

**Family  
Na>igation  
Project**

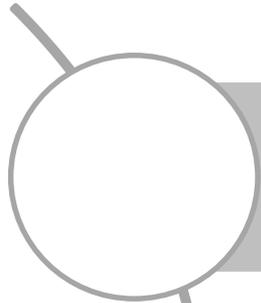
at Sunnybrook

**Improving access to mental health supports  
for transitional aged youth**

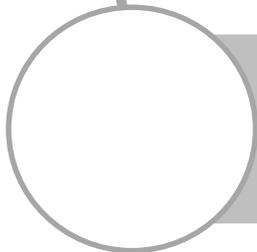
*Sugy Kodeeswaran, Executive Director  
Dr Anthony Levitt, Medical Director  
Dr. Roula Markoulakis, Scientist*

**Centre for Innovation in Campus Mental Health (CICMH)  
December 8, 2021**

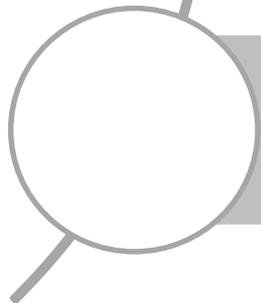
# Webinar Overview



Needs, barriers, and facilitators to accessing and transitioning through care and how navigation addresses these factors



FNP and the work we do



Two relevant case studies for the post-secondary population

# The issue



1 in 5 children and youth  
has a mental health challenge



5 out of 6 of those youth will **NOT**  
receive appropriate treatment

Significant barriers to access and transitions through  
the Mental Health and Addictions system

# What is Navigation?

- > A health care service aimed at improving patients' **access to and transition through** the health care system
- > Connects people to the most appropriate service and supports
- > Focuses on barrier reduction
- > Began in 1990 in the cancer care field to reduce health-related disparities for disadvantaged groups (Dr. Harold Freeman, Harlem Hospital)
- > Dozens and dozens of navigation services for MHA across Ontario alone

# Transitions in the PSE Context

Post-secondary students experience numerous transitions in care, such as:

- > **Loss of previous connections** to care (primary care, mental health care, etc.) if leaving home for school
- > **First experience** with mental health care needs and services
- > **Transitions between** supports available at **school and in the community** (e.g., upon completion of available sessions, upon graduation, etc.)

# Impact of Navigation Services on Youth of Transitional Age: An Evaluation (INSYTE)

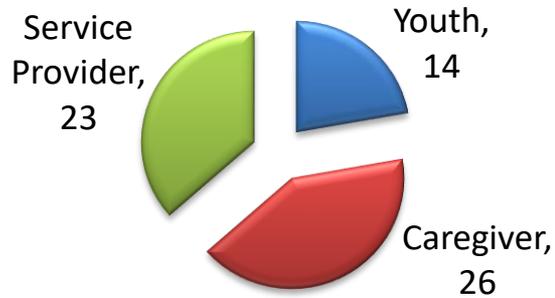
- > Transitional-aged youth (TAY) experience **individual and systemic barriers to care**, leading to difficulties accessing and transitioning through services within and across the child/youth and adult mental health systems
- > Wanted to **understand these needs** and **role of navigation** services

# INSYTE Study

- > Interviews and focus groups with
  - **TAY** with mental health and/or addiction concerns
  - **Caregivers** of TAY
  - **Service providers** working with TAY
  - **Decision-makers**
  
- > Asked participants about the **needs**, **barriers**, and **facilitators** of access to and transitions through care for TAY with MHA concerns

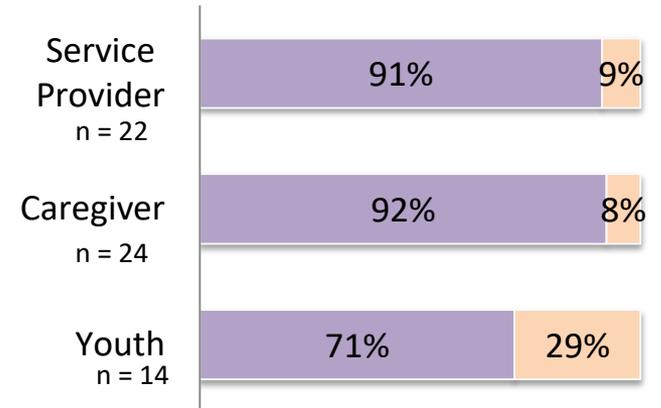
# INSYTE Study: Demographics

**Participant Type (n= 63)**



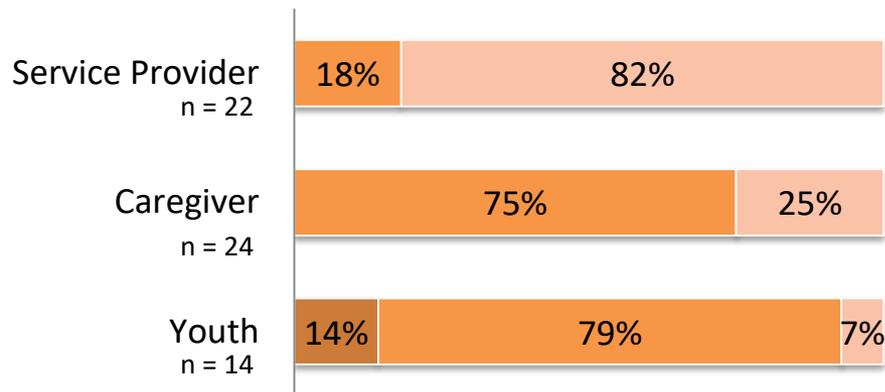
**Participant Gender**

Female Male



**Current Level of Education**

Secondary Postsecondary Postgraduate



# INSYTE Study - Themes

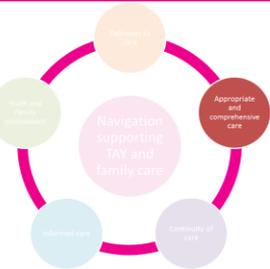


# INSYTE Study - Themes



“I suggest you start now...cause we just had to transition from the child and adolescent clinic to the adult clinic...In the same hospital, it was a 9 month wait. In the same hospital...One doctor referring to another doctor, 2 floors down” (Caregiver)

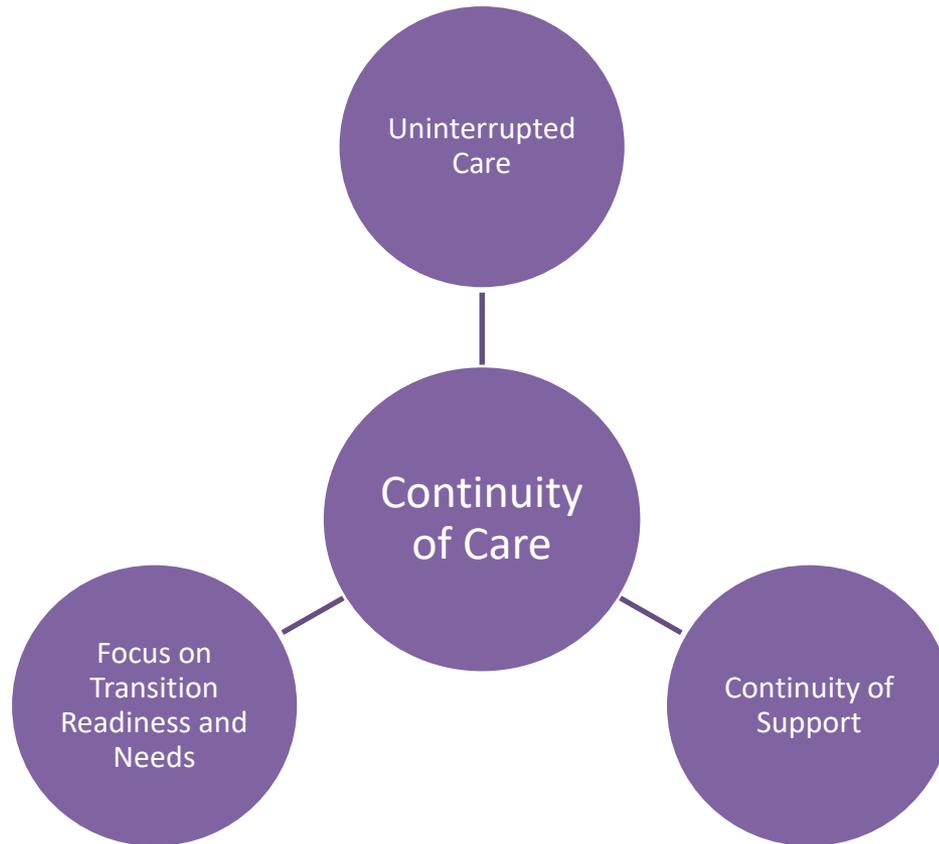
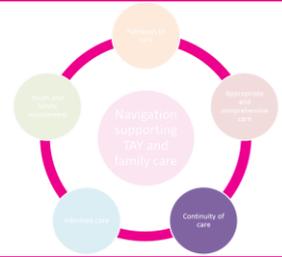
# INSYTE Study - Themes



“Looking at each patient more specifically and selecting the program that they thought would be best suited for them rather than giving them like a list of 20 different places and say go out and figure it out yourself. Because someone who is dealing with anxiety and depression doesn’t have the ability to do that. They are overwhelmed already. So to take the time and sort of just go through that list and say this would be a good fit for you.”

(Caregiver)

# INSYTE Study - Themes



“I guess when [my son] turned 16, he said “sorry, you know I can’t see you anymore, you need to see somebody else”. And we were like “who are you transferring him off to?” And he said “sorry I don’t have anybody” and so basically I was quite surprised that we were kind of left to our own devices to try to find somebody who can take us on.” (Caregiver)

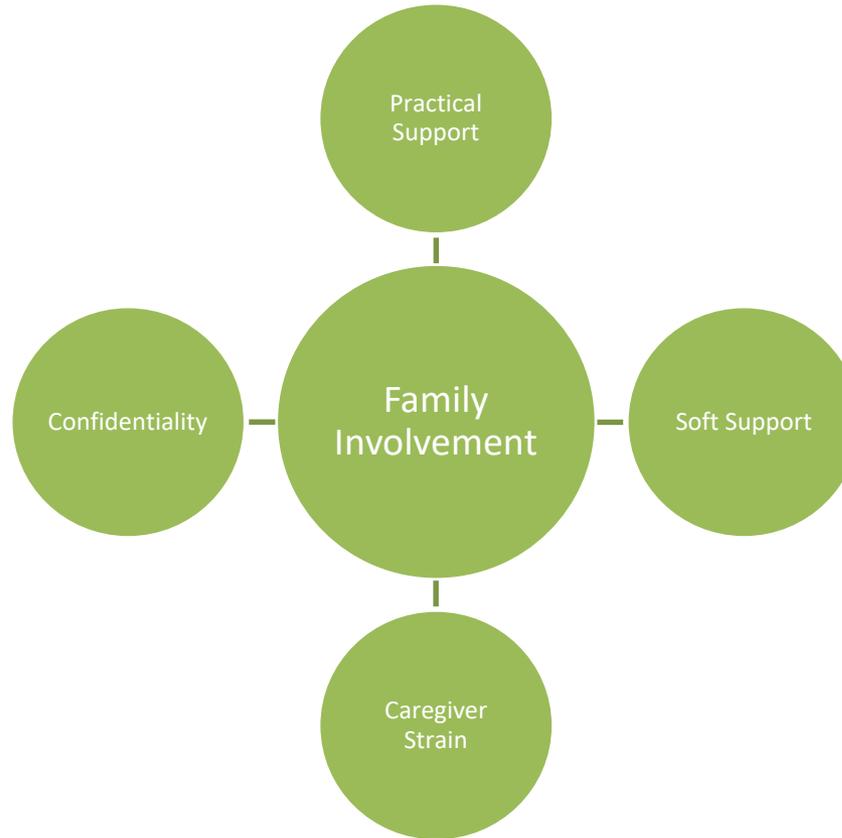
“It can look and feel like a whole different system, for both the youth and for the family. I think that can be daunting in itself. It could have a feeling of hopelessness, thinking oh my gosh, I have to do this all over again. Knowing that their youth is still going to present in the way they presented last year even though they’re a different age. And they have to now learn this whole new entire system on their own. That can be very overwhelming.” (Service Provider)

# INSYTE Study - Themes



“He was seeing me when I was more lucid and he was recommending a bunch of different things. That was pretty useful. Like presenting different options and not just telling me what to do, and allowing my family to be there and have a family consultation kinda thing. I think that’s important for the young adult.” (Youth)

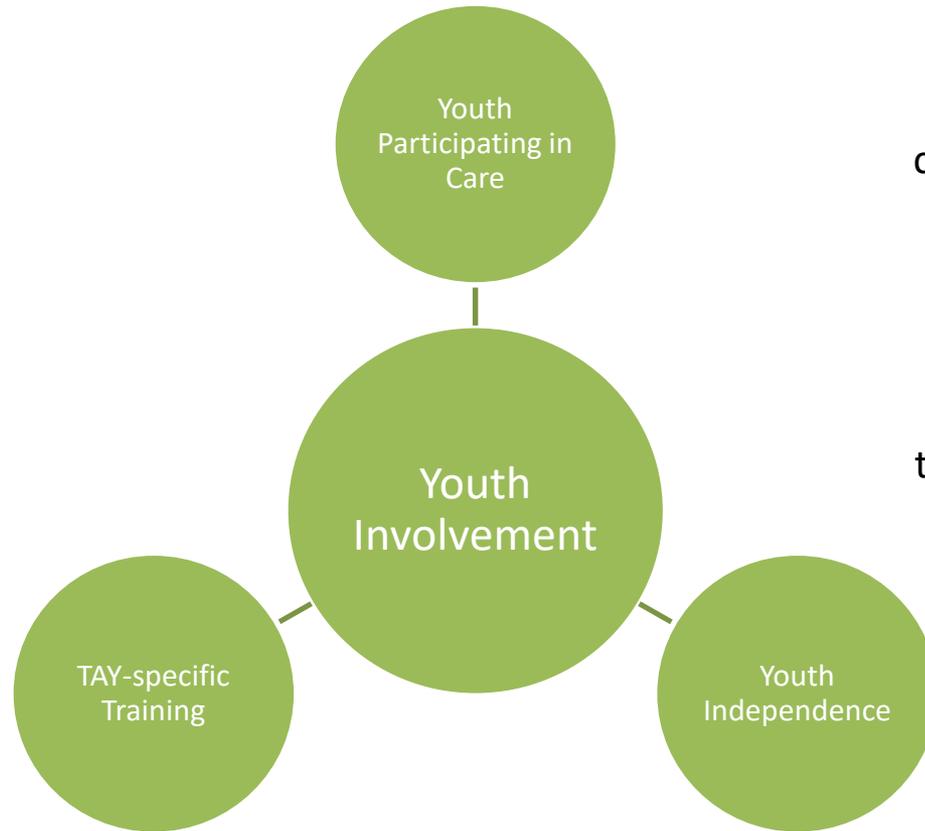
# INSYTE Study - Themes



“Going through some sort of publicly funded resources, it was just much less accessible in terms of there were lots of waitlists, and there weren’t lots of programs. Thankfully my family is in a position that we have some extended health coverage to cover private counselling but then I was also in a position with my family that we were able to pay for my counselling out of pocket.” (Youth)

“These young people are left to their own devices. And as parents, if they are over a certain age, we cannot intervene in any way. We cannot ask the doctors questions. You can ask but they’re not permitted, legally, to respond unless our child gives them permission. So as a parent, this has been probably the most-I meant to use the word frustrating but it doesn’t really capture the despair of watching your child struggle with a life-threatening illness and there is no one to turn to and say what can we do to help this child recover. It just, it doesn’t exist.” (Caregiver)

# INSYTE Study - Themes



“I’m mindful of the fact that it could all come crashing down if, I don’t know, she stops taking her meds or if something happens. It only takes one event, one, “I failed a course” and that’s it. And she goes off the rails, stops taking her meds, won’t go talk to someone and then we’re back to where we started from.” (Caregiver)

“You need to call in yourself, you can’t have your mom call in for you or anything. And there’s tons of people who are socially anxious talking on the phone and so they only text, they don’t like emails cause that’s for old people, so if we don’t have any texting service, they are not able to say I want treatment, and if they are not willing to leave a voicemail, or have a phone call conversation, that’s it, we can’t connect them, so that’s a huge barrier.”

(Service Provider)

# INSYTE Study - Themes



“A week is nothing compared to waiting for months and months. So you can’t expect more than that. I thought it was great...I thought it was just really very supportive...very empathetic, helpful to me, validation for me. And then also just feeling like I was talking to somebody who was giving me credible advice.”  
(Caregiver)

“I think it gives youth opportunity to feel supported in making a good choice. But knowing that if that choice isn’t the best one once they’re in it, that they can have a different choice. And they’re not gonna be just dropped out the door and told, “best of luck!””  
(Service Provider)

# Next steps

- > Important to recognize these needs and gaps in existing care to provide more:
  - Information and guidance
  - Proactive transition support
  - Warm handovers
- > Clear role for navigation services in supporting TAY and families

# Family Navigation Project

- > Co-founded and **co-designed** by system users with **Lived Experience**

## OUR VISION:

No family feels lost in the mental health and addiction system

- > **8 yrs** operating experience (since 2013)
- > Serves **youth ages 13-26** and their families across Greater Toronto Area
- > **Phone and email** based service
- > Blend of clinical and Lived experience
- > **Relationship-based approach including 1100+ service providers** across a variety of settings
- > 100% funded by philanthropy



# Family Navigation Project

- > navigated for **4300+ youth** across GTA and Ontario
- > expertise in navigating for the **most complex\* MHA cases**
- > Qualitative and quantitative **research and evaluation** to inform an **evidence-based service**

# Who makes the first connection?

82%

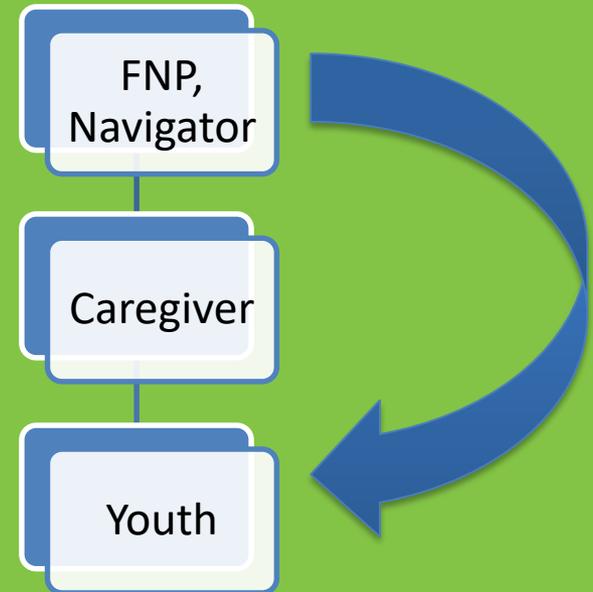
CAREGIVERS\*

18%

Youth

**\*CAREGIVER TYPES:**

67% Mothers | 12% Fathers | 4% grandparents, siblings, other



During the Pandemic % Youth reaching out directly DOUBLED

# HOW DO OUR CLIENTS HEAR ABOUT US?

43%

**Health Care Providers**

(Hospital, Community, Family Physicians)

34% Word of mouth | 4% Education system | 10% online search

# TWO FNP CASE STUDIES

# Case Study 1, BD

## 24 y.o. Master's Program

### **Duration of Navigation:**

- > 6 months, with reactivation 2 years later for 2-3 months

### **Intake situation:**

- > Living independently with partner

### **History of concerns:**

- > Diagnoses included GAD, Bipolar II, ADHD
- > Struggling with intense mood changes, changing quickly sometimes within the same day
- > Multiple medications trialed
- > Significant emotional dysregulation, crying at work, anger outbursts at home
- > Mood affecting school, work and relationship

### **Youth Goals for working with FNP**

- > Stabilize mood, to assist with school, work and romantic relationships
- > Connect with affordable therapeutic supports

### **Key Players at time of Intake**

- > Supported emotionally and financially by partner and family doctor

# Case Study 1, BD

## 24 y.o. Master's Program

### Navigation plan

- > *Psychiatric assessment:*
  - FNP Psychiatrist flagged possibility of complex mood
  - Provided language to support GP in referral
  - Mood Specialist diagnoses of ‘Mixed State Bipolar’,
- > *Therapy:*
  - Clinician at local hospital assessed that youth unable to manage therapy
  - Connected with Stella's Place, studio available, waitlisted for upcoming DBT group
- > *Family support*
  - Partner was youth's main support and caregiver when unwell
  - Navigator helps caregiver develop personal goals
  - Partner had benefits plan available, interested in private supports
  - Navigator provided private Therapist option, expertise working with young men and supporting individuals with loved ones experiencing emotional dysregulation
- > *Other*
  - Navigator assists with communication between Psychiatrist/School/Youth to complete paperwork for ODSP and Bursary

# Case Study 1, BD

## 24 y.o. Master's Program

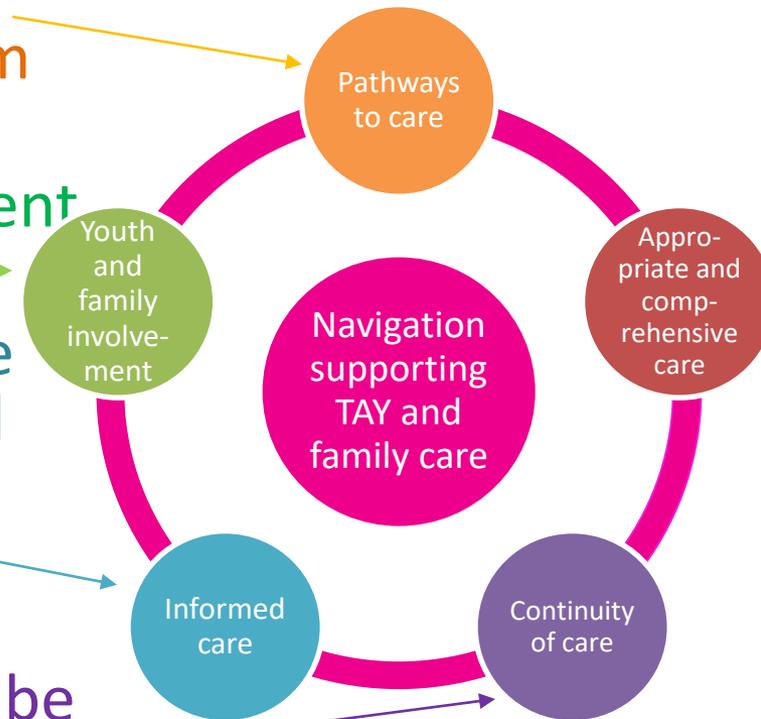
### Update:

- > Completed school
- > Youth and Partner engaged to be married
- > Complex mental health recovery - youth experienced ups and downs while trying to stabilize
- > Partner accessed his own support, beneficial with regards to self-care, psychoeducation and ability to provide support
- > BD unable to find work after finishing school
- > Referral to case management for closer and more long term support with goal setting and connecting to supports as needs change

# Case Study 1, BD 24 y.o. Master's Program

## Themes

- Assistance with communication with system partners is often needed
- Reduction in burden for client and caregiver is essential →
- Navigation is most effective when not “blind” to clinical evaluation
- Mental illness is not necessarily stable and navigation must adapt and be responsive and “get in the boat”



# Case Study 2, AD

## 20 y.o. 3rd year Undergrad

### **Duration of Navigation:**

- > 10 months

### **Intake situation:**

- > Living in campus dorm
- > Identifies as Afro-Haitian and Chinese
- > Studying Informatics

### **History of concerns:**

- > Diagnoses included GAD, OCD, depression, ?PTSD, misusing alcohol
- > Tired all the time, flashbacks, weight concerns, chronic pain

### **Youth Goals for working with FNP**

- > Clarify PTSD diagnosis
- > Better control of anxiety and OCD
- > New family doctor

### **Key Players at time of Intake**

- > Counsellor at University health service

# Case Study 2, AD

## 20 y.o. 3rd year Undergrad

### Navigation plan

#### > *Psychiatric assessment:*

- Referred to campus psychiatrist. Diagnosis anxiety and OCD
- Provided list of possible GP's to select from
- Prescribed meds and therapy

#### > *Therapy:*

- Self help group at Hope and Me,
- East Asian therapist, sliding scale
- Addictions counselling to be part of sessions

# Case Study 2, AD

## 20 y.o. 3rd year Undergrad

### Update

- > Youth elected to transfer to University closer to supports (friends) and in field closer to their passion
- > Following up with local CMHA for medication monitoring – early side effects but OCD and anxiety improving
- > Has scheduled assessment with affordable East Asian therapist

# Case Study 2, AD

## 20 y.o. 3rd year Undergrad

### Themes

- > Mental health and addictions support is most effective when culturally sensitive
- > Navigation for chronic illnesses is a longer term commitment
- > University health services can be very helpful – need for longer term and/or specialized follow up for some

# Conclusion

- > Navigation rapidly proliferating
- > Has made positive impact in oncology, but also now in dementia, MHA, complex care
- > Can alleviate health disparities improving patient and family outcomes
- > Not a band-aid, but rather an essential part of a healthy system (ie OHTs)
- > Look forward to discussions to ensure sure this work is integrated

# Canadian Healthcare Navigation Conference



CANADIAN  
HEALTHCARE  
NAVIGATION  
CONFERENCE

RE-IMAGINING  
HEALTHCARE NAVIGATION:  
Equity, Diversity, Inclusion, and Accessibility

## CALL FOR ABSTRACTS

**Abstract submissions** for the second annual Canadian Healthcare Navigation Conference will be **open on November 23, 2021**. Visit our website for more information about this year's theme and to view submission guidelines.

Submissions will be accepted until December 22, 2021.

Conference registration will open in January 2022.

## KEYNOTE SPEAKERS



JESSICA GEBOERS

**Jessica** graduated from the Ryerson University School of Journalism in June 2015. She currently works as a writer, content developer, and mentor for OWLware Ltd. in Toronto Ontario.

As a person with moderate Cerebral Palsy, Jessica has a passion for disability advocacy and using her work to promote disability awareness and accessibility.

She is a patient advisor and co-investigator for [CP-NET](#) and [CanChild](#), as well as a recently retired member of the Toronto Transit Commission's Advisory Committee on Accessible Transit ([ACAT](#)). Jessica also loves travel and music, especially attending concerts.



DR. TRACY BATTAGLIA

**Dr. Battaglia** is an Associate Professor of Medicine and Epidemiology at Boston University Schools of Medicine and Public Health where she serves as the Director of the Women's Health Unit.

She has 20 years of experience designing, implementing and evaluating health interventions that use community-engaged research methods and is a pioneer in the development of oncology patient navigation programs.

Her own experience as a two time cancer survivor fuels her passion. She currently serves as the founding Chair of the National Navigation Roundtable, whose goal is to ensure navigation services are available to cancer patients in need.



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 Canadian Healthcare Navigation Conference

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# Questions?



# Family Na>igation Project

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**Here to help youth and families. Contact us.**



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**familynavigationproject.ca**