In their own voices:

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

March 2022

The Hennepin County Children's Mental Health Collaborative promotes innovative service development and continuous quality improvement in the children's mental health system. In 2021, as part of our effort to achieve our vision of "a comprehensive, integrated, and culturally responsive mental health system," the Collaborative began planning to implement a System of Care approach.

> **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 organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs in order to help them to function better at home, in school, in the community, and throughout life.**

With our goal to center family voice in our planning process, we wanted to better understand parents' experiences entering the children's mental health system. How do they first come to understand that their child may have 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?

HENNEPIN COUNTY
CHILDREN'S MENTAL HEALTH COLLABORATIVE

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Project overview

Hennepin County parents of children with mental health issues were invited to participate in interviews. Recruitment flyers were translated into Spanish, Karen, and Somali. Outreach took place over several months, with invitations to participate posted through a variety of newsletters, mailing lists, and social media sites: Interviews were conducted by a team of trained interviewers, most of whom were parents of children in the mental health system. Interviews were conducted by phone or online. Interviews took approximately 45 minutes to complete, after which parents received a $25 gift card to Target or Walmart.

Parents involved with the Hennepin County Parent Catalyst Leadership Group (PCLG) helped develop a list of common services that parents may navigate when they identify that their child has a mental health need. Parents were asked about their experiences with these services as part of their interviews.

Who was interviewed?

A total of **49** parents completed interviews. Most parents lived in Hennepin County, including Minneapolis and many suburbs.

Participant demographics

	County population	Interviewed parents	Their children
Black or African American	14%	8%	11%
American Indian/ Alaskan Native	1%	8%	9%
Asian	7%	2%	9%
Hispanic/Latinx	7%	2%	6%
Non-Hispanic White	68%	79%	66%
Male	50%	4%	50%
Female	50%	96%	42%
Other	-	-	8%

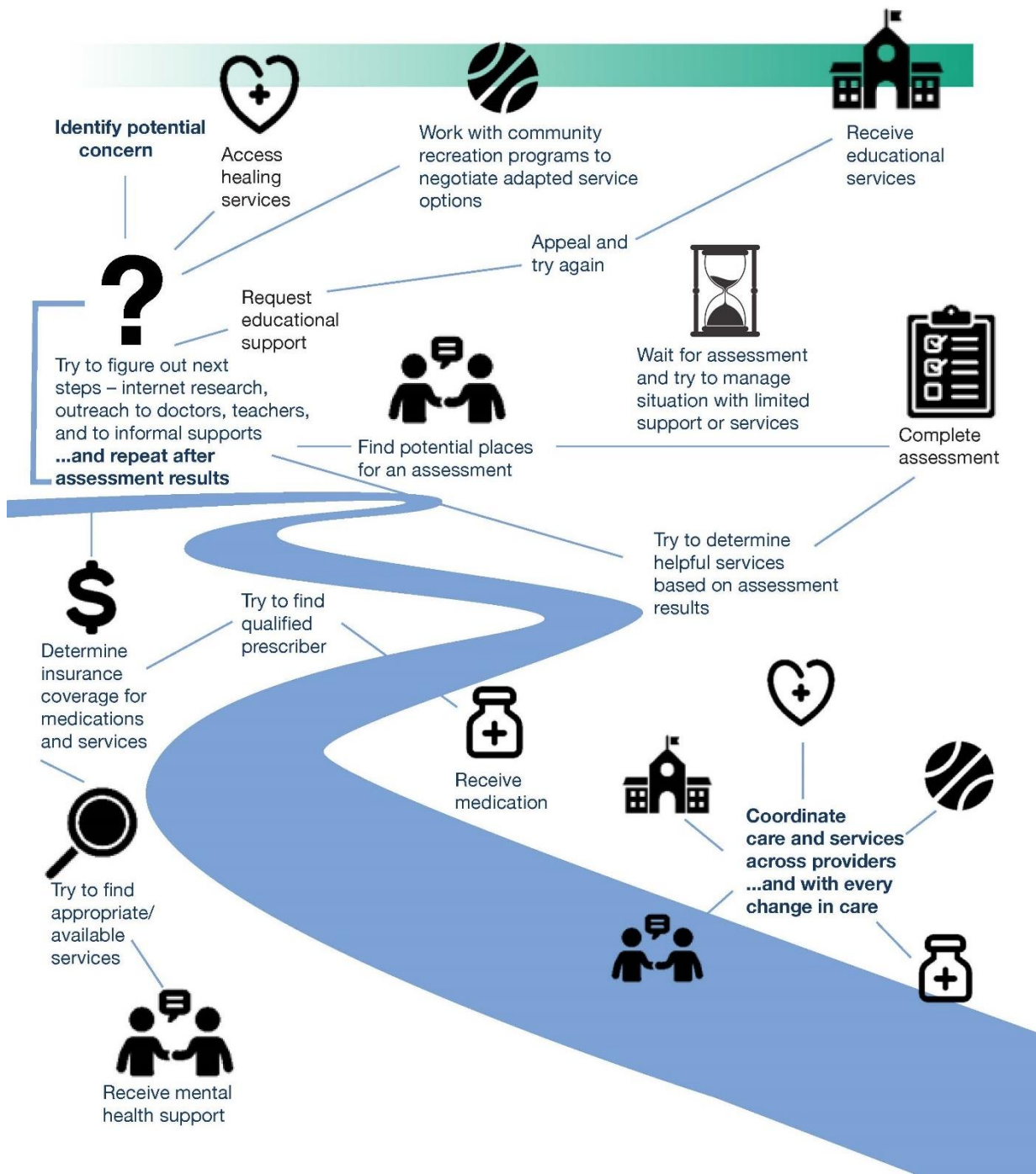## How did parents first identify their child's mental health concern?

There is no one way to enter the children's mental health system. The interviewed families represent a wide array of experiences. Children first exhibited issues at a variety of ages, from early childhood to high school. They exhibited a wide range of emotional or behavioral concerns. In some cases, the parent, or the child themselves, was the first to detect that something was wrong. Others were first identified by teachers, child care workers, or doctors.

Impact of COVID

This project focused on parents' experiences entering the children's mental health system within the last five years, which coincides with the COVID-19 pandemic. It is well established that the pandemic disrupted many community services, including children's mental health. While it was not mentioned in most interviews, some parents highlighted 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 – especially community-based services – were more significantly altered.

How do families move through the children's mental health system?

While every family has their own story to tell about their pathway through the children's mental health system, the graphic below illustrates a typical "journey" through children's mental health, as described by the interviewed parents. Overall, these journeys are challenging, as parents attempt to find resources in a complex system, face delays in receiving services, and advocate for their child in the face of systems that feel unsupportive.

Identify potential concern

Access healing services

Work with community recreation programs to negotiate adapted service options

Receive educational services

Appeal and try again

Request educational support

Wait for assessment and try to manage situation with limited support or services

Complete assessment

Try to figure out next steps – internet research, outreach to doctors, teachers, and to informal supports **...and repeat after assessment results**

Find potential places for an assessment

Try to determine helpful services based on assessment results

Determine insurance coverage for medications and services

Try to find qualified prescriber

Receive medication

Coordinate care and services across providers ...and with every change in care

Try to find appropriate/ available services

Receive mental health support

Key themes

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

Almost every parent highlighted a lack of easily accessible information about children's mental health. Parents consistently describe challenges figuring out what services would be helpful, and then finding those services. Due to a lack of centralized information, parents invest significant time into researching mental health services with limited knowledge of what to look for, what questions to ask, or what language to use. Many parents turn to the Internet to learn about children's mental health, while others talk to friends and families. While parents with more resources (time, finances, training) have some advantages in navigating the system, increasing access to information about mental health and available services was a top recommendation for many parents.

"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."

"[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 and I didn't know what to ask."

"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."

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

Having a child struggling with mental health can be a stressful experience for parents. Parents sometimes feel overwhelmed by their child's needs or fearful about their child's future. Some parents sacrifice their own self-care to attend to their family. Sometimes, the stresses of managing their child's mental health contributes to their own mental health needs, or impacts other family members. Parent stress is exacerbated by stigma, with some parents feeling shame and guilt about their child's situation. Stigma also makes it harder for them to share their experiences or to reach out for support from others.

"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 are being addressed. I am a single parent with my own mental and emotional health problems and I am struggling."

"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."

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

Support from professionals makes a tremendous difference to families seeking mental health services. Some parents connect with someone whose primary role is to provide support, such as case managers or service navigators working for insurance companies or health care systems. Others find someone willing to help, such as a doctor or teacher. Most families do not have access to this kind of support. However, many recommend navigation support as the most important way that the system of care could be strengthened.

"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."

"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."

"I wanted someone who was educated and understood our situation. Someone who could help me navigate the system. Someone who would not just give me resources, but would hold my hand and help me figure things out."

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

Connections with other peers are important in validating and supporting parents, and identifying potential services for children. While many parents first turn to their own friends and families, it often becomes important for them to connect with other parents of children with mental health concerns. Parents may connect with each other one-on-one, join parent support groups, or follow relevant Facebook pages. Access to peer support is another strong recommendation for improving parents' experience.

"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."

"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."

"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."

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

Once parents identify services for their children, many find that they are unable to access them. Shortages are described across the continuum of care, with parents unable to access outpatient therapy, psychiatric support, day treatment programs, residential care, and hospitalization. Waiting lists are especially long for diagnostic assessments, which delays access into other services as well. It is also hard for parents 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."

"Once the clinics heard that [my daughter] was minimally verbal, we were told that we couldn't be seen."

"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."

6 **Rather than experiencing partnerships with their providers, parents often have to actively advocate and "fight" for their children**

When asked for recommendations about how to improve 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. Rather than having this experience, parents often describe providers dismissing their concerns. Many need to continuously advocate for their children in an effort to receive accurate diagnoses and arrange supportive services. This dynamic is stressful, and parents feel they need to fight more strongly than should have been needed to receive 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."

"We need to stop with 'kids are just like that' and take parents seriously when they say that something is wrong."

Feedback regarding specific services

	Context	Positives	Challenges
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	A diagnostic evaluation assesses the child's symptoms and how well they are functioning in home, school, and other settings. An assessment is typically required before other mental health services or medication can be obtained.	• Assessments provide useful information to help parents select services and supports for their children. • Parents value assessors who provide clear and understandable information about the diagnosis and next steps.	• There are very long wait lists for assessments. • It is difficult and stressful for some children to complete assessments. • Children sometimes receive incorrect diagnoses. • When results are not clear, parents feel overwhelmed, confused, and hopeless.
96% of parents looked for **mental health treatment** services that might be a good fit for their child	Before a child can receive mental health services, parents need to find services that align with their needs. Parents often look for therapy, though some seek more intensive services.	• Support from professionals makes it easier for parents to find mental health services. • Peer support can also help parents find mental health services.	• Most parents do their own research to find services. • It is time consuming and difficult to find services that are an appropriate fit for their child's needs. • It can be stressful to select a program, and parents worry about making the wrong choice.
90% of parents **requested educational supports** for their child, such as pursuing an Individualized Education Plan (IEP) or 504 plan through their school district	For some youth, mental health concerns impact their ability to learn or succeed at school. Some students with mental health issues may qualify for educational supports or accommodations through an Individualized Education Plan (IEP) or a Section 504 plan.	• For some parents, school supports are easily obtained and helpful.	• It is difficult to understand and navigate the process of obtaining school supports. • Parents frequently need a well-trained advocate to help them obtain supports. • Parents frequently perceive the schools as oppositional. • Approved accommodations are not always provided, and effective supports are sometimes discontinued. • Some parents transfer schools to receive more educational support.
84% of parents tried to **access mental health services** or supports that might be a good fit for their child	Once parents find potential services, they might choose not to pursue treatment at that time. Parents may be undecided about whether to move ahead, look for other options, or wait and see how things change for their child.		• Families often face long waits for services. • Services may not be in accessible locations or at convenient times. • Services that look good on paper do not always end up being a "good fit."

	Context	Positives	Challenges
76% of parents **sought other supports** for their child, such as community recreational activities, sports programs, art programs, mentoring, etc.	Families often turn to community programs to help children release energy, express emotions, receive guidance, or gain socialization. Sports were most popular among the parents interviewed, followed by mentoring. Some parents looked for faith- or culturally-based activities, art classes, or other programs.	• Community programs have important benefits for children/youth. • Other parents are especially important in recommending community programs.	• It can be difficult to find services adapted for children with special needs. • A variety of logistical barriers limit participation. • Children may not feel comfortable or accepted participating in programs. • Community-based programs were frequently disrupted by the COVID-19 pandemic.
67% of parents attempted to **obtain medication** to treat their child's condition	Medication can be an important component of the treatment plan for mental health issues. Some parents work with a pediatrician or another primary health care provider to receive medication, while others receive specialized support from a psychiatrist or clinical nurse specialist.	• Health care professionals facilitate access to specialized providers for medication when needed. • Many parents feel that medication has been beneficial.	• Medications may not be effective or bring significant side effects.
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	Insurance plays an important role in covering the costs of services. Interviewed parents had a variety of insurance plans, including private plans and public plans, such as Medical Assistance (MA) or coverage under the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA). Some parents had both private and public insurance coverage.	• Sometimes, insurance easily covers desired services. • It is helpful to have support navigating insurance coverage.	• Insurance coverage often limits the types or amounts of services that children receive. • Some parents pay high amounts to cover co-pays, deductibles, and services that were not covered. • Coverage varies between public and private plans, with some parents moving onto public plans to increase access.
41% of parents **sought services from other healers** (such as herbalists, faith leaders, nutritionists or traditional healers).	In addition to, or instead of, Western mental health services, families may seek other health-care services, such as nutritionists. Others look to alternative healers, such as herbalists or acupuncturists. Faith-based practices, or culturally-grounded healing practices can be part of the service array for children.	• Some families value the opportunity to receive faith-based or culturally-grounded services. • Other healing services may be easier to access and more comfortable than other mental health supports.	• Some alternative health care options are expensive and unlikely to be covered by insurance. • Some families experience stigma when receiving services in faith-based settings.

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, 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 awareness:** Engage in parent education 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

To learn more about the **Hennepin County Children's Mental Health 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.

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

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