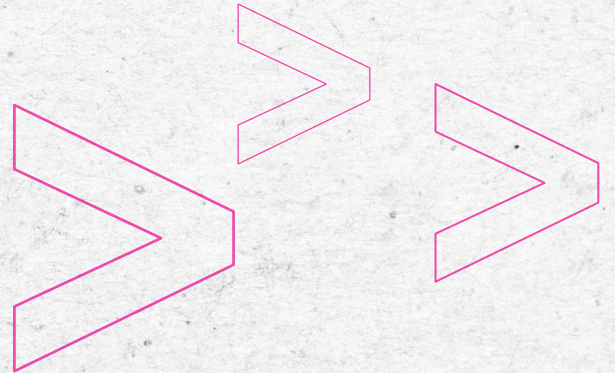


Transitions in Mental Health and Addictions Care

Toolkit for Transitional Aged Youth,
Caregivers, Service Providers, and
Decisions Makers



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Introduction

Transitional-aged youth (referred to more generally as youth throughout this toolkit; typically considered to be between 12 and 29 years of age) experience several changes socially, developmentally, biologically, and psychologically. Many mental health and addictions (MHA) issues first appear or increase in severity during this time. To help reduce the impact of MHA issues, early intervention is essential. However, as youth transition out of child services, they face numerous barriers that prevent them from receiving appropriate support. Such barriers are described and discussed throughout this toolkit. These barriers result in high levels of unmet needs among youth and a decrease in service use. They can also cause strain and impact caregiver's health and productivity. Therefore, resources need to be directed towards a proactive and coordinated approach^{9,10} to help youth and their caregivers address MHA concerns. Navigation services are one promising approach to improve access to appropriate and continuous support.

Navigation is a health care delivery support service that helps individuals find their way through the MHA system by reducing barriers, connecting them to appropriate supports, helping them understand the complex mental health system, and empowering them in managing their health. Navigators are patient-centered and guide individuals through their care plans. Navigation can be an important mechanism for supporting youth and their caregivers in accessing and transitioning through care.

About this Toolkit

This Toolkit contains a series of information sheets and guides with key considerations for youth, caregivers, service providers, and decision makers. These materials are based on two research studies conducted by the Family Navigation Project and our partners from 2019-2021. [Study 1](#) was a scoping review of the care needs and barriers and facilitators of access to care for youth with MHA concerns and their caregivers. [Study 2](#) was a qualitative exploration of youth, caregivers, and provider perspectives on the supports needed for access to MHA care.

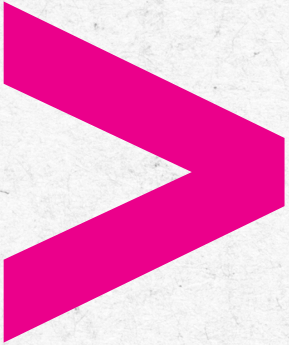
Acknowledgements

This toolkit was developed in collaboration with service providers, youth, and families. We would like to acknowledge and thank the following organizations for their input and feedback – Strides Toronto, Canadian Mental Health Association – Ontario Division, Ontario Association of Social Work, and Family Navigation Project (FNP). We would also like to thank the youth, caregivers, and service providers that took time to participate in FNP's research that supported the development of this toolkit. We would like to thank Canadian Institutes of Health Research for funding the research project that informed this toolkit.

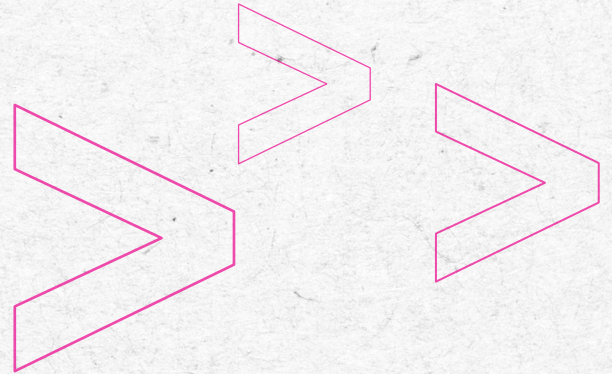
Glossary of Terms

There are many terms used in this toolkit that can have different definitions. For the purposes of this toolkit, these terms are defined as follows:

Accessibility	the practice of making information, activities, and/or environments usable and meaningful for everyone.
Caregiver	Someone who takes on the role of providing support for youth.
Confidentiality	the practice of protecting information and privacy by being selective about when, how, and whether information is shared with others.
Decision makers	Individuals in roles where they are creating policies or supporting operations of mental health and/or addictions services and programs. In these roles, they may be making decisions for a program, a group of other individuals, and/or system(s).
Diversity	variation in personal, physical, and social characteristics among individuals.
Equity	being fair and impartial.
Family	Family can include biological or non-biological immediate or extended family, friends, or others of importance to the youth, who have a role in the youth's care.
Inclusion	efforts made to include people from different backgrounds (e.g., racial, ethnic, socioeconomic, and cultural backgrounds).
Mental Health	Emotional, psychological, and social well-being.
Multidisciplinary	Involving several academic disciplines or professionals to bring multiple perspectives, rather than one discipline only.
Navigation	Services that help youth and families find, access, and transition through mental health care services and resources. Navigation services help youth and families overcome barriers to care, provide client-centered support, and support integrated care.
Peer support	People with lived experiences offering support to others, which can include emotional support, guidance, information, etc.
Service providers	Individuals with professional designations, offering mental health and/or addictions services to youth and families.
Stigma	Negative and/or unfair beliefs held by a society or group of people about something.
Transitional-aged youth	Youth typically considered to be between 12 and 29 years of age and experiencing several changes in their lives and in their healthcare as a result of their age and developmental stage. These can include transitions from child to adult health services, secondary to post-secondary education and/or work, moving away from home, becoming more financially independent, navigating relationships, etc. Referred to simply as youth throughout the toolkit.



Tools for Youth



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You Should Know About Accessing Mental Health and Addictions Care

Learning about mental health and addictions (MHA) care can help you feel prepared for transitions. Here's what we learned from our research participants (including youth) can be helpful to know when accessing MHA care.

1 Seeking help early is important.

Sometimes it can be complex and difficult to recognize signs or symptoms of MHA concerns. Even when signs are recognized, some youth and caregivers believe that MHA symptoms will resolve on their own. Fear, doubt, past negative experiences, and/or stigma also stop some youth from sharing their concerns. These can call cause delays in seeking help. Delaying help can worsen MHA concerns and impact your life negatively.

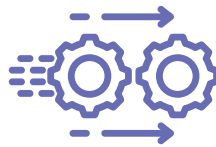
This is why accessing help as early as possible is important to learn how to manage your concerns and achieve your MHA-related goals.



“It’s very isolating to not actually open up about it.”
- Navigator

3 Transitions need to happen when you are prepared and ready.

Many transitions into the adult MHA system happen based on age. This might not be helpful to you because it does not consider when you are ready to move to the adult MHA system. You might not feel ready because these transitions are complicated and they did not get help with planning for transitions. Service providers might not have the time or resources to plan ahead of time. However, to help you get the right support, it is important for service providers to prepare you to make your own decisions and start transitions when you are ready.



“Maybe starting to say, ‘we only have one year left, here’s how we can start preparing you for adult services.’ That would definitely have been appreciated. It would have saved me a lot of headaches.” - Youth

2 Interruptions in care can happen.

You may experience interruptions in MHA care, especially when you turn 18 and have to transition from the child MHA system to the adult MHA system. Care can also be interrupted if you choose to end an unhelpful service in order to find something better for your needs. Sometimes, you might not receive enough information and support, leaving you confused and frustrated. Planning ahead and asking for support from your circle of care can help prevent interruptions.



“When I was in high school there was a counsellor at the school that we were able to go see. Once I graduated, I was no longer able to access that service... That transition was difficult.” - Youth

4 MHA care and information needs to be youth-appropriate and accessible.

Youth told us that they sometimes get support that is not appropriate or specialized enough for their unique needs and goals. Some youth might feel out of place because of their age. Some services might feel unwelcoming or unappealing.



“The environment’s very child-like and it’s like, I’m an adult, but I’m being treated like a child because that’s the only group that they know how to work with.” - Youth

It can be difficult to find helpful and organized MHA information, which prevents understanding and awareness of the adult MHA system. The structure and language of many websites can also seem outdated or overly professional. Lack of accessible MHA information can lead you to search for options online or ask family and friends, which unfortunately can cause you to rely on information that is inaccurate or unreliable.

Some barriers in the MHA system make it difficult to access care that is right for you. These barriers may include –

- Long wait times
- Costly services
- Inconvenient locations
- Restrictive eligibility criteria (requirements for age, diagnosis, referrals, etc.)
- Lack of culturally responsive resources

These barriers can cause you to feel stuck and hopeless. Due to these barriers, some youth are only able to access services when they are experiencing a crisis, meaning they are not connected with support from day to day. While there may be different solutions to deal with these barriers, we heard that youth want MHA services to be more friendly, appealing, and accessible.



5 Continuous support allows you to have stability in care.

Some MHA services tend to be short-term (i.e., 2-3 months), meaning that youth often start over and bounce between services. To access new supports, you might have to repeat your story to multiple service providers, which can be stressful. In short-term services, it can be difficult to build meaningful relationships with service providers. These experiences can be overwhelming and demotivating. Long-term, continuous support is needed for you to have stability in MHA care.

“When I was accessing a new service, the service provider was very conscious that sometimes people used services before and that having to repeat yourself and go over things again can be a difficult thing. So just the fact that these service providers acknowledged it, I found them to be helpful.” - Youth

6 Appropriate skills and approaches of service providers are essential.

Youth need and appreciate choice, participation, and independence in care. Skilled professionals can guide you in the right direction, help you make decisions, and understand MHA information. Proactive and compassionate service providers are essential to help you transition through MHA care.

When accessing MHA care, some youth encounter unhelpful service providers. Service providers told us that roles and responsibilities can sometimes limit them in providing meaningful support. Some service providers are not able to provide long-term support or learn about other services for you because of the divided nature of the MHA system. Service providers also need specific training to better understand and address youth needs and help guide you to what is next for you.

“Being able to have someone to act as a waypoint, a signpost, whatever you want to call it, to be able to put you in the right direction, and say here are the options, I think would be incredible.” - Youth

7 Coordination and collaboration can help you transition through the MHA system.

You may find that it takes a lot of time to understand the different ways to access MHA care. Some youth find it confusing and difficult to understand the pathways even if they are familiar with the MHA system. Some youth find services by chance. Youth often feel overlooked and lost due to unclear pathways or because their providers do not talk to each other. Disagreements between youth, caregivers, and service providers also make it difficult to navigate the MHA system. More coordination and collaboration among you, any involved caregivers, and your service providers can help everyone understand how to access and transition through MHA services.



Flexible MHA services can be helpful to access care.

Youth told us that flexibility is important when receiving and accessing MHA care. Youth find it valuable when MHA services offer different options to connect in-person and/or virtually (e.g., text, email, etc.) Some youth also need support in the evenings or on weekends but they note that many services are offered when they are busy with school or jobs. Youth also told us that having flexible age criteria would be helpful instead of starting or ending service abruptly at age 18. Some youth benefit when MHA services are flexible with including caregivers in their care.

9 Holistic approaches can help you address different goals and needs.

Along with transitions through the MHA system, you may experience multiple changes with school, housing, relationships, employment, etc. Trying to get support for each of these transitions separately can be exhausting and overwhelming. MHA services that use holistic approaches (ones that provide psychoeducation, peer support, support for schooling, support for housing, etc.), can help you address different goals and needs. Holistic approaches that provide family support can also help your family members understand and support you through the MHA system.

10 Involving caregivers requires communication.

Some youth involve caregivers because they provide practical support (paying for care, transportation, etc.) and/or emotional support (validation, reassurance, etc.). Some youth may feel that it is not appropriate or beneficial to involve caregivers because of problematic family dynamics (poor relationships, trauma, abuse, etc.). If you choose to involve caregivers, it is important to keep in mind that it can also be difficult to involve caregivers in your care due to confidentiality issues. Confidentiality-related barriers can cause some youth to feel alone, especially if they were relying on their caregivers to support them. Caregivers can also feel stressed and “left out of the loop.” In these cases, peer support and psychoeducation could be helpful to your caregivers, to help them manage their stress and support you in the best way possible. Communicating with your providers about the ways you wish to involve your caregivers in your care can be helpful.

“I think also that had I not been in a household where seeking mental health was encouraged, and where I spent much time knowing and practicing looking for services and having that experience growing up, I don’t think I would be nearly as comfortable being able to do it myself.”
- Youth

What Can Help When Transitioning between Child and Adult Systems

Upon turning 18, you may transition into the adult mental health and addictions (MHA) system from the child MHA system. Here is what you can look and ask for to support an optimal experience.

Note – Information for this tool was obtained from [Study 1](#). Citations are available upon request if you are interested in learning about the academic articles cited in this study.

- **Look for these qualities in service providers:**

- » **Supportive, motivating, approachable, and flexible**
- » Focus on building **meaningful relationships**
- » Actively involve **you** and **caregivers** (if you choose) in planning and decisions
- » Focus on your **strengths and preferences**
- » Help with **other needs** such as education and housing
- » **Clearly talk to you** about transitions at the beginning of treatment or at least six months before ending the service
- » Invite you to have **conversations** about transitions
- » Encourage **independence** while being available to you
- » Ask for your **feedback** and **opinions** (especially because your perspective may be different from others)
- » Focus on **development** rather than age



- **Ask for information and resources such as:**

- » **Types of supports** available and what to **expect** from them
- » **Peer support**
- » How your **family** can support you
- » What **policies** are in place to manage transitions
- » **Changes in confidentiality policies** as you transition into the adult system.
- » **How to manage** MHA concerns and other issues such as problems with finances and/or housing
- » **Barriers** to care you might come up against, such as strict eligibility criteria, long wait lists, and unclear information
- » **Differences** between the child and adult MHA system you might encounter



- **Ask for transitions to take place:**

- » When you are **ready**
- » **Slowly, proactively**, at **your pace**, and at an appropriate **time** decided together with your service provider
- » With **parallel care**, which means both child and adult service providers provide care leading up to, during, and for some time after transitions
- » With **roles and responsibilities** of everyone involved determined from the beginning
- » With opportunity for **tours** of services and **meeting with potential service providers** to make transitions easier

- **Ask services to:**

- » Consider using an **age window** (e.g. ages 18-30) when possible instead of an age cut-off (e.g. service ends at age 18)
- » Involve diverse service providers and ensure all providers take part in **cultural sensitivity and safety training**
- » Create opportunities to **learn from** and **share your experiences** with other youth
- » Have a **designated transition worker** to prepare you and make sure that you receive care without interruption and/or loss of support
- » Have programs that are **appropriate for your age** and use treatment models that are the **right fit and intensity level**
- » Create a **youth-centred model of care** to support transitions for youth specifically
- » Have a commitment to and/or focus on **equity, diversity, inclusion, and accessibility**
- » **Share information** with you in a way that's appealing to you, such as through social media
- » Promote **MHA awareness and reduce stigma**



What to Expect when Working with Navigation Teams

As youth, you may experience many changes or “**transitions**” after reaching a certain age and/or after completing a service. These transitions can interrupt your mental health and addictions (MHA) care. You may need more support during this time. **Navigation services**, like the Family Navigation Project at Sunnybrook, can support you during these transitions and help you find a MHA service that meets your needs. Successful navigation can help you feel and function better.

[Youth, caregivers, service providers, and navigators](#) told us the benefits and limitations of navigation services. Here’s what you can expect when working with navigation teams.

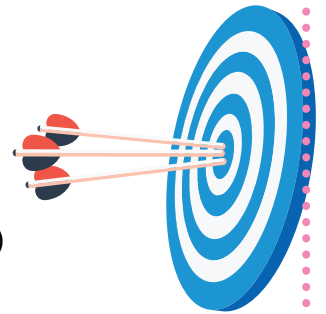


Benefits of Navigation

Navigators...



1. Work well with youth and caregivers experiencing **complex concerns** (i.e., multiple service needs, multiple diagnoses, complicated family dynamics, etc.).
2. Ask for **different types of information** to make a plan of care (i.e., goals, needs, challenges, etc.).
3. Commit to finding a **good service match** to address your unique goals.
4. Apply knowledge from **different perspectives** (e.g., psychiatry, social work, etc.) and offer **training** to help understand and access the MHA system.
5. **Advocate** for your needs by acting in your favor and supporting you throughout the MHA system.
6. Work with you to create, understand, and follow a **care plan**.
7. **Collaborate** with you to make plans and **adjust** options provided based on your preferences.
8. **Continuously support** you during your journey. They check-in often and are **open to reconnecting** after service has ended.
9. Find **creative solutions** if you are facing challenges (such as with finances, school, work, etc.).
10. Provide **emotional and moral support** (they actively listen, offer advice and encouragement, etc.).
11. Help **save time** and **reduce burden** by finding information and services for you.
12. **Work with other providers** (such as therapists, family doctors, etc.) to prevent you from repeating your “story” or experiences.
13. Can also **support your family** which can improve relationships and help deal with conflict.

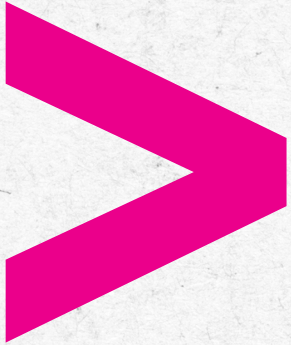


Limitations of Navigation

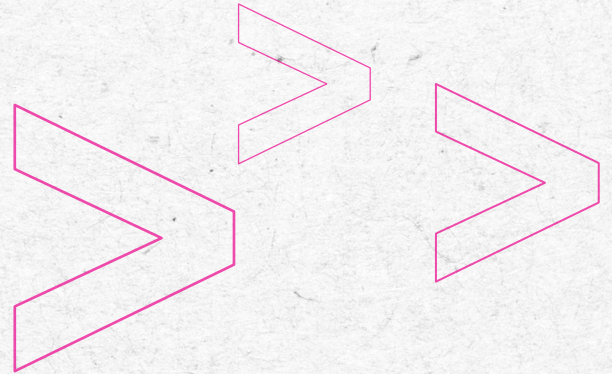
1. Navigators might not always be able connect you to the right supports because of **challenges in the MHA system** such as long wait lists and lack of resources.
2. If you like to talk to service providers in person, you may find **virtual navigation supports** limiting.
3. Navigation services **do not provide direct services**, which can be difficult if you are looking for immediate therapeutic support (such as 1:1 counselling, family counselling, etc.)
4. Some services are only available once the internal staff of an organization have completed their own assessments (this is called “**centralized access**”). Navigators may not always know information about wait times and services offered at organizations with centralized access.

“I found it a lot easier since meeting my Navigator. I found it a lot easier to connect with different services because part of what my issue was is I didn’t necessarily know where to look. [Online searching] only does so much. So a lot of the services that my Navigator introduced me to and that I have started accessing I don’t think I would’ve ever found by myself.” – Youth





Tools for Caregivers



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You Should Know About Accessing Mental Health and Addictions Care

As a caregiver supporting youth in accessing mental health and addictions (MHA) care, learning about the MHA system can help you and your youth feel prepared and equipped for transitions. Here's what we learned from our research participants (including caregivers) can be helpful to keep in mind when accessing and transitioning through MHA care.

1 Seeking help early is important.

It can be difficult and complex to recognize MHA signs and symptoms in your youth. Some caregivers might also believe that these signs are common adolescent behaviors that will resolve on their own. Caregivers may also worry about the stigma of mental health issues affecting youth and other aspects of their lives (e.g. school, work, etc.). This discourages some caregivers and youth from seeking help and opening up about their youth's MHA concerns to others. Delaying help can unfortunately allow MHA concerns to worsen and impact the youth's and family's life negatively. This is why accessing help as early as possible is important as it can help you and your youth learn how to manage their concerns and navigate the MHA system.

"There is nothing more frustrating than not being able to help get your child to the right kind of treatment for whatever his or her illness is." - Caregiver



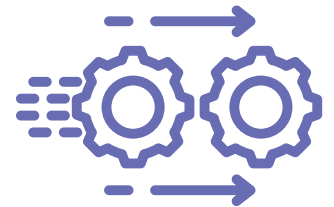
2 Interruptions in care can happen.

Youth often experience interruptions in MHA care, especially when they turn 18 and have to transition from the child MHA system to the adult MHA system. Some youth also experience interruptions if they discontinue a service that was not helpful. Youth and caregivers often do not receive enough information and resources support with planning for transitions in MHA care, which can leave them feeling confused and frustrated. Proper planning and support are important to help prevent interruptions in care.



3 Transitions need to happen when you are prepared and ready.

Services often transition youth into the adult MHA system when they reach a certain age (typically 18) and not when youth are prepared and ready. Youth also share that due to the lack of planning for transitions, they may not feel ready move to the adult MHA system. Youth also need planning to be simplified. Planning for transitions can be a challenge when service providers might not have the time or resources to plan ahead of time. However, it is important to prepare youth to make their own decisions and start transitions when they are ready, so that they can get the right support.



"I have to realize that she will have to be able to do it when she is ready, not when I think she should do it." - Caregiver

4 There is a need for MHA care and information to be youth-appropriate and accessible.

Some MHA services for youth are not appropriate and/or specialized enough to address their unique needs and goals. Some services can be too intense (e.g., intended for youth with greater care needs) or overly focused on prescribing medication to resolve symptoms. Caregivers also share that youth feel out of place because of their age or when services have clients where the majority are younger children or older adults. Youth might find the appearance of some services unwelcoming and unappealing.



“She is 22, so she is in meetings with people who are in their 40s or 50s struggling with mental health issues and learning DBT. How does a 22 year old who is trying to find herself relate to people in that age group?” - Caregiver

It can also be difficult to find helpful and organized MHA information to increase awareness of available supports. The structure and language of some websites can seem outdated or overly professional. The lack of accessible MHA information can cause caregivers to search for options online or rely on word of mouth, which may be inaccurate or unreliable. Caregivers often approach family doctors for MHA information, but may find that some doctors are not up-to-date on available resources.

“I’m not at all an expert and was faced with the most important thing to me in the world, my daughter and her mental health. And despite my education and abilities, I just felt unequipped to know where to go to get her the right help.” - Caregiver

Additionally, some barriers in the MHA system make it difficult to access care that is right for youth. Some barriers may include –

- Long wait times
- Costly services
- Inconvenient locations
- Restrictive eligibility criteria (requirements for age, diagnosis, referrals, etc.)
- Lack of culturally responsive resources

These barriers can impact accessibility of care and make youth and caregivers feel stuck and hopeless. Some caregivers work through these barriers by paying out-of-pocket for services, especially if it is urgent and they do not see any other choice. However, this is not a feasible solution for all families. Limited access to appropriate services also cause some youth and caregivers to only seek services when youth are experiencing a crisis. While there may be different solutions to tackle these barriers, youth and caregivers need MHA services to be more friendly, appealing, and accessible.

“It gets very expensive when you have to start paying for treatment. I’ve got five hundred dollar coverage, that’s not going to last very long. So I have to think about that too, I can’t pay two hundred dollars a session once a week. I just can’t do it.” - Caregiver

5 Continuous support allows youth to have stability in care.

Some youth find themselves starting from scratch and bouncing from one service to another because many MHA services tend to be short-term. They also have to repeat their stories to multiple service providers to access new support, which can be stressful. At or near the end of a service, youth and caregivers often take it upon themselves to research and contact services to ensure they will have continuous support. Caregivers often lack support during the transition period. Short-term services, in particular, make it difficult to build meaningful relationships with service providers and get their help to access continuous support. These experiences can be overwhelming and demotivating. Resources are needed to access long-term, continuous support because this allows youth to have stability in their care.

“I think almost everything I’ve done has been sort of just my own tenacity and research and finding programs, sort of doing whatever I need, writing letters, doing whatever I need to escalate my son’s ability to access them.” - Caregiver



6 Skills and approaches of service providers are essential.

“Having someone help guide you through and even holding your hand to show you what can be done to get you help or get you into group or activities where you can talk and get the help you need. It’s just extremely important that they are there to help you through that time because if you just leave someone on their own and say, find help, they are most likely not going to.” - Youth

When accessing MHA care, some caregivers connect with sympathetic service providers while some might encounter service providers who do not communicate information about MHA transitions effectively. Some youth are left without much choice about when, where, and how to access care. Some caregivers also want to be included in the process. Along with receiving information about supports, youth and caregivers need an empathetic professional to provide guidance, help them make decisions, and understand MHA information.

Service providers might have restrictive roles and responsibilities or experience system limitations that prevent them from providing meaningful support around transitions. Service providers also need youth-specific training to better understand and address their needs. Hence, service providers that proactively help you and youth plan for transitions and are empathetic and compassionate are essential to help you transition through MHA care.

7 Coordination and collaboration can help you and your youth understand and navigate the MHA system.

You and your youth may find that understanding the different pathways to accessing MHA care can be unclear. Some caregivers might find services by chance. It can also be difficult to navigate the MHA system if there are disagreements between youth, caregivers, and service providers. Unclear pathways and a lack of communication between providers often cause caregivers to feel overlooked and lost. This is why coordination and collaboration between youth, caregivers, and providers can help youth and caregivers better understand MHA service access and transitions.

8 Flexible MHA services facilitate access to care.

Flexibility is important to youth and caregivers when they are accessing and transitioning through MHA care. MHA services offering options to connect in-person or virtually (e.g., text, email, etc.) are valued by caregivers. Caregivers also share that services need to be flexible with their age criteria because some MHA services stop abruptly when youth turn 18. Caregivers also benefit when MHA services are flexible with including them in the youth's care. Caregivers appreciate services that operate with flexible schedules so they can provide youth with transportation or company outside of their work time. This is why MHA services with flexible technological options, age criteria, and service hours are important to support access to and transitions in MHA care.

"It can be very difficult because I am in a professional position. I can't always take that call because I'm on a business call, or I am in a meeting, I am travelling for business. I can't always in the moment address the support calling me." - Caregiver

9 Holistic approaches can help you and your youth address different goals and needs.

Many youth experience multiple transitions related to school, housing, relationships, employment, etc. Getting support for each of these transitions separately can be tiring and overwhelming. MHA services that use holistic approaches (ones that provide multiple supports at once, such as psychoeducation, peer support, support for schooling, support for housing, etc.) can help youth address different goals and needs. As caregivers, you may also feel strain when supporting youth. Holistic approaches that include family support can also help you address your own needs as well as understand and navigate the MHA system.

"I took time off work, my husband just had to take a leave of absence. It has affected our mental health, it has affected our relationship, it has affected everything." - Caregiver



10 Processes to involve caregivers change in the adult MHA system.

Caregivers often become involved in youth MHA care to provide practical support (e.g. money, transportation, etc.) and/or emotional support (e.g. validation, reassurance, etc.). There can also be instances where it is not appropriate to involve caregivers in the youth's MHA care. If youth choose to involve caregivers, it is important to keep in mind that caregivers can face several confidentiality issues that can prevent them from being involved in youth's care. Confidentiality related barriers can cause some youth to feel unsupported, especially if they were relying on their caregivers to support and advocate for them. Caregivers also feel stressed and left out of the loop during this time. In these cases, peer support, psychoeducation, and information about ways they can have input could be helpful to caregivers looking to manage their stress and understand how to be involved in youth's care.

"It's almost necessary involving family members because they're the ones that are holding a lot of this health information. They're the ones that are going to help youth engage and stay engaged and everything." - Navigator

What Can Help When Transitioning between Child and Adult Systems

When youth turn 18, they transition into the adult mental health and addictions (MHA) system from the child MHA system. Here's what you can look for and ask for to best support transitions as the caregiver of a youth with MHA concerns.

Note – Information for this tool was obtained from [Study 1](#). Citations are available upon request if you are interested in learning about the academic articles cited in this study.

- **Look for these qualities in service providers:**

- » **Supportive, motivating, approachable, and flexible**
- » Focus on building **meaningful relationships**
- » Actively **involve** the youth (and yourself, when appropriate) in planning and decisions
- » Focus on your **strengths and preferences**
- » Recognize **additional needs and circumstances** such as education and housing needs
- » **Clearly communicate** with you and youth about transitions at the beginning of treatment or at least six months before ending the service.
- » Gradually encourage **independence** with proper supports in place, in case youth need them
- » Asking for everyone's **feedback** and what youth need to successfully transition (especially because your perspective may be different from others)
- » Focus on **development** rather than age



- **Ask for information and resources such as:**

- » **Types of supports** available and what to **expect** from them
- » **Peer support** or the youth and for yourself, and/or family therapy
- » How to **support youth** in the best way possible
- » What **policies** are in place to manage transitions
- » How to **manage** MHA concerns and other concerns such as finances and housing
- » What **confidentiality policies** are in place and how these affect your involvement in the youth's care
- » What **barriers** to care you might encounter, such as strict criteria, long wait lists, unclear information, and/or adult services that don't match the service youth received before
- » **Differences** between the child and adult MHA system you should be aware of



- **Ask for transitions to take place in the following way:**
 - » When youth are **ready** instead of when they reach a certain age
 - » **Gradually, proactively**, and at an appropriate **time** and pace decided by you and the youth
 - » With **parallel care**, which means both child and adult service providers deliver care leading up to, during, and for some time after transitions
 - » With **roles and responsibilities** of everyone involved determined from the beginning
 - » With **tours** of services and **meetings with potential service providers** to make transitions easier

- **Ask services to:**
 - » Consider using an **age window** instead of an age cut-off (e.g. service ends at age 18) where possible
 - » View recovery from MHA concerns as a **continuous process** because recovery may be a lifelong journey
 - » Involve service providers from diverse backgrounds and provide them with **cultural sensitivity** and safety training
 - » Provide you with the opportunity to **learn from** and **share your experiences** with other families
 - » Assign a **designated transition worker** to you, if available, to prepare you and your youth, bridge the gap between the child and adult systems, and make sure that you receive care without interruption and/or loss of support.
 - » Have **age-appropriate programs** and use treatment models that are the **right fit and intensity level**
 - » Commit to and/or focus on **equity, diversity, inclusion**, and **accessibility**
 - » **Share information** with you in an appealing way
 - » Promote **MHA awareness** and **reduce stigma**



What to Expect when Working with Navigation Teams

As caregivers of youth, you may experience strain when helping youth find and access MHA support. Youth experience **many transitions** when reaching a certain age and/or when completing a service. These transitions can impact youth's mental health and addictions (MHA) concerns and increase their need for support.

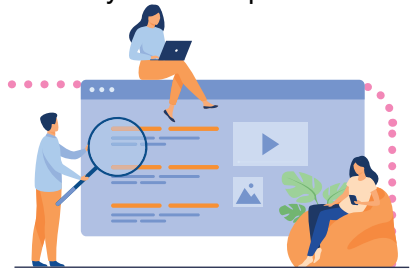
Navigation services can support you and youth during these transitions.

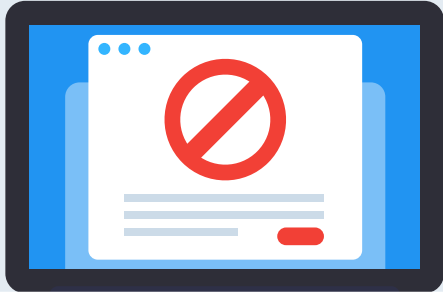
[Through interviews with youth, caregivers, service providers, and navigators](#), they told us what navigators can help with as well as potential limitations of navigation you should know about. Here's what you can expect when working with navigation teams.

Benefits of Navigation

Navigators...

1. Work well with youth and caregivers experiencing **complex concerns** (i.e., multiple service needs, multiple diagnoses, complicated family dynamics, health equity needs, etc.).
2. Complete **detailed assessments** to make an individualized plan of care.
3. Are committed to finding a **good service match** based on youth and caregivers' individual needs.
4. Will work with you and your youth to create, understand, and follow a **care plan**.
5. Have the **knowledge and training** needed to achieve goals and access the MHA system. They apply knowledge from **different perspectives** (such as psychiatry, social work, etc.) to provide support.
6. **Advocate** for your and your youth's needs by acting in your favor and supporting you throughout the system.
7. Will **collaborate** with you and your youth to make plans and decisions. They also **adjust** their suggestions based on yours and your youth's goals and preferences.
8. Find **creative solutions** for the challenges you or your youth might be facing.
9. Can be a source of **emotional and moral support** when you are experiencing frustration with your youth's care trajectory.
10. Help **save time and alleviate burden** by finding information and services for you and your youth.
11. Can **support your entire family** which can help improve relationships and deal with conflict.
12. Can **connect with other professionals** and work with them to prevent you needing to repeat your story multiple times.
13. **Continuously support** you and your youth during your journey. They check-in often and act as a constant point of contact. They are also **open to reconnecting** after navigation service has ended.





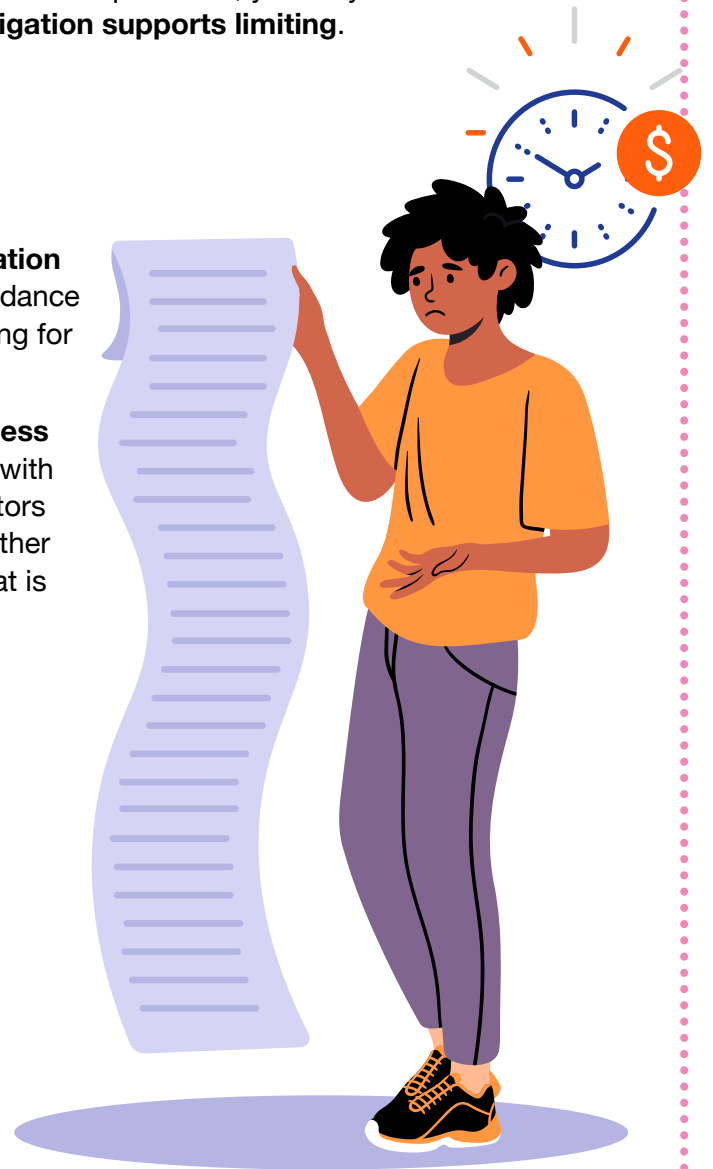
Limitations of Navigation

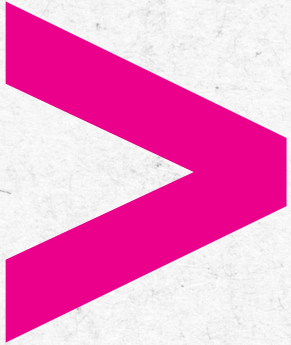
1. Navigators may experience difficulty finding immediate supports for your youth because of **challenges in the MHA system** such as long wait lists.
2. If you or your youth prefer in-person interactions with service providers, you may find **virtual navigation supports limiting**.

3. Some less intensive navigation services offer **information and resources**, but do not stay connected 1:1 for guidance and support. This may not be enough if you are looking for more comprehensive support.
4. Some services are available through **centralized access** which might limit how much a navigator can support with direct connection to these services. However, navigators can stay in touch with you and help connect you to other needed supports while you wait to receive service that is part of a centralized access system.

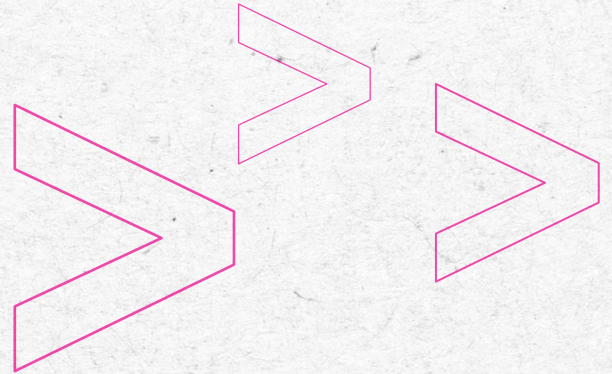
“Being a parent you get the brunt of the abuse and the frustration so I think honestly having that sort of liaison that can help sort of keep that momentum going and encourage the youth to continue to take advantage of the resource that are offered to them, it’s really important and it’s really key.”

- Caregiver





Tools for Service Providers



Family
Na>igation
Project

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

Youth, caregivers, and service providers told us about the challenges they experience when initiating, navigating, accessing, or transitioning through mental health and addictions (MHA) care. Here is what you should know about the challenges youth and caregivers encounter through their transitions in care.

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

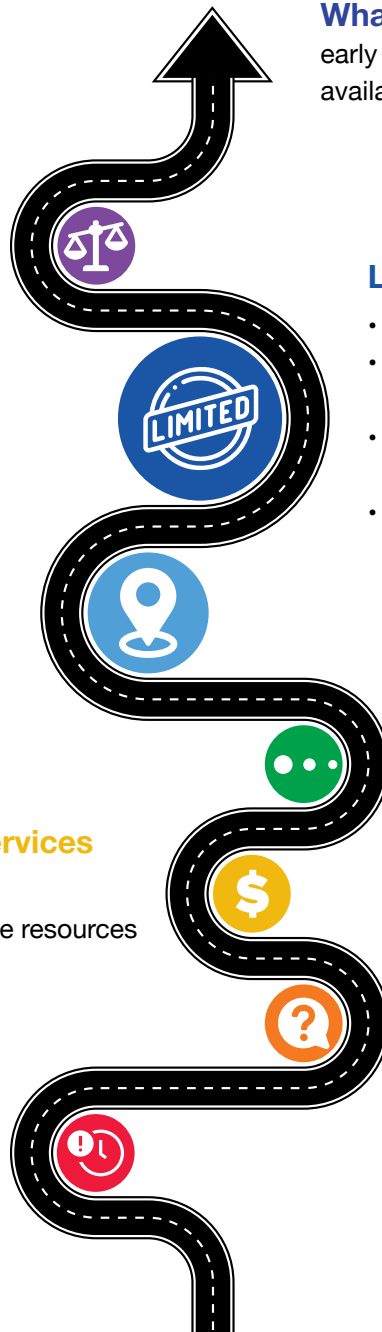
- Inconvenient service locations
- Lack of local supports

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. Start transition planning early and advocate for greater funding to increase availability of public and local resources.

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

“ We just had to transition from the child and adolescent clinic to the adult clinic. In the same hospital, it was a nine month wait. In the same hospital. One doctor referring to another doctor, two floors down, and so, I was terrified. I was thinking, what happens if you have to discharge her and we don't have another doctor lined up?” - Caregiver

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 I am trying to work on fostering the youth’s independence while also allowing them to have a close relationship with family.” – *Service provider*

Insufficient youth-specific training for service providers

Lack of youth independence encouraged in care

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. Engage in youth-specific training to empower youth and address barriers to care.



Appropriate and Comprehensive Care

Inappropriate care

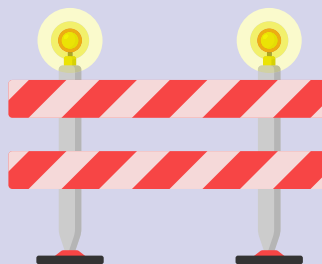
- Inappropriate level of care
- Mismatch/poor fit with service
- Lack of age-appropriate and specialized care
- Unappealing physical environment
- Excessive focus on symptom resolution

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. Adopt a youth-centered service model to offer developmentally appropriate care.

“ Yeah, so when I say general, I mean, services is kind of like a one size fits all approach, like you think you know, if someone can access a counsellor, like that one counsellor will be able to serve 100 people. But of those 100 people, everyone has different needs, everyone comes from sort of different background, everyone has different ways of thinking and if we are able to have you know, different services to accommodate the specific specific needs, upbringings and background of people I think they are not gonna be able to sufficiently serve all of them.” – *Service Provider*

Continuity of Care

Interruption to care

- Permination 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
- Arranging continuous services for self without support



What you can do. Engage in practice networks to break down siloes between services and systems.

“ It would have been helpful if you know, when she went to the hospital and she was attached to a psychiatrist, if they have been able to say, ‘Okay, now we are going to send you to this place and these people will provide you with treatment options.’ Specifics rather than, ‘Okay you get 6 appointments and then you are on your own. Here’s all the information and you figure it out,’ and then maybe you do and maybe you don’t. Maybe you have money for it, maybe you don’t and maybe you would get into a program in year after being on the waitlist and maybe you won’t.” - *Caregiver*

Informed Care

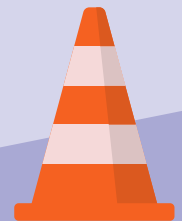
Access to resource information

- 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. Educate youth and caregivers about MHA care, services available that could be right for them, and how the system works in general.

“ But 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*

Family Involvement

Challenges with family involvement

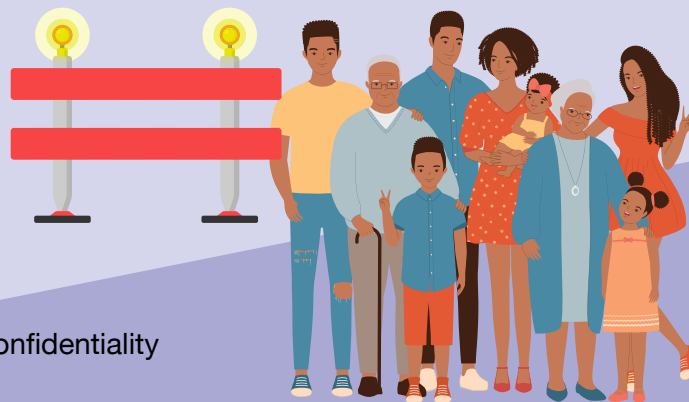
- Youth preference not to involve family
- Family not involved
- Family over-involved
- Conflict and challenging family dynamics

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.

“As an adult, now that she is as an adult, you have to let her do it on her own and she wants to so it's just mostly being supportive and listening...to her frustration when she can't get the help she needs. More being supportive now than anything.” - *Caregiver*

“Some of the youth we deal with have so much family trauma, or their families are just so unwell that it wouldn't be helpful to have them [involved].” - *Navigator*

How You Can Support and Engage Youth and Families – Key Considerations

Youth and their families experience numerous barriers, facilitators, and care needs when accessing and transitioning through mental health and addictions (MHA) care. Here are key considerations for service providers when supporting and engaging youth and their caregivers, based on a scoping review of literature on the topic.

Note – Information for this tool was obtained from [Study 1](#). Citations are available upon request if you are interested in learning about the academic articles cited in this study.

Holistic Supports

Youth and caregivers need flexible, comprehensive, and specialized supports offered by committed and responsive providers.

Consider the following –

- Involve youth in the transition process, at their own pace.
- Youth can experience evolving needs and circumstances. They may be experiencing multiple transitions at the same time, such as changes in living and school along with changes in their mental health care.
- Youth may be at various stages of development, such as ability to manage their own care, financial independence, etc.
- If possible, consider adopting an “age window” as an alternative to an arbitrary age cut-off.
- It can be helpful to frame transitions as “continuing on” instead of “aging out”.
- Acknowledge and work with the youth’s individual strengths and preferences.
- Teach skills that help youth learn to cope with their MHA concerns.
- Participate in cultural sensitivity and safety training to help you provide inclusive services and acknowledge diversity in identities among youth.
- If possible and appropriate, include caregivers as they may wish to be involved throughout the transition process and may have their own unique needs.
- Continuously monitor the needs of youth after transitioning from your care.
- Provide hope for the future.

Proactive Preparation

An essential facilitator to promote access to MHA care is a gradual and proactive approach, preventing youth from experiencing an abrupt loss of support.

Consider the following –

- Plan for transitions well in advance. Have resources readily available to inform youth of what they can expect and to help them feel prepared.
- Discuss transitions clearly and directly at the onset of treatment or at least six months before ending service. Make sure youth and caregivers are aware that they can have these conversations in the first place.
- Recommend and help arrange tours of the next service.
- Have conversations with other service providers that may provide support in the future to ensure care continuity and a warm handover.
- Develop and implement policies to manage transitions.



Empowering youth and Families in Transitions

Empower youth and caregivers during the transition process through engagement, education, and mentorship.

Consider the following –

Engagement

- Actively include youth in care decisions and establish care environments that encourage youth to voice their needs and concerns.
- Develop a youth-centered transition model by gaining feedback from youth who have transitioned as well as ones that are currently transitioning. Obtain feedback about disengagement from services and the facilitators of successful transitions.
- Ensure caregiver involvement when appropriate, while gradually promoting youth independence throughout the transition process.

Education

- Provide information to youth on how to confidently manage their care.
- Educate youth and their caregivers on MHA in general, how the child system differs from the adult system, available supports, and what to expect. Offer this information to youth in the form of awareness campaigns and in accessible settings such as schools.
- Inform caregivers about confidentiality policies and how these affect their involvement in the youth's care.
- Provide training on MHA promotion and youth's unique needs to service providers.

Mentorship

- Offer youth and caregivers opportunities to discuss their experiences with alumni of the services and with peers with similar experiences.



Collaborative Relationships

Collaboration among youth, their caregivers, and service providers is another essential facilitator for access to and transitions through MHA care.

Consider the following –

- From the beginning of transition planning, determine the roles and responsibilities of everyone involved.
- Build positive relationships with youth and other service providers through an approachable, genuine, and friendly attitude.
- Maintain open, honest, and continuous communication with everyone involved in the youth's care.
- Establish transparency and ensure that all stakeholders have the opportunity to provide input about their unique perspectives and needs.
- Connect youth with someone like a transition worker to act as a link between systems and prepare youth for the transition.
- Provide parallel care where possible, wherein service is provided in a joint manner by providers in both child and adult systems for some time before, during, and after transitions.

Systemic Considerations

Systemic barriers need to be addressed to facilitate access to MHA care for youth.

Consider the following –

- Ensure that services are age-appropriate, use the right treatment modality, and are suitable and appealing for youth and their needs.
- Consider and communicate about barriers that impede access to care for youth and caregiver members such as restrictive admissions criteria, lengthy wait lists, and unclear information about when services from the child system end and ones from the adult systems commence.
- Provide support in addressing youth and their caregivers' financial and geographical barriers.
- Take into account the differences between the child and the adult MHA systems.
- Understand that youth, their needs, and their perspectives are distinct from younger children and older adults.
- Advocate for and enhance equity, diversity, inclusion, and accessibility within your service.

Understanding Caregiver Experiences and Supporting Caregiver Involvement in Youth Care

Understanding caregiver experiences in supporting their youth in accessing and transitioning through mental health and addictions (MHA) care is important so that you can understand caregiver roles and effectively support caregivers in your work. Here are considerations shared by participants (including caregivers) that service providers can be aware of when working with youth and caregivers.

Caregivers offer **practical support** by -

- finding, learning about, and recommending services
- providing financial support
- bringing youth to appointments
- encouraging and coaching youth to access services
- checking in with service providers
- completing paperwork
- participating in assessments and treatments

“We both had to learn how to navigate the system, which was a full-time job on top of a full-time job for both of us.”

- Caregiver

Caregivers can offer **soft support** by -

- advocating for youth
- emotionally supporting youth
- normalizing access to care and encouraging participation in care
- understanding the youth's triggers
- being understanding and empathetic toward their youth

Caregivers can experience **confidentiality concerns** as youth move to adulthood.

They can feel -

- unsure about the youth's care
- shut out or in the dark, without a clear understanding of confidentiality
- left out of youth's treatment
- a need to be included to effectively support youth

Caregivers can experience **strain** when managing various aspects of youth's care.

They can feel -

- overwhelmed when balancing caregiving with other responsibilities
- negative effects on their mental health and relationships
- a sense of responsibility to organize and facilitate the youth's care
- unequipped or that they are failing their youth
- as though they are suddenly expected to become experts on the system
- powerless and helpless
- unsure about how to help the youth in the future if they exhaust their current options



“I don't get to go into those appointments. So I have no idea what happens. My daughter will tell me some of what's going on. But I don't have the benefit of being able to provide that objective perspective, to go to the psychiatrist and say, well she says this is happening, but from outside, this is what it looks like. I don't get to be a part of that.” - Caregiver

How Navigation Can Support Transitions – What You Should Know

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 mental health and addictions (MHA) care transitions and make the process smoother. [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 support access to and transitions through MHA care for youth and their caregivers.

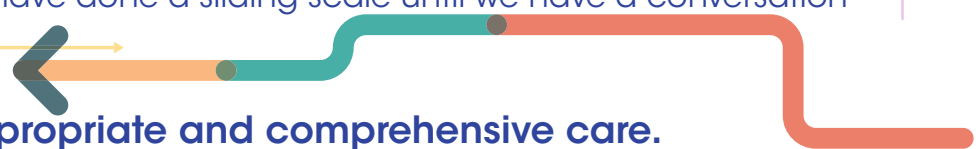
Navigation helps traverse difficult pathways.



- Navigators help youth and families find and access services.
- Navigators help save youth and families' time by leading the process of researching and finding services.
- Navigators support youth and families with understanding and progressing through the care pathway.
- Navigators develop creative solutions to a wide range of challenges faced by youth and families.
- Navigators facilitate collaboration among service providers and communicate youth and family "stories" to minimize repetition for the client.
- Youth and families can turn to a navigator for support to prevent a need for crisis interventions.
- Navigators advocate for youth and families' needs along with advocating for changes that need to occur within the system.

"it really helps you find the right things instead of spinning your wheels and getting frustrated and feeling lost" - Caregiver

"we have actually been successful with a couple of service providers considering doing a sliding scale who would never have done a sliding scale until we have a conversation with them." - Navigator

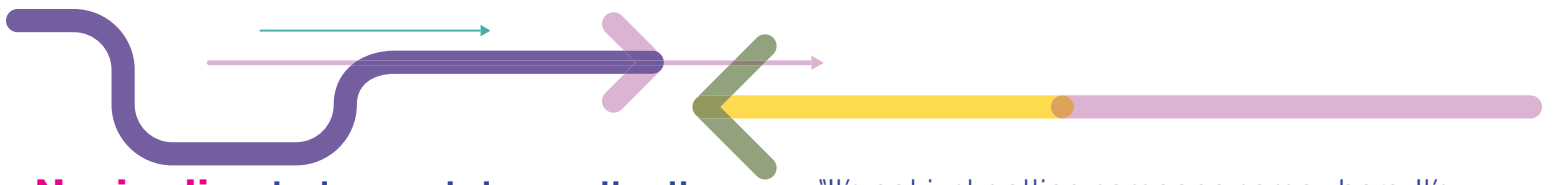


Navigation helps ensure appropriate and comprehensive care.

- Navigators conduct comprehensive assessments to plan care effectively.
- Navigators offer service options that best match the needs and goals of youth and families.
- Navigation services are ideal for intensive and complex cases.

"[When] there's complexity with the service itself or with the need itself, and that's where navigation really comes in... the navigator will actually contact [the service] and ensure that they're sending them to a place that has the capacity to meet that need. and I think that's where the specialized, individualized approach that navigation takes on the case from the get go, that's what differentiates it from [other supports] where essentially the client needs to fit into how they sort of analyze and set up their pathways of service. With navigation really we will develop a pathway based on what the story tells us." - Navigator

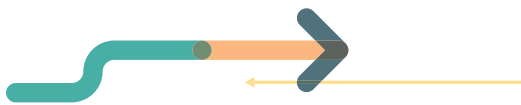
"Gather information about what the youth has been experiencing, a little of their background, mental health background, educational background, personal background, family background, what they have tried, what was helpful, what wasn't helpful, what their goals would be, so what would interest them. It's really taking the time to learn about them and what they would feel would be most helpful for them." - Navigator



Navigation helps sustain continuity of care.

- Navigators provide continuous support and suggest care options that will promote continuity along the care trajectory.
- Navigators maintain an open-door policy to encourage youth and families to reactivate with the program whenever needed.

"The service navigator would kind of help facilitate that referral and be with that client until the referral has come through. And then we have also seen the service navigator stick around for the first little bit, say if a client who is staying in a different program, they would stick around and make sure things are still going smoothly to relay any information to those service providers as needed and to be there if the client needs assistance in any regard while they are in that program. Not necessarily connected through the entire year of the service that they were referred to but just throughout that transition stage, before letting them go which I think is super helpful especially if they run into any issues or maybe the program is not a good fit for them. The service navigator is still connected to them and can work with them to find something that may be better suited for their needs." - *Service provider*

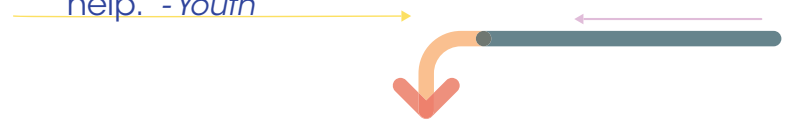


Navigation helps support informed care.

- Navigators offer resource options that respond to youth and families' needs and preferences.
- Navigators offer information to enhance informed choice and participation in care.
- Youth and families' goals are supported through the navigators' knowledge, training, and expertise.
- Psychoeducation provided by navigators enables youth and families to be better equipped with language and skills needed to access the MHA system.

"It's not just getting someone somewhere. It's how do we do that? From a referral to this is the way we talk to service professionals. How can I make that easier instead of "here's list of [services]," I'm going to contact them and I'm going to make sure that they're a good fit. Taking the legwork and frustration away from the client. It's not just getting from point A to point B, it's being able to break down and educate families and make the process in between easier." - *Navigator*

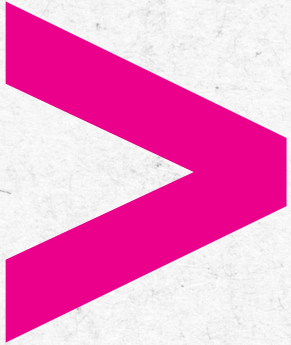
"They help with finding resources that I previously might have not known about, that they exist, or that my doctor may have not mentioned. That's probably the biggest help." - *Youth*



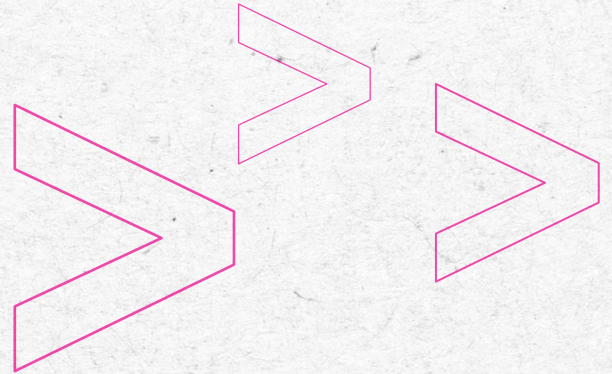
Navigation helps facilitate youth and family involvement.

- Navigators provide youth - and family-centered support and adapt resource recommendations to accommodate for their preferences, goals, and changing situations.
- Navigators emotionally support and validate youth and their families.
- Alleviating caregiver strain and improving family functioning by supporting caregivers in finding and understanding services is another important role of navigators.
- Navigators support family members by involving them throughout the navigation process, building therapeutic relationships, responding promptly, and instilling hope and confidence.

"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*



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

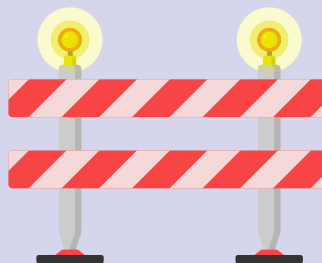
- Inappropriate level of care
- Mismatch/poor fit with service
- Lack of age-appropriate and specialized care
- Unappealing physical environment
- Excessive focus on symptom resolution

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

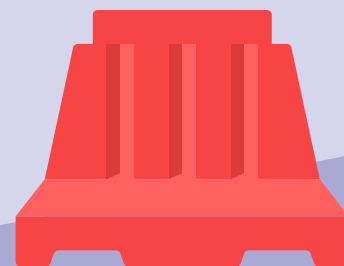
- Termination of services
- Loss of support
- Discontinuous supports
- Minimal follow-ups or check-ins from services

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

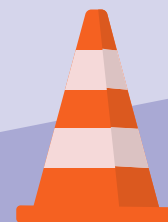
Guidance

- 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*

“So that’s a barrier itself that I didn’t even know navigation services existed. like I don’t know where to turn for help.” - *Service provider*

Family Involvement

Challenges with family involvement

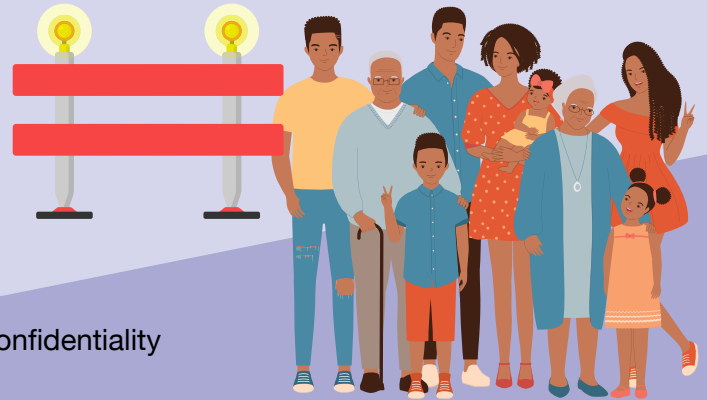
- Youth preference not to involve family
- Family not involved
- Family over-involved
- Conflict and challenging family dynamics

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.

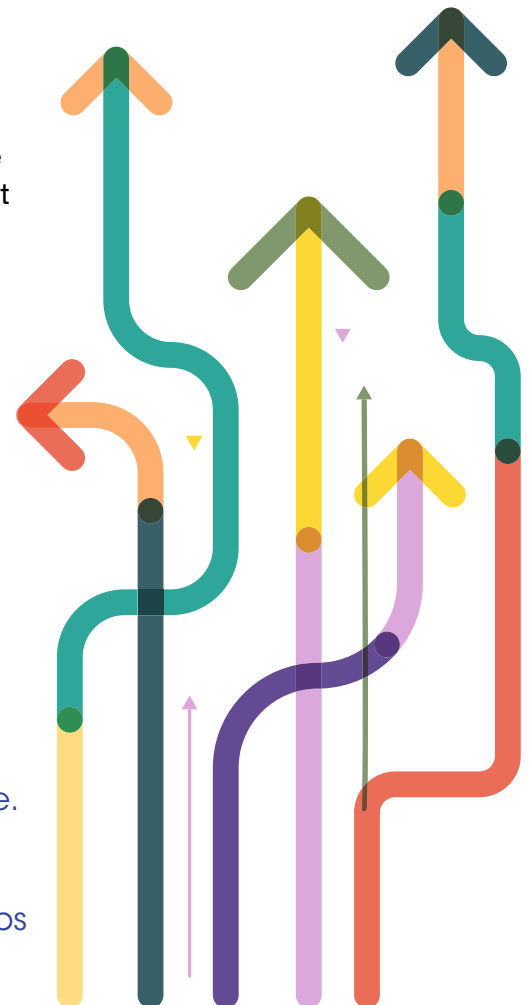
Navigation helps traverse difficult pathways.

- 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

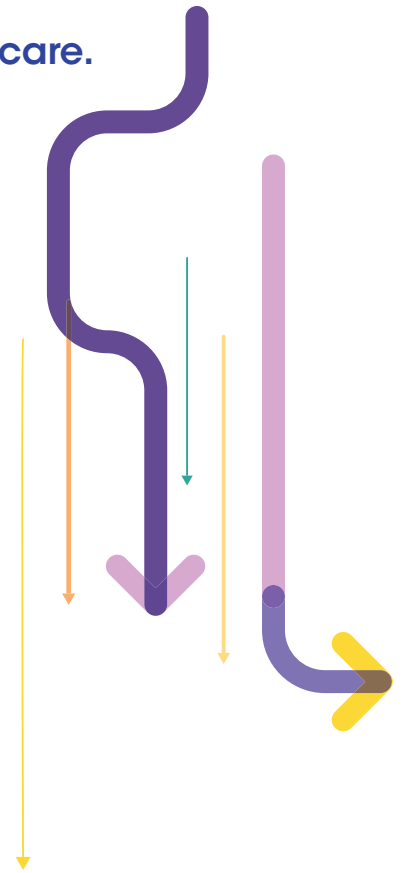


Navigation helps ensure appropriate and comprehensive care.

- 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.

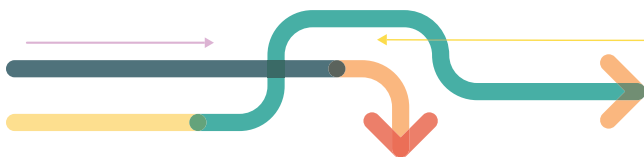
“I think with our program, there’s more flexibility around that so if someone needs to spend twenty, thirty or forty minutes with me, I’m able to do that...I think that speaks volumes for our program. It’s really, I think, the meaning of patient-centred, that we’re molding our program around what fits 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



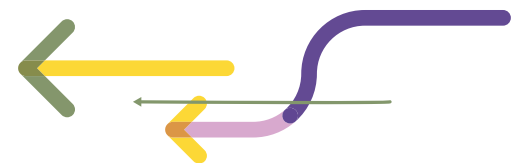
Navigation helps sustain continuity of care.

- 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.

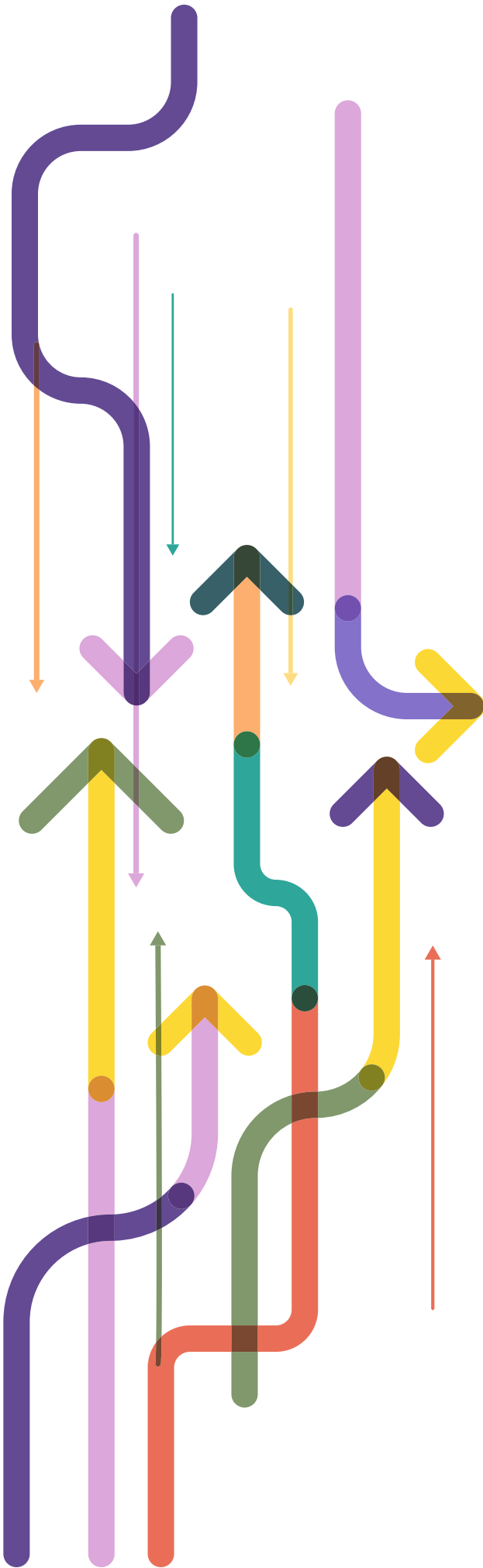
“He was recommending a bunch of different things. That was pretty useful. Like presenting different options and not just telling me what to do, and allowing my family to be there and have a family consultation kinda thing. I think that’s important for the young adult.” - Youth

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.

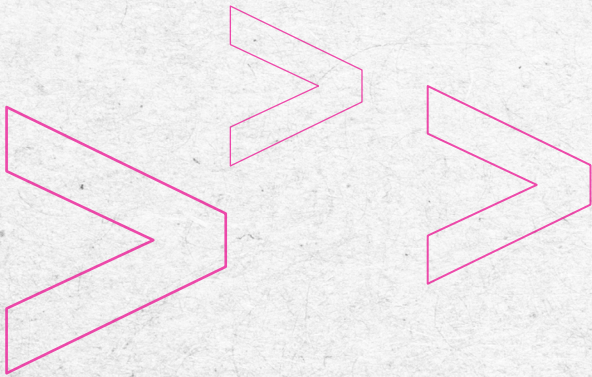
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