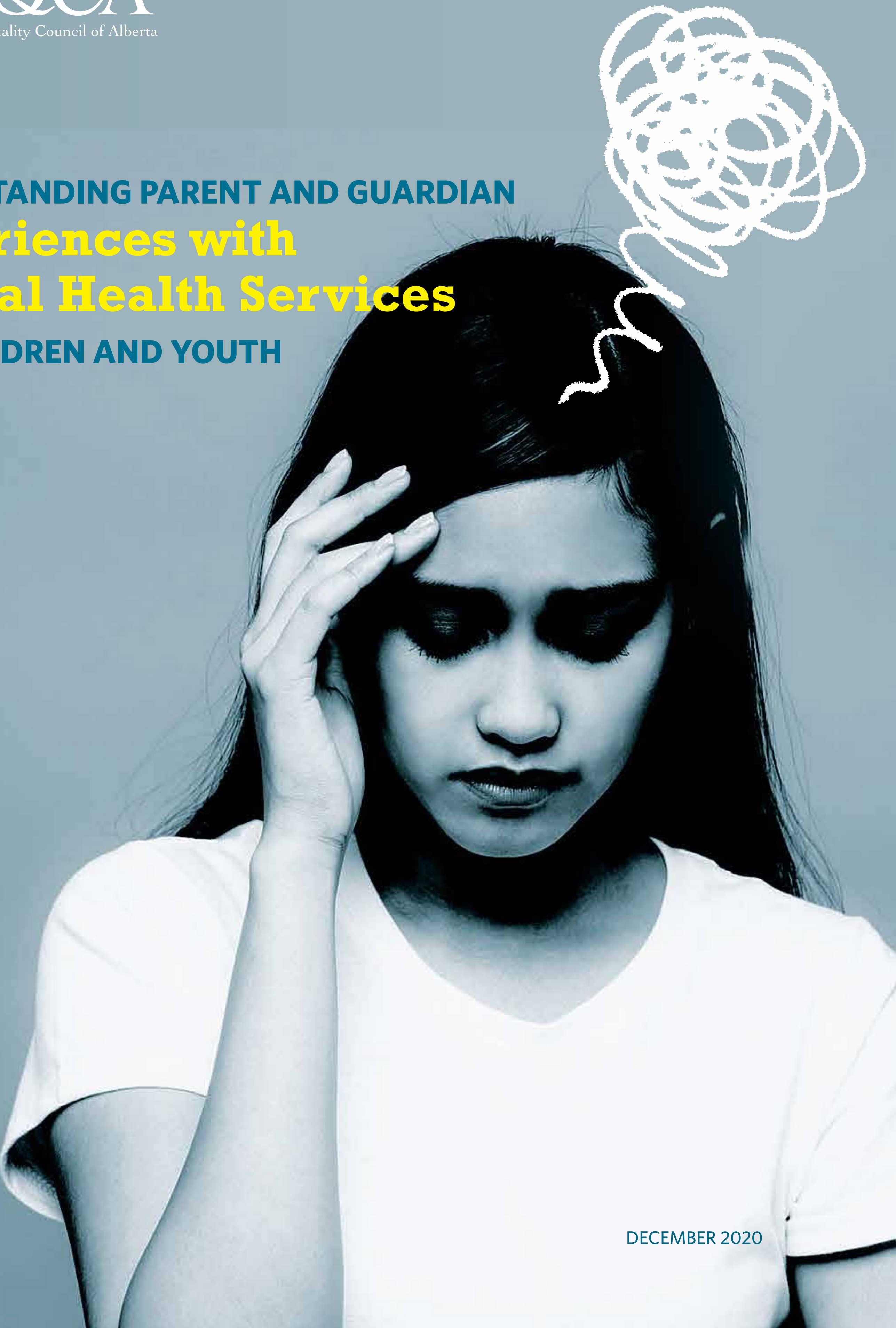
HQCA
Health Quality Council of Alberta

UNDERSTANDING PARENT AND GUARDIAN Experiences with Mental Health Services FOR CHILDREN AND YOUTH



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About

THE HEALTH QUALITY COUNCIL OF ALBERTA (HQCA)

The HQCA is a provincial agency that pursues opportunities to improve patient safety, person-centred care, and health service quality for Albertans. The HQCA gathers and analyzes information, and collaborates with Alberta Health, Alberta Health Services, health professions, academia, and other stakeholders to drive actionable improvements.

Acknowledgements

The HQCA wishes to acknowledge the parents and guardians who contributed their time and insights to this project. This work would not have been possible without close to 400 parents and guardians who participated in our engagement activities. This included a brief online survey and 30 parents and guardians who shared their in-depth experiences with navigating mental health and addiction services for a child or youth via interviews.

The HQCA would also like to acknowledge our Stakeholder Advisory Committee who provided valuable input throughout this project. The committee included representatives from government, health, social, and community organizations, as well as patients and family members. Representatives from the following organizations participated in the committee:

- Addiction and Mental Health Strategic Clinical Network (AHS AMH-SCN)
- Alberta Children's Services
- Alberta Education (AE)
- Alberta First Nations Information Governance Centre (AFNIGC)
- Alberta Health (AH)
- Alberta Health Services (AHS)
- Canadian Mental Health Association (CMHA)
- HQCA's Patient and Family Advisory Committee (PFAC)
- Friendship Centres
- Primary Care Networks (PCNs)
- Sinneave Family Foundation

All Stakeholder Advisory Committee meetings were co-chaired with Alberta Health project advisors, Ryan Lacanilao and Allison Heath.

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Introduction

This report provides insight into the experiences of parents and guardians while navigating their child's or youth's addiction or mental healthcare journey in Alberta.

To capture these experiences, the HQCA conducted **30 in-depth interviews** with parents and guardians of children and youth between the ages of eight and 22, who required addiction or mental health services in the last three years. Interview participants were recruited through a brief online survey and the interviews were conducted from September to November 2019. Parents and guardians were **selected from five designated communities** (Grande Prairie, St. Albert, Red Deer, Airdrie, and Lethbridge) across Alberta. These communities are similar in size and in the availability of services, as well as located in each of the five Alberta Health Services Zones.

The findings cannot be considered generalizable to all families in each of the five target communities or to Alberta as a whole, but their stories are real, important and illustrative, nevertheless. These stories can **facilitate the 'systems thinking'** that is an important foundation of the project and of informing collective system improvements.

The work was requested by Alberta Health to inform future addiction and mental health performance measurement. More information can be found in the Appendix. For any further technical or methodological questions, or details about the brief online recruitment survey, please contact the HQCA office (info@hqca.ca).

HOW to read this report

For ease of reading, throughout this report addiction and mental health services are referred to as AMH services. The parent and guardian interview participants are referred to as parents/guardians, and their children or youth as simply children. The term 'continuum of supports' is used to describe supports and services that range from promotion to prevention, early identification, intervention, and specialized services.

In each section of this report, the parent/guardian experiences are illustrated through direct quotes from interviewees (shown in italics) and provide the following diverse perspectives:

- parents/guardians of children with complex needs
- low and high income families
- parents/guardians living in a rural/remote community
- Indigenous families[1]
- co-parenting parents/guardians
- parents/guardians of gender diverse/non-binary children
- parents/guardians of children experiencing anxiety, suicidal ideation, or substance use issues

To provide further insight into the parent/guardian experience, a fictional character (Amy) and her family's story is presented throughout this report. Amy's story is based on the actual experiences shared by parents/guardians.

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[1] The Indigenous families who shared their experiences are not representative of all First Nations, Métis Nation, Métis Settlements, and Inuit peoples in Alberta.

Key findings – the big picture

Listening to the voices of parents/guardians is a vital source of information to inform improvement efforts in AMH services for children.

The key findings are intended to contribute to current discussions about how parents/guardians navigate AMH services for their children, with the goal of improving transitions in care and connection to the continuum of supports in the community.

The addiction and mental health JOURNEY

Parents/guardians often talked about a journey when sharing their experiences with obtaining appropriate AMH services for their child. The word 'journey' was used because the parents/guardians' experiences often went on for as long as 20 years, and in many cases their experiences are still ongoing. Each of the parent/guardian journeys had challenges and obstacles, as well as positive events and influences. Additionally, some parents/guardians who had more than one child requiring AMH services reported quite different journeys for each child.

> *"I actually have had three children that I have accessed into different areas of mental health . . . I've got three different journeys…"*
>
> *[Parent/guardian]*

Although each journey was unique, the common goal shared by all parents/guardians was to obtain appropriate AMH services for their children, which would support the child's well-being and create a positive outcome for the children and family.

OVERARCHING CONCEPTS found in each journey

Based on the experiences shared by the parents/guardians, three overarching concepts were identified to provide insight into the key elements and complexity of each journey. These concepts are referenced throughout this report and include:

Access to addiction and mental health services: typically, each journey began with the parent/guardian recognizing that their children required AMH services for an emotional or behavioural concern followed by the seeking of those services. Examples of the types of services initially accessed include school counselling services, family doctors' offices, mental health clinics, hospital emergency departments, and family and community services.

Teamwork and communication: After parents/guardians gained access to the appropriate AMH services for their children, teamwork and communication were found to be very influential in the overall experience and outcomes for the children. Teamwork and strong communication were important in three areas: among different service providers, between service provider(s) and the family, as well as within the family.

Coordination of care and follow-up: Throughout each journey, coordination of care and follow-up were identified as contributing to positive outcomes for the children. This included the care responsibilities assigned to service providers, such as ensuring referrals and transitions went smoothly, and circling back with families to check in on their progress. Coordination of care requires teamwork and communication across institutional and healthcare professional boundaries.

Each journey is COMPLEX AND UNIQUE

Each parent/guardian had a uniquely different journey. In order to represent the complexity of the journeys shared by parents/guardians, the board game Chutes and Ladders is used in this report as a metaphor to shine a light on the multiple barriers and the continuum of supports that can influence a single journey. With great consideration for the seriousness and importance of the parent/guardian experience, this metaphor illustrates how parents/guardians can feel like they take two steps forward and one step back when obtaining appropriate AMH services for their children.

Chutes represent the barriers and obstacles which delayed or back-tracked the journey.

Ladders represent enablers and the continuum of supports that helped progress the journey

An added layer to the complexity of these journeys is the impact on other family members. It was identified that every journey affected not just the parent/guardian and children, but every family member.

How the journey can be IMPROVED

Parents/guardians shared what would have made their journey easier. Some of the improvements parents/guardians talked about most frequently include:

Support in accessing services:

- having one consistent person/place (connector) responsible for helping parents/guardians navigate the system
- navigation support in accessing other services (e.g., for low income families who need to access a school program or for a rare disorder)
- ensuring there are specialized and knowledgeable providers who are aware of available resources

Availability of resources:

- increased availability of age-appropriate supports, such as psychiatric hospital unit for children, more child psychologists and psychiatrists, as well as youth centers
- increased availability of specialized resources, such as mental health hospital beds

Public education that:

- recognizes and promotes support groups and parent groups as a valuable resource, especially for learning about helpful strategies to try out at home
- reduces the stigma around mental health – spreading more widely the message that mental health struggles are nothing to be ashamed of

Encourage service providers to:

- not show judgement towards parents/guardians, such as indicating a lack of parenting skills or labelling them as a chaotic family
- increase follow-ups on referrals and appointments, as well as improve communication with the family
- consider the family as a unit, including the wellbeing of parents/guardians and siblings

The beginning of the journey for parents/guardians

Amy's story

My name is Amy and I live with my eldest child Matthew, my second born child Nate and my youngest child Susan. I am a single mom. I left my husband four years ago when he again attacked me and my kids and was then arrested. My husband has always been addicted to gambling to a point where we did not know how to pay our bills. Two of my kids struggle. Matthew, who is 21 now, started having issues when he was eight. He would lie, steal, and then became physical in school and towards his siblings. That is when his long journey started. Nate, who is 16 years old now, started cutting at the age of 12 and that is when our second journey started.

The starting point for these parent/guardian journeys should be reflected on to further understand the complexity and diversity of the stories heard.

Parents/guardians reported seeking AMH services for their children for a wide spectrum of emotional and behavioural concerns. There were multiple concerns for some children, and in many cases the children's needs became more complex over time. Some journeys started when the children were very young; others after entering school or during the teenage phase.

Parents/guardians of children noted a wide range of conditions when they began to seek help. This includes the following mental health or addiction, neurological, and behavioural conditions along with any concurrent non-mental health disabilities:

- anxiety
- depression
- trauma from sexual abuse
- trauma from domestic violence
- fetal alcohol syndrome
- suicide attempt
- eating disorder
- addiction
- rare disorders
- autism
- attention deficit disorder/obsessive-compulsive disorder/attention deficit hyperacivity disorder

> *"It starts with domestic violence for my [child] . . . So, that traumatized my [child], to start with."*
>
> *[Parent/guardian]*

> *"What prompted me to reach out to begin with, [my child] was [age] and expressing to me that [they] felt that nobody loved [them] and that nobody wanted [them] and that [they] would be better off if [they] weren't in this world. . . . I had no idea where to go, who to turn to."*
>
> *[Parent/guardian]*

> *"At [age] we began to notice that [the child's] personality had changed. Over time we realized that [the child] wasn't eating the way [they] ought to be and as we were starting to get concerned, we got a phone call from school, saying [they] hadn't eaten [their] lunch."*
>
> *[Parent/guardian]*

Overarching concepts found in each journey

Based on the experiences shared by the parents/guardians, three overarching concepts were identified to provide insight into the key elements and complexity of each journey.

Access

Teamwork and communication

Coordination of care and follow-up

Access to addiction and mental health services

Amy's story

When Matthew first started showing concerning behaviours, it took quite some time before we got help for him because the school councillor told us that he was just going through a phase and that it would go away. Then I went to a walk-in clinic and the doctor also advised us to wait, as it might be just Matthew adjusting to a new teacher at school. But it was not just a phase and it did not go away, and no one listened to me. We finally got my oldest child a therapist through my employee assistance plan (EAP), but that plan only covered six visits. So, what was the point? After pushing and pushing I got a referral to a psychiatrist. But again, he dismissed my child's issues saying that he was just a bored kid.

With my middle child Nate, it was smoother, and all my experience finding support for Matthew helped me throughout this very different journey. Nate is 16 years old now and started cutting at the age of 12. First, I went to my family doctor, who I have known for four years and who is always available to see me and my kids. He referred Nate to a child psychiatrist, but it turned out that we had to wait six months to see him. I had to go with that because private services were not an option as that was too much money. I lost my job shortly after I left my husband and no longer had access through my employee assistance plan. One night, Nate was terribly upset and threatened to self-harm. I did not know what to do. So, I took Nate to the emergency department, but nothing happened, no doctor came. We were just sitting there for hours and at some point, Nate refused to stay any longer, so we went home without any help. We went back to our family doctor the next morning. Our family doctor phoned the child psychiatrist and explained Nate's situation. We were able to see her within two weeks which was still a very tough time, as I was in a constant state of hyper-vigilance and fear that my child would self-harm again, or worse...

Access to addiction and mental health services

After parents/guardians determined that their children had emotional or behavioural concerns the first action taken in their journey was to access AMH services. Parents/guardians shared that overall they experienced more barriers than enablers when accessing AMH services for their children. The main factors that contributed to more or less effective access to these services included:

- **availability of appropriate and/or qualified service providers**
- **length of waitlist or referral period**
- **available finances and insurance coverage**
- **attitudes of service providers and school staff**
- **appropriate and timely identification**
- **additional challenges navigating mental healthcare, justice and social services**

Availability of appropriate, qualified service providers: Most parents/guardians said that when seeking help for their children, a frequent barrier was a lack of age-appropriate services, such as specialists and qualified providers. This was especially problematic in rural/remote communities.

> *"It's just too bad that there isn't more child psychiatrists around, but what do you do if there is none around?"*
>
> *[Parent/guardian living in a rural/remote community]*

Access to addiction and mental health services

Parents/guardians cited that their initial contact was often with their family doctor or the school counsellor, who then referred them to or connected them with a mental health provider. However, these providers often lacked the specific knowledge or qualifications to provide AMH services to children. Examples include how to address childhood trauma (e.g., sexual abuse, domestic violence and suicide in the family) or how to support children with very high and complex needs.

Another concern expressed by parents/guardians was the lack of support to address crisis situations requiring immediate attention. In some of these situations, parents/guardians sought care for their children at hospital emergency departments, but had to wait for hours and were often not assessed as severe enough, and consequently, were sent home or left without being seen.

In many of these childhood trauma and crisis situations, parents/guardians reported they were provided prescription medication only with no other support strategies for helping their children at home.

A lack of age-appropriate supports and specialists, such as psychologists specializing in eating disorders or mental health professionals with experience in gender diverse clients, was reported more frequently in rural/remote communities. These families had to commute to an urban centre to access appropriate support for their children. Commute times ranged from two to twelve hours when living in rural/remote communities. This long commute was a financial burden for some parents/guardians as it often included taking time off work and travel costs such as gas and staying overnight. Consequently, we heard that some parents/guardians were forced to avoid out-of-town specialist appointments completely.

> *"I can't take Monday, Tuesday, and Wednesday to drive to [city], because there's no way I can afford [dollar amount] a day in gas and parking and then [dollar amount] in lost wages."*
>
> *[Co-parenting parent/guardian]*

Length of waitlist or referral period: Parents guardians shared that the long wait times to access AMH services, as well as extended periods between appointments is a significant barrier. This can be extremely stressful and burdensome for parents/guardians when their children need immediate help. The children, on the other hand, often lost their motivation to accept help during the long waiting period.

> *"You have a child that agrees to go, and by the time that that door's open for you, they have lost the comfort in thinking that it's okay to go, and that makes it really, really tough."*
>
> *[Low income family]*

Access to addiction and mental health services

Available finances and insurance coverage: In order to overcome long waitlists, parents/guardians sought out private AMH services when they could afford them. Parents/guardians who had AMH services covered through employer benefit packages had some financial relief; however, benefits often only cover a limited number of visits and the service providers frequently focused on adults. In one heartbreaking story, the parent had to decide between purchasing food or paying out-of-pocket for a therapy session. Even more financial stress was experienced in relation to accessing AMH services when parents were experiencing other financial or emotional hardships such as job loss or court proceedings.

> *"Over the years, we have paid [thousands of dollars], out of our own pocket, for [our child's] mental health care, and I don't think it's right. . . . At times we've said to each other 'What would have happened if we didn't have the money?' And we're quite convinced that [our child] would be dead in that case."*
>
> *[Co-parenting parent/guardian]*

Attitudes of service providers and school staff: Parents/guardians encountered judgemental attitudes from service providers during their journey, such as perceived ignorance, stigma, and trivialization. For example, some parents/guardians felt their concerns were labelled as "just a phase" and not taken seriously. In other cases, parents/guardians felt judged or blamed for their children's struggles because of their difficult family circumstances, such as a low income or domestic violence.

Parents/guardians also experienced negative attitudes from their child's school teacher, school counselor, or principal. This sometimes led parents/guardians to switch to a school with accommodating and understanding staff who worked together to ensure their children's needs were addressed.

> *"I think one of the biggest mistakes I made at the time was that - and I think this is how we ended up with the "chaotic" label - was that I admitted that my [partner] has [issues]."*
>
> *[Parent/guardian of children with complex needs]*

Appropriate and timely identification: Parents/guardians also experienced hurdles when their children received the wrong identification or no identification at all, which required accessing AMH services all over again and thus, further delayed their journey. Some parents/guardians reported that it took years to get an accurate identification or diagnosis and some children had multiple diagnoses. During this delay in the parent/guardian journey diagnostic criteria can change, resulting in the children not meeting the specific diagnostic criteria required for access to additional funded supports for their children. Moreover, a few parents/guardians reported their children were medicated without any diagnosis.

> *"We still don't have a diagnosis. We're medicating with [medication] without a diagnosis, which is quite frustrating, because I don't know how to proceed as a parent."*
>
> *[Indigenous family]*

Access to addiction and mental health services

Finally, an inaccurate diagnosis is specifically problematic as the school can sometimes only accommodate attending to the children's additional needs when there is an Individualized Program Plan (IPP) in place. A few parents reported that a diagnosis is required to get additional funding for creating and supporting the IPP. However, in some cases, school districts have IPPs in place without a formal diagnosis, and in other cases, there is no IPP required to receive additional supports.

> *"[The school] was impossible to deal with. And it took more than a year to get an IPP established."*
>
> *[Co-parenting parent/guardian]*

Additional challenges navigating mental healthcare, justice, and social services: Overall, parents/guardians found AMH services in Alberta to be very complex, and often reported they felt lost in the mental health system as they did not know where to go or if they were on the right track. This was especially difficult when their children moved among different AMH services. Moreover, if the children missed a certain number of appointments or the provider moved away or went on leave, their file was sometimes closed. In order to reopen the file, parents/guardians reported that the whole intake process had to be started again including all the paperwork.

> *"It is an absolute nightmare, because you just finish with one service, and you've gone through this whole rigmarole. It's taken months . . . and then you have to start all over again, because there's no connect between the two services."*
>
> *[Parent/guardian of children with complex needs]*

The added involvement of the justice or the social system can further challenge navigation. For example, co-parenting was identified as a significant obstacle, particularly when legal proceedings are required because of one partner's unwillingness to provide consent for their children's treatment.

> *"It's hard to get my children the proper care because that's the justice system right now, and having to have both parents consent, that's what I find hard."*
>
> *[Co-parenting parent/guardian]*

Foster parents and permanent guardians face additional barriers such as different rules and policies around medical rights. Obtaining additional social services supports at home was reported to be difficult and frustrating for respondents and some of them gave up on the process.

Some parents/guardians also expressed frustration with approaches to care that did not address the "bigger picture", i.e., the whole family, or body and mind together.

Teamwork and communication

Amy's story

Finally, after researching and pushing again, I got Matthew into a social skills program, which connected him with a different psychiatrist. Matthew had a connection with this psychiatrist and after getting diagnosed with an impulse control disorder, he was started on medication. When Matthew was set up with the social skills program, we experienced improvements on many levels. I felt that Matthew was in good hands. It was a great relief that I finally did not have to repeatedly tell Matthew's story, which always felt so intimidating as it is not easy to talk about all these sensitive topics over and over again. Moreover, I did not have to deal with a frustrating amount of paperwork anymore and signing consent forms. However, I still had problems with the school. They were hard on me because Matthew had been physically aggressive in school. They did not ask what was going on, they did not provide any help for Matthew, and they just gave me the feeling that I am a bad mom. I finally decided to switch schools, and this was extremely helpful. The principal and the teachers at the new school were quite understanding and accommodating of Matthew's difficulties.

Nate was finally set up with a child psychiatrist and through working with her, it appeared that Nate struggled with finding their gender identity. At this point the child psychiatrist connected Nate with a specialized psychologist who Nate felt safe with and who also got them into an amazing program with other gender diverse children their age. Nate still struggles with mood swings and melt downs and there are phases where they miss a lot of school. However, the principal and the teachers at their school are very empathetic and supportive of Nate's journey in finding their gender identity.

Once parents/guardians were able to access AMH services for their children, teamwork and communication was reported as being important for the overall experience and outcome for the children. Teamwork and communication were important in three different areas: among different service providers, between service provider(s) and the family, as well as within the family. The main teamwork and communication factors that contributed to effective care flow included:

- **school involvement**
- **relationship with service provider**
- **information sharing and teamwork between providers**
- **communication within the family**

School involvement: A recurring message from respondents was the essential role children's schools play during the journey. The school can make a positive difference by noticing the children's struggles, helping the parents/guardians to connect with needed AMH services, and providing additional supports in the classroom. Some parents/guardians reported instances of school staff not acknowledging their concerns or being judgemental of mental health concerns. These experiences caused some parents/guardians to switch schools or start home schooling.

> *"The first school [the child] was at, we didn't have good communication and it wasn't really helping and supporting. So, I found a different school that was more willing to be on board."*
>
> *[Indigenous family]*

Teamwork and communication

The majority of parents/guardians reported a more positive experience, and talked about the school being accommodating with empathetic teachers and qualified school counsellors who referred them to programs and specialised AMH services, if needed. Unfortunately, school counsellors were sometimes only based in high schools and not available in elementary or middle schools.

> *“I have to admit, [the teachers] were my strongest support, and still are. I mean, they have [the child] all day. They see what’s going to happen or what has happened.”*
>
> *[Parent/guardian of children with complex needs]*

Relationship with service provider: Once connected with a provider, a trusted relationship between the family and their service provider was identified as crucial – otherwise the family often lost motivation to use the service or their children were not engaged. Parents/guardians described the following key factors as important to creating a trusted relationship with their service provider: listening to and taking the concerns shared seriously; providing a non-judgemental ‘safe space’ for the children; and, ensuring the family has resources and strategies to support them in their day-to-day life.

The inability to maintain an ongoing relationship with a trusted service provider was a source of frustration for parents/guardians. Some examples included providers changing jobs, moving away, or taking leave. This was specifically problematic for rural/remote living families as it often resulted in having to start their journey all over again.

> *“[The child] always really liked the therapist. [The therapist] did [take] leave … and the [person] that filled in, just didn't have the same rapport with [the child].”*
>
> *[High income family]*

Information sharing and teamwork among providers: Parents/guardians shared that they often have to tell their story again and again, which is especially intimidating when sensitive topics are involved, such as sexual abuse or domestic violence. Parents expressed lack of certainty about whether providers were sharing information behind the scenes; however, hoped or assumed that they were.

> *“You have to retell your story every single time, and it drives me nuts. I wish there was a more streamlined way that your story, your case, your file, whatever it is, could be passed among people, instead of having to redo it all the time…”*
>
> *[Parent/guardian of transgender child]*

Teamwork and communication

In a few journeys, parents/guardians stated that patient information about their children was shared among different providers, who worked together with the family. This information was shared using paper files, and some family members talked about signing consent forms to allow the information to flow. Moreover, parents/guardians appreciated when providers kept them in the loop and informed.

> *"For our family, we need to all be involved, and the doctors and the counsellors. We really all need to work together."*
>
> *[Indigenous family]*

Communication within family: Based on the interview responses family environment has a critical impact on the course of the journey. A problematic family situation (e.g., strained co-parenting relationship, domestic violence) can make an already challenging journey even more difficult. On the other side, open and honest communication about the child's struggles within the whole family had a positive impact on the journey. Similarly, a positive environment at home also helps the children to cope better with their struggles.

Coordination of care and follow-up

Amy's story

And this is the bitter part of our story. Matthew improved a lot with the help of the program, but as soon as he turned 18, everything we achieved, collapsed. There was no plan in place to transfer him into the adult system, and Matthew is not capable of making the best decisions for himself. Becoming a legal adult also meant that he lost me, the person who would push and advocate for his treatment. Matthew moved out two years ago, and he stopped taking his medications. He is now self-medicating with other substances instead. I am at the point again, where I do not know what to do.

Our family doctor has been most helpful over the past four years and he followed up with the whole family. 'Nathalie' has just recently requested to be referred to as Nate and now uses the pronouns he/him. Thankfully, things are better now for him compared to his brother Matthew. He still sees his psychologist and performs really well in school.

Parents/guardians consistently cited coordination of care and follow-up as a contributing factor to their ability to navigate AMH services and supports. Coordination of care and follow-up refers to the responsibilities assigned to service providers, such as ensuring referrals and transitions go smoothly, and circling back with families to check in on their progress. Key factors that parents/guardians reported contributed to effective care flow include:

- **family doctor as a care coordinator**
- **parent/guardian role as advocate for care**
- **coordinated transitions between providers**
- **follow up with family**
- **transition plan to adult mental health system**

Family doctor as a care coordinator: Family doctors, with whom parents/guardians often connect first when seeking help for their children, were identified as playing a significant role during the journey. In a few cases, parents/guardians talked about their family doctor as being a good connector, who coordinated referrals and regularly checked in with the family. In other cases, parents/guardians noticed a lack of knowledge about mental health concerns and available resources.

> *"Family doctors aren't very good with mental health stuff, I found."*
>
> *[Indigenous family]*

Coordination of care and follow-up

Parent/guardian role as advocate for care: In almost every journey the parents/guardians acted as advocates for their children, spending a substantial amount of time on research to understand the mental health system and available options. This advocate role included initiating and pushing for referrals, pointing out resources their provider was not aware of, bringing binders of information to each provider, and filling out tremendous amounts of paperwork with repeating information. This was cited as a large burden on parents/guardians.

Overall, journeys for parents/guardians who were knowledgeable about available resources and how to navigate the system were more likely to be reported as having successful outcomes in their journeys. In relation to that, parents/guardians consider parent support groups (face-to-face or online) as very helpful resources to learn from shared experiences.

> *"Everything has been driven by me, everything. I literally see the path for a lot of these youth, a lot of these mentally ill—if there's not an advocate, if there's not a supporter, you're done."*
>
> *[Parent/guardian of child experiencing substance use issues]*

Coordination of care and follow-up

Coordinated transitions between providers: Some parents/guardians stated that the referral or transition to a new service provider was a simple and successful process. Others reported that their service provider did not provide a referral, or a treatment or discharge plan, and often parents/guardians had to self-refer and create their own plan for next steps.

> *"It was a lot of … refusing to just not get the support and the answers. With my [child] I self-referred to [social skills program] which kind of started the ball rolling."*
>
> *[High income family]*

Follow-up with family: Most parents/guardians shared that service providers did not follow up or check in on them. Only a few interview participants reported they received phone calls, text messages, or emails from their service provider. For these participants, the follow-ups and check ins contributed to better outcomes for their children by ensuring timely and regular responses to the children's changing and/or additional needs.

In a few journeys, the school teacher or counsellor connected with the parent/guardians by calling or texting to see how their children were doing, if they had improved or gotten worse, and how the situation was at home.

Moreover, one parent/guardian mentioned a program that sent a person to the house to check in on the family.

> *"The school checks in often. With the counsellor, I have a very back and forth communication, like all throughout the whole year quite often."*
>
> *[High income family]*

Transition plan to adult mental health system: A few parents/guardians reported having no issues, as their children received continued help through AMH services after turning 18 years old. For others, the journey changed course drastically when the children entered the period of emerging adulthood, around ages 17 to 25. During this time the children often lost medical coverage under the parents'/guardians' benefit plan, the parents/guardians were no longer able to act as the children's advocate, and the young adult assumed responsibility for making decisions about the care they received. In all these situations, the flow of care received by the children was greatly interrupted.

> *"That's where the major sort of break happened with my [child], was that transition… It was supposed to be a warm handoff, and it was an absolute mess. And that's where we lost services, and we lost [the child] for a while."*
>
> *[Parent/guardian of child experiencing substance use issues]*

Parents/guardians expressed uncertainty, worries, and concern about their children's transition to adult AMH services and supports as there was often no clear plan in place. Some parents/guardians worried their children were not capable of making decisions in their own best interest.

In another journey the parent considered private AMH services for the transition process.

The impact each journey had on the whole family

Amy's story

The past few years have been hard on our whole family, not just Nate and Matthew, but also my youngest child, Susan. We are trying to have open and honest conversations with her, but she often isolates herself in her room. There have been many situations, where I just felt stressed and exhausted, and recently I connected with a parent group. The families I met had similar experiences. This gave me a lot of comfort and support and I picked up many strategies on how to best deal with everything at home. This helped improve the situation a lot.

Each child's journey significantly impacted the entire family. Many parents/guardians felt they were drowning, stressed, overwhelmed, anxious, burnt out, and exhausted.

Some parents/guardians stated that they felt they were failing as a parent/guardian, which undermined their confidence as a parent/guardian, and consequently jeopardized their physical and mental wellbeing. Parents/guardians also shared that it helped to have support from family and friends, as well as to have a positive relationship with their spouse/partner/ex-partner.

> *"Exhausted. I feel like it's been traumatic, to say the least, and that things could have been done a lot better for [the child], and I just feel defeated."*
>
> *[Parent/guardian of child experiencing anxiety]*

Parents/guardians also said they had to **take time off from work** (e.g., for a child requiring constant supervision such as for suicidal risk or to attend appointments during work hours). Some went on leave from their work to cope, and others reported an impact on their work due to a lack of sleep. A few parents/guardians also said their marriage was compromised and that more arguments arose. These parents/guardians reported seeking couples counselling, and in some cases a family breakdown.

> *"I couldn't function at work anymore. I was getting two or three hours' sleep. All I kept doing was looking, looking for answers and research."*
>
> *[Parent/guardian of child experiencing suicidal ideation]*

Parents/guardians spoke about **effects on siblings**. For example, some parents/guardians shared there was conflict between siblings, or sibling(s) feared one another. Another concern expressed was that other children in the family were neglected because the child receiving mental health care required a lot of extra attention. In some cases, the siblings were stigmatized in school by peers and by other parents.

> *"Kids at school tell [the sibling that their sibling is] crazy. [The sibling's] lost friends. There's stigma... and of course, there's judgment from other parents, that we are somehow to blame."*
>
> *[Parent/guardian of child experiencing substance use issues]*

Parent/guardian insights for improvement

Amy's story

Overall, my experience would have been much better, if teachers and doctors would take children's issues more seriously and address the struggles they are facing. I would have also wished that there was a plan in place for Matthew when he transitioned out of the program that was helping him so much. As I mentioned before, I am at the point again, where I do not know how to best support my oldest child.

During the interviews, parents/guardians shared insights about what would have made their experiences better. Below are some of the improvements, parents/guardians talked about most frequently.

In general, parents/guardians felt that AMH services for children need to improve, especially when it comes to funding and resources. Specifically, parents mentioned the need for **more mental health hospital beds and support** in accessing other services (e.g., for low income families who need to access a school program or for a rare disorder). Long wait times and lack of resources often left private AMH services as the only option to get help for their children. Parents/guardians expressed the need for **age-appropriate supports** (e.g., psychiatric hospital unit for children, more child psychologists and psychiatrists, youth centers).

> *"They ought to have had a lot more funding and a lot more beds because they were full all of the time and I know they are right now and that's not okay."*
>
> *[Parent/guardian of child experiencing anxiety]*

Some parents/guardians reported that having **one consistent person/place** (connector) who helps navigate the system would have contributed to a better experience.

> *"And it would be nice to have a one-stop-shop because it was hard, all of those steps . . . I need to figure out how to get this kid some help. But if we had just started right from the beginning, and they'd asked the right questions, and they worked with us, maybe I needed to advocate more for myself too, and my [child]"*
>
> *[High income family]*

Besides increased funding and resources, parent/guardians also wished to see appropriate help, such as specialized and knowledgeable providers who are **aware of available resources**. Related to that, parent groups have been mentioned as a valuable resource, especially learning about helpful **strategies to try out** at home.

> *"It would be helpful, at some point, if somebody would have given us a suggestion, instead of us giving the suggestions."*
>
> *[Indigenous family]*

Parent/guardian insights for improvement

Parents/guardians would like to see that stigma around mental health and the trivialization of their concerns be reduced, and **the message of not being ashamed of mental health struggles** be spread more widely. Relatedly, parents/guardians wished that providers did not pass judgement, such as indicating a lack of parenting skills or labelling them as a chaotic family. This would require that the provider take the children's struggle seriously and listen to parents/guardians instead of brushing them off.

> *"It was always framed as if I was doing something wrong, and as a mother, I knew I wasn't, and if someone had just listened, I think it would have made a big difference."*
>
> *[Parent/guardian of children with complex needs]*

Parents/guardians suggested more frequent follow-up on referrals and appointments, as well as improving communication between providers and the family, as there was **often a breakdown in the flow of care**.

> *"I think if they were willing to do better communication with me, I could have supported [the child] better here at home."*
>
> *[Parent/guardian of child experiencing anxiety]*

The journey could also be improved by considering the family as a unit, including the wellbeing of parents/guardians and siblings. It was felt that **everybody in the family is impacted** and that it is important to look at the "bigger picture".

> *"But the greater picture is that as a family unit, yes, we were definitely not, we were lost in the system, for sure. We weren't even considered . . . it's no different than when somebody has cancer. It's not just the person who has cancer, it's the whole family that wants the support system."*
>
> *[High income family]*

- ✓ **provide navigation support in accessing services**
- ✓ **more specialized and knowledgeable providers**
- ✓ **increase availability of age-appropriate supports**
- ✓ **increase availability of specialized resources**
- ✓ **promote support groups and parent groups**
- ✓ **reduce the stigma around mental health**
- ✓ **increase follow-ups on referrals and appointments**
- ✓ **consider the family unit**

Visualizing the journey

With great consideration for the seriousness and importance of the parent/guardian experience, the board game Chutes and Ladders was used as a metaphor to represent the complexity of the journeys shared by parents/guardians.

During consultation with this project's Stakeholder Advisory Committee, this board game metaphor really resonated with individuals, and the visualizations that follow shine a light on the multiple barriers and the continuum of supports that can influence a single journey. Beginning with Matthew's more difficult journey, moving to his brother Nate's more seamless journey, and finally, the ideal journey is presented.

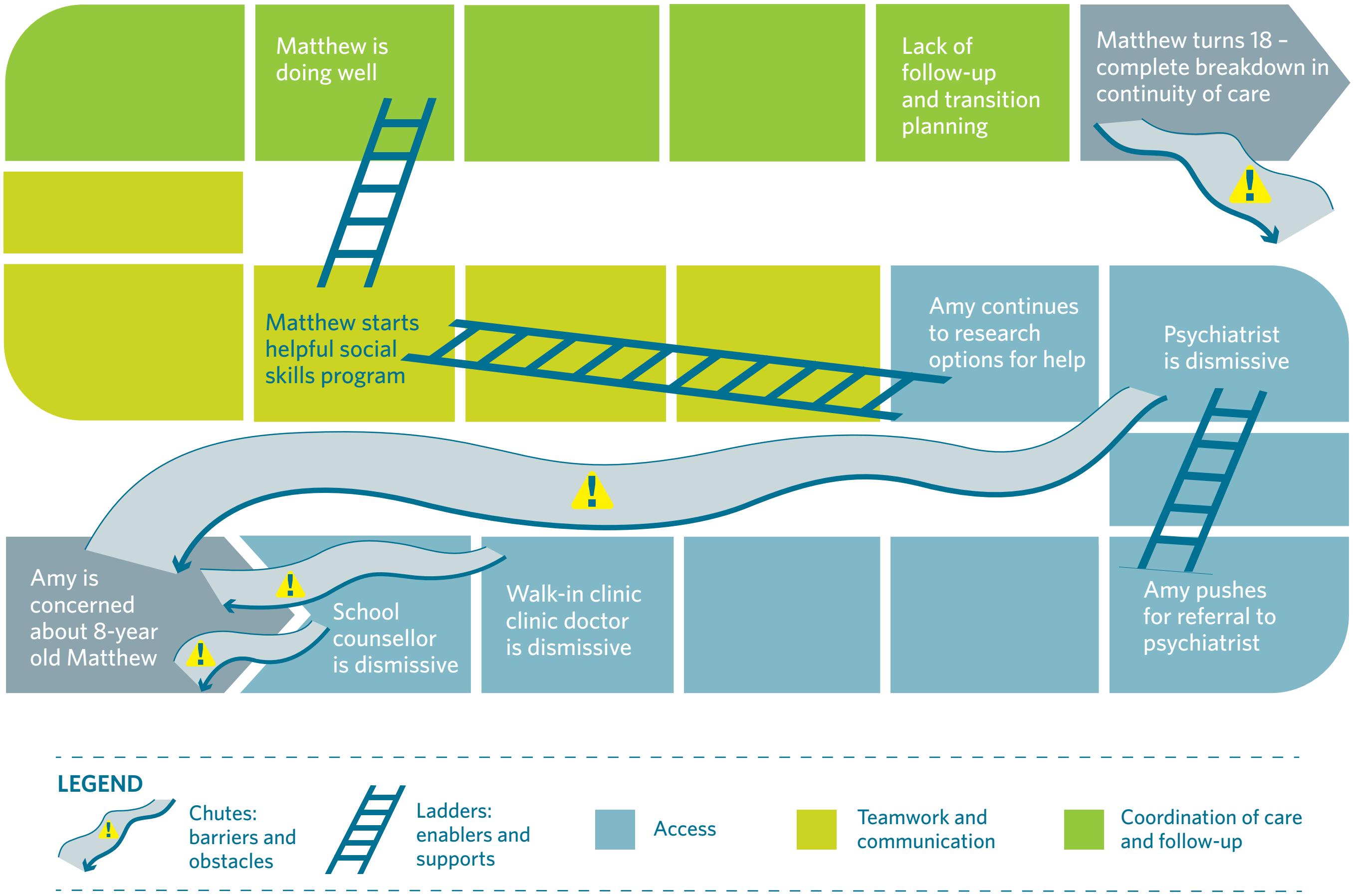
Chutes represent the barriers and obstacles parents/guardians faced which delayed or back-tracked their journey to acquire appropriate AMH services for their children.

Ladders represent enablers and the continuum of supports that helped progress the parents'/guardians' journey to acquire appropriate AMH services for their children.

Access >>>>>>>>>>>>>> Teamwork and communication >>>>>>>>>>>>>> Coordination of care and follow-up

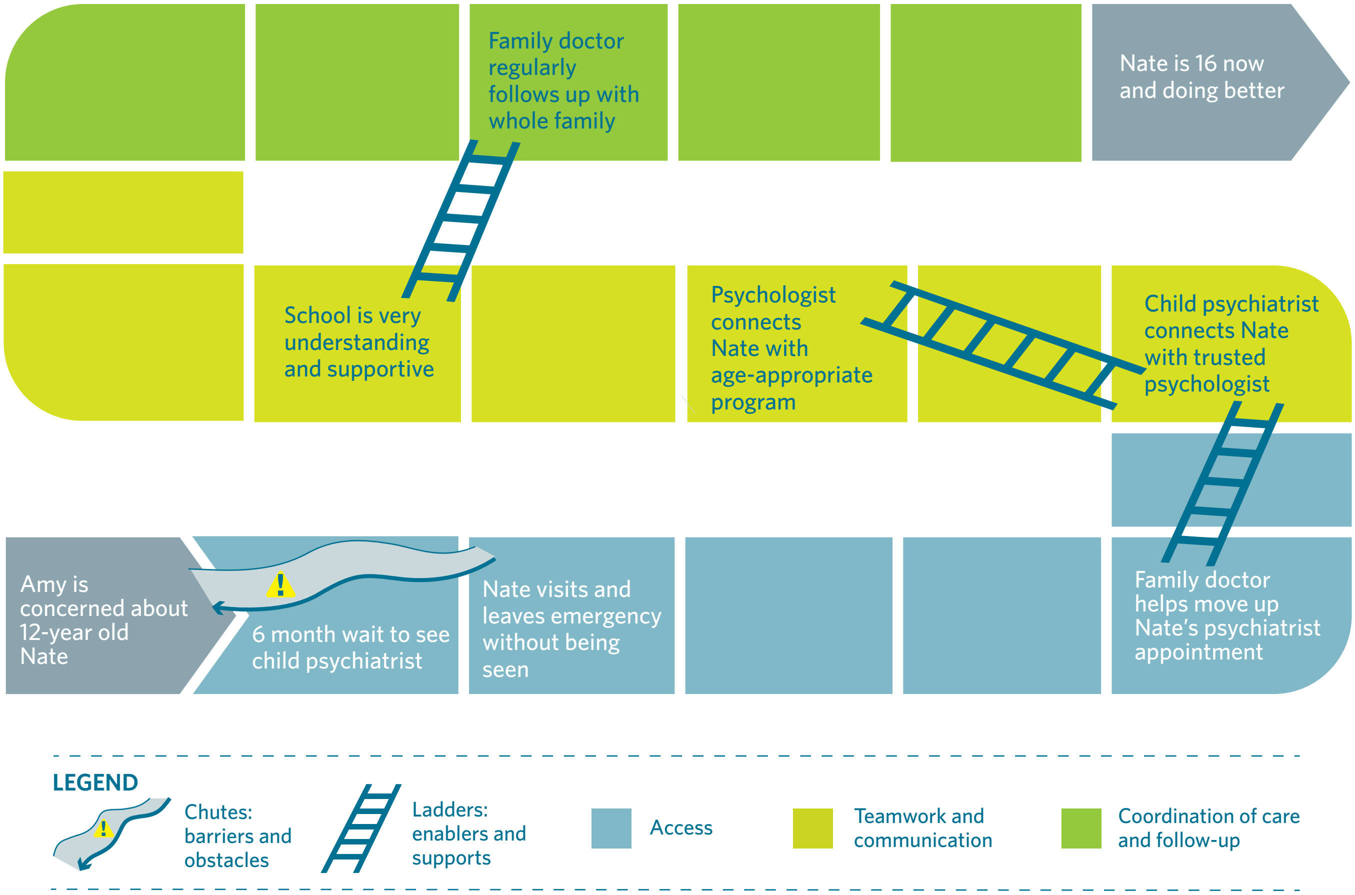
Amy's Story – MATTHEW'S journey

Through the fictional story of Amy and her son Matthew's journey, the chutes and ladders illustration below depicts a journey that has more barriers (chutes) than enablers (ladders). With Amy's story of Matthew's journey, the school counsellor and the doctor at the walk-in clinic were dismissive of her concerns (chute – delayed access). Even after she pushed for a referral to a psychiatrist, she again encountered dismissive attitudes (chute – delayed access). In her search for help, Amy finally gets Matthew into a helpful social skills program (ladder – teamwork and communication). However, the lack of follow-up and transition planning when Matthew turned 18 led to a complete breakdown in continuity. Matthew was no longer eligible for the program and decided to stop taking his medication and started substituting with other substances (chute – breakdown in continuity of care when transitioning to adult system). As a result of these experiences, the whole family was impacted.



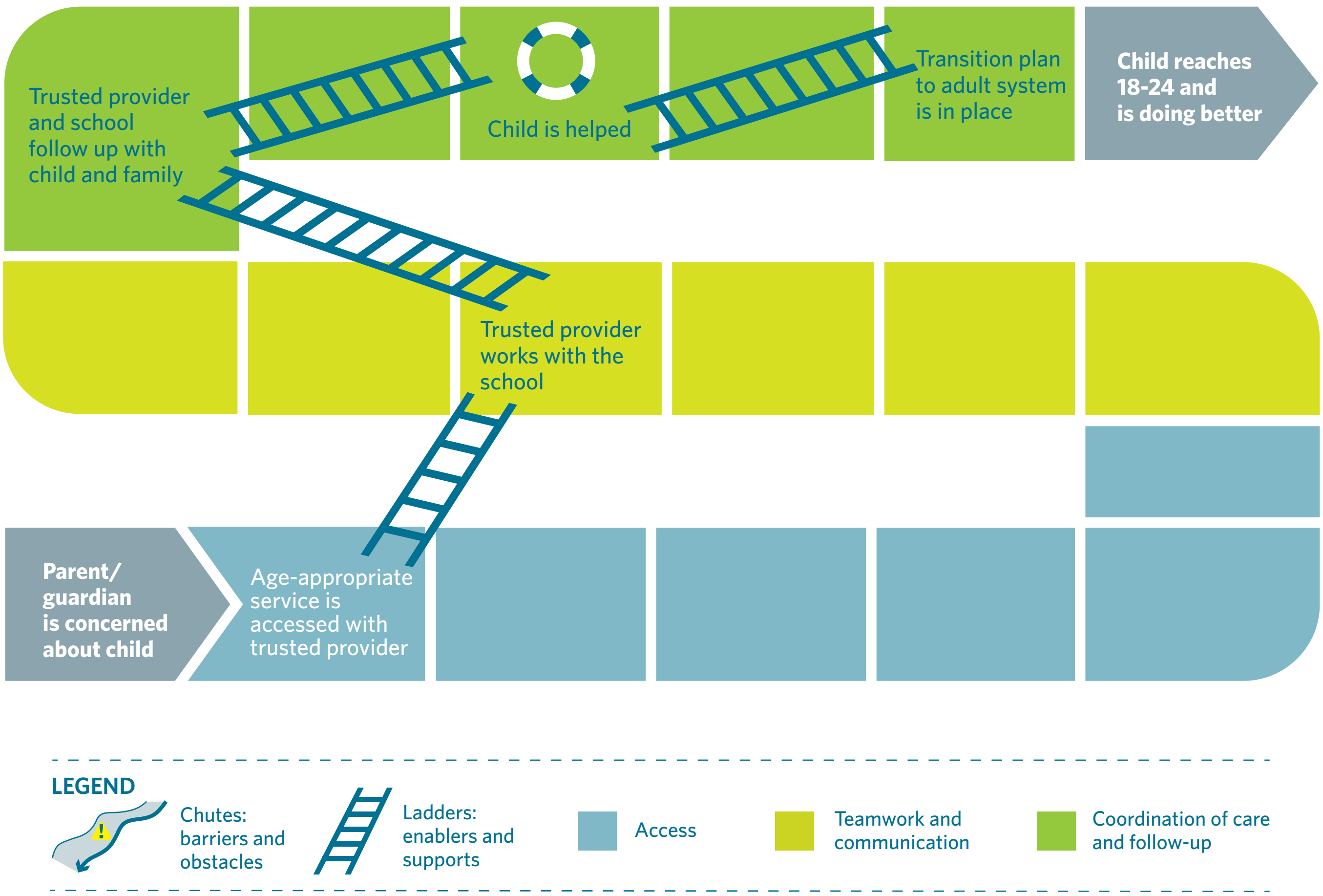
Amy's Story – **NATE'S journey**

Visualizing Nate's journey as a board game metaphor shows that the journey overall went much smoother. When Nate showed self-harming behaviour, the child was to wait six-months to see a child psychiatrist (chute – delayed access). In addition, Nate left the emergency department without being seen (chute – delayed access). In her search for help, Amy was supported by her family doctor, who phoned the child psychiatrist in order for Nate to be seen sooner (ladder – family doctor helps with timely access). From this point, Nate's journey went smoothly. The child psychiatrist connected Nate with a trusted specialized psychologist, who connected Nate to an age-appropriate program (ladder – teamwork and communication). The school was also very understanding and supportive (ladder – teamwork and communication). Moreover, over the past four years, Amy has been seeing a very supportive family doctor who helped push referrals and always followed up with the whole family (ladder – continuity of care and follow up).



The IDEAL journey

Based on the combined experiences of the 30 parents/guardians, an ideal journey was created using the board game metaphor. Common elements of such a journey include the parent/guardian obtaining immediate access to age-appropriate AMH services (ladder), their children getting connected with a trusted provider who is able to provide an accurate assessment and care plan (ladder). This trusted provider also follows up regularly with the family, and coordinates timely referrals as the children's needs change, or ensures there is a transition plan in place before the children enter the adult system (ladder).



Conclusion

This report summarizes information collected in 2019 from 30 parents/guardians, in five communities across Alberta, who had emotional or behavioral concerns about one or more of their children and attempted to or received AMH services and related community supports. It describes the complexities of the parent/guardian journey to obtain appropriate AMH services for their children – with **a successful journey being described as one that contributes to the children's well-being and creates a positive outcome for the family.** On the other hand, some journeys were characterized as long and challenging which can be very burdensome for the children, and also to their families.

Parents/guardians interviewed were at different stages in their journeys. Some parents/guardians felt they were successful; these success stories were often attributed to engaged teachers, helpful community programs, proper assessment, and sometimes the right medication, and/or a trusted provider that was supportive throughout the journey.

Other parents/guardians reported their children are slowly progressing or are still struggling with little improvement. Often in these stories, progress was derailed by the lack of access to appropriate AMH services, attitudes of service providers or school staff, and the children transitioning to adult AMH services with no plan or supports in place.

It is clear, that **many parents/guardians in Alberta still carry a heavy burden** for navigating and advocating for AMH services and supports for their children. Many factors can affect the process either positively or negatively. The journey is not a simple path, and one significant obstacle can bring an otherwise successful journey back to "square one".

"I was successfully able to help my [my child] out of that really, really, really dark and lonely path that [the child] was on. I don't think the system works very well and so, yes, I am speaking for the other parents and families that are affected by this and may not have resources, and may not know what to do."

[Co-parenting parent/guardian]

Appendix

Methods

In an extensive stakeholder consultation process from February 2017 to June 2018, Alberta Health (AH) designed a framework called **PLUS: Principles Leading to a User-focused System** for Addiction and Mental Health Services in Alberta. The framework comprises eight principles that describe the desired future state of a patient experience, each with a set of key questions. The principles apply across populations, but certain ones may resonate most with specific populations. They were collaboratively developed by a group that included people with lived and living experience, Indigenous organizations, non-governmental organizations, Indigenous Services Canada, Alberta Health Services, and multiple provincial ministries.

1) **Holistic.** Respond to the unique needs of each individual, family, and community.
2) **Barrier-Free.** Even the most vulnerable people receive the services they need.
3) **Seamless.** Individuals experience care as connected and coherent.
4) **Culturally Safe.** Respect each person's choices and diverse perspectives.
5) **Proactive.** Promote positive mental health and eliminate stigma.
6) **Trauma-informed.** View substance use and mental illness through a lens of trauma-informed health care rather than criminality/morality.
7) **Strengthened Supports.** Empower staff, informal caregivers, support groups, and Elders/Knowledge Holders.
8) **Responsive.** Embrace new ways of doing things to support continuous improvement.

In partnership with AH, the Health Quality Council of Alberta (HQCA) conducted this project from January 2019 to June 2020 to support the implementation of the framework by answering key questions related to the third principle, the navigation of AMH services that emphasize fluidity of care and connection to the continuum of supports in the community. This study focused specifically on the third principle as it relates to children and youth.

The third principle (seamless care) and associated key questions

Easy to navigate service systems that emphasize fluidity of care and connection to supports in the community. Collaborate across programs and with service providers and community partners to provide clear entry points, care pathways, appropriate referrals, and follow-up support/resources and to build a culture where information sharing for the benefit of clients, within the bounds of confidentiality, is the norm.

1. What does the patient trajectory look like? Where does fluidity of care break down (e.g., bottlenecks, hurdles, gaps, transition points, etc.)? Where are patients potentially being lost by the system?
2. How many times do clients have to tell their story? How many providers do they have to go through to actually get appropriate service?
3. How well are service providers coordinating care for their clients and ensuring appropriate continuity?

Appendix

Parent and guardian engagement

From June to August 2019, the HQCA launched a survey to identify parents/guardians with positive and negative experiences when navigating help for their children. 633 parents/guardians accessed the online survey and two people completed the survey questionnaire by interview over the phone. 387 of the 633 (61 per cent) completed the online survey and of those, 199 indicated willingness to participate in an in-depth interview: 43 Grande Prairie, 29 St. Albert, 34 Red Deer, 43 Airdrie, and 50 Lethbridge.

From the 199 parents/guardians who were willing to participate in an in-depth interview, the Stakeholder Advisory Committee (SAC) selected between eight and 11 cases from each community. The HQCA project team went through these preselected cases to pick the six cases per community that would receive the first invitation for an interview. The six cases were systematically identified by looking for the most successful cases and least successful cases (generally based on their continuity of care experience ratings), and also considered disability status (as that was a point of interest in this particular study). The extra cases selected by SAC members were kept as back-up if any of the initial parents/guardians were unable or unwilling to participate. Two trained interviewers conducted the interviews at times that were convenient for the parents/guardians. Interviews were conducted between September and November of 2019.

Of the thirty parents and guardians who shared their experiences of care:

- 18 (60 per cent) parents/guardians had to navigate AMH services and services for additional non-mental health-related difficulties.
- Five (17 per cent) parents/guardians identified as an Indigenous person and eight parents/guardians and (27 per cent) identified their child as an Indigenous person.
- Four (13 per cent) parents/guardians identified their child as non-binary or transgender.
- Three (10 per cent) parents/guardians have a household income less than $25,000 and five (17 per cent) parents/guardians between $25,000 and $50,000.
- Most parents/guardians shared journeys of more than one child.
- The children were between eight and 22 years old at the time of the survey, which contributed to understanding transitions from elementary school to junior high school to high school and to the adult system.

To ensure informed consent for the interviews, parents and guardians were asked to give verbal consent at the beginning of the interview to participate in the interview. This process of informed consent aligned with health research ethics best practice. Most interviews were audio recorded, transcribed, and analyzed for themes by two analysts to ensure validity of the findings.

Appendix

Interview guide

The interview guide was drafted based on scientific survey methods and finalized in consultation with the Stakeholder Advisory Committee. It included three sets of key questions based on themes about continuity of care in Alberta Health's PLUS framework for addiction and mental health services:

1. **First set of key questions:** Please tell me more about your experience with moving between AMH services. Would you say that you felt lost in the system? Was there anything in your life or your children's life that made it hard to get the help your children needed? What do you wish happened to make your experience better?
2. **Second set of key questions:** You said in your survey and your story that you saw [list of providers]. Did you see anyone else? You said in your survey that you had to see [number of] people before you got the care your children needed. Please tell me more about that. Please tell me about how you shared information about your children's history and needs with the people you were working with. How was the information about your children shared among the AMH services?
3. **Third set of key questions:** Please tell me more about how all the people that you were working with worked with each other. What could they have done to make things better for your children, especially at times when your children's situation or needs were changing? Do you know who to go to if your children have future needs or their needs change?

The interview ended with asking the parent/guardian how they feel overall about their experiences with AMH services, as well as how things were going with the family now.

Limitations

There were several obstacles to overcome throughout the project, as well as limitations in the methods. The scope of this project focused only on parents' and guardians' experiences, on English language only, and targeted communities in each of the five Alberta Health Services Zones: Grande Prairie, St. Albert, Red Deer, Airdrie, and Lethbridge. These communities are similar in size and in the AMH services available. The special lens for this project was on disability in addition to mental, behavioural, or emotional concerns.

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