Coordinated Specialty Care in the United States: An Overview and Roadmap

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Advancing Early Psychosis Care in the U.S. IEPA 11 Conference – Broadening the Scope Boston, MA

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Welcome to Boston!

30 States
8 Countries
4 Continents
Disclosures

- I have no personal financial relationships with commercial interests relevant to this presentation

- The views expressed are my own, and do not necessarily represent those of the NIH, NIMH, or the Federal Government
Schizophrenia Facts

- Symptoms include altered perceptions, thinking, and disorganized behavior
- Initial diagnosis between ages 16-30
- Unemployment, homelessness, and incarceration are common
- People with schizophrenia die nearly 30 years earlier than other people
- ~2.5 million U.S. citizens are affected
Early Intervention Matters

- Rapid remission of positive symptoms
- Fewer relapse episodes
- Lower rates of psychiatric hospitalization
- Better social and vocational functioning
- Increased quality of life

Correll et al., *JAMA Psychiatry*, 2018
Coordinated Specialty Care (CSC)

- Medication/Primary Care
- Cognitive & Behavioral Therapies
- Supported Employment & Education
- Family Education and Support
- Case Management

Shared decision making framework

Peer involvement and leadership
A Decade of Progress

2008
• 2 States
• <20 CSC Programs
• <100 Clinicians
• <500 Youth

2018
• 49 States
• 265 CSC Programs
• ~1,000 Clinicians
• ~10,000 Youth

Scientific Traction

State and Federal Investments

Early Psychosis Learning Community
Partnerships are Key

- Early Psychosis Researchers
- State and Federal Healthcare Agencies
  - State Mental Health Authorities
  - Centers for Medicare and Medicaid Services
  - Health Resources and Services Administration
  - Substance Abuse and Mental Health Services Administration
- Advocacy and Professional Organizations
  - National Alliance on Mental Illness
  - National Council for Behavioral Health
  - National Association of State MH Program Directors
  - Prodrome and Early Psychosis Program Network
- Peer Leaders
CSC in Three Acts

2008-2010: Limitations of typical care

2010-2015: Feasibility and effectiveness of CSC

2015-2018: Bringing CSC to scale
Recovery After an Initial Schizophrenia Episode
A Research Project of the NIMH
Limitations of Typical Care

Median duration of untreated psychosis is 74 weeks in community clinic settings
Addington et al., 2015, *Psychiatric Services*

Only 61% of FEP patients receive medications in line with Schizophrenia PORT recommendations
Robinson et al., 2014, *American Journal of Psychiatry*

<5% of FEP patients with cardio-metabolic risk factors receive appropriate medical care
Correll et al., 2014, *JAMA Psychiatry*

Persons with FEP are 3-8 times more likely to die in the year following initial diagnosis, often by suicide
Simon et al., 2018, *JAMA Psychiatry*
Feasibility and Effectiveness

- **RAISE Early Treatment Program**
  - John Kane
  - Nina Schooler
  - Delbert Robinson

- **RAISE Connection Program**
  - Lisa Dixon
  - Jeffrey Lieberman
  - Susan Essock
  - Howard Goldman
Implementing Coordinated Specialty Care for Early Psychosis: The RAISE Connection Program

Lisa B. Dixon, M.D., M.P.H., Howard H. Goldman, M.D., Ph.D., Melanie E. Bennett, Ph.D., Yuanjia Wang, Ph.D., Karen A. McNamara, M.S.W., Ph.D., Sapna J. Mendon. M.S.W., Amy B. Goldstein, Ph.D., Chien-Wen J. Choi, M.S., Rufina J. Lee, M.S.W., Ph.D., Jeffrey A. Lieberman, M.D., Susan M. Essock, Ph.D.

An Interactive Tool to Estimate Costs and Resources for a First-Episode Psychosis Initiative in New York State

Jennifer L. Humensky, Ph.D. Lisa B. Dixon, M.D., M.P.H. Susan M. Essock, Ph.D.

Practical Monitoring of Treatment Fidelity: Examples From a Team-Based Intervention for People With Early Psychosis

Susan M. Essock, Ph.D., Ilana R. Nossel, M.D., Karen McNamara, L.C.S.W.-C., Ph.D., Melanie E. Bennett, Ph.D., Robert W. Buchanan, M.D., Julie A. Kreyenbuhl, Pharm.D., Ph.D., Sapna J. Mendon, L.M.S.W., Howard H. Goldman, M.D., Ph.D., Lisa B. Dixon, M.D., M.P.H.
After 2 years, Coordinated Specialty Care was superior to usual community care on:

- Engagement in treatment
- Quality of life
- Symptomatic improvement
- Involvement in work or school
- Cost-effectiveness

CSC worked better for patients with a shorter duration of untreated psychosis

Specialized Treatment Early in Psychosis Program

After 1 year, Specialized Treatment Early in Psychosis was superior to usual care on:

- Likelihood of hospitalization
- Number, length of inpatient episodes
- Vocational and academic engagement
- Symptomatic improvement

The STEP public-sector model supports the feasibility and effectiveness of CSC

Srihari, Cenk, Suat et al., *Psychiatric Services*, 2015
Bringing CSC to Scale

Dates and First Episode Psychosis (FEP) Milestones

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>Jul. 2009</td>
<td>NIMH clinical trials for FEP commence</td>
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<tr>
<td>Dec. 2013</td>
<td>NIMH implementation study completed</td>
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<td><strong>Jan. 2014</strong></td>
<td><strong>P.L. 113-76: $22.8M set-aside for FEP</strong></td>
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<td>Apr. 2014</td>
<td>NIMH/SAMHSA FEP guidance to states</td>
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<tr>
<td>May 2014</td>
<td>SAMHSA technical support to states begins</td>
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<tr>
<td>Oct. 2015</td>
<td>NIMH clinical trials for FEP completed</td>
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<tr>
<td>Oct. 2015</td>
<td>CMS coverage of FEP intervention services</td>
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<tr>
<td>Dec. 2015</td>
<td>P.L. 114-113: $50.5M set-aside for FEP</td>
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<tr>
<td>May 2017</td>
<td>P.L. 115-31: $53.3M set-aside for FEP</td>
</tr>
<tr>
<td>Mar. 2018</td>
<td>P.L. 115-141: $68.5M set aside for FEP</td>
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Mental Health Block Grant Plans: [https://bgas.samhsa.gov/](https://bgas.samhsa.gov/)

Cumulative Number of States with Early Psychosis Intervention Plans
States’ Stage of CSC Implementation

National Registry of Evidence-Based Programs and Practices Implementation Scale

1SAMHSA (2012). A Road Map to Implementing Evidence-Based Programs.
Early Intervention Programs, 2008

August 2008 – 12 clinics
Early Intervention Programs, 2017

August 2017 – 220 clinics
OnTrackNY Program

- OnTrackNY is a statewide CSC program for recent onset psychosis
- 325 individuals ages 16–30 were followed for up to one year
- Education and employment rates increased to 80% by six months; hospitalization rates decreased to 10% by three months
- Global functioning measures improved continuously over 1-year

Nossel et al., *Psychiatric Services*, 2018
Looking Ahead

Connecting the U.S. early psychosis community
Early Psychosis Intervention Network (EPINET)
EPINET Goals

- Establish a national learning healthcare network among early psychosis clinics
- Standardize measures of clinical characteristics, interventions, and early psychosis outcomes
- Adopt a unified informatics approach to study variations in treatment quality, clinical impact, and value
- Cultivate a culture of collaborative research participation in academic and community early psychosis clinics
Hub and Spoke Structure

National Data Coordinating Center
Future Challenges for U.S. Programs

CSC Effectiveness

- How to reduce DUP to <3 months in U.S. communities?
- How to effectively mitigate risks for early mortality?
- How to enhance social, academic, and work outcomes?
- How to extend recovery beyond initial episode of care?
- How to increase the person’s prospects for long-term physical health and psychological well-being?
Future Challenges for U.S. Programs

CSC Infrastructure

- How many CSC programs are required nationwide?
- How to meet the needs of rural and underserved areas?
- How to grow and maintain a well-trained workforce?
- How to achieve sustainable funding for CSC programs?
- How to broaden and deepen societal and political interest in early intervention for psychotic disorders?
Advancing Early Psychosis Care
In the United States

The Larry J. Seidman Award for Leadership

Presented to

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Beth Israel Deaconess Medical Center

For vision, commitment, and strong leadership in organizing the first national educational conference for early psychosis clinicians in the United States.

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