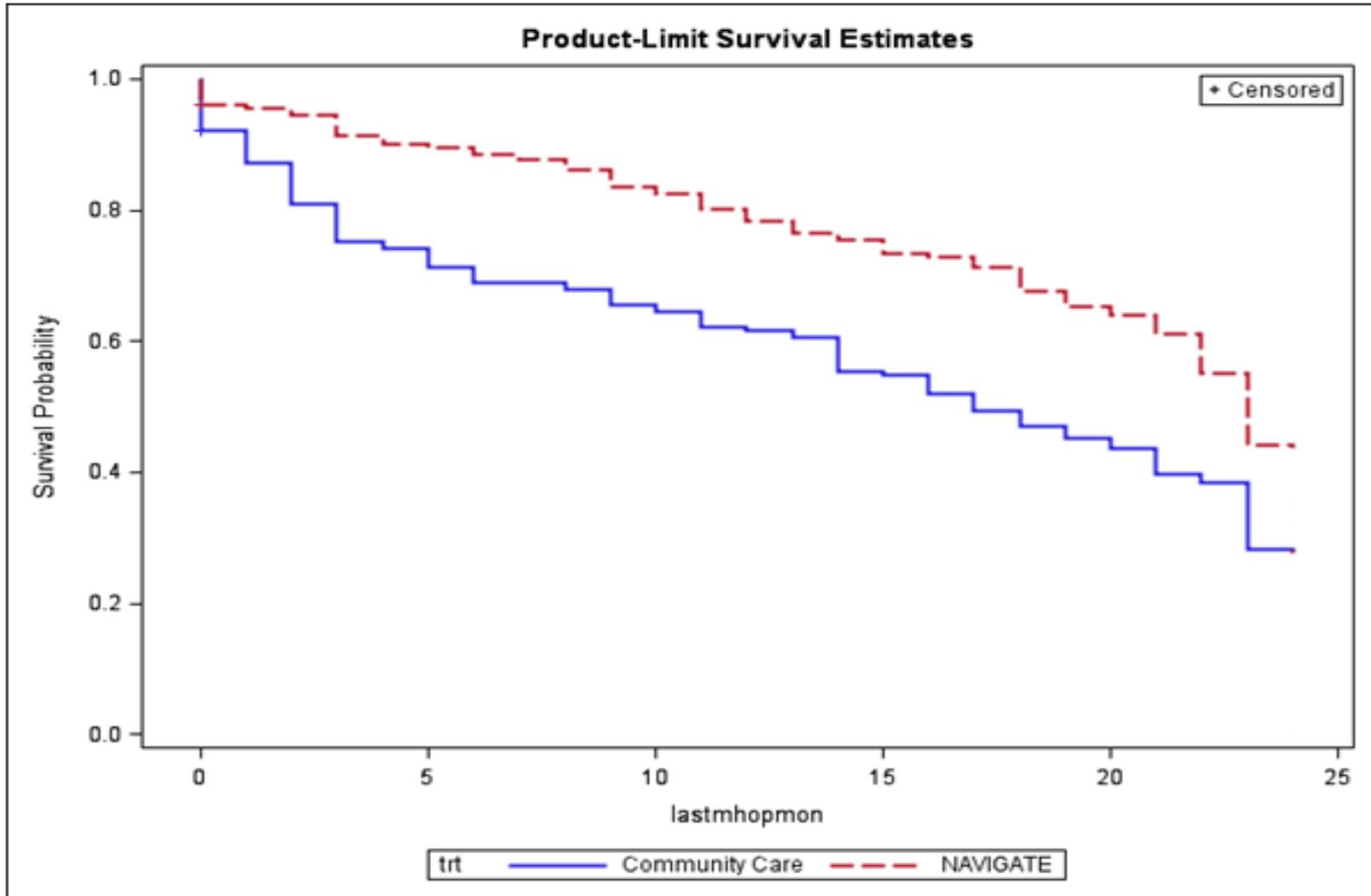
- Cluster Randomized Trial comparing clients (N= 223) at 17 sites randomized to Navigate vs at 17 sites randomized to usual care (N=181) for two years
- Navigate clients significantly more likely to remain in treatment, experienced significantly greater improvements in quality of life, were more likely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

Kane et al. Am J Psychiatry. 2015 Oct 20:appiajp201515050632.

# NAVIGATE Participants Stayed in Treatment Longer

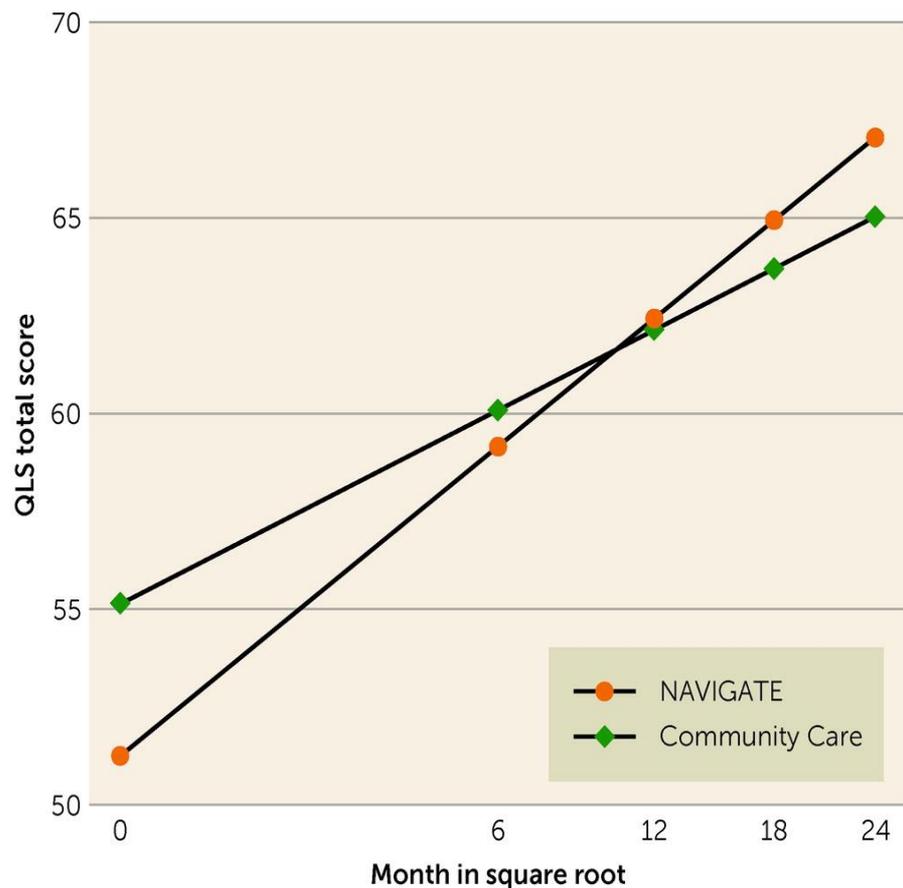
Time to Last Mental Health Visit

(Difference between treatments,  $p=0.009$ )

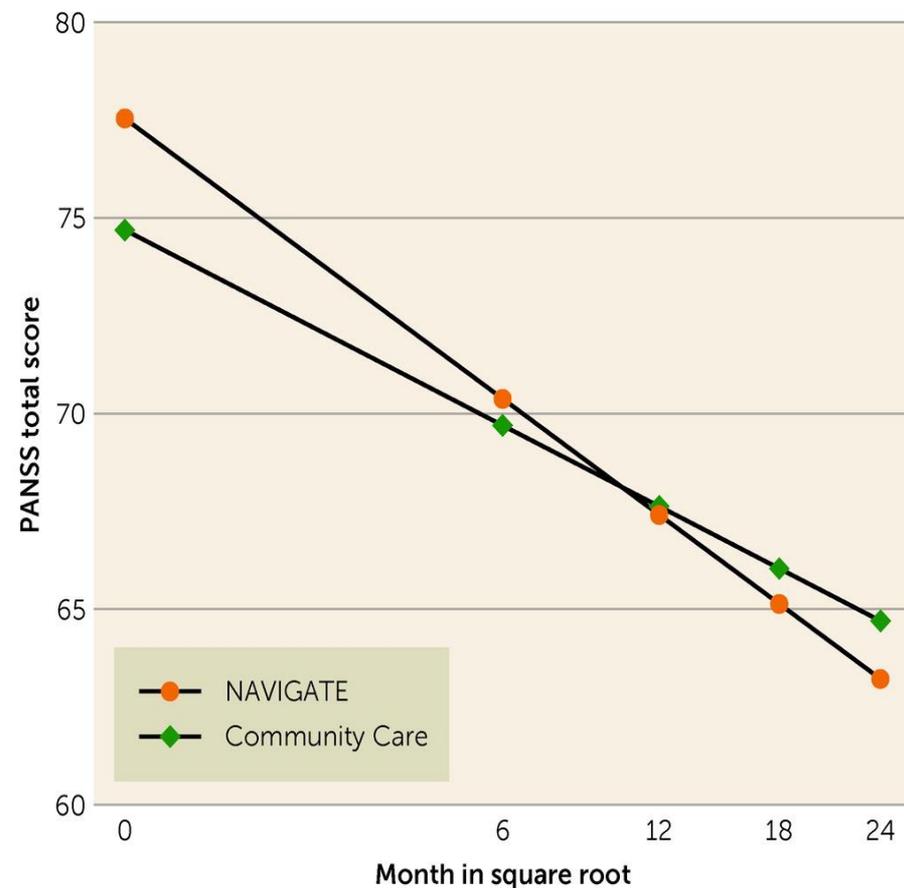


## From: Comprehensive Versus Usual Community Care for First-Episode Psychosis: 2-Year Outcomes From the NIMH RAISE Early Treatment Program

A. QLS total score<sup>b</sup>

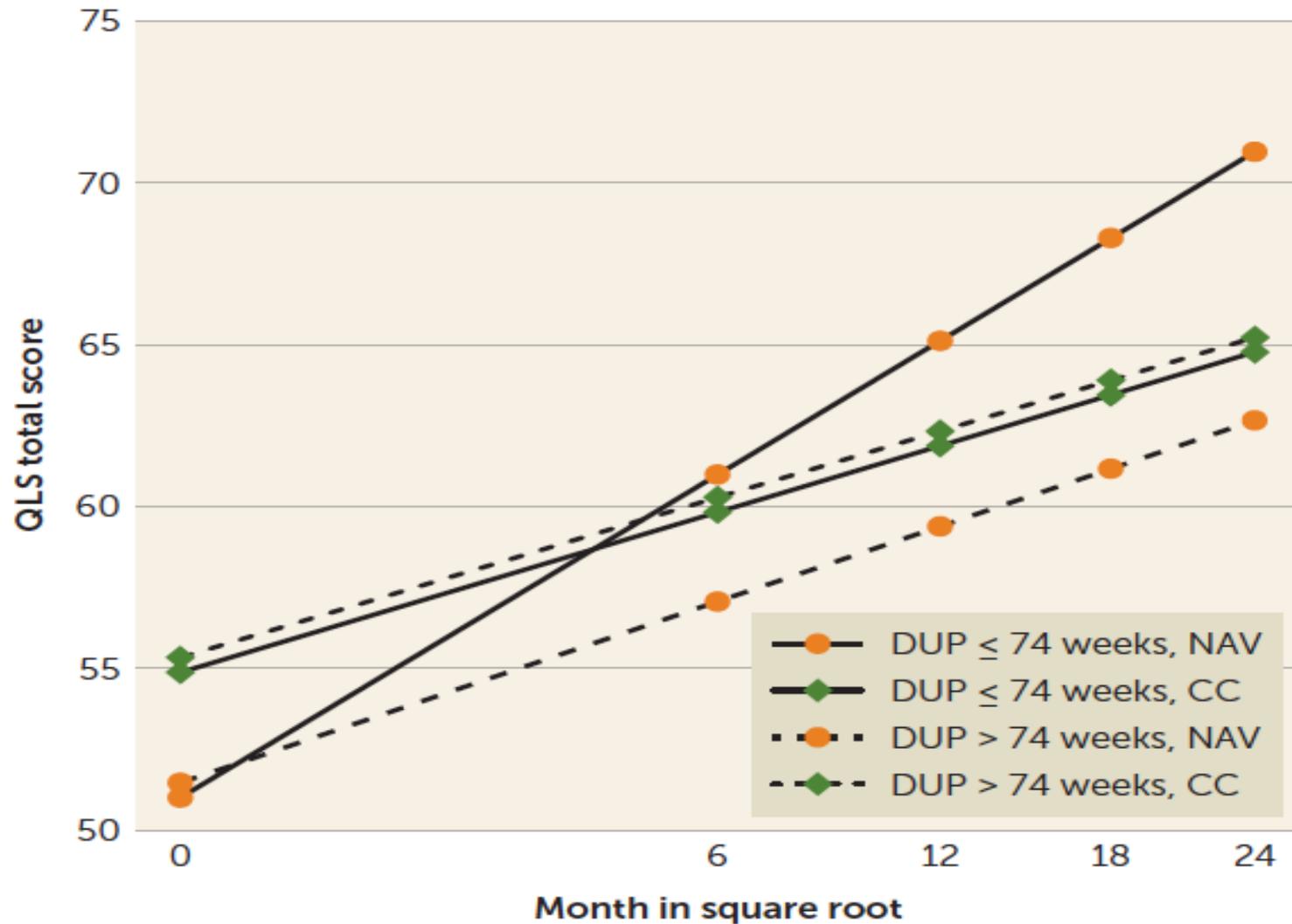


B. PANSS total score<sup>c</sup>



c Treatment by square root of time interaction,  $p=0.016$ .

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



Thank you!

