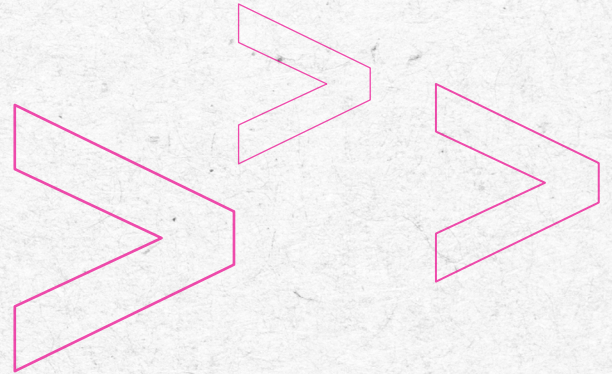


Tools for Caregivers



Family
Na>igation
Project

at Sunnybrook

10 things

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



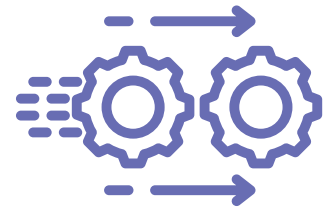
2 Interruptions in care can happen.

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 empathic 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.

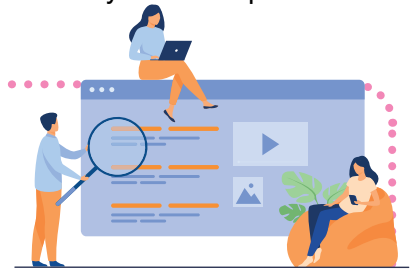
Navigation services can support you and youth during these transitions.

[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.





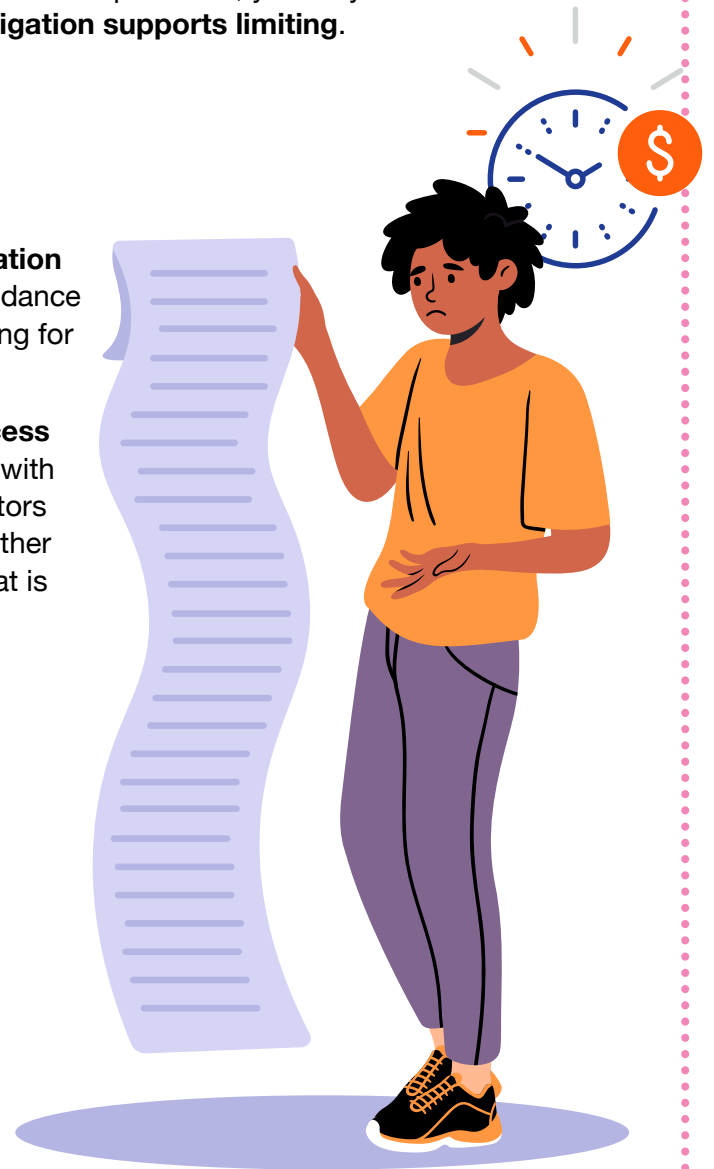
Limitations of Navigation

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



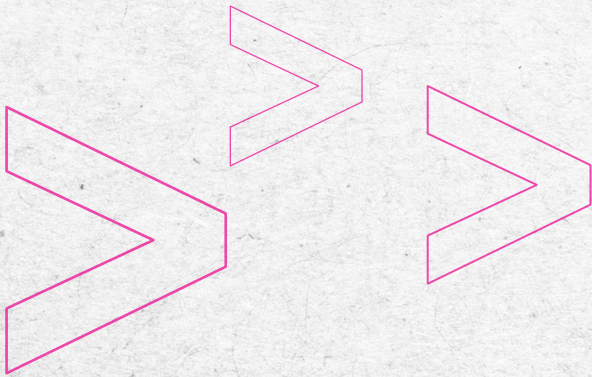
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