Family work with transition age young adults

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Center for Practice Innovations℠
at Columbia Psychiatry
New York State Psychiatric Institute
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Learning Objectives

- To learn about a flexible approach for working with young adults and their family members
- To become familiar with common reactions and needs of families of young adults experiencing a mental health condition
- To learn about unique skills and tools for involving families in care and care planning
- To learn about options that teams can provide to clients and families regarding family involvement

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**

Defining Family

- Consider endorsing a broad definition of family
  - Includes the immediate, extended, blended and family of choice
  - Includes siblings, parents, grandparent, significant others, and other natural support people (e.g., close friends, extended family, romantic partner)
  - Cultural considerations of who to include

“Big Picture” Intent

To go beyond viewing families only as source of collateral information

To go beyond providing information and support to families;

To enlist them as allies and partners;

To focus the family treatment on assisting the young person

A humbling reminder for us:

Families are there before us, during the time with us, and long after…

Common Experiences of Families

Common Reactions

- Confusion/Shock
- Fear/Anxiety
- Anger/Frustration
- Grief/Sense of Loss
- Helplessness
- Feeling Overwhelmed
- Shame/Guilt
- Distancing/Isolation
- Denial

Family members' experience of a young adult with a mental health condition

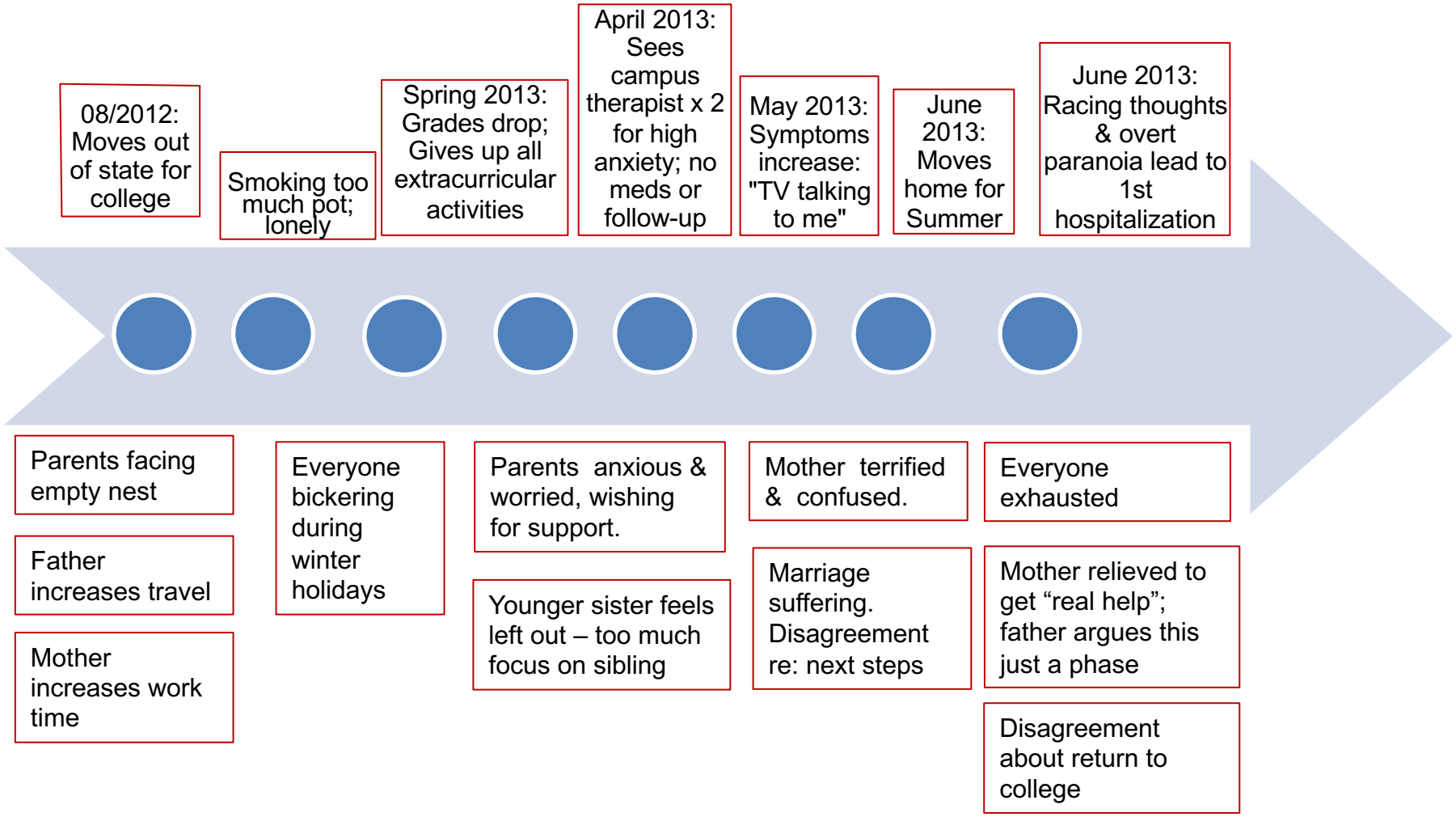
- Disruptions in family routines
- Changes in family roles and responsibilities (e.g. extended parenting)
- Financial hardships
- Differences in opinions about what to do and how to help
- Lack of knowledge about mental health and recovery
- Loss of social support/reduced participation in social activities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

2 Key Points:

1 – For some people, be prepared to see some families at their worst

2 – This is typically not always how they've been

A Family's Experience: Timeline Exercise



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Some Challenges…

- What to do when young person is ambivalent or does not want family members involved?
- What to do when families are disengaged?
- What to do when families do not understand about mental illness? Lack of awareness?
- What to do when families have a ton of conflict or are doing “all the wrong things”?
- What to do when families are insisting on “driving the treatment” and making decisions for the person?
- What to do when families are really protective and not aligned with person’s goals (e.g., work, living independ.)?
- What to do when stigma prevents the family from participating in services?

Chat Box Question

Do these types of challenges resonate with you?

Other successes or challenges you'd like to share re: your work with families?

Over-simplified, but important…

"*Understanding…compassion…respect*" – Families will unite with the treatment team when given these.

Joyce Burland & Laurie Flynn

FLEXIBILITY & CHOICES

KNOWLEDGE EXCHANGE & COLLABORATION

What Might You Offer

Early engagement with family

Family sessions with team members (with one or multiple team members)

Family psychoeducation in individual sessions,

Family psychoeducational groups (monthly)

Connections to community education/support services/resources

What Might You Offer (*cont.*)

Brief family consultation on specific topics/skills

Problem-solving sessions

Crisis intervention and safety planning

- After-hours access to team and/or services

- Long term planning (transition)

- Open lines of communication with any team member

Family Involvement:

It all starts with a Shared Decision Making (SDM) conversation with the young person

Strategies to discuss uncertainty or ambivalence

When the individual does not want family involved or is ambivalent…

- Choose one person rather than the whole family
- Is there another support person that can be included (not necessarily nuclear family)?
- Are there any ways that they would be willing to have family involved; discuss different levels of family involvement
- Revisit the option at a later date

Tease out…

- Do family members have specific needs that may not align with the young person's needs?
  - Is the person okay with the team addressing those family needs (in general)?
- Is the person okay with addressing family needs without sharing personal information or details about the young person?
  - Is person okay with family attending a monthly group, with stipulation that practitioners don't share personal information/details about him/her?

**There are choices: frequency, timing, mode (in person v. phone), who to include, topics that are "off limits", length of contacts, etc*

IT'S NOT ALL OR NOTHING

Values Clarification Exercise

Goal:

- Help clarify personal values and how they relate to family involvement in care

Exercise steps:

- Sort cards with life values into very categories of importance
- Discuss possible family involvement in relation to each value

F. Values Clarification Exercise

The goal of this exercise is to help participants clarify their personal values and how they relate to family involvement in care, through the use of the values clarification exercise. The team leader first provides three pieces of paper labeled "Very Important," "Moderately Important," and "Little or No Importance" at the top. Participants are given the list of values cards and asked to sort them into three piles (very important, moderately important, little or no importance). These values cards include concrete issues of interest to most persons (e.g., "getting along with my family") and those of special relevance to persons with serious psychiatric illnesses (e.g. "staying out of the hospital," "keeping symptoms to a low level," "not embarrassing myself in public"). If a participant says "I don't know," the team leader prompts with, "Make your best guess." If this does not help the participant make a choice, the team leader can make a "Do Not Know" category.

"I want to understand what is really important to you in life. Here is a set of life values cards. They describe experiences and values that are important to some people but not to others. Would you please read each one and then put in the pile which reflects how important that value is personally, to you?"

After all the cards are sorted, the team leader then takes the pile of most importance and discusses how family might be related to each value by asking the participant:

"How do you think your family being involved in your care and getting more support might be related to (this value)?"

Life Values for the Cards

- Living independently in my own apartment or house
- Paying my bills
- Getting along with my family
- Having a fun social life
- Having friends
- Being self-sufficient
- Meeting new people
- Having a partner
- Dating
- Staying out of the hospital
- Feeling proud of myself
- Having nice clothes
- Having a nice car
- Not embarrassing myself in public
- Having something productive to do with my time
- Having extra money
- Keeping my symptoms to a low level
- Having a hobby
- Helping others
- Making others who care about me proud
- Recovering from my mental/emotional problems

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Family Involvement Decisional Balance

Goal:

- Explore reasons and ways to involve family
- Strengthen commitment to involving family

Exercise steps:

- Identify benefits to family involvement
- Identify challenges
- Determine most important pros and cons

Good Outcomes from Having Family More Involved in Care:
1. 2. 3. 4. 5. 6. 7. 8.
(Examples: relatives might feel calmer if they know the doctor, might be able to manage medication better, relatives might be able to help me more if I have a symptom flare-up, relatives might be able to help me reach some of my goals)
Challenges from Having Family More Involved in Care
1. 2. 3. 4. 5. 6. 7. 8.
(Examples: might risk privacy, might feel too controlled, might lead to more fights)

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Family Involvement:

Help Families Think Through What Options are the "Best Match"

(Using shared decision making)

Information – Support - Skills

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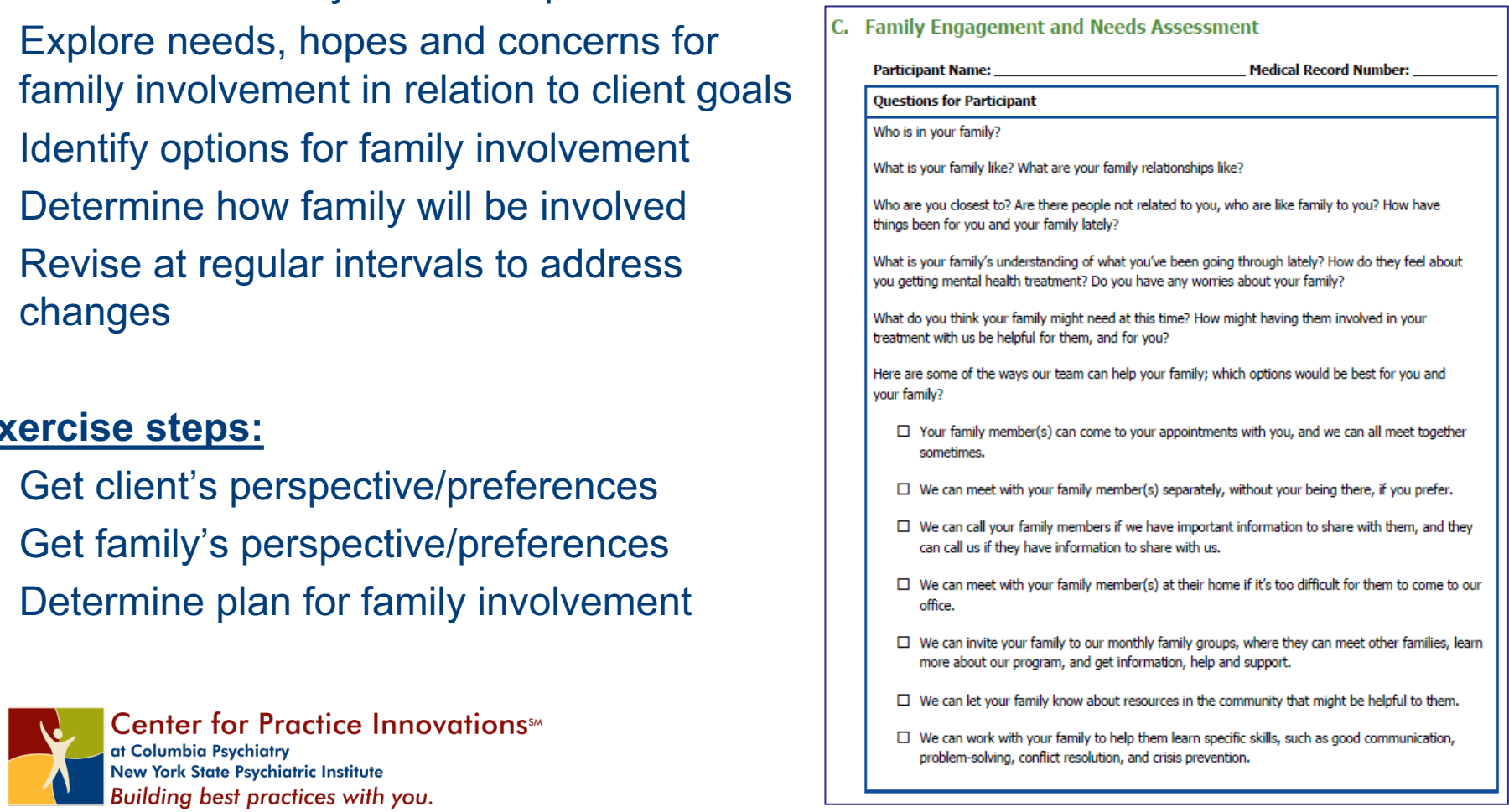
Family Needs Assessment

Goals:

- Engage & build rapport
- Learn about family relationships
- Explore needs, hopes and concerns for family involvement in relation to client goals
- Identify options for family involvement
- Determine how family will be involved
- Revise at regular intervals to address changes

Exercise steps:

- Get client's perspective/preferences
- Get family's perspective/preferences
- Determine plan for family involvement



C. Family Engagement and Needs Assessment

Participant Name: _____ Medical Record Number: _____

Questions for Participant
Who is in your family?
What is your family like? What are your family relationships like?
Who are you closest to? Are there people not related to you, who are like family to you? How have things been for you and your family lately?
What is your family's understanding of what you've been going through lately? How do they feel about you getting mental health treatment? Do you have any worries about your family?
What do you think your family might need at this time? How might having them involved in your treatment with us be helpful for them, and for you?
Here are some of the ways our team can help your family; which options would be best for you and your family?
☐ Your family member(s) can come to your appointments with you, and we can all meet together sometimes.
☐ We can meet with your family member(s) separately, without your being there, if you prefer.
☐ We can call your family members if we have important information to share with them, and they can call us if they have information to share with us.
☐ We can meet with your family member(s) at their home if it's too difficult for them to come to our office.
☐ We can invite your family to our monthly family groups, where they can meet other families, learn more about our program, and get information, help and support.
☐ We can let your family know about resources in the community that might be helpful to them.
☐ We can work with your family to help them learn specific skills, such as good communication, problem-solving, conflict resolution, and crisis prevention.

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Key Questions for Families (1)

- “Tell us about [person’s name] when he/she is at his/her best.”
- “What is your understanding of your family member’s difficulties?”
- “How does your community understand what is going on?”
- “What are some of your concerns about your family member?”
- “What would you like to be different/better for your family member?”

Key Questions for Families (2)

- “What are your thoughts about your family member’s goals?”
- “How have your family member’s experiences affected you and the rest of your family?
- “What do you feel you need at this point?”
- “How can our team be most helpful to you?”

“Big Picture” Message

We have several different types of things we can do together. And what you may want or need may change over time.

Let’s talk about which fits with what you want and can do now?

Cultural Formulation Interview

- Provides an opportunity for everyone in the room to put things together
  - Helps clinicians understand what came before the illness and how the family contextualizes the illness
  - Facilitates understanding of what will come after (e.g., how the client and family will relate to treatment, their goals/expectations, and what choices they will make)

DSM-5 Cultural Formulation Interview

4 Domains and 16 Items

- ❑ Cultural definition of the problem
- ❑ Cultural perceptions of cause, context and support
- ❑ Cultural factors affecting self coping and past help-seeking
- ❑ Cultural factors affecting current help-seeking

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Cultural Formulation Interview (CFI)

Supplementary modules used to expand each CFI subtopic are noted in parentheses.

GUIDE TO INTERVIEWER	INSTRUCTIONS TO THE INTERVIEWER ARE ***ITALICIZED.***
The following questions aim to clarify key aspects of the presenting clinical problem from the point of view of the individual and other members of the individual's social network (i.e., family, friends, or others involved in current problem). This includes the problem's meaning, potential sources of help, and expectations for services.	*INTRODUCTION FOR THE INDIVIDUAL:* I would like to understand the problems that bring you here so that I can help you more effectively. I want to know about ***your*** experience and ideas. I will ask some questions about what is going on and how you are dealing with it. Please remember there are no right or wrong answers.
CULTURAL DEFINITION OF THE PROBLEM	
CULTURAL DEFINITION OF THE PROBLEM (Explanatory Model, Level of Functioning)	
Elicit the individual's view of core problems and key concerns. *Focus on the individual's own way of understanding the problem.* *Use the term, expression, or brief description elicited in question 1 to identify the problem in subsequent questions (e.g., "your conflict with your son").*	1. What brings you here today? *IF INDIVIDUAL GIVES FEW DETAILS OR ONLY MENTIONS SYMPTOMS OR A MEDICAL DIAGNOSIS, PROBE:* People often understand their problems in their own way, which may be similar to or different from how doctors describe the problem. How would *you* describe your problem?
Ask how individual frames the problem for members of the social network.	2. Sometimes people have different ways of describing their problem to their family, friends, or others in their community. How would you describe your problem to them?
Focus on the aspects of the problem that matter most to the individual.	3. What troubles you most about your problem?
CULTURAL PERCEPTIONS OF CAUSE, CONTEXT, AND SUPPORT	
CAUSES (Explanatory Model, Social Network, Older Adults)	
This question indicates the meaning of the condition for the individual, which may be relevant for clinical care. *Note that individuals may identify multiple causes, depending on the facet of the problem they are considering.*	4. Why do you think this is happening to you? What do you think are the causes of your [PROBLEM]? *PROMPT FURTHER IF REQUIRED:* Some people may explain their problem as the result of bad things that happen in their life, problems with others, a physical illness, a spiritual reason, or many other causes.
Focus on the views of members of the individual's social network. These may be diverse and vary from the individual's.	5. What do others in your family, your friends, or others in your community think is causing your [PROBLEM]?

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Practical components of a family treatment approach

- Individual family psychoeducation
- Multiple family groups
- Topic-specific skills training (e.g., relapse prevention)
- Structured problem-solving activities
- Involvement in transition planning

Psychoeducation

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

Practitioner can engage in psychoeducation with person/family as an individual family or in the family group format

Psychoeducation Elements:

- **Learning exchange**
- A sequenced curriculum or talking points that:
  - guides facilitators
  - offers condition-specific information
  - provides general information on stress and coping
- Time for processing
- Strategies to enhance functioning
- Adjust approach based on culture and language

A) Emotional Reactions

It is vital to encourage respect of each person's feelings when discussing this topic so that everyone feels comfortable and safe to express him/herself. Share with the families some common emotions and reactions that occur when a loved one develops a psychotic illness. Discuss the ways that these common reactions are relatable or dissimilar to their experiences.

Sample Dialogue: Families from a variety of backgrounds have described similar experiences related to having a family member who has experienced psychosis. Here are some common emotions that can come up. Some of them might be relatable and others might be different from your experience.

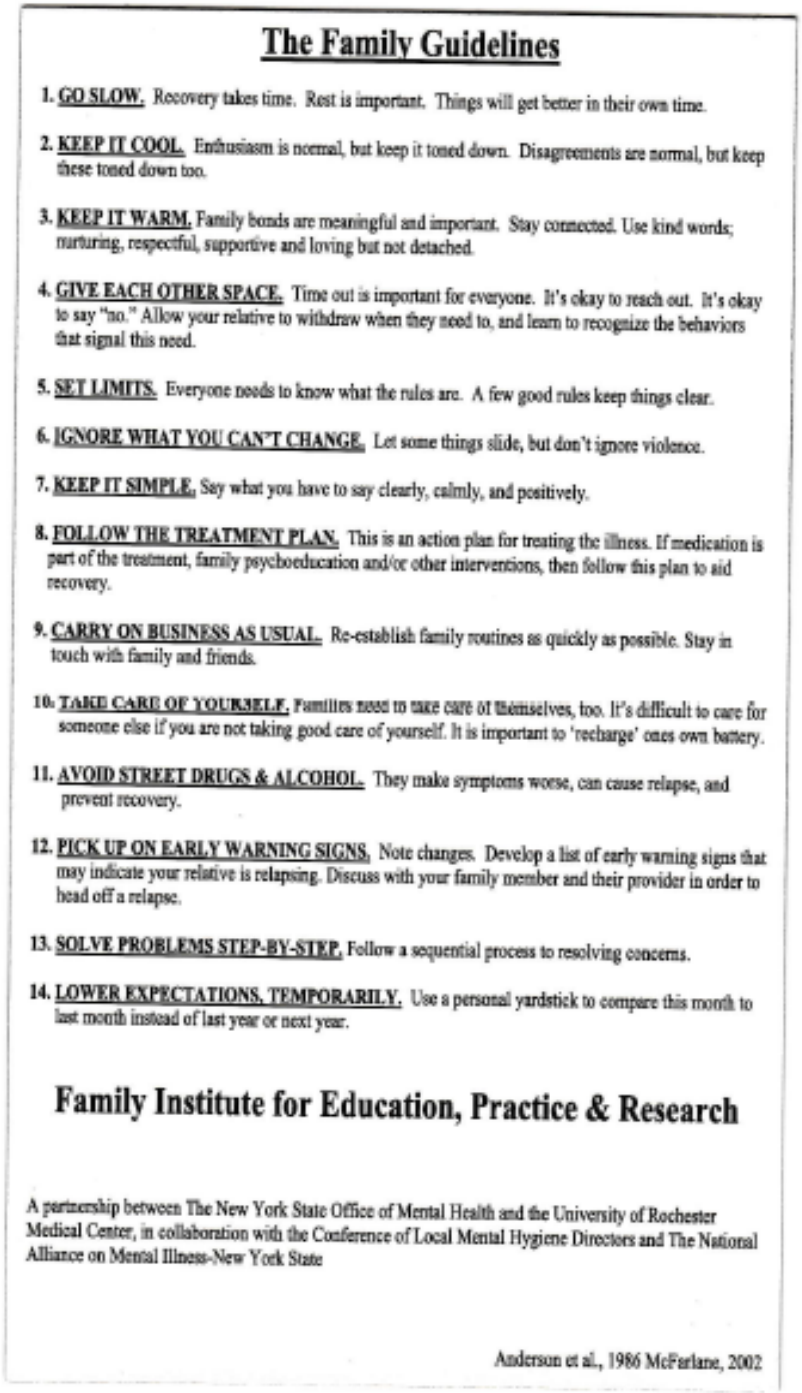
- **Sadness** – Some family members and/or the young person may feel sadness that life is different from how it used to be, that the young person no longer feels or seems "like them self" and for the pain that each family member might be going through.
- **Apprehension/worry** – Family members and the young person might feel concerned that the hopes, dreams, and expectations for the young person seem less attainable since the start of illness. Families and/or the young person might wonder whether or how much life may need to adjust due to the onset of psychosis, how long it may last and what to expect.
- **Guilt** – Family members and/or the young person may feel that they played a role in, or are responsible for, the young person developing psychosis. Some might believe that the young person's ability to get better solely lands on their shoulders (the young person might also believe this).
- **Confusion** – For many family members, the onset of psychosis comes "completely out of the blue." Some family members and/or the young person may feel confused about the diagnosis of psychosis, the causes of it, associated behaviors, and how to respond. There is often confusion about how long psychosis may last, and whether people need to adjust their hopes and aspirations for the future.
- Misattribution – Some may feel that psychosis isn't a "real" problem, that the young person has full control over symptoms but isn't using it, or that there is a simple solution, "fix" or "cure" for symptoms.
- **Resentment or embarrassment** - Some family members and the young person may feel resentful or be embarrassed because their lives are so different from that of other families and young people.
- Anger – Some feel that it is not fair that they, or their loved one, has psychosis and may feel angry about how the symptoms impact their own lives.
- **Uncertainty about treatment** – Many family members understandably have questions about the different aspects of treatment including, what will be helpful, what will be challenging (such as medication side effects), and how long treatment components may last (such as medication or therapy). For instance, people wonder, "Will I/will my son need this level of treatment forever?"
- **Fear** – Some family members and young people are fearful of what might happen when their loved one is experiencing psychosis. Some people are concerned that the young person may attempt to

Monthly Family Groups

- Best when facilitated by two team members
- ~1 ½ hours in length; admission is ongoing
- Includes:1) presentation of education/information and 2) discussion of any family problems/issues
- Family members can attend with or without young person – decision for teams
- Types of topics
  - What is psychosis/depression/anxiety disorder?
  - What causes it? What can make it better or worse?
  - What is recovery?
  - Treatment for mental health conditions

Consider using the "Family Guidelines"

The Family Guidelines have been used successfully with people with mental health conditions for decades.



The Family Guidelines

1. **GO SLOW.** Recovery takes time. Rest is important. Things will get better in their own time.
2. **KEEP IT COOL.** Enthusiasm is normal, but keep it toned down. Disagreements are normal, but keep these toned down too.
3. **KEEP IT WARM.** Family bonds are meaningful and important. Stay connected. Use kind words; nurturing, respectful, supportive and loving but not detached.
4. **GIVE EACH OTHER SPACE.** Time out is important for everyone. It's okay to reach out. It's okay to say "no." Allow your relative to withdraw when they need to, and learn to recognize the behaviors that signal this need.
5. **SET LIMITS.** Everyone needs to know what the rules are. A few good rules keep things clear.
6. **IGNORE WHAT YOU CAN'T CHANGE.** Let some things slide, but don't ignore violence.
7. **KEEP IT SIMPLE.** Say what you have to say clearly, calmly, and positively.
8. **FOLLOW THE TREATMENT PLAN.** This is an action plan for treating the illness. If medication is part of the treatment, family psychoeducation and/or other interventions, then follow this plan to aid recovery.
9. **CARRY ON BUSINESS AS USUAL.** Re-establish family routines as quickly as possible. Stay in touch with family and friends.
10. **TAKE CARE OF YOURSELF.** Families need to take care of themselves, too. It's difficult to care for someone else if you are not taking good care of yourself. It is important to 'recharge' ones own battery.
11. **AVOID STREET DRUGS & ALCOHOL.** They make symptoms worse, can cause relapse, and prevent recovery.
12. **PICK UP ON EARLY WARNING SIGNS.** Note changes. Develop a list of early warning signs that may indicate your relative is relapsing. Discuss with your family member and their provider in order to head off a relapse.
13. **SOLVE PROBLEMS STEP-BY-STEP.** Follow a sequential process to resolving concerns.
14. **LOWER EXPECTATIONS, TEMPORARILY.** Use a personal yardstick to compare this month to last month instead of last year or next year.

Family Institute for Education, Practice & Research

A partnership between The New York State Office of Mental Health and the University of Rochester Medical Center, in collaboration with the Conference of Local Mental Hygiene Directors and The National Alliance on Mental Illness-New York State

Anderson et al., 1986 McFarlane, 2002

As a team…

We encourage you to think about how you might incorporate family psychoeducation into your work to assist people. *There is flexibility!*

- 1:1 with individual families
- As a team with individual families
- Incorporate some content into monthly family group

One option to address a wide range of issues/concerns is a problem solving approach…

How to Introduce the Problem Solving Process

Tell everyone about the process

- **Most people want to know "what can we do" or "what should we do?" – here's a way to help that's proven to work**
- **Evidence based – lots of research**
- **Some of the most challenging problems can be broken down into pieces and addressed**

Suggest that the problem solving process can help everyone in the family/system.

Ask if people want to take some time to do problem solving?

Introducing the Problem Solving

Bottom line:

"We are all putting our heads together to come up with solutions and figure out what to do next."

Group Exercise: Problem Solving Steps

1. Define the Problem
2. List All Possible Solutions
3. Discuss Advantages & Disadvantages
4. Choose Solution that Best Fits
5. Plan How to Carry-Out Solution
6. Review Implementation (next meeting)

Step One:
Define the problem, concern or goal

- Talk about the concern
- Listen carefully, ask questions – get ALL opinions
- Write the concern in a solvable way
- Narrow things down, pick one aspect
- Consider wording: What can X do to help Y to Z ?
    - Example: What can mom do to help John remember to get up at 7:30am for school without it seeming like she's nagging him?

Step Two:
List all Possible Solutions – "brainstorming"

- Ask for ideas to address the problem
- Encourage them to consider things they have already tried and
- Refrain from judging solutions as silly or unrealistic
- Put down ALL ideas, even the ones people may not agree with

Step Three:
Discuss Each Possible

List of pros and cons

Option 1: He can set an alarm and get up on his own

Pros/Advant.	Cons/Disadv.

Step Four:
Choose the "Best" Solution

- Choose the solution or solutions that they believe can best solve the problem
- Encourage people to delete options they are not willing to try
- Table the other solutions

Step Five:
Plan How to Carry Out the Solution

Help the young person and family go into detail about how to carry out the plan. They would determine any resources needed and major pitfalls they would need to overcome. The practitioner will:

- Guide the process (ask the questions below)
- Assist the person and family
- Leave time for review
- Give the person and family a copy of the step-by-step plan

Who: _____

What:_____

When:_____

Where:_____

Other:_____

RELAPSE PREVENTION

Two related yet different things…

1. Crisis intervention / safety planning
2. **Relapse prevention and wellness self management**

Opportunities to discuss relapse prevention with families

- Timing:
  - At the very beginning of involvement with practitioner/team
  - Whenever a young adult is willing to involve family – is there common ground?
  - During a hospitalization, and/or immediately following a crisis
  - Any time a family expresses “I don’t know what to do or how to help?”

Opportunities to discuss relapse prevention with families

What are people's experiences discussing relapse prevention with families?

Relapse Prevention

- Key messages for families:
  - Severe symptoms usually don't just come out of the blue
  - Preventing or minimizing periods of increased symptoms is an important part of recovery
  - Learning about early warning signs can help you predict and prevent a relapse
  - Not blaming or judging anyone
- Teach families about how severe symptoms of a condition typically unfold

Steps in relapse prevention planning

- Discuss with young adult
- Introduce the idea to families
- Identify early warning signs
- Identify triggers
- Discuss coping skills (past / future)
  - What worked in the past? What didn't?
- Develop a plan on what to do and when
- Re-visit plan periodically; especially after a relapse occurs

Early warning signs

- Early warning signs are subtle changes in a person's inner experiences or outward behavior that signal a relapse may be starting

- The family can help by being an "early warning system" and extending the reach of the team

Types of early warning signs

- feeling overloaded
- finding it harder to keep track of what they are thinking and what others are saying
- feeling disconnected
- desire or need to be alone
- difficulty screening out distracting information and sensations
- difficulty focusing or understanding what they are hearing
- changes in perceptual experiences – visual experiences may become brighter or sounds louder
- sleep disturbances
- depressed mood
- irritability
- increased suspiciousness
- unexplained difficulty at/skipping school or work

Timeline of early warning signs and triggers in past

- Create a timeline with the young person and family:
  - 24-hours before crisis?
  - 2-3 days before crisis?
  - 1 week before the crisis?
  - 2 weeks before the crisis?
- Encourage “detective” mindset
- Involve as many family members as possible

Designated Observer

Transition Planning – Including Families

- Provide guidance around several aspects of discharge planning to explore with families, such as:
  - Family's thoughts, reactions, concerns
  - Specific plans for if things are going well? And if things get worse?
  - Specific community services available
  - Ways families may advocate (with person) for services
  - Following up after discharge

Videos from OnTrack and Pat Deegan, PhD

2 resources for you to explore on your own:

Pat Deegan's video about Shared Decision Making. "Chapter 6: You are part of the team". [PAT DEEGAN VIDEO FOR PEOPLE AND FAMILIES]

"Spirit of OnTrack" Video

Chapter 3: Navigating the Duty to Care and Dignity of Risk [VIDEO BY PAT DEEGAN]

Discussion, Q & A

Thank You!