

# INVOLVING FAMILIES AND CARERS IN YOUTH MENTAL HEALTH

*Collaborating with service providers across cultures and  
promoting family peer support*

19<sup>th</sup> Canadian Collaborative Mental Health Care Conference  
June 1-2, 2018



**ACCESS** OPEN MINDS  
ESPRITS OUVERTS

Family and Carers / Familles et aidants

SPOR network funded by the Canadian Institutes of Health  
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Strategy for Patient-Oriented Research

**SPOR**

Putting Patients First 



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# PRESENTER DISCLOSURE

- **Presenters:** Mary Anne Levasseur, Srividya Iyer, Ph.D and Manuela Ferrari, Ph.D

- **Relationships with commercial interests:** none

- **Grants/Research Support:**

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- **Speakers Bureau/Honoraria:** none

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# Learning Objectives

- ▶ Identify barriers that deter family/carer involvement in caring for affected youth
- ▶ Determine learning needs of families/carers and service providers in collaborating to care for affected youth
- ▶ Develop family/carer capacity to receive support, education and resources in caring for their youth through family peer support

# Agenda

- ▶ **CONTEXT: ACCESS Open Minds Network**
- ▶ **FOCUS: Involving families/carers in youth mental health**
- ▶ **ACTIVITY 1 - Barriers**
- ▶ **ACTIVITY 2 - Collaboration**
- ▶ **Family Peer Support**
- ▶ **Discussion**
- ▶ **What we learned**

# ACCESS Open Minds is:

A national research and evaluation network transforming youth mental healthcare across Canada through:



Generating new  
knowledge &  
evidence



Creating a pan -  
Canadian  
network



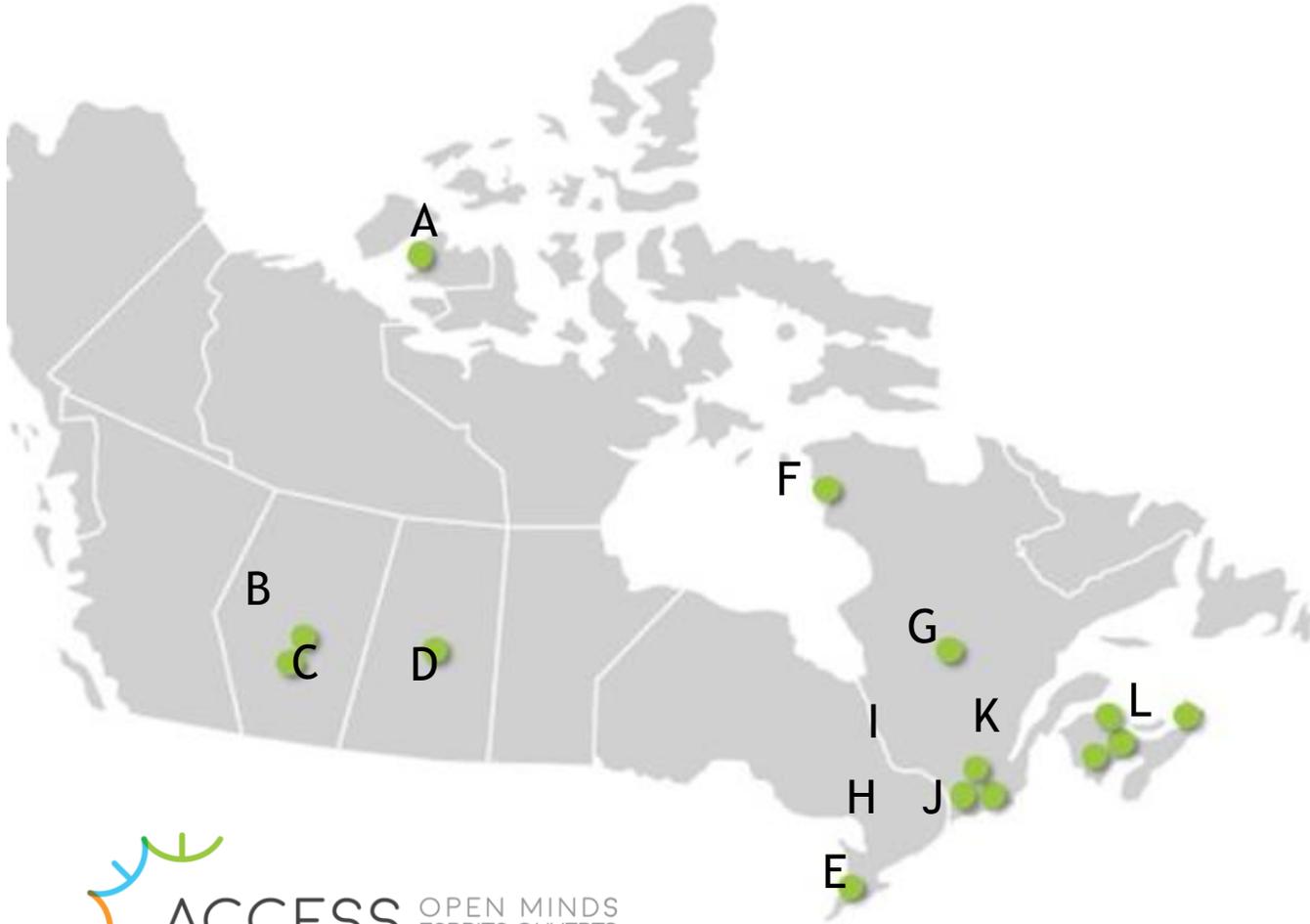
Providing high  
quality mental  
health care &  
services



Involving young people  
& their families/carers



# ACCESS Open Minds Sites



- A:** Ulukhaktok, NT
- B:** Edmonton, AB
- C:** University of Alberta, AB
- D:** Sturgeon Lake First Nation, SK
- E:** Chatham-Kent, ON
- F:** Puvirnituk, QC
- G:** Cree Nation of Mistissini, QC
- H:** Dorval-Lachine-LaSalle, QC
- I:** Parc-Extension, QC
- J:** RIPAJ-Montréal, QC
- K:** Province of New Brunswick (P.E.R Saint John, Péninsule Acadienne, Elsipogtog First Nation)
- L:** Eskasoni First Nation, NS

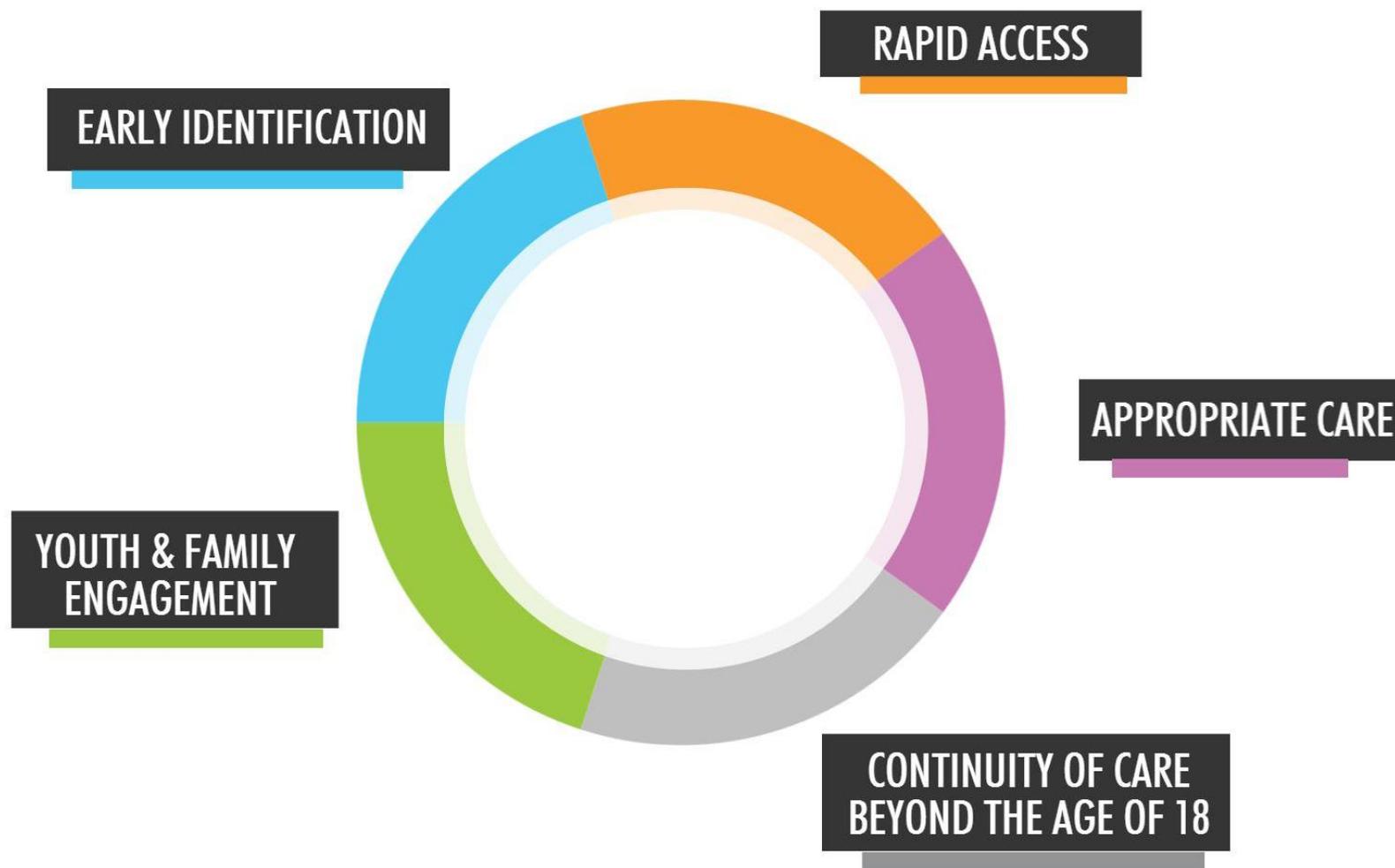


# Project Components

- ▶ **Service Planning**
- ▶ **Service Delivery**
- ▶ **Service & Program Evaluation**
- ▶ **Research & Advancing Knowledge**



# Service Planning: Transformation Based on Five Core Elements



# Youth and Family/Carer Engagement



# ACCESS Family and Carers Council

## *Families helping families: Mission*

- ▶ Helping families/carers connect with each other
- ▶ Providing families/carers with practical tools and resources in caring for and supporting their youth
- ▶ Sharing stories about lived experience and ideas about self-care

# ACCESS Family and Carers Council

## *Families helping families: Guiding Principles*

- ▶ Information and education
- ▶ Emotional support and self-care
- ▶ A collaborative relationship with service providers
- ▶ Actively involved in the young person's care and recovery

# Family Defined

*“A circle of care and support offering enduring commitment to care for one another related either biologically, emotionally or legally and takes into account those who the “client” identifies as significant to his/her well-being.”*

Ontario Centre of Excellence for Child and Youth Mental Health (2011)

An overarching term (in accordance with the definition adopted by ACCESS Open Minds research project):

*“Acknowledging that the definitions of “family” are constantly changing and complex in our society, we will broaden the definitions to include not just the constituents of a typical nuclear family but others who may be significantly engaged in the lives of youth (extended family; blended family, friends, mentors etc.), and be guided by youth and families in arriving at these definitions.”*

Kirmayer, L., Simpson, C. & Cargo, M. (2003)

# Why is family involvement important in caring for youth with mental health problems?

## Family<sup>3</sup>

- ▶ Is part of a youth's life before youth even reaches the first point of contact with mental health service
- ▶ Assists in finding/gaining access to services in crisis
- ▶ An important resource in the treatment and recovery of youth
- ▶ Offers support to youth in crisis and can positively impact youth mental health outcomes
- ▶ Involvement can mean fewer inpatient admissions, shorter stays, better quality of life<sup>6</sup>

# Why is it important to support the family in caring for their youth?

- ▶ In a better position to support their youth and to cope with the impact of having a family member with a serious mental illness
- ▶ Disengaged families are not part of the treatment and recovery process of their youth - in other words, they are not part of the solution
- ▶ Greater burden on youth to deal with “two teams”; risk increases for youth to become disengaged through failure to attend and non-adherence to treatment, resulting in poorer outcomes
- ▶ Involving families as part of the treating team increases chances of positive outcomes for youth and family recovery

# What does supporting families look like?

## Service providers

- ▶ have basic knowledge and understanding of family work
- ▶ make family engagement a part of clinical practice
- ▶ employ a collaborative approach to engage and involve families in caring for their young person
- ▶ offer family peer support

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## BARRIERS

# Vignette Part 1: Joanne and Paul

Two weeks ago Joanne brought her 19 year old son Paul to the emergency room of the local hospital. For some time Paul has not been his usual self. He no longer associates with friends, is having difficulty keeping up with his courses at college and spends lots of time in his room playing video games. When he does venture out, he seems preoccupied with the neighbours, worried they were watching him all the time. Two weeks ago Paul confided to his mother he wasn't feeling well, that random thoughts were racing through his head all the time and he felt his heart was beating too fast. He wanted to go to the hospital.

Paul was assessed and referred to a psychiatrist and also a case manager. He met with his psychiatrist who later prescribed medication. He also met with his case manager twice. At home Paul is still experiencing considerable difficulty in coping with his symptoms but doesn't want to talk about it. Joanne feels bad for her son and wants to help, but she is not sure what to do.

# Barriers: Activity 1

Break up into small groups to discuss (15 min.)

- ▶ What do you think are some of the barriers that deter families/carers from being involved in caring for their affected youth?
- ▶ What are some of the barriers that deter families/carers from collaborating with service providers to assist their affected youth throughout treatment and recovery?

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# What are the BARRIERS?

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# LEARNING NEEDS

## Vignette Part 2: Joanne and Paul

Paul has been in treatment for two months and sees his psychiatrist every two weeks. Paul meets with his case manager, Sandra, once a week for about one hour. Paul likes talking with his case manager. Sandra reports that Paul seems to be doing well. He says he is taking his medication which helps him sleep better. He also tells Sandra that he is spending less time playing video games and more time studying.

Joanne is worried about her son. He still doesn't want to talk much about what is going on, and tells her everything is fine. Joanne noticed that Paul is still spending lots of time in his room and she thinks he's been skipping classes. She also noticed that Paul seems agitated and now doesn't want to eat meals with the family. Joanne asked Paul if she could come to the next meeting with the psychiatrist, but he told her he can handle it on his own.

# Learning Needs: Activity 2

Break up into small groups to discuss (15 min.)

- ▶ What do you think are some of the learning needs of families/carers and service providers so that they can collaborate in caring for youth with mental health problems?
- ▶ What changes could be implemented (between families/carers and service providers) to make collaboration possible?

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# What are the LEARNING NEEDS?

# Family Peer Support As A Tool

Families have three main needs in caring for their youth with mental health problems<sup>4</sup>

- ▶ Information about what is happening to their youth
- ▶ Active involvement in their youth's care and recovery
- ▶ Meaningful emotional support

# Importance of Family Peer Support Worker

- ▶ Family peer support workers play a valuable role in engaging and supporting families/carers of affected youth as part of the treating team
- ▶ Peer support is recognized as a part of best practices for psychological health and well being<sup>5</sup>
- ▶ Through peer support training, families/carers with lived experience who desire to help others in similar situations, can add value to the healthcare experience for many

# Family Peer Support Worker

- ▶ A family peer support worker is usually a paid, trained non-clinician with the experience of having a family member with mental illness
- ▶ Offers family the opportunity to share experiences and concerns
- ▶ Helps family identify and explore solutions to challenging situations
- ▶ Shares information and resources
- ▶ Lends emotional support
- ▶ Can be a valuable member of the treating team

# Family Peer Support: Locations and Types

- ▶ ER and inpatient unit - short term until referral
- ▶ Community clinic - short term until referral
- ▶ Clinic Programs - medium to long term while youth receives services
- ▶ Community organizations - formal (education & training<sup>6</sup>) and informal
- ▶ Online
- ▶ In the community

# Family peer support: An example

- ▶ Between January 2012 and December 2016, more than 120 family support group meetings were held at PEPP-Montréal. **The primary objective of this pilot project was to provide new family members of PEPP clients with assistance and support from family member caregivers with lived experience.**
- ▶ At the end of 2016 an online qualitative survey was sent to 74 family members who were registered for family support meetings during this time.
- ▶ A total of 44 people completed the survey:
  - ▶ English survey: 27 (22 attended meeting; 5 did not attend any meeting)
  - ▶ French survey: 17 (14 attended meeting; 3 did not attend any meeting)

# Learning by peer sharing

*“I was alone. A single parent without family nearby. The experience weighed very heavily and watching my child through an episode, I could not bear it alone. I cannot explain the level of distress. A very dark stage in my lifetime and I didn't know how I could cope. It was shock, unbelievable and a lot of emotions all at once”*

- ▶ *I attended the first meeting so that I can learn about my son's illness. I needed to learn about the medications, why my son did not want to take his meds. I needed to learn why was he self medicating with marijuana. My life, my family had fallen apart. I had to learn and develop coping skills.*
- ▶ *We learned so much and we respected each other. Without the help of the Family Support Counselor my son would not be where he is today. Today my son is taking his meds on his own and is starting to co-operate with his recovery team.*
- ▶ *Hearing and sharing experiences with other families which I valued tremendously and learned from. Knowing you are not alone somehow helps.*
- ▶ *It helps me knowing that I am not alone through this. That there are other people going through the same thing as me or worse and they have no help. There should be more groups available.*
- ▶ *It helped me to become less judgemental and more respectful of my son. Our ability to talk harmoniously greatly improved. My son knows that I love and care about him as do his siblings and other extended family members. My son contacts us more often on his own initiative. He almost always returns our messages to him.*

# Quick tips on facilitating family involvement in youth mental health

## PART I - Engaging families and carers

- ▶ **INFORMATION AND OUTREACH:** Plan an event for families and carers in your community. Invite community members to learn more about youth mental health
- ▶ **INVITATION:** At the event, invite families and carers to sign up to attend a family peer support group facilitated by a family member caregiver with living experience or a member of your team preferably with family work experience
- ▶ **ORGANIZE** the family peer support group so members may share experiences, discuss challenges and brainstorm solutions in supporting their affected youth.
- ▶ **COMMUNITY MAPPING:** The family peer support facilitator may invite family members to start mapping their community's resources in order to build capacity among family members to better support their youth

# Quick tips on facilitating family involvement in youth mental health

## PHASE II - Engaging clinic team members

- ▶ **COLLABORATION WITH THE TEAM:** Inviting the peer support facilitator or liaison person to speak to team members about the needs and concerns of families/carers in caring for their young person (e.g., seminars, workshops)
- ▶ **COLLABORATION WITH FAMILIES AND CARERS:** Inviting families/carers to become more engaged in the care of their young person (e.g., psychoeducation, navigating the healthcare system, seminars, workshops)
- ▶ **INTEGRATE** the family support worker or a family member representative into clinic team meetings to foster improved communication among clinicians, youth and families/carers

# We talked about

- ▶ Why it is important to involve families/carers in youth mental healthcare
- ▶ Barriers to family/carer engagement in youth mental healthcare
- ▶ Promoting collaboration between families/carers and service providers
- ▶ Family peer support as tool in responding to family/carer needs
- ▶ Engaging families where they are at

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# Contacts

## **Mary Anne Levasseur**

National Lead & Coordinator, ACCESS Open Minds/Esprits ouverts Family and Carers Council

Coordinator Family Peer Support PEPP-Montreal

Email: [maryanne.levasseur@gmail.ca](mailto:maryanne.levasseur@gmail.ca)

## **Srividya Iyer**

Scientific-Clinical Director, ACCESS Open Minds/Esprits ouverts

Psychologist and Researcher, PEPP-Montreal

Assistant Professor, McGill University

Email: [srividya.iyer@mcgill.ca](mailto:srividya.iyer@mcgill.ca)

## **Manuela Ferrari**

Research Associate, PEPP-Montreal

Email: [manuela.ferrari@douglas.mcgill.ca](mailto:manuela.ferrari@douglas.mcgill.ca)