Promoting Meaningful Family Involvement in Coordinated Specialty Care Programming for Persons with First Episode of Psychosis

Tuesday, May 19, 2015 – 2pm Eastern
First

- Thank you for including me in this presentation
- I have been working with persons with schizophrenia and their families for over 30 years
- It is an honor and a privilege
Agenda for this presentation

- Reasons for involving families
- What it’s like for families
- What do families need?
- How we can give families what they need
- Principles of working with families
- Examples of what families can do to help
Why involve families in treatment of psychotic disorders?

- Treatment programs which involve the person’s family have long been recognized as increasing positive outcomes.
Combined Results of Family Programs on 2 year cumulative relapse rates

- **Standard Care** (N=179): 64%
- **Single Family Treatment** (N=207): 28%
- **Multiple Family Group Treatment** (N=266): 28%
- **Single & Multiple Family Group Treatment** (N=243): 26%
Understanding the positive effect of families

- Based on the Stress-Vulnerability Model, families figure into almost every aspect of what helps recovery from psychosis.
Stress Vulnerability Model

Medications

Alcohol and Drug Abuse

Biological Vulnerability

Symptom Severity Relapses

Social Support

Coping Skills

Meaningful Activities

Stress
First episode clients are often even more affected by family involvement

- More often living at home with families
- Relying on family for financial and other types of support
- At critical age for determining future success in school and work
What’s it like for families: putting ourselves in family’s shoes

Most common signs of emerging psychosis:

- Performance in school, work, or family life is rapidly dropping
- Spending a lot of time alone
- Doing or saying strange things
- Seem depressed or irritable
- Having problems sleeping
What families often feel when their loved one experiences common emerging signs

- Worry
- Frustration
- Fear
- Helplessness
- Anxiety
- Extreme stress
Often additional signs emerge, which further affect family

- Hostility or suspiciousness
- Decline in personal hygiene
- Flat, expressionless gaze
- Inability to cry or express joy
- Inappropriate laughter or crying
- Depression
Additional signs, cont’d

- Oversleeping or insomnia
- Odd or irrational statements
- Forgetful; unable to concentrate
- Extreme reaction to criticism
- Strange use of words or way of speaking
What families in a first episode program need

- Factual information about psychosis
- Strategies to deal with difficult situations at home
- Support
- Answers to their questions
- Access to treatment team
- Shared-decision making with the team
- Hope
How we can give families what they need

- Provide education about psychosis
- Teach coping skills
- Imbue hope in recovery
- Involve them in treatment planning
- Let them know how they can support involvement in treatment
- Equip them to monitor the symptoms and communicate with the team
Principles of Working with families

• Try to see the world through their eyes
• Assess the family’s needs; start there
• Provide education; decrease blame, guilt and stigma
• Keep tension and conflict in family meetings to a minimum
• Use shared decision-making
• Address needs of all family members
• Daytime and evening hours
• Provide a comfortable meeting place
• Offer home visits if needed & wanted
• Routinely invite families to be involved in care from the beginning
• Introduce to NAMI
• Above all, offer hope and optimism
Examples of what families can do to help

- Encourage the taking of medications
- Helping their loved one report side effects and other concerns to prescriber
- Offer transportation to treatment AND to social opportunities
- Encourage the pursuit of personal goals like school and work
Additional examples of what families can do to help

- Be available to listen to loved one’s concerns
- Discourage alcohol and drug use
- Help solve problems
- Engage in stress-reducing activities
- Celebrate progress
- Provide hope and optimism in the future
In conclusion

• Families can be critical to recovery
• First episode programs should routinely provide families with ample education and support
• Families should be included in individual’s treatment as much as possible
• Family components are vital to first episode programs
For more information:

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Agenda

- Keys concepts or components of family models
- Describe options for family services/involvement
- Engaging families in care
- Considerations and potential challenges in working with families
Keys to Family Models

- Family friendly team
- Efforts to engage family throughout treatment
- Decisions concerning nature and extent of family involvement are made in collaboration with young person and family member
- Offering a range of services and options for involvement
- Flexibility
Family Friendly Team

- Understands the unique experiences and needs of families of individuals with FEP
- Active outreach to family at all points during the treatment process
- Efforts to minimize barriers to involvement
  - Flexible hours/meeting locations
  - Method of contact (e.g. in person, phone, etc)
  - Options for involvement/support
Education

• **Key elements**
  
  • *Offers information and education on topics relevant to family members of individuals with FEP*
  
  • *Typically includes information on:*
    
    • Specific topics such as symptoms, etiology and illness course, recovery, etc.
    
    • Skill building such as stress management and coping, problem-solving, communication skills, advocacy
  
  • *Often provides opportunity for support*
Options for Providing Education

- **Multifamily Educational Groups**
  - Regularly held groups (often monthly) with multiple families
  - With or without the young person
  - Some set core topics; additional topics based on group members’ needs

- **Individual Educational Sessions**
  - Conducted with individual families
  - With or without young person
  - Set educational topics and/or additional topics based on individual needs

- **Other Educational Resources**
  - Access to written information, handouts, DVDs, recovery videos, etc
Involvement in Ongoing Care

- Treatment Planning Meetings
- Meetings with young person and team members (e.g. primary clinician, psychiatrist, etc.)
- Regular meeting/calls with team members
- Phone contact with team members as needed
Engaging Families in Care

- Engagement starts at the first contact
  - *Initial phone call/inquiry to team regarding services*
  - *Initial intake or meeting with team about program*
  - *Later in care, after discussion with the young person*
Engaging Families in Care

Important to understand:

• Changes the family has observed or noticed and how they understand or make sense of those changes
• Concerns and questions the family has
• How long the situation has been going on; how has the situation changed over time
• If/where the family has gone to seek help/support and their views on the utility of that support
• What services/supports the family may need in order to support the young person and themselves
Engaging Families in Care

Important to convey:

• Understanding of the families situation and concerns

• Recognition of feelings of frustration, fear/worry, confusion, uncertainty, anger, etc.

• Availability of services and supports and information on how to connect with those services
Deciding How to Involve Family

- Gain understanding of young person’s support network and relationship with those supports
- Provide information on the potential benefits of and possibilities for family involvement
- Explore pros/cons of family involvement, particularly with regards to young person’s treatment goals
- Discuss options for involvement and decide what best fit needs/preferences
Family Involvement Over Time

- Needs and preferences of both the young person and the family change over time
- Need for ongoing assessment and reassessment of needs
- Regular, ongoing evaluation of how the team can help to address needs of both young person and family
Considerations When Working with Families

• Family member’s relationship to the young person
• Prior experience with mental illness and/or the mental health system
• Cultural considerations
• Developmental considerations
• Young person is a minor vs. adult
Challenges to Involving Families

• Differences in treatment goals or strategies
• Differences in expectations regarding treatment and recovery
• Religious/cultural differences
• Respecting autonomy and independence
• When young person is uncertain about or does not want family involvement
"One Family's Perspective"

Tom Simpson

Father of a Participant in the NAVIGATE Early Treatment Program
Darcy Gruttadaro, J.D.
Director
NAMI Child & Adolescent Action Center
Family Involvement in FEP Programs

- Wonderful to see family support and education in early and first episode psychosis (FEP) programs (CSC for RAISE).
- Families have long played a key role in the lives of their children living with mental illness. They want to better understand and address the challenges that come with early psychosis.
NAMI Grassroots’ Involvement

- NAMI is working at the grassroots’ level with researchers, programs and state policy makers to develop tools for youth, families and young adults.

- One example: NAMI MN
  - *Early Episode Psychosis: an educational program for young adults and families.*
  - *Understanding Psychosis ~ Resources and Recovery.*
NAMI’s FEP Learning Community

- NAMI grassroots leaders are becoming more engaged in this work.
- NAMI created an FEP Learning Community to educate and inform the grassroots about early and FEP programs.
- The level of interest and involvement is high with about 40 NAMI grassroots leaders involved in this work.
NAMI’s FEP Learning Community

What are we doing with the learning community?

- Offering family and young adult leaders the chance to hear directly from leading researchers and program directors.
- Hearing from their peers on innovative ways of working with early and first episode psychosis programs.
- Brainstorming on how NAMI can help to bring these programs into more communities.
What is NAMI doing to spread the word about early and first episode psychosis?

- Developing outreach strategies and resources.
- Adapting NAMI programs that reach children, youth, young adults and families to include information about early and FEP.
- Creating toolkits to educate and inform community leaders about these programs.
NAMI’s FEP Learning Community

- We recently launched a new web-section of resources – a work in progress: www.nami.org/feplearningcommunity.
- NAMI is a trusted source of information for families, youth and young adults.
- Collaboration and partnership are key in the broader dissemination and implementation of these programs.
NAMI’s Strategic Focus on FEP

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QUESTIONS?