Family Navigation Project

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Beyond list-giving: Exploring the need for youth and family Mental Health and Addiction Navigation Services in Ontario and how it can be done!

Children's Mental Health Ontario Annual Conference

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Michelle Di Febo & Staci Weingust

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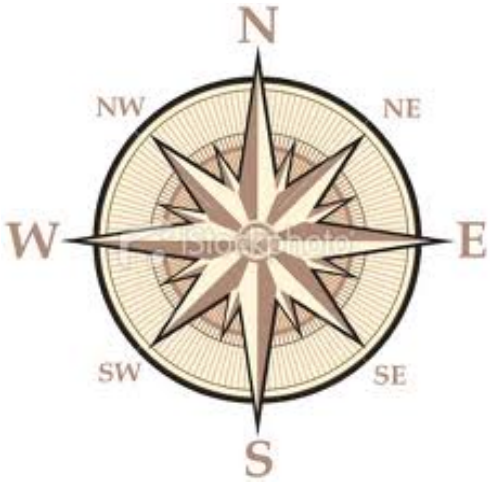

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The History of Navigation (US)

- Original concept of patient navigation by **Dr. Freeman in 1990** (*Harlem Hospital for cancer care*)
- U.S. policymakers "**Patient Navigator Outreach and Chronic Disease Prevention Act of 2005**"
- 2008 **– *Harold P. Freeman Patient Navigation Institute***
- 2015 **– *American's College of Surgeon's Commission on Cancer*** require accredited cancer facilities to have a ***Patient Navigation*** program

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The History of Navigation (Canada)

- One of the **first navigation programs** in Canada was in **Nova Scotia** in 2001
- As programs evolved, **functions became more professionalized** – often being taken over by **nurses** and **social workers**
- 2011 – ***Canadian Medical Association Journal*** stated that "**patient navigation**" was becoming the "**norm**"
- 2012 –***Canadian Partnership Against Cancer*** provides a detailed **set of competencies** for professional navigators

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What is Navigation?

- **Patient *or* Care Navigators**: they are trained healthcare workers who help patients "navigate" their care journey, most often within the hospital or healthcare service.

  (Oncology Nurse & Health Navigators)

- **System Navigators**: their primary role is to help create effective links between appropriate health and social resources.
- **Family Navigators**: provide family support, education, advocacy, coaching, information and follow-up services to link families with additional community resources.

What is navigation:

What conditions are appropriate?

- No clear treatment pathways established in the system (complex system)
- Multiple services are required in the treatment plan
- Multiple service providers are available in the system, but they are not interconnected
- Illness involves family members/caregivers in a substantive and often stressful way
- Chronic or recurrent illnesses (ie. cancer, HIV, Alzheimer's, austism)

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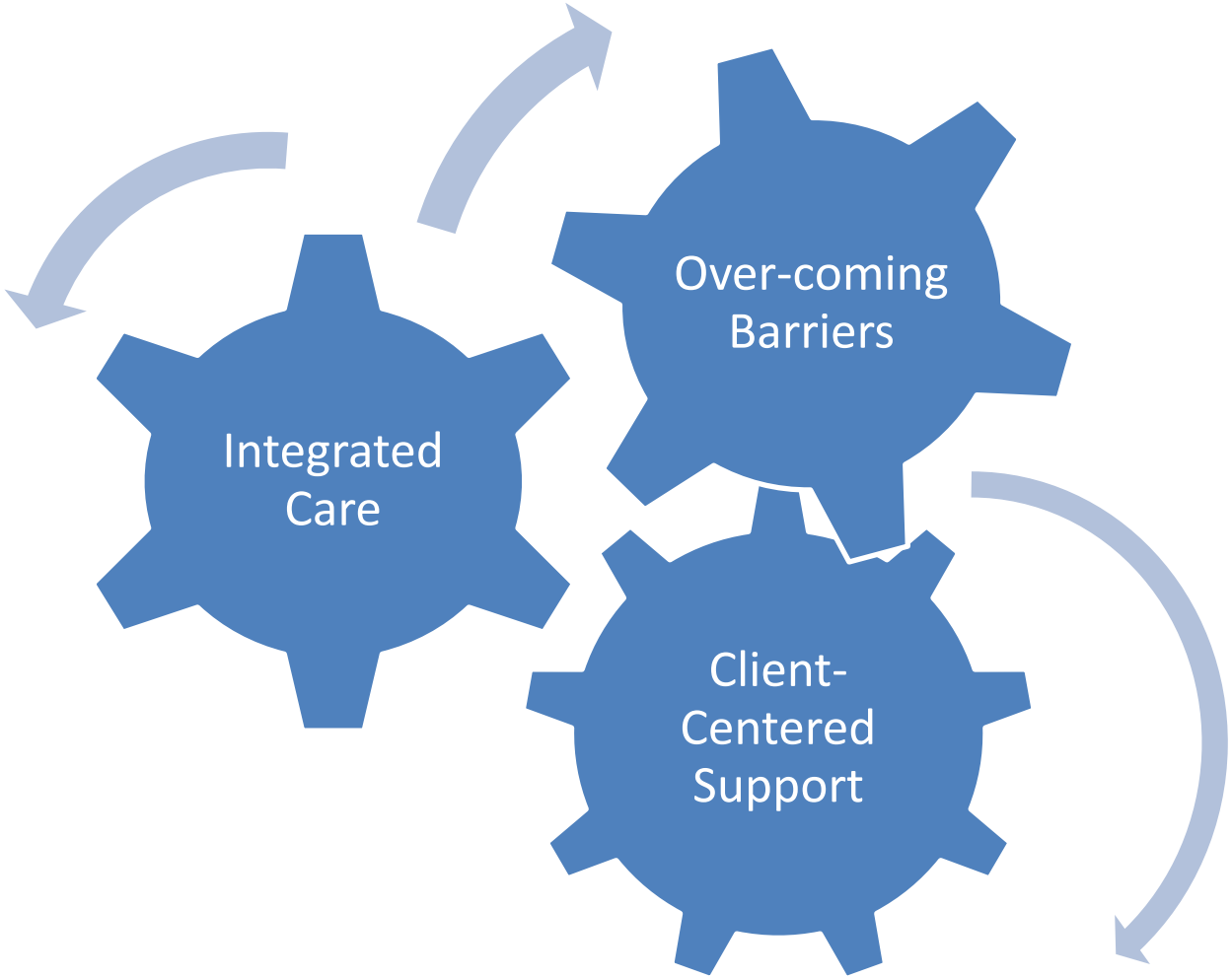
What is Navigation?

Scoping Review

Mullen, Levitt, Markoulakis et al, 2016



(2016, Mullen, J., Levitt, A., Markoulakis, R.)

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What is Family Navigation?

- Various models:
  - In hospital vs. in community
  - Navigators who are clinical vs. those with lived experience
  - Differing age categories
  - Variance in focus of concerns (ie. behavioural, judicial, addiction)
  - Difference in roles
  - Crisis vs. non-crisis
  - Some with support groups & community programs
- Research? Best practices?
- Education/Credentials?

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Our History
By Families, for Families

- **Started by parents with lived experience**, who had come up against hurdles in finding care for their children
- Determined to **make change** so other families wouldn't have to experience the same struggles
- Implored psychiatric leadership at Sunnybrook to take action!
- Envisioned a **high-caliber, personalized service** in which they could place their **trust** – a service that would **match** the youth and family with the right professional or program in a timely way
- **When we couldn't find one, we built one**

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Our History (cont'd)

- Sunnybrook was committed to the program vision
- Secured a commitment from **RBC** in 2013 for the "**Run for the Kids**" to support the program which seeded the program; and since have garnered **support** from other private donors
- Program unofficially **launched** in **November 2013** in response to overwhelming number of calls after the first run
- Over the **past four years**, program has continued to grow to meet needs and overcome system barriers

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Why focus on families?

- Families/caregivers are most often the initiators of **health care support**
- Families are the **guardians of important medical and family history information**
- Families are often the only, or at least, the most valuable way of **monitoring for progress of treatment**
- Families are often the centre of the environment in which the youth is living
- Few services exist that orient their support to the **whole family**

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Mental health stats (Ontario)

- **1.2 million youth** are affected by mental illness and **less than 20%** receive treatment
- **60% increase in hospitalizations** for youth seeking treatment for mental health issues since 2009
- **Over 9,000 youth waiting** for long-term psychotherapy
- **Suicide is 2nd most common cause of death** among youth age 15-19 in Canada
- Stats Canada found that **caregiving for an individual with MHA is more stressful**, with greater negative impacts on emotional well-being, then other caregiving roles

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Our Model of Care

"Blend expert clinical care with the knowledge & understanding of lived experience to connect families to the right care at the right time."

- Model designed by parents with lived experience
- Free service, phone and email based
- Families/caregivers of youth 13-26 in the Greater Toronto Area (*population 6.4 million*) with mental illness and/or addiction
- Navigators are clinically trained professionals
- Psychiatric oversight in all cases
- Peer support through Parent Advocate with Lived Experience
- Profiling & Resource matching
- Collaboration and coordination with other service providers
- Address needs of the whole family; using family-centred care

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Why families contact us

- Don't understand mental illness/addictions or the system of services
- Know their child needs help, but can't figure out a way into the system
- They are in the system,
  - but can't figure out how to advocate for their loved one
  - know how to advocate, but not getting the help they need
  - getting the help, but multiple resources not coordinated
  - help available, but can't get their youth to attend or follow up
  - youth willing, but exhausted all possible local resources
  - exhausted all possible local and international resources

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FNP Team

- Medical Director
- Administrative Director
- Director of Strategic Planning & Partnerships
- Psychiatrists (2)
- Navigators (9)
- Parent Advocate with Lived Experience (PAL)
- Intake Worker
- PhD Research Coordinator
- Research Assistant
- Admin Support and Data Coordinator
- Students (2 *summer*)
- Family Advisory Council (FAC) (12)

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Navigation Process

- Self-referral via phone or email (caregiver or youth)
- Screening with Intake Coordinator
- Triaged to a navigator (2-3 days)
- Intake Assessment
- Team review
- Resource finding, collaboration and coordination with other service providers (private or public)
- Exploring options with family/youth
- Working collaboratively with other services
- Continued support to family/youth
- Follow-up
- Deactivation

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FNP
Who we serve/stats

Total # of families navigated to date:	**2000**
Navigator Caseload:	**40-50**
# of new clients per month:	**50-55**
Average "length of stay":	**4 months**
Average number of family members involved in a navigation episode:	**2.1**
Average age of youth of concern:	**19**
Cases in which the parent is the initial contact:	**87%**

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Surveying the Need for Navigation in Ontario

- Methods
  - Cross-sectional quantitative survey
  - Target: Adults ages 35-65 caring for a youth age 30 or under
  - Screened in if caring for youth with mental health, emotional, behavioural, or substance use issue of concern
  - n = 259 out of 840 respondents

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Prevalent Concerns

Issues

Difficulties with academics	126 (49.6%)
Outbursts of anger or rage	105 (41.3%)
Difficulty sleeping	103 (40.6%)
Lacking energy or motivation	100 (39.4%)
Worrying constantly	98 (38.6%)

Diagnoses

Depression	78 (30.1%)
Attention Deficit Hyperactivity Disorder	72 (27.8%)
Generalized Anxiety	55 (21.2%)
Autism Spectrum Disorder	32 (12.4%)
Obsessive Compulsive Disorder	21 (8.1%)

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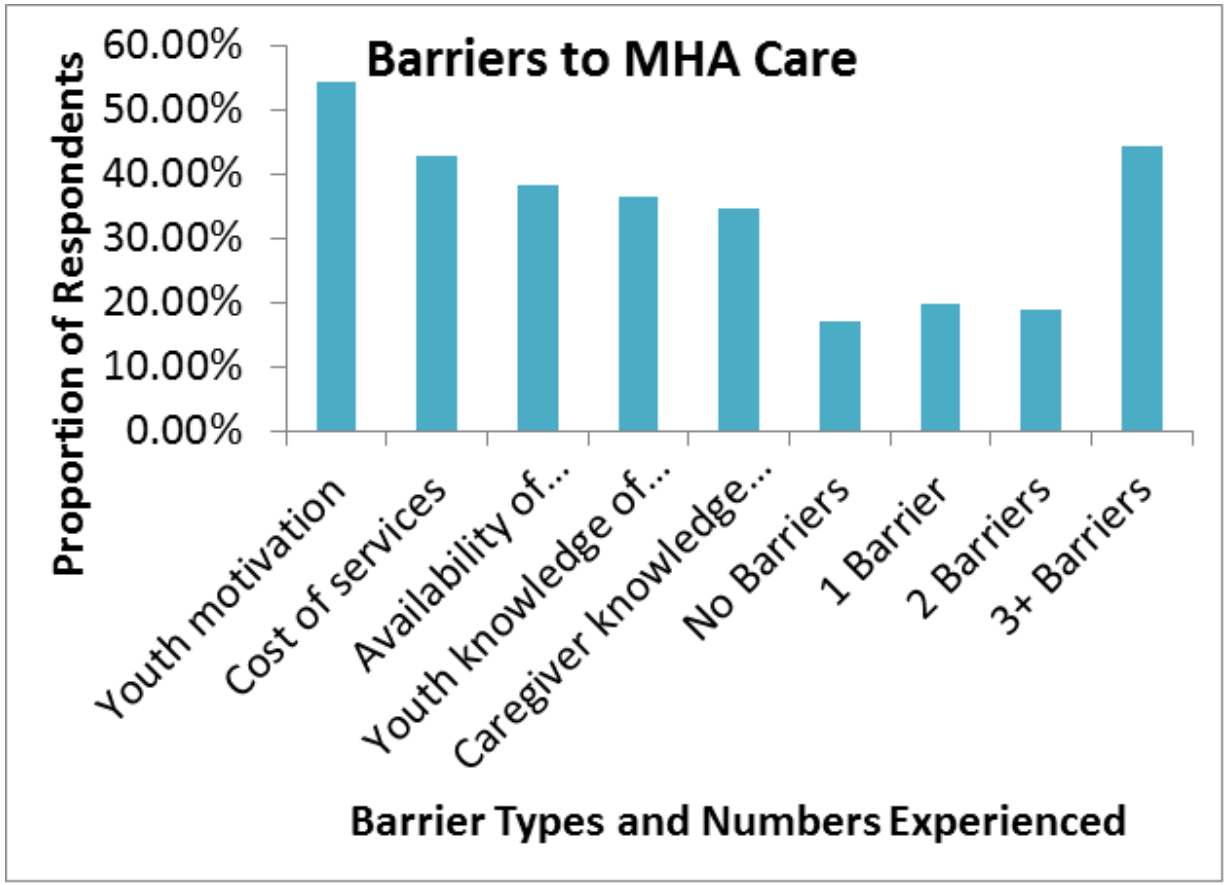
Prevalent Concerns (con't)



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Navigation example

- Mother calls about her 16 y.o. daughter Maria
- ADD diagnosed in grade 3
- 2 years ago her mood began to change, with depression and anxiety
- Last year her marks started to decline and she developed severe nausea and vomiting associated with anxiety
- Started using marijuana to control nausea over 1 year ago
- More than a dozen visits to ED

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Navigation example – Part II

- Dad is overwhelmed. Found daughter's THC in the car 6 months ago and took it to relax. Now smoking daily and refuses to engage in resolving daughter's medical crisis
- Younger sister (12) distressed; recently Maria is constantly irritated and angry, especially with sister
- Mom has taken time off work to try to deal with Maria's situation
- Maria refuses to go for psychiatric or psychological assistance and denies she has drug issue – THC is only thing that controls her nausea

What would you suggest?

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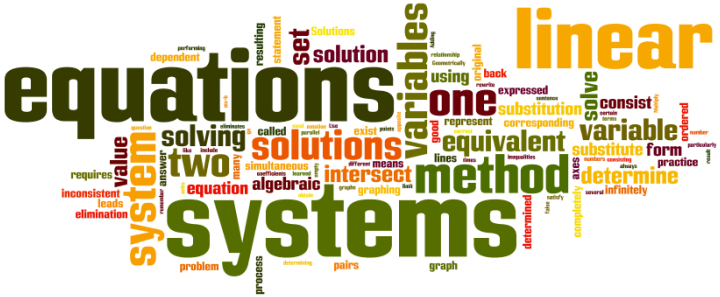
System Implications

- Creation of a family navigation model and process that can be replicable in other jurisdictions (*manualization*)
- Collect and publish learnings from a model rooted in lived experience
- Sharing of effective practices through reporting of program outcomes
- Reporting gaps in the system from the perspectives of clinical providers and families
- Transforming the system through collaborative care



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