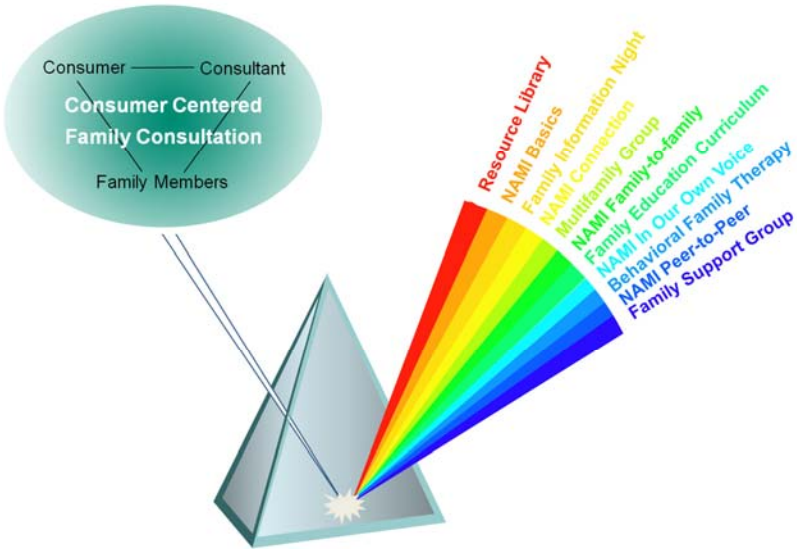
Consumer Centered
Family Consultation Guidebook



Developed by
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New York State Office of Mental Health

University of Rochester Medical Center

Family Institute for Education, Practice & Research

Consumer Centered Family Consultation Guidebook
for
Consumers, Families and Clinicians
of
Mental Health Services

Developed by
Family Institute for Education, Practice & Research
University of Rochester Medical Center
Department of Psychiatry, Long-Term Care Program
315 Science Parkway Suite 400
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In collaboration with

New York State Office
of Mental Health (NYSOMH)

University of Rochester Medical Center (URMC)
National Alliance on Mental Illness, New York State (NAMI, NYS)
& Conference of Local Mental Hygiene Directors (CLMHD)

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The development and support for the widespread implementation of the Consumer Centered Family Consultation through the Spectrum of Family Services Initiative was made possible by the New York State Office of Mental Health, University of Rochester Medical Center in collaboration with the National Alliance on Mental Illness and the Conference of Local Mental Hygiene Directors.

Welcome

Congratulations on your decision to learn more about Consumer Centered Family Consultation (CCFC). We believe this consultation model's easy and straight-forward approach will be beneficial to each person who participates. The model emphasizes the importance of each person in the recovery process: you-the consumer, your family or other support people you choose, and the provider of mental health services. The approach itself is short-term, matter of fact and to the point. This guidebook will give you a clear sense of what to expect from a consultation.

Anne M. Smith, LMSW, Executive Director
Family Institute for Education, Practice & Research

Acknowledgements

The development and support for the Spectrum of Family Services Initiative has been made possible by the active leadership of Michael F. Hogan, Ph.D, Commissioner of the New York State Office of Mental Health and Eric D. Caine, MD, Chairman Department of Psychiatry, University of Rochester Medical Center.

Special appreciation is extended to Anthony Salerno Ph.D., Co-Director of Evidence Based Practices Initiative, New York State Office of Mental Health, for his active leadership, his passion for involving families in the mental health system and for his continuous support of the Family Institute for Education, Practice & Research.

Sincere gratitude and admiration is extended to the New York State Office of Mental Health, Office of Consumer Affairs Director and Special Assistant to the OMH Commissioner John Allen Jr.; Advocacy Specialists, Thomas O'Clair, and former Advocacy Specialist, Ralph Blackshear. Their first hand knowledge, formal education and genuineness have improved all aspects of the mental health system as a whole. Together they have brought their experience and expertise to assist others in their healing and recovery journey.

It is an honor and a privilege partnering with the National Alliance on Mental Illness, New York State Chapter (NAMI, NYS) and the Conference of Local Mental Hygiene Directors (CLMHD). The working relationships between these professional and compassionate individuals continue to help make the Consumer Centered Family Consultation and Spectrum of Family Services Initiative a success.

A special thanks to all of the consumers and families whose lived experiences aided us in a true working partnership in the development of the Spectrum of Family Services Initiative in New York State.

Endorsements of Consumer Centered Family Consultation

Donald Capone states: "The Consumer Centered Family Consultation Guidebook provides an important resource to concerned families as they work with a loved one struggling with mental illness. Effective family involvement plays a critical role in successful recovery. A resource such as the guidebook is vital for families in helping with their loved one."

Donald Capone, Executive Director
National Alliance on Mental Illness, New York State Chapter

Judith Carrington states, "The Family Institute for Education, Practice and Research is invaluable as the only organization in New York State devoted to bringing together mental health professionals, consumers and family for joint recovery education and training. For the first time, using an optimal route to include families in the treatment and recovery process of the consumer, The Family Institute for Education Practice & Research brings information and competency to families. With that also comes hope for us struggling families, previously excluded from treatment and often blamed for the mental illness of our loved one. We have our New York State Office of Mental Health to thank for their ongoing support of this enlightened and progressive initiative".

Judith Carrington
Family Member
Founder, *Mental Health Resources*

Lisa Dixon states, "Mental illness can have a huge impact on family life and relationships. Research has shown the huge impact that providing assistance to families and working with families can have on the recovery of a family member with mental illness. Families can provide supports and encouragement. Families can provide material assistance. Working effectively with families can reduce stress for all concerned. CCFC permits assistance to families and consumers to be delivered in consumer centered fashion".

Lisa Dixon, M.D., M.P.H. Professor
University of Maryland School of Medicine
Director, Division of Health Services Research
Deputy Director and Associate Director of Research
VA Capitol Health Care Network MIRECC

Endorsements of Consumer Centered Family Consultation

Edie Mannion states, "It has become increasingly recognized that supportive, educational, collaborative family interventions which harness the care and concern of family members contribute to positive recovery outcomes for individuals and their family members/significant people. Yet, family involvement in many adult public behavioral health systems is still crisis driven rather than proactive and based on best practices due to a variety of systemic and organizational barriers. The Family Institute for Education Practice & Research is a pioneer in disseminating a user-friendly, consumer-centered model for overcoming these barriers, making New York one of the states leading the way in offering adults family-friendly public behavioral health services".

Edie Mannion, MFT
Co-Founder of the Training & Education Center (TEC)
Mental Health Association of Southeastern PA
Member of the Pennsylvania Psychiatric Leadership Council's Family Committee

Shirley Glynn states, "Social support is a key component of recovery from serious psychiatric illness. Consumers and their relatives often confront many complicated issues during the recovery process—decisions about appropriate residences, the benefits and costs of taking medication, finding and succeeding at work or school and the like. The Consumer Centered Family Consultation (CCFC) model offers an accessible and effective framework with which families can be helped to address these issues during a limited series of sessions. The model is useful and easily grasped by mental health professionals and they appreciate its practicality and flexibility. The training materials are well-designed and appealing. The CCFC package is unique—I am unaware of any program like it—and it is an invaluable resource in the mental health field".

Shirley M. Glynn, Ph.D.
Research Psychologist
Department of Psychiatry and Biobehavioral Sciences
Semel Institute, University of California Los Angeles

Thomas O'Clair states, "The New York State Office of Mental Health recognizes the importance of family involvement in the recovery of psychiatric disabilities. Whenever illness or injury occurs, the recovery process is expedited with the inclusion of supports inside as well as outside of a clinical setting. The New York State Office of Mental Health realizes that family involvement is usually the most natural and nurturing set of supports one could hope for. It is because of the familial bonds, compassion and desire to see a loved one succeed in life, which makes these supports so strong and natural. The work of the Family Institute for Education, Practice & Research promotes finding the means of enhancing these supports to make them some of the strongest supports available to an individual".

Thomas (Tom) O'Clair
Recipient Affairs Specialist, Family Issues
NYS Office of Mental Health

Comments from Participants after Receiving a Consumer Centered Family Consultation

Consumers

I gained a better understanding of who my mother is and how she relates to me and how I should relate to her. Overall, it was helpful. I think it gave us a level of comfort that we didn't have before. I found it to be the way to go. If you want to just keep the peace all the way around and it improves your relationships. I think cause everybody knows where everybody stands.

Family Members

I'm much more hopeful and I feel that there are people out there that want to help my son. Knowing that I have this team behind me has taken a lot of the pressure off and I don't feel all of it depends on me. It's just good to know that I can turn to this team if I really need to. It makes a big difference having that.

Clinicians

I think what a person needs to have when you do these family consultations is a very open, non-threatening, gentle approach to get them to realize that they are the ones basically conducting it. I think the strengths are that it's presented in an open ended fashion where it's ongoing and you're not relegated to any part of the treatment process for them to be engaged. I think it's continuing to educate the family members on psychoeducational information on mental illness, medication management, resources in the community to help that client access those supports that he or she needs. I think that's one of the benefits of the model.

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1 Introduction

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- Descriptions:
  - Consumer Centered Family Consultation
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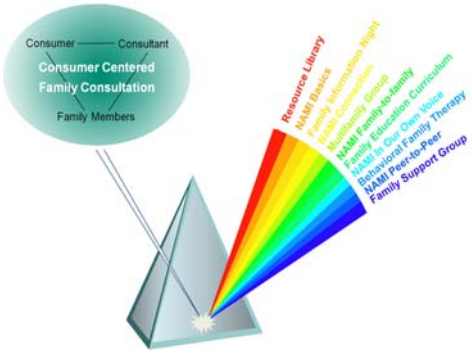


1 Introduction

Purpose of the Guidebook

The purpose of this guidebook is to provide an orientation to the Consumer Centered Family Consultation (CCFC) model for consumers of mental health services, their families and/or chosen support network. It is organized into three sections: Engaging Strategies, Consumer Centered Family Consultation and Additional Resources for all participants.

Consumer Centered Family Consultation

Consumer Centered Family Consultation (CCFC) is a brief, education-based engagement and consultation service that is typically completed in one to three sessions. It promotes collaboration among adult consumers of mental health services, members of their family or social network, and service providers to support each consumer's recovery. CCFC is characterized by:

- Consumer Centeredness-the consumer is at the center of all decisions.
- Collaboration-CCFC promotes an equal partnership between consumers, families and providers.
- Education Orientation-CCFC provides basic information about: mental health diagnoses, causes, treatments and services; family guidelines on how to support the consumer and family; and community and agency resources.

Flattened Triangle Approach

The flattened triangle approach is a concept that all parts of the treatment triangle (consumer, family & provider) are viewed as being on equal levels of the playing field. Each participant brings to the field their own expertise and strengths. It is not a hierarchical approach, where the provider is on the top, but instead the triangle is laid out flat as in a ball field. The commonality is that they are coming together to combat mental illness and to assist the consumer with reaching their goals. They are then given the opportunity as a unit to work toward the recovery goals of the consumer.

1 Introduction

Guiding Principles for Consumer Centered Family Consultation Services
(From the NYS Office of Mental Health, Office of Consumer Affairs)

Natural supports-is essential for people who are embracing a renewed hope for creating a better life in recovery. The following Guiding Principles reflect a humane approach to all mental health services. These principles are particularly vital to Consumer Centered Family Consultation as they help to create an atmosphere of trust and personal growth for the recipient and the family.

Collaboration-is vital to the recovery process and can serve as a stepping-stone to a successful experience for each individual involved. The transparency of the collaborative strategy ensures that everyone is an equal stakeholder and all communication maintains a fluid exchange, enhancing mutual respect and perpetuating sustainable trust. Consumer Centered Family Consultation is an intervention designed to support family members/significant others participation in treatment services based on the desire and informed consent of the recipient.

Shared Decision Making-is an ongoing transformation of power sharing. It allows for risk, accomplishments and unsuccessful attempts. This recognized best practice manifests the values and principles of the recovery process and augment the innate right of individual dignity. The inherent qualitative outcome/s for the recipient and the personal gratification for the practitioner radically magnify a new paradigm for clinical implications. Consumer Centered Family Consultation can become another service modality for this Best Practice.

Self-Directed Recovery-is rooted in the assumption that when given the opportunity, real options and proper supports, people can define and pursue what they need in order to create and maintain their quality of life. Individual choice is a natural freedom and a personal need. There is a growing body of research that strongly suggests that self-help and peer support are instrumental to wellness and personal growth for people engaged in recovery. Consumer Centered Family Consultation can be a medium to help a loved one explore alternative options that may compliment their recovery.

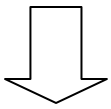
1 Introduction

Creating a Family Oriented Mental Health System

A family oriented mental health system insures that mental health programs routinely and proactively offer comprehensive education and support services to family members and others in the consumer's social network. The services are designed to engage and involve family members and others in supporting the treatment and recovery of consumers through education, advocacy, support and problem solving assistance. Take a look and see how your agency is doing at these, and offer to help add more services if you would like. These performance standards are organized into the three major areas of a mental health program or agency:

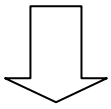
Assessment: Intake and ongoing assessments are designed to identify:

- The expressed wants/expectations of consumers related to the involvement of family members.
- The needs/wants of the consumer's family/support network for information, support, advocacy and problem solving assistance related to the consumer's mental health problems.
- The family/social network resources and strengths related to promoting the consumer's treatment and recovery.



Service Planning and Delivery: The program has an accessible system to engage and involve family members for consumers who want and can benefit from their involvement. The program should have:

- Designated family services coordinator
- Performance expectations of practitioners (e.g., routine provision of family consultation services)
- Informational materials

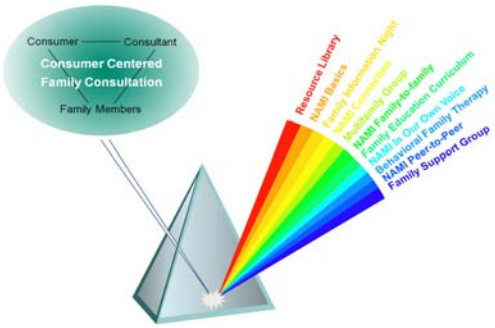


Evaluation of Outcomes & Performance:

- Progress notes and periodic treatment plans identify and address outcomes related to the provision of family programs
- Strategies to identify and involve family supports in the consumer's treatment.
- The agency/program collects, analyzes and acts upon family/support network data to make continual and informed improvements.

2 Engaging Strategies

- Tools to Guide the Decision Making Process:
  - Decision Guide for Consumers
  - Consumer & Family Needs Assessment
  - Consumer Center Family Consultation Brochure



Decision Guide
Guiding Principles + Flattened Triangle

What is this guide about?

This guide helps adults with mental health concerns and their providers. It's a tool for making decisions about whether to involve your family members or friends to help your recovery goals and treatment.

Step 1 Involving People

Let's talk about people who care about you and people you trust. Let's talk about how they can help support your recovery.

This is important because studies show treatment is more effective and recovery is better when we have support from people important to us. When families feel support, they are better able to assist their loved ones.

Involving others is **your choice**, and **you decide** what kind of help you prefer. Family or friends may help you by:

- Providing information that helps develop a quality service plan
- Providing information about warning signs and triggers for relapse
- Being part of a staying well plan, and agreeing to help in difficult times
- Encouraging and supporting your recovery efforts
- Learning about your mental health needs, and how to respond in ways helpful to you
- Learning about your goals, and how to support your effort to achieve them

Step 2 Discussing Concerns

People may have concerns about including family or friends in their treatment. If so, we can discuss these so you can make the best decision for you.
Here are some common concerns:

- ☐ In the past, when my family members met with my clinician, it was uncomfortable or upsetting
- ☐ I'm concerned that you, my clinician, will listen more to them and take their side instead of mine

2 Engaging Strategies

- ☐ I'm worried you might change your opinion of me.
- ☐ I don't want to burden others.
- ☐ I want to protect my privacy.
- ☐ The people I want to include don't want to be involved.
- ☐ If I ask and they refuse, I'll feel hurt or rejected.
- ☐ I want to manage my mental health concerns on my own.
- ☐ Involving others would be too stressful.
- ☐ Other concerns

Let's talk about your concerns…

_____

_____

Step 3 Support People

Let's think about people in your life, either family members or friends, who support you in difficult times, or those who help you to achieve your personal goals.

- ☐ Who do you spend holidays or birthdays with?
- ☐ Who do you turn to for support or help when you need it?
- ☐ Whose praise or encouragement makes you feel good?
- ☐ Who phones, emails or sends you letters or cards?

List below who you might consider involving in your treatment and recovery:

Name:	Relationship to me:
_____	_____
_____	_____

Step 4 1st Meeting & Beyond

Consumer Centered Family Consultation involves one to three meetings between you, your supports and your clinician. It's an opportunity for your supports to learn important information about your treatment, and how to support your recovery.

You are at the center of all decisions – who to invite and what topics to discuss. At the first meeting, we usually connect with one another, and later typically will review important information, like:

- General guidelines about how family members or friends can support you
- Your treatment program, team, and services, and who to contact with concerns
- Mental health diagnoses, treatments, and services
- Additional resources from the treatment program, agency, and community that can help you and your loved ones

2 Engaging Strategies

Step 5 Pros & Cons

Is the Consumer Centered Family Consultation right for you? List your pros and cons.

Pros:

_____

_____

_____

Cons:

_____

_____

_____

Step 6 Next Steps

Involving others is an important decision. Make it carefully. Before you choose, here are steps you may wish to take:

- Give a copy of the Consumer Centered Family Consultation brochure to your family member or friend to read
- If you're unsure, agree to talk about it later
- If you're not comfortable with this, we'll put it aside
- If you're ready to invite someone, discuss the options (For example: do you, the clinician or both of you invite the people to the consultation)

Consumer & Family Needs Assessment Survey

This survey is intended to help consumers, their families and other supports to identify areas to discuss with their treatment team to help with the recovery process.

A. Please check any services or contact you have already received from this agency.

___ Therapy and/or Medicine
___ Group Services
___ Family Consultation
___ No contact
___ Case Management Services
___ Family Education
___ Phone contact
___ Other (please list below)

_____

B. Please answer the following questions with a rating from the scale below:

1 = Not at all important to me
2 = Only slightly important to me
3 = Somewhat important to me
4 = Very Important to me

I want to receive:

1. More information about the treatment I am receiving……. 1 2 3 4
2. Information about the medication I am taking and its side effects…….....1 2 3 4
3. Information about the causes of mental illness to better understand me……. 1 2 3 4
4. Help to talk about how my illness affects the whole family…… 1 2 3 4
5. Information about professional help if and when I begin to relapse…… 1 2 3 4
6. Information about things they can do to help me …… 1 2 3 4
7. Knowledge about how to identify signs/symptoms of mental illness……..... 1 2 3 4
8. Information about how to help my family cope with my illness……..... 1 2 3 4
9. Knowledge about community resources for families affected by mental illness……. 1 2 3 4
10. Knowledge about community resources for people affected by mental illness……1 2 3 4

_____

C. Other subject matters I would like discussed include:

_____

_____

D. I am interested in receiving more information related to:

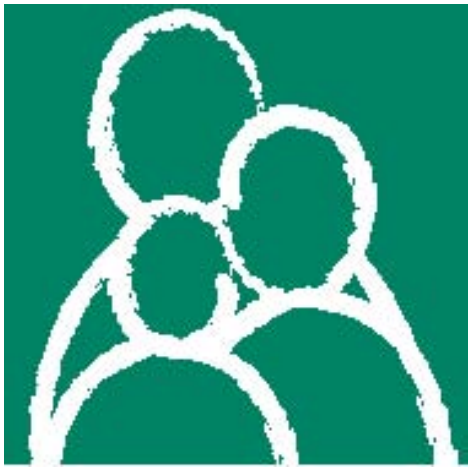
___ Family Information Nights
___ Family Education Programs
___ Resource Library
___ Support Groups
___ Multifamily Group
___ Single & Multiple Family Psychoeducation
___ Behavioral Family Therapy
___ National Alliance on Mental Illness (NAMI)
___ Other (please list) _____

2 Engaging Strategies

Consumer Centered Family Consultation Brochure

The following information is taken from the CCFC Brochure that can be downloaded from the Family Institute website www.nysfamilyinstitute.org. The brochure is designed specifically for families and other supports of consumers. Ideally, the consumer and provider work together to decide how to present the brochure to your support system.

Consumer Centered Family Consultation



A brief service for consumers of mental health services, their chosen support system, and their clinician – all working together to support the consumers' recovery process.

2 Engaging Strategies

What is Consumer Centered Family Consultation (CCFC)?

CCFC is a brief consultation strategy that:

- Promotes the recovery process and staying wellness plan for consumers of mental health services
- Promotes collaboration between consumers, their family members, their social support system, and their clinicians
- Provides information about mental health diagnoses, treatments, and services
- Provides family guidelines for how to support consumers and family, and solve problems
- Facilitates referrals to community, program, and agency resources that can support the recovery process and wellness plan of consumers

What is the purpose of a consultation?

The purpose of a consultation is to support the recovery efforts and the wellness plan of consumers who are receiving services from a mental health agency.

Family members and other interested parties often want to know how they can help. A CCFC can answer that question in 1 to 3 meetings.

How can family members and other supports contribute to a consultation?

For a person recovering from a mental health situation, family members offer the most valuable support that no one else can provide: *love*, *hope*, *shared history*, and *shared memories*.

When a consumer enrolls in a mental health program, gathering the person's history is critical to developing a comprehensive treatment plan. Consumers and family members together can describe the details of healthy times and also troubling times in the consumer's life.

This information helps the clinician identify strengths as well as problem areas, and pinpoint a diagnosis. This information helps develop the treatment plan which is the written document that outlines areas of concern in the consumer's life, and identifies ways to make improvements.

Time and time again, family involvement has been found to be crucial to the recovery process of consumers. Their shared histories, memories, and love, and their working as partners with the clinician, can help improve the quality of life for consumers.

How long does the consultation take?

Family Consultation is a brief and time limited service usually involving no more than three face-to-face meetings.

2 Engaging Strategies

Who participates in a consultation?

Anyone can take part in the CCFC as long as the consumer gives consent. Ideally, the person or persons involved will have an interest in the consumer's well-being and are able to support the consumer's recovery process and staying well plan.

Participants in a CCFC May Include:

- Consumer
- Family members
- Other supportive people agreed upon by the consumer
- Clinician

How can I become involved in a consultation?

Typically, the process begins with the consumer. If the person is unsure about taking part in a CCFC, she/he may complete a decision guide. The guide is completed with a clinician from the treatment team. The guide is a tool to help consumers make an informed decision about taking part in a CCFC and who to invite.

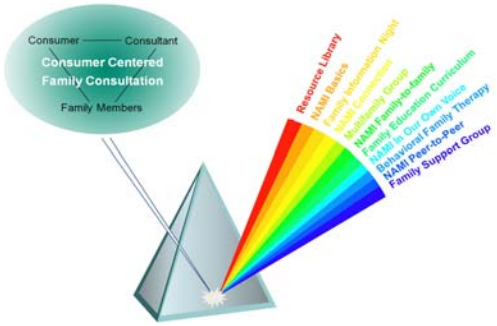
If you desire to be part of a consultation, and haven't heard from your loved one about CCFC, discuss your interest with her/him. Together, you can arrange to meet with the clinician, and learn ways to support your loved one's recovery process and wellness plan.

Plan for reaching out to family/ social network

- ☐ The consumer will discuss CCFC with their family using the brochure as a guide.
- ☐ The consumer and provider will reach out to family together.
- ☐ The provider will reach out to family.
- ☐ Other_____

3 Consumer Centered Family Consultation

- Consumer Centered Family Consultation Chart
- Consumer Centered Family Consultation Details
  - Connect
  - Define & Prioritize
  - Plan and/or Provide Next Steps
  - Spectrum of Family Services



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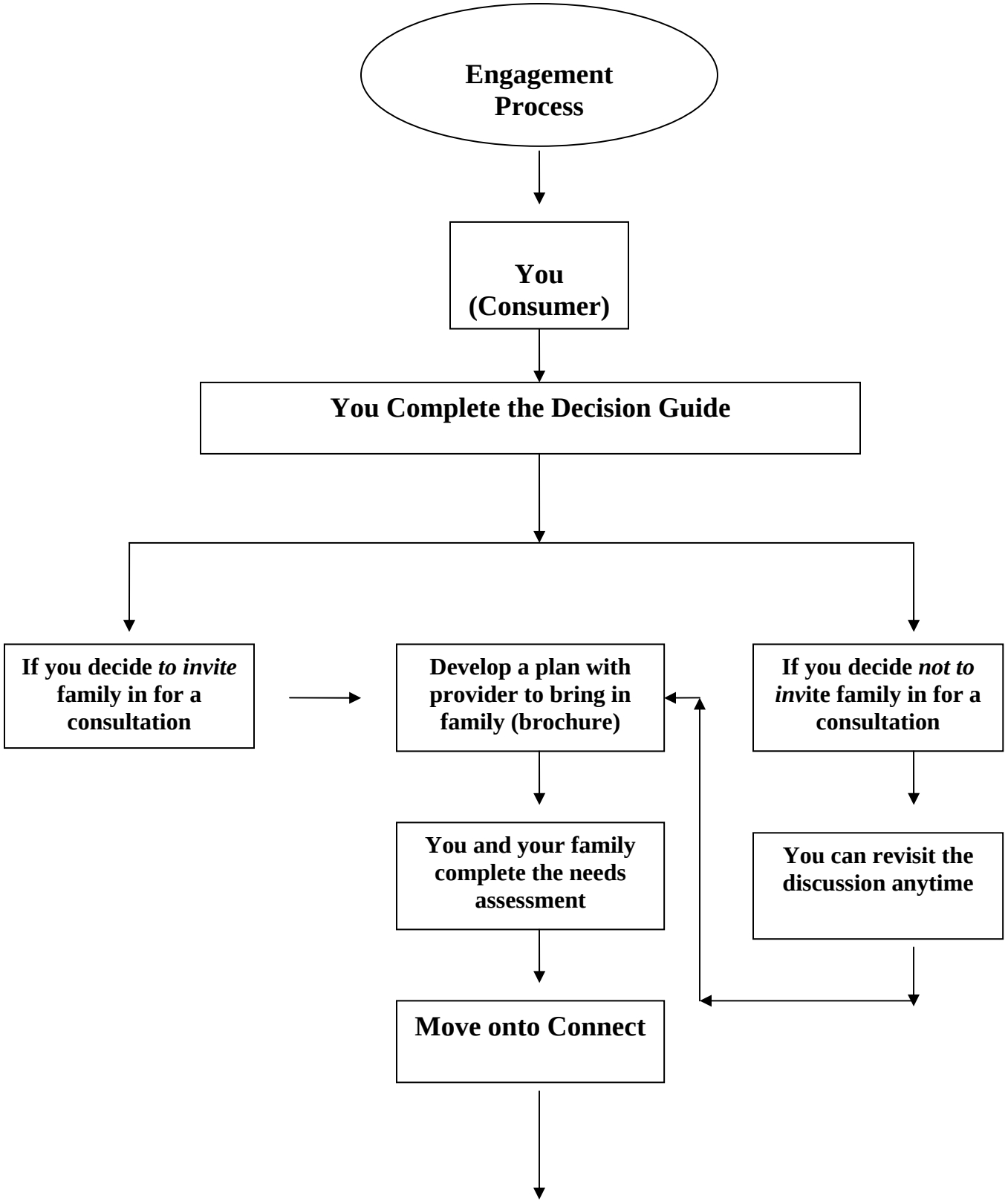

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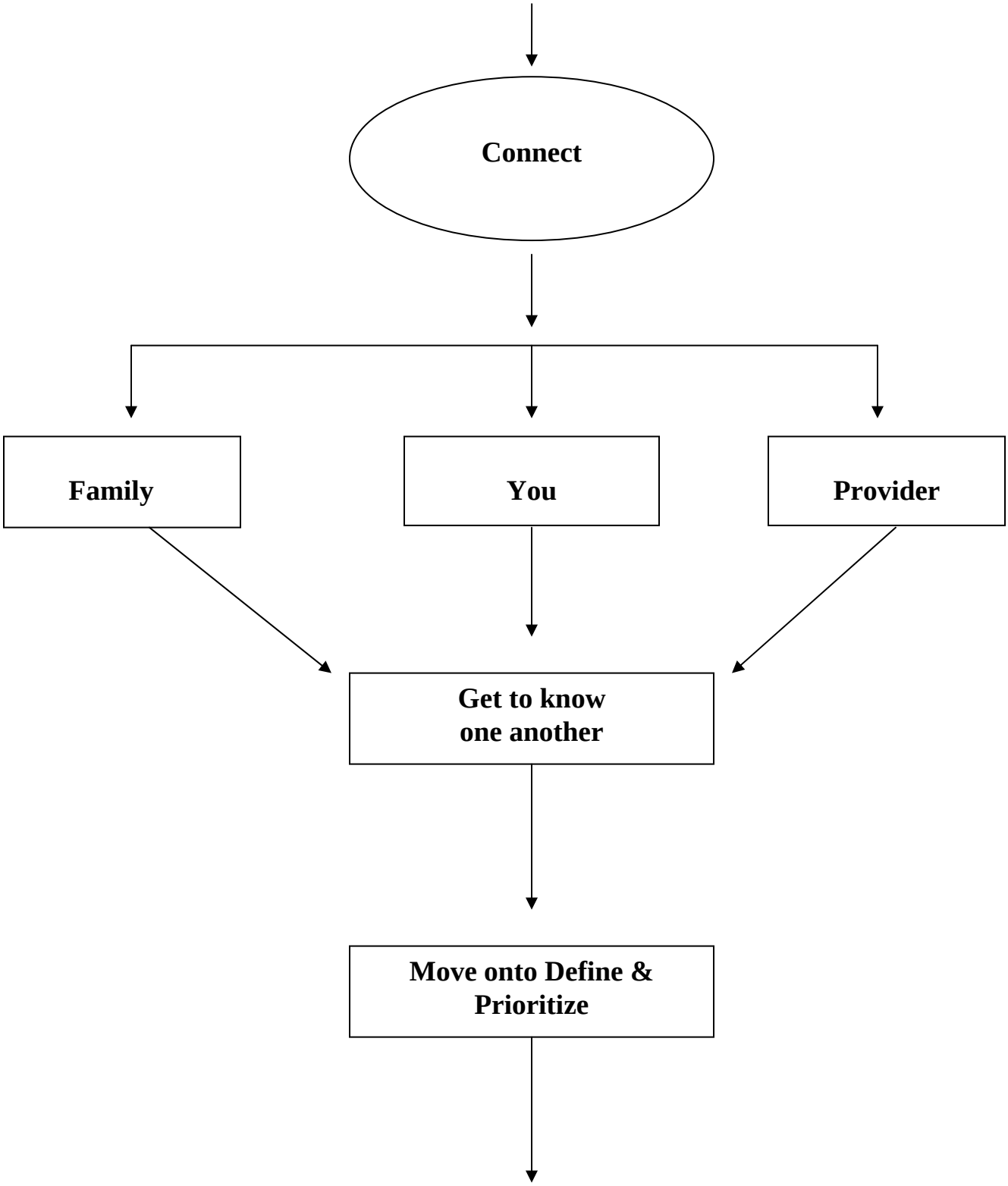

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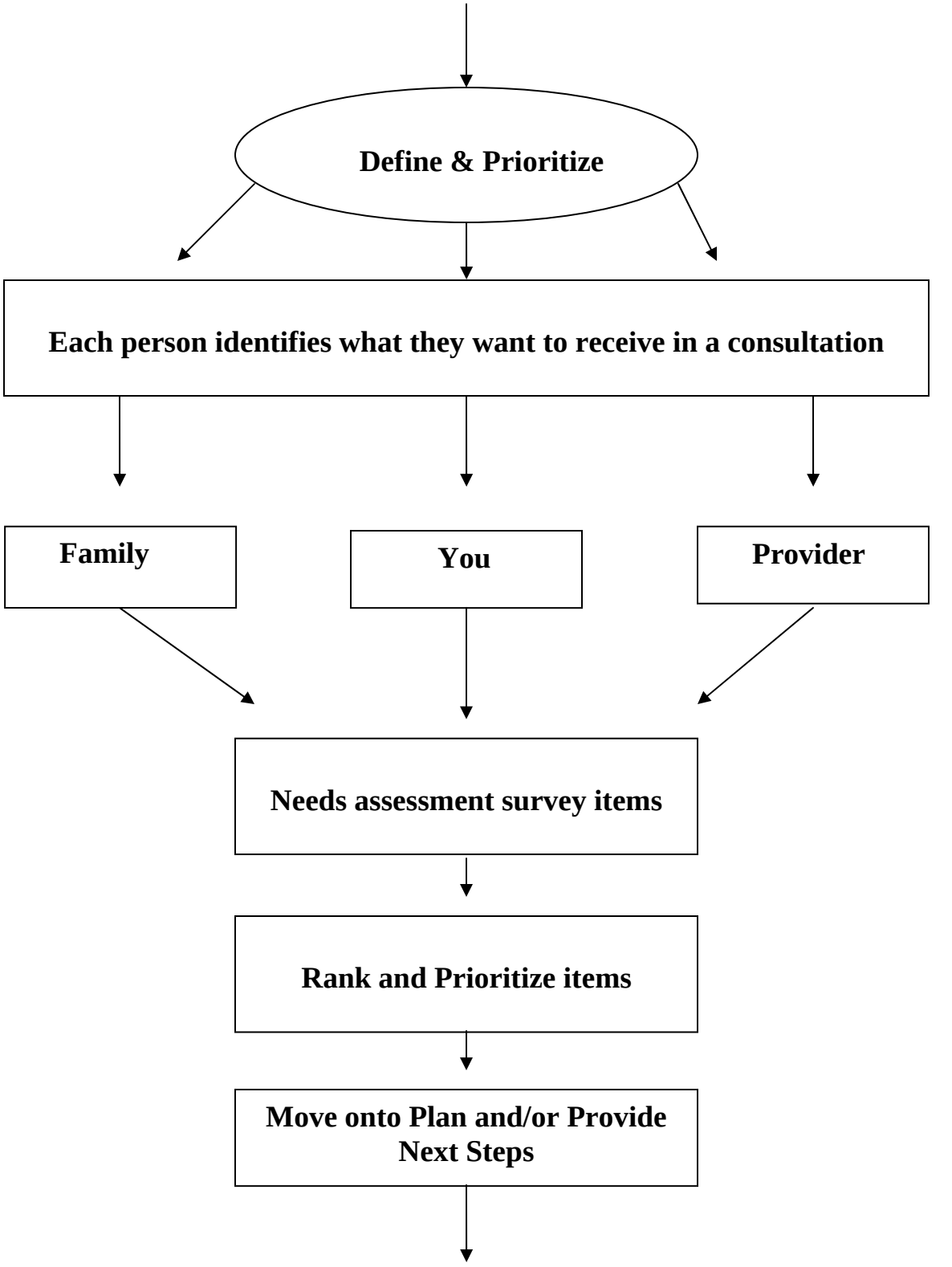

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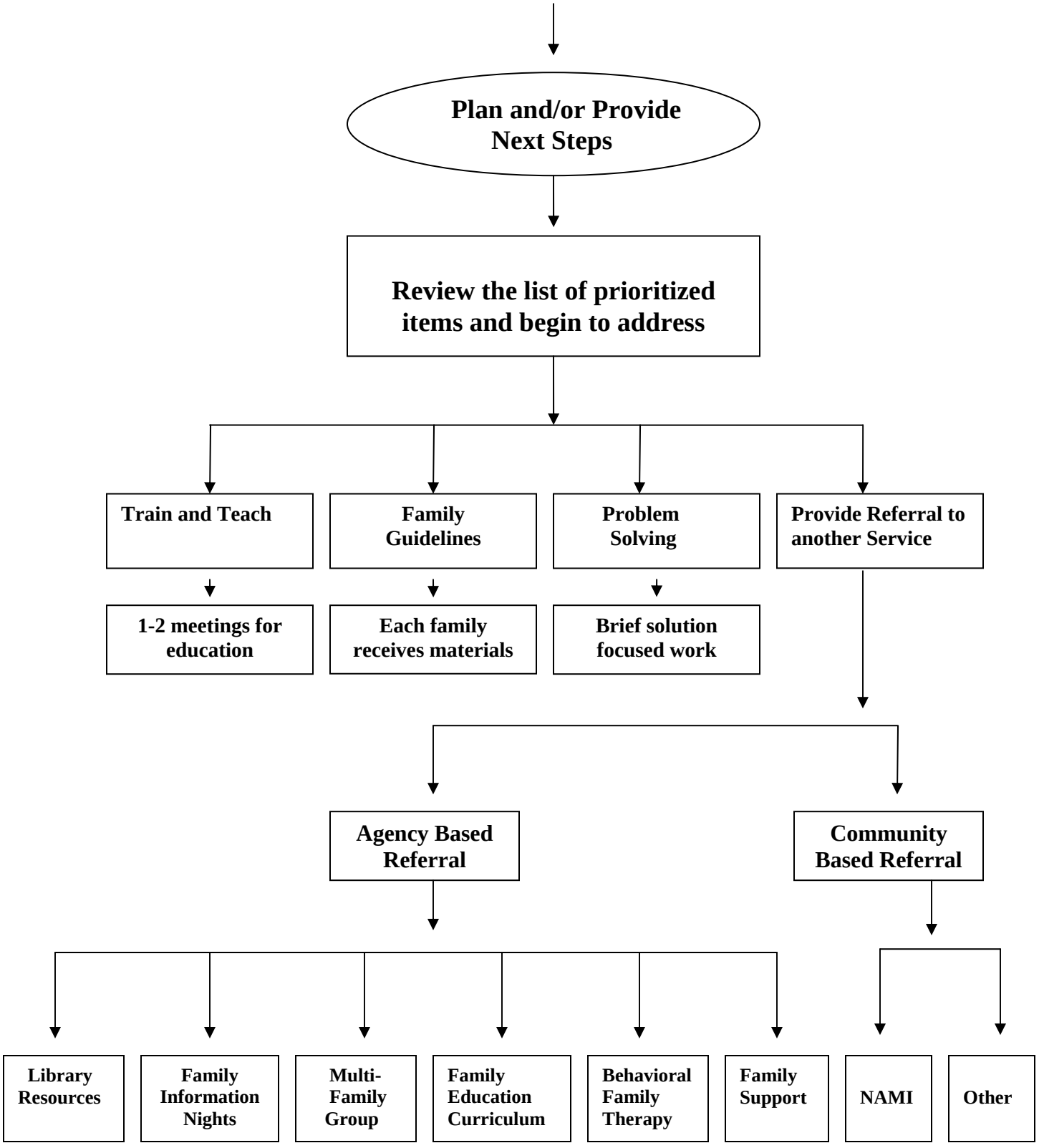


3 Consumer Centered Family Consultation

Consumer Centered Family Consultation (CCFC) is a service designed to get people together who care about you so they can provide you with meaningful support. Sometimes just coming together is enough. Other times you and your family may want to learn more about your diagnosis and ways to prevent relapse. In other situations, learning what resources are available to help with your recovery process is needed. One goal of CCFC is to get everyone on the same page, and to get to know one another. One of the benefits of participating in a consultation is that it is easier to reach out to one another when you have an established relationship.

The CCFC Model is set up in a straight-forward fashion. This next section will walk you through the three steps of a Consumer Centered Family Consultation:

1. Connect
2. Define and Prioritize
3. Plan and/or Provide Next Steps

Connect

During the ***connect*** phase of CCFC, the goal is to get to know one another. Although mental health concerns are important, it is equally important to remember there is more to a person and a family than the illness. When there is an established connection there is a sense of trust which makes it easier to connect again in the future.

There are many different ways to connect with others; perhaps through common hobbies, interests or themes. When going through the connecting process providers will be asking questions about you and your family's interests. Together, let us think about some areas that we might discuss as a way to connect with one another and write the ideas below.

Please list a few things below that you would be comfortable sharing about your interests.

_____ _____ _____

_____ _____ _____

What would you like the consultant to ask about your family members interests?

_____ _____ _____

_____ _____ _____

3 Consumer Centered Family Consultation4

Define and Prioritize

During the ***define and prioritize*** stage you and your family will ***define*** areas to set the agenda for the consultation. You may have items you want addressed and your family may have other items they would like addressed. Additionally, the clinician conducting the consultation may have other items. Many of these may be the same. Sometimes they are different. In these situations, the clinician will work with you and your family to merge these agendas.

Once these areas have been identified, and the agenda items have been merged, ranking them and ***prioritizing*** will take place. The highest priority items will be addressed first and down the line. Together the participants will decide what can be accomplished in the consultation. If they decide some topics need longer term attention or would be better addressed in a different forum, then referrals can be made to help meet these needs.

Using the *Consumer and Family Needs Assessment* survey, please list the items you, your family and the provider would like on the agenda for the consultation.

You **Your Family** **Provider**

List which items are the same:

1. _____ 2. _____ 3. _____

List the order of priority to address these items:

1. _____ 2. _____ 3. _____

Merge the agendas items together to form an agenda:

1. _____

2. _____

3. _____

4. _____

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps

The stage entitled: ***Plan and/or Provide Next Steps*** is when you focus on the areas agreed upon. If you and your family want education about mental illness or perhaps to learn how to live with the illness, then this would take place. If you and your family need more in-depth education and support, then perhaps a referral would be made to another program within the agency or in the community for this to take place.

Listed below are some methods to address your identified needs in a consultation.

Training and Teaching-clinician provides information about the mental health diagnosis, what to do to take care of yourself and what supports are available to help with your recovery.

Family Guidelines-family members are often interested in knowing what they can do to provide support. There is no simple set of guidelines that would apply to everyone. How family members may help depends on many factors that may be unique to the person's condition and situation. For a common list of guidelines, please see the *Family Guidelines* in the Additional Resources section of this guidebook.

Problem-Solving- is a skill that is intended to help you overcome problems interfering with your recovery. Some examples of problem solving may be concerns related to living, learning, work and social skills. This is not to be confused with family therapy. Please see *Basic Problem Solving* in the Additional Resources section of this guidebook.

Referring-may take the form of the clinician informing you of resources in the community where you and/or your family can receive ongoing support and education-such as the National Alliance on Mental Illness. Additional supports may be available through the agency where you receive services, such as a multifamily group or an ongoing family support group. These would be appropriate referrals if you desire ongoing support within the agency. There are other options as well that you can discuss with the provider.

If you have any questions concerning the consultation process please use the space provided below:

1st Stage-Connect: _____

2nd Stage-Define and Prioritize: _____

3rd Stage-Plan and/or Provide Next Steps: _____

Other: _____

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps-Spectrum of Family Services

Family Service	Led by	Intensity	Duration	Setting	Consumer Included?
Treatment options offered to all consumers through an agency					
Integrate Family into Intake and Treatment Plan	Professionals	Initial consultation then ongoing	No limit	Agency	Yes
Consumer Centered Family Consultation	Professionals	15-60 minute meetings	1-3 Meetings	Agency or Community	Sometimes
Treatment options available as an adjunct to other services through an agency					
Multifamily Group	Professionals	60-90 minute meetings every 2 weeks	At least 9 months – but could go up to 2 years	Agency	Yes
Family Information Nights	Professionals, Family and/or Consumers	Typically 60 to 90 minutes	Monthly, Quarterly, or Semi-Annual	Agency or Community	Yes or No
Family Education Curriculum	Professionals, Family and/or Consumers	Typically 60 to 90 minute classes	1-10 Topic-oriented classes	Agency or Community	Yes or No
Resource Library	Professionals, Family and/or Consumers	Mailings/Library sign-out	Mailings/Loaned as needed	Agency or Community	No
Behavioral Family Therapy	Professional	60 minutes Weekly	3-6 mo. Assessment 6 mo.-2 year Therapy Phase	Agency or Home-based	Yes
Family Support Group	Professionals, Family and/or Consumers	Typically 60 minutes	Occasional, ongoing as needed	Agency	Sometimes
Community options through NAMI-NYS					
NAMI Basics	Trained Parents	Once a week	6-weeks	Community	No
NAMI Connection	Consumers	Monthly/Biweekly 60-120 minutes	No limit	Community	Yes
Family-to-Family Education	Family Members	Weekly 90-120 minutes	12-weeks	Community	No
In our own Voice	Trained Consumers	As Needed	No limit	Community	Yes
Peer to Peer	Trained Mentors	Weekly	9-weeks	Community	Yes

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps-Spectrum of Family Services

Consumer Centered Family Consultation

Purpose: To integrate the consumer's family and/or chosen supports into the recovery process of the consumer.

Duration: 1-3 meetings with a consumer of mental health services, their family and/or chosen supports.

Components: Engaging with Consumer; Engaging with their family and/or chosen Support system; followed by a three step process of CCFC: Connect, Define & Plan.

Multifamily Group

Purpose: A psychoeducational program that can be delivered to an individual family or in a group of 5-8 consumers of mental health services and their families to address mental health educational needs, communication and problem solving skills to support the consumer's recovery from mental illness.

Duration: Longer term intervention (9-24 months or longer)

Components: It has three discrete components: 1. Joining sessions with the consumer and family members before the group begins; 2. A full day educational workshop leading up to 3. Group meetings that are held every 2 weeks for 90 minutes. The group follows a standardized agenda: 15 minutes socializing, 20 minutes go-around, 5 minutes problem identification, 45 minutes problem solving, 5 minutes wrap up and socializing.

Family Information Night

Purpose: An informational meeting hosted by a mental health agency/program that has a feel of an Open House with food & drinks being provided.

Duration: Flexible, One time, multiple times per year and/or quarterly.

Components: Flexible depending on the needs of the consumers and their families. Formal presentations by agency staff can be made and/or outside speakers could present on topics related to mental health recovery and resources.

Family Education Curriculum

Purpose: To provide reliable psychoeducational materials in a classroom setting for consumers of mental health services, their families and/or their chosen support system.

Duration: Takes place over several weeks and/or months

Components: Workshop model led by a mental health professional and peer consultant that follows a standardized syllabus.

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps-Spectrum of Family Services

Resource Library

Purpose: To provide relevant psychoeducational materials to support the recovery mental health consumers.

Duration: Ongoing.

Components: Psychoeducational materials made available to consumers of mental health services and/or their families or chosen support system. It is maintained by consumers, families, and/or clinicians.

Behavioral Family Therapy

Purpose: To address the psychological needs of each family member and various subgroups in the family, where there is at least one person in the family who has a mental health problem.

Duration: A longer term intervention (12-24 months)

Components: There are five discrete components: Assessment of each individual in the family, Education, Communication Skills Training, Problem Solving Training and Special Problems areas.

Family Support Group

Purpose: A long-term maintenance group for consumers of mental health services and/or their supports to sustain the recovery efforts of consumers.

Duration: Long term-open ended group with rolling enrollment.

Components: Flexible agenda that follows Dr William McFarlane's model for Multifamily Groups: including socializing, go-around, problem identification/solving and ending with socialization.

The National Alliance on Mental Illness-New York State Chapter is the state organization of the National Alliance on Mental Illness, the nation's largest grassroots organization for people with mental illness and their families. Founded in 1979, NAMI has affiliates in every state and in more than 1,100 local communities across the country.

NAMI-NYS provides support to family and friends of individuals with mental illness and persons living with mental illnesses through more than 50 affiliates statewide. Key programs of NAMI NYS include: NAMI Basics, Connections, Family-to-Family and In Our Own Voice.

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps-Spectrum of Family Services

NAMI Basics

Purpose: NAMI Basics is an education program for parents and other caregivers of children and adolescents living with mental illnesses. The program was developed around elements that have been extensively tested and found to be highly effective in the field.

Duration: The NAMI Basics course is taught by trained teachers who are the parent or other caregivers of individuals who developed the symptoms of mental illness prior to the age of 13 years. All instruction and course materials are free to class participants.

Components: Introduction to emotional reactions of the family to the trauma of mental illness; Insights into the lived experience of the child living with the mental illness; Current information about diagnoses; Current research related to the biology of mental illness and the evidence-based treatment strategies available, including medications; Workshops; Information about how to interact with the school system and the mental health system; Exposure to personal record keeping systems; Information on planning for crisis management, relapse, locating supports and services within the community and advocacy initiatives designed to improve and expand services.

NAMI Connection

Purpose: To support adults living with mental illness. These groups offer a casual and relaxed approach for members to share challenges and successes of coping with mental illness. Participants should feel welcome to drop by and share feelings, difficulties, or successes.

Duration: Meets weekly for 90 minutes.

Components: Free of charge; flexible structure without an educational format, does not recommend or endorse any medications or other medical therapies. Support groups are open to all adults with mental illness, regardless of diagnosis.

3 Consumer Centered Family Consultation

Plan and/or Provide Next Steps-Spectrum of Family Services

Family to Family

Purpose: Developed by Joyce Burland of National NAMI, the curriculum provides participants with clear, accurate, and practical information on topics such as the categories: the biology of mental illness; medications and research; crisis management; communication skills; problem solving; self-care; advocacy, and recovery.

Duration: 12-week family psychoeducation course

Components: Offered to and taught by - individuals who have a loved one with a serious mental illness. The course - taken by over 115,000 individuals nationwide to date – is offered by NAMI-NYS affiliates free of charge.

In Our Own Voice

Purpose: Mental health consumers or former consumers share their individual experiences of recovery and transformation.

Duration: All presentations are offered free of charge and last 2-3 hours.

Components: Public education program developed by NAMI, in which two trained consumer speakers share compelling personal stories about living with mental illness and achieving recovery.

Peer-to-Peer

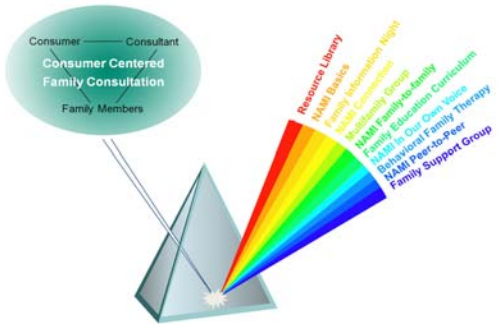
Purpose: An experiential course for people with serious mental illness who are interested in establishing and maintaining their wellness and recovery. The course is being written by Kathryn Cohan, a person with a psychiatric disability who is also a former provider and manager in the mental health field. An advisory board comprised of consumer members of NAMI in consultation with Joyce Burland, Ph.D is guiding the curriculum's development.

Duration: Nine, two-hour units taught by a team of three trained mentors who are personally experienced at living well with mental illness.

Components: A course with hand-out materials and other tangible resources: an advance directive; a "relapse prevention plan" to help identify tell-tale feelings, thoughts, behavior or events that may warn of impending relapse and to organize for intervention; mindfulness exercises to help focus and calm thinking; and survival skills for working with providers and the general public.

4 Additional Resources

- Family Guidelines
- Hospital Checklist
- Communicating with a Person with a Mental Illness
- Educational Resources
- Mental Health Advance Directives
- Stress Management
- Responding to Hallucinations, Delusions & Illusions
- What is Relapse?
- Basic Problem Solving Steps
- Progress Note
- Family Institute Website & Other Website Resources



4 Additional Resources

Family Guidelines for Consumer Centered Family Consultation

Family members are often interested in knowing what they can do to support their family member's treatment and recovery. There is no simple set of guidelines that would apply to everyone. How family members may help depends on many factors that may be unique to the person's condition and situation. Below is a list of some basic facts and information about mental health problems and what family members may consider in their efforts to help their loved one.

1. No fault problem

Serious mental health problems are no one's fault. Symptoms of mental illness are often due to a person's inherited sensitivity to stress. People with great support and loving family members may nonetheless develop a serious mental health problem because of a biological sensitivity. It's important not to blame the person or yourself for these problems.

2. No right way for everyone

There is no single right way to help a person with serious mental health problems. Paying attention to your loved one's response to your efforts, asking for guidance from the treatment team, getting ideas from other family members with a loved one in treatment may be helpful.

3. Keep things calm

People with mental health problems often do best when the day-to-day stressors, including social stressors are manageable. Like most of us, feeling pressured, criticized and getting into arguments is usually not helpful and may make symptoms worse.

4. Respect the persons need to regulate stress

Sometimes a person with mental health problems needs space and a time out from activities that people usually don't think of as being too stressful. Asking the person what they need during those times may be helpful. For example, asking and respecting whether the person wants to participate in family activities such as parties, vacations and family gatherings.

5. Focus on the positive

It's very common for family members to be on the look out for problems and to focus on what's going wrong. It may be helpful to recognize and express what's going right, even if it seems like a small thing.

6. Communicating clearly and to the point

Sometimes people with mental health problems may find it hard to pay attention and understand what is being said. It may be helpful to communicate in a way that is clear and to the point. It may also be helpful to check out what the person has understood.

Family Guidelines for Consumer Centered Family Consultation

7. Remain hopeful

Research has shown that with treatment and support, people with serious mental health problems can make progress in their lives and accomplish goals that are satisfying. Setbacks are to be

expected. Relapse is common. Ongoing support from others, especially during difficult times, is an important ingredient in the recovery process. Talk with trusted others about your hopes and expectations.

8. Get to know your loved one's treatment providers

With the permission of your loved one, get to know the people who provide mental health services, what treatments and services are being provided and ask how you can help.

9. Get to know and learn more from other family members

Many family members find it helpful to meet with other family members who also have a loved one dealing with serious mental health problems. There are organizations throughout the country that offer family members and their loved ones an opportunity to gain knowledge about the mental health system and to learn and support each other.

10. Address dangerous situations (self harm and harm to others and property)

Knowing who to call and what to do in an emergency is helpful. Discussing this with your loved one's treatment team, learning from the experience of other families, and educating yourself about the resources available in your community may be helpful.

11. Physical health supports one's recovery

Recognize that people with mental health problems do best when they can also take care of their physical health needs. Supporting a healthy lifestyle that includes exercise, good eating habits following up with physical health care appointments can make a big difference.

12. Recognize that stigma associated with mental illness is common

It's common for family members to feel isolated and alone. Stigma may hold family members back from discussing their loved one's situation, avoid social or family activities and to blame themselves. Meeting with other family members who also confront stigma is often helpful.

13. Take care of yourself

Find time to enjoy the social and recreational activities that are most satisfying to you. Taking opportunities to recharge one's batteries and find space to relax helps all of us handle the challenges of life including supporting our loved ones. Emotional and physical exhaustion interferes with our ability to be of help to others.

4 Additional Resources

Hospital Checklist

Patient Information

Patient's Hospital Address:

_____
_____
_____

Patient's Phone Numbers
Hospital Unit Public Phones: _____
Front Desk numbers: _____
Home: _____Cell: _____

Visiting Hours and Other Pertinent Information:

_____
_____

Current and Past Medical Diagnoses:
Current diagnosis (if any) _____
_____
_____

Medication(s)_____
_____
_____
Primary care physician: _____
Psychiatrist: _____
Dentist: _____

Physical Diagnoses:

_____
_____
_____
_____
_____
_____

4 Additional Resources

Hospital Checklist

History of Mental Illness/Brain Disorders in the Family:

_____

_____

_____

Professional Contact Information::
Attending Psychiatrists
#1 Name: _____
Phone numbers: _____Cell: _____Fax:_____
Contact days & hours: _____Best times to call: _____
#2 Name: _____
Phone numbers: _____Cell: _____ Fax: _____
Contact days & hours: _____Best times to call: _____

Social worker:
Name: _____Shift from/to _____
Phone numbers: _____Cell: _____Fax: _____
Contact days & hours: _____Best times to call: _____

Nurse Practitioner:
Name: _____Shift from/to _____
Phone numbers: _____Cell: _____Fax: _____
Contact days & hours: _____Best times to call: _____

Caseworker/ Case Manager:
Name: _____Shift from/to _____
Phone numbers: _____Cell: _____Fax: _____
Contact days & hours: _____Best times to call: _____

Unit Manager or Medical Director:
Name: _____Shift from/to _____
Phone numbers: _____Cell: _____Fax: _____
Contact days & hours: _____Best times to call: _____

Religious Counselors:
Name: _____Shift from/to_____
Phone numbers: _____Cell: _____Fax: _____
Contact days & hours: _____Best times to call: _____

4 Additional Resources

Hospital Checklist

Peer Advocate Counselors:
Name: _____Shift from/to _____
Phone numbers: _____Cell: _____ Fax: _____
Contact days & hours: _____Best times to call: _____

Working Diagnosis:
A) Upon admission:_____
_____

B) Upon discharge:_____
_____

Treatment Goals:
_____
_____
_____

Initial Medications:
1) Name _____ Dosage/when to take _____
Benefits_____
Side Effects _____
Contact doctor (name(s)_____

2) Name _____Dosage/when to take _____
Benefits_____
Side Effects _____
Contact doctor (name(s)_____

3) Name _____Dosage/when to take _____
Benefits_____
Side Effects _____
Contact doctor (name(s)_____

4) Name _____Dosage/when to take _____
Benefits_____
Side Effects _____
Contact doctor (name(s)_____

4 Additional Resources

Hospital Checklist

5) Name _____Dosage/when to take _____
Benefits_____
Side Effects_____
Contact doctor (name(s)_____

Discharge Medications:
Same as inpatient?
Yes:_____
_____
_____
No:
_____
_____
_____
If outpatient medications differ from inpatient medications, please note the changes:
_____

Doctor's contact information:
_____

Hospital Checklist was adapted from Family Institute for Education, Practice & Research, Mental Health Resources, National Alliance on Mental Illness of New York State (NAMI-NYS), & New York State Office of Mental Health. (2010, January 5). *Family survival handbook: Reaching mental health recovery together: Tools for and by families*. © (Available from National Alliance on Mental Illness of New York State (NAMI-NYS), http:www.naminys.org/FSH-All2010.pdf

4 Additional Resources

Communicating with a Person with a Mental Illness

Persons with a psychiatric disability at times can:	We must be willing to:
Have trouble with reality.	Be simple, truthful.
Be fearful.	Stay calm.
Be insecure.	Be accepting.
Have trouble concentrating.	Be brief, repeat.
Be over stimulated.	Limit input, not force discussion.
Easily become agitated.	Recognize agitation, allow escape.
Have poor judgment.	Not expect rational discussion.
Be preoccupied.	Get attention first.
Be withdrawn.	Initiate relevant conversation.
Have changing emotions.	Disregard.
Have changing plans.	Keep to one plan.
Have little empathy for you.	Recognize their lack of empathy as a symptom of their disability.
Believe delusions.	Ignore, don't argue.
Have low self-esteem and lack of motivation.	Stay positive...if circumstances so dictate.

Adapted from a talk given by Christopher Amenson, Ph.D., to the San Luis Obispo chapter of the California Alliance for the Mentally III (CAMI).

4 Additional Resources

Educational Resources

What is Mental Illness?

Mental Illness is a serious illness or disease that results in disruption of functioning in all areas of life and usually lasts for a long time.

Major types of mental illness include:

(1) Schizophrenia
(2) Bipolar disorder
(3) Major depression
(4) Other psychotic disorders

Serious mental illness is a disorder in functioning of the brain, the body's organ that controls all actions and experiences.

Four categories of mental illness symptoms include:

1. Perceptions-disorders of the senses: vision, hearing, taste, touch, smell, time, position in space and balance, including hallucinations.
2. Thoughts-confusion, memory loss, inability top pay attention
3. Moods-depression, excitement, irritability and mood swings
4. Behavior-withdrawal, aggression or violence, pacing, agitation, unusual or bizarre behaviors-

A diagnosis is made through using several clinical tests, including psychiatric evaluation/mental status exam; physical or medical examination and laboratory tests; psychological tests, social history, or nutritional, legal and educational issues. Remember that mental illness is a disorder of the brain. No one caused it; no one is to blame for it.

Mental illness is treated using methods that broadly attack the illness, such as:

1. Medication to bring symptoms under control
2. Medication treatment to maintain health and rule out physical illness
3. patient education to learn about the illness and its treatment
4. Psychotherapy to solve problems and learn to cope with the illness
5. Illness monitoring and relapse control to lessen the chance of getting sick again
6. Rehabilitation to learn or relearn personal, social and job skills

4 Additional Resources

Educational Resources

The information below is taken from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-TR), July, 2000.

Psychosis
Psychosis is the loss of contact with external reality due to brain malfunctioning that can be triggered by disease, substances, injury, or anything else that affects brain function. The malfunctioning brain actually "plays tricks" on the person, resulting in experiences with no basis (or only "a grain of truth") in external reality. The two most common forms of psychosis are **hallucinations** and **delusions.**

Hallucinations
A. Sensory perceptions (e.g., sounds, sights, tastes, smells, or physical sensations) that have a compelling sense of reality of a true perception but occur without external stimulation of the relevant sensory organ. The person may or may not have insight into the fact that he or she is having a hallucination.*
B. The most common type of hallucination is an **auditory hallucination** involving the perception of sound. Most commonly, a person hears *voices* other than the voices of real people speaking. Other types of hallucinations include:

1. **Visual-**involving sight, which may consist of formed images such as people, or unformed images such as flashes of light.

2. **Gustatory**-involving taste, usually creating unpleasant tastes.

3. **Somatic**-involving the perception of a physical experience localized within the body, such as a feeling of electricity.

4. **Tactile-**involving the perception of being touched or of something being under one's skin, most commonly the sensation of receiving electrical shocks or something crawling under one's skin.

5. **Olfactory-i**nvolving the perception of odor, such as burning rubber.

Delusions
Delusions are false beliefs based on incorrect inferences about external reality that are firmly sustained despite what almost everyone else believes and despite obvious proof or evidence to the contrary. The beliefs are not one ordinarily accepted by other members of the person's culture. Delusions are classified, according to their content.

The most common types of delusions include:

Persecutory or Paranoid: A delusion in which the central theme is that one (or someone one knows) is being attacked, harassed, cheated, persecuted, or conspired against.

4 Additional Resources

Educational Resources

Grandiose: A delusion of inflated worth, power, knowledge, identity, or special relationship to a deity or famous person.

Bizarre: A delusion that involves a phenomenon that the person's culture would regard as totally implausible.

Delusional Jealousy: The delusion that one's sexual partner is unfaithful.

Control: A delusion in which feelings, impulses, thought or actions are experienced as being under the control of some external force rather than being under one's control.

Ideas of Reference: A delusion whose theme is that events, objects, or other persons in one's immediate environment have a particular significance. These delusions are usually negative, but can be grandiose.

Thought insertion: The delusion that a thought is not one's own, but rather inserted into one's mind.

Thought broadcasting: The delusion that one's thoughts are being broadcast out loud so that they can be perceived by others.

Somatic: A delusion whose main content relates to the appearance or functioning of one's body.

Mood-congruent psychotic features
Hallucinations or delusions whose content is consistent with the typical themes of a depressed mood (e.g. personal inadequacy, guilt, disease, death, nihilism, or deserved punishment), or manic mood (e.g., inflated worth, power, knowledge, or identity, or a special relationship to a deity or famous person). There may be themes of persecution that relate to self-critical ideas, deserved punishment or inflated self-worth.

Mood-incongruent psychotic features
Hallucinations or delusions whose content is NOT consistent with the typical themes of a depressed or manic mood *(see above).* Examples of mood-incongruent psychotic features include thought insertion, thought broadcasting, persecutory (or paranoid) delusions without self-critical or grandiose content, and delusions of being controlled whose content has no apparent relationship to any of the themes listed for depressed or manic mood episodes.

4 Additional Resources

Educational Resources

Mental Health Recovery

Mental health recovery is not the same as the dictionary definition of recovery. *The American Heritage Dictionary* defines "recovery" as "to restore to a normal state. To regain a normal or usual condition or state, as of health." New definitions of "recovery" in mental illness have grown out of a revolutionary dialogue in the mental health field that happened over the last 10 years as a result of effective consumer and family advocacy movements, communication with constituents in the substance abuse field, and the *Final Report of the President's New Freedom Commission on Mental Health (2003*), which found that the U.S. mental health system, with its focus on "managing" chronic mental illness, has failed to help most people with mental illness attain wellness and live meaningful lives in the community. The following definitions of "mental health recovery" have common themes such as hope, choice, individuality and recovery as a "process" and an "attitude," not a cure or end point:

"Recovery does not mean cure. Recovery is an attitude, a stance, a way of approaching the day's challenges. It is not a perfectly linear journey. There are times of rapid gains and disappointing relapses. There are times of just living, just staying quiet, resting, regrouping. Each person's journey of recovery is unique. Each person must find what works for him/her. This means that we must have the opportunity to try and to fail and to try again. In order to support the recovery process, mental health professional (and family members, added) must not rob us of the opportunity to fail. Professionals (and family members) must embrace the concept of…the dignity of risk and the right to failure IF they are to be supportive of us."
-Patricia Degan, *PsychiatricRehabilitation Journal, 19(3)*

"Recovery is a process, sometimes lifelong, through which a consumer achieves independence, self-esteem, and a meaningful life in the community. Recovery can be facilitated by particular features of care and the care system; it can also be inhibited by other features. Hence, we can speak of recovery-oriented planning and recovery-oriented services."
-Kathryn Power, M.Ed. (director of the Center for Mental Health Services-CMHS) and Ronald Manderscheid, Ph.D. (chief of the Survey & Analysis Branch within the Substance Abuse & Mental Health Services Administration –SAMHSA)

"Recovery is not remission, nor is it a return to an existing state: Recovery takes place through creation of new patterns of behavior that make lives more satisfying and productive."
-Harriet Lefley, Ph.D., Professor of Psychology, University of Miami

The *Final Report of the President's New Freedom Commission on Mental Health, Achieving the Promise: Transforming Mental Health Care in America (2003),* calls for comprehensive planning by each state and individualized plans for each consumer so there is movement towards "recovery-oriented consumer- and family centered care."

4 Additional Resources

Educational Resources

Symptoms of Schizophrenia:

A. **Characteristic symptoms:** Two or more of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):

1. Delusions (i.e., (false ideas believed by the person, but not by other people in his/her culture.)
2. Hallucinations (i.e., sensory experiences with no external stimuli...most commonly, hearing voices.)
3. Disorganized speech
4. Grossly disorganized or catatonic behavior (e.g., remaining in one place or posture for a long time without responding to external stimuli).
5. Negative symptoms (i.e., lack of emotional expression, lack of motivation, lack of speech)

Note: Only one criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping a running commentary on the person's behavior or thoughts, or two or more voices conversing with each other.

B. **Social/occupational dysfunction:** For a significant portion of the time since onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected interpersonal, academic or occupational achievement).

C. **Duration:** Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet criterion A and may include periods of prodromal (warning signs) or residual (lingering) symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).

D. **Schizoaffective and Mood Disorder exclusion:** Schizoaffective Disorder and Mood Disorder with Psychotic Features have been ruled out because either (1) no Major Depressive, Manic or Mixed Episodes have occurred concurrently with the criterion A symptoms, or (2) if mood episodes have occurred during criterion A symptoms, their total duration has been brief relative to the duration of the active and residual periods.

E. **Substance/general medical condition exclusion:** The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.

F. **Relationship to a pervasive developmental disorder:** If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are present for at least a month or less (or less if successfully treated).

4 Additional Resources

Educational Resources

What are the Major Mood Disorders?

Major Mood Disorders are mental disorders that involve a severe depression. This depression differs from normal sadness or grief in the following ways:

1. It keeps the person from functioning normally in his/her everyday roles (e.g., wage-earner, student, homemaker, etc.).
2. It includes medical symptoms such as:
    a. Appetite disturbance with weight loss or gain
    b. Sleep disturbance (increase or decrease)
    c. Loss of sexual drive
    d. Loss of energy, fatigue
    e. Slowed movement or agitation
    f. Slowed thinking, poor concentration
3. It lasts longer than a few weeks, usually 2 to 4 months or longer
4. It is not necessarily triggered by life stresses that are usually associated with depression or grief (e.g., death in the family, divorce, etc.)
5. It usually occurs in people who have a family history of severe depression, bipolar disorder, or other mood disorders. These can be masked by a family history of drug or alcohol abuse/addiction.
6. It may be accompanied by other types of mood episodes such as Manic Episodes, Mixed Episodes, or Hypomanic Episodes.

There are three types of **Major Mood Disorders**:

1. **Major Depressive Disorder** formerly called Unipolar Depression.

2. **Bipolar I Disorder** formerly called Manic Depression.

3. **Bipolar II Disorder,** following criteria in order for **Major Depressive Disorder** to be diagnosed:

A. Presence of a single **Major Depressive Episode** (for Single Episode Type), and presence of two or more Major Depressive Episodes (for Recurrent type).
Note: To be considered separate episodes, there must be an interval of at least 2 consecutive months in which criteria are not met for a Major Depressive Episode.

Criteria for a **Major Depressive Episode** are:

1. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either 1) depressed mood or (2) loss of interest or pleasure.
Note: Do not include symptoms that are clearly due to a general medical condition or mood-incongruent delusions or hallucinations.

Educational Resources

a) “Depressed mood, most of the day, nearly every day, as indicated by either subjective report (e.g.., feels sad or empty) or observation made by others (e.g., appears tearful). Note: In children and adolescents, can be irritable mood.

b) Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others).

c) Significant weight loss when not dieting or weight gain when (e.g., a change of more than 5% of body weight in a month) or decrease or increase in appetite nearly every day. Note: In children, consider failure to make expected weight gains.

d) Insomnia (not sleeping) or hypersomnia (sleeping too much) nearly every day.

e) Agitation (restlessness) or retardation (being slowed down) nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).

f) Fatigue or loss of energy nearly every day.

g) Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self reproach or guilt about being sick).

h) Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or observed by others).

i) Recurrent thoughts of death (not just fear of dying) recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

2. The symptoms do not meet criteria for a Mixed Episode.

3. The symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning.

4. The symptoms are not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

B. The Major Depressive Episode is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

C. There has never been a Manic Episode, Mixed Episode or a Hypomanic Episode. Note: This exclusion does not apply if all the manic-like, or hypomanic-like, symptoms are substance or treatment induced or are due to the direct physiological effects of a general medical condition."

Different Types of Major Depressive Disorder:

A. Mild, moderate or severe (depending on the level of severity).

B. With or without psychotic features (hallucinations and/or delusions) and psychotic features can be either mood congruent or mood-incongruent.

C. Chronic (i.e., full criteria have been met continuously for at least the past 2years).

D. With Catatonic Features (i.e., immobility, stupor, rigid posture, lack of speech, excessive, purposeless activity, or repeating whatever is said).

E. With Melancholic Features (i.e., loss of pleasure in all or almost all activities, distinct quality of depressed mood, usually worse in the morning, early morning awakening, marked agitation or retardation, significant weight change, excessive or inappropriate guilt).

F. With Atypical Features (i.e., mood brightens in response to positive events, weight gain or increased appetite, sleeping too much, heavy feelings in arms or legs, and long-standing pattern of interpersonal rejection-sensitivity that results in significant social or occupational impairment).

G. With Postpartum Onset (i.e., onset of episode within 4 weeks of postpartum)

H. With or without Inter-episode recovery (i.e., whether full remission is attained between the two most recent episodes).

I. With seasonal pattern (i.e., onset and remissions occur at a particular time of the year, and this has occurred in at least 2 episodes in the last 2 years, and seasonal episodes significantly outnumber non-seasonal episodes over the person's lifetime).

Bipolar I Disorder

A. The DSM *IV TR* lists the following different classifications of Bipolar I Disorder, depending on the most recent episode:

1. **Single Manic Episode:** Presence of only one Manic Episode and no past Major Depressive Episodes.

2. **Most Recent Episode Hypomanic:** Currently (or most recently) in a Hypomanic Episode, there has previously been at least one Manic Episode, and the mood symptoms cause clinically significant distress or impairment in social, occupational or other important areas of functioning.

3. **Most Recent Episode Manic**: Currently (or most recently) in a Manic Episode and there has previously been at least one Major Depressive Episode, Manic Episode, or Mixed Episode *(see below).*

4. **Most Recent Episode Mixed:** Currently (or most recently) in a Mixed Episode and there has previously been at least one Major Depressive Episode, Manic Episode*),* or Mixed Episode.

5. **Most Recent Episode Depressed:** Currently (or most recently) in a Major Depressive Episode and there has previously been at least one Manic Episode or Mixed Episode.

6. **Most Recent Episode Unspecified:** Criteria, except for duration, are currently (or most recently) met for a Manic Episode, a Hypomanic Episode*),* a Mixed Episode, or a Major Depressive Episode and there has previously been at least one Manic or Mixed Episode.

B. In all types the mood episodes are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

C. The diagnostic criteria for Manic, Hypomanic and Mixed Episodes are as follows:

1. Criteria for a **Manic Episode** are:
   a. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least 1 week (or any duration if hospitalization is necessary).
   b. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree.
      1) Inflated self-esteem or grandiosity.
      2) Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).
      3) More talkative than usual or pressure to keep talking.
      4) Flight of ideas or subjective experience that thoughts are racing.
      5) Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli).
      6) Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation.
      7) Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).
   c. The symptoms do not meet criteria for a Mixed Episode.
   d. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in unusual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

e. The symptoms are not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication, or other treatment) or a general medical condition (e.g., hyperthyroidism). Note: Manic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder.

2. Criteria for a **Mixed Episode** are:

a. The criteria are met both for a Manic Episode *(see above)* and for a Major Depressive Episode *(see above).*

b. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in unusual social activities or relationships with others, or to necessitate hospitalization to prevent harm to self or others, or there are psychotic features.

c. The symptoms are not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication, or other treatment) or a general medical condition (e.g., hyperthyroidism). Note: Manic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder.

3. Criteria for a **Hypomanic Episode** are:

a. A distinct period of persistently elevated, expansive, or irritable mood, lasting throughout at least 4 days, that is clearly different from the usual non-depressed mood.

b. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:

1) Inflated self-esteem or grandiosity.
2) Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).
3) More talkative than usual or pressure to keep talking.
4) Flight of ideas or subjective experience that thoughts are racing.
5) Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli).
6) Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation.
7) Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments).

c. The episode is associated with an unequivocal change in functioning that is uncharacteristic of the person when not symptomatic

.

d. The disturbance in mood and the change in functioning are observable by others.

e. The episode is not severe enough to cause marked impairment in social or occupational functioning, or to necessitate hospitalization, and there are no psychotic features.

f. The symptoms are not due to the direct physiological effects of a substance (e.g., drug of abuse, a medication, or other treatment) or a general medical condition (e.g., hyperthyroidism). Note: Hypomanic-like episodes that are clearly caused by somatic antidepressant treatment (e.g., medication, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder.

Bipolar II Disorder

In order for Bipolar II to be diagnosed:

A. Presence (or history) of one or more Major Depressive Episodes *(see above).*

B. Presence (or history) of at least one Hypomanic Episode *(see above).*

C. There has never been a Manic Episode *(see above)* or a Mixed Episode *(see above).*

D. The mood symptoms in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

E. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Different types of Bipolar I and Bipolar II disorder:

A. With rapid cycling (at least four episodes of a mood disturbance in the previous 12 months that meets criteria for a Major Depressive, Manic, Mixed or Hypomanic Episode). Episodes are separated either by partial or full remission for at least 2 months or a switch to an episode of opposite polarity (e.g., Major Depressive Episode to Manic Episode).

B. Mild, moderate or severe (depending on the level of severity).

C. With or without psychotic features (hallucinations and/or delusions) and psychotic features can be either mood congruent or mood-incongruent.

D. Chronic (i.e., full criteria have been met continuously for at least the past 2 years).

E. With Catatonic Features (i.e., immobility, stupor, rigid posture, lack of speech, excessive, purposeless activity, or repeating whatever is said).

F. With Melancholic Features (i.e., loss of pleasure in all or almost all activities, distinct quality of depressed mood, usually worse in the morning, early morning awakening, marked agitation or retardation, significant weight change, excessive or inappropriate guilt).

G. With Atypical Features (i.e., mood brightens in response to positive events, weight gain or increased appetite, sleeping too much, heavy feelings in arms or legs, and long-standing pattern of interpersonal rejection-sensitivity that results in significant social or occupational impairment).

H. With Postpartum Onset (i.e., Onset of episode within 4 weeks of postpartum)

I. With or without Inter-episode recovery (i.e., whether full remission is attained between the two most recent episodes)

J. With seasonal pattern (i.e., Onset and remissions occur at a particular time of the year, and this has occurred in at least 2 episodes in the last 2 years, and seasonal episodes significantly outnumber non-seasonal episodes over the person's lifetime).

What are the Warning Signals of a Major Mood Disorder?

A. The presence of several of the following symptoms may indicate the presence or recurrence of a major mood disorder:

1. Changes in mood or personality
2. Withdrawal from others; abnormal self-centeredness
3. Persistent depression, apathy, or extreme mood swings
4. Excessive anxiety, worries, or fears
5. Changes in eating or sleeping patterns
6. Difficulty in coping with daily activities
7. Strange ideas that reflect the elated or depressed mood
8. Inappropriate emotions
9. Denial of obvious problems
10. Increased use of alcohol; use of drugs
11. Violent or suicidal thoughts or actions
12. Anger or hostility out of proportion to the situation

B. If several of these warning signals are present and persist for several weeks or longer, a qualified medical opinion should be sought.

4 Additional Resources

Educational Resources

How often do Major Depressive Episodes and Manic-Depressive Episodes Return?
A. Studies show that about 15 to 50% of people who have a Major Depressive Episode will never have another one.

B. For the remaining 50 to 85% of people with Major Depressive Disorder or Bipolar Disorder, the number of recurrences of mood episodes varies among individuals. Studies show that the median number of episodes in a lifetime for people with Bipolar Disorder is about 11.

C. Over 75 - 90% of people suffering from Major Depressive Disorder or Bipolar Disorder can achieve substantial relief from the symptoms through treatment.

D. Studies indicate that although individuals each develop their own pattern of cycling in and out of mood episodes, the time between episodes grows shorter as the illness progresses, with the average between the first and second episodes being 3 years, the average between the second and third episodes being 2 years, and the average between the third and fourth episodes being 1 and 1/2 years.

What Causes Major Mood Disorders?
A. These disorders tend to run in families, and evidence suggests that the predisposition to develop these disorders is genetically inherited. For example, certain chromosomal segments have been found to be defective in some cases of Manic Depression.
B. Major Depression occurs twice as often in females as it does in males. Bipolar Disorder occurs equally in males and females.
C. Research has supported the following influences as factors* in a person's predisposition to these disorders:

1. Neurotransmitter imbalances (e.g. norepinephrine, dopamine, serotonin, acetylcholine).
2. Electrolyte imbalances (electrolytes are substances that carry electric current. They help nerve cells communicate with each other.)
3. Hormonal imbalances
4. Abnormal brain waves
5. Abnormal sleep patterns
6. Disturbances in the internal "biological clock" (i.e., abnormal biorythms)
7. Hyperactive stress response (increased cortisol secretion)

D. The following environmental events are the 6 most likely to trigger mood episodes in people who have a genetic vulnerability:

1. Death in the family
2. Separation and divorce
3. Physical illness
4. Threat to one's sexual identity
5. Work failure
6. Disappointment in a child

Mental Health Advance Directives

E. Some research indicates that certain personalities, thought patterns and behavior patterns are associated with people who are experiencing Major Depressive Episodes, but it is not yet clear whether these traits are a cause of the depressive episode, a result of the depressive episode, or both.

What Patients Need to Know About Mental Health Advance Directives
If you take the opportunity in advance, you have the right to direct the type of mental health treatment you want, even in the event you cannot make sound decisions due to an occurrence of mental illness. A mental health advance directive is a document that allows you to decide and write down how you would like your mental health treatment handled in the future.

What does a mental health advance directive do?
A mental health advance directive is much like a living will for health care. A person with or without a mental illness can specify how treatment decisions should be made if the person becomes unable to make sound choices due to the mental illness. You may create a directive that gives someone else the legal authority to make mental health decisions for you if you are unable to make sound decisions. You can say what types of decisions you want made for you and even what those decisions should be. The person you choose to make the decision is called an agent. You can also write down instructions about the treatment you wish to receive. For instance, the directive can say what medication you do or do not want and why, or describe ways to calm you when you are upset. You can have a directive that only appoints an agent or one that only provides instructions about treatment, or a directive that does both.

When does a mental health advance directive apply?
A mental health advance directive goes into effect only if a person becomes "incapacitated" according to State law. When a person is not incapacitated, that person can make decisions about mental health treatment at that time without the help of an agent or prior instructions. A person with a directive can choose in advance whether or not he or she can change or cancel the instructions in the directive if he or she becomes incapacitated. If a person with a directive chooses to not be able to change or cancel the directive on becoming incapacitated, that person may receive treatment based on the directive even if the person says he or she does not want to be treated at the time.

What does incapacitated mean?
"Incapacitated" is a legal term, which generally means that a person cannot make sound decisions about his or her care or treatment. Before a person can be declared incapacitated, certain health-care providers or a court must examine the person and decide whether he or she understands information that is needed to make decisions regarding his or her health care. If the person is found to be incapacitated, then the mental health advance directive will apply.

Who can I appoint to make mental health decisions for me?
The person you choose to make mental health decisions for you should be someone you trust. Unless the person is also your spouse, adult child, brother, or sister, you cannot pick the following people as your "gent": your doctor, an employee of your doctor or an administrator, owner, or employee of the healthcare facility in which you live or are a patient.

Mental Health Advance Directives

Do hospitals require that I have a mental health advance directive?
Hospitals do not require that you have a mental health advance directive, but hospital staff must ask if you have one. If you do have one, the hospital must write this information in your chart. A hospital cannot discriminate against a patient based on whether or not the patient has a directive.

Can I change my mental health advance directive?
The best way to change your mental health advance directive is to cancel or revoke it. To cancel or revoke your directive, you must make a statement in writing stating that you want to cancel or revoke the directive and sign it. You or your agent must give copies of the statement canceling or revoking your directive to everyone who got copies of your directive. You may be able to cancel or revoke your directive only when you have capacity, unless you chose in the directive to be able to cancel or revoke the directive when you do not have capacity. If you change your directive and make a new directive, you should give new copies to your family, doctor, attorney, agent and others that might need a copy. Your health-care provider must know about the change or it will not be effective.

Where should I keep my mental health advance directive?
You and your family should agree on a place to keep your original mental health advance directive. Copies should be given to your family members, doctor, attorney, and anyone you have appointed as an agent to make decisions for you if you become incapacitated. If you are being admitted to the hospital, you should take a copy with you.

Will hospitals and my doctor honor my mental health advance directive?
Hospitals and doctors support patients' rights to make decisions about their mental health care. They will honor mental health advance directives that meet state law requirements, medical and ethical practice standards, and policies and procedures of the hospital. Hospitals and doctors must tell you their policies on directives and whether they know of any conflict between your directive and their policies. If the policies conflict, you or your agent will have to decide whether to continue treatment even though it may not follow your directive's instructions. If the hospital or doctor cannot follow part of the directive, the rest of the directive is still valid.

What if I have a living will or durable power of attorney for health care?
If you already have a living will and/or durable power of attorney for health care that applies to medical decisions, you should review what it says. The living will and durable power of attorney for medical decisions will be in effect except where they conflict with what your mental health advance directive says. To avoid confusion, you may want to consider having only one person be your agent to make health-care decisions for both mental health and medical decisions. You may also want an attorney to review how the documents fit together.

How do I prepare a mental health advance directive?
A standard form for a mental health advance directive is provided in each state. You may want to involve your health-care provider and/or attorney in making a directive. If you think a directive

Mental Health Advance Directives

would be a useful planning tool, contact one of the following agencies. They can assist you in finding a lawyer who will help you write a directive, in some cases for little or no fee.

Example of Advance Directive

I, _____, being of sound mind, willfully and voluntarily execute this mental health advance directive to assure that if I should be found incompetent to consent to my own mental health treatment, my choices regarding my treatment will be carried out despite my inability to make informed decisions for myself.

If a guardian or other decision-maker is appointed by a court to make health care or mental health decisions for me, I intend this document to take precedence over all other means of determining my intent while competent. This document represents my wishes and it should be given the greatest possible legal weight and respect.

If the surrogate(s) named in this directive are not available, my wishes shall be binding on whoever is appointed to make such decisions.

If I become incompetent to make decisions about my own mental health treatment, I have authorized a mental health care surrogate to make certain treatment decisions for me. My surrogate is also authorized to apply for public benefits to defray the cost of my health care, to release information to appropriate persons, and to authorize my transfer from a health care facility.

My mental health care surrogate is:

Name: _____

Address: _____

Day Telephone: _____ Evening Telephone: _____

I, _____, mental health care surrogate designated by_____, hereby accept the designation. _____

(Signature of Mental Health Care Surrogate) (Date)

If the person named above is unavailable or unable to serve as my mental health care surrogate, I hereby appoint and want immediate notification of my alternate mental health care surrogate as follows:

Name of Alternate: _____

Address: _____

Day Telephone: _____ Evening Telephone: _____

I, _____, alternate mental health care surrogate designated by_____, hereby accept the designation._____

(Signature of Alternate Mental Health Care Surrogate) (Date)

Complete the following or initial in the blank marked yes or no:

A. If I become incompetent to give consent to mental health treatment, I give my mental health care surrogate full power and authority to make mental health care decisions for me. This includes the right to consent, refuse consent, or withdraw consent to any mental

health care, treatment, service, or procedure, consistent with any instructions and/or limitations I have stated in this advance directive. If I have not expressed a choice in this advance directive, I authorize my surrogate to make the decision my surrogate determines is the decision I would make if I were competent to do so. _____Yes ____No

B. My choice of treatment facilities are as follows:

1. In the event my psychiatric condition is serious enough to require 24-hour care, I would prefer to receive this care in this/these facilities:
Facility: _____
Facility: _____

2. I do not wish to be placed in the following facilities for psychiatric care for the reasons I have listed:
Facility/Reason: _____
Facility/Reason: _____

C. My choice of a treating physician is:
First choice of physician: _____
Second choice of physician: _____

I do not wish to be treated by the following physicians:
Name of physician: _____
Name of physician: _____

D. My wishes regarding confidentiality of my admission to a facility and my treatment while there are as follows:

1. _____ My representative may be notified of my involuntary admission ___Yes ___No
2. _____ Any person who seeks to contact me while I am in a facility may be told I am there. _____Yes _____No
3. _____ I consent to release of information about my condition and treatment plan ____Yes ____ No to the following people: _____ _____
4. _____ I do not consent to the release of information about my admission or treatment to anyone unless I give specific consent at the time of the request or as otherwise allowed by law. ____Yes ____ No

E. If I am not competent to consent to my own treatment or to refuse medications relating to my mental health treatment, I have initialed one of the following, which represents my wishes:

1. _____ I consent to the medications that Dr. _____ recommends.
2. _____ I consent to the medications agreed to by my mental health care surrogate, after consulting with my treating physician and any other individuals my surrogate may think appropriate, with the exceptions found in #3 below.

3. _____ I specifically do not consent and I do not authorize my mental health care surrogate to consent to the administration of the following medications or their respective brand name, trade name, or generic equivalents: (list name of drug and reason for refusal)_____
_____
_____
4. _____ I am willing to take the medications excluded in #3 above if my only reason for excluding them is their side effects and the dosage can be adjusted to eliminate those side effects.
5. _____ I have the following preferences about psychiatric medications:
_____
_____

F. My wishes regarding Electroconvulsive Therapy (ECT) are as follows:
1. _____ My surrogate may not consent to ECT without express court approval.
2. _____ I authorize my surrogate to consent to ECT.
3. Other instructions and wishes regarding ECT are as follows:
_____
_____

G. If, during a stay in a psychiatric facility, my behavior requires an emergency intervention, my wishes regarding which form of emergency interventions should be made in the following order: (fill in numbers, giving 1 to your first choice, 2 to your second, and so on until each has a number). If an intervention you prefer is not listed, write it in after "other" and give it a number.

___ Seclusion
___ Physical restraints
___ Both seclusion and physical restraints
___ Other: _____
___ Medication in pill form
___ Medication in liquid medication
___ Medication by injection

H. State law prohibits a mental health care surrogate from consenting to experimental treatments that have not been approved by a federally approved institutional review board without my prior written consent or the express approval of the court.
_____ I consent to my participation in experimental drug studies or drug trials
_____ I do not wish to participate in experimental drug studies or drug trials

I. If I am incompetent to give consent, I want staff to immediately notify the following persons that I have been admitted to a psychiatric facility.
Name: _____ Relationship: _____
Address: _____
Day Phone: _____ Evening Phone: _____
Name: _____ Relationship: _____
Address: _____
Day Phone: _____ Evening Phone: _____

Mental Health Advance Directives

J. Other instructions I wish to make about my mental health care are (use additional pages if needed):_____
_____
_____

By signing here I indicate that I fully understand that this advance directive will permit my mental health care surrogate to make decisions and to provide, withhold, or withdraw consent for my mental health treatment.

Printed Name (Declarant): _____
Signature: _____Date: _____

This advance directive was signed by _____ in our presence. At his/her request, we have signed our names below as witness. We declare that, at the time this advance directive was signed, the Declarant, according to our best knowledge and belief was of sound mind and under no constraint or undue influence. We further declare that we are both adults, are not designated in this advance directive as the mental health care surrogate, and at least one of us is neither the person's spouse nor blood relative.

Dated at _____, this _____day of _____, _____
(County & State) (Day) (Month) (Year)

Witness 1:

_____
Signature of witness 1

_____
Printed name of witness 1

_____
Home address of witness 1

_____
City, State, Zip Code of witness 1

Witness 2:

_____
Signature of witness

_____
Printed name of witness 2

_____
Home address of witness 2

_____
City, State, Zip Code of witness 2

4 Additional Resources

Stress Management

Family Stress, Coping, and Support
The family must be in good health to care for and support a relative with mental illness. Mental illness affects the family in a number of ways, involving long-term stress, grief of loss, and the consumption of emotional and financial resources as well as of time and energy.

Stages of Coping
Families go through the following stages of coping with the illness: denial, blame, anger, depression, and acceptance. The duration and order of these stages varies considerably among different families and different members of the same family go thorough these stages at different rates.

Stress Management
Stress is caused by internal and external physical and psychological factors. Stress can be caused by environmental events such as death of a loved one, divorce, financial difficulties, marriage, and other events. It can also be caused by internal pressures such as expectations and goals.
Signs and symptoms of stress include physical signs such as blushing, fast breathing, or heart pounding; psychological signs such as worrying, anxiety, or irritability; and behavioral signs such as pacing, lasing out at others or absenteeism form work. Managing stress is done by making life style changes such as providing good nutrition, exercise, rest and sleep, and leisure activities, limiting alcohol and smoking; and by making psychological changes such as changing expectations, setting priorities, and setting goals. Relaxation and other therapies may also be helpful.

Tips for Survival
It is important that you as family members take good care of yourselves. These following strategies can help:

1. Say what you'll do---do what you say.
2. Practice instead of try.
3. Monitor your blood pressure.
4. Avoid riding the emotional roller coaster.
5. Get professional feedback and information.
6. Get involved in support networks.
7. Trade off responsibilities with other families.

Stress and How to Manage It
Stress has been called the "wear and tear of life". It comes from internal and external pressures. Stress can be both positive and negative. Stress is the body's natural response to the requirement for change or adjustment and is a normal and natural process.
Stress works on the body thorough the stress response—the body responds by preparing you for "fight" or "flight" in the following three-phase process:

1. Alarm phase—recognizing and preparing to deal with the stressor
2. Resistance phase—coping with the stressor and returning to normal
3. Exhaustion phase—continued stress breaks down the ability to resist

4 Additional Resources

Stress Management

Effects of Stress on the Body
Stress affects the body in many ways, both short and long term. Some of the physical effects of stress are blushing, gritting of teeth, “butterflies”, an anxious feeling, heart pounding, increased breathing, clenched fists, and sweaty palms. Mental or psychological effects include fear and anxiety, insomnia and fatigue, reduced concentration, and aggravation of psychiatric symptoms. Behavioral/life effects are reduced problem-solving ability, decreased work performance, alcohol or drug abuse, irritability and easy anger at others, and surrender or a failure to cope. Long-term effects may be illness such as headaches, ulcers, heart disease, arthritis, high blood pressure, cancer, diabetes, and other chronic diseases.

Types of Stress
Stress can be both positive and negative. Stressors usually considered positive include marriage, birth of a child, new job, moving to a new home, or vacation. Stressors usually thought of as negative include loss of a loved one, divorce, loss of a job, financial problems, noise, or internal stress such as expecting too much of yourself.

Stress and Mental Illness
Mental illness is a brain disorder that affects perceptions, thoughts, moods, and behavior, and causes the person to be vulnerable to stress. Therefore, it is extremely important for the person with mental illness to be aware of stress and to be able to recognize and manage stress.

Ways of Coping with Stress
There are many ways of coping with stress. Four key factors in managing stress in mental illness are as follows:

1. Staying healthy through proper nutrition; adequate rest and sleep; regular, vigorous exercise; leisure time activities; and avoidance of alcohol, drugs, and tobacco.
2. Keeping down stress by learning to recognize when you are under stress, knowing what situations stress you, learning to avoid stressful situations, planning only what you can comfortable accomplish, keep down the “noise” in the environment, and asking for help form family and friends.
3. Regular relaxation by learning progressive relaxation, daily meditation, and doing what you find relaxing.
4. Changing the way you think about things by changing “self-talk” and engaging in self-behavior modification and reality-based problem-solving counseling.

4 Additional Resources

Responding to Hallucinations, Delusions & Illusions

1. **React calmly** – Try to stay calm and matter of fact. Showing that you are upset may only increase the person's anxiety.

2. **Listen**– Listen non-judgmentally to the person's concerns.

3. **Avoid arguing** – Do not argue with the person about their experience or try to convince them that what they are experiencing is not really happening. This belief or hallucination is very real for them and arguing will only increase their anxiety.

4. **Avoid agreeing** – If you agree with the person's beliefs or hallucinations, you risk making the situation worse or becoming part of their delusion.

5. **Validate their feelings** – This is an important supportive strategy. It empathizes and acknowledges the person's feeling. For example, if the person if feeling upset and angry because of an auditory hallucination, you might say something like: "I am not hearing that voice but I know it's really upsetting for you." This helps to build trust and rapport.

6. **Give lots of reassurance** – Express concern and care. Reassure the person that you understand how upsetting it is for them, that they are safe, and that you are on their side and want to help them. You may need to say this repeatedly.

7. **Check for environmental triggers** – Environmental stimuli may trigger a hallucination or an illusion. For example, patterned wallpaper designs may look like bugs crawling and the TV, radio, photos or mirrors can also trigger hallucinations. They can be turned off, covered up or removed. On the other hand, if a there are not many cues in the environment to stimulate and orient the person, this can also lead to hallucinations and delusions.

8. **Use distraction** – If possible, distract the person with other activities.

9. **Recognize that not all hallucinations are upsetting** – Not all hallucinations and delusions are upsetting or disturbing to the person.

10. **Inform** – Let your supervisor or the doctor know immediately if the person you are caring for experiences hallucinations or delusions. A medical assessment is needed immediately.

4 Additional Resources

What is Relapse?

The following material comes from *Partnership for Recovery*, © 1995 Cynthia Bisbee, PhD

Relapse

- Illness symptoms return—episode
- Relapse follows different patterns
- Early warning signs often can predict relapse
- Relapse may be due to many different causes:
    - Change in medication
    - Physical illness
    - Stress
    - Alcohol or drug use
    - Illness cycles

Self-Observation and Illness Monitoring

- Learning to recognize presence of symptoms
- Monitoring symptoms regularly
- Getting treatment early or making changes

Relapse Response Plan Involves:

- Increasing medication (with doctor's approval)
- Decreasing all stimulation
- Increasing structure
- Getting crisis treatment if needed

Relapse Prevention

- Communicate with family about symptoms
- Notify doctor or other professional
- Make management or other treatment changes:
    - Increase or change medication
    - Decrease stress
    - Change nutrition, exercise, rest
- Seek crisis intervention, treatment, hospitalization

You can take certain actions to help manage symptoms and to maintain a nontoxic environment to help decrease the chances of relapse.

Medication Adherence

- Understand the medication regimen. Communicate with your family about how to take your medications. Talk with the doctor or other health care professional to understand the schedule, and ask questions to understand all details.
- Ensure you take medications as prescribed. Ask your family or friends to help you to stay on track and remind you if you need reminding.
- Store medications properly in a cool, dark place, away from heat and light.
- Ask your family or friend for help in noticing side effects. Communicate the side effects to the doctor or health care professional.

4 Additional Resources

What is Relapse?

Healthful Life Style Habits

- Maintain a balanced, healthful diet of moderate protein, complex carbohydrates, low fat, minimal refined sugar, and a balance of foods from all food groups. Keep caffeine out of the diet—it is a stimulant that works in the brain and may require you to take additional medication.
- Engage in vigorous, aerobic exercise daily for 30 minutes. Any choice of aerobics will do—walking, jogging, running, bicycling, swimming, or jumping rope.
- Avoid alcohol and drugs.
- Get adequate rest and sleep.
- Target your relaxation by meditating, listening to quiet music, taking a warm bath, reading, or engaging in any relaxing activity. If possible, take relation therapy.

Stress and Stimulation Management

- Have a daily structure. Have a routine of wake-up, meals, productive activities, rest, and leisure. Make limited changes at first, with gradually increasing complexity and amounts of productive activity as you recover.
- Keep down the stress level by reducing environmental "noise" (actual noise—loud sounds, music; talking, number of people you must encounter; amount of expressed emotion in the environment; or complexity of the lifestyle.
- Keep a balance of stimulation, enough stimulation to avoid negative symptoms and provide motivation to recover, but not so much stimulation to increase positive symptoms. It is an art that each person and family will have to learn individually.

Environmental Drills

Have plans for when a relapse occurs. Increase medication (with doctor's approval); decrease all stimulation (noise, people in and out, visits or trips away from home, amount of contact with family, activities, or required chores); and take other environmental actions as needed.

On the next page you will find a worksheet to help you understand how to decrease your chances of relapse.

What is Relapse?

Worksheet Assignment
Decreasing Your Chances of Relapse

Name _____ **Date** _____

What does relapse mean to you?

_____
_____
_____
_____
_____

Name four things you can do to help prevent relapse.

1. _____
2. _____
3. _____
4. _____

List three things you can change in your home to make the environment less harmful.

1. _____
2. _____
3. _____

What do you do if you think a relapse is coming on?

_____
_____
_____
_____

4 Additional Resources

What is Relapse?

Symptom Checklist

1. Make a list of your symptoms.
2. Record symptoms on Symptom Checklist.
3. Check every day to record if symptoms occurred.
4. Watch for increase in symptoms.
5. Take action when you think a relapse is coming.

Symptom Checklist Sample

Symptom	Mon.	Tues.	Wed,	Thurs.	Fri.	Sat.	Sun.
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10.							
Total for Week							

4 Additional Resources

Basic Problem Solving Steps

The problem solving process in family consultation is a 6-step process borrowed from the business community. The process helps to organize potentially emotionally laden material into a step-by-step, sequential process that allows the family, consumer and others to look at details in the decision making process and to assist them with devising a plan of action to overcome a problem.

Step One: What is the Problem, Concern or Focal Point?

The family consultant asks the family to talk about their concern, a problem or a focal point. Listen carefully and ask questions. Get everybody's opinion. Then, write it in a way that best defines it in a solvable way.

_____

_____

_____

Step Two: List All Possible Solutions

Ask the family for all of their ideas on how the concern could be addressed or solved. Encourage them not to dismiss things they have tried already and not to judge their possible solutions as being silly, etc. Put down all ideas, even ones you may not agree with. Get everybody to come up with at least one possible solution.

The Consumer Centered Family Consultant is also encouraged to offer possible solutions. Stress that this is brainstorming section of problem solving process. No pros and cons should be discussed at this time-just free association… brainstorming. This is often a fun, light-hearted process once the family and consultant truly allow themselves to be free to share any idea without fear of judgment or failure. Many creative ideas can come from this step of the problem solving process.

1. _____

2. _____

3. _____

Basic Problem Solving Steps

Step Three: Discuss Each Possible Solution

Once the list of possible solutions has been generated, the Family Consultant leads a discussion with the family about the main advantages and disadvantages of each item from the list of possible solutions (pros and cons).

Step Four: Choose the "Best" Solution

The Consumer Centered Family Consultant encourages the family to choose the solution or solutions that can be carried out the most easily to solve the problem. During the process the Family Consultant also could encourage the family to delete any solutions they know they would not be likely to implement.

Step Five: Plan How to Carry Out the Best Possible Solution

This is the step where the Family Consultant helps the family go into more detail on how to carry out the plan. The family would determine any resources needed and major pitfalls they would need to overcome. Assist the family as needed. Practice difficult steps. Leave time for review and give the family a copy of the step-by-step plan.

Who: _____

What: _____

When: _____

Where: _____

Other: _____

Step Six: Review Implementation and Praise all Efforts

At a follow-up consultation meeting, the family consultant would focus on the achievements the family experienced. Review the plan and make any revisions as necessary. The Consumer Centered Family Consultant always accepts responsibility for failure the family experienced to help alleviate any further sense of demoralization they may have experienced.

Progress Note

Consumer Centered Family Consultation Progress Note

Consumer Name: _____ Date of consultation: _____
ID number: _____ Session duration: _____
Consumer present? (circle) Yes No Family Member(s):_____
Location: _____ Family Consultation: (circle session number or write in other)
Relationship(s) to Consumer: _____ (1) (2) (3) Other_____

Consumer Engagement: Date in which the consumer signed the release of information: ____

Consumer's expectation/wants regarding the consultation with family: _____

_____

Service plan goal to be supported by the consultation? _____

_____

Presenting problems/needs/wants of family: Please check all that apply and provide a brief summary.

___ Information about the consumer's mental health issues (e.g., diagnosis, causes, treatments)
___ Family relationships (e.g., communication, coping strategies)
___ Support (e.g., options for linkage to professional and community sources of emotional and social support)
___ Practical assistance and advocacy (e.g., navigating the mental health system)
___ Other problems/ needs/wants

_____

_____

Consultation services provided: Please check all that apply and provide a brief summary.

___ Basic information related to the consumer's mental health
___ Guidelines and strategies to support family relationships
___ Information about community resources, including NAMI
___ Problem solving strategies related to specific problem areas
___ Other (please specify)_____

Disposition/Outcome: Please check all that apply and provide a brief summary

___ No further consultation needed or desired at this time.
___ Schedule additional consultation meeting
___ Refer to other agency services (e.g., support group, MFG, consultation with other staff)
___ Refer to NAMI or other community resources/ supports
___ Other (specify) _____

Signature of person completing consultation: _____Date: _____

4 Additional Resources

Family Institute Website & Other Website Resources

The Family Institute's website is intended to be a useful resource for providers who are interested in conducting Consumer Centered Family Consultations, multifamily groups and other family services for consumers of mental health services. To go to the website follow this link: www.nysfamilyinstitute.org. If you need additional resources that are not in the website and you need help locating these, please do not hesitate to ask for our assistance. The photo below shows what the home page of the site currently looks like.

4 Additional Resources

Family Institute Website & Other Website Resources

Consumer Centered Family Consultation Brochure http://www.nysfamilyinstitute.org

Family Institute for Education, Practice & Research http://www.nysfamilyinstitute.org

Family Resource Manual http://www.nysfamilyinstitute.org

HIPPAA Resource Manual http://www.nysfamilyinstitute.org

National Alliance on Mental Illness, New York State Chapter http://www.naminys.org

National Institute of Mental Health http://www.nimh.nih.gov

New York Association of Psychiatric Rehabilitation Services http://www.nyaprs.org/

New York State Conference of Local Mental Hygiene Directors http://www.clmhd.org

New York State Office of Mental Health http://www.omh.state.ny.us

SAMHSA www.samhsa.gov

University of Rochester Medical Center, Department of Psychiatry

http://www.urmc.rochester.edu/psychiatry