Strategies and Rationale for Working with Families
Lisa Dixon, M.D., M.P.H.
Professor of Psychiatry, Columbia University Medical Center
Director, Center for Practice Innovations

The Care Transitions Network

National Council for Behavioral Health
Montefiore Medical Center
Northwell Health
New York State Office of Mental Health
Netsmart Technologies
Agenda

• The importance of family support and family involvement in the lives of individuals who have serious mental illness

• Implementing the evidence based practice, “Family Psychoeducation.”—the promise and pitfalls

• A next step: REORDER as a person and family centered approach to including families in care while promoting recovery.
Agenda

• The importance of family support and family involvement in the lives of individuals who have serious mental illness

• Implementing the evidence based practice, “Family Psychoeducation.”—the promise and pitfalls

• A next step: REORDER as a person and family centered approach to including families in care while promoting recovery.
Contributions of Family Members and Being a Family: What Do We Know?

• In general, research shows that many individuals with mental illness have extensive contact with their families.
• Many individuals receive an array of helpful supports from their family.
Family Contact and Support Helps

- Among individuals with schizophrenia not living with family, those with family contact had better work and overall school performance.

- A study of over 900 individuals with schizophrenia in Australia found a positive association between family contact and better social role functioning.

Brekke J, Mathiessen: Psych Services 1995: 46; 1149-55
Evert H et al.: Soc Psych Psychiatr Epidem 2003: 38(4); 180-8
Family Support and Substance Use Outcomes for Persons with Mental Illness and Substance Use Disorders

- Randomized trial of treatment for people with co-occurring severe mental illness and substance use disorders
- Greater average family expenditures and caregiving hours associated with increased likelihood of abstinence

<table>
<thead>
<tr>
<th></th>
<th>Abstinent (SD) N=31</th>
<th>Nonabstinent (SD) N=129</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Caregiving Expenses Per Month</td>
<td>$398 (417)</td>
<td>$362 (482)</td>
</tr>
<tr>
<td>Average hours of family caregiving per month</td>
<td>51.36 (48.90)</td>
<td>49.68 (55.64)</td>
</tr>
</tbody>
</table>

Substitution between Formal and Informal Care for Persons with Severe Mental Illness and Substance Use Disorders

• Patients who consistently received higher amounts of informal care (long-term) were less costly to treat in the formal system.

• A 1% decrease in formal costs for every 4%-6% increase in mean hours of informal care.

• Consistently high levels of informal care may substitute for formal care, or vice versa.

Expressed Emotion

• Family’s level of “expressed emotion” consistently associated with more rapid readmission to hospital of relative with schizophrenia

• Elements of expressed emotion include “critical comments” and “emotional over-involvement”

• Observation led to development of family psychoeducation models

• Cultural dimension important

• Correlation is not causation
Agenda

• The importance of family support and family involvement in the lives of individuals who have serious mental illness

• Implementing the evidence based practice, “Family Psychoeducation.”—the promise and pitfalls

• A next step: REORDER as a person and family centered approach to including families in care while promoting recovery.
What is Best Practice? PORT 2010

• Persons with schizophrenia ... should be offered a family intervention that lasts at least six to nine months. Interventions that last six to nine months have been found to significantly reduce rates of relapse and re-hospitalization.

• Key Elements:
  • duration of at least nine months
  • illness education
  • crisis intervention
  • emotional support
  • training in how to cope with illness symptoms.
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

Family Support/Education and Recovery

• Interview of 825 individuals with schizophrenia as part of PORT study
• Examined different service factors and recovery (hospitalization, day hospital, saw psychiatrist, saw social worker, has therapist)
• Only service related to recovery was family psychoeducation
• Correlated with greater hope, knowledge and recovery of consumer

## Predictors of Successful Linkage to Outpatient Care (N=229)

<table>
<thead>
<tr>
<th>Predictor</th>
<th>b</th>
<th>Chi-sq</th>
<th>P</th>
<th>Adj OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Started Outpatient Program Before Discharge</td>
<td>1.37</td>
<td>6.81</td>
<td>0.009</td>
<td>3.90</td>
<td>1.40-10.82</td>
</tr>
<tr>
<td>Family Meetings/Support Services</td>
<td>1.32</td>
<td>6.37</td>
<td>0.01</td>
<td>3.74</td>
<td>1.34-10.41</td>
</tr>
<tr>
<td>Discharge Plan Discussed with Outpatient Clinicians/Staff</td>
<td>1.36</td>
<td>9.06</td>
<td>0.003</td>
<td>3.91</td>
<td>1.61-9.50</td>
</tr>
</tbody>
</table>

Receipt of Family Services: Patient Field Study (N=539)

Only 30% of patients reported that families received even education.

What are the perspectives of XXX psychiatrists?
XXX Psychiatrist Survey: In What Percentage of Clients….

N=27
Psychiatrist Survey: What are the most important reasons causing you to try have family contact?

- To obtain collateral information (20/27)
- To solicit family support (10/27)
- To verify treatment and compliance/noncompliance (7/27)
- To discuss treatment plan (4/27)
- For purposes of risk management (3/27)
- To discuss housing issues (2/27)
XXX Psychiatrist Survey: What are the most important barriers to direct contact with families?

- Patient consent (13/27)
- Lack of cooperation from family (4)
- Unable to contact family (2)
How helpful is it to you when other treatment team members have contact with families?

- A lot
- A moderate amount
- A little
- None at all

N=27
So Where Does This Leave Us?

- We need to find ways to bridge the gaps between family members, consumers and providers!
- We need to do this in a manner that builds on recovery principles, that is consistent with work flow and training, and maximizes benefits for the consumer and family.
Agenda

• The importance of family support and family involvement in the lives of individuals who have serious mental illness

• Implementing the evidence based practice, “Family Psychoeducation.”—the promise and pitfalls

• A next step: REORDER as a person and family centered approach to including families in care while promoting recovery.
The Problem

• Overwhelming evidence that family participation in the mental health care of individuals with mental illness contributes to improved consumer and family outcomes

• Consistent evidence that such participation does not occur in majority of cases with adult consumers

• There are numerous reasons for this gap; one is failure to engage consumers and family members in this process
What is Shared Decision-Making?

The process of interacting with patients who wish to be involved in arriving at informed, values-based choices when 2 or more medically reasonable treatment options have features that patients value differently.”


“...a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients’ information, sense of autonomy, and/or control over treatment decisions that affect their well-being.”

Partnership in Care: REORDER
REcovery ORiented DEcisions for RElatives Support

Goals:
To Promote Consumer Recovery
To Optimize Family Involvement in Care

Our Clinical Research Team and Funding

Dr. Shirley Glynn  Los Angeles
Dr. Amy Drapalski  Baltimore
Dr. Amy Cohen  Los Angeles
Dr. Deborah Medoff  Baltimore

Funding for Project: VA Health Services Research and Development (HSR&D) grant (IIR 04-255) to Dr. Dixon
REORDER Goals

• Increase consumers’ empowerment, hope, recovery, satisfaction with mental health care and family relationships
• Increase family members’ satisfaction with mental health care and family relationships
• Increase rates and numbers of clinician-family contacts
• Increase rates of participation in FPE
Principles of REORDER

• Individualized and person-centered approach
• Based on shared decision making
• Facilitating consumer responsibility in engaging their family support network
• Holistic emphasis: understanding consumer as a “whole person” embedded in network of relationships
REORDER Structure

- Clinician or Family Member Provider
- Individual sessions

2 Phases
  - Phase 1: Consumer; 2-3 45-minute sessions
  - Phase 2: Family; 2-3 45 minute sessions (initially family alone; add consumer)

Flexible: which support figure; how many supports attend; if consumer is part of Phase 2; home visits; how often meet
REORDER Consumer Phase

• A trained clinician/family member works with the consumer to identify recovery goals, clarify the benefits of family involvement and the individual’s feelings about such involvement.

• Overall Goals:
  • to resolve consumer-based barriers to family involvement
  • to empower consumers to encourage and facilitate their family’s involvement
  • to encourage their mental health providers to involve their families in appropriate ways.
Consumer Session One

• General Introduction (4 minutes)
• Developing an alliance and obtaining background information (10 minutes)
• Clarifying the consumer’s conceptualization of the current psychiatric problem (8 minutes)
• Identifying the members of the consumer’s family and nature of relationships (10 minutes)
• Determining whether the consumer is willing to have family be engaged in treatment (5 minutes)
• Rehearsing inviting the family to the REORDER program and talking about it with the treatment team (10 minutes)
• Ending the session (3 minutes)
Consumer Session Two Goals

• Continue to develop an alliance with the consumer

• Clarify or strengthen the participant’s commitment to have his/her family involved in his/her treatment. These motivational exercises are tailored to the consumer’s current motivation and comfort level with family involvement in care.
## 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>
<td></td>
</tr>
</tbody>
</table>
## 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>
</tbody>
</table>
Collect info, concerns, recovery goals, contact and relationships with relative, and prior family involvement in care.

Provide information about the potential benefits of and options for relative involvement.

Discuss preferences for relative involvement and help them make a decision.

Motivational interviewing techniques and a values clarification exercise are completed.

Efforts to invite relative and outcome reviewed, if applicable.

Consumer invited relative who agrees.

Consumer invited relative who can’t or won’t.

Consumer is not interested.
REORDER Family Phase

• With the consumer’s permission and if the family is amenable, the REORDER clinician engages in education and support with the relatives

• Goals: To strengthen the family member’s ability
  • To provide information and support to the family member
  • To strengthen the family member’s ability
    • to support the consumer
    • to interact effectively with the consumer’s regular treatment team.
Family Session One Goals

• Develop an alliance with the relatives
• Clarify the relative’s conceptualization of the current psychiatric problem
• Determine the relative’s level of engagement and/or willingness to engage with the treatment
• Encourage family involvement with the treatment team
• Make an assessment of what content would be most useful for participants in the following sessions
Family Session Two Goals

• Continue to develop an alliance with the relatives
• Strengthen the communication with the relatives and the treatment team, if the consumer consents
• Provide illness education tailored to the needs of the participants
• Encourage engagement in appropriate family support programs
• Clarify or strengthen the participant’s commitment to have his/her family involved in his/her treatment.
Family Session Three Goals

- Continue to develop an alliance with the relatives
- Strengthen the communication with the relatives and the treatment team, if the consumer consents
- Provide illness education tailored to the needs of the participants
- Encourage engagement in appropriate family support programs
- Address any pending issues prior to termination.
REORDER Study Aims (RCT)

- To evaluate the effect relative to enhanced treatment as usual (e-TAU) of REORDER on family involvement in care and care processes (family-clinician contact, FPE, satisfaction with care).
- Evaluate the effect of REORDER on veteran outcomes (symptoms, measures of recovery, family functioning and satisfaction)
Inclusion Criteria

• Age 18-75
• Schizophrenia, Psychotic Mood Disorder
• At least two OP mental health consumer in last six months
• Evidence of patient contact with family member or caregiver over last 6 months
• Currently in an outpatient, community or transitional residence, short-term (time-limited) or residential rehabilitation program
• Deemed stable enough to participate by clinicians
Expectations Regarding Benefits of Family Involvement (N=230)

- Help consumer with illness
- Help Family with Stress

% of Participants

- Agree
- Disagree/Mixed
Concerns Regarding Family Involvement (N=230)
Perceived benefits of involvement significantly predicted more desire for services!
REORDER RCT Results: Compared to Enhanced TAU

• Consumer Outcomes
  • Reduced paranoid ideation (p=.004)
  • Improved recovery (MHRM)(p=.025)

• Relative to six months before randomization, significant increase in number of in person visits between family and “regular “ clinical team

Consumer Centered Family Consultation

- Consumer
- Consultant
- Consumer Centered Family Consultation
- Family Members
- Resource Library
- NAMI Basics
- NAMI Information Night
- NAMI Connection
- Multifamily Group
- NAMI Family to Family Curriculum
- NAMI In Our Own Voice
- NAMI Education Curriculum
- Behavioral Family Therapy
- NAMI Peer To Peer
- Family Support Group

Care Transitions Network
with Serious Mental Illness
Decision guide for involving family or friends to support treatment and recovery

What is this guide about?

This guide helps adults with whole 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 whole health goals and treatment.
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 will share some of their perspectives and experiences
• **Discuss**: how to handle “curveballs”
ABC’s of Consumer Centered Family Consultation

• Connecting
• Defining & prioritizing wants/needs
• Planning action steps
Connecting

Initial stage of a Consumer Centered Family Consultation:

- Casual conversation
- Review and describe the purpose and limits of a consultation meeting
- Support the family in telling their story
- Demonstrate understanding via empathic responding
- Commend family members for taking steps to work together and point out other strengths of the family
Defining and Prioritizing Wants/Needs

- Consultant shares his/her perspective
- Elicits reactions of family members and consumer to consultant’s perspective
- Merges perspectives on shared values and goals
- Creates a list of consumer and family wants & needs
- Engages consumer and family members in deciding on high priority issues
- Identifies high priority issues and discusses next steps
Planning Action Steps

• Address high priority wants and needs
  – Imparting information about their loved one’s whole health needs, treatment and other services
  – Exploring the degree to which the family member is willing and able to provide support in the manner preferred by the consumer
  – Offer guidelines for families related to supporting their loved one’s treatment and recovery
  – Provide emotional support
  – Provide information about resources in the community
  – Direct assistance and advocacy to help family navigate the health system
Putting It Together

- Families are important and their involvement in care can be a game changer.
- A consumer and family centered approach to involving families in care can overcome many barriers and facilitate recovery!
- REORDER provides a set of tools.
Thank you!

www.CareTransitionsNetwork.org
CareTransitions@TheNationalCouncil.org

The project described was supported by Funding Opportunity Number CMS-1L1-15-003 from the U.S. Department of Health & Human Services, Centers for Medicare & Medicaid Services.

Disclaimer: The contents provided are solely the responsibility of the authors and do not necessarily represent the official views of HHS or any of its agencies.