Canadian
Consortium for
**Early Intervention
in Psychosis**

Family-Centred Practice

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Disclosures

Srividya N. Iyer, Ph.D

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Laurie Roeszler

- None

Acknowledgment and Gratitude

The Douglas Hospital Research Centre is located on unceded Indigenous lands. The Kanien’kehá:ka Nation is recognized as the custodians of these lands and waters. Tiohtiá:ke, commonly known as Montreal, is historically known as a gathering place for many First Nations. Today, it is home to a diverse population of Indigenous and other peoples. We respect the continued connections with the past, present, and future in our ongoing relationships with Indigenous and other peoples within the Montreal community.

Le Centre de recherche Douglas est située en territoire autochtone, lequel n’a jamais été cédé. Nous reconnaissons la nation Kanien'kehá: ka comme gardienne des terres et des eaux sur lesquelles nous nous réunissons aujourd'hui. Tiohtiá:ke / Montréal est historiquement connu comme un lieu de rassemblement pour de nombreuses Premières Nations, et aujourd'hui, une population autochtone diversifiée, ainsi que d'autres peuples, y résident. C’est dans le respect des liens avec le passé, le présent et l'avenir que nous reconnaissons les relations continues entre les Peuples Autochtones et autres personnes de la communauté montréalaise.

Outline

- Why families?
- How are we doing with respect to family involvement?
- Barriers to family involvement
- How can we be family-centred?
    - What do guidelines recommend?
    - Menu of options
- Discussion

Why Families?

Familia Supra Omnia

As the creeper that girdles the tree trunk, the law runneth forward and back;
For the strength of the pack is the wolf, and the strength of the wolf is the pack.

—Rudyard Kipling, *The Jungle Book*

Broad, inclusive definition of family

Why Families?

- Families structurally different, but often serve similar functions
- Patients in EI are young; many live with or have regular contact with families (Perälä et al., 2007).
- Families often initiate help-seeking (Claxton, Onwumere, & Fornells-Ambrojo, 2017)
- Families already provide diverse supports (emotional, instrumental, treatment-related)

Why Families?

- **Compelling and consistent evidence**
  - Involving families improves service engagement, medication adherence, social & work-study outcomes, relapse reduction, subjective recovery, mortality (Camacho-Gomez & Castellvi, 2020; Leclerc et al., 2015; Claxton et al., 2017; Boydell et al, 2010; Windell et al., 2015; Oluwoye et al., 2020; Ran et al., 2016; Reininghaus et al., 2014; Conus et al., 2010; Iyer et al., 2020)
  - Family interventions reduce relapse for 6-12 months to 2 years, compared to treatment as usual and even compared to other treatments (Pilling et al., 2002; Rodolico et al., 2022)

Why Families?

- Psychosis profoundly impacts families (Bibou-Nakou et al, 1997; Jungbauer & Angermeyer, 2002; Jungbaueret al., 2004; Ferrari et al., 2015; Boydell et al., 2014; McCann et al, 2009).
- Families not just as instrumental in securing better outcomes for patients (Levasseur et al., 2018)
- Families should be helped not only in better supporting their young family member with psychosis, but also with their own needs (Levasseur et al., 2018)

How are we doing with involving families?

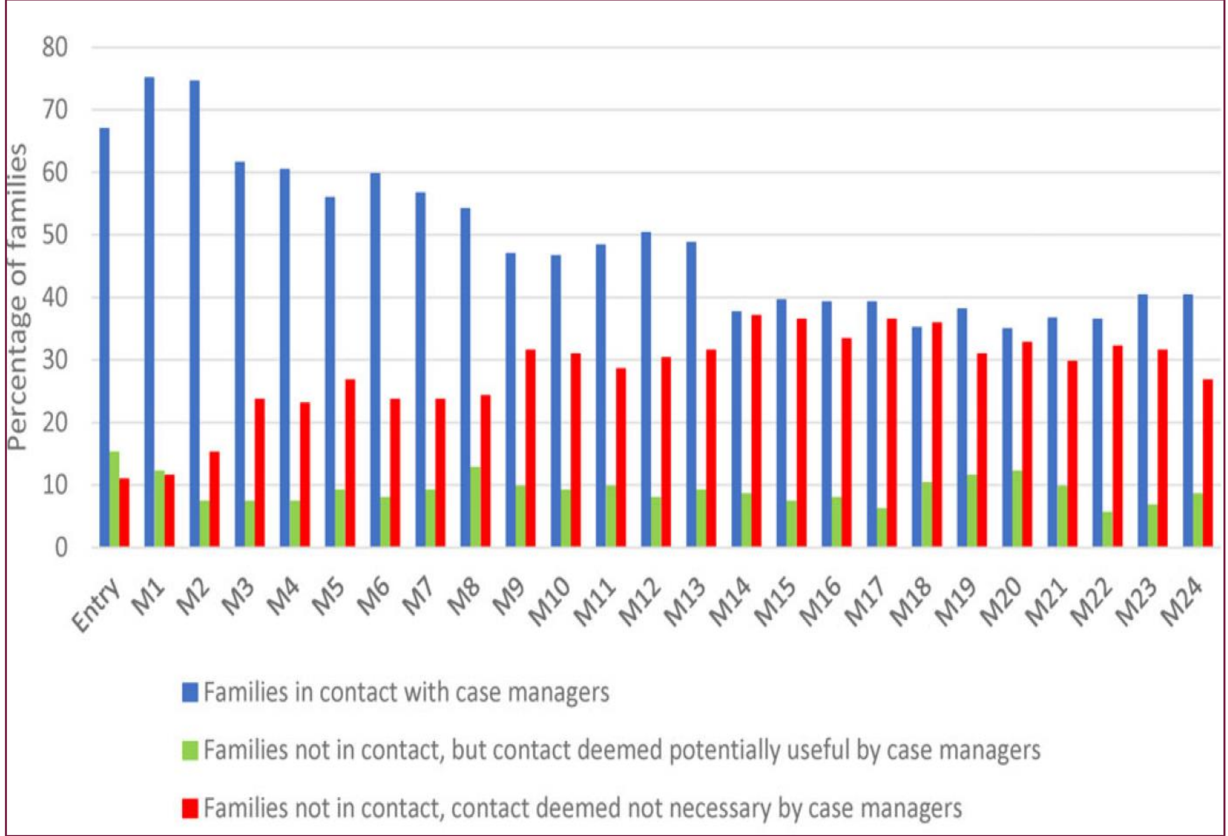
Lots Going Well

- EI is generally oriented to involve families, as reflected in all Canadian guidelines (Martin et al., under review)
- Families of most patients have some contact/involvement with treating team (Bertulies-Esposito et al., 2020; data from our learning health system)
- Nearly all EI services offer some form of family psychoeducation (Nolin et al., 2016; Bertulies-Esposito et al., 2020; data from our learning health system)

Families not in Contact Throughout Treatment

- Most guidelines recommend at least monthly contact throughout
- Family and treatment contact for an average of 11/24 months; Clinicians saw contact as “not necessary” in months with no contact (Iyer et al., 2020)
- High early on, declines later (Iyer et al., 2020;

Data from our learning health system)



Iyer et al., 2020

How are we doing?

- Uptake of family interventions (including psychoeducation) not always monitored & not always high (Iyer et al., 2011)
- Inconsistent implementation of family interventions across clinics (Bucci et al., 2016; Eassom et al., 2016; Nolin et al., 2016; Bertulies-Esposito et al., 2020)
- Limited deployment of family peer support (e.g., 1/11 programs in our Quebec learning health system)
- U.S. data: racial-ethnic differences noted in the uptake of family interventions such as psychoeducation (Oluwoye et al., 2018)

Families Desire Consistent Involvement and Sometimes Feel Excluded

- “As a parent, I may try to contact the case manager say, “Oh, this is what has happened because we haven't had an appointment recently.” I don't reach the case manager, I reach a voicemail or I send an email... I'm sending because there's a crisis or I'm sending to give an update or to ask a question about something. And then the case manager tries to reach be 3-4-5 days later but that crisis is over…”

- “So that is how I used to function because I got frustrated. And sometimes there are times that depending on the divide that you feel, you feel like, “Oh, maybe I'm being too much. Maybe I’m overly interested in this and I'm asking too much. Maybe I'm getting too much. I should keep quiet. And this is because of how they make you feel. If they make you feel that way, then sometimes it's hard for the parent to be the one trying to contact …”

Family members in Montreal, focus group discussion (Martin et al., in preparation)

Barriers to Family Involvement

History and Context

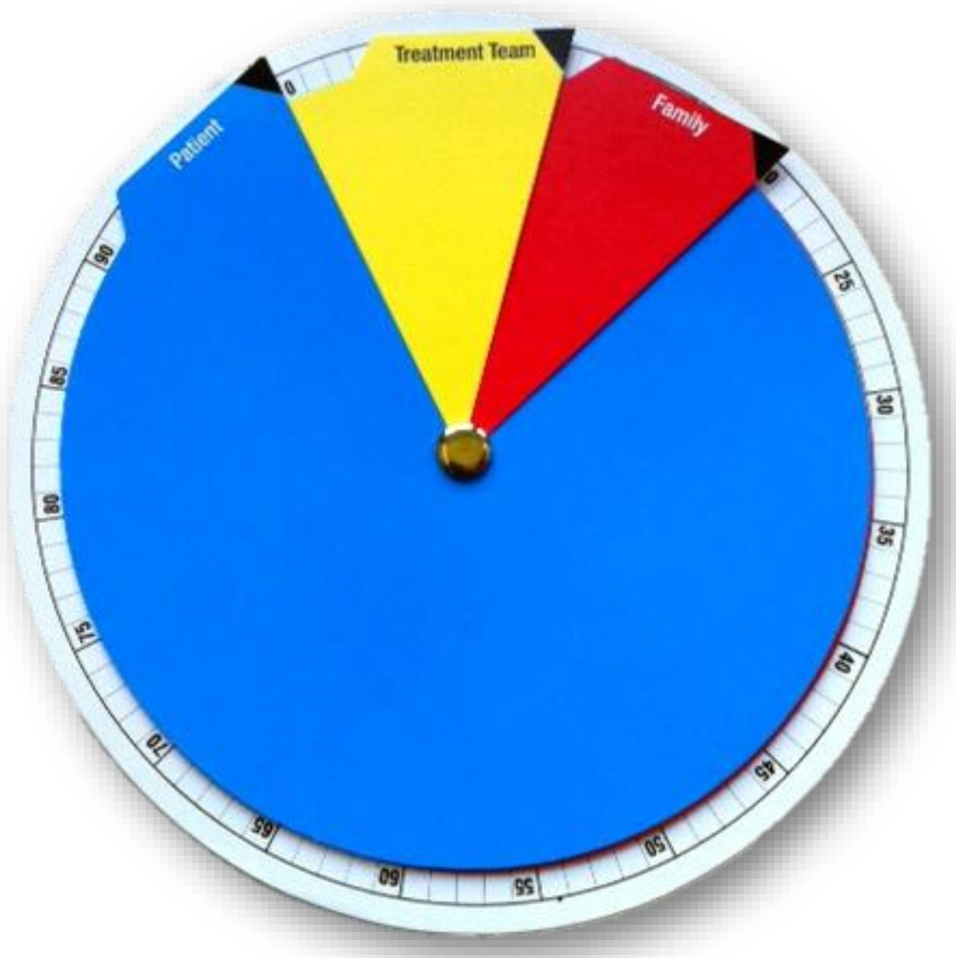
Blame and exclusion (1930-1940)

Expressed Emotions (1950 onwards)

Partnership and advocacy but within larger structures… (1990 onwards)

Perceptions about Roles and Responsibilities

- More and consistent contact with families in Chennai (Iyer et al., 2020)
- Do stakeholder groups in Chennai and Montreal distribute responsibility differently?
- **Montreal:** Patients > Treatment team > Family (substantially lower)
- **Chennai:** Families > Treatment team = patients



Tool created by Iyer (2012); Tool paper Iyer et al. 2020

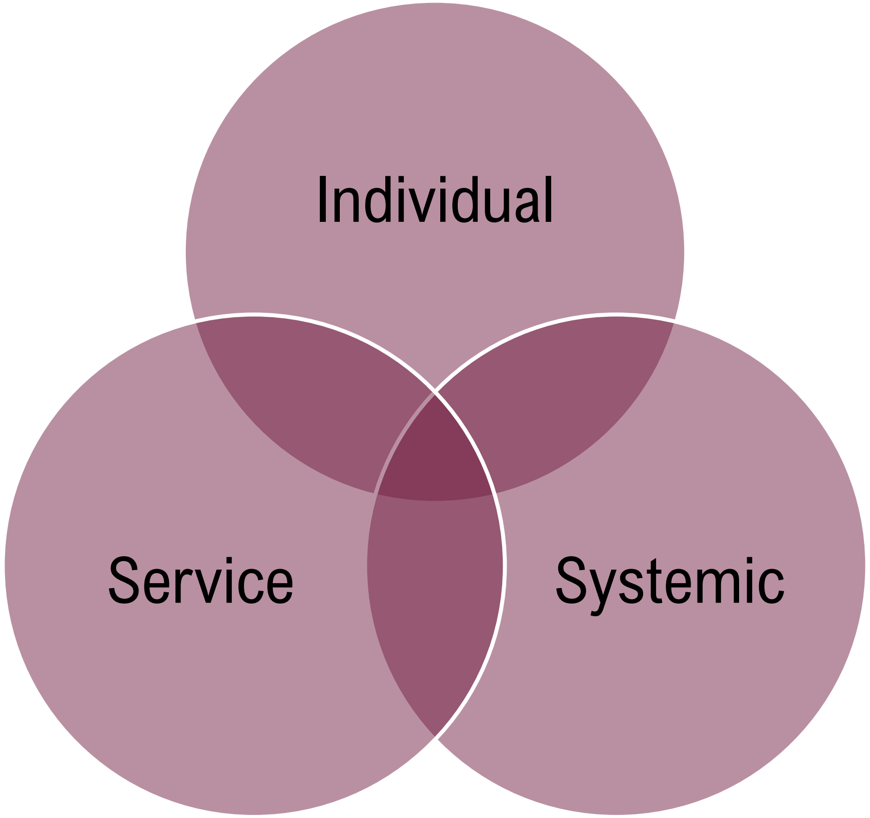
Perceptions about Roles and Responsibilities

Chennai: Primacy of family	Montreal: Primacy of individual
“It gets consumed, I think, by the family, becomes a family issue when somebody has an illness.”	**“I think the person himself should be responsible…you have to do some effort on your own.”**
“The cultural system is such that it will absorb any of the problems that the individual has.”	“You’re the first person who should take ownership of your recovery.”

Barriers to Family Involvement in Care

1. Confidentiality and privacy considerations among **patients**; history of strained relationship between patients and their families

2. Lack of adequate skills, high workload, and reimbursement concerns among **clinicians**



3. **Families**
   a. Interventions offered too soon or too late
   b. high unmet needs and burden
   c. perception that external support is unnecessary
   d. other home or work commitments, inconvenient timings and locations, long duration of interventions
   e. preference for individual as opposed to group formats
   f. perception that the content of interventions is not relevant

Selick et al., 2017, Eassom et al., 2014

How can we be more family-centered?

Menu of options: “Family work is client work”

- **Communication with treating team and participation in decision-making (as far as possible)**
- Being able to connect with EI team to figure out how to get help for a family member with psychosis
- Support by a family peer navigator in the initial screening phases
- Involvement in discharge planning and navigating post-EI
- Support for tricky issues like housing, substance use
- Self-care and negotiating loss
- Reframing “difficult” families, e.g.., “what skills can they be supported with”?
- Family interventions
  - Family psychoeducation
    - Important that this is delivered by clinical teams, and not just family peer support providers
  - Family Connections
  - Cognitive Adaptation Training for families
  - Family peer support

Young People as Embedded

- Families/carers/networks as integral
- Innovative opportunities in thinking beyond “individuals” as exclusive units of our attention
    - Patient-centred # individual-centred
    - “Our program serves young people with psychosis **and their families/carers**” versus “Our program serves young people with psychosis” in our consent form!

Simple is Good

- **Two best-bets**
  - **Track and maintain contact** (yes/no) between family and treatment team throughout treatment. Reduces service disengagement and improves other outcomes (Iyer et al., 2020)
  - **Family psychoeducation**
    - 2022 meta-analysis: family psychoeducation alone reduced the relapse rate significantly when compared with treatment as usual (10% vs 37%), and to a larger extent than more complex interventions (10% vs 17%) such as systemic family therapies, family psychoeducation combined with behavioural skills training, or family psychoeducation combined with interventions addressing the emotional climate of the family (Rodolico et al., 2022)

Equity, Diversity and Inclusion (EDI)

- Notions about self and family, as well as psychosis and treatment, are shaped by culture and context

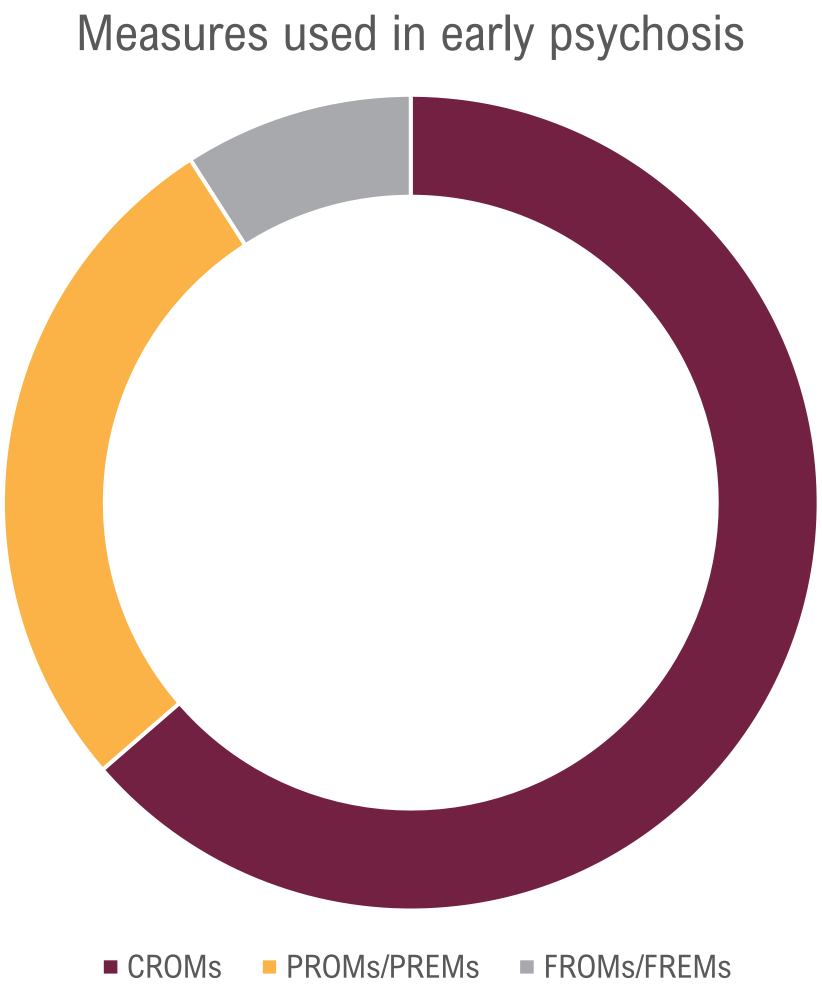
- How do we best integrate EDI considerations in being family-centred?

Recommendations from Guidelines

- Involvement in treatment planning & shared decision-making
- Family peer support
- Family education/ psychoeducation
- Family communication/contact
- Psychosocial interventions (e.g., family therapy)
- Involvement in transition/ discharge planning
- In relapse prevention
- Involvement around inpatient care/hospitalization
- **Description of service/ program given to families**
- **Linking families with other supports in community**
- **Family involvement in program/ service improvement**
- **Community outreach/referrals**
- **Assessing family-focused and family-reported outcomes (e.g., family satisfaction, needs)**

Martin et al., in preparation

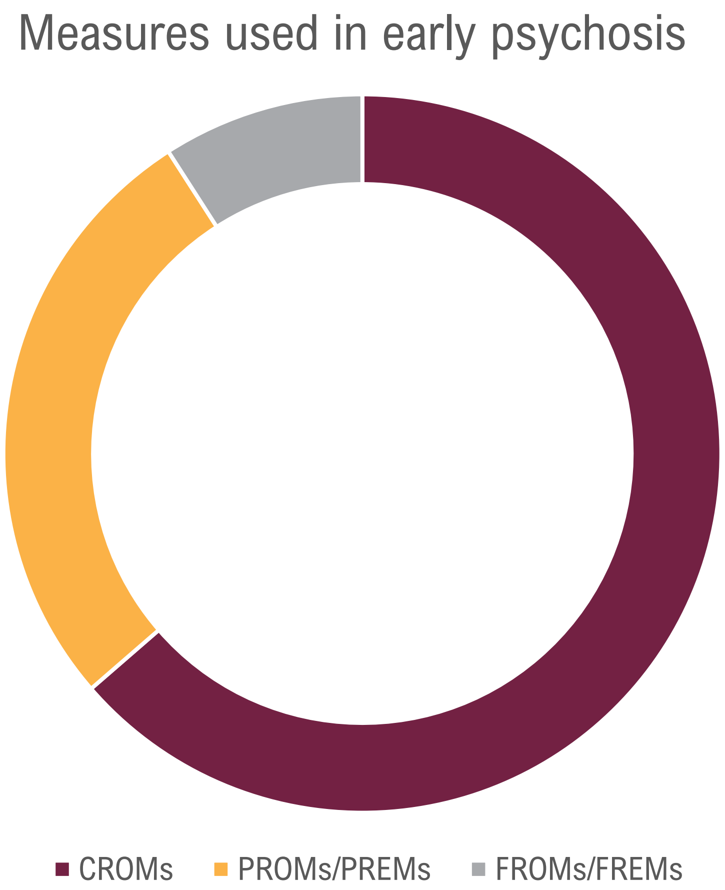
Learning Health Systems & Measurement-Based Care



Legend
CROMs – Clinician-Reported Outcome Measures | PROMs – Patient-Reported Outcome Measures | PREMs – Patient-Reported Experience Measures
FROMs – Family-Reported Outcome Measures | FREMs – Family-Reported Experience Measures

Ferrari et al., 2022

Learning Health Systems & Measurement-Based Care


Measures used in early psychosis


ORIGINAL ARTICLE

WILEY

Show me you care: A patient- and family-reported measure of care experiences in early psychosis services

Srividya N. Iyer[1,2] | Aarati Taksal[2] | Ashok Malla[1,2] | Helen Martin[1,2] | Mary Anne Levasseur[3] | Megan A. Pope[2] | Thara Rangaswamy[4] | Padmavati Ramachandran[4] | Greeshma Mohan[4]

Legend
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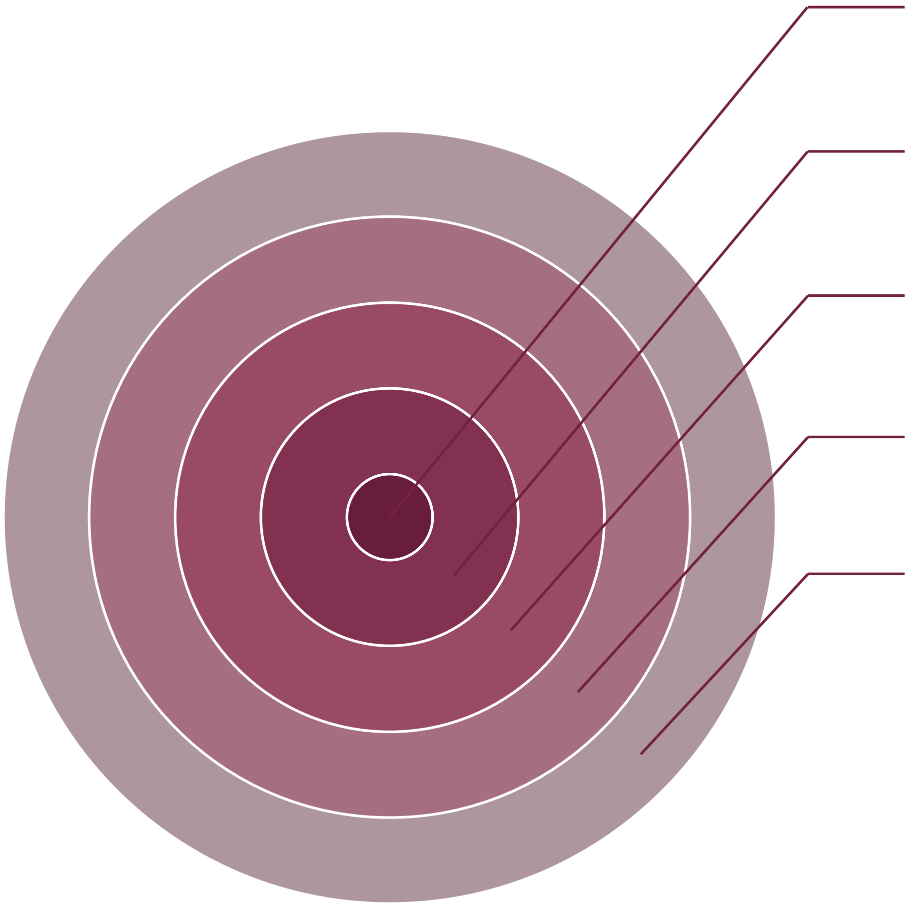
Holistic Family-Centered Practices



Families **as care providers** (instrumental, and emotional support)

Families **as care recipients** (psychoeducation, family peer support groups, multi-family group therapy, crisis intervention)

Families **as equal partners** in shared decision making + treatment (what treatment, when, in what manner)

Families **as advocates** (rights, preferences, and needs of patients and themselves)

Families **as partners in services** design, delivery, and research (co-designing services, research and knowledge dissemination)

Discussion

- Share one family-focused practice that you or your program use that you are proud of
- Share positive experiences you have had as a family member with a treating team so others can learn

Q & A

To submit a question please use the “Ask A Question” button on the top right of your screen.

Ask A Question

Laurie Roeszler can be reached by emailing laurie.roeszler88@gmail.com

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