The Family Navigation Project: An innovation in supporting youth with mental health and/or addictions concerns and their families

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Objectives

- Develop an understanding of this model of family-centered navigation for youth with mental health and/or addictions (MHA) concerns and their families
- Assess the role of navigation services in the MHA system
- Appreciate the nuances of developing a navigation plan when focusing on the whole family
Today’s discussion

• What is “navigation”
• Our focus on youth and families
• About FNP (our story, our process, our numbers, our impact)
• Role for navigation within the system
• Case study

Alert: Audience participation required!
Navigation

It's amazing how much easier it is to get somewhere when you know where you're going.
The origins of navigation

• Originated within Cancer and HIV health care systems (Freeman, 2008)
• Found to be effective in alleviating health care disparities and ensuring equitable access to quality care (Fischer, Sauaia & Kutner, 2007)

“No person with cancer should have to spend more time fighting their way through the cancer care system than fighting their disease”

Dr. Harold Freeman
When is navigation appropriate?

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

1 in 5 children and youth has a mental health challenge

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

75% increase ED visits & 65% increase hospitalizations

Suicide is 2nd leading cause of death among ages 15-19 in Canada

Sources: ICES, CIHI, StatsCan
Why youth mental health?

• Youth aged 15 to 24 are more likely to experience mental illness and/or substance use disorders than any other age group. (*StatsCan*)

• People with a mental illness are twice as likely to have a substance use problem compared to the general population. (*Rush et al, 2008*)

• *Caregiving for an individual with MHA is more stressful*, with greater negative impacts on emotional well-being, *then other caregiving roles* (*Slaunwhite et al., 2016*)
Why *family* navigation?

• **Youth often:**
  – may not recognize they have an illness
  – may not be motivated to seek help
  – may not express their concerns directly or fully

*Much of the above is due to the nature/symptoms of the illness itself and/or stigma*

• **Family is often:**
  – the holder of health information
  – the engine driving help-seeking behaviour
  – the best gauge of severity and progress
  – a large contributor to the health of the youth and their progress
  – have the same or similar or other mental health or addiction issue
About Family Navigation Project (FNP)

• Started out of need identified by parents with “lived experience”
• Continued family partnership and co-development

OUR VISION:
No family feels lost in the mental health and addiction system

• Non-profit program, launched in Nov 2013
• Funded by Philanthropy with infrastructure support from Sunnybrook

Join us
Saturday
September 14 2019
About FNP

- Serves youth aged 13-26 and their families
- Phone and email-based program
- Free service
- Blend of clinical and lived experience
- Serves all of GTA
  (Toronto, Halton, Peel, York, Durham)
System Navigation

- FNP is connected with >1,000 resources/service providers which include:
  - Community, hospital, regional & -based programs
  - Specialized treatment centres (day, residential, camps)
  - Independent Practitioners (psychiatrists, psychologist, social workers, GPs, etc)
  - Individual & Family Counselling & Parental Support
  - Spanning Public and Private Sectors
  - Spanning various systems: Health, Education, Justice, Social Services & Housing, Child Welfare
  - etc.
FNP Process -
How we help families
The FNP Process

- Youth ages 13-26 with MHA concern
- Living in GTA (youth or family)
- Self-referral
- No diagnosis needed
- Response within 1 business day
The FNP Process

> Clinically trained navigators
> Needs assessment
> Goal-setting
> Regular business hours with flexibility to meet clients’ needs
The FNP Process

Screening ➔ Intake

Team Review

- Interdisciplinary team approach
- Psychiatric oversight in all cases
- Generate resource options for the youth and family
- Refer to Parent Advocate with Lived Experience (PAL), if appropriate
The FNP Process

- **Screening**
  - Explore options with family and youth

- **Intake**
  - Find and connect to services for youth & family
  - Collaborate with service providers when exploring fit
  - Extensive knowledge of resources

- **Team Review**

- **Resource Matching**
The FNP Process

Screening → Intake → Team Review → Resource Matching

- Present options to family and youth
- Support in connecting with agreed-upon services
- Prepare youth and family to know what to expect
The FNP Process

1. Screening
2. Intake
3. Team Review
4. Resource Matching
5. Follow-up

- Check-in with youth and family
- Revisit resource options if needed
The FNP Process

1. Screening
2. Intake
3. Team Review
4. Resource Matching
5. Follow-up
6. Explore options with family and youth
7. Inactivation

- Inactivate once family is well supported
- No discharge – family can always reactivate
Why do families contact FNP?

Don’t understand illness or the system, or don’t know if their child needs help

Know their child needs help, but can’t find a way into the system

In the system, but don’t know how to advocate or negotiate care and communication

Know how to advocate, but can’t find the specific help their child needs, or can’t coordinate multiple services

Exhausted all possible local and/or regional and/or national and/or international options
Themes of family-navigation

• Resource Finding and Matching
• Advocating for and empowering families
• Facilitating communication and relationship building within system
• Coordinating care
• Psychoeducation and support for families

Compassionate persistence

Overall barrier reduction
Our Numbers – Who have we helped?

Since 2013, navigated for >2800 youth
- Support ~2.1 individuals per family
- ~50-60 new clients per month

Average age of youth is 18.5 yrs
- 50% of youth have concurrent disorders (both mental illness and addiction)

Initial contact is from parents 85% of time
- Over 50% of clients hear about FNP from other service providers

Average episode of navigation is 4 mths
- “stay in the boat” with family
Our impact - Evaluation & Research
FNP Program Evaluation

• Regular evaluation surveys with clients
  — 2 time points (intake, 4 mths)
  — ~20 minutes to complete

• Developed in extensive consultation with FNP staff, youth and families, and system stakeholders

• Provides key information to drive care; refine navigation and service delivery
Our Impact

After 4 mths with FNP, caregivers report:

• Higher life satisfaction for them and their youth
• Better mental health in their youth
• Lower caregiver strain
• Lower stress levels in their youth

Caregivers report high satisfaction with:

• Promptness of FNP response (95%)
• Appropriateness of recommended resources (89%)
• FNP staff listening (93%) and cultural sensitivity (88%)

Participants satisfaction with FNP service:

• Likely to recommend FNP service to family and friends (90%)
FNP Research: Evidence-based

- Randomized controlled trial (RCT)
  - Do youth and families receiving navigation services experience better outcomes than those who do not (i.e. self-navigation)?
  - In addition to health and functioning outcomes, will reveal important information regarding wait times, cost effectiveness, system integration

Results coming summer 2019!
Nature of the need – estimated demand

Percent of caregivers of youth* experiencing some emotional, behavioural, mental health, or addictions concern who are highly likely to benefit from navigation by Ontario Region, 2016

Ontario – 38% (259,969 families)

Northwest ON – 33% (3,234 families) (North West LHIN)

Southwest – 42% (80,701 families) (Erie St. Clair, South West, Waterloo Wellington, Central West, Hamilton Niagara Haldimand Brant, Central West, part of North Simcoe Muskoka LHINs)

City of Toronto – 33% (44,387 families) (Toronto Central, part of Mississauga Halton, Central West, Central and Central East LHINs)

Northeast ON – 33% (13,841 families) (North East and part of North Simcoe Muskoka LHIN)

Eastern ON – 27% (25,491 families) (South East and Champlain LHINs)

Greater Toronto Area – 42% (92,315 families) (Mississauga Halton, Central West, Central and Central East LHINs)

* Up to age 30 for percentages; up to age 24 for calculation of households
Source: Ontario Survey of Need for Family Navigation; Statistics Canada
Navigation Case Study

• Rafaela calls in October, after hearing about FNP through the annual Race for the Kids, regarding her son John (18)
• John was assessed as gifted at a young age, but struggled academically throughout elementary and secondary school
• This past year John failed the school semester; stopped playing sport, guitar, and socializing
• He refused to attend classes, and had no motivation to complete online courses
• He is isolating himself in his bedroom, with a reversed sleep/wake cycle, spending wake hours online gaming
• John is using marijuana daily to self-medicate, and refusing all other supports
• John was taken to hospital by police 3 weeks prior when he expressed paranoid beliefs and subsequently attempted suicide by cutting himself
• Episode diagnosed as drug-induced psychosis
• Hospitalized for 2 weeks and discharged to day program, to begin 4 weeks post-discharge
What would you do?

• Consider...
  – What are the 2-3 main concerns for John?
  – What are the 2-3 main concerns for the parents?
  – What interim resources might be available in the 4 weeks at home before the day program commences
Navigation Case Study
–additional concerns

• Parents observing continued ‘strange’ behavior at home, worried about John’s safety in the home – may still be using THC. Refusing all intervention. Not attending Day Program.

• Two younger sisters (13 and 15) at home, John can be verbally aggressive with them

• Parents, recent immigrants from South America, identify having different parenting styles, struggling to get on the same page and their relationship is strained as a result

• Siblings exhibiting signs of stress and worry, youngest beginning to refuse school

• Rafaela has taken time off work to manage the situation
What would you do?

• Consider...
  – List as many barriers to optimal health as you can
  – What can be done to reduce caregiver strain?
  – What can be done when a youth refuses to accept care and is not yet at a point where he must be involuntarily detained in an acute care facility?
Navigation Case Study: What happened after FNP involved?

- Rafaela not sure what navigation can offer and is weary of what the system can provide given her experience
  - Connected with FNP’s PAL (Parent Advocate with Lived Experience) to gain understanding of another family’s journey and experience in navigating system, as well as peer support
- Navigator connects parents with a parent coach
  - receives psychoeducation regarding psychosis, addiction and role as caregivers, create safety plan and boundaries for his behavior in the home.
  - John also attends and together they create home contract.
  - Siblings meet independently with parent coach, questions answered regarding psychosis
With help of navigator, parents provide day program with brief written summary of observed behaviours post-discharge, John scheduled for follow-up assessment with psychiatrist

- Dad to transport John to day program. Rafaela to pick him up, but able to return to work

John following house expectations regarding no substance use and attending day program. Navigator also finds publicly funded drug counseling for John.

John continues to game, but time limited by family contract
Navigation Case
What happened after FNP involved?

- Siblings connected with therapist for ongoing therapeutic support, although attendance not yet 100% for older sib.
- Parents begin couple’s therapy to strengthen relationship and communication
- Parents report overall stress level reduced in home
- Episode of Navigation complete, however family aware that FNP available to collaborate and support hospital day program discharge plan if needed
A note of thanks
...from mom to the navigator

“The Family Navigation Project is truly an amazing program and there are no words that can express our sincere gratitude for all the help and support you provided during times when I felt there was nowhere to turn. John’s doing a bit better and is working hard to try to return to his school. I hope all is well with you. Good luck with the Race”
Living with Mental illness & Addiction is hard. Getting help shouldn’t be.
Here to help youth and families. Contact us.

1-800-380-9FNP
1-800-380-9367

familynavigation@sunnybrook.ca

familynavigationproject.ca
Questions?