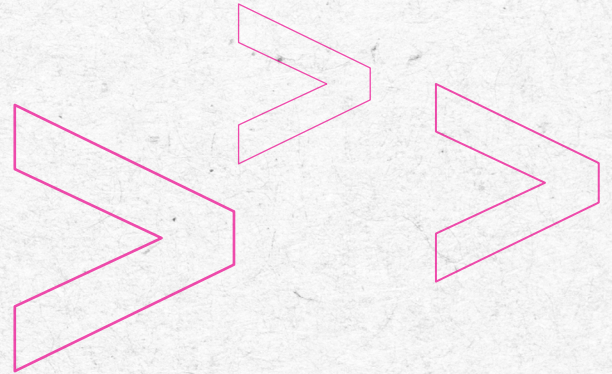




Tools for Decision Makers



Family
Na>igation
Project

at Sunnybrook

Challenges Experienced by Youth and their Families in Mental Health and Addictions Care

Youth, caregivers, and service providers in a qualitative study discussed the challenges they experience when initiating, navigating, accessing, or transitioning through mental health and addictions (MHA) care. What you can do as decision makers to support youth and caregivers is also highlighted below.

Pathways to Care

Inequities in care

- Lack of culturally responsive supports
- Restrictive eligibility criteria (age, MHA concern, location, requirement for formal referrals, etc.)

Geographical location

- Inconvenient service locations
- Lack of local supports

Financial cost of services

- Costly services
- Lack of affordable/free resources

Delays in seeking help

- Difficulty sharing MHA concerns
- Reluctance to access service or initiate care
- Stigma and/or trauma
- Lack of early interventions
- Fear/mistrust of care



What you can do. Advocate for greater funding to increase availability of public and local resources and to improve provider capacity and wait times.

Limited resource availability

- MHA system overloaded
- Services focusing on quantity instead of quality
- Situations escalate to crisis before accessing support
- Service providers diffuse responsibility to manage heavy workloads

Waiting for care

- Long waitlists and wait times
- Lack of immediate/timely supports

Unclear care pathways

- Difficulty navigating MHA system
- Feeling lost, hopeless, and frustrated
- Falling between the cracks
- Disagreements about care pathway
- Lack of care coordination

"Had I known there were services for me for my particular case out there, I feel like I might have been able to, instead of trying and failing in so many different therapies and services, I would have been more able to accurately diagnose and treat the problem that I actually did have than throw a bunch of things at it and see what happen. So I think that would have helped me a great deal cause the earlier that I again, the earlier you can notice the problem, the earlier you are able to treat it. So for me, it took me such a long time to figure out the problem that was bothering me. But also, it also took a long time to find people who would let me talk about it so if I could find a place that I could have talked about it earlier on, I feel like I would have been able to make a lot more progress." - Youth

Youth Involvement

“ Sometimes we have family members involved where, there is an enmeshment with the youth, [the youth] are very agreeable to their parents being involved because they are actually not used to doing things on their own so, that’s where I see them more often and then I am trying to work on fostering the youth’s independence while also allowing them to have a close relationship with family.” – *Service provider*

Need for youth independence to be encouraged in care

Insufficient youth-specific training for service providers

Lack of youth participation in care

- Inadequate consideration of youth’s developmental needs
- Challenging to encourage youth to participate in care

What you can do.

Offer youth-specific training to service providers so that they can most effectively engage youth in their care.



Appropriate and Comprehensive Care

Inappropriate care

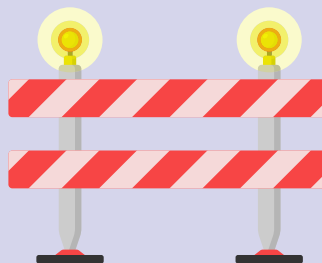
- Inappropriate level of care
- Mismatch/poor fit with service
- Lack of age-appropriate and specialized care
- Unappealing physical environment
- Excessive focus on symptom resolution

Skill and approach of service provider

- Service providers being dismissal and having poor bedside manner
- Prescribing medication too quickly
- Ineffective communication with service providers
- Jargon
- Service provider role constraints

Comprehensiveness of support

- Lack of holistic supports (e.g., ones that take into consideration school, employment, family and peer support, etc. in addition to MHA needs)
- Inflexible services
- Insufficient in-person supports
- Lack of psychoeducation
- Lack of technologically-savvy services



What you can do. Advocate for services to adopt a youth -centered service model to offer developmentally appropriate and comprehensive care.

“ [Youth] would say to them, ‘this is not the right person for me, I don’t feel comfortable,’ ‘well, that’s who we have assigned you to and there isn’t a whole lot we can do about it.’ ” – *Caregiver*

Continuity of Care

Interruption to care

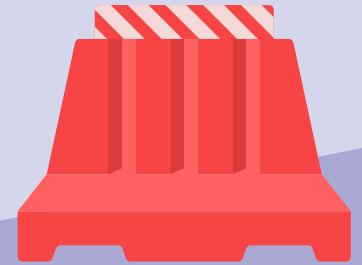
- Termination of services
- Loss of support
- Discontinuous supports
- Minimal follow-ups or check-ins from services

Transition readiness and needs

- Lack of transition planning
- Inadequately preparing youth for transitions

Lack of continuity of support

- Needing to repeat “stories” numerous times for each new service
- Lack of long-term support
- Starting from scratch



What you can do. Form practice networks and support your staff to take part, in order to break down siloes between services and systems.

“When we were in school, it’s a little bit easier just because pretty much every post-secondary institutions have some sort of mental health counselling centre in place...but I definitely feel like it’s a lot harder after I graduated.” - *Youth*

“So I think the planning needs to happen early on, it needs to really sit with the person that’s already established, like the treatment plan and a relationship with the client, whether that involves the family or not, and so it needs to occur really early.” - *Navigator*

Informed Care

Access to resource information

- Difficulty finding information
- Lack of awareness and understanding of available services
- Unequal access to information/resources
- Insufficient meaningful connection and validation/moral support from service providers

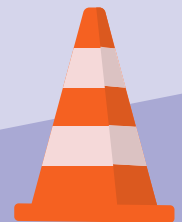
Guidance

- Lack of guidance and support with navigating the MHA system
- Ineffective informal navigation by service providers
- Unclear definition of navigation

Lack of choice in care



What you can do. Ensure services you oversee provide education for youth and families about MHA care and the system.



“I do think looking back that if there were more resources available through my school or my community, if they were advertised better or more accessible then I would have been able to seek help earlier.” - *Youth*

“
know where to turn for help.” - *Service provider*

So the

Family Involvement

Challenges with family involvement

- Youth preference not to involve family
- Family not involved
- Family over-involved
- Conflict and challenging family dynamics

Confidentiality Issues

- Confidentiality limitations preventing families from supporting and learning about or providing input into youth's care
- Families feeling left out of the loop

Caregiver strain

- Balancing caregiving with other responsibilities
- Caregivers feeling responsible for youth's care
- Caregivers prioritizing youth's care over self
- Caregivers uncertain about youth's future
- Caregivers feeling powerless



What you can do. Inform family members about confidentiality policies. Offer families resources and support.

“Youth might think that they have anxiety and that’s what they need help with, and the parent may think that they have a problem with smoking cannabis and that’s what they need help with. Then the reality might be a actually lot more family dynamics and communication issues, and relationship issues, and so how do they know where to go?” - Navigator

What Is Youth Mental Health and Addictions Navigation For?

Youth experience numerous transitions when they reach a certain age and/or when care at a service ends. **Navigation services** can support youth during these transitions and make the process smoother to avoid exacerbating mental health and addictions (MHA) concerns. [From a series of interviews and focus groups](#) with youth, caregivers, and service providers (including navigators), here are the many ways they told us navigation services can support access to MHA care for youth and their caregivers.

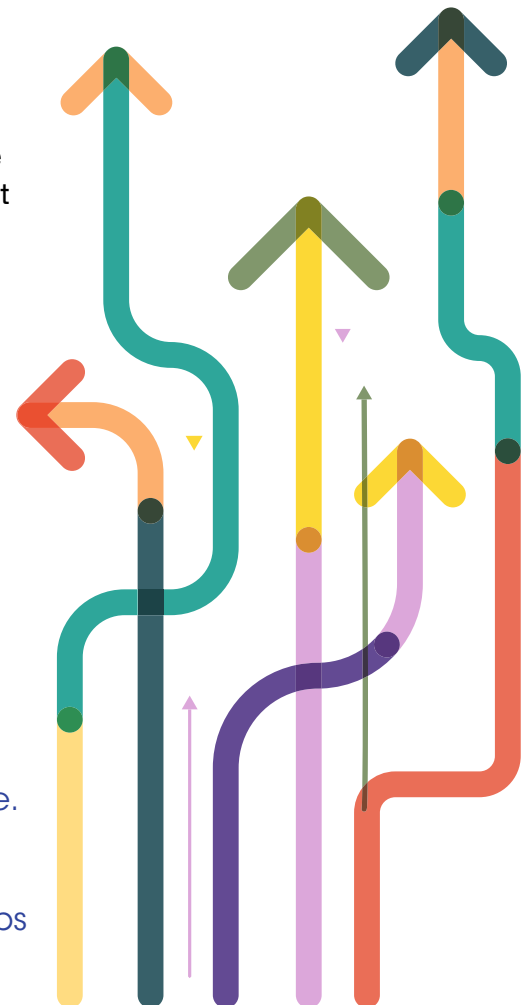
Navigation helps traverse difficult pathways.

- Navigators **connect youth and families to supports** and offer important information and resources to enhance MHA and system literacy.
- Navigators help youth and their family **save time and resources** by conducting research and finding services.
- Navigators **facilitate and improve access** to services for youth and families.
- Effective navigation may help with more **efficient use of MHA system resources**.
- Navigators enhance youth and families' **understanding of the care pathway**.
- Navigators present **creative solutions** to barriers and challenges within the system.
- Navigators **coordinate supports**, facilitate communication between service providers, and help prevent youth and caregivers needing to repeat their stories.
- Navigators actively **advocate** for the youth and families' needs and for changes that need to be made within the system and/or service
- **Limitation** - navigators may experience difficulties in finding appropriate supports for youth due to challenges within the system such as long wait lists, unavailable or unspecialized resources, etc.
- **Limitation** – some youth and families may prefer in-person interaction rather than virtual or phone-based navigation services.

“The navigation team, when I talked to them, was a bit of a lifesaver because they went and did all that work with me and for me, and they're experts at it.” - Caregiver

“I think it'd save money for the mental health care system. I think it'd save lives.” - Caregiver

“I think it's a particular, unique way the navigators will engage with other professionals, in very much of a collaborative stance. Even when we're advocating for our clients to access services, always within a relationship-based collaborative model, of moving things forward, but maintaining those positive relationships at the same time. Knowing that engaging in a positive relationship with another professional will produce more than if you don't develop that relationship.” - Navigator

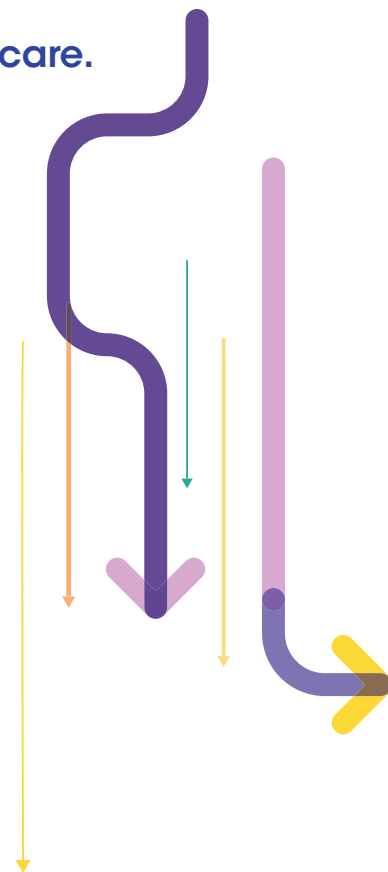


Navigation helps ensure appropriate and comprehensive care.

- Navigators provide **well-matched** service options based on youth and family needs and goals.
- **In-depth needs assessments**, conducted by navigators, supports care planning.
- Navigation services are ideal for **complex and intensive cases**.
- **Limitation** – navigation services can be confused with information and referral services or centralized access. These supports serve different purposes.

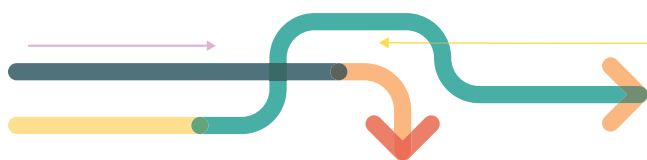
“I think with our program, there’s more flexibility around that so if someone needs to spend twenty, thirty or forty minutes with me, I’m able to do that...I think that speaks volumes for our program. It’s really, I think, the meaning of patient-centred, that we’re molding our program around what fits the person, not some image of what we think the program should be.” - Navigator

“When something is not helpful, a family can let the navigator know that this isn’t working and we have the flexibility to change the path.” - Navigator



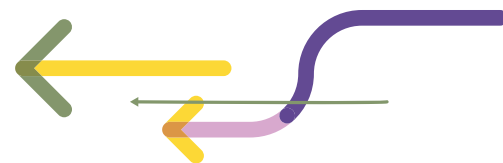
Navigation helps sustain continuity of care.

- Navigators ensure that youth and their families receive **continuous support** through frequent check-ins and by remaining a constant touchpoint.
- Navigators are willing to **reconnect** after discharge.



“Our organization will stay involved as long as the family needs and...we also have the opportunity for families to reengage with us at a later date, should something change.” - Navigator

“..... [My navigator’s] been wonderful. She checks in with me all the time, you know, just to be a human being.” - Caregiver



Navigation helps support informed care.

- Navigators provide youth and families with **expertise, psychoeducation, and training** that enhances youth and their families’ ability to achieve their goals and access the MHA system.
- Navigation adopts a **multidisciplinary approach** to provide appropriate support.
- Navigators **involve youth and families** in care planning through open conversations about resource options.
- **Limitations** – navigation services that provide information/resources alone may not be enough – youth express a need for additional support including guidance, mentorship, and support with connecting to services.

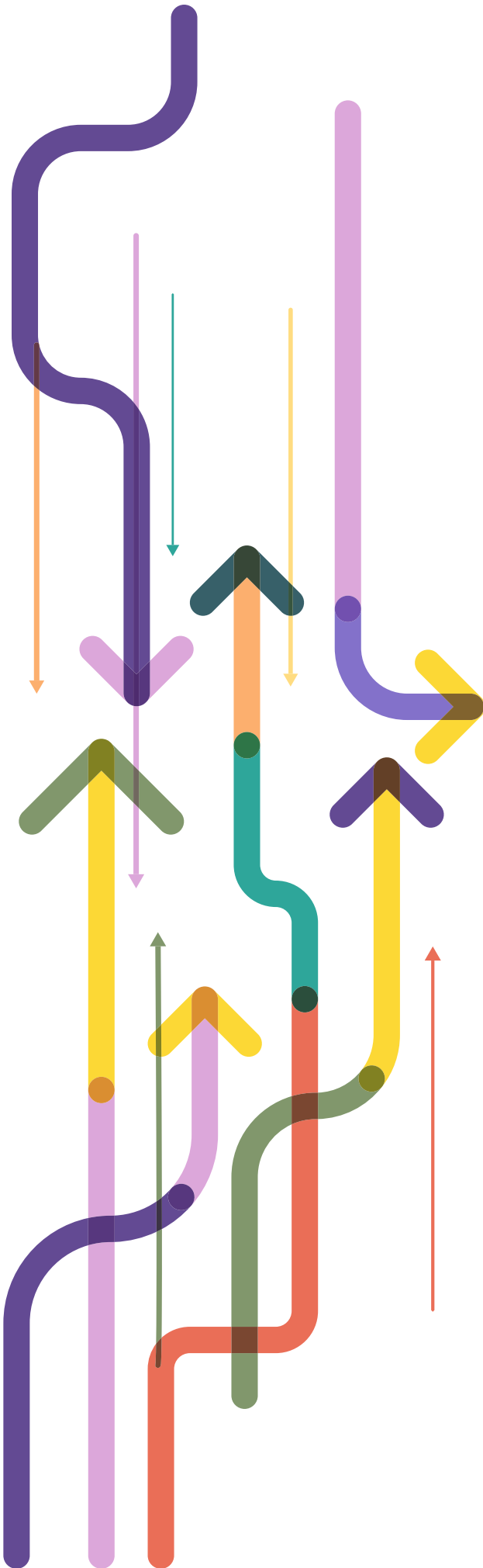
“He was recommending a bunch of different things. That was pretty useful. Like presenting different options and not just telling me what to do, and allowing my family to be there and have a family consultation kinda thing. I think that’s important for the young adult.” - Youth

Navigation helps facilitate youth and family involvement.

- Navigators are **client-centered and flexible**. They accommodate recommendations based on youth and families' goals and preferences.
- Navigators provide **emotional and moral support**.
- **Improvement in MHA symptoms and functioning** for youth can be noted as a result of successful navigation.
- Navigators actively **involve youth and their families** in the decision making and care planning process.
- Navigators help **improve family functioning and relieve caregiver strain** resulting from finding services and understanding the MHA system.
- Youth and families appreciate and express a need for **peer support** within navigation services.

“Being a parent you get the brunt of the abuse and the frustration so I think honestly having that sort of liaison that can help sort of keep that momentum going and encourage the youth to continue to take advantage of the resources that are offered to them, it's really important and it's really key.”

- Caregiver



Conclusion

This toolkit included tools for youth with MHA concerns, caregivers, service providers, and decision makers. The tools highlighted the experiences of youth and caregivers, what they can expect when accessing MHA care along with what can help, and how navigation can support transitions. Overall, youth and their caregivers, experiencing transitions from the child MHA system to the adult MHA system, need knowledge about the different pathways to care and the MHA system along with holistic supports, proactive preparation, youth and family-appropriate care, and continuity in care. Navigation services, such as the Family Navigation Project, can help simplify the process of accessing MHA services, provide individualized resource options and long term support, and collaborate with youth and caregivers throughout their transition journey.

About The Family Navigation Project

The Family Navigation Project (FNP), at Sunnybrook Health Sciences Centre in Toronto, Ontario, is a non-profit, free-of-charge service for transitional aged youth (TAY) ages 13-26 with MHA concerns. FNP supports youth and families living in the City of Toronto, Peel Region, York Region, Durham Region, and Halton Region (i.e., Greater Toronto Area). The Youth Advisory Council (comprising youth with lived experience) and the Family Advisory Council (comprising parents and caregivers with lived experience) are continually involved in providing guidance to the FNP. Learn more about the Family Navigation Project at sunnybrook.ca/familynavigation.

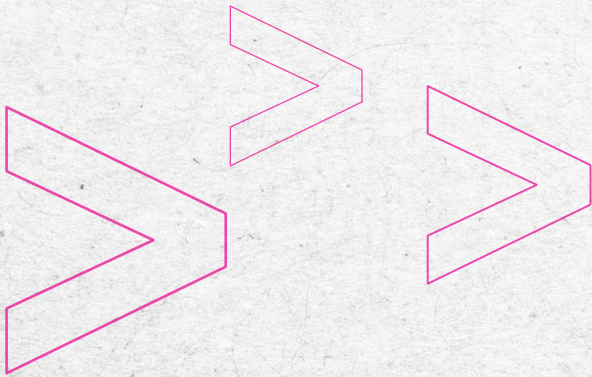
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