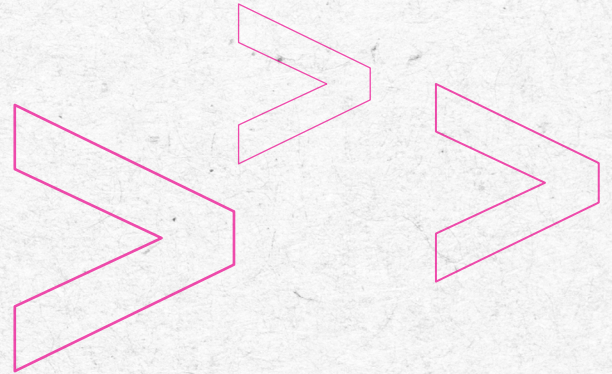




Tools for Service Providers



Family
Na>igation
Project

at Sunnybrook

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

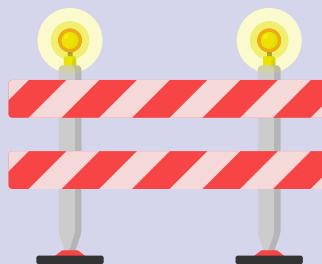
- Inappropriate level of care
- Mismatch/poor fit with service
- Lack of age-appropriate and specialized care
- Unappealing physical environment
- Excessive focus on symptom resolution

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

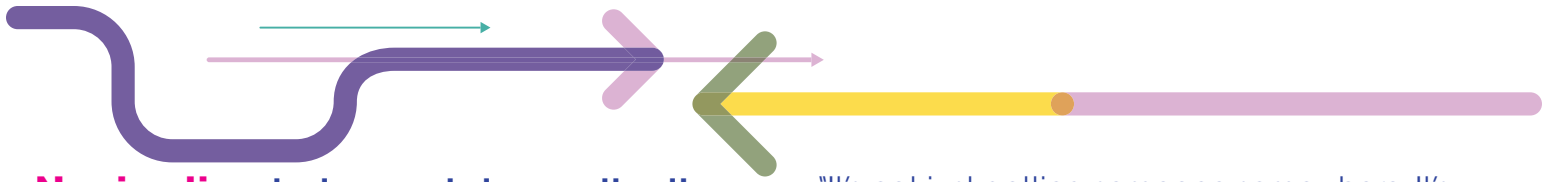


Navigation helps ensure appropriate and comprehensive care.

- 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

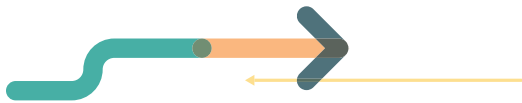
"Gather information about what the youth has been experiencing, a little of their background, mental health background, educational background, personal background, family background, what they have tried, what was helpful, what wasn't helpful, what their goals would be, so what would interest them. 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*

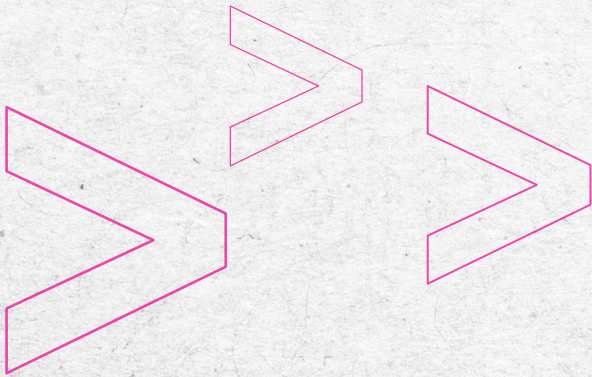
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