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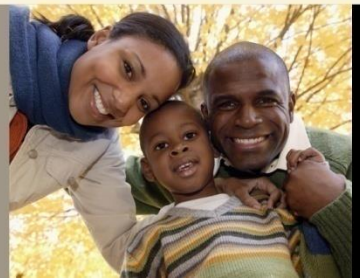
Promoting Meaningful Family Involvement in Coordinated Specialty Care Programming for Persons with First Episode of Psychosis

Tuesday, May 19, 2015 – 2pm Eastern



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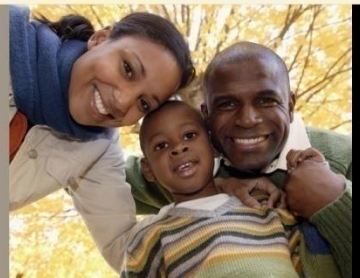
Susan Gingerich, M.S.W.

Training Coordinator

NAVIGATE Early Treatment Program



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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**

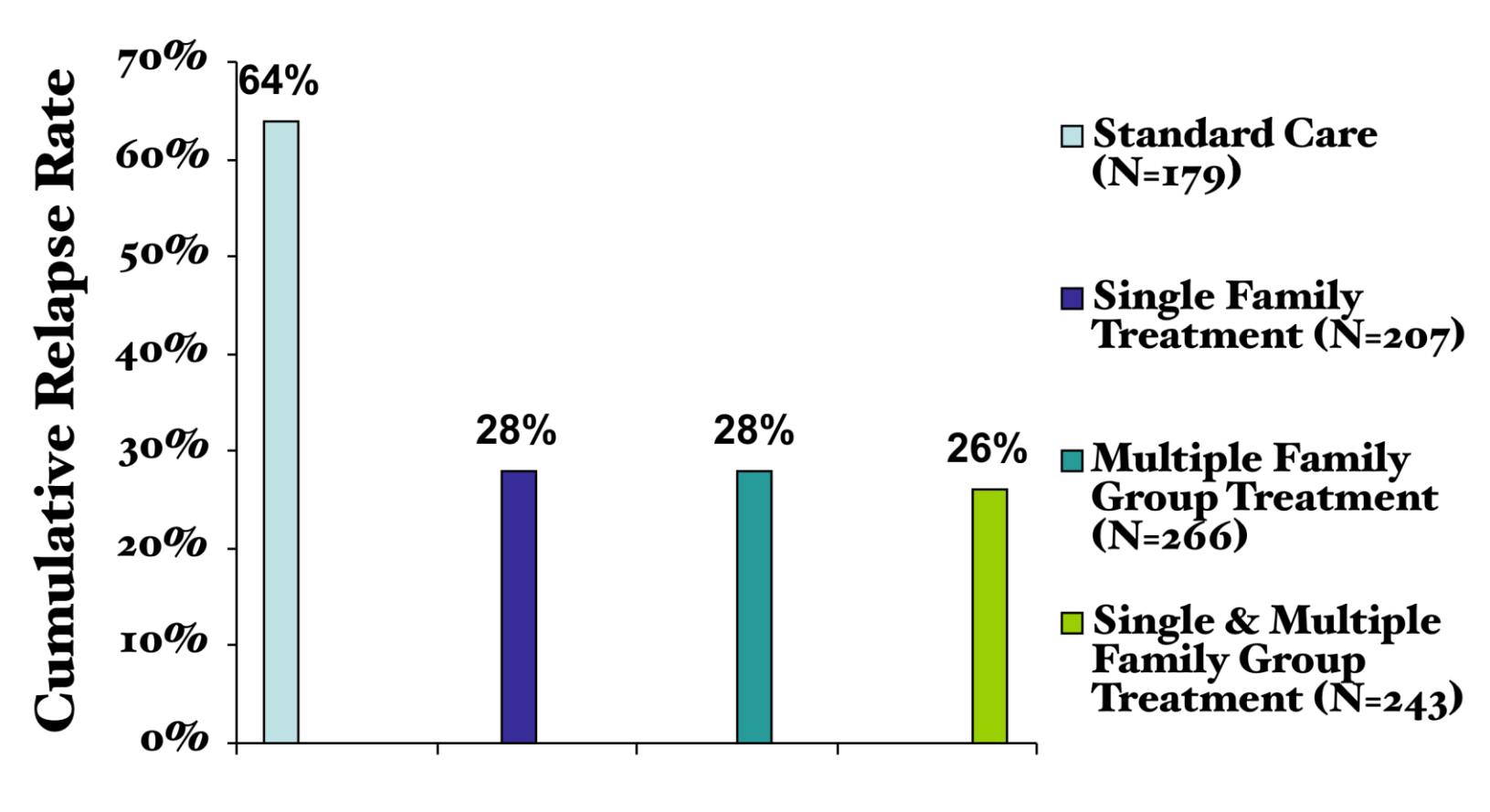
Agenda for this presentation

- 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**

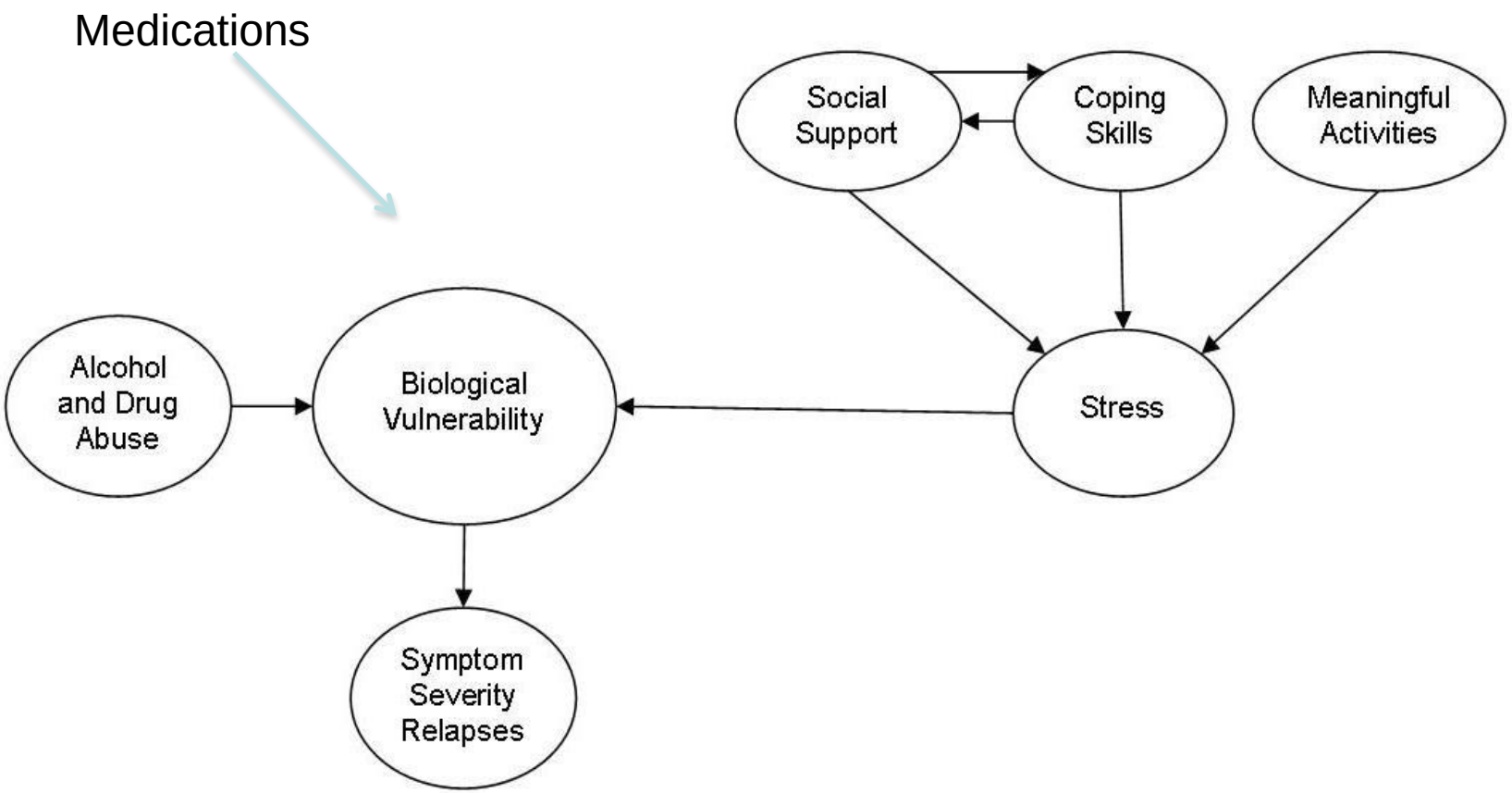
Combined Results of Family Programs on 2 year cumulative relapse rates



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



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

Principles of Working with families, cont'd

- 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

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For more information:

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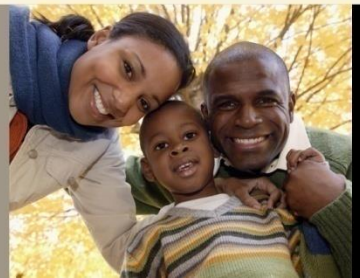

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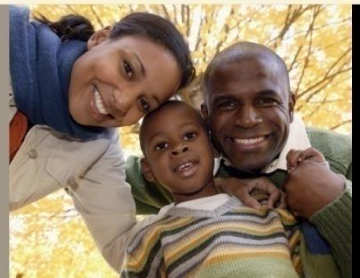

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Agenda

- 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

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"One Family's Perspective"

Tom Simpson

Father of a Participant in the NAVIGATE Early Treatment Program

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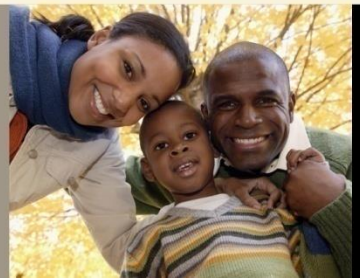
Darcy Gruttadaro, J.D.

Director

NAMI Child & Adolescent Action Center



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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.*

NAMI's FEP Learning Community

- **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

For more information:

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QUESTIONS?

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