In their own voices:

Parent experiences entering the Hennepin County children's mental health system

A journey map prepared by the Hennepin County Children's Mental Health Collaborative

March 2022

HENNEPIN COUNTY
CHILDREN'S MENTAL HEALTH
COLLABORATIVE

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Introduction

The Hennepin County Children's Mental Health Collaborative (CMHC) provides a forum for a diverse and representative group of stakeholders to influence the development and ongoing operation of an accessible and effective children's mental health service system within the County. In 2021, as part of our effort to achieve our vision of "a comprehensive, integrated, and culturally responsive mental health system," we began planning to implement a System of Care approach.

System of care

A system of care is a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health and related challenges and their families that is (a) organized into a coordinated network, (b) builds meaningful partnerships with families and youth, and (c) addresses their cultural and linguistic needs in order to help them to function better at home, in school, in the community, and throughout life.

The CMHC promotes innovative service development and continuous quality improvement in the children's mental health system by embracing system of care principles and available research on children's mental health services. Our goals for the system of care include improving:

- lives of children and youth;
- lives of families;
- service delivery and coordination of services, and;
- costs and quality of care.

System of care guiding values

The Hennepin County Children's Mental Health Collaborative's system of care efforts are guided by the following core values:

1. The children's mental health service continuum includes a **comprehensive and integrated** array of services and supports.
2. Services are **individualized** to meet the unique and specific needs of the child, youth, and family.
3. Services are provided in the **least restrictive** and most appropriate setting.
4. Services are **coordinated** at the system and individual service levels.
5. **Youth and family** are at the center of all planning, at both an individual service level and a larger system level.
6. **Prevention and early intervention** strategies are necessary in the overall continuum of services.
7. A **health equity lens and a cultural humility perspective** are used to address disparities and ensure access to culturally and linguistically competent services.
8. Decisions are **driven by data** and research on best practice.

Project overview

In 2021, we launched a strategic planning process to establish priorities for service and system enhancements for the Hennepin County Children's Mental Health System of Care. It was important that this planning aligns with our guiding values. It was especially critical that we centered family voice in our planning process. We opted to create a journey map highlighting parents' experiences with the County's children's mental health system.

Journey maps

A journey map is a visualization of the process that a person goes through to achieve a goal. A journey map starts by identifying a series of potential actions that someone might take to reach this goal, then integrates their thoughts and emotions about this process. Journey maps can be used to visualize someone's experience with a specific service or program. They can also be used to visualize experiences that people face in navigating more complex systems, centering consumer point of view as they move through various system touchpoints.

The children's mental health system is extremely complex. We narrowed our focus to system entry, exploring steps that parents take as they determine that their child has a mental health issue and they seek services for the first time. There are a number of questions to explore about these experiences. How did parents first come to recognize that their child had a mental health concern? What services did they look for to support their children? What worked well for them in navigating the system? What challenges did they face? What support did they receive to help them identify and access services? What recommendations do they offer for how to improve parents' experiences?

Our goals for the project included:

- Documenting strengths of the current system;
- Illustrating and prioritizing challenges, barriers, and areas for improvement;
- Identifying family-centered solutions to systemic issues; and
- Building shared understandings across stakeholders regarding parents' experiences.

Participants

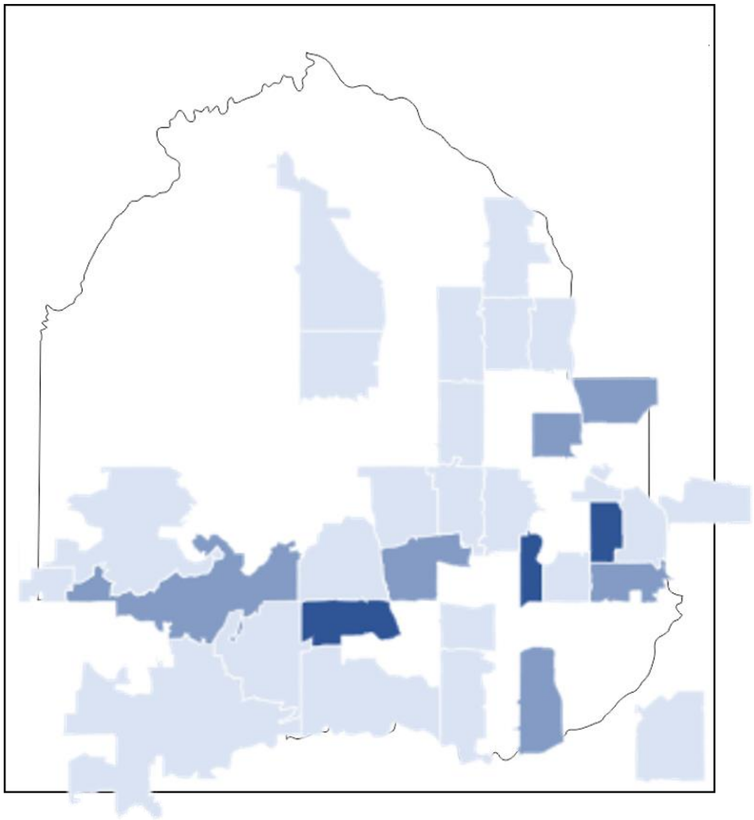
Our goal was to interview parents with recent and diverse experiences in the children's mental health system. Recruitment flyers were created and translated into Spanish, Karen, and Somali. Outreach to parents took place over several months in late 2021, with invitations to participate posted through:

- The Hennepin County Children's Mental Health Collaborative newsletter;
- Hennepin County community engagement mailing lists;
- the Parent Catalyst Leadership Group;
- the National Alliance for Mental Illness- MN (NAMI-MN) newsletter;
- Family Service Collaboratives across the county;
- Parent advisory and support groups;
- Facebook groups; and
- Children's mental health service providers.

Data collection process

Recruitment information was widely distributed across the County. Interested parents registered online to talk to a trained interviewer. Most interviewers were Hennepin County parents with children in the mental health system.

Parents scheduled interviews at times that were convenient for them, including weekends and evenings. Interviews were primarily conducted by phone or online via zoom, though a few were conducted in-person. Each interview took approximately 45 minutes to complete. Following the interview, parents received a $25 gift card to either Target or Walmart.



Parents were eligible for interviews if they had received services within the last five years in Hennepin County. A total of **49 parents** were interviewed.

Most parents lived in Hennepin County, including Minneapolis and many suburbs (see map of respondents, right). Some parents lived slightly over the border into neighboring counties, but all had received services within the County.

Almost all parents interviewed (96%) were female. Gender was more evenly distributed among their children (50% male, 42% female, 8% other).

Participant race/ethnicity

	Overall county population	Interviewed parents	Their children
Black or African American	14%	8%	11%
American Indian and Alaskan Native	1%	8%	9%
Asian	7%	2%	9%
Hispanic/Latinx	7%	2%	6%
Non-Hispanic White	68%	79%	66%

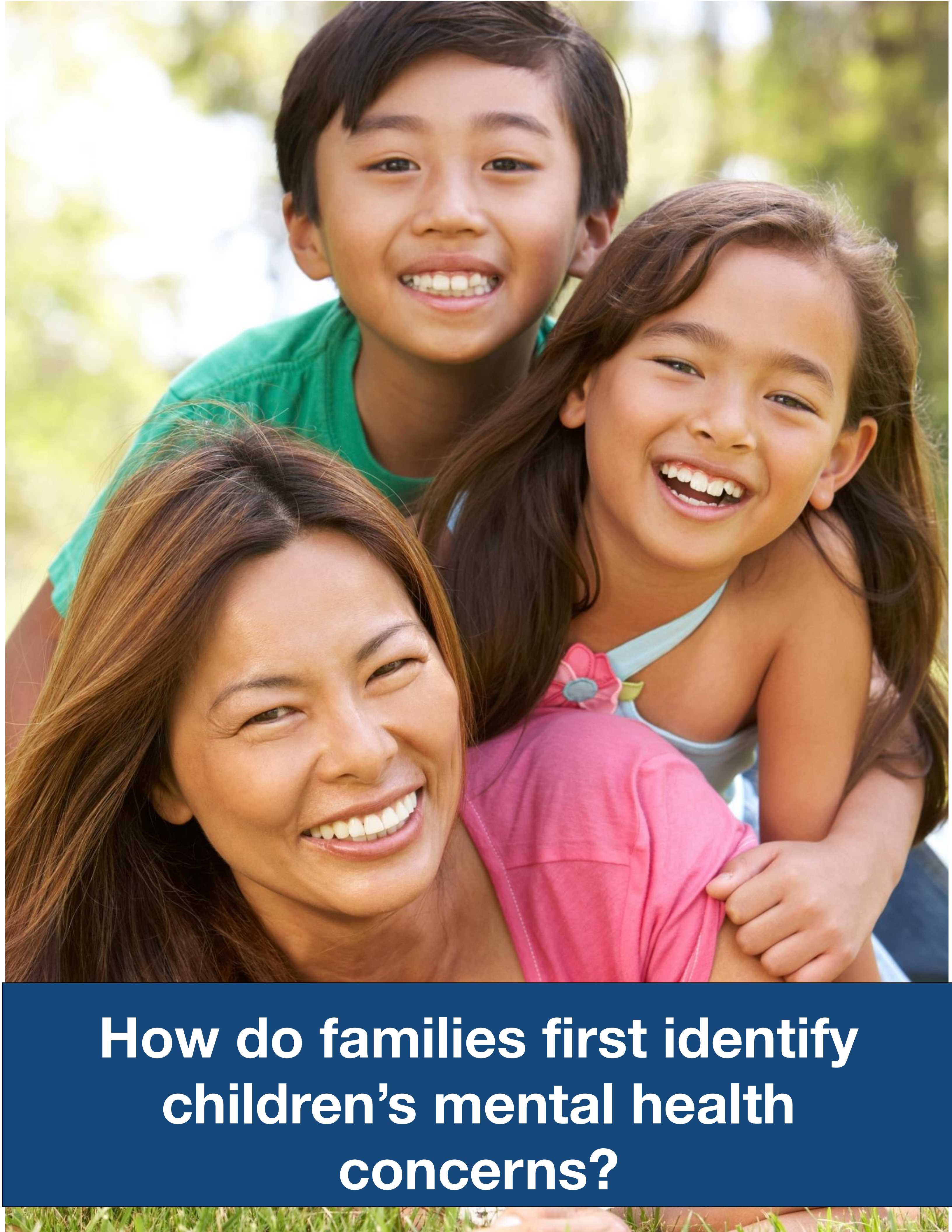
Seventy-nine percent of the interviewed parents were white. Other parents were Black or African-American (8%), American Indian and Alaskan Native (8%), Asian (2%), and Hispanic/Latinx (2%). Parents were asked to also identify the race/ethnicity of their child with the mental health concern. The percentage of children identified as Black/Indigenous/People of Color (BIPOC) is greater than that of the parents. In some cases, the parent and child had different racial or ethnic backgrounds because the child identified as bi-racial. Some parents/guardians were foster parents to children of a different racial/ethnic background than their own.

Equity considerations

It was important that our interviews encompassed a full range of perspectives and experiences with the children's mental health system. While the interviewed parents had diverse backgrounds, we did not fully reach our goal of inclusive participation. For example, no parents requested an interview in a language other than English, though the invitation to do so was advertised in the recruitment flyers (which had also been translated). As a result, our findings do not reflect the experiences of parents who may have faced linguistic barriers in seeking services.

Among the parents interviewed, their narrative descriptions of their experiences and their ratings of these experiences did not vary significantly based on their background. However, we know that families can have very different experiences with mental health services and systems based on their race, ethnicity, socioeconomic status, LGBTQ status, and other factors.

To better represent the diverse array of family experiences with children's mental health, key findings from the literature are infused throughout this report and were used to help shape the recommendations for next steps. We welcome further dialogue with the community in an ongoing effort to ensure that our system reform reflects the perspectives of all County families.



How do families first identify children's mental health concerns?

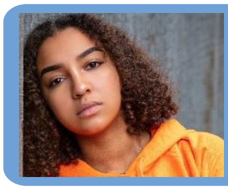
Initial identification of a mental health concern

There is no one “story” about how families entered the children’s mental health system. The families interviewed for this project represented a diverse array of experiences, in terms of how they first identified that their child had a potential mental health concern and why they decided to seek support. Children first exhibited mental health concerns at a variety of ages, from early childhood to high school. They first developed a wide range of emotional or behavioral symptoms, and ended up receiving a variety of diagnoses, such as mood disorders, anxiety disorders, autism spectrum disorders, and attention-deficit hyperactivity disorder.

Often, the parents were the first to detect that something was wrong. Sometimes, it was the child who first identified that they needed support. Some children were first identified as having potential mental health issues by teachers, child care workers, or doctors. The following examples illustrate the varying ways that parents began their journeys into the mental health system.

how did families first identify a mental health need?

In kindergarten, he started having trouble at school. He couldn’t follow directions, couldn’t sit still, and was crawling under tables. The parent/teacher conference was where they suggested that there was a problem.



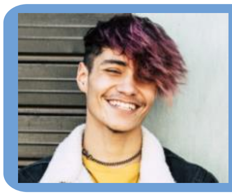
When she was 14, she wouldn’t go to school or do what she was supposed to be doing. She was oppositional and hard to get along with.

There was domestic violence in our house when my daughter was young. She started having panic attacks whenever things reminded her of her experiences.

She told us she was feeling down and sad. She said that she was not harming herself, but recognized that she needed to talk with someone to deal with her emotions.

My son was in middle school when he attempted suicide. He was having intrusive thoughts and feeling vey anxious about social situations, school work, and other things.

I started getting calls from school. At first it was weekly, but got to the point that it was nearly every day. Teachers would tell me that he misbehaved, that they didn't know how to work with him, or that he was refusing to do what he was told. It was always addressed as a discipline issue.



When my child was 12, they asked to see a therapist because they were feeling anxious and wanted to talk to someone. Eventually, they came out as trans.

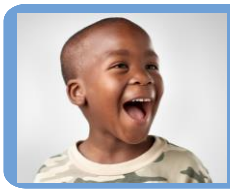
In 2nd grade, he asked what was the point of living. He would lie about being sick to avoid school. His stomach hurt all the time, and he would cry at night about things that were causing him stress.

In 6th grade, he threatened to harm himself with a knife because a girl did not like him. His behavior escalated to threatening harm to others. At home, he was physically destructive and we had a lot of conflicts.

At 16, my daughter confided in a friend that she was having suicidal thoughts. Her friend told her mother, who told me. That's the first time we were aware of what was going on.

When she was 3, she had difficulty with transitions. Her child care providers tried to manage her through discipline, but things got worse. She had trouble sleeping and was clinging to us. She failed her socioemotional screening and was referred for assessment.

At 4, my daughter starting doing unusual things. She talked about hurting herself. She would spin until she fell. Her anger was out of control and she had massive tantrums. She would say that she was a bad person and nobody liked her.



We noticed that he wasn't hitting developmental milestones. He was really delayed, especially with talking. He didn't understand people's feelings. He's unusually tactile, always touching things and wanting to put them in his mouth.

She began struggling when she was a freshman in high school. She seemed withdrawn. Then, we saw 50 cuts on her leg and realized she needed help

How do parents enter the children's mental health system?

Experiences entering the children's mental health system

A core goal of this project was to identify the steps that parents take when seeking support for their children with mental health needs. The results highlight the fact that there is no one consistent path that parents take. Their pathways vary depending on their child's age and situation and their "entry point" into services.

Parents involved with the Hennepin County Parent Catalyst Leadership Group (PCLG) helped develop a list of services that parents may navigate when they identify that their child has a mental health need, such as mental health services, medication, or educational support. These services formed the structure for the parent interviews. At the conclusion of the interviews, almost all parents said that this list encompassed all of the services that they sought for their child.

Typical steps in parents' journeys

All parents sought a diagnostic assessment for their children

The one universal in parents' experiences was that they all sought a diagnostic assessment for their child. Assessments are important early steps in helping parents understand their child's needs and identify appropriate services. A diagnostic assessment is often required before other services can be obtained.

Impact of COVID

Our focus for this project was to understand parents' experiences entering the children's mental health system within the last five years. It is important to note that, for many parents, this meant that they were navigating entry into services during the COVID-19 pandemic.

While it is well established that the pandemic disrupted many community services, including children's mental health, the pandemic was not mentioned in most of the interviews.

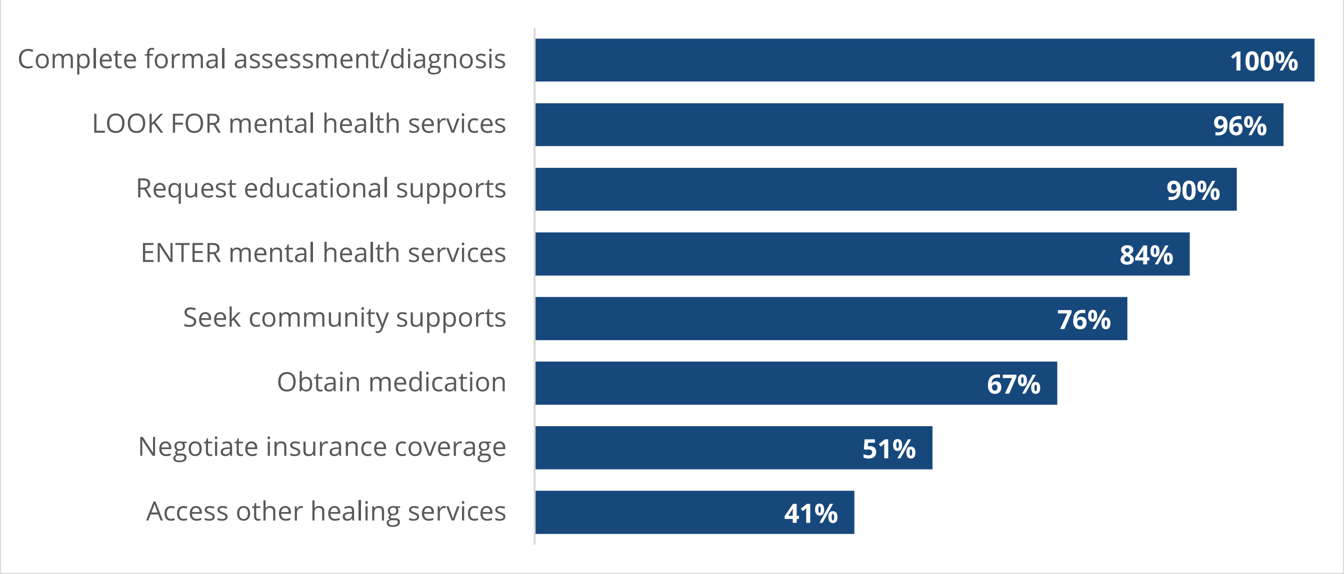
However, some parents did highlight ways in which their experiences were impacted by the pandemic. Most described temporary impacts, with mental health supports pivoting quickly to online services (which improved access for some families, while worsening it for others). Some services – such as community-based services – were more likely to be discontinued during the pandemic.

Parents seek a variety of services to meet their child's needs

Services that parents sought may have included:

- Mental health support, such as individual, group, or family counseling;
- Educational/learning supports, such as through an IEP or Section 504 plan;
- Community-based programming (such as mentoring, sports, or art programs);
- Medication; and/or
- Other healing services, such as physical health care services or culturally- or faith-based supports.

Percentage of parents reporting that they sought services for their child

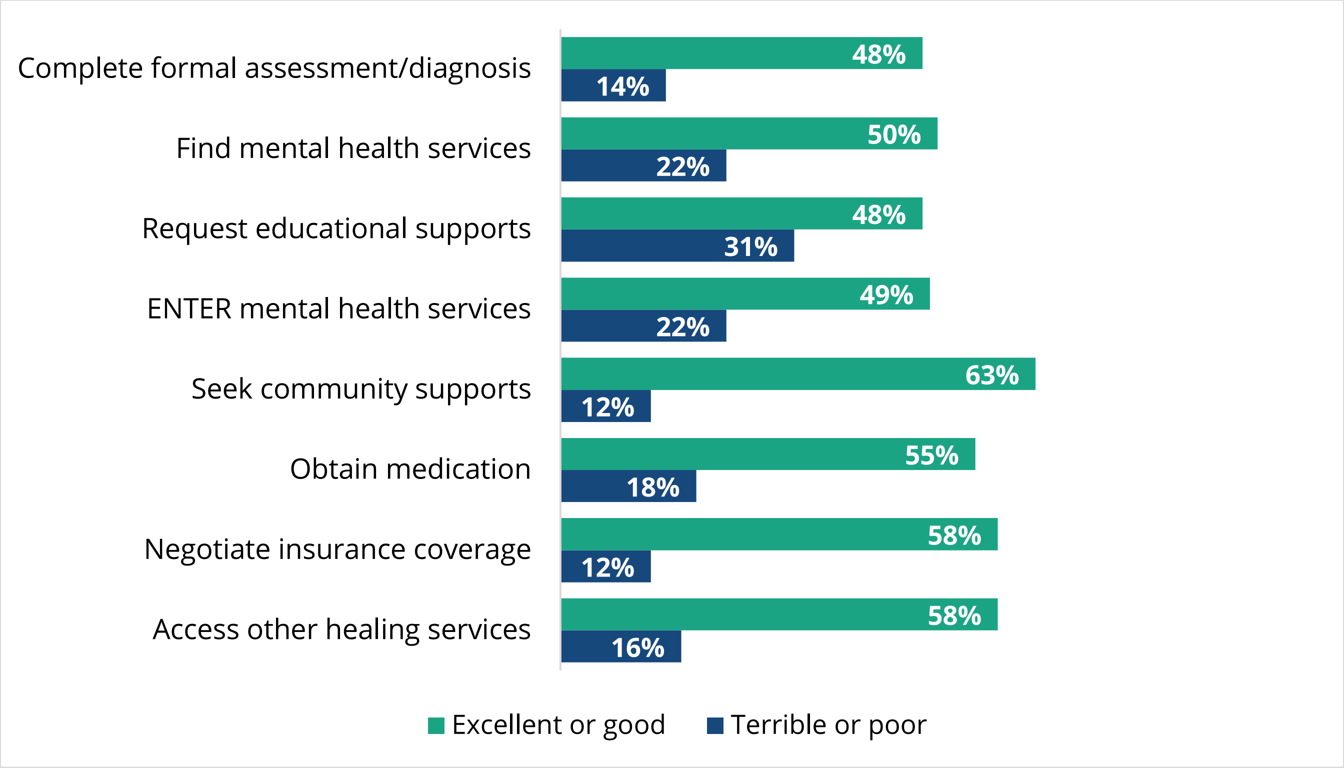


Parents provided mixed ratings of their experiences with services

During the interviews, parents were asked to describe their experiences with each of these services, including their successes in obtaining services, the challenges that they faced, and the people who supported them. Parents who sought services were also asked to provide an overall rating of each experience, describing each service as "terrible," "poor," "fair," "good," or "excellent."

Overall, parents offered more positive ratings than negative. However, a pattern emerges in the narrative descriptions of their experiences. While parents often described ways that the services had been beneficial, almost all parents needed to overcome significant challenges to obtain these services. It appears that parents who provided positive ratings tended to emphasize the **benefits** of the services themselves, while those offering more negative ratings tended to emphasize the **challenges of accessing** them.

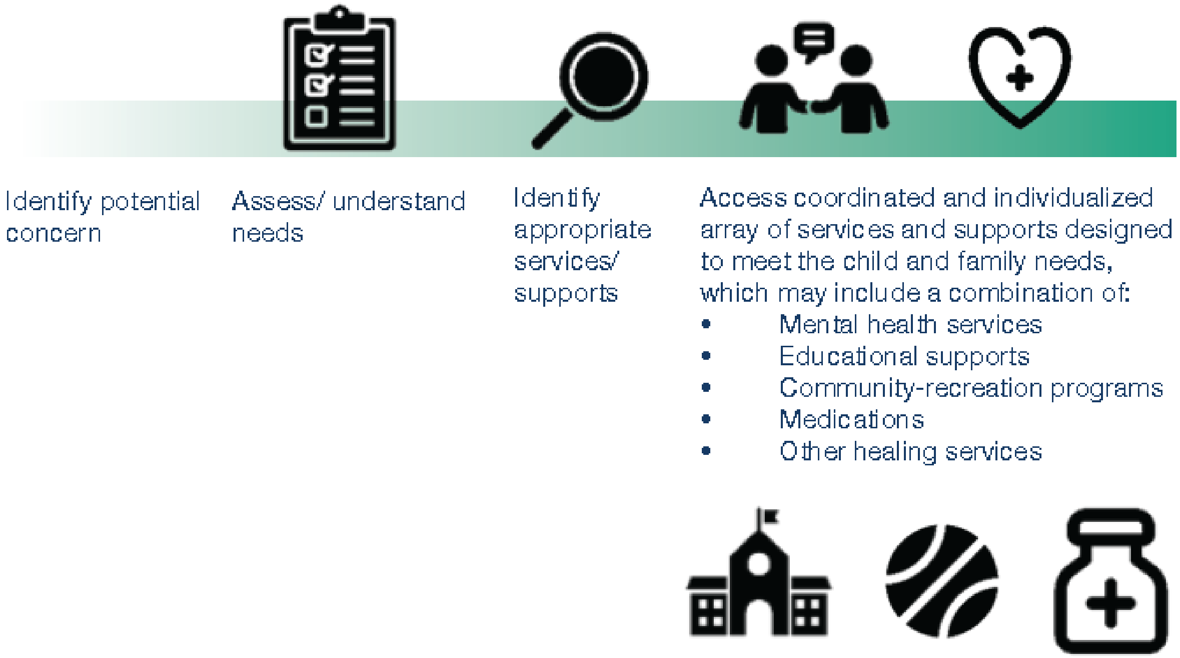
Parent ratings of services/supports



Journey map

Journey mapping involves creating a visual representation of consumers' movement through a service or system. If everything is moving smoothly, and services are accessible when needed, parents' journeys into the mental health system could look fairly simple and streamlined. In an ideal system, parents would identify a potential concern, and receive an assessment to more deeply understand their child's needs and to identify potentially useful services. Following the assessment, they would easily find and access the right services to meet their child's needs, and these services would be coordinated to provide a consistent and supportive circle of support around the child and family.

What the children's mental health system journey COULD look like



Identify potential concern

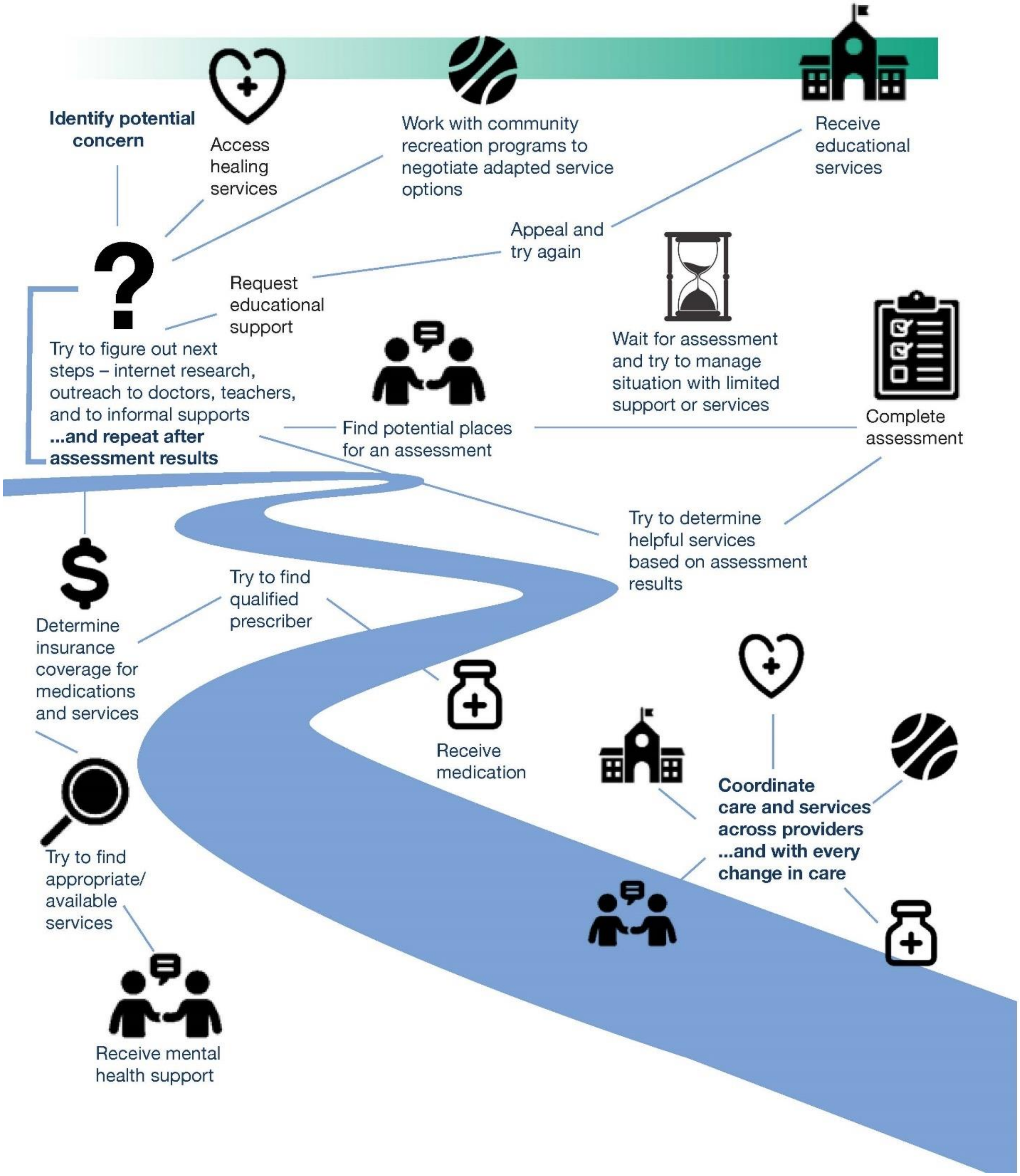
Assess/ understand needs

Identify appropriate services/ supports

Access coordinated and individualized array of services and supports designed to meet the child and family needs, which may include a combination of:
- Mental health services
- Educational supports
- Community-recreation programs
- Medications
- Other healing services

In reality, the journey through the children's mental health system is not so easy or direct. Based on parents' descriptions of their experiences, the actual journey tends to be characterized by delays, confusion, and "false starts" as parents explore services only to realize that their child is not eligible, there are no openings in the program, or the program is not actually a good fit for what their child needs.

What the children's mental health system journey ACTUALLY looks like



Overall, how do parents describe their experiences with the children's mental health system?

Overall themes

During the interviews, parents were asked about their overall impressions of their journey through the children's mental health system. They were also asked specifically about different types of services that they may have pursued (such as mental health treatments, educational supports, or medications).

As illustrated in the upcoming section of the report, parents often offered positive assessments of the services that their child and family received. While they offered positive reflections on the benefits of services, they also described very consistent and pervasive challenges in accessing these services. Across all interview sections, six core themes emerged consistently.

Interview themes

⊖ The children's mental health system is difficult to understand and difficult to access

Almost every parent interviewed for this project highlighted a lack of easily accessible information about children's mental health. Parents consistently described challenges figuring out what services would be helpful for their child, and then finding those services. They expressed frustration about the general lack of centralized information about the mental health system and providers and uncertainty about how to get started in seeking services.

Parents frequently invested significant time and resources into researching children's mental health services. Because they were typically new to this system, their research was complicated by the fact that many did not know what to look for, what questions to ask, or what language to use when searching. Many parents turned to the Internet to learn about children's mental health, while others started by talking to their friends and families.

> *"It's very unclear and you figure it out on your own. You are guessing about what you need. You hope you end up in the right place."*
>
> *"Everything is on your own. You are given nothing that says what the next step is or how to get help."*
>
> *"I was lost and didn't know what to do. No one listened to me."*

> *"[It was challenging] being told different things by different people and just wanting to know what to do. I had to rely on the Internet. I had to ask a lot of questions but I didn't know what to ask."*
>
> *"I was given no instructions [from the pediatrician] except to get her help immediately. We felt blindsided and scared."*
>
> *"I felt as if I had no support from anyone. You'd call somewhere to try and get answers and nobody could give you a direct answer. When I'd try and ask for help in finding out information, I was basically told to look it up myself."*
>
> *"Having to make decisions that are permanent without enough information is the worst type of help."*

Parents with more resources (time, finances, training) had some advantages in navigating the system. While the parents interviewed for this project had a wide variety of backgrounds and resources, some felt that they carried some advantages that helped them navigate the system. Some parents had more previous knowledge than others due to professional connections with the children's mental health field. For instance, some parents worked as teachers or social workers, which increased both their knowledge of the system and their access to other people who could provide guidance and support. Other parents had more flexible time or greater financial resources, and felt that this made the research process easier.

> *"We're fortunate that we have resources to try things. For people who don't, it would be even scarier."*
>
> *"I'm in the health care field myself and am good at research. It was challenging for me. How does someone with less resources than me do it?"*
>
> *"We had a family friend who is an executive at a mental health agency, so we had a personal resource to help us get in. Not everyone has that. And I have capacity to call every week to see if the wait list has moved."*
>
> *"My experience finding services was more positive because I don't have a language barrier, I'm not a single parent, I work in the field, and I have time to do thorough research."*

Equity considerations

Cultural background plays a powerful role in shaping perceptions of mental health and appropriate interventions and impacting access to information about mental health services and supports.

The interviewed parents described fairly consistent and significant challenges in learning about the children's mental health system. Their descriptions of these experiences were similar across cultural backgrounds. We know, however, that there are significant disparities in access to information about children's mental health services. The causes of these disparities are complex and multi-faceted.

Some of these factors include:

- Families may be directed to Western mental health treatments that do not align with cultural values, requiring more effort to find appropriate services.
- Experiences of racism and discrimination may impact families' safety and willingness to seek support from more easily located government systems or large systems (like schools and large provider agencies).
- There is a general lack of linguistically- and culturally-translated materials about the children's mental health system and available services, creating barriers in understanding information.
- BIPOC families are over-represented among families in poverty, which can lead to lower time and resources to explore children's mental health services.

Source: Gopalkrishnan, N. (2018). Cultural diversity and mental health: Considerations for policy and practice. *Frontiers in Public Health*, 6 (129).

As part of the interviews, parents shared their top recommendations for strengthening the children's mental health system of care. Increasing access to information about mental health and available services was a top recommendation for many parents.

> *"Just knowing what services are out there is a mystery. Is there some way of informing or educating parents about what services are available and how their child could be helped by the system? It would be a great help."*
>
> *"We need more access to information for folks like us, people without a big network. People who don't have family. We are immigrants, first generation with non- native speaking family members. Our networks are people we know, people at work or our neighbors. We don't know other people."*
>
> *"Transparency. I should*
>
> *be able to access all of the same things and resources the social workers see. Then I don't have to rely on people we don't know or trust to tell me what is available for my child."*

> *“Make it easier for parents to know what is possible for their kids. Don't make us try to figure it out without any information. Not everyone is going to be able to dig in and dig down.”*
>
> *“No one told us the options that were out there. That’s what we need as parents, more informational support. Even if we understand that it’s on our own time to pursue them, we need to know about things in order to do that.”*

Parents struggle with their own stress and anxiety while trying to also support their children

Having a child struggling with mental health can be stressful for parents. Many parents shared stories of their own struggles, while also trying to support their children. Parents sometimes felt overwhelmed by their child’s needs or fearful about their child’s future. Some parents sacrificed their own self-care to attend to their family. Sometimes, the stresses of managing their child’s mental health contributed to their own mental health needs, or impacted other family members.

> *“We need more love and care for parents, because, man, it’s hard to be in a family with kids having mental health challenges.”*
>
> *“I wish somebody had told me how important it is for me to take care of myself because I almost fell apart.”*
>
> *“In all of the paperwork I have done and all of the providers I have seen, I don’t feel my own needs were addressed. I am a single parent with my own mental and emotional health problems and I am struggling.”*
>
> *“I wish that it was automatic that if you sought services for your child that they would also recommend supports for the family. If you’re dealing with this for your child, what resources can we offer to you?”*
>
> *“I needed somebody to talk to. What do you do when you bring a suicidal kid home? How do you keep them safe? It’s hard on a parent. You take it one day at a time.”*

Parent stress was exacerbated by stigma, with some parents feeling shame and guilt about their child’s situation. Sometimes, stigma took the form of parents feeling ashamed of what their family was going through, or feeling guilty that they may be responsible for their child’s condition. Stigma also made it harder for them to share their experiences or to reach out for support from others.

> *"It feels traumatic while you are going through it. That adds an element of why it's hard to navigate – dealing with your own shame, fear, and emotions about what is going on with your kid."*
>
> *"You feel a lot of guilt and wonder where you went wrong. It was a long time before I realized that this is not something that I caused and not something I could have stopped."*
>
> *"We want what's best for our kids, and fear prevents us from doing what we need to do…fear of our child not being 'normal' and fear of not being able to navigate supports. We need more places where parents can share their experiences and let others know that it's okay."*
>
> *"If you don't go and look for support, there are a lot of people pretending that everything is okay. There is a lot of stigma, and unwillingness to talk about things that are not okay."*
>
> *"I needed reassurance that it wasn't the end of the world and that things were okay. I needed it to be normalized. I needed to feel less alone."*
>
> *"I feel the stigma of having a child who is struggling. We need more social campaigns about that, highlighting that your child's troubles are not your fault as a parent. It's so hard to talk to other parents. It was isolating to need so many services and not hearing other parents talking about it."*

Families have an easier time accessing services when a supportive professional works with them

Support from trained professionals made a tremendous difference to families seeking mental health services. It was helpful when parents found a professional who could support them in identifying services and figuring out next steps for their child. Some parents connected with someone whose primary role was to provide this kind of support, such as case managers (employed through the County or other agencies) or service navigators (such as those working for insurance companies or health care systems). Other parents felt fortunate to find someone with professional knowledge who was willing to help, even though their primary role was not to help parents navigate the system. For example, some parents found doctors or teachers who were willing to invest extra time and energy to help them understand how to find and access care.

> *"The social worker through the pediatrician's office helped us figure out what to do. They took a lot of time with us – answered questions, explored options."*
>
> *"The [insurance company] behavioral navigator was helpful in terms of the logistics of what is covered and what our options are."*
>
> *"Our county case manager changed everything. I finally found somebody to advocate for us, who let us know what was reasonable and what kinds of things to ask for. We would not have gotten the services without the assistance."*
>
> *"The case managers have been great –we had to figure a lot of things out together. It was good not to be alone through the processes."*

Access to supportive professionals or navigators was also a frequent recommendation for improving the system for parents. Most families did not have access to this kind of supportive professional. However, many recommended navigation support as the most important way that the system of care for children and families could be strengthened.

> *"I wanted someone who was educated and understood our situation. Someone who could help me navigate the system and would, as a whole. Someone who would not just give me resources, but would hold my hand and help me figure things out. [That would have helped me] get him the care needed and also have support myself."*
>
> *"I have spent days and days and days doing my own research and being on the phone. It's unfair for the parents. There should be someone there to help them."*

Peer support is instrumental in supporting parents and helping them connect with services

Connections with other peers were important in validating and supporting parents, and identifying potential services for children. While many parents first turned to their own friends and families for support and guidance, it often became increasingly important for them to connect with other parents of children with mental health concerns. They found that these parents not only understood and accepted what they were going through, but also offered many suggestions for resources or services. Parents generally had to seek this peer support on their own, with social media being especially helpful in finding parents. Some parents met other parents in provider waiting rooms. In some cases, parents connected with each other one-on-one, while others joined parent support groups or followed relevant Facebook pages.

> *"If you mention your child has a condition and you're trying to get services, it's other parents who will talk and help. It's not institutional support at all, it's other parents."*
>
> *"A friend was able to help as she had dealt with the same experiences with her child."*
>
> *"I reached out to other parents online. I have a few colleagues with autistic children – while mine is not autistic, these were parents who "got me." They understood – parents of children who were not struggling did not get it."*

> *"The first year was overwhelming. One of the first people that gave me true support was my neighbor, who had a daughter with a mental health challenge. When we started having issues, she provided guidance."*

Access to peer support groups was also one of the strongest recommendations from parents for how their experience could be improved. Parents who had not accessed peer support often suggested this support as an important strategy for improving their experience in the children's mental health system. Those who had accessed peer support sometimes wished that it had been found earlier or easier.

> *"A weekly parent support group would have been great, so I could talk with parents who have kids with the same issues."*
>
> *"I would have liked to be connected with a good support group."*
>
> *"It would be helpful to have more support groups. The only one I can find meets once a month in the evening which I can't go to. I belong to several Facebook groups. I wish there were more in-person opportunities, like someone who meets weekly."*
>
> *"I needed a village. My circle isn't big enough to include people who went through this. I needed elders who had been through it before."*

⊖ Once a child's needs are identified, it is often difficult to obtain services

It was difficult for many parents to find services. Once parents did identify potential services for their children, many found that they were unable to access them. Shortages were described across the continuum of care, with parents saying that they were unable to access outpatient therapy, psychiatric support, partial hospitalization and day treatment programs, residential care, and hospitalization. Waiting lists were especially long for diagnostic assessments, which then delayed access into other services as well. Parents also found it hard to find specialized services for children with complex or unique needs, such as cognitive impairments, histories of aggression, or health challenges.

> *“[Program] had a 9-12 month wait list that turned into 2 years. Early intervention is so important and families are missing the window to get the help their child needs.”*
>
> *“There was a lack of in-home providers for therapy, even before COVID.”*
>
> *“Once the clinics heard that [my daughter] was minimally verbal, we were told that we couldn’t be seen.”*
>
> *“It is really hard to find psychiatry or emergency psychiatric help. There have been times in the last year that we felt that he could have used hospitalization, but you can’t get in. Even finding a psychiatrist is hard.”*
>
> *“We need significant investment in growing and improving the profession. We need more people doing this work, we need to pay people well, and we need the work to be done in a culturally competent way.”*
>
> *“We’re in a mental health crisis. To not be able to get in [for a hospital bed] for months when you have a child who is suicidal...that is too much.”*

Rather than experiencing partnerships with providers, parents have to actively advocate and “fight” for their child

A common theme in parents’ experiences was the feeling that they were not being heard, and that they had to actively “fight” to receive services for their children. Parents wanted to feel that providers were listening to them, validated their perspectives, and partnered with them to support their children.

Instead, parents often felt that providers dismissed their concerns or requests for support. Many described needing to continuously advocate for their children in an effort to receive accurate diagnoses and arrange supportive services. This dynamic was stressful, and parents needed to fight more strongly than should have been needed to connect their children with services.

> *“It felt like [the provider] wasn’t listening to my child or to me. I felt like crying at times.”*
>
> *“They did not take us seriously or listen to what we said the problems were.”*
>
> *“Like everything with mental health, if the parent doesn’t push nothing happens. We just kept pushing and asking questions and seeing what else can be done.”*
>
> *“They gave us the [diagnosis that we thought was right] just to get us off their back.”*
>
> *“We felt he needed residential treatment, but the county denied it. We asked how appeals work and they wouldn’t help us. We had to fight. We were on our own.”*
>
> *“People kept saying it was too early and that we should wait until the next appointment [to discuss concerns]. I felt brushed off.”*

Parents wanted more validation from, and partnership with, providers. When asked for recommendations for improving parents’ experiences with children mental health, many parents requested that professionals listen to their concerns, validate their perspectives, and use their input to guide service delivery for their children.

> *"My older son took his own life when he was 13. We have schizophrenia in our family and we know a lot about it, but we just kept being told by his physicians, therapists, and psychiatrist that he was too young. Why couldn’t something have been done to help him earlier?"*
>
> *“We need to stop with ‘kids are just like that’ and take parents seriously when they say that something is wrong.”*
>
> *"[We need] professionals to not just shrug off [parent concerns] and act like it’s nothing big.”*

Recommendations

Service providers

- Distribute resources designed to help parents understand the structure of the children's mental health system and recommendations for finding services.
- Review websites and assess ease of finding information useful for families seeking services (such as age ranges served, specialization areas, services provided, and insurance accepted).
- Use professional development and reflective supervision to support providers in identifying and addressing explicit and implicit biases that impact their work with families.
- Adopt "whole family" practices that include proactively offering resources and support to parents and other family members.
- Expand use of family navigation services, working with families to identify and access appropriate services.
- Provide opportunities for parents to connect with other parents for support and resource-sharing.
- Assess the alignment of agency practices with principles of family-driven care and develop plans to improve alignment.
- Pursue opportunities to integrate mental health services with other systems, such as health care
- Offer resources to help parents connect with peer support and education programs in the community

Principles of family-driven care

- Families have complete and accurate information about their child and available services
- Children/youth and their families are the primary decision makers with respect to care planning
- Families are respected and valued throughout the process
- Families have access to peer support
- Care plans are tied to the family's beliefs, values, and preferences
- Services build on youth and family strengths
- Barriers created by stigma are removed
- Each family's culture is celebrated and honored

Sources: Federation of Families for Children's Mental Health

System

- Create culturally- and linguistically-translated tools and resources to help parents learn about services and how to access them.
- Identify root causes of disparities in access to mental health services and develop services or policies to address them.
- Engage in parent education campaigns, to build understanding of children's mental health and available services and to reduce stigma.
- Provide training and other infrastructure to support behavioral health navigation services offered by professional navigators, care coordinators, case managers, or trained parent support specialists.
- Compile and distribute resources related to peer support for families, including identification of culturally-specific peer support networks.
- Support policy efforts designed to expand, diversify, and support the children's mental health workforce across the service continuum.

How do parents describe their experiences with specific services?

Receiving a diagnostic assessment

Once aware of a potential mental health issue, all interviewed parents sought a more formal assessment or diagnosis. There are several reasons why this was the most common step taken by parents:

A diagnostic evaluation is designed to assess the child's symptoms and how well they are functioning in home, school, and other settings.

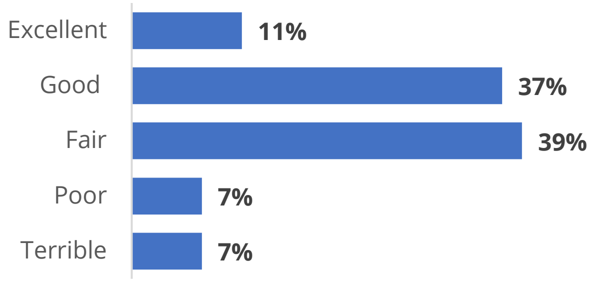
The assessment can be important in understanding the nature of a mental health condition, and what services or supports may be beneficial.

An assessment is typically required before other mental health services or medication can be obtained.

100%

of parents decided to have their child **more formally assessed or diagnosed by a professional** once they because aware of a potential mental health concern

Parent experiences with diagnostic assesments



Summary of interview themes

Strengths

Assessments provided useful information to help parents select services and supports for their children.

Parents valued assessors who provided clear and understandable information about the diagnosis and next steps.

Challenges

Parents faced very long wait lists to complete assessments, often delaying access to other services.

It was difficult and stressful for some children to fully participate in assessments due to cognitive/developmental issues, sensory regulation difficulties, trauma, and other issues.

Parents sometimes received incorrect diagnoses, which delayed provision of appropriate services.

When providers did not share clear information about the diagnosis and next steps, parents left the assessment feeling overwhelmed, confused, and hopeless.

Interview themes

⊕ Assessments helped validate parents' perceptions and increased their understanding

Assessments can be instrumental in increasing parents' understanding of their child's mental health. For some parents, assessments validated their own impressions and concerns. Other parents highlighted the importance of clarifying confusing symptoms or identifying potential treatment options. Many parents had positive ratings for the assessment, with 49% of the parents rating their experience with the assessment as "good" or "excellent."

> *"[The assessment] was positive for me because I could read about her diagnosis and different parenting techniques that I could use."*
>
> *"It was the first time that somebody else saw what we were seeing. It was a miracle to have someone with credentials confirm the diagnosis. Now that we know what it is, someone can help her."*
>
> *"I got a lot of insight into my child from talking to the provider."*
>
> *"We finally had some answers."*

⊖ Long waitlists caused significant delays in completing assessments and accessing other services

There were long delays in obtaining an assessment. Parents were often told that they would need to wait 6-12 months for an assessment, with some facing even longer delays. Some parents requested assessments from multiple agencies, to increase the chances that they would move quickly up at least one wait list. Parents were frustrated with the wait, with some calling clinics weekly to see if any opportunities for a faster assessment had become available.

Because the assessments are often required to determine eligibility for services or to identify appropriate services, many children were unable to access other services while they waited. Parents were frustrated that the assessment serves as a "gateway" to other services. Until the assessment was completed, children often were unable to participate in other therapeutic services or receive medication.

> “Where we went was based on where we could get in. I was on multiple waiting lists.”
>
> “I was frustrated with the length of time to get an assessment and to get the results. It speaks to the lack of providers.”
>
> “Many places have significant wait lists. You might wait a year for the evaluation and in the meantime, you struggle and wait. You cannot get the services during that time.”
>
> “A year ago, it was very urgent that we [get an assessment]. We had a child expressing self-harm and we couldn’t get anywhere until we cried or begged. Even then, we still waited months.”
>
> “The woman started the assessment, then said we needed to reschedule, after we already waited months. We have been struggling for years. I finally thought someone was going to help us and they scheduled us for appointments another 3 months out. I ended up sobbing. It was quite a let-down. We had placed so much hope on that appointment and they were so dismissive of us.“

⊖ The assessment process itself was stressful for some children and families

The assessment process did not feel designed to be comfortable for children or families. Some children struggled to participate in the process, especially those with sensory regulation issues, a history of trauma, or anxiety. Assessment rooms were sometimes small, uncomfortable, and sterile. Parents struggled to explain the process to their children, so that they could feel prepared and relaxed for the assessment. For children with co-occurring cognitive or developmental delays, it was especially difficult to fully participate in the assessment process.

> “It was hard for my son to open up to [the assessor].”
>
> “My daughter can’t do some assessments because of her cognitive disability. She can only go so far with some assessments so they couldn’t do the whole assessment.”

> *"The rooms were tough – 4x4 boxes that brought out sensory or regulation issues. My kid would flee, which is common. None of the providers had a 'social story' for what to expect for kids – until I asked [provider] to create one."*

In some cases, it was difficult to obtain a correct diagnosis, especially when children had more complex mental health symptoms. Some parents expressed frustration with incorrect diagnoses, which led to the child receiving inappropriate services, or no services at all while they waited for a revised assessment.

> *"The process of obtaining a correct diagnosis for [our child] has led to unnecessary trauma and has failed her for three years. [Delays and misdiagnoses] took away three years of a child's right to receive proper medication and treatment for her mental health conditions."*
>
> *"Early intervention wasn't available to my daughter due to the incorrect diagnosis."*
>
> *"It took some time to get in for an assessment because he's complicated medically. It was hard to find someone who knew what they were doing and had the knowledge that I felt was necessary."*

Parents valued assessors who provided clear information about the diagnosis and next steps

Assessments are only valuable when providers explain the results and the implications for the child. About half of the parents felt that the provider provided clear assessment results, agreeing that the provider helped them understand their child's diagnosis and helped them identify potential services that may be appropriate for the child's needs. When this was the case, parents expressed gratitude to the assessor, and felt that the assessment was an important step towards receiving the services that would benefit their child.

> *"Before she even wrote up her formal diagnosis, she explained to me the tests she had performed and what she would be writing in her report. "She didn't use a lot of those "doctor words." She explained to me where he had difficulties and what areas were not a concern. She broke it down so we could understand it."*
>
> *"She did a great job. She went through page by page and was really good at explaining".*
>
> *"I got a lot of insight into my child from talking to the provider. I got more from those 30 minutes than I did from the report."*
>
> *"We left with clear next steps and they provided a lot of resources – not availability but resources."*

⊖ Some parents left the assessment feeling confused, overwhelmed, and hopeless

Many families felt overwhelmed and confused following the assessment. Some did not understand what the diagnosis was, while others wanted more information about what the diagnosis meant for their child. Specific requests included having the results described in “non-scientific” terms, and receiving more guidance about potential next steps.

> *“To this day, we still don’t really know what [the diagnosis] is. We don’t know what to say when people ask what he has.”*
>
> *“[The assessment] gave me ideas but was overwhelming. We have names for this, but now I have more tasks to figure out what to do to help.”*
>
> *“The results were shared too quickly. As a parent you are trying to take notes, but it was a dump of information in 30 minutes. There’s no capacity for follow-up.”*
>
> *“They gave us some papers and advised us to read some more literature. So, we started reading and learning more on our own. It wasn’t explained well.”*
>
> *“[The assessor was] speaking in medical terms that made no sense.”*
>
> *“It took weeks to get the final written report and we couldn’t get services until that report was done. This was right before COVID and we didn’t realize how much every day mattered.”*
>
> *“I was confused – lost in a sea of a lot of information.”*
>
> *“They told me I had to wait 4 months for an explanation of the results. Meanwhile, nobody would tell me what the diagnoses were. I ended up asking them to email me the results and I would figure it out myself.”*
>
> *“They just handed me the diagnosis. I wasn’t looking for a label. I was looking for a menu of services or recommendations. What would be the right mix of services or supports for my kids? It would be lovely if the people who made the diagnosis could connect you with someone who could tell you what it means and what kinds of services may be appropriate for kids like yours. Not generic recommendations, but customized.”*

Interactions with the assessors left some parents feeling hopeless or shamed. Several parents described feeling that the provider blamed them for their child's condition. Others left the assessment feeling discouraged about their child's prognosis, and wished for more information about promising approaches for supporting their child.

> *"You get a diagnosis and then you get knocked down. When you stand up, now what?"*
>
> *"I understood [the results], but it sounded more like no hope. In fact, they made it sound worse than it actually turned out to be. I wish they had given more hope."*
>
> *"[The provider doing the assessment] was very shaming. It was overwhelming."*

Recommendations

Service providers

- Develop materials to explain to children and families what to expect during the diagnostic assessment process.
- Develop warm and child-friendly spaces for assessments, designed to be comfortable for children with sensory regulation issues, trauma, and other backgrounds.
- Provide training and reflective supervision to ensure that providers doing assessments deeply reflect and address implicit bias.

Equity considerations

There are significant disparities in access to, and results of, diagnostic assessments based on race/ethnicity and poverty

The parents interviewed for this project described fairly consistent challenges in obtaining diagnostic assessments. Their ratings of this experience, and their narrative descriptions, did not vary significantly based on their cultural backgrounds.

However, research illustrates that there are significant disparities in accessing assessments in the first place, as families with more flexibility and resources may be able to invest more time contacting providers and advocating for an assessment to be completed. However, the disparities run much deeper.

As stated by Fadus and colleagues (2020): "Diagnostic evaluation of psychiatric disorders in children and adolescents relies in part of subjective interpretations of information from a clinician…however, environmental and sociocultural influences can make the diagnosis of psychiatric disorders challenging."

Noting the prevalence of disparities, such as a greater likelihood for some BIPOC children to receive diagnoses of disruptive behavior disorders, while White youth are more likely to be diagnosed with ADHD, these authors note that professionals may "interpret behaviors differently based on race or ethnicity, putting vulnerable populations at risk."

Another significant issue is that many of the instruments commonly used in the assessment process have not been developed for or tested with BIPOC populations. Tests that are not equivalent in terms of language or content cross-culturally or likely to yield disparate results.

Sources: Gopalkrishnan, N. (2018). Cultural Diversity and Mental Health: Considerations for Policy and Practice. *Frontiers in Public Health*, 6 (129) and Fadus, MC. et al. (2020). Unconscious bias and the diagnosis of disruptive behavior disorders and ADHD in African American and Hispanic youth. *Academic Psychiatry*,44, 95-102.

- Collect feedback from families to ensure that assessment results are shared using language that is understandable and culturally relevant.
- Follow up with parents after assessments to address emerging questions.
- Provide specific guidance regarding services or supports that may be appropriate based on the child's diagnosis, and information about how to access these services.
- Monitor results of diagnostic assessments to explore potential disparities by race, and develop action plans to reduce disparities if found.
- Use assessment tools that are culturally-grounded, and/or validated across cultural backgrounds.

System

- Build system capacity to provide timely and appropriate assessments.
- Reduce reliance on completed assessments to determine eligibility for therapeutic services, to allow families timely access to supports.

Finding mental health services

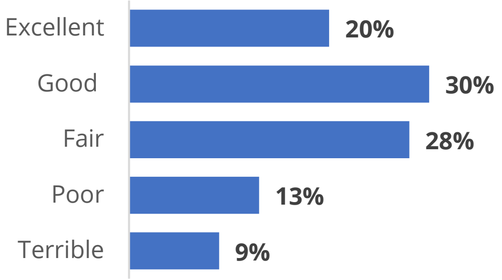
The interviews were used to hear about parents' experiences with different services. Related to mental health services, parents were first asked about their experiences trying to **find** mental health services. Because finding services did not guarantee entry into services, parents were asked separately about whether they were able to **access** mental health services.

Almost all parents (96%) sought mental health services for their children. Most often, these parents looked for therapy or counseling, though some described looking for more intensive services, such as day treatment, partial hospitalization, or residential treatment.

96%

of parents looked for **mental health treatment** services that might be a good fit for their child

Parent experiences finding mental health supports



Summary of interview themes

Strengths

Support from professionals – such as health care staff and case managers – made it easier for parents to find mental health services.

Peer support also helped parents find mental health services.

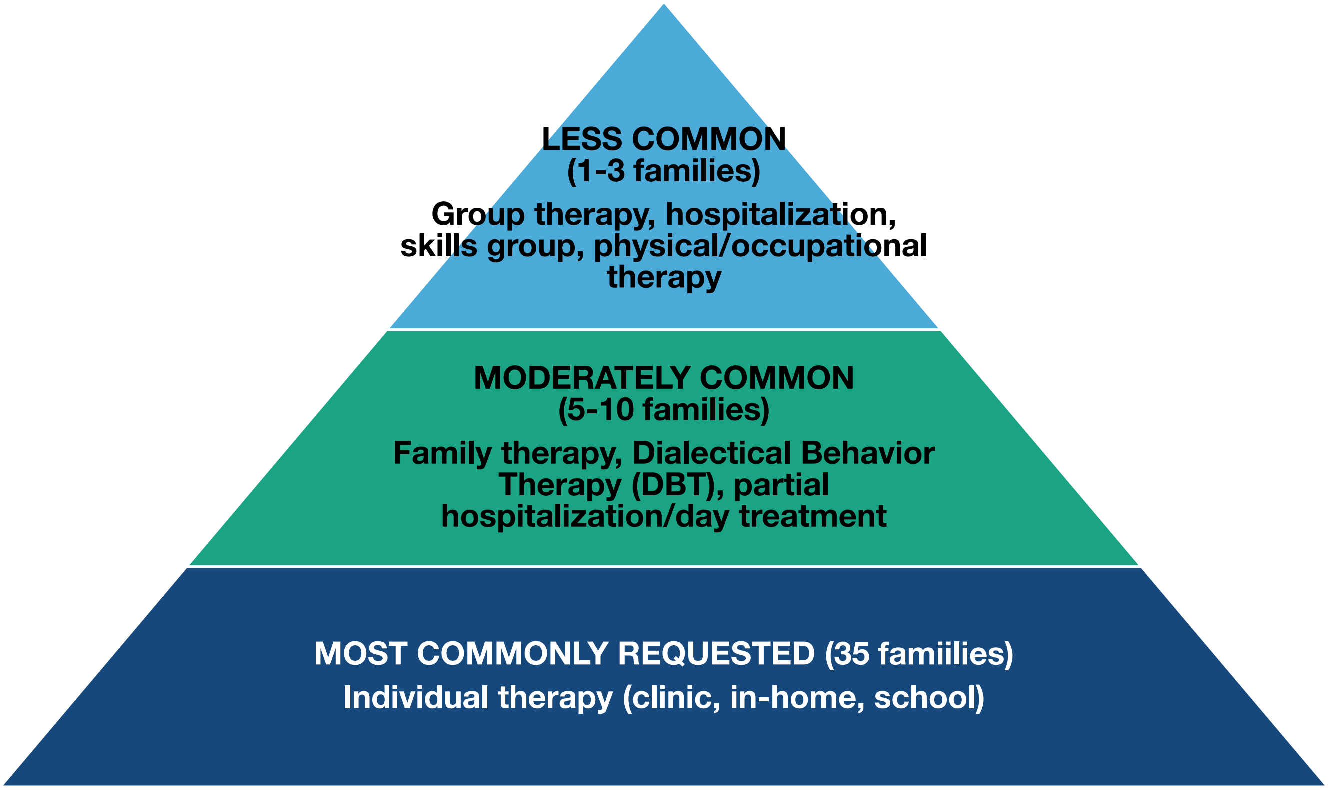
Challenges

Parents typically needed to do their own extensive research to find mental health services.

It was time consuming and difficult to find services that were an appropriate fit for their child's needs.

It could be stressful to select a program, and parents worried about making the wrong choice.

Types of mental health services sought by parents as they entered the children's mental health system



LESS COMMON
(1-3 families)
Group therapy, hospitalization, skills group, physical/occupational therapy

MODERATELY COMMON
(5-10 families)
Family therapy, Dialectical Behavior Therapy (DBT), partial hospitalization/day treatment

MOST COMMONLY REQUESTED (35 famiilies)
Individual therapy (clinic, in-home, school)

Interview themes

Families struggled to find mental health services on their own

As noted earlier in this report, many parents invested significant time and energy to learn about the children's mental health system. This pattern was especially true when it came to finding potential mental health services. Parents described efforts to search online for services, followed by calls to potential providers. Calls were not always returned, requiring parents to try again or to look for other alternatives.

> *“I just went online and googled ‘mental health services’.”*
>
> *“I feel like I've been home, trying to do the research, being on the internet, and calling places. It’s very time consuming. Maybe I'm not the right person for finding places for my kids, because this is not my field.”*
>
> *“I looked at a lot of websites and read a lot of bios.”*
>
> *“I google places online. I call places and leave voicemails and I don’t get a call back.”*

Parents had an easier time finding services with support from providers, especially through health care and case management

Professionals within the health care system helped connect some families with services. Parents described resources provided by their doctors, some of whom worked in clinics that integrated medical and behavioral health care. In some cases, insurance company representatives helped parents find appropriate mental health services for their children.

> *“Medical Assistance offered a one-stop location to find all the providers and services I needed.”*
>
> *“They (services/therapist) were already embedded in our medical clinic.”*
>
> *“[Child’s] psychologist at the time was at [our health care provider] so we got inhouse referrals.”*
>
> *“It was awesome to have the doctor’s recommendations.”*
>
> *“Our pediatrician was good telling us who to go to.”*
>
> *“The insurance representatives helped me find accepted providers and services.”*

Most families were not connected to case management services through either the County or a service provider. However, those that were felt that the case manager was instrumental in helping them find services.

> *"My case manager helped me find residential and outpatient treatment."*
>
> *"Our case manager told us about some treatments that we didn't know about. She found a provider, which was one of the most critical supports for us."*
>
> *"[Case managers] have been wonderful support. They are good at giving us ideas about next things we could try."*
>
> *"I had a case worker from [agency] who was really good at helping to find resources."*

⊕ Some parents also used informal peer support to find services

Other parents also provided some useful suggestions. A few parents highlighted suggestions from other parents being helpful as they looked for mental health services.

> *"I had support from friends who had put their kids in some of the more intense programs. I was able to talk to peers and take recommendations."*
>
> *"The help that I've gotten has been from other moms, not from any formal source."*
>
> *"I get a lot of information from the [Facebook group]. People will post there. Otherwise, it's a lot of internet research and going in blind."*

⊖ While families find information about services online, it is hard to tell whether services will be the "right fit"

Some parents identified promising services online, only to find that their child was not eligible to receive them or that the services did not align with their child's needs. Parents found it frustrating trying to determine whether or not services listed online were appropriate for their child. In some cases, the child was not eligible due to issues such as age. In other cases, the services were not a good fit for their child's specific needs, or the child had a co-occurring condition that prevented their participation in services. Often parents were not able to make this determination without calling the programs to request additional information, and not always receiving a return call (or waiting a long time for this call). Some services sounded promising online, but then parents heard negative feedback from other parents andwere unsure how to proceed.

> *"I had to vet clinics. I only got through a few and they didn't take kids her age."*
>
> *"There wasn't much available for him because of his communication challenges."*
>
> *"He qualified for partial day treatment but ironically they said that the aggression issues meant that he wasn't a good fit for it."*
>
> *"We found a private therapist. We don't technically meet the diagnosis criteria anymore but we keep going because we need support and I'm afraid that we couldn't get back in."*
>
> *"As soon as they see his diagnoses, they won't take him."*
>
> *"It was hard to find programs that were a good fit for what she needed."*
>
> *"I couldn't find a therapist who was an expert at dealing with anxiety in a young child with autism."*
>
> *"Some programs wouldn't let him go there unless he met certain criteria. Or we had to go through one program before we could get him into another one."*
>
> *"Now that aggressive behavior is emerging, I don't know how to go about finding a program that is a good fit for her."*
>
> *"The big challenge was that a lot of the psychology people wouldn't see [child]. Once the clinics heard that she was minimally verbal we were told that we couldn't be seen. Maybe I just haven't found the right person to help me, but it's been hard to find the right fit. The generic recommendations didn't fit her and didn't lead anywhere."*

⊖ It could be stressful to select services and parents worried about making the wrong choice

Parents wanted to feel confident that they were choosing a good service or provider. Some parents talked about the importance of finding a program that was likely to help their child, and their fear of making the wrong choice. Several described wanting more feedback from other parents, to help them feel more confident that they had found a good program or agency.

> *"We were afraid to go some places that had openings because we heard bad things from other parents. The fear of trying something and having it suck was strong. We were just so afraid –even if we heard about something, we didn't know how to get more information."*
>
> *"Finding services is challenging. You are the one that has to do the research and how do you know if it's a good place? It's hard to know the quality places if you don't hear things from other people."*

Equity considerations

BIPOC families face additional barriers to finding mental health services for their children

Cultural background significantly impacts health seeking behavior. As stated by Hernandez and colleagues, "culture influences what gets defined as a problem, how the problem is understood and which solutions to the problem are acceptable."

Shame and stigma can be higher in some cultural communities, creating greater reluctance to seek mental health care. If they do seek care, they may experience additional barriers to finding services. Providers may not translate information into other languages, creating linguistic barriers to learning about available services. It may be harder to determine whether services are appropriate, and whether they integrate culturally-grounded practices.

The fear of finding the "wrong" service can also be stronger in some cultural communities. Anxiety about seeking services can be stronger when parents need to worry about exposing their child to the bias, discrimination, and racism that occurs too often in service delivery systems.

Sources: Gopalkrishnan, N. (2018). Cultural diversity and mental health: Considerations for policy and practice. *Frontiers in Public Health*, 6 (129);

Harris, T.B. et al. (2020). Achieving mental health equity: Children and adolescents. *Psychiatric clinics of North America*,43, 471-485.

Hernandez M, et al. (2009). Cultural competence: a literature review and conceptual model for mental health services. *Psychiatric Services*, 60, 1046–50.

Recommendations

Service providers

- Distribute resources designed to help parents understand the structure of the children's mental health system and recommendations for finding services.
- Review websites and assess ease of finding information useful for families seeking services (such as age ranges served, specialization areas, services provided, and insurance accepted).
- Expand use of family navigation services, working with families to identify and access appropriate services.
- Provide opportunities for parents to connect with other parents for support and resource-sharing.
- Pursue opportunities to integrate mental health services with other systems, such as health care.
- Offer resources to help parents connect with peer support and education programs in the community.
- Engage community leaders from BIPOC organizations to reduce public stigma and encourage help seeking for mental health issues.
- Ensure that bilingual front desk staff and/or intake coordinators are available to answer questions from parents seeking to learn about services.

System

- Create culturally- and linguistically-translated tools and resources to help parents learn about services and how to access them.
- Identify root causes of disparities in access to mental health services and develop services or policies to address them.
- Engage in parent education campaigns, to build understanding of children's mental health and available services and to reduce stigma.
- Provide training and other infrastructure to support behavioral health navigation services offered by professional navigators, care coordinators, case managers, or trained parent support specialists.
- Compile and distribute resources related to peer support for families, including identification of culturally-specific peer support networks.

Accessing mental health services

While almost all parents (96%) looked for mental health supports, fewer (84%) tried to access these services. Some parents found services that were a good fit for their child, and 49% of the parents rated their experience accessing services as “good” or “excellent.”

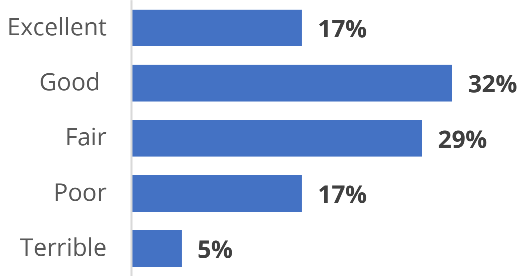
Once parents found a potential service, there were a number of reasons why they might choose not to pursue treatment at that time. Parents might be undecided about whether to move ahead, look for other options, or wait and see how things change for their child.

Finding a potential service that aligned with their child’s needs was an important first step. However, parents often faced a unique set of challenges when deciding to pursue these services.

84%

of parents tried to **access mental health services** or supports that might be a good fit for their child

Parent experiences accessing mental health services



Summary of interview be themes

Strengths	Challenges
	Once a potential service was identified, families often faced long waits to enter mental health services. It could be difficult to find services in accessible locations and at convenient times. Services and providers that looked good on paper did not always end up being a “good fit” The COVID-19 pandemic disrupted access to services.

Interview themes

Once a potential service was identified, families often faced long waits to enter mental health services

As described earlier, families needed to do significant amounts of research to find programs that sounded appropriate for their child. Once they identified a program, many parents found that the program did not have capacity to serve their child. Sometimes parents were simply told that the program was not accepting new clients. Other times, parents were offered a space on the program's wait list, with an expectation that it would be months before a spot may open up for their child.

> *"There were no services recommended in our area for eating disorders that didn't have a very long wait list."*
>
> *"The person we wanted for psychotherapy is highly sought after, and we were told that we could expect to be on the waiting list for 1 1/2 years. In the meantime, we went to other therapists but they weren't the right fit."*
>
> *"The waitlist was the hardest part."*
>
> *"It was challenging as there was always a waiting list. They did an intake online [for program] and we are still on a waiting list 1 ½ years later."*
>
> *"It seems as if there is always a waiting game. There aren't nearly enough workers to get the help that's actually needed right now and not a month or more from now."*
>
> *"There is just no availability. They aren't even taking waitlists at some places. The root cause is lack of providers and therapists. If you do get in, the wait list is so long."*
>
> *"We were on 4-5 waiting lists and we waited months to get into a group."*

It could be difficult to find services available in accessible locations and at convenient times

It was difficult for many parents to manage the logistics of services. Locations were not always convenient, requiring parents to travel long distances or navigate public transportation. Time was a significant factor. Some services were not available at convenient times, requiring the child to miss too much school or other important activities to participate. Some services simply required too much time, causing challenges for the parent or family. Difficult paperwork and a lack of childcare for other children during appointments can also contributed to parents' stress.

> *"[It was hard to find] anyone near our house and scheduling things so I don't have to take my kid out of school all the time."*
>
> *"Services were hard to schedule around school and other activities."*
>
> *"I don't have the flexibility professionally to be able to get child to services. Appointments were not at convenient times."*
>
> *"Location is important. Is the greater good keeping [child] in school, or pulling him out for therapy? It's not like my neurotypical daughter leaving school for a doctor's appointment. It's hard to disrupt his routine."*
>
> *"We also did PCIT and that was really great. It was just hard logistically…too much of a commitment."*
>
> *"The distance was hard…and timing and trying to fit it into my schedule and my child's schedule. I am a single mom working full time and my child is in school."*
>
> *"Trying to find childcare [for other children] was impossible, making it necessary for me to take all of my kids to the appointments."*
>
> *"When you do find somewhere to possibly go, they need all sorts of paperwork completed. I've filled out the same paperwork so many times."*

Services and providers that looked good on paper were not always a "good fit"

Parents often did significant research to find services or providers to help their child, and then might wait months to start these services. Sometimes the services themselves were just not quite what the parent expected. Programs that sounded promising ended up not being equipped to support their child. A few parents were surprised and frustrated when programs stopped serving their child due to the very behaviors that had led them to seek services in the first place.

> *"Many therapists did not understand how to help her. Day treatment was highly traumatizing. The second in-patient was more of a positive experience, but the program did not have the right tools to be helpful for her."*
>
> *"It was stressful to get her into residential treatment. After her being there for 2 weeks, they decided she was not a good fit due to aggression."*
>
> *"He was sent to day treatment for making threats at school. They kicked him out or doing the behavior that put him there in the first place. He was booted out of every day treatment program he was ever in."*

The "match" between the family and the mental health provider was critical. A few parents described ways in which they felt that they had found a positive fit with a provider, feeling that their child connected with the provider and that they were working in partnership to support the child.

> *"I really loved that the therapist didn't try to solve what was going on at that time, but rather wanted to get kids comfortable in therapy, so that later in life, talking to someone wouldn't be as hard if they were struggling."*
>
> *"In home therapy went well as the therapist was really able to connect with my son."*
>
> *"The benefit for us is getting feedback from the therapist that we're on the right page."*
>
> *"Eventually the kids got the perfect match with the person who would best meet their needs."*

Often, the personality or characteristics of the provider ended up being a poor fit for the child or the family. Some parents struggled with the decision to try again with another provider. They wanted to find the "right" provider for their child, while also feeling overwhelmed by the prospect of starting again with research and wait times.

> *"It is hard to find a good match. The person that you start with may just be a test. It worked well to talk first by phone to see if it was a good match. Sometimes we needed to start over."*
>
> *"It's finding the right fit – he needs a male with a certain personality style and we're still trying to find the right match."*
>
> *"We needed a 'trial and error' period for our child to find someone they felt comfortable talking to."*
>
> *"[Child's dad] was abusive and my son needed trauma-informed treatment. The therapist insisted on including the dad in treatment even though there was that history, which caused additional trauma."*

> *“Accessing trans-competent care was extremely challenging. I even had to explain pronouns to some of them.”*
>
> *“We could not continue with the first psychologist because he was pushing me to put [my son] into a juvenile facility, which wasn’t where I was hoping to go. I wanted to try treatment. He wanted to try a ‘scared straight’ approach, and I didn’t agree with that.”*

The COVID-19 pandemic disrupted access to services

Many parents who sought mental health services in the past five years experienced disruptions to the COVID-19 pandemic. The pandemic made it harder to access some services, due to issues such as workforce shortages. Families that relied on in-home supports found that those services were generally discontinued. Educational supports were also impacted, as schools worked to create strategies to adapt accommodations or provide support in the context of distance education.

> *“Everything is in my home. I would have liked to find services outside of my home so that she can socialize even just a little.”*
>
> *“COVID contributed to a lack of services. Schools, pediatrician etc. all said he could benefit from services, but finding any during pandemic was really difficult.”*
>
> *“The pandemic was harder. There was no in-person support and long waiting lists and people not working.”*
>
> *“Providers weren’t always doing in-home therapy due to COVID.”*

Some services transitioned into online platforms, offering telehealth appointments to children and families. For some families, this shift was positive, making services more convenient and accessible. However, many children were not comfortable with virtual services, or were unable to participate using that format. The loss of in-person services also impacted children by reducing their opportunities for socialization and increasing isolation.

> *"Many parents don't want to do therapy online and many clinics are currently doing only that."*
>
> *"Because being online made it things easier to access some services – we can see therapist in Saint Paul even though we live in Minnetonka. This allows her to take some autonomy to do it virtually by herself. It also removes stresses related to weather, traffic, etc."*
>
> *"The place that we found for [service] was 45 minutes away, so it was a tremendous burden to schedule, missing school etc. Due to COVID, it went online, which was better. The option for doing online therapy and OT was amazing. I hope that online accessibility stays because it was a gamechanger."*

Recommendations

Service providers

- Expand opportunities for families to receive services at convenient times, including evening hours.
- Offer options for telehealth services, to increase convenience of accessing services.
- Expand options for in-person services in accessible locations, including co-locating services in a variety of other service settings.
- Provide opportunities to have introductory phone or in-person meetings with providers, to assess "fit" before waiting to enroll in services.
- Use professional development and reflective supervision to support providers in identifying and addressing explicit and implicit biases that impact their work with families.
- Pursue opportunities to integrate mental health services with other systems, such as health care.

System

- Identify root causes of disparities in access to mental health services and develop services or policies to address them.
- Support policy efforts designed to expand, diversify, and support the children's mental health workforce across the service continuum.
- Create financial incentives to encourage formation of multi-sector partnerships

Receiving other healing services

While Western mental health services, like counseling or therapy, can be an important part of the service array for children, they are not the only approaches that may be beneficial. Families may choose to seek a variety of other services to support their child's well-being.

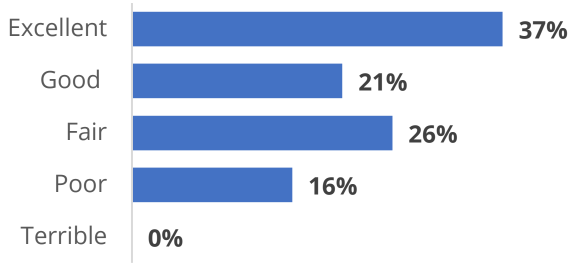
Some families chose other health-oriented services, such as nutritionists. Others looked to alternative healing methods, such as herbal remedies or acupuncture. Families may also seek services that align closely with their family's values. Faith-based practices, or culturally-grounded healing practices can be important services.

Within the interviewed parents, 41% sought services from these types of healers. Of these parents, 58% rated their experiences with these services as 'good" or "excellent."

41%

of parents **sought services from other healers** (such as herbalists, faith leaders, nutritionists, acupuncturists, traditional healers, etc.).

Parent experiences accessing other healing services



Summary of interview themes

Strengths

Some families valued the opportunity to receive faith-based or culturally-grounded services.

Some families found other healing services easier to access and more comfortable than other mental health supports.

Challenges

Some alternative health care options were expensive and unlikely to be covered by insurance.

Some families experienced stigma when receiving services in faith-based settings.

Interview themes

⊕ Some families valued the opportunity to receive faith-based or culturally-grounded services

For some BIPOC families, it was very important to them that their child and family received services that were grounded in their cultural traditions. A few parents also commented on the importance of receiving faith-based supports.

> *"They wove in traditional approaches that I found helpful. My grandma was [a service provider] and always shared elements from our culture. Pre-colonialism, we healed trauma through dance and ceremony. This was outlawed then eventually allowed again, but now carries shame. I like having those elements there because I believe it helps to heal generational grief and trauma if we turn to culture as we did historically. I find peace and connection with that."*
>
> *"It was important that we were in a place of faith, and an environment that my granddaughter knows."*
>
> *"We have a strong faith and believe strongly in prayer, so having lots of people standing with us here was very powerful."*

⊕ Families found other healing services easier to access and more comfortable than other mental health supports

There were several ways in which parents found healing services more accessible and more comfortable than other services. A few felt that the staff were easier to work with, highlighting their kindness, openness, and approachability. Others appreciated that they could make appointments more quickly or at more convenient times than they could for other services

> *"The staff are receptive, understanding, more positive. They actually show that they care more [than other providers], and they are more intentional about why they are doing [this work]. It's not about their paychecks, and that comes across."*
>
> *"[Provider] knew how to talk to kids. She was less intimidating, gentler. She has been open to hearing about the actual things going on with my kids. This has been more helpful than Western medicine."*
>
> *"They're easier to get in to see."*

Some alternative health care options were expensive and unlikely to be covered by insurance

Some health-based healing services were not covered by insurance, which made it difficult for families to afford them.

> *"It was challenging because a lot of places didn't take my insurance. For instance, I could only find one Integrative Pediatric Therapist who was covered."*
>
> *"It's not covered by insurance, probably due to [traditional providers] being in partnership with the pharmaceutical industry."*
>
> *"The biomedical doctors were extremely expensive."*
>
> *"They were on the right track and had seen a lot of kids like my son. However, it wasn't covered by our insurance."*

Some families experienced stigma when receiving services in faith-based settings

While it wasn't mentioned frequently, several parents described stigma-related barriers to receiving services, particularly in faith-based settings. These parents felt that other people in these settings were less comfortable with, and accepting of, mental health issues.

> *"People at Church judge and bully her. Her social skills are different and she is very outspoken. People don't know how to handle her."*
>
> *"I didn't feel comfortable sharing our background about mental health issues. I feel that there is a lot of stigma attached and people are not always sympathetic."*

Equity considerations

BIPOC families may be more likely to use other healing supports

Much of the theory and practice of mental health comes from Western cultural tradition. Research has found that some of these approaches, such as talk therapy, may not be the most useful form of intervention for some cultural groups.

Members of any cultural community may value healing services other than Western mental health approaches. However, members of some cultural groups may be especially drawn to alternative approaches that resonate with their values, such as traditional healing practices or movement-based therapies. They may also be more likely to turn to other professionals, such as community elders, religious leaders, or traditional healers.

Sources: Gopalkrishnan, N. (2018). Cultural diversity and mental health: Considerations for policy and practice. *Frontiers in Public Health*, 6 (129).

Alegria,M., Vallas, M., & Pumariega, A. (2010). Racial and ethnic disparities in pediatric mental health. *Child and Adolescent Psychiatric Clinics of North America*, 19(4), 759-774.

Recommendations

Service providers

- Pursue opportunities to integrate traditional healing practices into mental health care.

System

- Engage faith communities in collaborative planning about children’s mental health.
- Create financial incentives to encourage formation of multi-sector partnerships, including with culturally-based and faith-based institutions.

Accessing community programs

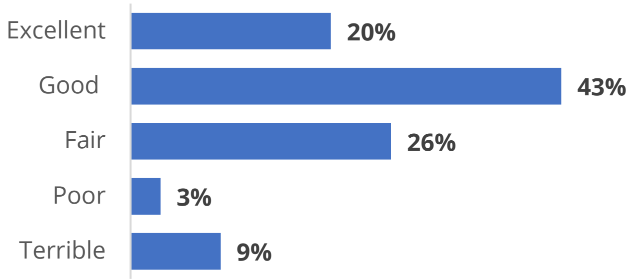
In addition to mental health services and other healing services, families often turned to other types of community programs, such as sports, art classes, or mentoring. While these programs may benefit children in a number of ways, there are a number of reasons why parents may seek these services as part of their plan for supporting their child's mental health.

Parents may look for services to help children release energy, express emotions, receive guidance, or gain socialization. Parents may also value these services as an opportunity for some respite from the challenges of parenting.

76%

of parents **sought other supports** for their child, such as community recreational activities, sports programs, art programs, mentoring, etc.

Parent experiences with community supports

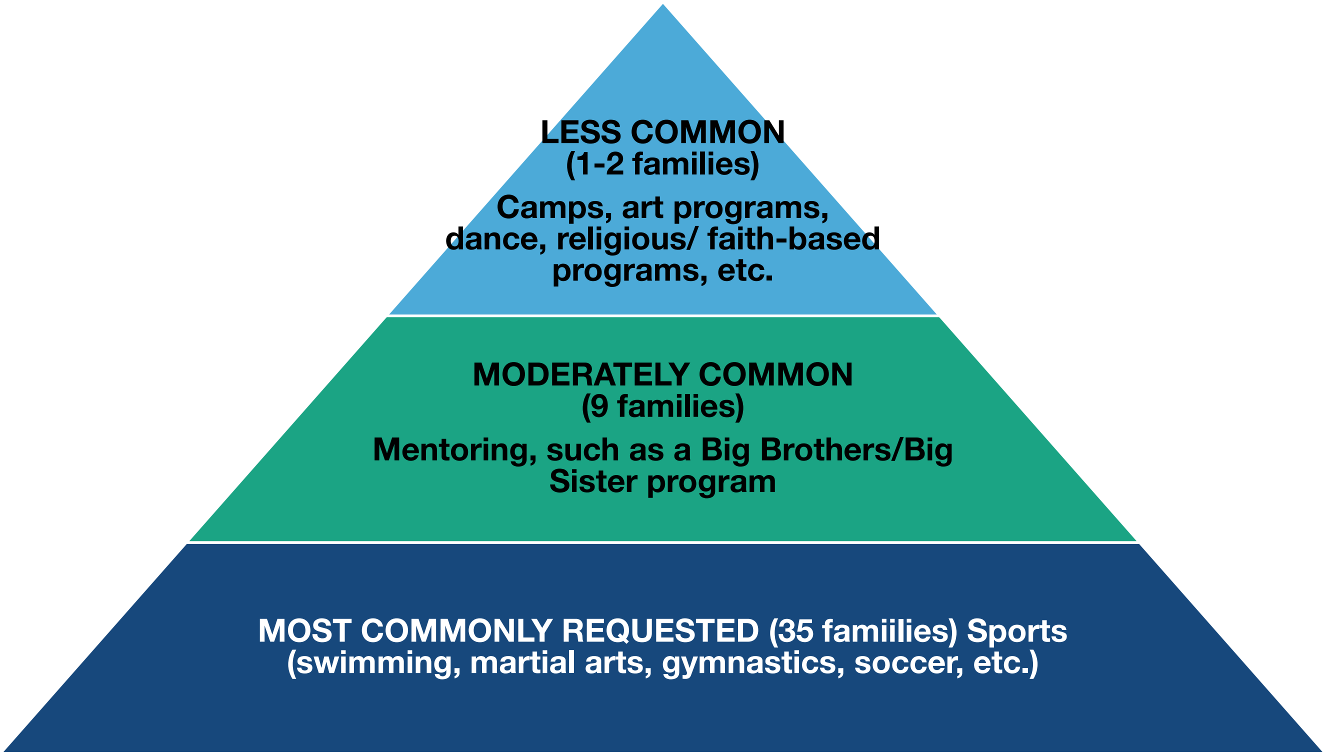


Seventy-six percent of the parents interviewed for this project sought community services for their child. Two-thirds of these parents (63%) rated their experiences with these services as "good" or "excellent."

Summary of interview themes

Strengths	**Challenges**
Community programs had important benefits for children/youth.	It could be difficult to find services adapted for children with special needs.
Other parents were especially important in helping parents find appropriate community programs.	Once parents found appropriate services, a variety of logical barriers limited participation.
	Children sometimes did not feel comfortable or accepted participating in programs.
	Community-based programs were frequently disrupted by the COVID-19 pandemic.

Types of community services sought by parents as they entered the children’s mental health system



LESS COMMON
(1-2 families)
Camps, art programs, dance, religious/ faith-based programs, etc.

MODERATELY COMMON
(9 families)
Mentoring, such as a Big Brothers/Big Sister program

MOST COMMONLY REQUESTED (35 famiilies) Sports (swimming, martial arts, gymnastics, soccer, etc.)

Interview themes

Community programs had important benefits for children/youth

Parents often sought community-based programs due to the benefits for their child’s mental health. Participating in programs such as sports, arts, or mentoring can help reduce mental health symptoms and provide opportunities for children to socialize with others.

> *“We keep him more scheduled rather than less because that’s an important tool for managing his anxiety. I would want him in sports and community activities for general well-being, but he does more because it’s better for his mental health.”*
>
> *“She’s calmer and more focused after martial arts.”*
>
> *“[His mentoring group] included kids that were like him, and it helped with socializing.”*

⊕ Other parents were especially important in helping parents find appropriate community programs

For other types of supportive services, parents sought input and guidance from a combination of service providers and other parents. However, as it relates to community support programs, parents mostly turned to each other for suggestions. Parents were able to recommend services that have benefitted their own child, or offer insight into which programs are more ready and willing to accommodate children with special needs.

> *"A lot of times it seemed like social workers didn't know about community supports. I learned about them from other special needs moms. There was a lounge at the hospital and we'd share names of all of the things that we had tried or had done."*
>
> *"Families in the waiting room [suggested activities]."*
>
> *"Facebook has good local groups for parents of kids with special needs [where I could get ideas for programs."*

⊖ It could be difficult to find services adapted for children with special needs

Many children with mental health issues do not require any modifications or adaptations to participate in community-based programming. However, for some families, it was important to find programs that could accommodate their child. Depending on their child's needs, some parents looked for programs that could support children with sensory sensitivities, high levels of anxiety, limited socialization skills, behavioral challenges, or emotional regulation.

> *"The programs specifically for children with special needs were excellent. The ones that were not were not as good."*
>
> *"The coaches were horrible in terms of supporting him. They did not understand him and did not do any accommodations."*
>
> *"The programs said that they didn't have anyone who could work with [my son]."*

> *“We looked for a mentoring program and a sport. Because of his mental health, he couldn’t get into them. We couldn’t find any programs that fit him and his needs.”*
>
> *“Church activities didn’t work. She needed too much help due to her behavior. I got phone calls that my child was acting out.”*
>
> *“He did a community education course this summer but got kicked out. He did camp, and I got calls every week.”*

While this option was not available for all parents, due to limited time or other resources, some parents chose to support their child’s activities more directly. Sometimes, this meant simply staying present at activities to support their child’s behavioral or emotional needs. Some parents became coaches or led programs so that they could address any emotional or behavioral needs themselves.

> *“Most services are not adaptive, but most instructors have grace. However, I need to stay on site during the activity.”*
>
> *“Sports can be difficult from a sensory regulation perspective. I don’t think [child] could do it without his father coaching. Because his father can tell when he’s revving up, he can help [child] right away.”*
>
> *“We intentionally do sports for [child] but his dad has to coach because things can go south quickly. It’s a big investment of time.”*
>
> *“I needed to provide extra support to my daughter during Girl Scouts so I became a troop leader.”*

Once parents found appropriate services, a variety of logistical barriers limited participation

Logistical barriers made it challenging for some families to participate in community programs. Some parents found it stressful to manage the logistics of scheduling services and completing paperwork. Cost was prohibitive for some families, which limited their opportunities to participate.

> *“There were long wait lists and a complicated application process…very long and drawn out.”*
>
> *“We applied for scholarships but the program was still too expensive.”*

Children may not feel accepted or comfortable participating in programs

Finding a program that sounded promising was not always enough. Sometimes, the program still ended up not aligning well with the child’s interests or comfort level. Programs could sometimes end up being an uncomfortable experience for children, if they felt anxious, embarrassed, or rejected by the other participants.

> *[Child] didn’t like [the program] due to not being socially ready.”*
>
> *“[Child] was anxious about all of the kids. Instead of feeling included, she just felt anxious and forced to go.”*
>
> *“It was a challenge when my son would feel singled out, knowing he was not like a lot of children around him.”*
>
> *“We wanted [our daughter] to have positive experiences and for people to understand her. Nothing ever went really well. We’ve pulled out of a lot of programs before the end to not break our daughter’s spirit.”*

Community-based programs were frequently disrupted by the COVID-19 pandemic

Interviews were generally conducted with parents who sought services for their children within the previous five years, which encompasses the COVID-19 pandemic. While the pandemic disrupted many services, parents talked about the particular impact of the pandemic on sports and other community recreation programs. While many mental health services transitioned into other formats, such as telehealth models, many community-based programs were suspended during the pandemic. Parents felt this impact, feeling that important supports simply were not available.

> *"COVID caused a lot of things to close or limit participation. The ones that are still available are less accommodating."*
>
> *"COVID has made it really challenging to find groups for [my son] to meet other kids. It's so hard to have group meetings right now."*
>
> *"My daughter was enrolled in art programs before the pandemic; however the pandemic led to these programs' cancellation."*

Recommendations

Community-based programs

- Expand availability of community-based programs adapted to meet the needs of children with mental health needs.

System

- Compile and distribute information about community-based programs for children with mental health needs.
- Offer resources and training, such as mental health first aid training, to community-based program staff.
- Offer financial support to parents to increase access to community-based programs.

Requesting educational support

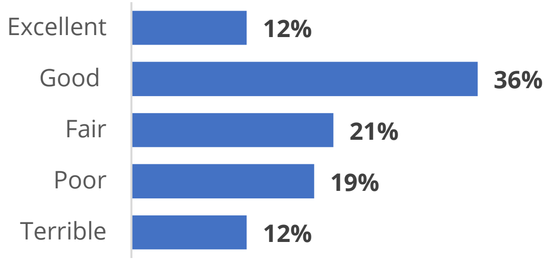
Not all children with mental health needs have academic challenges. However, mental health concerns sometimes impact ability to learn or succeed at school. Some students may qualify for educational supports or accommodations through an Individualized Education Plan (IEP) or a Section 504 plan.

Unlike other school-based supports, such as counseling or social-emotional programs, Individual Education Plans and Section 504 plans are provided under Federal guidelines to students who qualify. Most interviewed parents (90%) did seek educational support for their students, requesting coverage under one of these programs. Almost half of these parents (48%) rated their experience with these supports as “good” or “excellent.”

90%

of parents **requested educational supports** for their child, such as pursuing an Individualized Education Plan (IEP) or 504 plan through their school district

Parent experiences with educational supports



Summary of interview themes

Strengths	Challenges
For some parents, school supports were easily obtained and helpful.	It was difficult to understand and navigate the process of obtaining school supports. Parents frequently needed a well-trained advocate to help them obtain educational supports. Parents frequently perceived the schools as oppositional, requiring them to advocate strongly for support. When accommodations were approved, they were not always successfully provided by the schools. Effective supports were sometimes discontinued by the schools. Some parents transferred schools in hopes of receiving more educational support.

IEP and Section 504 plans

An Individualized Education Plan (IEP) is provided through the Individuals with Disabilities Education Act (IDEA). An IEP provides students with accommodations to ensure they receive appropriate instruction in the least restrictive environment. Students may qualify for an IEP if they have a disability that negatively impacts their educational progress, such as autism, emotional disturbances, intellectual disabilities, or learning disabilities.

Section 504 plans are covered under Section 504 of the Rehabilitation Act, a federal civil rights act that ensures an individual cannot be discriminated against on the basis of a disability. Under a 504 plan, schools create personalized accommodations such as preferential seating, extended time on classwork or assessments, or other supports. Students are eligible for a Section 504 plan if they have a disability that interferes with learning or another major life activity, including mental health conditions.

Adapted from: 3 Types of School Supports to Help Students with Mental Health Conditions | NAMI: National Alliance on Mental Illness

Interview themes

⊕ For some parents, school supports were easily obtained and helpful

School-based educational supports can be an important resource for students with mental health conditions. Some families described successes related to the ease of requesting services, their communication with the school, and the helpfulness of the provided accommodations.

> *"I would have to credit the school for giving [child] her first when evaluation. The IEP was just right. They did their best to give her what she needed."*
>
> *"She has a 504 and the school has been great in providing accommodations."*
>
> *"Support from the school system was fantastic. The lines of communication and meetings were great."*

It was difficult to understand and navigate the process of obtaining school supports

For many parents, it was a challenge to obtain information about how to request school supports. Some parents described struggles understanding the difference between an IEP and a Section 504 plan and the school's process for determining eligibility. Several had difficulty understanding the difference between a medical diagnosis provided by a health care professional and a determination of educational eligibility under the Individuals with Disabilities Education Act. Many parents felt that the school did not provide clear or helpful guidance to help them navigate the process.

> *"I relied on the school to educate me on how this all works. They did the absolute minimum."*
>
> *"For the IEP, I was lost and didn't know what to do. No one was listening to me. I didn't know where to go."*
>
> *"Honestly, nothing worked well or was positive."*
>
> *"Without telling us, they went with a lower level of support. They did a 504 and not an IEP without explaining it to us. I wouldn't know the difference. They said they would help and then they pulled one over on us."*

Parents frequently needed to find a well-trained advocate to help them obtain educational supports

An overarching theme from the interviews was that parents frequently turned to informal and formal supports for assistance navigating access to children's mental health services. The importance of an advocate or navigator was especially true for school services, with parents needing assistance to understand and manage the process. However, unlike other services covered in the interviews, parents generally found that specialized support was needed as it related to school services.

Parents felt most successful navigating the process when they were supported by (a) a school staff person, such as a teacher; (b) a case manager or other health navigator; or (c) a professional advocate specializing in working with the schools. Other more informal support sources were less useful, as parents described the importance of understanding the nuances of how to approach requests and what language to use when talking to the schools.

> *“[Community advocates] were helpful. We copied them on communication with the school and they helped us file appeals when needed.”*
>
> *“Our case manager changed everything. I finally found somebody to advocate for us, who let us know what was reasonable and what to ask for. We would not have gotten accommodations without the assistance.”*
>
> *“It was kind of random. I felt grateful that the teacher liked [child] and knew that I didn’t know anything about [how to pursue school support]. She gave me the right language to use.”*

Parents frequently perceived the schools as oppositional, requiring them to advocate strongly for support

Parents described their relationship with the school as adversarial. They experienced the schools as “resistant” to providing supports, or felt that the schools were actively “blocking” their requests. This conflict took a variety of forms. First, some parents felt that the schools intentionally delayed responding to a request for educational supports.

> *“She deserved an IEP. I spent a whole year fighting for it and trying to get them to make a decision.”*
>
> *“The school dropped the ball and didn’t move forward. I had to write a firm letter because they didn’t get the assessment done within the required number of days. They kept delaying the process and not following up.”*
>
> *“I learned fast that I have to be their advocate or we would just fall through the cracks. I don’t like confrontation. I’m very easy-going, but I learned the hard way that I had to be that way.”*
>
> *“I asked for [a 504] and we didn’t have the first meeting about accommodations for 8 months.”*

Second, many parents felt that the schools dismissed their concerns about their child. Sometimes, this dismissal resulted in a denial of eligibility for school supports. Parents frequently found that they needed to appeal the school’s decision, or even threaten legal action, before services were approved.

> *“We had to appeal twice before we got the IEP.”*
>
> *“Once [community advocates] were involved, the school began to take the appeal more seriously. After the appeal, the school found [child] to be eligible for an IEP.”*
>
> *“I got to the point I called the county prosecutor and asked what evidence they need that I pulled my child out of school for mental health reasons. I finally just quit working with school altogether and was seriously looking into a lawsuit.”*
>
> *“There was pushback from the school. Luckily, I know enough to bring support to with me. Now I bring [child’s] out-of-school time program staff, her drama therapist, and her social worker to the IEP meeting.”*

Third, some parents perceived that the school had limited resources, and was unable to support every student that qualifies for services. Several perceived that these resource concerns resulted in their child being found ineligible for accommodations.

> *“The school counselor did not want to do an IEP. She said there were other kids that needed it more.”*
>
> *“It felt like there's a quota for the district for how many students can have accommodations. Maybe it’s a financial thing. But there was a reason why the school counselor didn't want [my child] to have accommodations.”*

Approved accommodations were not always provided by the schools

While it was difficult for many parents to navigate the process of being approved for school supports, receiving approval did not end their struggles. Once accommodations were approved through the IEP or Section 504 plan, these accommodations were not always provided. Some parents perceived their schools as unable to successfully offer the accommodations due to workforce or other resource limitations.

> *"504s are non-existent. There is no follow-through from teachers. It's a running joke from parents that a 504 is like an extra post-it note on the teacher's desk."*
>
> *"They couldn't follow the accommodations because they had too many kids and a lot on their plate."*
>
> *"I had trouble getting them to follow the IEP. The teacher was relying on the other students to support him, which was not in the IEP. He was getting missed and falling through the cracks."*

In other cases, parents felt that the offered accommodations were not going to be sufficient to meet the child's needs. Some felt that the school did not know how to effectively support their child, while others felt that the school was not able or willing to personalize the accommodations for their child.

> *"[Child's] been on an IEP for years but the school district doesn't offer any supports. They will only do things one way and they won't do anything else – it's not individualized. I had to take him to another place, which is very expensive, to help teach him. There are things that work for him that they won't do."*
>
> *"[The school] found [working with child] pretty challenging. There were areas of the IEP that were just trial and error in terms of what worked."*

⊖ Effective supports were sometimes discontinued by the schools

Some parents struggled to ensure that their children continue to receive helpful services over time. To be eligible for educational supports, students must demonstrate educational challenges as a result of their mental health condition. When supports were effective, students demonstrated improvement, resulting in schools determining that accommodations were no longer necessary. When accommodations were withdrawn, however, the child's learning or performance could be negatively impacted.

> *The challenge is that he's doing well. Because he's 'doing well', they want to back off on supports."*
>
> *"It's great that they have given accommodations, but it also then prevents her from getting other services because she is doing well. It's great and not great."*
>
> *"The overall message from the school was that they were hurrying to get her off these services, pushing to get her out of special education."*
>
> *"[After a few years with a 504], he had good grades and was doing fine. The counselor took some accommodations off the 504 without asking or talking about it. Now he's struggling terribly academically."*

Some parents transferred schools in hope of receiving more support

When schools were unable or unwilling to support the child, parents may transfer child to a new school. Of the 44 parents who sought educational supports, 8 (18%) transferred their child to a new school in hopes of receiving better support. Some parents switched to another public school, while others opted for a private or charter school.

> *"We didn't feel like our high school was equipped to handle his challenges so we moved into another program in the school district. It's a special program with more support for someone with his type of IEP."*
>
> *"After years of battling the school, I pulled [child] from school and put them in a different district. Then I had to start over again with the new district."*

Equity considerations

There are significant disparities in access to educational supports on the basis of race/ ethnicity, poverty, and gender

The parents interviewed for this project described fairly consistent challenges in obtaining educational supports. Their ratings of this experience, and their narrative descriptions, did not yield significant differences based on parents' race or ethnicity.

However, other research has highlighted variation in receipt of educational supports, especially related to Section 504 plans. Students are more likely to be approved for a 504 plan if they are:

- Male
- White
- Attending a wealthier school

As stated by the Center for American Progress, an independent, nonpartisan policy institute:

"These disparities can be attributed to the advantages of families that can spend the time and money advocating for 504 services, securing professional help, and paying for psychoeducational testing. Furthermore, if a school does not evaluate the needs of a student suspected of requiring a 504 plan, support may only be provided after parental intervention or litigation, which also takes time and money."

Sources: Center for American Progress (2021). Returning To School Must Include a Reinvestment in Section 504 Plans - Center for American Progress and the New York Times (2019). Need Extra Time on Tests? It Helps to Have Cash.

> *"Eventually I gave up [on requesting supports from the school] and put my kid into [a specialized charter school] instead."*

Recommendations

Schools/school districts

- Provide clear and accessible information to parents about eligibility for Individualized Education Plans (IEP) and Section 504 plans, the process of requesting supports, and their rights under these Federal guidelines. Ensure that all information is culturally relevant and translated into multiple languages.
- Communicate with parents throughout the application, evaluation, and decision-making process. Include parent input when developing or modifying IEPs and Section 504 plans.
- Recommend alternative school-based services when students are found to be ineligible for IEPs or Section 504 plans.
- Train school counselors and other staff in family-driven care principles, and strategies to ensure that family voice is encouraged and valued.
- Monitor Section 504 requests and decisions to identify potential disparities, and develop plans to reduce these disparities.

Service providers

- Provide training to care coordinators/case managers/navigators to help them support parents in requesting educational services, including attending school meetings as needed. If these services are not provided through the agency, help parents connect with trained community advocates.

System

- Increase state- and local-level investigations and monitoring related to civil rights complaints under Section 504.
- Increase funding for Section 504 implementation to supplement tax revenues, especially in communities with lower tax bases.

Obtaining medication

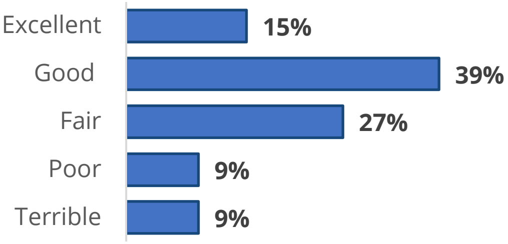
Not all children require medication to address their mental health need. However, medication can be an important component of the treatment plan for a variety of mental health issues, such as Attention Deficit Hyperactivity Disorder (ADHD), depression, or anxiety.

Two-thirds of the parents interviewed for this project (67%) did try to obtain medication for their child. Some of these parents worked with their child's pediatrician or another primary health care provider to receive medication, while others may have received specialized support from a psychiatrist or clinical nurse specialist. Over half of the parents (54%) rated these experiences as "good" or "excellent."

67%

of parents attempted to **obtain medication** to treat their child's condition

Parent experiences obtaining medication



Summary of interview themes

Strengths

Health care professionals helped facilitate access to specialized providers for medication when needed.

Many parents felt that medication has been beneficial.

Challenges

Parents described challenges finding medications that were effective and did not bring significant side effects.

Interview themes

⊕ Health care professionals helped facilitate access to specialized providers for medication when needed

Parents described several different pathways to obtaining medication. Some children and youth were prescribed medication for their mental health condition from their pediatrician or other primary health care provider. Others, especially those with more severe or complex conditions, needed to see a specialized provider, such as a psychiatrist or clinical nurse specialist. Primary health care providers played an instrumental role for parents, helping them access specialized providers, advocating for appropriate medication, and providing information about potential prescriptions.

> *"Our pediatrician was instrumental in navigating [medication] with us. I trust her and I know that she advocates for us. She helped me understand what was going on and pointed me in the right direction. She took the time to talk to me and talk things through with me."*
>
> *"The one person who helped me get on the right road was a pain and palliative doctor in the hospital. When we got the referral to him, it made all the difference. He did a really good job advocating with the team."*
>
> *"Our current provider listens to us, is responsive and available, and makes appointments for us if we can't get in. She's open to trying just about anything and understands the complexities of my child's conditions."*

⊕ Many parents felt that medication has been beneficial

Many of the parents who sought medication for their child described the benefits of receiving appropriate treatment. Appropriate medication helped relieve children's symptoms, and improved their functioning at home, at school, or in other settings.

> *"He is a lot better off with the medication – it has made a big difference."*
>
> *"We didn't have to try a lot before we found something that works."*
>
> *"I can tell that she's more of herself when she's on the right medication".*
>
> *"We were able to get her on a medication that helped her and had some good conversations with the psychiatrist."*

⊖ It could be hard to find effective medications that do not bring significant side effects

While medication was ultimately beneficial for many children, it often required some "trial and error" to find the right medication. Some parents were frustrated by the process of trying multiple medications before finding the right one. Others had difficulty managing the side effects of the treatments prescribed for their children, describing sometimes significant and dangerous side effects.

> *"There was a lot of trial and error in finding the right doc/medication."*
>
> *"It was an incredibly long and confusing roller coaster of what meds worked and what meds didn't."*
>
> *"There were some fairly scary side effects at one point and we didn't know what to do or whom to call."*
>
> *"She didn't know how to help my daughter. She kept trying medication after medication and it was backfiring on my daughter. It was exhausting."*
>
> *"They sent us down a wrong path, combining two medications that caused a suicide attempt."*

Equity considerations

There are significant disparities in access to medication on the basis of race/ ethnicity

The parents interviewed for this project described fairly consistent successes and challenges in obtaining medication. Their ratings of this experience, and their narrative descriptions, did not yield significant differences based on parents' race or ethnicity.

However, other research has shown significant and persistent disparities in the use of psychotropic prescription drugs for children and adolescents. African American and Latino youth in particular are significantly less likely to receive adequate treatment. One review concluded that across all studies, "white children were at least two times more likely, if not more so, to receive psychotropic medication than nonwhite children."

The same review also described the various factors that may contribute to these disparities. concluding that BIPOC youth face a variety of barriers, "including population barriers (socioeconomic disparities, stigma, poor health education, lack of activism), provider factors (deficits in cross-cultural knowledge, skills, patient-orientation, and attitudinal sensitivity), and systemic factors (services location and organization, training, culturally competent services, etc."

Source: Alegria,M., Vallas, M., & Pumariega, A. (2010). Racial and ethnic disparities in pediatric mental health. *Child and Adolescent Psychiatric Clinics of North America, 19(4),* 759-774

Recommendations

Service providers

- Monitor prescription practices to assess disparities in amounts or types of medication prescribed and develop strategies to reduce disparities as needed.

System

- Support policy efforts designed to expand, diversify, and support the children's mental health workforce across the service continuum.

Negotiating insurance coverage

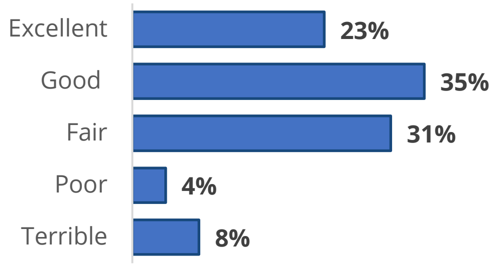
It is likely that all parents who sought services through the health care or mental health care systems needed to work with their insurance company to cover these services. However, only about half of the parents (51%) said that they needed to work directly with their insurance company to determine their child's eligibility for services, or to negotiate coverage for needed services. Fifty-eight percent of these parents described this experience as "good" or "excellent."

The interviewed parents had a variety of insurance plans. Most had a policy through a private company, such as a plan offered by an employer. Some had a public insurance plan, such as Medical Assistance (MA), or were covered under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). Some parents had both private and public insurance coverage to navigate.

51%

of parents needed to **work with their insurance company** to determine their child's eligibility for services or supports or to negotiate coverage for needed services

Parent experiences negotiating insurance coverage



Summary of interview themes

Strengths

Sometimes, insurance easily covered desired services.

It was helpful to have provider support navigating insurance coverage, through service agencies or the insurance companies themselves.

Challenges

Insurance coverage often limited the types or amounts of services that children received.

Some parents paid high amounts to cover deductibles, co-pays, and services that were not covered.

Coverage varied between public and private plans, with some parents moving onto public plans to increase access.

Interview themes

Sometimes, insurance easily covered desired services

Some parents, including some on private and some on public plans, felt that they had a relatively easy time arranging services for their child. Several mentioned that they had high quality plans, and that they are generally able to receive coverage for their child’s services.

> *“They didn't butt in and question much at all. We've had good coverage and therapy seeking was always covered.”*
>
> *“I generally have good insurance. They have mostly covered what I need. Her out of pocket expenses max out in January every year and we haven’t heard of any billing issues.”*
>
> *“Everything she needed was covered.”*

Insurance coverage often limited the types or amounts of services that children receive

Some parents said that their insurance did not cover services that they wanted at all, while others said that insurance limited how much service that their child could have covered. Insurance sometimes limited the choice of provider, with companies restricting their options to providers within their coverage network.

> *“We received two referrals. The person we wanted wasn’t covered by insurance, so we went with the other.”*
>
> *“I thought [agency] would be a good place to go. It took about a year to get seen. They finally called to say that we were at the front of the list, then said that they couldn’t do it because of her insurance.”*
>
> *“I never pursued some services because they weren’t covered by insurance.”*
>
> *“Her therapist moved from in-network to out-of-network. [Insurance company] is notorious for not working outside of their network. I worked with them so the therapist could request in-network coverage. I didn’t even try with neuropsych – not a fight that I wanted to take time on.”*

> *“We don't have thousands and thousands of dollars, so insurance had a huge say in where we did services.”*
>
> *“We spent a long time researching programs. We, finally found one that [our daughter] would try, but insurance wouldn’t cover it.”*

⊖ Some parents paid high amounts to cover deductibles, co-pays, and services that are not covered

Many parents talked about the high out-of-pocket costs of services. Some families had large deductibles, and needed to cover the costs of services until the deductible was met. When services were not covered, families needed to decide whether to try to pay for the services themselves. Some parents found a way to manage, saying that they would do whatever it took to cover services for their child. However, others simply could not afford to do so, requiring them to forego services that were too expensive.

> *“A specific kind of therapy was recommended. We could only find it through a very specialized clinic that is private and we’d have to pay hourly. I was laid off so that’s not an option…but you want to find a way and help your kid.”*
>
> *“We started looking at counseling and other things but everything is out of pocket so we had to stick to what was medically necessary.”*
>
> *“[Insurance] paid their part of the bill, but we have to pay the first $15,000. The doctor said we should look into meds, but it would be very high cost every month. Whatever we do for her, we pay for ourselves out-of-pocket because of the deductible. Now I have to think not only about the wellbeing of our child but also have to do this mental math to see if we can afford it.”*
>
> *“It's expensive, but I would do anything.”*
>
> *“We have a very high deductible, so we pay for almost everything.”*
>
> *"It’s a high deductible plan, so I’ve been hitting my $10,000 deductible every year. Also, multiple times I would get an estimate from them about how much something would cost, but then the cost would be so much more. In one case, they predicted $3,000 out-of-pocket, but it was actually $7,500 in the end.”*

> *“It didn't matter how much it would cost. I would sell a kidney to get her what she needed.”*
>
> *“Everything we looked at was too expensive.”*

Public insurance plans provided stronger coverage than private plans, and some parents moved onto public plans to increase access to care

It was seen as advantageous to be on public insurance, such as Medical Assistance. These plans were accepted by more providers and covered more services. Some families, that is those who had lower-incomes or whose child could qualify as having a disability, applied for coverage under public plans towards a goal of better supporting their child with mental health needs.

> *"A lot of therapy places didn’t accept private insurance – that was the number one problem. Many only accepted people on MA."*
>
> *“Private insurance was rough. It was a crapshoot in terms of whether it would be a good experience or a bad experience. MA is always helpful as a backup option, covering specialized medications.”*
>
> *“Our family has MA, so we’ve never had any issue with getting anything covered.”*
>
> *“We started with [private insurance], but eventually had to go on the state plan (MA) because her services were being denied.”*
>
> *“[Our private insurance] stopped covering the program, so we had to move to TEFRA/MA (and go through the process of having him deemed medically disabled.)”*

It was helpful to have support navigating insurance coverage

Parents valued having someone helping them with insurance issues. Some parents received support directly from their insurance companies, connecting with someone who helped them determine eligibility, find covered providers, and resolve billing issues. Others said that their providers worked directly with the insurance companies, so that the parents did not have to be as deeply involved in these discussions.

> *"The social worker from the hospital would also call the insurance company with me. She would give me information to help me figure it out."*
>
> *"The navigator role was a good one. They could poll providers for you and let you know what clinics are available, and kept me from needing to keep restarting my story."*
>
> *"[The insurance company] help line was great. They could talk it through and gave recommendations about how to code services, etc. They were helpful but I needed to work with them and would not have figured it out on my own."*
>
> *"I found some good people at the insurance companies who could help."*
>
> *"The program took care of insurance and told us what we were covered for."*

Recommendations

Service providers

- Provide navigation support to parents to help them negotiate insurance coverage for services.

System

- Support initiatives designed to expand coverage for children who are uninsured and underinsured, to reduce the high out-of-pocket cost for care.
- Promote parity in insurance coverage, not just between physical and mental health care but between public and private insurance plans.
- Support policies working to promote Accountable Care Organizations, in which health care providers work together to promote coordinated, high-quality, and cost-effective care.
- Support policies allowing families to purchase public insurance plans.

How can we improve parents' experiences with the children's mental health system?

Summary of recommendations

Mental health service providers

- **Adopt family-driven care principles**: Assess alignment of agency practices with principles of family-driven care and develop plans to improve alignment; adopt "whole family" practices to proactively support parents; use parent feedback to improve services; and develop warm and child-friendly spaces for services (especially for diagnostic assessments).

- **Increase convenience of services**: Offer services at convenient times and locations for families, including home- and school-based services, and offer telehealth appointments for families who prefer them.

- **Develop or distribute resources**: Proactively develop and/or disseminate resources to help parents understand the children's mental health system and available services.

- **Provide navigation support**: Expand use of navigation services, working with families to identify and access appropriate school and community supports; provide guidance following assessments regarding appropriate services; and follow-up with parents after assessments to address emerging questions.

- **Promote behavioral health equity**: Monitor agency performance to assess disparities (in assessment results, prescriptions, service outcomes, or parent satisfaction) and develop plans to reduce them; provide training and reflective supervision to ensure that providers identify and address explicit and implicit biases that impact their work; and use culturally-appropriate assessment tools.

- **Develop integrated care partnerships**: Pursue opportunities to integrate mental health services with traditional healing practices, school services, and health care systems.

- **Make it easier for parents to learn about services**: Review websites and assess ease of finding information for families seeking services (such as age ranges served, specialization areas, services provided, and insurance accepted); and provide opportunities to have introductory phone or in-person meetings with providers, to assess "fit" before waiting to enroll in services.

- **Promote peer support**: Provide opportunities for parents to connect with other parents for support and resource-sharing.

Schools/school districts

- **Make it easier for parents to request educational supports:** Provide clear, culturally-accessible information to parents about eligibility for Individualized Education Plans (IEP) and Section 504 plans, the process of requesting supports, and their rights under Federal guidelines.

- **Partner with parents to support students:** Communicate with parents throughout the application, evaluation, and decision-making process; include parent input when developing or modifying IEPs and Section 504 plans; recommend alternative school-based services when students are found to be ineligible for plans; and train school staff in family-driven care principles.

- **Promote behavioral health equity:** Monitor Section 504 and IEP requests and decisions to identify potential disparities, and develop plans to reduce these disparities.

System

- **Develop and strengthen workforce**: Support initiatives to expand, diversify, and support the children's mental health workforce, including increasing providers who can conduct diagnostic assessments.

- **Develop resources**: Compile and distribute culturally- and linguistically-accessible resources for parents to help them: (a) learn about and access mental health services; (b) connect with peer support networks; and (c) find community-based programs for children with mental health needs.

- **Diversify and strengthen partnerships**: Expand system-level partnerships to support the development of the children's mental health system of care, including engagement with health care systems, faith-based and culturally-based programs, and youth recreation programs.

- **Build community and parent awareness**: Engage in parent education and social media campaigns, to build understanding of children's mental health and available services and to reduce stigma.

- **Promote equity**: Develop frameworks related to behavioral health equity, monitor disparities in access to or quality of mental health services, and develop policies to actively promote equity.

- **Develop and provide training**: Offer training to build skills of community-based program staff, behavioral health navigators, and parent/peer support specialists to strengthen family-driven approaches, support children and parents, and facilitate access to care.

- **Provide financial support to parents**: Offer grants or scholarships to help parents cover costs of mental health support, including access to community-based programs.

- **Expand peer support opportunities**: Develop and advertise opportunities for parents to engage with peers for education and support.

- **Support public policy reform**: Support policies designed to strengthen access to or quality of children's mental health services, such as strengthening Section 504 implementation and compliance, expand health care coverage for children who are uninsured or underinsured, promote parity in insurance coverage, and promote Accountable Care Organizations, etc.

- **Include parent voice in system planning**: Ensure that parent voice is included in system-level planning and implementation, through participation in leadership boards, advisory groups, and research.

To learn more

HENNEPIN COUNTY
CHILDREN'S MENTAL HEALTH
COLLABORATIVE

Hennepin County Children's Mental Health Collaborative

The Hennepin County Children's Mental Health Collaborative's mission is to provide a forum for a diverse and representative group of system stakeholders to influence the development and ongoing operation of an accessible and effective children's mental health service system within Hennepin County. The CMHC promotes innovative service development and continuous quality improvement in the children's mental health system by embracing the system of care principles and available research on children's mental health services.

To learn more about the Collaborative's efforts to strengthen the children's mental health system of care: Visit our website (https://hccmhc.com/) or contact Laura LaCroix-Dalluhn at Laura@LaCroixDalluhnConsulting.com.

Hennepin County Parent Catalyst Leadership Group (PCLG)

The Hennepin County Parent Catalyst Leadership Group works to empower Hennepin County families to become valued advocates and decision-makers at all levels of the children's mental health system through education, outreach, and support. They offer opportunities for parent support, education, and leadership.

To learn more about the PCLG's work to support parents: Visit our website (https://hccmhc.com/pclg/) or contact Margaret Sullivan at hcpclg@yahoo.com.

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