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An Overview of Coordinated Specialty Care (CSC) for Persons with First Episode Psychosis: A Presentation to State Planning Councils

Monday, April 13, 2015 – 3pm Eastern



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Recovery After an Initial Schizophrenia Episode

RAISE

A Research Project of the NIMH

Early Treatment Program



RAISE-ETP: Executive Committee

John Kane – Principle Investigator	The Zucker Hillside Hospital (ZHH)
Delbert Robinson	ZHH
Nina Schooler	SUNY Downstate
Jean Addington	University of Calgary
Christoph Correll	ZHH
Sue Estroff	UNC
Kim Mueser	Boston University
David Penn	UNC
Robert Rosenheck	Yale University
Mary Brunette	Dartmouth University
Jim Robinson	Nathan Kline Institute
Patricia Marcy	ZHH – Project Director



• **Key Consultants:**

- Tom Tenhave and Andy Leon assisted in designing the trial.
- Robert Gibbons, Don Hedeker and Hendricks Brown reviewed the data analytic plan.
- Haiqun Lin led the analysis.



PRINCIPAL NIMH COLLABORATORS



Robert Heinsen
Susan Azrin
Amy Goldstein



The Problem of First Episode Psychosis

- **Poor recognition**
- **Longer duration of untreated psychosis related to worse outcomes**
- **Lack of youth-friendly, patient-centered treatment**
- **Inadequate psychoeducation and family involvement**
- **High rates of medication non-adherence**
- **High rates of dropout from treatment**



Specified Aims of RAISE

- 1. Develop an integrated treatment model for First Episode Psychosis (FEP) that**
 - *maximizes functioning*
 - *promotes symptomatic recovery*
 - *can be brought to scale*
- 2. Compare the intervention to prevailing treatment approaches for FEP**
- 3. Conduct the study in non-academic, U.S. community treatment settings**



NAVIGATE Intervention

- Overall goal is recovery, not maintenance
- Team-based, multi-component intervention
- Shared decision-making to insure client and family involvement in treatment planning and execution
- Training and on-going consultation to insure fidelity
- Services supported through current reimbursement mechanisms



NAVIGATE Components

Provider	Component
Program Director	Establish referral networks, speed enrollment, assure team cohesion
Physician/Nurse Practitioner	FEP-specific pharmacotherapy via computerized decision support system
Individual Resilience Therapist	Recovery-focused education/support; integrated addictions treatment
Family Therapist	Family psychoeducation and support; communication and problem-solving
Employment/Education Specialist	Return to school or competitive work



NAVIGATE Training and Supervision

- **Several in-person trainings**
- **Team member's guide/manual**
- **Site Director**
 - *Monthly consultation calls with the central team*
- **Individual Resiliency Training**
 - *Weekly supervision sessions with site director*
 - *Consultation call every two weeks with the central team*
- **Family Treatment**
 - *Consultation calls every two weeks with the central team*
- **Supported Employment and Education**
 - *Weekly supervision from site director*
 - *Consultation calls every two weeks with the central team*



The Outreach Plan: What it is and how to use it

- **Plan is for target advertising & education**
- **Audience to be targeted**
 - *Referral sources*
 - *Public organizations*
- **Activities to be done**
- **Timeline for completion of tasks**
- **Evaluate the benefit**



Target Audience: Referral sources

- **Mental health**
 - *Family physicians*
 - *Mental health clinics, addiction services*
 - *Hospitals, emergency rooms*
- **Educational establishments**
 - *College, school and university counseling*
- **Other public services**
 - *Police*
- **Most suitable contact**



Target Audience: Public organizations

- Goal is to convey information to the general public
- Libraries
- Community and recreation centers
- Public talks on mental health
- Most suitable contact



Education

- **Informing family physicians, gatekeepers and agencies about the importance of early intervention**
 - *Education about early symptoms*
 - *Education about early detection*
 - *Referral*
- **Public education**
 - *Education about early symptoms*
 - *Education about early detection*
 - *Available resources*



Referrals

- Streamline approach to receive referrals that fits with existing system
- How are you going to identify them?
- How many ways can referrals come in?
- What is the consultation process for potential referrals?
- Develop site specific recommendations on how to deal with different sources of referrals



Maintaining engagement: get it right at baseline

- Develop good relationship at baseline
- Clear about everything
- Be with them each step of assessment/engagement
- Demonstrate efficiency
- Added touches-age appropriate
- More tolerant – different than usual clinical care
- Demonstrated patient centered care



Maintaining engagement: keep it going

- Efficiency
- Know when they are coming to clinic
- Remember who they are
- Chat
- Become a friendly face around the place
- Make them feel they belong
- Reminders
- Flexible (within reason)



Randomized Controlled Trial

- *NAVIGATE vs. Community Care*
- *Cluster/site randomization*
- *Two-year treatment period*
- *On-site recruitment and engagement*
- *Remote assessment of primary and secondary clinical outcomes*



RAISE-ETP Study Design with Cluster/Site Randomization



Inclusion Criteria

- **Age 15 – 40**
- **SCID confirmed diagnosis**
 - *Schizophrenia*
 - *Schizophreniform disorder*
 - *Schizoaffective disorder*
 - *Brief Psychotic disorder*
 - *Psychosis NOS*
- **No more than 6 months lifetime antipsychotic medication exposure**
- **First episode of psychosis**



Outcome Assessments*

- **Primary Outcome Measure**
 - *Heinrichs-Carpenter Quality of Life Scale*
- **Key Secondary Outcome Measures**
 - *Positive and Negative Syndrome Scale*
 - *Calgary Depression Rating Scale*
 - *Treatment received*
 - *School and employment activity*

* Subset of RAISE ETP outcome measures reported February 6, 2015

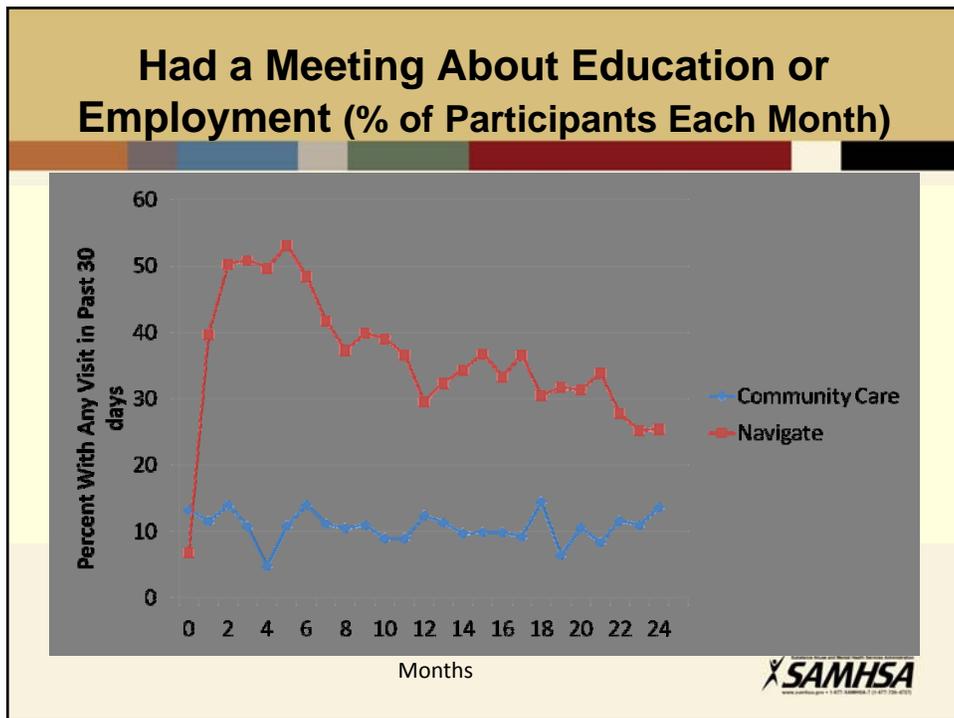
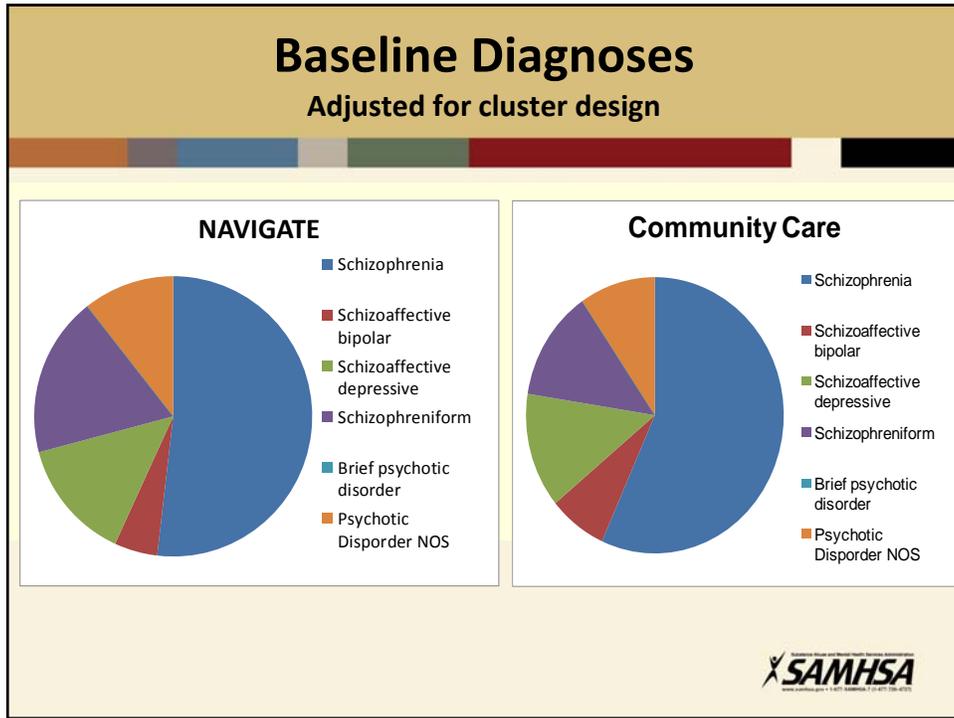


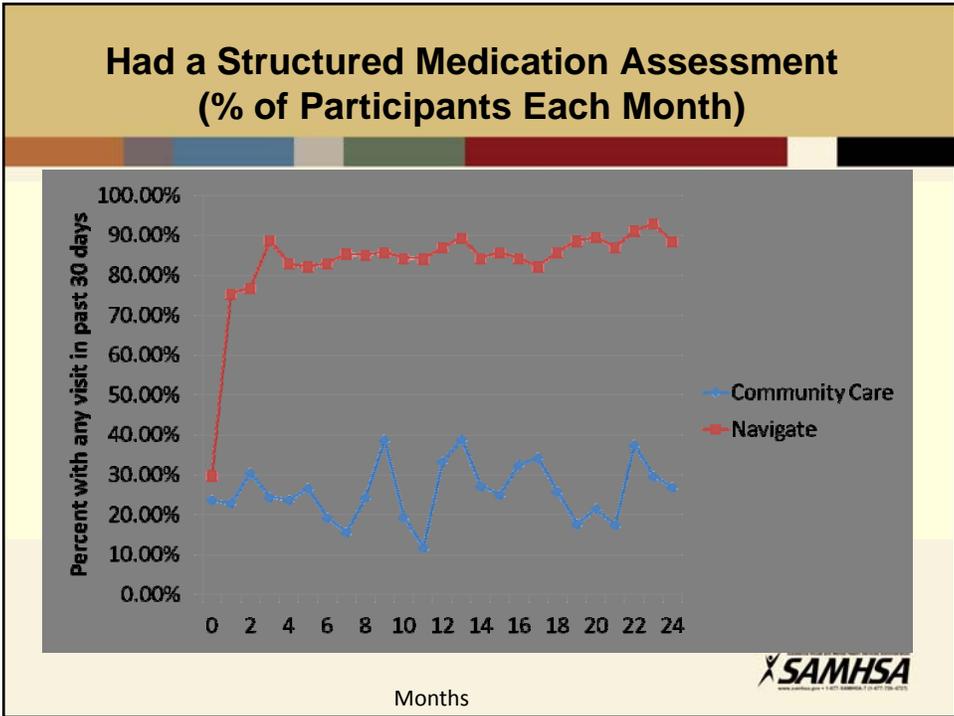
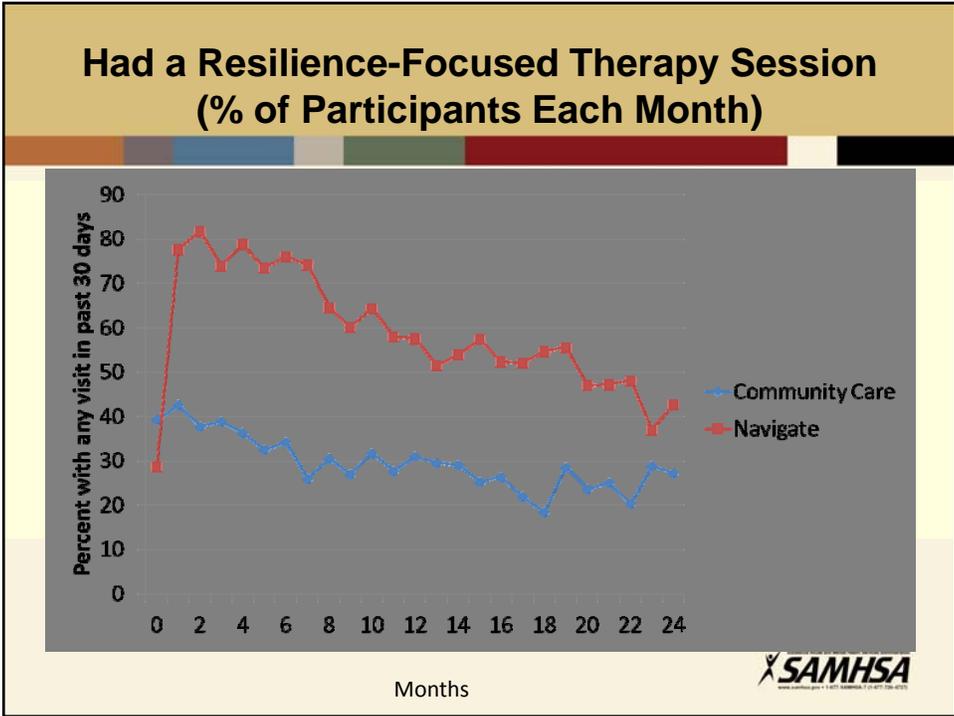
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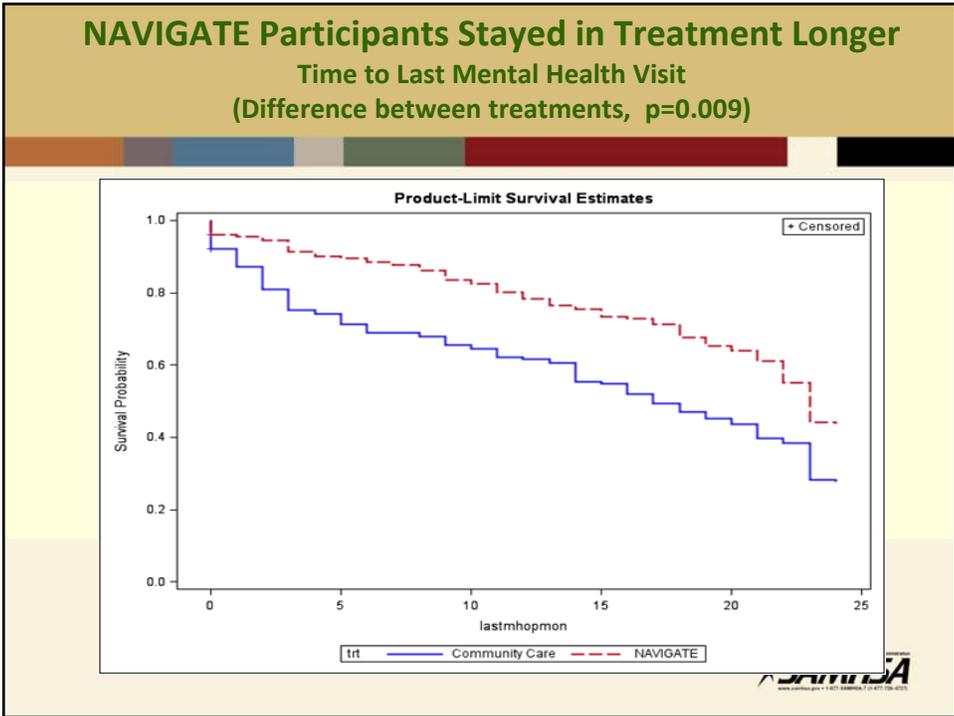
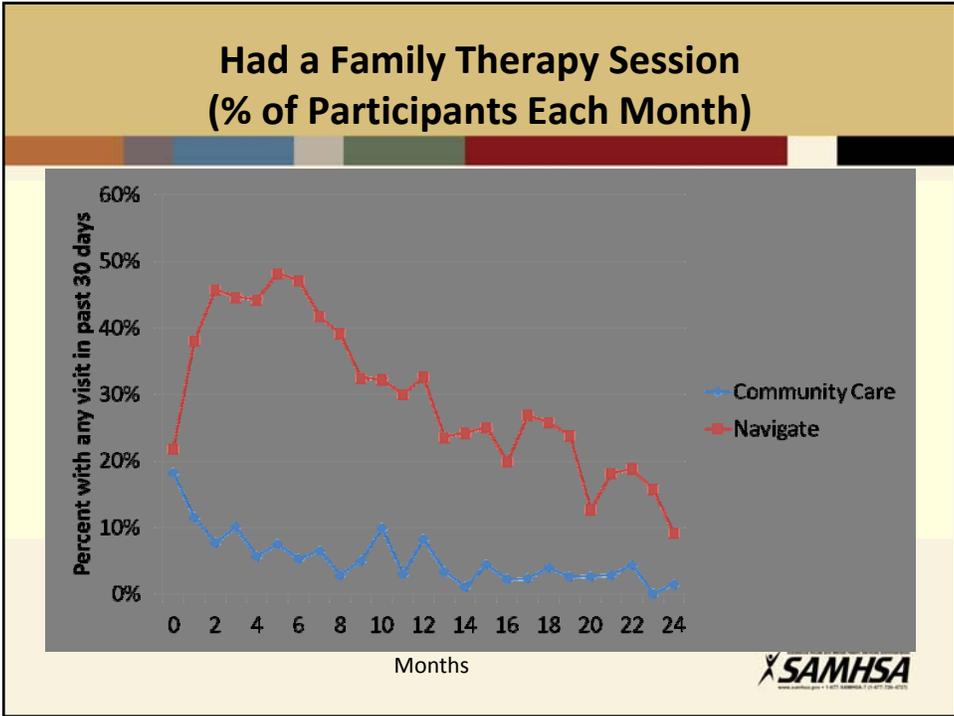
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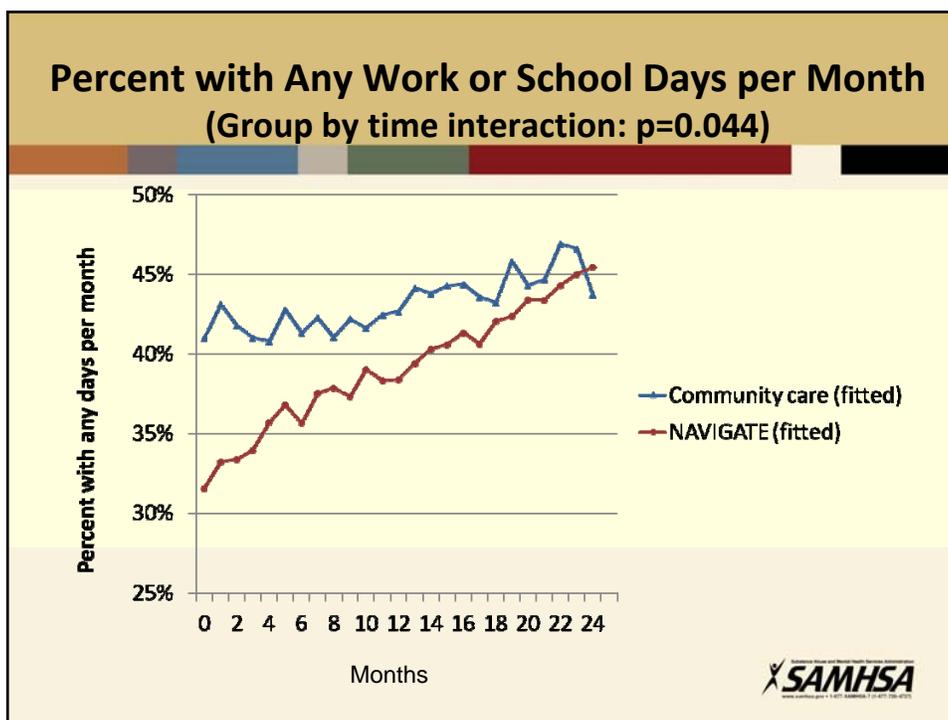
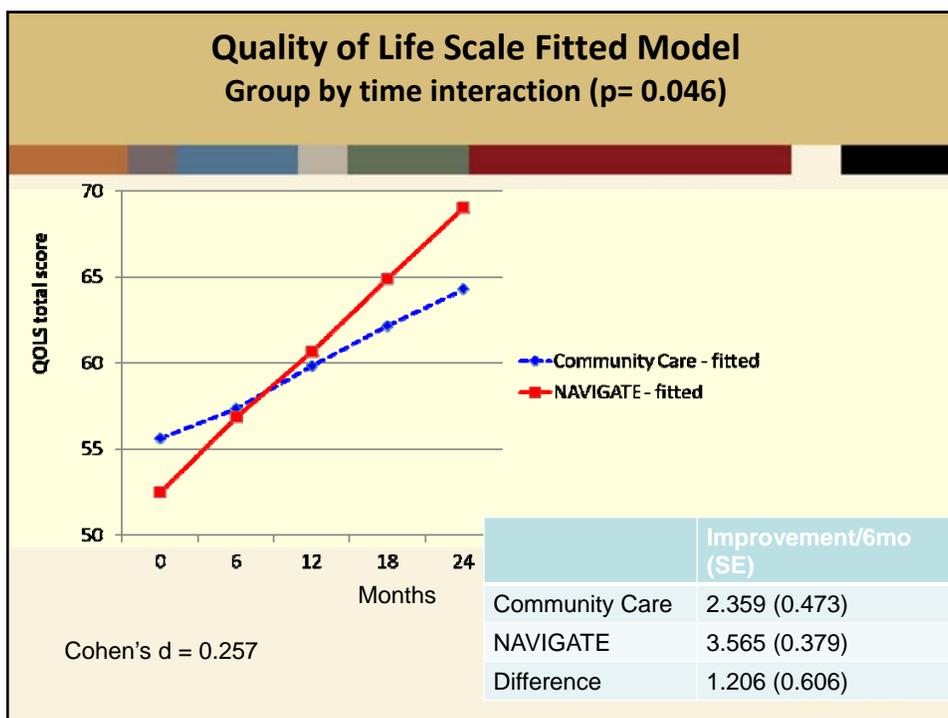
	NAVIGATE	Community Care	p-value
Age and Gender			
Age (mean)	23.5	23.2	
Males (%)	77.6	66.2	.05
Race			
White (%)	65.9	49.9	
African American (%)	25.4	44.1	
Other (%)	8.7	6.0	
Role Functioning			
In school (%)	14.9	25.5	.03
Working (%)	12.6	16.6	
Prior Hospitalization (%)	76.2	81.6	.05











Conclusions

- Recipients of NAVIGATE were significantly more likely to remain in treatment and experienced significantly greater improvement in the primary outcome measure (i.e., quality of life).
- They were more likely to be working or going to school.
- NAVIGATE participants showed a significantly greater degree of symptom improvement during the first 6 months of treatment and maintained those gains over time.
- DUP appears to be an important factor in NAVIGATE effectiveness.
- These results show that a coordinated specialty care model can be implemented in a diverse range of community clinics and that the quality of life of first episode patients can be improved.



NIH National Institute of Mental Health Transforming the understanding and treatment of mental illnesses. SEARCH

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Mental Health Information Publications Educational Resources Clinical Trials — Participants Statistics Help for Mental Illnesses

RAISE
Recovery After an Initial Schizophrenia Episode
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Home > Health & Education > Mental Health Information > Schizophrenia

Coordinated Specialty Care for First Episode Psychosis - Resources

- ★ Evidence-Based Treatments for First Episode Psychosis: Components of Coordinated Specialty Care
- RAISE Coordinated Specialty Care for First Episode Psychosis Manuals
- RAISE Early Treatment Program Manuals and Program Resources
- OnTrackNY Manuals & Program Resources
- Voices of Recovery Video Series

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



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The Role of People with Lived Experience in Coordinated Specialty Care

Tamara Sale, MA
Director, EASA Center for Excellence
Portland State University



EASA Center for Excellence



Coordinated Specialty Care

- **Goal is to identify person quickly & enter into empowering relationship**
 - *Focus on voluntary, proactive outreach and engagement*
 - *Goals are strengths-focused and person-centered*
 - *Developmental progress, school and work are central*
 - *Lower medication doses & attention to side effects*
- **Families are supported and educated**



Oregon Early Assessment and Support Alliance



- **Statewide effort to integrate early psychosis best practices**
 - *2001 started in 5 counties; 2007 started statewide expansion*
 - *94% state population covered now*
 - *Universal access for first episode within last 12 months; ages 15-25 with psychosis symptoms consistent with schizophrenia or bipolar*
- **2014 served 547 young people & families**



Barriers to Entry Addressed by EASA

- **Lack of community awareness & long delays**
- **Insurance & paperwork requirements**
- **Lack of outreach capacity (huge gap between voluntary & involuntary)**



Barriers Addressed by EASA

- Negative assumptions & lack of focus on what people want & need
- Services not based on evidence
- Lack of support for families
- Lack of youth-friendly, person-centered treatment



EASA

- **Based on the Early Psychosis Prevention and Intervention Center (EPPIC) in Australia, <http://eppic.org.au/>**
 - *Evolved based on emerging evidence-based practices & research and direct experience/feedback*
- **Still evolving**
 - *All CSC elements plus systemic focus, occupational therapy, peer support and participatory decision making*



The Role of Lived Experience in EASA

- People with lived experience played key roles on original design and oversight groups, on hiring committees
- Advisors and teachers
- Advocates and partners
- Clinical team members & community partners
 - *Peer support*
 - *Nursing*
 - *Research roles*
 - *Entering social work & occupational therapy*



Connection to Advocacy

- Voluntary alternative to neglect followed by involuntary
- Olmstead Decision
- Parity laws
- Person-driven care
- Family engagement



Structural Accountability

- **EASA practice guidelines, training, fidelity review emphasize:**
 - *Participatory decision making at all levels*
 - *Hiring committees, oversight, requesting feedback, agency boards, etc.*
 - *Feedback-informed treatment and person-centered planning*
 - *Peer support – formal and informal*
 - *Ongoing involvement of graduates*



EASA's Young Adult Leadership Council

- **Foundation for statewide governance**
- **Young adults' vision: "creating a thriving community and revolution of hope"**
- **Continual learning process**
- **Developing policy, practice recommendations; engaging in training & system redesign**



Peer Support within Coordinated Specialty Care

- **Not a defined role in most models**
 - *Possible for someone to receive treatment but never meet anyone in recovery*
- **2010 became priority for EASA statewide; growing number of programs have formal role**



Peer Support Roles

- **Engagement**
- **Education**
- **Reinforcing resilience, strengths, hope**
- **Challenging stigma**



Lessons for Planning Council Members

- Early Psychosis Coordinated Specialty Care helps moves the system toward:
 - Early, easily available support that is most relevant and helpful
 - Keeping people in charge of their own lives and their own services
 - Positive outcomes being the norm
- People with lived experience play crucial roles throughout
- Early identification and effective care tie well to other priority areas & legal rights



Upcoming Webinars on Peer Support in Early Psychosis

- April 29, 2:30-4 Eastern time
- May 24, 2:30-4 Eastern time



A Few Resources

- **Coordinated Specialty Care Links:**
<http://www.nimh.nih.gov/health/topics/schizophrenia/raise/coordinated-specialty-care-for-first-episode-psychosis-resources.shtml>
- **NASMHPD Environmental Scan (early psychosis programs):**
http://www.nasmhpd.org/docs/Pat%20Shea/Environmental%20Scan%20%202.10.2015_1.pdf
- **EASA:** www.easacommunity.org





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Providing Family Friendly and Family-Centered Services Within CSC Programs

Lisa Dixon, M.D.
 Director, Center for Practice Innovations
 Professor, Columbia University Medical Center






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.

Why Consider Family?

- When a young person faces mental health challenges, the family feels it too
- Family members can have a host of different feelings that are often overlooked
- Evidence suggests that considering the family and its experiences can have positive impact on the young person's journey towards recovery



Impact of Psychosis on the Family

- Disruptions in family routines
- Changes in family roles and responsibilities (e.g. extended parenting)
- Financial hardships
- Differences in opinions about what to do and how to help
- Loss of social support/reduced participation in social activities
- Other family members feeling neglected or left out
- Feeling stigmatized



Core Principles of Family Friendly Services

- Active outreach to family throughout the entire treatment process, from engagement, to ongoing treatment, and through discharge
- Minimize barriers to family involvement
 - *Flexible hours/meeting locations*
 - *Use of supplemental email/telephone contact*
 - *Availability of resources/educational materials*
 - *Stigma*



Context and Basic Approach in Providing Family Services

- A broad definition of family
 - *Includes the immediate, extended, blended and family of choice.*
- Attempt is made for decisions regarding the nature and extent of family involvement to be made with attention to
 - *Promoting collaboration with the young person and family*
 - *Assessing young person and family needs/preferences*
 - *Enhancing shared decision making to determine the nature and extent of family involvement*
 - *Regulatory requirements for children under 18*



Overview of Services

- Planning meeting with team, young person, and the family
- Ongoing, regular meeting with primary clinician
- Basic Psychoeducation
- Contact “when needed”
- Brief Family Consultation
- Monthly family psychoeducation groups ^{a1}
- Referrals to NAMI and community supports if needed
- “Family Nights”



Deciding How Family Should be Involved

- Educate the family member(s) about options for family involvement and available family services
- Help young person and family member(s) decide which services would best meet their needs and/or the needs of their family
- Develop a plan for implementing the decision



Slide 55

a1 do we want to separate these two since they are different
amy, 9/11/2014

Planning Meeting With The Team

- Family and young person and team can benefit from meeting together to discuss progress and planning.
- Having everyone at a meeting promotes
 - *collaboration and care integration*
- Facilitates
 - *Communication (gets everyone on the same page)*
 - *Opportunities for problem solving across bio-psycho-social domains*



Regular Meetings with Primary Clinician

- Weekly or biweekly meetings can be offered
- Focus of these sessions may vary depending on the individual family needs
- Serve to provide ongoing engagement, communication, education, and support



Basic Psychoeducation

- All participants and family members should receive basic education on psychosis, its treatment, recovery, etc.
- Handouts, pamphlets, DVDs, recovery videos, books



Contact When Needed

- Family and young person may not be able to meet on a regular basis but may find it helpful to be able to schedule meetings as *things come up*.
 - *Phone calls*
 - *In home or office meetings*



Brief Family Consultation

- When there is a particular problem/need that cannot be addressed in regular meetings with Primary Clinician or the team
- Brief (typically 1-3 session) and focused (tailored around specific goal/need)
- Examples of common consultation goals
 - *Communication skills (could be between young person/family member or between family members)*
 - *Problem-solving or conflict resolution skills*



Evidence-Based Family Psychoeducation Programs

- Designed to improve family knowledge, communication and problem-solving skills, and offer family support
- Typically a structured program, administered by a trained mental health professional
- Lasting anywhere from 9 months up to 2 years
- When client and family preferences are taken into account can lead to greater family participation (Dixon et al, 2013)



Monthly Psychoeducational Groups

- Conducted by Recovery Coach with assistance from Primary Clinician and other team members as appropriate
- Approximately 1 ½ hours in length
- Includes
 - 1) *presentation of education/information and*
 - 2) *discussion of any family problems/ issues, problem solving strategies and skill building*
- Family members can attend with or without the young person
- Rolling Admission



Part 1: Information/Education

- Each session focused on a topic relevant to families of individuals with first episode psychosis
- Approximately 45 minutes
- Collaborative: a mix of presenting and discussing information, allowing opportunity to share personal experiences
- Several core topics; others chosen based on needs and preferences of group members



Part 2: Discussion of Problems/ Issues Facing Group Members

- What is covered depends on the needs of the group members
- Approximately 45 minutes
- Goal is to help resolve any problems/ issues group member may be facing
 - *Compare and contrast strategies*
- When appropriate, problem-solving and/or communication skills can be modeled within the group to resolve immediate issues, address communication concerns, provide opportunity for skills-building



Family Night

- Invite newly admitted young people and their families/significant others to a family night
 - *Orientation to OnTrackNY*
 - *Orientation to clinicians and their different roles*
- If a number of young people are getting ready to transition and graduate from the program, a family night could be offered to discuss
 - *Next steps*
 - *Community supports*

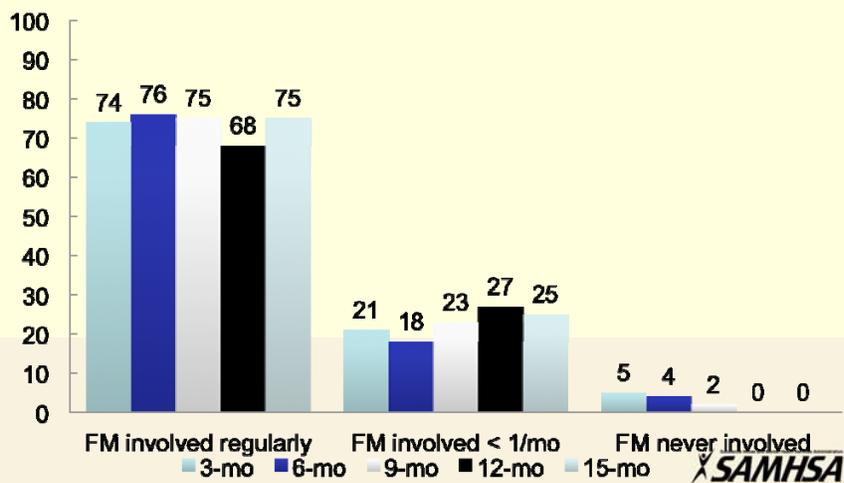


Connections to Community Based Services for Families

- NAMI
- Individual therapy
- Couples therapy



Extent of Family Participation Over Time OnTrackNY



RAISE Connection Engagement Study Overview

		Interviewed		
		NY	MD	Total
Clients	well engaged, early in tenure	4	5	9
	well engaged, late in tenure	4	5	9
	<u>not</u> well engaged, early in tenure	1	4	5
	<u>not</u> well engaged, late in tenure	4	5	9
		Total:	32	
Family Members	of well engaged client	4	5	9
	of client <u>not</u> well engaged	4	5	9
		Total:	18	



Initial Engagement

In the beginning... we really didn't know what to do. We didn't trust anybody.... [but]I saw that someone had to help us and we needed help. We were kind of like skeptical and... and all this personal information that you have to give out.... We were kind of like "oh my God, is this something good??"



Personal Challenges

It's really nice, just so understanding. I have to say I've never felt like, I mean I've been frustrated but I've never felt like anybody in the group was frustrated with her or me or [with] anything going on which, there have been times it kind of amazed me.



Family Concerns & Engagement

You automatically think... what did I do wrong? What could I have changed? What did I not give my son that he needed? And *then* it was more of a protection [feeling]. It was I could care less what anybody thinks. I have to fix my son, I have to see what's wrong, and I have to make him so he can be a functional adult.



Structural Facilitators

There is not a lot of programs like this where you can just come and have each person in a different area just supporting you like a team of professionals...working together.... I mean this is excellent and I really want all the people [who] really need... to take advantage of it.



Summary

- Families play critical role in lives of young people in CSC programs
- Evidence suggests critical value of including families in care
- Approach challenge with person and family centered approach
- Provide choices and family psychoeducation





Questions?



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