ENGAGING FAMILY SYSTEMS IN EARLY PSYCHOSIS CARE

MISSOURI'S 3RD ANNUAL EARLY PSYCHOSIS CARE CONFERENCE

4.22.25

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NE OHIO MH HIGHLIGHTS

https://www.cleveland.com/akron/2018/06/foudners_day_expected_to_draw.html

https://www.uakron.edu/chp/images/Museumentrance.jpg

https://i.ytimg.com/vi/jC6kxhs-ras/maxresdefault.jpg

REMEMBERING

FREDERICK J. FRESE, PH.D.

1940 - 2018

https://thepulse.neomed.edu/wp-content/uploads/2018/07/PUL_07.23.18_Frese-1.jpg

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BEST PRACTICES IN SCHIZOPHRENIA TREATMENT (BEST) CENTER

Established in 2009, BeST Center is 1 of 3 Coordinating Centers of Excellence housed within the Department of Psychiatry in the College of Medicine at Northeast Ohio Medical University (NEOMED).

- Address the needs of individuals diagnosed with schizophrenia-spectrum and other psychotic disorders – and their family systems/natural supports
- Assist in the implementation of evidence-based and promising best practices with external partners
  - Offer training, consultation, education and outreach activities, services research, and evaluation
- Ensure that successful implementation leads to sustainable practice

BeST CENTER MODEL

- BeST Center's Consultant / Trainers have expertise in both their practice area and implementation science
  - Family-Based Services (Family Education & Support)
  - FIRST Coordinated Specialty Care for First Episode Psychosis
  - Cognitive Behavioral Therapy for Psychosis
  - Cognitive Remediation
  - Pharmacotherapy for Psychosis
  - Integrated Primary and Mental Health Care
- Consultation is available on an ongoing basis

BeST Center Programs

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BEST CENTER & EARLY PSYCHOSIS

- FIRST Coordinated Specialty Care for First Episode Psychosis (FIRST)
  - Part of the initial RAISE / NAVIGATE project
  - Initial implementation in 2010
  - 14 Ohio teams; 21 Illinois teams
- Clinical High Risk for Psychosis
  - Ohio team established in 2018 – SAMHSA grant
- Project ECHO: First Episode Psychosis
- All BeST Center programs intersect with FIRST

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LEARNING OBJECTIVES

- **At the conclusion of this session, attendees will be able to:**
  - Summarize the important role of family systems in early psychosis care
  - Describe how a provider can take a systems approach to early psychosis care
  - Identify at least 2 strategies for engaging family systems

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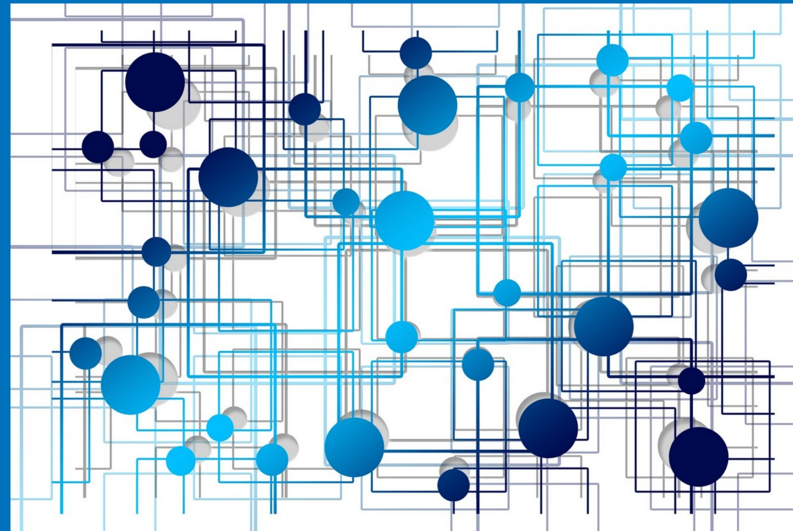
A "SYSTEMS APPROACH" TO CARE



DEFINING “FAMILY”

- Those identified by the individual as playing a significant, meaningful role in their life
  - Those who reside with and/or have influence in the individual’s life
  - Those who care for or about an individual diagnosed with a mental illness
  - Could be a blood relative, significant other, neighbor, friend, or other support person
- Think broadly and inclusively*

"FAMILY SYSTEM"

- Network of individuals with bi-directional impact on – and influence over – one another
  - Complex
  - Interconnected
  - Interdependent – health and functioning of individuals impacts system and all other individuals in system
  - Roles and functions of each individual within the system
  - Subgroups within a family system
  - Ever-evolving

"SYSTEMS APPROACH TO CARE"

- How we think about and conceptualize our work
- Moving from a "client-centric" approach to more planfully, strategically, and skillfully engaging the individual's family system / support network that surrounds them
  - Still individual-driven

So, how do we go about this?

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CASE FORMULATION

CASE FORMULATION

- Where to begin:
  - When conceptualizing a case, it is critical to consider their system (aka those who surround / impact / influence the individual)
- Infusing / incorporating a family system approach into individual case conceptualization

CASE FORMULATION

At minimum, make sure to inquire about and include:

- Individual's level of interest / openness to involving family system
- In what ways / at what level is family system engaging with the individual?
- In what ways / at what level is family system engaging with the treatment team?
- Family belief system (e.g., culture, relationship dynamics)
- Family system needs / goals / values
- Impact of illness on the family system
- Impact of family system on illness (and illness trajectory)
- Action plan:
  - With individual
  - With family system
  - With other team members / as a team

Questions for consideration:
What are the individual's strengths and supports (e.g., **family, friends**)?
What are the individual's recovery goals? What are the family system's goals? How do these **goals align?** And **differ?**
What symptoms, behaviors, or interactions (e.g., **with family system**) interfere with the above goals?
What current stressors impact the individual? What stressors impact the family system?
What life experiences (e.g., **family of origin,** trauma, work / school) help in understanding the symptoms and behaviors described above? What **social or cultural influences** impact the individual?
How does the individual **relate to family members, friends, other supports**? What **patterns of interaction** are you noticing (e.g., conflicts, lack of involvement, over-involvement, positive interactions)?
How have you / how might you **involve the family system?** And **maintain involvement?**

THE WHO, WHAT, WHERE, WHY, WHEN AND HOW OF FAMILY SYSTEMS WORK

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THE WHY

STEP 1:
UNDERSTANDING THE "**WHY**"

Understanding the role of family systems in treatment and recovery

- *When <u>knowledgeable and appropriately supportive</u> family systems are engaged in treatment, outcomes for everyone are improved*[1,2]:
  - Reductions in psychiatric relapses[3,4] and psychiatric hospital readmissions[4,5]
  - Improved: family well-being[3,4,6], family relationships[7], social and occupational functioning[4,6], treatment adherence[4], overall quality of life[8], and work and role performance[9]
  - Decreased: substance use[10], perceived family burden[7], burnout and exhaustion[11], economic impacts and costs of care[4,6,12] (including shorter length of inpatient hospitalization stays[13])

([1]Glick, Stekoll & Hays, 2011; [2]Jewell et al., 2005; [3]Dixon & Lehman, 1995; [4]McFarlane et al., 1995; [5]Pitschel-Walz et al., 2001; [6]Falloon, 1985; [7]Cuijpers, 1999; [8]Alshowkan, Curtis, & White, 2012; [9]Brekke & Mathiesen, 1995; [10]Clark, 2001; [11]Angermeyer et al., 2006; [12]Mangalore & Knapp, 2007; [13]Pfammatter, Junghan, & Brenner, 2006)

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STEP 1:
UNDERSTANDING THE "WHY"

- **Schizophrenia Patient Outcomes Research Team (PORT)[1]**
  - Recommends providing family-based services
  - One recommendation is to provide a family intervention
    - Duration of at least 6-9 months
    - Ideally, this would be in the form of the evidenced-based Family Psychoeducation
    - Schizophrenia PORT recommends shorter-term interventions (at least 4 sessions in less than 6 months) when longer-term interventions are not practical or desired

([1]Dixon et al., 2010)

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STEP 1:
UNDERSTANDING THE "**WHY**"

- We're typically thrilled when an individual has an appropriately supportive and knowledgeable family system
  - This could (*and should*) be the "norm"
- It is the expectation – not the exception – that family systems are engaged in care (when appropriate)

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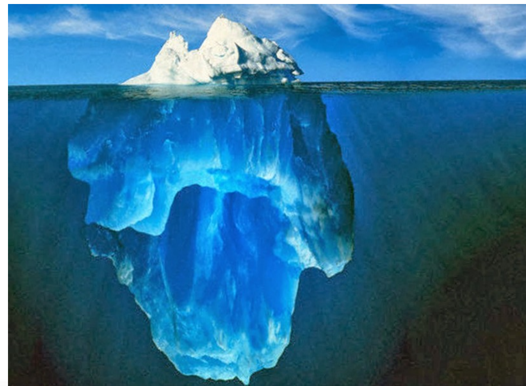
STEP 1:
UNDERSTANDING THE "WHY"

- It is a provider's role to have an inquiring mind…genuine curiosity about not just the individual's inner world, but also the world that surrounds them – and how these two things are working together

- Disservice to individuals when this is not occurring



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POWER AND INFLUENCE

STEP 2:
RECOGNIZING AND RESPECTING THE POWER OF THE SYSTEM

- How might we think about "**power**" in the context of family systems?
  - Can be positive, negative, or both
  - Influence over the individual
  - Impact on the individual
  - Power differentials

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STEP 2:
RECOGNIZING AND RESPECTING THE POWER OF THE SYSTEM

- "Respecting the system" in the context of power
  - The system has power and influence
    - If we do not know beliefs / values within the system, and treatment recommendations do not align (or even go against) these values, this can alienate the system and lead to frustration and tension
    - This potentially puts the individual in a double-bind, causing increased stress and anxiety

WE MUST DO OUR PART TO UNDERSTAND THE SYSTEM

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STEP 3:
UNDERSTANDING AND IDENTIFYING COMMON FACTORS THAT INFLUENCE FAMILY SYSTEMS

- Illness
- Religion / spirituality
- Beliefs, values
- Heritage, traditions
- Life experiences (individual or shared)
- Trauma (individual or shared)
- **Cultural factors**
- Others?

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A CLOSER LOOK AT CULTURE

A CLOSER LOOK AT CULTURE

- Culture[1]
  - System of knowledge, concepts, rules, practices
  - Learned
  - Transmitted across generations
  - Dynamic – change over time
  - Variables that impact how we experience our world
- Culture influences:
  - Beliefs, values, behavior, how MH and MH treatment are viewed, etc.
- Understanding cultural context of individual and family system's illness experience is necessary for assessment and ongoing treatment[1]

([1]APA, 2013)

A CLOSER LOOK AT CULTURE

CULTURE

Language

Communication

Courtesies

Rituals

Roles

Customs

Relationships

Practices

Expected behaviors

Values

Thoughts

Manners of interacting

https://images.saymedia-content.com/.image/t_share/MTc0OTg4MzE4NDMyNTAzMjM2/a-simple-guide-to-cultural-competence-for-educators.jpg

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SERVICE ACCESSIBILITY FOR CULTURALLY DIVERSE INDIVIDUALS

- Culturally diverse communities have lower rates of accessing MH services in the community[1]
  - More likely to present in crisis / for inpatient care when they do access services[1]
- Common challenges:[2]
  - Transportation
  - Differing cultural belief systems re: cause of MI
  - Limited culturally-relevant services
  - Limited services and resources available in various languages
  - Stigma (leading to delayed, or lack of, help-seeking)

([1]Orygen, 2016; [2]Crisanti et al., 2015)

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What are examples of diverse communities with whom you all work in the early psychosis / psychosis space?

How have you acknowledged, addressed, overcame any challenges you might have faced?

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A CLOSER LOOK AT CULTURE
ACCULTURATION

- "The *process* of cultural and psychological change that takes place as a result of contact between cultural groups and their individual members"[1,2]
- "…a *process* of attitudinal and behavioral change experienced by individuals who live in multicultural societies or who have come in contact with a different culture…"[3]
- **"The *process* of learning and incorporating values, beliefs, language, customs, and mannerisms of the new [area in which they live]"[4]**

([1]Berry, 1997; [2]Berry, 2004; [3]Delgado-Romero, Mollen, & Ridley, 2004; [4]Mody, 2007)

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A MODEL OF ACCULTURATION

Acculturation Model

	Identification with Heritage culture: **HIGH**	Identification with Heritage culture: **LOW**
Identification with US culture: **HIGH**	**Integration (Bicultural)**	**Assimilation**
Identification with US culture: **LOW**	**Separation**	**Marginalization**

(Image: Truong, H-T; Model: Berry, 1997)

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CONSIDER: VARYING DEGREES OF ACCULTURATION

- When one individual (or subgroup within a family system) has a different level of acculturation, how might this impact:
  - the entire family system?
  - the relationship between individual and their family system?
  - the relationship between family system and providers?

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A CLOSER LOOK AT CULTURE
RURAL

- Common challenges in rural communities:[1]
  - Travel / transportation – large geographic area
  - Limited crisis intervention services
  - Limited access to, understanding of, and use of MH services (namely those for psychosis)
  - Stigma related to accessing services
  - Confidentiality concerns
  - Resource shortages
  - Lack of health insurance

([1]Crisanti et al., 2015)

A CLOSER LOOK AT CULTURE
RURAL

- Primary care, emergency care, and substance use treatment are key in early psychosis treatment – but are limited in rural communities[1]
    - Higher rates of untreated co-occurring SUD and MH disorders in rural vs urban communities[1]
- Many rural communities have limited access to psychosocial interventions, which are a critical aspect of care in CSC for FEP and in transitioning out of CSC for FEP services[1]

([1]Crisanti et al., 2015)

A CLOSER LOOK AT CULTURE
RACE

- Non-Hispanic Black youth in early psychosis services are less likely to receive important early intervention services, such as Family Psychoeducation[1]
- Black individuals with psychosis and their family systems have a unique experience navigating treatment[2]
  - Oftentimes there is a perceived lack of benefit of treatment as a result of medical mistrust or anticipated discrimination based on historical experiences[2]
  - When Black individuals share their experiences with racism, providers must be aware of such occurrences to avoid unintentionally invalidating or pathologizing the experiences[2]

([1]DeLuca et al., 2022; [2]Gibbs et al., 2022)

IMPROVING AND ENSURING EQUITABLE SERVICES

- We live in a diverse environment with many different cultures, beliefs, values operating within and across family systems
- Sometimes individuals and family systems will leave services prematurely if they feel that providers are not understanding of their religion / spiritual practice or cultural beliefs

How can we address this before disengagement from services?

(Gurak, Weisman de Mamani, & Ironson, 2017)

STRATEGIES FOR EQUITABLE SERVICES

- ***Consider cultural context**[1]
  - Are their experiences culturally normative?
  - Are the "unusual" beliefs shared by the family system?[1]
  - What does the family system believe has caused the current circumstances?
  - How does the individual's presentation deviate from their cultural norm (frequency, duration, intensity, distress)?
    - Helpful to **gather information from family systems** (and **influential members of the community**, if/when possible) to answer these questions

([1]DeLuca et al., 2022)

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STRATEGIES FOR EQUITABLE SERVICES

- Consider how our own cultural backgrounds as a providers might impact assessment
  - Be prepared to confront racial diagnostic biases that can (at least in part) contribute to racial disparities when diagnosing psychotic disorders
    - An individual might use other words when describing the illness experience – caution not to over-pathologize or mislabel an individual's experiences
- Engage in ongoing process of **cultural humility**[1]
  - The awareness and openness to different lived experiences that shape people, and inequalities that influence our assumptions about the world[1]

(DeLuca et al., 2022)

STRATEGIES FOR EQUITABLE SERVICES

- **Build a strong rapport to work with diverse systems by understanding the family system's:**
  - Cultural background[1]
  - Family dynamics – roles, expectations, structure, points of disagreement or contention[1]
  - Belief(s) / value system(s)[1]
  - Varying levels of acculturation[1]
  - Languages spoken in the home[1] – accessibility of materials, availability of resources, use of interpreters[1]

([1]Orygen, 2016)

STRATEGIES FOR EQUITABLE SERVICES

- **Build a strong rapport to work with diverse systems by understanding the family system's:**
  - Social and familial norms[1]
  - Internal and external stigma[1]
  - Confidentiality concerns[1]
  - Family system's preferences in providers' approach
- This understanding can increase a family system's level of trust and comfort with providers

([1]Orygen, 2016)

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STRATEGIES FOR EQUITABLE SERVICES

- Do not be afraid to ask about cultural / spiritual beliefs[1]
- Emphasize that religious / spiritual beliefs, diversity in cultures, and mental health treatment **can all work together**[1]
- Identify personally relevant interventions to reduce disparities and increase engagement[2]
- Build aspects of culture, values, etc. into treatment plan[3]

([1]Gurak, K., Weisman de Mamani, A., & Ironson, G., 2017; [2]DeLuca et al., 2022; [3]Orygen, 2016)

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TOOL FOR UNDERSTANDING AND ASSESSING CULTURE

- **DSM 5's *Cultural Formulation Interview (CFI) tool*** (pgs. 749-759)
  - Helps to inform diagnosis and treatment planning
  - 16 questions: cultural identity, cultural conceptualization of distress, psychosocial stressors and cultural features of vulnerability and resilience, cultural features of relationship between individual and provider, overall cultural assessment
  - 2 versions: individual and "informant" (knowledgeable other)
  - https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-assessment-measures

(APA, 2013)

Cultural Formulation Interview (CFI)

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

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

(APA, 2013)

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RESOURCES

- National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care
  - Provides blueprint to make culturally appropriate services available
  - Provides resources and guidance for organizations
  - https://thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedNationalCLASStandards.pdf

(U.S. Department of HHS, Office of Minority Health)

RESOURCES

- Toolkit for Modifying EBPs to Increase Cultural Competence
  - Provides orgs with structure for making modifications to EBPs to assist with meeting the needs of various cultural groups (including rural communities)
  - https://www.montclair.edu/profilepages/media/8019/user/toolkit.pdf

(Samuels, Schudrich, & Altschul, 2009)

SUMMARY OF A SYSTEMS APPROACH TO CARE

3 Steps:

- Understand the "why"
- Recognizing and respecting the power of the system
- Understanding and identifying common factors that influence family systems

Tools:

- DSM 5 Cultural Formulation Interview

ENGAGING FAMILY SYSTEMS

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"ENGAGEMENT"

- Why is this an important piece for us to discuss?
  - Numerous barriers (individual, family system, provider, org, logistical)
  - Consistency:
    - Is this engagement with the individual? With the team?
  - Engagement looks different within and across family systems
  - **How are members of the team conceptualizing family system engagement *for this particular family system, at this particular time?***

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"ENGAGEMENT" CONSIDERATIONS

- AND does this **align** with the family system's definition and understanding of what engagement (with the individual and the team) looks like?
  - Does this definition **fit** the family system's current **needs**? And their current **capacity** and **abilities**?
  - Are there any barriers interfering with engagement?
  - Has the system's engagement with the individual and/or the team changed over time? Any contributing factors that are known?
  - What has worked to maintain engagement in the past?
  - Are there any commonalities that occur when the system seems to disengage?

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EXPECTATIONS

- Highlights the importance of discussing and aligning **expectations**
  - Ensure individual, family system, and provider / team are using shared definitions (e.g., recovery, wellness, engagement)
  - Not having initial discussions about expectations and then checking back in can lead to frustration and disappointment – with self, others in family system, provider / team, MH system

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THE WHO

STEP 1:
IDENTIFYING THE "**WHO**"

- **Explore who supports the individual**
  - Who might participate?
  - Who do they reside with?
  - Who plays a meaningful role in their life?
  - Who has influence of any kind over the individual and their decision-making?
  - Who were they once close with?
- Individual-driven

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STEP 1:
IDENTIFYING THE "WHO"

- **Sample questions:**
  - "**Who do you (or would you like to)** talk to if you're having a rough day or if you have good news to share?"
  - "Who would you call in an emergency or if you are in need of assistance?"
  - If they respond "no one," ask "Who do you wish you could call?"
    - Begin to identify barriers to this relationship and explore if there is interest in rebuilding (*potential meaningful goal*)

STEP 1:
IDENTIFYING THE "**WHO**"

- **Sample questions:**
  - "**Who calls you** if they are having a rough day? If there is an emergency? If they have good news to share?"
  - If they respond "no one," ask "Who do you wish would call you?"
  - Reminds them of their value / worth, responsibility to others, role within their family system / network, sense that they are part of something larger than themselves, they have something to offer others (*potential meaningful goal*)
    - These are vital part of life – and vital for wellness and recovery
    - They are not always the one in need

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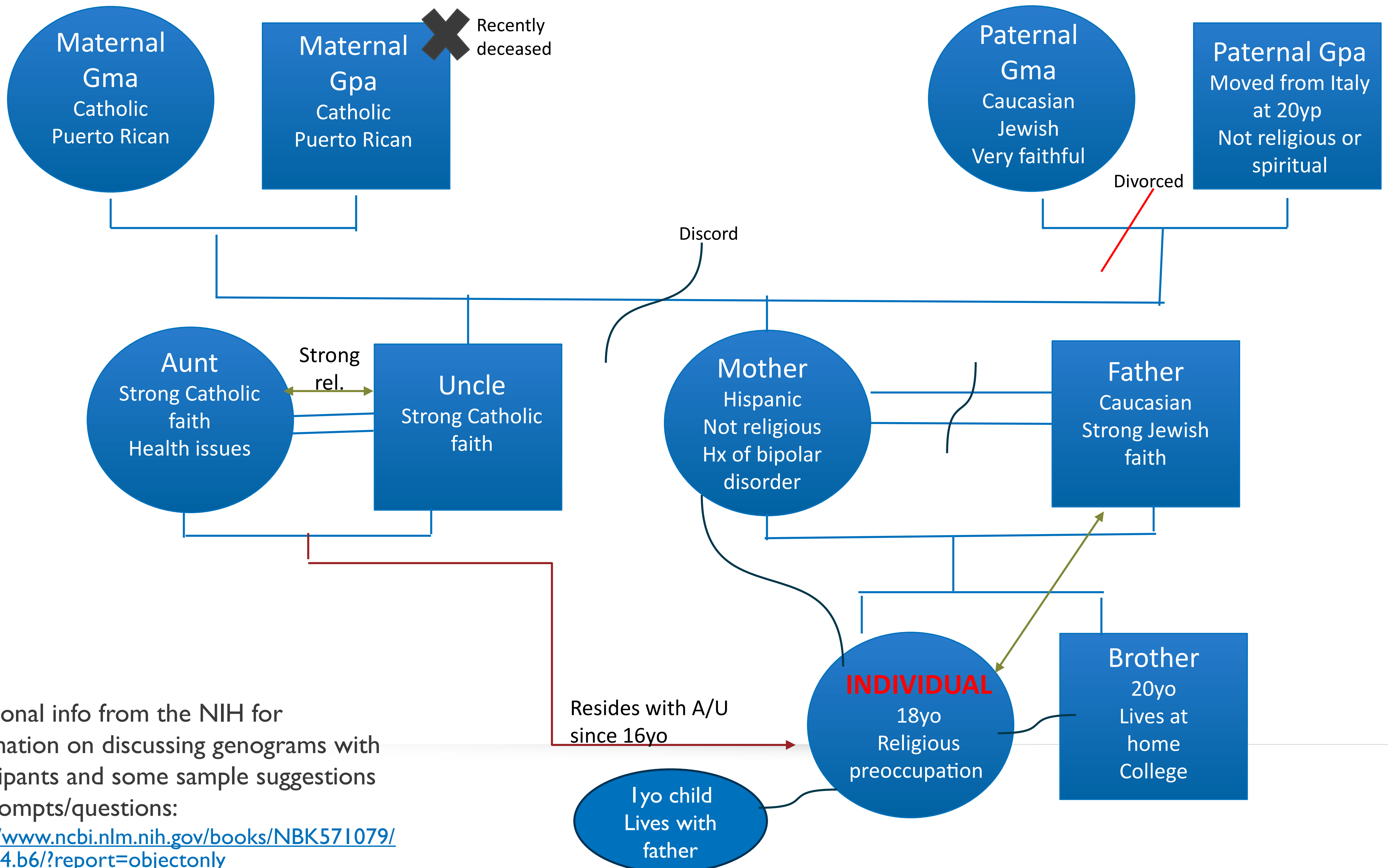
TOOL FOR IDENTIFYING THE "WHO"

- **Genogram** (even if done informally) can assist with:
  - Understanding the current family system – interdependent / interconnected unit
  - Gathering historical information that has impacted the family system
- Consider including the family system in building out the genogram, if / when they engage



Maternal Gma
Catholic
Puerto Rican
Maternal Gpa
Catholic
Puerto Rican
Recently deceased
Paternal Gma
Caucasian
Jewish
Very faithful
Paternal Gpa
Moved from Italy at 20yp
Not religious or spiritual
Divorced
Discord
Aunt
Strong Catholic faith
Health issues
Strong rel.
Uncle
Strong Catholic faith
Mother
Hispanic
Not religious
Hx of bipolar disorder
Father
Caucasian
Strong Jewish faith
Resides with A/U since 16yo
INDIVIDUAL
18yo
Religious preoccupation
Brother
20yo
Lives at home
College
1yo child
Lives with father
Additional info from the NIH for information on discussing genograms with participants and some sample suggestions for prompts/questions:
https://www.ncbi.nlm.nih.gov/books/NBK571079/box/ch4.b6/?report=objectonly

STEP 1:
IDENTIFYING THE "**WHO**"

- **Once they have identified a potential member of their family system:**
  - Explore their relationship with this individual
    - Are they satisfied with this relationship?
    - What is their communication like?
    - What do disagreements between them look like?
    - Has it ever gotten physical? Any history of DV or PO? **(DUE DILIGENCE)**

STEP 1:
IDENTIFYING THE "**WHO**": CONSIDERATIONS

- Discuss the potential for involving their family system
  - Share how involving their system can lead to improved outcomes *for all involved*
- Explore what family system involvement might look like
  - Benefits and potential undesirable consequences of involving the family system
  - Discuss their hesitations and concerns – normalize and validate these
  - Do benefits outweigh potential risks?

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TOOL FOR IDENTIFYING THE "WHO"

- **Ottawa Personal Decision-Making Guide**
  - Helps to clarify preferences and values related to treatment or other issues / decisions
  - Can assist the individual as they consider involving the family system

(O'Connor, Stacey, & Jacobson, 2015)

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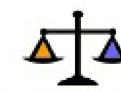
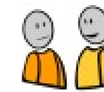
Ottawa Personal Decision Guide

For People Facing Tough Health or Social Decisions

You will be guided through four steps: ❶ ❷ ❸ ❹

❶ Clarify your decision.

What decision do you face? Whether or not to take medications

What is your reason for making this decision? Everyone keeps telling me I need to take medication

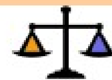
When do you need to make a choice? In 2 days when I see my psychiatrist

How far along are you with making a choice?
- ☐ Not yet thought about the options
- ☒ Thinking about the options
- ☐ Close to making a choice
- ☐ Already made a choice

❷ Explore your decision.

Knowledge

List the options and main benefits and risks you already know.



Values

Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters "a lot". No stars means "not at all".

Certainty

Consider the option with the benefits that matter most to you and are most likely to happen. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option (Benefits / Advantages / Pros)	How much it matters Use 0 to 5 ★s	Reasons to Avoid this Option (Risks / Disadvantages / Cons)	How much it matters Use 0 to 5 ★s
Option #1 Take medication	Remain stable and out of hospital	★★★★★	Dulls my mind	★★★★
	My parents and team want me to	★★★	Taking them every day is a hassle	★★
	Control voices	★★★★★	Other people will know	★★★
Option #2 Not take medication	I will feel like "myself"	★★★★	Being hospitalized	★★★★★
	Don't have to remember them	★★	Voices are distracting	★★★★
	I have control	★★★	Parents/team feeling disappointed	★★★
Option #3				

Which option do you prefer? ☒ #1 ☐ #2 ☐ #3 ☐ Unsure

(O'Connor, Stacey, & Jacobson, 2015)

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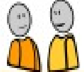


Support

Who else is involved?	Family		Psychiatrist		Treatment Team	
Which option do they prefer?	Option 1		Option 1		Option 1	
Is this person pressuring you?	☒ Yes	☐ No	☒ Yes	☐ No	☐ Yes	☒ No
How can they support you?	Listen to my reasons		Work to find the right balance		Help me talk to psychiatrist	

What role do you prefer in making the choice?

- ☐ Share the decision with...
- ☒ Decide myself after hearing views of...
- ☐ Someone else decides...

Who? Parents and psychiatrist

❸ Identify your decision making needs.

Knowledge	Do you know the benefits and risks of each option?	☒ Yes	☐ No
Values	Are you clear about which benefits and risks matter most to you?	☒ Yes	☐ No
Support	Do you have enough support and advice to make a choice?	☒ Yes	☐ No
Certainty	Do you feel sure about the best choice for you?	☐ Yes	☒ No

The SURE Test © 2008 O'Connor & Légaré.

People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps two ❷ and four ❹ that focus on your needs.

❹ Plan the next steps based on your needs.

Decision making needs ✓ **Things you would like to try**

Knowledge

If you feel you do NOT have enough facts

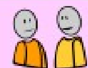
- ☒ Find out more about the options and the chances of the benefits and risks.
- ☒ List your questions.
- ☒ List where to find the answers (e.g. library, health professionals, counsellors):

Psychiatrist

Values

If you are NOT sure which benefits and risks matter most to you

- ☐ Review the stars in the balance scale to see what matters most to you.
- ☐ Find people who know what it is like to experience the benefits and risks.
- ☐ Talk to others who have made the decision.
- ☐ Read stories of what mattered most to others.
- ☐ Discuss with others what mattered most to you.



Support

If you feel you do NOT have enough support

- ☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends).
- ☐ Find help to support your choice (e.g. funds, transport, child care).

If you feel PRESSURE from others to make a specific choice

- ☐ Focus on the opinions of others who matter most.
- ☐ Share your guide with others.
- ☐ Ask others to complete this guide. Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, consider the other person's opinion. Take turns to listen to what the other person says matters most to them.
- ☐ Find a neutral person to help you and others involved.

Other factors making the decision DIFFICULT

I am comfortable with my decision but I wish that I could feel less numb

List anything else you need:

To find out more information about how I can feel more like myself and not so medicated.

(O'Connor, Stacey, & Jacobson, 2015)

TOOL FOR IDENTIFYING THE "WHO"

- **Ottawa Personal Decision-Making Guide**
  - https://decisionaid.ohri.ca/docs/das/OPDG.pdf
  - https://decisionaid.ohri.ca/opdg_video.html
  - For additional information on patient decision aids from the Ottawa Hospital and Research Institute, including a decision guide for two people, please visit the online resources listed at https://decisionaid.ohri.ca/decguide.html

(O'Connor, Stacey, & Jacobson, 2015)

STEP 1:
IDENTIFYING THE "**WHO**": CONSIDERATIONS

- Once the individual has identified members of the family system they could potentially invite to participate:
  - Discuss the possibility that the identified member(s) of the family system may decline to participate at this time
    - If declined:
      - Process the disappointment / frustration with the individual
      - Practice perspective-taking regarding why they may have declined

STEP 1:
IDENTIFYING THE "WHO": CONSIDERATIONS

- **Before bringing systems together, ensure:**
  - Appropriate releases are signed
  - No current POs or DV history

THE HOW

STEP 2:
IDENTIFYING THE "**HOW**": EXTENDING AN INVITATION

- Decide *who* will invite the identified member(s) of the family system
  - Share that the individual *identified them as someone meaningful* in their life
  - Discuss how being engaged / involved can lead to improved outcomes *for all involved*
  - Emphasize that there is **HOPE** – and *recovery is the expectation*, not the exception
  - Let them know that their experiences, observations, expertise, perspectives are **invaluable**

STEP 2:
IDENTIFYING THE "**HOW**": EXTENDING AN INVITATION

- Being involved allows for relationship – and therefore direct access – to providers / care team
- Help family system to understand they have a role in treatment and recovery – and they have a seat at the "table"
  - What their role is / could be
  - That their role will change / look different over time

STEP 2:
IDENTIFYING THE "**HOW**": CONSIDERATIONS

- Explore what involvement might look like
  - Benefits and potential undesirable consequences
  - Discuss their hesitations and concerns – normalize and validate
  - Do benefits outweigh potential risks?

STEP 2:
IDENTIFYING THE "**HOW**": CONSIDERATIONS

- Should they choose to move forward, prepare should things not go as anticipated
- *Note: If they feel the timing is not right for them to participate, encourage them to call the individual *to share* life updates *and to ask* for (reasonable, appropriate) help and support

TOOL FOR PREPARING AND INVITING: REORDER

- **Recovery Oriented Decisions for Relative's Support (REORDER)**[1]
  - Client-centered
  - Recovery-oriented approach to optimize involvement of others
  - Strategy to introduce the idea of engaging others in treatment
    - Encourages *consideration* of involving others in treatment
  - Increase likelihood that involved others will participate *constructively* in treatment and recovery

([1]Glynn, Cohen, Drapalski, & Dixon, 2014)

TOOL FOR PREPARING AND INVITING: REORDER

- Structured / manualized
- Basic principles of Motivational Interviewing and Shared Decision-Making
- Provider-friendly – use of rehearsals; sample scripts and agendas
- Brief / time-limited intervention
  - 2 phases, 6 sessions total:
    - 3 sessions with individual
    - 3 sessions with member(s) of family system (sessions 5 and 6 can include the individual)

([1]Glynn, Cohen, Drapalski, & Dixon, 2014)

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STEP 2:
IDENTIFYING THE "**HOW**": IF SYSTEM AGREES TO PARTICIPATE

- During information gathering, if the family system struggles with remembering recent or historical events / observations, consider use of:
  - Timeline
  - Tracking

TIMELINE AND TRACKING

- Walking them through a **detailed timeline**
  - Major life events or moments (both positive and negative) that had an impact on the individual
  - Start with how they got to current treatment -> ~6 months prior to treatment -> when they first noticed changes -> childhood overview -> back to current day -> discuss hopes for future
- **Encouraging them to track** *desirable and undesirable* behaviors and symptoms

STEP 2:
IDENTIFYING THE "**HOW**": IF SYSTEM AGREES TO PARTICIPATE

- Get their perspective on their relationship with the individual
  - Are they satisfied with the relationship?
  - What is their communication like?
  - What do disagreements between them look like?
  - Has it ever gotten physical? Any history of DV or PO? **(DUE DILIGENCE)**
  - Keep an ear out for high levels of expressed emotion (criticism, hostility, emotional over-involvement)[1]

([1]Tompson et al., 2000)

THE WHEN

STEP 3:
IDENTIFYING THE "WHEN"

- Identify the opportunities!
  - Invite family systems to participate from the beginning of services, when possible
  - Reach out with a positive update or a question where you could benefit from their expertise and experience
- Strike while iron is hot
  - Check in with how they (themselves) are doing following a crisis or during times of high stress, if the individual is hospitalized, if the individual will be discharged soon (help to prepare them and discuss any concerns), to offer resources and support, etc.

STEP 3:
IDENTIFYING THE "**WHEN**"

- Initial call to schedule for services
- Intake
- Regularly scheduled check-ins with family system
- Calls with positive updates
- Major events or changes within the family system
- Responsibility of all providers / team members
- Crisis / hospitalization
- Others?

THE WHERE

STEP 4:
IDENTIFYING THE "**WHERE**"

- Some members of family systems may not have had previous involvement at a MH agency
  - Is the lobby / waiting room inviting? Calming? Highlights diverse groups and different ages (photos, posters, resource materials)?
- Consider – and be mindful of – the space
  - Find a calming and comfortable space for meetings
  - Ensure the space is large enough to accommodate all those participating
- Is there a virtual option if in-person is not feasible (e.g., childcare, transportation, work schedules)?

SUMMARY OF ENGAGING FAMILY SYSTEMS

4 Steps:

- Identify the:
  - "Who"
  - "How"
  - "When"
  - "Where"

Tools:

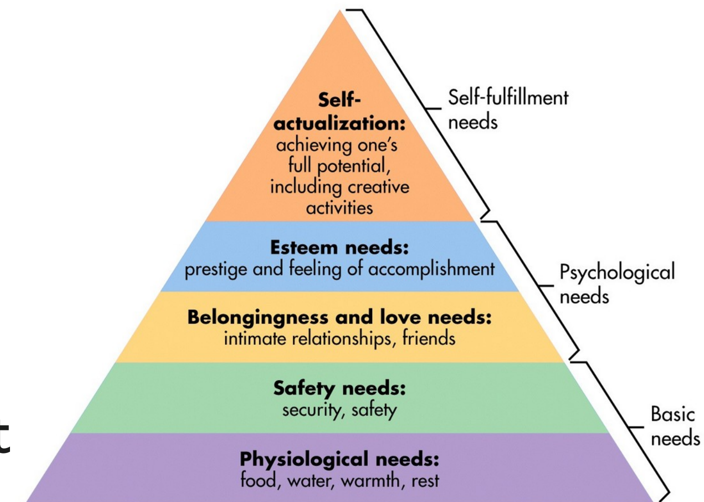
- Genogram
- Ottawa Personal Decision Guide
- REORDER

FAMILY SYSTEMS: NEEDS, WANTS, HOPES, & GOALS

THE WHAT

STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: NEEDS**
  - Of the family system and of each individual within the system
  - Vary over time
  - Guide the content of educational sessions
    - What they already know about MH, treatment, etc.
  - Practical / basic
    - When not met, very difficult to engage in treatment
    - May need to start here first



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(Maslow, 1943)

STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: READINESS**
  - To engage with the individual and the team – and to what degree
    - Caution to not over-tax – consider how dual roles could increase stress and tension of members of the family system
    - Balancing roles and responsibilities
  - For what information, how much information, and at what pace
    - Caution not to overwhelm
  - System's capacity, capability, energy, openness

STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: HOPES**
  - Understand their hopes to understand their fears for the future
  - Share stories of recovery
  - Explore their values to assist with defining and achieving goals (*meeting goals give hope*)

STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: GOALS**
  - Start with a *discussion of values* and what is meaningful to them (as individuals and as a family system)
  - Consider use of **Personal Goals and Values Card Sorting Task**[1]
    - Sort printable cards into Not Important, Important, Very Important
    - Identify top ~5 Very Important cards
    - Ask open-ended questions about what made them select this card, what it means to them personally, how it relates to target goal / behavior, etc.
    - https://casaa.unm.edu/assets/inst/values-card-sorting-task-for-individuals-with-schizophrenia.pdf
    - [For a *Personal Values Card Sort for Kids* (by Aria Fiat): https://blog.cincinnatichildrens.org/wp-content/uploads/2022/12/Values-Card-Sort-for-Kids.pdf]

([1]Moyers & Martino, 2006)

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STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: GOALS**
  - If struggling to align goals:
    - All can agree the overarching / ultimate / primary goal is:
      - ❑ The individual *and* the family system are happy, healthy, and living their best lives
      - ❑ Need to maximize the opportunity for success and optimal performance – providers / team can assist with this!

STEP 1:
IDENTIFYING THE "**WHAT**"

- **Assess the system: WANTS**
  - To be heard, understood, part of team, of help
  - Respect
  - Transparency and inclusion
  - Support and hope
  - Guidance
  - Resources and how to access them
  - Educational information and skill-building

MEETING THEIR NEEDS

STEP 2:
BEGIN BY UNDERSTANDING PERSPECTIVES

- Discuss with individual and members of family system their perspectives:
  - "Family"
  - Family system structure (hierarchy, alliances)
  - View their role in system – and satisfaction with this
  - View others' roles in system – and satisfaction with this
  - Contributions of all members of family system
  - What they would change
  - Ideal family system – and how this compares to actual / current family system

(Weisman de Mamani et al., 2014)

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS

- Offer **support and hope**
- Provide **educational information:**
  - Practical information
  - Values, goals, and strengths
  - Illness information (including positive, negative, and cognitive symptoms)
  - Treatment options
  - Recovery

(Hupp, 2021)

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS: INFORMATION

- Provide **educational information:**
  - Anosognosia
  - Early warning signs, triggers / cues, and how to address them to prevent a relapse or crisis
  - What to do should a crisis situation occur
  - Psychiatric Advance Directives
  - Substance use and its impact on mental health

(Hupp, 2021)

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS: SKILLS

- **Skill-building:**
  - Communication (including the importance of language and decreasing expressed emotion)
  - Basic problem-solving
  - Stress management and coping
  - How to be appropriately supportive of the individual
    - Give hope, offer praise, encourage and support goals, minimize stressors in the environment, model desired behaviors, show respect and understanding
  - **Preparing for appointments**

HELPING FAMILY SYSTEMS PREPARE FOR APPOINTMENTS

- Prepare an **agenda** – updates and highest priorities at top
- **Organize** thoughts / concerns – be concise
- Be **specific** with questions, concerns, requested information, updates / feedback (consider utilizing a worksheet that tracks symptoms, desired behaviors, undesirable behaviors)
- **Write** down requests / questions and bring them to appointment
- **Practice** – consider use of role plays
- **Take notes** during the appointment
- Have a **trusted member** of family system **join** appointment

(Deegan, n.d.)

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS: RESOURCES

- **Resources:**
  - Practical (think Maslow)
  - Org / agency, local / community, state (e.g., National Alliance on Mental Illness)
  - Provide information on how to access the resources
  - Assistance with navigating the MH system (and other systems, where applicable)

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS: TRANSPARENCY, SUPPORT, INCLUSION

- **Transparency and inclusion:**
  - Providers are encouraged to share the skills they are working on with the individual so the skills can be reinforced by the family system between sessions
- **Support:**
  - Support for self, individual, family system (e.g., National Alliance on Mental Illness)
  - In their efforts to support their loved one
  - Emphasize the importance of self-care

STEP 2:
MEETING THE FAMILY SYSTEM'S NEEDS: GUIDANCE

- **Guidance:**
  - May not know what they do not know
  - May not know what they need
  - Provide them with a roadmap and be their guide

ROADMAP FOR ENGAGING LOVED ONES

WHERE...

- Where do **WE** go from here/next steps?

WHAT

- What are their needs and how can the team assist?
- VALUE CARDS; OTTAWA GUIDES

WHEN

- When did things begin to change? Walk the team through their journey thus far.
- TIMELINE

HOW

- How are things going (in various aspects of each of their lives)?
- How might the team be able to help?

WHO

- Who are the major players?
- Who should be involved – either now or in the future?
- GENOGRAM

WHY

START HERE

- Do they know why they are here

  Is everyone on the same page?

STEP 3:
MAINTAINING ENGAGEMENT

- Over time, continue to build rapport and trust by:
  - Demonstrating genuine **care, concern, and curiosity** – and an appreciation for what they do and their willingness to be part of the team
  - Being **consistent**
  - **Following through**
  - **Checking in** on them and how they (themselves) are doing
  - **Responding** to identified concerns or needs

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STEP 3:
MAINTAINING ENGAGEMENT

- **Call with good news** / positive updates!
- **Encourage family system to reach out** for help and support – and to call to share important updates, frustrations, and successes

SUMMARY OF FAMILY SYSTEM: NEEDS, WANTS, HOPES, AND GOALS

3 Steps:

- Identify the "what" by assessing the system
- Considerations for meeting the system's needs
- Maintaining engagement

Tools:

- Personal Goals and Values Card Sorting Task
- Roadmap

CLOSING THOUGHTS

CLOSING THOUGHTS

- **Following up and following through** can go a long way when connecting with family systems
- **Support the members of the family system**…they have each been on their own journey
- **Be a guide** by providing family systems with a roadmap
- The vast majority of the time, family systems are **well-intentioned** and have the individual's best interests at heart
    - Show appreciation for the efforts of well-meaning family systems

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CLOSING THOUGHTS

- If the family system does not agree with the diagnosis or treatment, but they will still speak with the provider / team or drive the individual to appointments…
  - It is likely that they are experiencing some internal **ambivalence**…but they are **still supporting** the individual in treatment
    - This speaks volumes!
    - Opportunity to find the **common ground** – or use the shared goal of individual and system wellness – and build from there

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COMMON OCCURRENCES

- Divorce / separation
- Parent of the individual has MI
- Child of the individual has MI
- Sibling of the individual has MI
- Individual has limited support
- Family system has limited resources
- Distrust of providers
- Anosognosia
- Stigma
- Discord or disagreement within family system
- Difficult family dynamics
- Limited or inconsistent engagement

COMMON CHALLENGING SCENARIOS

- How (and how much to) involve parents of a young adult
- Family system:
  - Does not want to be involved at this time
  - Has never been responsive or engaged
  - Has disengaged from the individual and/or provider / team
  - Is very engaged and driving treatment
  - Is struggling as a whole, which is negatively impacting the individual
  - Exhibiting complex family dynamics
  - Appears to be "enabling" the individual

COMMON CHALLENGING SCENARIOS

- It feels as though the family system is working against treatment recommendations
  - System does not agree with / accept diagnosis or illness
    - Believes the symptoms have a different cause
  - System does not want the individual on medication **vs** believe medication is the only answer
  - System is internally divided – disagreement re: illness, treatment recommendations, beliefs / values, etc.
  - System only attends medication appointments

Together, we can ensure that family systems work does not become a lost art…

ADDITIONAL RESOURCES

- National Alliance on Mental Illness (NAMI) – national, state, local
  https://www.nami.org
- Students with Psychosis https://sws.ngo
- Strong365 https://strong365.org
- CureSZ https://curesz.org
- SAMHSA's National Training and Technical Assistance Center for Early Serious Mental Illness
  - Screening, assessment, and resources for individuals and families
    https://www.samhsa.gov/technical-assistance/esmi-tta/providers/identification-screening-assessment

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NEOMED / BeST CENTER PROJECT ECHOs

- View recorded informational didactics from Project ECHOs www.youtube.com/@NEOMEDProjectECHO
    - First Episode Psychosis Project ECHO
    - For anyone working professionally in mental health (including substance use treatment), physical health, and/or integrated mental and physical healthcare
    - For individuals living with mental health conditions
    - For family members and other natural supports

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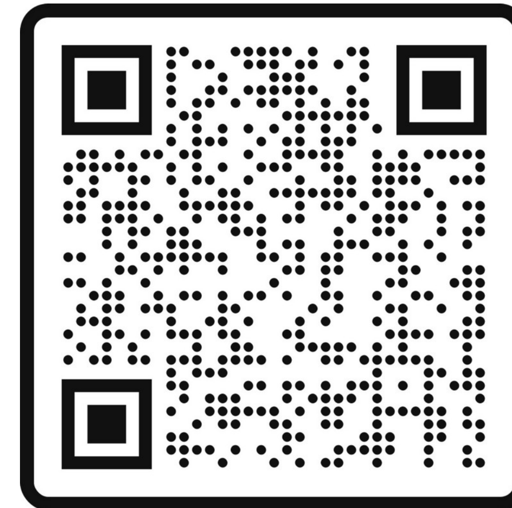

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  [For more information on CIT-S and free access to handouts, see Weisman de Mamani, A., McLaughlin, M., Altamirano, O., Lopez, D., & Ahmad, S. (2021). *Culturally informed therapy for schizophrenia: A family-focused cognitive behavioral approach – Clinician guide*. Oxford University Press.]

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