Shared Decision Making for Family Involvement

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Are your families important to you?

Why or why not?
Do you want someone to support you (in some way) when the going gets tough?
Do we think that people diagnosed with a serious mental illness (SMI) are any different?
Inclusion of families in care of individuals diagnosed with SMI well established to improve outcomes

Dissemination of evidenced-based family psychoeducation (FPE) models have largely failed to have deep penetration and sustainability

Patient and family-centeredness has been limited
Why Consider Family Interventions?

• Recommendation of the President’s New Freedom Commission potentially relate to family issues:

Mental health care is consumer and family driven.
Families play an active role in the lives of persons with severe mental illnesses.
Families (Can) Provide:

- Crisis Intervention Help
- Case Management
- Counseling
- Help with Basic Needs
- Socialization and Rehabilitation Opportunities
- Advocacy

White Paper of NAMI New York State, 2006
Family Experience:

- Considerable subjective burden, e.g., anxiety, worry, grief, sadness

- Considerable objective burden, e.g., expenditure of time, resources

- As recovery movement has evolved, so has recognition of benefits and gratifications of relationships with “ill” persons and of caregiving.
Family Work as Best Practice

People with mental health concerns who have on-going contact with their families (or wish to) should be offered a family based intervention which provides a combination of:

- education about the illness
- family support
- crisis intervention
- problem solving skills training
- practical guidance
Impact of Single-Family, Multiple-Family, and Combined Approaches on Relapse Rates in Major Outcome Trials

- Average relapse rates across 11 RTC’s (N = 895)
- Mean length of treatment = 19.7 months

Problems with Implementing Family Services for People with SMI

• Consumer (and family’s) preferences often left out of the process

• Engaging consumers regarding this issue is not always easy for practitioners
An Effective Approach to Involving Families Must:

• Address consumers’ concerns regarding family involvement
• Promote consumers’ control of care
• Educate consumers regarding benefits of family involvement and participation in care
• While working toward promoting utilization of EBP and its precursors of basic family involvement
Common Experiences of Consumers (and Practitioners)

- Consumers are angry/frustrated with families and don’t want involvement
- Initially, there simply are no family members
- Consumers want their families involved only in specific ways
- Consumers are worried family involvement will take away their own control
- “Burned bridges”
- People are traumatized (consumer; family)
- Families say “no” to involvement if asked
- Families don’t know how to be involved in helpful ways
Family/supports involvement: “To be or not to be?”

It all starts with a conversation with the consumer
Possible Goals

- Help the consumer make an informed decision about whether or not to include family in his/her treatment.
- Identify how the family can become more productively involved in his/her care; specifically in their recovery goals.
- Activate the consumer to promote this participation him/herself.
Tools to help with conversations with consumers
# Values Clarification Exercise: Part 1

<table>
<thead>
<tr>
<th>Very Important</th>
<th>Moderately Important</th>
<th>Little or Not Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live Independently</td>
<td>Meeting new people</td>
<td>Have a nice car</td>
</tr>
<tr>
<td>Recovering from my psychiatric problems</td>
<td>Have nice clothes</td>
<td>Having extra money</td>
</tr>
<tr>
<td>Staying out of the hospital</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Values Clarification Exercise: Part 2

<table>
<thead>
<tr>
<th>Important Values I have</th>
<th>How Family Involvement Might Help or Hurt</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live independently</td>
<td></td>
</tr>
<tr>
<td>Recovering from my psychiatric problems</td>
<td></td>
</tr>
<tr>
<td>Staying out of the hospital</td>
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</tbody>
</table>
Review Values Clarification Tool

Copies of the Values Clarification tool are available on the Family Institute website (see “Resources”):

www.nysfamilyinstitute.org
## Decisional Balance Exercise

<table>
<thead>
<tr>
<th>Benefits of Family Involvement</th>
<th>Concerns about Family Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worry about me less</td>
<td>Invade my privacy</td>
</tr>
<tr>
<td>Less arguing</td>
<td>Mother is sick</td>
</tr>
<tr>
<td>Might help me better if I have a symptom flare up</td>
<td>Might feel too controlled</td>
</tr>
</tbody>
</table>

Practitioner: “Okay. Let’s talk about which ones really count? Which are most important to you?”
Review Decisional Balance Tool

Copies of the Decisional Balance tool are available on the Family Institute website (see “Resources”):

www.nysfamilyinstitute.org
Consumer Perceptions of Benefits of Family Involvement

Study: Recovery ORiented DEcision-making for Relatives Support (REORDER)
Authors: Lisa Dixon, M.D., Shirley Glynn, Ph.D., Amy Cohen, Ph.D., Amy Drapalski, Ph.D.
Consumer Perceptions of Barriers to Family Involvement

Study: Recovery ORiented DEcision-making for Relatives Support (REORDER)
Authors: Lisa Dixon, M.D., Shirley Glynn, Ph.D., Amy Cohen, Ph.D., Amy Drapalski, Ph.D.
What is this guide about?

This guide helps adults with mental health concerns and their clinicians. It’s a tool for making decisions about whether and/or how to involve family members or friends in support of recovery goals and treatment.
Decision Guide

- The guide integrates the principles of shared decision making
- The guide provides the consumer and clinician with an easy to understand, practical step by step approach to decision making
- The guide offers a framework to begin a conversation with consumers about including others in their recovery process
- The transparency of a written guide helps to build safety and trust in the therapeutic relationship
Review Decision Guide Tool

Copies of the Decision Guide are available on the Family Institute website (see “Resources”): www.nysfamilyinstitute.org
For consumers who chose to involve families (NYS), how many conversations occurred during the engagement process?

• 2.43 conversations (on average)

Less than one-quarter of consumers wanted to involve their family/supports after an initial engagement contact

• Any effort made by the clinicians to engage with consumers about expanding their circle of support adds value to the service provided
  – Conversation itself can be empowering and validating
Planning Meeting(s)
(Prior to family outreach; if client has already consented to family involvement)

- 1-2 conversations between consumer and practitioner
- **Emphasis**: Consumer is in the “driver’s seat” and has choices
- **Plan**: the goals/issues to discuss during CCFC (and what *not* to discuss)
- **Plan**: outreach method to family/supports
- **Prep**: the family often wants to share some perspectives and experiences
- **Discuss**: how to handle “curveballs”
Review Planning Tool

Copies of the Planning Tool are available on the Family Institute website (see “Resources”):

www.nysfamilyinstitute.org
Consumer Preference for Family Involvement in Care

Study: Recovery ORiented DEcision-making for Relatives Support (REORDER)
Authors: Lisa Dixon, M.D., Shirley Glynn, Ph.D., Amy Cohen, Ph.D., Amy Drapalski, Ph.D.
% of Participants with Clinician/Family Contact

- **REORDER**
  - 6 Months Before: 10
  - 6 Months After: 10

- **Comparison**
  - 6 Months Before: 20
  - 6 Months After: 20
What Now?

Possible approaches if consumer wishes to invite family/supports to participate in recovery
Tips for Outreach with Family/Supports

• Set aside enough time to discuss their possible involvement

• Introduce yourself with a focus on your role in helping consumer

• Share some personal aspect(s) of yourself to foster genuine relationship building

• Explain that this is a proactive phone call and not crisis oriented

• Make sure to tell them that you’re not inviting them to family therapy

• Explain the goals (e.g., inviting them to treatment team meeting; inviting them to CCFC meeting; helping them best support loved one)
Tips for Outreach with Family/Supports (Con’t)

• Explain: your work is consumer driven and their loved one has given permission for everyone to talk with one another

• Ask if they are interested in participating in the recovery of their loved one in a specific way. Let them know it’s time-limited.

• If interested, set up a time and work out logistics (date, time and location)

• If not interested, ask if you can call them again in the future and give them your phone number for them to call if they change their mind

• Thank them for their time and consideration and end with comments that instill hope
Common characteristics of Effective FPE Programs

- Show concern, empathy
- Provide information
- Avoid blaming
- Promote adherence to medications
- Flexible, individualized treatment

- Encourage family to develop outside supports
- Instill hope
- Take a long term perspective
- Strengthen communication and problem solving skills
Address the wants/needs of consumers (and families)

- Referrals and linkage with NAMI
- Family involvement in treatment/recovery meetings
- Provide consultation and education
- Agency-sponsored group family information and education opportunities
- Invite to longer term family psychoeducation
- Refer to other community programs
Community-based Supports

• NAMI - many services
  (www.naminys.org)
  – Monthly support groups
  – Information nights
  – Family to Family Education Program
Non-Clinical Program: NAMI Family to Family Education Program

- Developed by Joyce Burland
- Structured 12-week program with weekly 2-3 hour sessions
- Taught by trained family members
- Trauma-recovery and stress-coping model
- In 40+ states with corps of trained teachers and well-established and self-sustaining training model
Questions, Answers & Discussion