New Hampshire
Medicaid Care Management

MEMBER SEMI-STRUCTURED INTERVIEWS
SUMMARY REPORT
SPRING 2023

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Prepared by:
LISA HORN, OWNER/PRESIDENT
HORN RESEARCH LLC

PO BOX 148 SLATERVILLE SPRINGS, NY 14881 | LISA @HORNRESEARCH.COM | 607-316-2748
WWW.HORNRESEARCH.COM

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Horn Research confirms that no one conducting this study had a conflict of interest with AmeriHealth Caritas New Hampshire (ACNH), New Hampshire Healthy Families (NHHF), or Well Sense Health Plan (WS).

EXECUTIVE SUMMARY

The New Hampshire Department of Health and Human Services (DHHS) conducted an independent qualitative study of parents or guardians of children enrolled in the Medicaid Care Management (MCM) Program who were involved with the New Hampshire Division for Children, Youth and Families (DCYF) for at least 365 days, and had two or more behavioral health (BH) medications that they were routinely taking for at least nine months. Horn Research[1] interviewed 28 parents/guardians between June 26, 2023, and August 2, 2023. The study explored seven points of inquiry: Description of Participants, Experience with Medicaid Managed Care, Quality of Well-care, Quality of BH Care, Access to Information, Experience with Telehealth, and Suggestions for Improvement.

Overall, participants said they sufficiently understood their child's health plan and were confident they could get answers to any of their questions. Participants appreciated the coverage for their child's care, the ease of insurance use, and the customer service and case management support. The challenges associated with their child's managed care organization (MCO) were limited provider options within the network, including mental health, dental, and vision providers; and minor difficulties with prior authorization. Nearly all participants said the insurance coverage was not a limiting factor in receiving care. Only two participants reported any knowledge of the MCO's complaint process. Almost all participants reported receiving case management either currently or in the past, but only a handful of participants were currently receiving the service through their child's MCO. Generally, participants reported positive experiences with their case management interactions.

All of the participants in the study reported their child had access to well-care, but over a third said their primary care provider (PCP) had changed in the past year. Participants reported having a good relationship with their child's PCP and highly rated the care. Very few participants said they experienced any difficulties with the PCP. Nearly all participants said the PCP had discussed nutrition, exercise, and weight. About half said the discussion had a positive impact on their child. The vast majority of children were up-to-date with their vaccines. Only two-thirds of participants said the PCP had evaluated their child's mental and emotional health during their well visit. For the most part, participants agreed that the PCP's level of engagement with their child's mental health was appropriate. All children in the study currently were on medication. Less than half of participants said they had been advised to try alternative options before or while taking the drug. Those who had received suggestions generally agreed that they were helpful. Less than two-thirds of participants said they received ongoing, regular medication counseling for their children. Participants not receiving medication counseling expressed concern about having access to a psychiatrist to manage changes in medication. Nearly all participants said their child had access to other primary care services, such as sick care.

Over three-quarters of participants said their child received care from a BH care provider. Generally, participants reported positive appraisals of the BH care providers, but some reported limited effectiveness, varying levels of competency, and challenges with provider turnover. Over half of participants said their child's BH care provider had changed within the past year. The reasons for the change included the provider not meeting the child's needs, turnover within the practice, retirement, and the child's return from residential treatment. Many participants reported long waitlists for care, a general lack of providers and services, and a lack of providers covered by insurance. As a result of the lack of available care, nearly half of participants said their child had not received care soon enough. Two-thirds of the children receiving BH care support said their child's PCP was knowledgeable about

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[1] Horn Research is a contractor of Health Services Advisory Group, which is NH's External Quality Review Organization.

that care. Participants who reported their child's PCP and BH did not communicate about the child's care said they did not wish they would.

Participants relied on their child's healthcare providers to answer their questions about their child's health and, usually, did not have challenges getting their questions answered. Participants said they prefer to research independently and interact one-on-one with a provider when they are learning about health. Nearly all participants said they received information and reminders from their MCO, but a minority found the information useful. Only a handful said the information impacted their decision-making. Most participants reported using telehealth for their child, but half said their experience was not positive. Participants said it was difficult for their child to focus during telehealth visits, which limited the success of the mental healthcare appointments. Other participants appreciated the convenience of telehealth, particularly for providers far from their homes.

The bulk of suggestions for improvement by participants centered on the availability of providers, particularly mental health providers, dental and vision providers, and a desire for more pharmacy options. Participants also noted the need for more residential treatment options, respite care, in-home support, and better crisis response. Participants said there was a need for better information on the resources available and efforts to decrease stigma. Participants mentioned an opportunity for MCOs to be more proactive in providing support and resources for families in times of crisis and connection to other families experiencing similar challenges.

Based on the experiences and feedback reported by interview participants, the findings from this report generated four recommendations for the MCOs and two recommendations for DHHS.

For MCOs:

Incentivize current mental healthcare providers to accept Medicaid
Participants reported that the lack of mental healthcare providers who accepted their insurance resulted in delayed care for their children. Finding ways to increase the number of current mental healthcare providers who accept Medicaid may result in reduced waitlists and greater access to care.

Participate in efforts to create a diverse pipeline of new mental healthcare providers
Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.

Provide respite care coverage and access to vetted respite care resources
Participants frequently mentioned the need for respite care. Programs that require beneficiaries to make upfront payments to respite care providers and wait for reimbursement significantly limits access to care for low-income families. In addition, requiring families to find appropriate and safe respite care options without guidance creates an additional burden that can prevent access to care.

Assess families' need for case management periodically and provide proactive support
Participants noted appreciation for the case management support they were currently and had previously received from their MCO and other agencies. Families with children with mental healthcare needs can have periods of relative stability followed by high-need times. MCOs should periodically assess a family's need for case management and provide support if needed. In addition, following up

with families when a hospitalization or residential treatment has occurred to offer case management support could ease transitions back to community-based providers.

For DHHS:

Provide information on the benefits of Medicaid to prospective foster parents
Participants noted that concerns about care costs may prevent some families from participating in the foster care system. Providing information on Medicaid and other benefits available through the foster care system and adoption may increase the number of families interested and willing to participate.

Participate in efforts to create a diverse pipeline of new mental healthcare providers
Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.

INTRODUCTION

In support of an external quality review of New Hampshire's MCM Program, Horn Research gathered qualitative data from parents of children with the following criteria:

- Were involved with the New Hampshire DCYF for at least 365 days,
- Had two or more BH medications that they were routinely taking for at least nine months, and
- Were enrolled in the MCM program.

The sample population included parents from across New Hampshire. Horn Research conducted telephonic qualitative interviews between June 26, 2023, and August 2, 2023.

The study explored Seven Key Points of Inquiry developed in collaboration with DHHS to structure the information gathered from participants. The Key Points of Inquiry included:

1. **Description of Participants**
2. **Experience with Medicaid Managed Care**
3. **Quality of Well-care**
4. **Quality of BH Care**
5. **Access to Information**
6. **Experience with Telehealth**
7. **Suggestions for Improvement**

METHODOLOGY

Horn Research engaged a standard qualitative data-gathering process as detailed below.

Sample Size and Composition

DHHS provided a population list (N=123) of parents of child beneficiaries in the MCM Program. The study included all parents on the population list.

Participant Recruitment

Horn Research sent the initial sample of members a letter (Appendix 1) on June 19, 2023, that explained the project, asked for participation, and offered participants a $50 gift card. Email and text message follow-ups sent to potential participants encouraged their involvement. Participants completed the interviews between June 26, 2023, and August 2, 2023.

The general rule applied to determining sample size for qualitative interviews was the point at which the information reached "saturation." Saturation refers to when no new themes emerge from interviews. Horn Research completed a total of 28 interviews. The completed number of interviews for this study adequately met the data saturation expectation.

Data Collection Process

Horn Research conducted the semi-structured interviews by telephone. An experienced facilitator led the telephone interviews, with participant responses captured in real-time through verbatim notetaking. An Interview Guide (Appendix 2) directed the conversations to address the Key Points of Inquiry. The interviews lasted approximately 25–30 minutes. All participants received a summary of the project's purpose at the beginning of the interview, and the facilitator read a statement verifying the confidentiality of the information collected. All participants received a $50 gift card in the mail in appreciation of their participation in the project. The identities of the interviewees remained confidential to the interviewer and not revealed to the New Hampshire Medicaid Program.

Data Analysis and Validity

After completing the telephone interviews, Horn Research analyzed the information by identifying, coding, and categorizing primary patterns in the data. The consistent patterns found in the data analysis and the representative sample support the validity of the information gathered but should not be assumed to be *statistically* representative of the whole population. The information provided in this report should be used to identify salient issues relevant to the population, provide contextual information for the larger assessment process, and identify avenues for further research. Horn Research slightly edited quotes from interview participants for content and clarity.

DESCRIPTION OF PARTICIPANTS

Participants were asked a series of questions about themselves and the resources available to them.

Demographic Details

Study participants represented all three MCOs in proportions similar to the total population (*Table 1*). There were no discernable differences in responses to any of the study questions by MCO.

Table 1. Number of Participants and Percent of Population by MCO

	Interviewed Participants		Study Population
County	**Number**	**Percent**	**Percent**
AmeriHealth Caritas	2	7.1%	2.4%
NHHF	11	39.3%	41.5%
Well Sense	15	53.6%	56.1%

Study participants were more likely to be older than the population (*Table 2*).

Table 2. Number of Children and Percent of Population by Age

	Interviewed Participants		Study Population
Age Group	**Number**	**Percent**	**Percent**
5-9	4	14.3%	17.9%
10-13	14	50.0%	41.5%
14-18	10	35.7%	40.7%
Mean age	12.5		12.6

Table 3. Number of Children and Percent of Population by Gender

Age Group	Interviewed Participants		Study Population
	Number	Percent	Percent
Female	10	35.7%	32.5%
Male	17	60.7%	67.5%
Non-binary/Other	1	3.6%	-

All but one participant reported being the custodial guardian or parent of the child. One participant said she shared custody with her ex-husband. Fourteen participants said they adopted their child through the foster care system. There were no discernable differences in responses to any of the study questions by adoption status.

Seven participants said the child was the only child in the household (*Table 4*).

Table 4. Number of Participants by the Number of Children in the Household

Number of Children	Interviewed Participants	
	Number	Percent
1 child	7	25.0%
2 children	9	32.1%
3 children	7	25.0%
4 +	5	17.9%

Employment Status

The interview participants reported a variety of household types (*Table 5*). Seven of the participants said there was no employed adult in their household. Four participants said both adults in the home were employed full-time.

Table 5. Number of Employed Adults in Household

Household Employment Status				
Interviewed Participants Employment Status	Spouse Full-Time	Spouse Part-Time	Spouse Not Employed	No Spouse
Participant Full-Time	4	0	1	5
Participant Part-Time	3	0	0	1
Participant Not Employed	7	0	3	4

Student Status

Only one participant said they were a full-time student.

Resources and Support

Housing

All participants acknowledged having safe and stable housing. Participants reported living in their housing for an average of 12 years.

The bulk of participants reported that their households included only parents and children. One participant said her intellectually disabled sister was living in her household. One participant said their family of three also had her sister-in-law's family of four living with them.

Food security

Four participants said they had worried about whether their food would run out before they had more money to buy more during the past year. One participant said it happened every month because half of her income went to rent each month. Two participants said it happened a few times a year, and one other said her family's challenges started after the enhanced supplemental nutrition assistance program (SNAP) benefits were cut off. Two participants said they regularly used the food pantry in their community. One participant said she sometimes got help from her sister or her workplace.

Transportation

Most participants (N=22) said they had access to reliable transportation. Six participants said they experienced challenges with their transportation. Four participants noted challenges affording and maintaining their vehicles. One participant said, *"In the next two weeks, the vehicle won't pass inspection, and we will not have transportation. I'm kind of panicked about that and trying to see if I only pay rent and lean hard on pantries if I can afford to buy something with the rest of my social security money. I've been spending a lot more on food since we don't have that $600 from SNAP. I haven't been able to put any money in the car."* Another participant shared, *"It's just that we have older vehicles, and they need a lot of repair. They're paid off but need a lot of repair, and it's too expensive to buy a new vehicle. We just put $2,000 in the van last year and need to put another $2,000 in now."* One participant said the biggest challenge she experienced with transportation was traveling with the children to see their biological parents for visitation. She said, *"The distance is far. It's a four-hour visit and two hours to travel back and forth. That's become difficult, but we do it for the kids."* One participant said the challenge in her household was that there was only one vehicle. She said, *"We only have one car. My son-in-law has one, but if he takes it to work, I'm without a car. If I have something to do in the afternoon, I take him to work. It's a lot of coordination."*

Twenty-two participants said they were aware of the Medicaid transportation support. Twelve participants said they had never used the service, and seven said they used it long ago. Three participants said they had experienced difficulties with the transportation services. One participant said she had trouble with drivers. She said, *"It's definitely a touch-and-go program. Sometimes, appointments take longer than they're supposed to be, and (the drivers) threaten to leave you. That's upsetting when you're not close to home. Any time I have to use them, it happens. I have to tell the doctor that I need to get in and out. I had one driver that didn't show up and still got paid for it."* Another participant said the reimbursement process was complicated. She said, *"It was difficult. It took a lot of time to schedule the appointments, and I had to eventually put them on a set repeat, but no one told me that they expired after a certain amount of time. I didn't have it for a month or two, even though I submitted those. It almost took more time than it was worth. I'm an occupational therapist, but I quit because my kids needed me to case manage them. They all have disabilities. My time was worth more than I ever got from the reimbursement."*

Internet Access

All but one participant confirmed internet access on at least one type of device (*Table 6*). Nearly all (N=26) could access the internet through their cell phone. Almost three-quarters (N=20) said they had access through a computer, and eighteen participants said they had a tablet with access to the internet. Twenty-three participants said they accessed the internet through more than one device.

Six participants said they sometimes had issues with their internet being inconsistent. One participant summed it up as, *“The service here is terrible. There is a huge bandwidth problem. We only have one provider.”*

Table 6. Number and Percent of Participants by Access to the Internet

Regular access to the internet	Number	Percent
Phone	26	93%
Tablet	18	64%
Computer	20	71%

Childcare

Thirteen participants said they did not need childcare because their children were old enough not to need supervision. Nine participants said they had access to childcare. Three participants said they did not have access to childcare, and three said they needed respite care.

EXPERIENCE WITH MEDICAID MANAGED CARE

The interview questions included asking participants to describe how well they understood their health plan, their experience soliciting and receiving support from their MCO, to provide information on what they liked best about their MCO, to describe any challenges or problems they had experienced with their MCO, and to share what they knew about their MCO’s complaint process. Overall, participants said they sufficiently understood their child’s health plan and were confident they could get answers to any of their questions. Participants appreciated the coverage for their child’s care, the ease of insurance use, and the customer service and case management support. The challenges associated with their child’s MCO included limited provider options within the network, including mental health, dental, and vision providers; and minor difficulties with prior authorization. Nearly all participants said that insurance coverage was not a limiting factor in receiving care. Only two participants reported any knowledge of the MCO’s complaint process. Almost all participants reported receiving case management at some point, but only a handful were currently receiving the service through their child’s MCO. Generally, participants reported positive experiences with their case management interactions.

Understanding of Health Plan

Most participants described at least a basic understanding of their child’s health plan. Only four participants said they did not understand the plan at all. One of these participants said, *“I don't know what his plan is. I just go to the doctor and assume it's covered. If it's not, I have to find another way to pay for it.”* The other three participants who said they did not understand the plan were similarly unconcerned. One said, *“I have not, honestly, tried to figure it out. When the paper comes in the mail, I don't read it. I deal with it as stuff comes along. He's needed some specialty services over his lifetime, and we have never had any trouble accessing anything we have wanted or needed. We haven't had to fight for things.”*

Eighteen participants said they had a basic understanding of the health insurance plan or understood it well enough. These participants agreed that most of their child’s care was covered without question. One participant shared, *“I feel like I understand it well enough. I am a nurse and have always had health insurance myself, so I had my own experiences with insurance and what it covers and what it doesn't. He's been with me for seven years, and I've never had any issues where I've needed to know any more than what I do. It covers medical and dental but doesn't cover orthodontics. I know those basics and* *never needed to know anymore. We've never had any problems getting any medications covered or visits covered. I'm sure there are other things that they offer, but I haven't needed to access them. I don't need a free helmet. I'd rather someone else get it."* Another participant said, *"I understand it fairly well. Some of the stuff that has cropped up, we weren't sure about. Some are paid, and some aren't. Some is learned as we go."*

Seven participants said they understood the plan very well. Two of these participants mentioned their connection with employment in healthcare that contributed to their understanding. One participant said, *"My wife works for Dartmouth Hitchcock, so she works with all those departments with billing. We are very informed on that."* Parents who adopted their children were more likely to say they understood their child's health insurance plan.

Support from MCO

For the most part, participants said they contacted their MCO by calling the toll-free number on the back of their child's insurance card when they had questions (N=15). One participant said, *"I call them directly. It's very easy."* Two of these participants noted some challenges associated with getting their questions answered. One participant said being on hold was a time burden. She said, *"I have to call the general number, and then I'm on hold forever. I will eventually get somebody to help me, but it is a long waiting process."* One other participant said, *"The only difficulty is getting in touch with somebody. One time, I had a question, and the person who answered didn't know the answer. Trying to forward me to the right person was challenging."*

Six participants said they relied on the child's doctor's office to answer questions about their health insurance coverage. One participant shared, *"Almost every doctor's office can inform you what's covered and what isn't. They are all very familiar with each plan and what it can do. Most of the time, I don't have to go further. A couple of times, there were things that were messed up, and I called."* Another participant shared, *"Our PCP for pediatrics has a special needs case manager who is a nurse. Anything we have needed, she reaches out and coordinates. All of the little kids have special needs. If we needed a referral, she coordinated all of that. It was very straightforward."* All of these participants said they had gotten their questions answered quickly.

Four participants mentioned that a case manager at the MCO was typically one of the ways they got answers to their questions. They also mentioned calling the toll-free number as a source of information and support. One of these participants said, *"I call the number on the back of the card. It's pretty easy. There's also a nurse case manager I have the number for."* One participant said the case manager often could not answer her questions. She said, *"I had a case worker for a while. It took a long time getting back to me. She would have to go find out the answers. I tend to ask a lot of questions, and they don't have the answer."*

Two participants said they looked information up on the MCO's website or other internet sources. One participant said, *"I honestly haven't had questions for a long time. A while back, we were trying to navigate some medications for him. We were figuring out providers who would prescribe and whether they would take Medicaid. That was mostly through the provider's websites. We just did our research on it. I was just calling or looking at websites to see what insurance they took."*

Two participants said they had no questions to be answered but recognized they could contact the MCO if needed. One participant shared, *"I know there's a number on the back of the card I could call, but can't think of any questions I have had."*

One participant said they had previously asked the foster care support worker. One participant said his wife always knew the answers to any questions.

Positive Experiences with MCO

Nearly half (N=13) said the most appreciated aspect of their child's MCO is the extent of coverage provided by the MCO. One participant shared, *"They covered, with no question, his intensive ABA* [applied behavioral analysis] *therapy. He has autism. He had 37 hours per week for a year and a half, and I never had to worry about anything. [The provider] accepted Well Sense. There were no issues with bills and no issues of whether he qualified. We had to wait for the prior authorization, but it was not onerous. They covered that completely, and it's quite costly. He has mental health issues that this autism is a part of, and Well Sense has covered all his therapy. His private occupational therapy is always approved and always easy to work with. It was great with the transition from foster to adopted status, too."* Another participant said, *"It's incredibly comprehensive in terms of coverage. We have been able to see a variety of doctors, urgent care, emergency room, primary care, and specialists with no issues with being seen or being covered."*

> *"Everything is covered pretty much. I don't have to worry about co-pays. I feel safe knowing my kids are covered, in case something happens."*

Four participants said they liked that the insurance was easy to use. One participant shared, *"I like that it's easy. I don't have to jump through hoops."* One other participant said, *"I know there are a lot of choices out there under the Medicaid umbrella. We continued to choose Well Sense because of its ease of use and coverage. We've had foster kids that had something else and have not found it user-friendly or as good as coverage without fighting."*

Four said they appreciated the communication and customer service from the MCO, particularly having a case manager to support them. One participant said she liked having access to a case manager for her child. She said, *"I even know the name of the lady. I've called her so many times. And she calls once a month to see if we need anything."* Another participant said, *"I like that there is good communication. I had a case manager, so each week, they called and followed up with me."*

Two participants said they liked their child's MCO's rewards program. One participant who had fostered and adopted her children said, *"I really like that they give car seats. I didn't have any car seats when I got the children."* Another parent said, *"I like that they give incentives. For instance, if you go to a regular annual physical for the year, they give you money on a card. If you do other health screenings, they give you money, and you can use it at Walmart or other places. It's very helpful."*

Two participants remarked on the provider network as a favorite aspect of the MCO. One participant said, *"What I like best is that most providers will take it in this state."* The other participant shared, *"I like the convenience of it. Locally, we have enough pharmacies and doctors that take it. I'm in a good area for everybody taking it."*

> *"I like that I don't have to pay for prescriptions. That couple of dollars makes a difference if you're sick with cancer. It was a thing for me."*

One participant said she liked everything about the MCO, and one other said she could not think of anything she liked about the MCO.

Challenging Experiences with MCO

Half of the participants said they had not experienced any challenges or difficulties with their child's MCO.

> *"There is no psychiatric provider in New Hampshire taking new patients. The community health clinic is not even putting people onto a waiting list they're so full."*

Three participants remarked on the lack of mental health providers, particularly psychiatrists, accepting the insurance. One participant said, *"I guess the lack of coverage for his therapist. There are not many psychiatrists who take the insurance. We couldn't find anyone in our catchment area that was available to us. We have to pay out of pocket $250 for every appointment. Even our other insurance won't cover it."* Another participant said, *"My daughter needed an individual therapist, but I had a really hard time finding someone who took Well Sense. I got feedback from a provider who said to switch to NHHF during open enrollment because they're easier to work with. They said Well Sense is not easy to deal with. So, right now, I'm paying out of pocket for her therapist. But I'm planning to move her to my Blue Cross/Blue Shield to cover her mental health stuff. I can keep her on until she's 26 on that. I already switched them to my dental insurance because mine covered orthodontics. I kept Well Sense as secondary insurance."* This participant was exceptionally knowledgeable and capable of finding the best coverage and availability of care for her children. She was also able to pay out of pocket to ensure her child received care. She said, *"Finding someone taking new patients was the number one challenge, and I gave up on insurance coverage initially. The first person who could take her, I asked which insurance they did take. That put it in my head to switch her to my insurance, and I figured that out. I was planning to switch when she turned 18 anyway. That was triggered by someone else, but I might have figured it out eventually. I'm in healthcare, so I have a little bit more knowledge. My husband is an insurance agent, so we have a little more luck in that sense to have some of that knowledge and resources."*

Three participants said they had experienced minor challenges with their child's MCO prior authorization process.

Two participants said their child's MCO had refused to pay for specific medical care. One participant said the MCO had not paid for part of her son's surgery. She said, *"My son had his tonsils and adenoids out, and for some reason, they paid for everything except the pathology. And when I called the hospital, they said it was rejected by NHHF. I don't know why. The surgery and recovery were covered. I haven't taken care of that yet."* Another participant said, *"The only problem I've had with them is that if there's a doctor's office that's out of network, it's really hard to get them to budge to cover it. I've even appealed, and they've denied that. I've found that a huge challenge."*

One participant said her child's MCO did not include sufficient pharmacies in its network. She said, *"There have been pharmacies that didn't accept Well Sense, and so we had to change pharmacies. That has been a challenge because there's been a shortage of the medication, and if the pharmacy doesn't have the meds in, we can't go to another pharmacy. We have to find one that takes Well Sense and has the medication."*

One participant said their child's MCO did not have a sufficient provider network for dental care. She said, *"The closest dentist that could work on my granddaughter's and grandson's teeth is an hour away. It's the same with eye doctors. We had one in town, but he's not accepting Medicaid anymore. It's hard because my granddaughter goes to school for four hours every day. We have to make sure we can get* *appointments in those hours."* One other said their child's MCO had insufficient vision providers within their network and provided inadequate coverage. He said, *"I think our biggest problem is vision with Well Sense. Finding a provider is hard, and the amount they will cover for prescriptions is not enough. All three of our kids need glasses. They will cover lenses, but the frames will be $150-$200."*

One participant said a challenge had been the timeline of when her son's medication is made available. She said there is a minimal overlap between when the prescription runs out and when she can access the refill. She said, *"My biggest challenge is my son's medication is a controlled substance. It's not always convenient to get there and get it the day he's out of it."*

One participant said the family reimbursement process was burdensome. She said, *"The only thing I hate is the reimbursement for family. Trying to get the doctor to sign and fill it out properly is hard. There's usually some number they're supposed to put down. I think they move through things quickly. I have had some kickbacks saying we need more information, and I just throw it away. I try my best, and if it doesn't work the first time, I give up."*

One participant said it was an unduly complicated and lengthy process to get her child's name change resolved with the MCO. She said, *"After adoption, getting the name changed on the card took a year. It was easy to receive service; [we just had to make sure the doctor] billed under his previous name. The phone loop to try to get that handled was painful. I kept going around and around. It took long enough that I couldn't resolve it myself. I called DCYF and asked for help. It was unclear whether it was Medicaid's fault, DCYF's, or Well Sense."*

One participant said the recertification process for Medicaid was burdensome. She said, *"I don't know that it would be the insurance, but the recertification process with Medicaid was the more difficult piece of it. They didn't get the facts and information. Doing it online can be clunky because I thought I successfully submitted it, but the insurance got canceled because of something. That happened two or three times in the past six years. It didn't get any easier or better. I'm not a fan of the NH EZ website."*

Access to Care through MCO

Only one participant said care was not available to their child due to what she assumed was a lack of coverage from their MCO. She said, *"My child spent some time at the hospital and was not ready to be released, but the hospital was insisting. I believe the last week wasn't paid for because the doctors were saying he was OK. Doctors calling to get a ride for you shouldn't be a thing. It felt like I was being held hostage. It's borderline kidnapping. You want to call the state and say I abandoned my child and get DCYF involved. I ended up calling them. Two days after [the hospital] called the transport company [to pick up my child from the hospital], my child told me he didn't think he could stick to the safety plan. If someone tells you they can't do that...it was a nightmare. I don't know how much that was due to the insurance company or the doctors. If the insurance stops paying, the doctors stop playing."*

Other participants said their challenges were not related to a lack of coverage but reiterated the challenges associated with a lack of providers taking new patients and accepting their insurance.

Understanding of the MCO Complaint Process

Only two of the 28 participants knew of their child's MCO's complaint process. One participant said, *"I think I've skimmed it when I did the renewal, and it just seems normal. I think all insurance companies have a complaint process, and it seems to run with the same verbiage and process."* One other participant said she knew it was possible to file an appeal through the MCO but had never done so. All other 26 participants said they had no reason to complain and were unaware of the complaint process.

Case Management

Five interview participants said they received case management services for their children through their MCO. Two participants said they appreciated that the case manager regularly checked in with their family. One said, *"I have spoken to a couple of people a couple of times. Somebody calls a few times a year to check-in. I like that they check-in. If I have questions, they navigate me where I need to be."* One participant said the support from the case manager was helpful. She said, *"I'm always able to find out whatever I need to find out."* One other participant said she appreciated that the support was available to her family if they needed anything. One participant said the communication from the case manager was appreciated. She said, *"That she's readily available. She responds quickly to emails."*

None of these five participants said there was anything they disliked about the case management support they received.

Six additional participants said they had received case management from their MCO in the past but had been discontinued because they no longer needed it.

Thirteen participants said their child received case management from another organization. Four participants had previously received case management services from the MCO, and one was still currently receiving MCO case management.

Five participants said they liked that their case manager was knowledgeable and helpful and had helped them find answers and providers for their child. One participant shared, *"We have one from where she goes to therapy. They're helpful with finding things if there's a resource I need, like a camp or a program that she might be interested in. They also have a grant that they can get once in a while to help pay for a program. That's helpful as well."* Another participant said, *"Their communication is great. The staff is knowledgeable and has helped us in crisis and planning. They were key in getting us into the residential services he needed. They've been there every step of the way and are always following up to check on us. They have a good documentation process with where his goals are and have a person-centered planning tool they use. They get to know the family and the youth and let us drive the meetings."* One other participant said the case management support she received from the other organization was more helpful than what she received from her MCO. She said, *"I've had some help when the case manager was a nurse researching the medical pieces to find a provider. Some of that research on not only providers but also who takes the insurance and what skill level people are. I've needed a lot of help. I do a lot of filling out forms. The one case manager who was really helpful (not at NHHF) would help me fill out forms and send them to me, and I would review and sign them. Taking some of that off my plate is very helpful. I have three kids with IEPs* [individualized education programs]. *That kind of stuff, doing that research and filling out forms, instead of just saying go into this thing and fill out the form is, the most helpful."*

Three participants said they liked that the case management services they received through other organizations also incorporated in-person, one-on-one support for their child. One participant said, *"I like the fact that they get the one-on-one time. It's sneaky therapy. They don't know they're getting therapy. They're just spending time with someone they enjoy being with."*

Three participants said they did not find the case management helpful, and one other said that their case manager checked in, but no significant support was offered or needed.

One participant said she had several case managers and support people to meet her children's complex needs. She said, *“We have help through school, a mental health provider, through the PCP, through One Sky. I'm a highly educated person who seeks resources for my children. The nurse case manager gets us specialist care. I'm a big believer in the kids having a supportive network of team members. Everybody has their role to play. It's the opposite of having too many hands in the kitchen. Having so many people involved provides the robust support they need.”*

Most (N=8) of the thirteen participants said there was nothing they disliked about the case management received from other community organizations. One said she felt the case manager needed to be more available to be supportive. One additional participant said she felt the high turnover at the agency resulted in poor quality support. She said, *“I had three different people at one point. They're not always stable. We've been there for eight years, since she was ten, and had at least five different social workers. The first one was great, but then she retired, and then the others were kids who had just graduated from college. I think I did more work for them than they did for me. It evolved from helping me with coordinating appointments, school, and services to being involved in visiting with my doctor and going to school, which made things harder at school. The biggest problem was their interpretation of what was going on with my daughter, and ended up with too many hands in the pot. She was bringing up past issues that were not an issue at the moment, which was steering the school in the wrong direction and making them want to kick her out. That was an issue that happened three or four years back. Since then, I was pretty adamant about whether and who to invite to school meetings for the IEP. The school district has had a really good person who helped in those ways.”*

One said that the case management did not provide any helpful support and did not do much. She said, *“Mostly it’s just them calling and saying how are you doing. We are hooked up with about five agencies, each called case management, but they just pass you off.”*

One participant said she was concerned about her child aging out of case management and that there was no plan to continue that support. One participant reiterated her desire for help filling out forms.

QUALITY OF WELL-CARE

The interview questions included asking study participants to describe the quality of their well-care, including their relationship with their child’s provider, their access to medication and vaccines, nutrition guidance, mental health evaluation, and their experience with BH care for their child. All of the participants in the study reported their child had access to well-care, but over a third said their PCP had changed in the past year. Participants reported having a good relationship with their child’s PCP and rated the care highly. Very few participants said they experienced any difficulties with the PCP. Nearly all participants said the PCP had discussed nutrition, exercise, and weight. About half said the discussion had a positive impact on their child. The vast majority of children were up to date with their vaccines. Only two-thirds of participants said the PCP had evaluated their child’s mental and emotional health during their well visit. For the most part, participants agreed that the PCP’s level of engagement with their child’s mental health was appropriate. All children in the study were currently on medication. Less than half of participants said they had been advised to try alternative options either before or while taking the medication. Those who had received suggestions generally agreed that they were helpful. Less than two-thirds of participants said they received ongoing, regular medication counseling for their children. Participants not receiving medication counseling expressed concern about having access to a psychiatrist to manage changes in medication. Nearly all participants said their child had access to other primary care services, such as sick care.

Access to Well-Care

All participants said their child had a well-care exam within the past year.

Change of Providers

Ten participants said they had changed their child's PCP within the past year. Six participants said the change was due to their provider leaving the practice, and two others said the PCP had retired. One participant said she had switched her child's PCP to a doctor serving the rest of the family. One participant noted that her child had been in residential treatment and had a provider there before coming home.

Relationship with Provider

The bulk (N=22) reported having a positive relationship with their child's PCP. Four of these participants were with a new provider. One participant mentioned that having the same provider for the family was good. She said, *"It is great because our entire family sees the one. It makes it easy for all of us. Because our insurance is taken there, they know the whole family, which is really helpful in a lot of situations."* Another participant said, *"He's great. We started off with one provider who saw him for the first five years, and he left, and we switched to someone else. Both are equally wonderful. We struggled with my son's ADHD* [attention deficit hyperactivity disorder] *and trauma, and it was really hard, but they were really great at listening to us and helping us make a plan and what medications might help or not help."*

> *He is excellent. He has seen all of our children and sees all of our foster children.*

Two participants were not pleased with their new provider. One of these participants said, *"We used to have one we really loved. Unfortunately, she left. There's a new one that replaced her, and we don't really love her. We have seen her a couple of times."* Two other participants said it was too early to evaluate their experiences with the new PCP.

One participant said they did not like the constant turnover of providers at the practice. She said, *"It's been a different person for the last three years, so it's not a good relationship. The practice he's in has had such turnover. We haven't seen the same person twice in three years."*

One participant noted minor issues related to their child's PCP. She described, *"Actually, she was their doctor way before I got the children, and so, she has a longer history than I do. We've butted heads a couple of times. It's more that she wants to see the kids every three months, and I feel that's unnecessary. And she wants more access to the psychological stuff, and I don't need too many hands in the pot. It becomes complicated with my daughter. She needs a focused type of support. I understand why the doctor wants to do it, but I don't feel that she has that type of relationship with my daughter that would help in the long run. It really hasn't been a major issue. She wants it, and I say no."*

Evaluation of Provider

All participants said their child's PCP treated them and their child with courtesy and respect. The vast majority of participants rated the quality of support provided by their child's PCP as a five on a scale of 1-5, where 1 equals very poor quality of support and 5 equals excellent quality of support. The participant who rated the PCP as a 3.5 explained her rating by saying the current PCP was not as good as the previous PCP who left the practice. One of the participants who rated her child's PCP as a 4 said she chose that rating, *"because nobody's perfect. I don't feel like anybody really deserves a 5. A 5 would be going above and beyond. It's normal care. We're treated with respect. It's not like she's canceling or retiring on us early."*

Most participants agreed when asked whether they thought their child's PCP understood their child's needs. Three participants said they were unsure because the PCP was new to their family. One participant said she had mixed experiences with her child's PCP. She said, *"Yes and no. Only because I had been talking about questioning her having scoliosis since she was little. I had always been concerned about that. They said "nope" and checked her back but only checked her cervical and thoracic areas. When she went in last time because of severe constipation, they saw on the x-ray that she did have scoliosis. Now she's ten and needs to go to an orthopedic. I think [the PCP is] good at sending us to the right specialist. I think she's very thorough as far as taking time with me and, hearing my concerns and, gives me what she can, and researches what she can. I wouldn't say she's bad as a provider. I don't think she's knowledgeable in all areas. My children had my pediatrician for a long time, and then she retired, and this one is a younger, newer doctor."*

Table 7. Number and Percent of Participants Saying PCP Understands Needs

PCP understands needs	Number	Percent
Yes	24	86%
To be determined/new PCP	3	11%
Mixed experiences	1	4%

Nearly all participants also agreed that their child's PCP explains things in an easy-to-understand way. Two participants said it was still too early to know.

Table 8. Number and Percent of Participants Saying PCP Explains in Easy-to-Understand Way

PCP explains in easy-to-understand ways	Number	Percent
Yes	26	93%
To be determined/new PCP	2	7%

Table 9. Number and Percent of Participants Saying PCP Treats with Courtesy and Respect

PCP treats with courtesy and respect	Number	Percent
Yes	26	93%
To be determined/new PCP	2	7%

Positive Experiences with PCP

Eight participants said they liked that their child's PCP listened to their concerns and was easy to talk to. One participant shared, *"He always takes time to listen and makes sure we don't leave there with any questions or pain. And he's good with medicine. He just made a change on [my son's] medication to increase it to even longer-acting. That was so when he gets into high school, the nurse doesn't have to give him meds at noon-time. I appreciate that. It puts my son in a different perspective that he doesn't have to worry about being seen taking meds. The doctor is a very kind person."* Another participant said, *"Honestly, I just love that they listen to me. I'm a pediatric nurse. The first thing we are taught is to listen* *to the parents. They know the child best. It's easy to get bulldozed by medical professionals. I find that the PCP really listens to me and is interested in helping me work through the issues and get a good solution. They are very receptive when I have to call. I have never felt like I have had to fight, and I have had to fight with everyone else, the school, etc."*

Eight participants said they appreciated their child's skilled and knowledgeable PCP. One participant said, *"When you need an answer to something, there's this human piece, and there's the medical piece, and he balances both beautifully. He connects with you on a human level, but also, medically, does not leave any stone unturned."*

> *I think the time she takes with us and understanding our concerns. She really tries to find an answer for us as best she can. If she doesn't know, she researches it.*

Six participants said they appreciated the availability of their child's PCP for regular and emergency appointments. One participant shared, *"It's a small-town area. We never have to wait more than a few moments. It's not like one of those huge places with 50 people in the waiting room. They also have evening hours one or two nights a week. It's very accommodating. They're very friendly and knowledgeable. They're amazing."*

Four participants said they liked that the PCP had a holistic view of the family, including other children in the household. One participant shared, *"She definitely sees our family as a whole and is tuned with the children's individual needs. When you have kids with mental illnesses and they live in the same household, they are all intertwined. If one has an episode, that's going to set off a chain reaction. It's great they all have her and that she genuinely cares about my kids."* Two others said they liked that the PCP had a history with the family, providing continuity of care.

One participant was hopeful that because the new PCP is young, they will have her long-term. She said, *"She's younger, so I feel like this doctor might stick around a little longer. We've had a few doctors here - one retired, one I switched, and then a week after, he retired. This is better to have someone younger. The last thing you want is to go through is several doctor switching."*

One participant appreciated the honesty provided by the PCP, and one other said she liked the patience of the PCP.

Challenging Experiences with PCP

Twenty-one of the 28 participants said they had nothing negative to say about their child's PCP. One additional participant said she did not know enough about the new PCP to have a response.

Two participants said their biggest concern about their child's PCP was the lack of availability. She said, *"He's not super accessible because he has a lot of clients."*

One participant said her biggest challenge was that the provider seemed less welcoming and engaging than their prior provider. She said, *"She's foreign, and sometimes she seems a little bit short and to the point. Our doctor before remembered us every time we came in. This doctor is just kind of short."*

One participant reiterated her concern about her daughter's delayed diagnosis of scoliosis. She said, *"I wouldn't say she's bad as a provider. I don't think she's knowledgeable in all areas."*

Another participant remarked on the difficulties associated with turnover in providers. She said, *"The turnover has been difficult. My 18-year-old had to go to a physical and had to see a female. He was mortified. The turnover has been pretty significant."*

One participant said she thought her child's PCP was overly cautious and the number of appointments required was burdensome and unnecessary. She said, *"The only thing is that [needing to bring him in every] three months. It's ridiculous. If I need to bring the child in, I will. I understand where her thoughts are. I think she's just concerned with the child's welfare."*

Nutrition

Only two participants said their child's PCP had not discussed nutrition, weight, and exercise with them at their last well visit. These two participants noted that their child was older, and they were not in the exam room with them.

Six participants said there was no issue with their child's weight, and the PCP had not discussed anything regarding diet and exercise.

Five participants said their child's PCP had discussed their child's weight issues and talked with the child about diet and exercise. One participant said they were referred to a nutritionist. One participant said, *"We were discussing ways to lose weight. She's a little chunky, so there were topics of different foods, maybe try keto, and different exercises like walking and getting about. We spent a half hour on the conversation. It was very helpful. I think she really listened to it as well."*

Three additional participants said their child's increased weight resulted from their medication. The discussion with the PCP involved how to best manage the weight gain, including diet, exercise, and seeing a nutritionist. One participant shared, *"That was one of our concerns. She had been put on a medicine, unbeknownst to us, that ended up with severe weight gain. That was mostly what we focused on, and we checked for diabetes. We took her off the medicine, and she has lost some of the weight."*

Five participants said their child had issues with low weight, and the discussion was centered around increasing the child's appetite. All of these participants noted that their child's medication decreased their appetite and was the primary cause of the low weight issues. One participant said, *"He's very good, except for his weight. He gains and loses weight. He's diagnosed with hyperactive disorder and ADHD. He can eat and eat and not gain an ounce. My child is a scrawny, tall child."*

Three participants said the PCP had discussed the importance of exercise and outside time. Two participants said the PCP had generally discussed diet and exercise, but there was no particular issue to be resolved.

One participant noted that her child has autism and, as such, had significant eating issues that were not simple to resolve. One other participant said her daughter was referred to a nutritionist due to the effects of being a picky eater. She said, *"It was very brief. We just talked about her being a picky eater. She referred us to a nutritionist because she also has severe constipation, which is related to what she eats. She's small for her height, and her weight has picked up over this year. She is still within her range, but fatigues fast, and her activity level has changed. We talked mostly about diet and where she was on the scale, but nothing significant about activity. She's in aerial class and softball.'*

Impact of Discussion

Twelve participants said the discussion about weight and nutrition positively impacted their child. Eight participants said their child was engaging in dietary changes, and four said their child was increasing their activity and exercise levels. One participant said, *"She's doing her exercises. We tried keto, but it didn't work. I don't cook anything boxed. Everything is homemade."* Another participant said, *"She has to see a nutritionist to lose some weight. She talked about eating different foods, trying to pick healthy foods, and tasting the foods. She tried to work with her. There has been some improvement."*

Three participants said their efforts with their child were still in process through testing and referrals. Four participants said the discussion did not positively impact their child's efforts to eat better or exercise more. One participant shared, *"My daughter is very focused on her weight to the point she can be a little bit unhealthy about her eating habits. She was talking to the doctor about it. The doctor always talks about that you need to do specific things to lose weight, but my daughter doesn't necessarily do them. But they got a message across. She understands what healthy eating is."*

Two participants said their child was taken off the medication causing weight issues. One participant shared, *"He's back on track with where he is. His BMI* [body mass index] *is perfect. He's been biking 10 miles a day."*

Seven participants said no advice or change was needed for their child concerning diet, exercise, or weight.

Vaccines

The vast majority (N=26) of participants said their children were current with their vaccines. One participant said her child had not had his flu shot. She said, *"He agreed to take all the other vaccines if he didn't get the flu shot. He's resistant to shots."* Another participant said the only vaccine her child had not received was the Coronavirus disease 2019 (COVID-19) shot. She said, *"I decided there wasn't enough information on the long-term side effects."*

All but two participants said they had not experienced any challenges accessing vaccines for their child. One participant said getting the flu shot was tricky. She said, *"They didn't have the drive-through one. I was able to get him one eventually."* Another participant shared that being a foster parent had created additional vaccine challenges. She said, *"The only thing is the understanding of the provider on when you can sign/not sign for immunizations as a foster parent. It's just understanding that you're not refusing. You just can't legally sign the paperwork. Once they are aware, they have a nurse come in and sign. You can come up with creative ways around making that work, but that little piece of it can be challenging. That procedure can get tricky. If you're at a doctor's office that has experience with how fostering works, then they usually have the procedure."*

One other participant noted the challenges associated with vaccines for adoptive parents. She said, *"This doctor is huge on vaccines. The kids hadn't been vaccinated because their dad was not interested in it. But, if she's going to go to college, I know they are going to ask for that. So, for the last year and a half, we were building all those vaccines back up. The doctor created this whole big plan for when to get them all. That was amazing."*

Mental Health Evaluation

Participants were asked to describe their experience with their child's PCP evaluating their mental and emotional health. Eighteen participants said the PCP had asked questions and discussed their child's mental and emotional health. One participant said, *"He does a questionnaire, and if he answers yes to anything, she talks with him and gives him resources he might need. He said he didn't think he had enough food, and she made sure we knew about the food shelf."*

Six participants said that while the PCP did check in, they primarily deferred to the child's psychiatrist. One participant shared, *"Yes, but we also have a therapist for that. He has PTSD* [post traumatic stress disorder] *and ADHD and is traumatized about the loss of his mom and the previous home where he was abused."*

Two participants said their PCP was very involved with their child's mental health. One participant said, *"All my kids are on the spectrum, and it's easy to tell when they walk in. My son has been with me since he was two months old. The PCP did his first intake appointment 24 hours into care. They did the normal autism check at 18 months, and there were questions about his hitting milestones. He has all that on the computer. They have been very good with my kids at juggling the dynamic. I've been there with his biological parent, and they helped manage how we secure the information we need when the parents obviously have mental health issues. The PCP was kind and made sure DCYF that the information was accurate for his file. They just did a really good job."*

Two participants said the PCP had noted issues with their child's mental health after the discussion. One participant said, *"She is in the process of connecting us to an organization because we are having trouble with his emotional and mental abilities. He hasn't been in school since February. He was suspended for 14 and a half days, and they could expel him. He does have anger issues and aggression. We are getting a referral."* The other participant said, *"She saw it for herself, I guess. We were already in the process of getting into Manchester Mental Health at that point."*

Seven participants said the PCP had not broached mental health in the wellness visit, three of whom noted that their child sees a psychiatrist. One participant wished she received more support and guidance from her child's PCP. She said, *"I don't think we did talk about it because my child has been seeing mental health providers for years. She has PTSD and a lot of anxiety. They don't really cover what is really developmentally appropriate. They don't go over what should be typical for this age. That would be helpful for me. My kids all have special needs. I know some norms based on my job, but I don't know what typical is. That kind of framework would be helpful. I know in some of my training I've done for my kids is talking about risk factors for trauma. My doctor never talked about that. I did a lot of trauma courses on my own and found a lot of the trauma rating scales. That would have been helpful for understanding the impact on development."*

Two participants said they did not recall whether the PCP had discussed mental health. One said, *"I don't really remember it. My daughter has depression and anxiety. So, those would have been touched on. She does sometimes have self-harming behaviors, and that does concern the doctor. Usually, when that happens, it's a much bigger conversation with me after and during the appointment. But I don't remember it being a huge conversation this last time."*

One participant said that because their child is older, they were not privy to whether mental health issues were discussed. She said this could be an issue with her child. She described, *"They ask, know his history, see the ER visits, they know about that. But by the same token, he goes in by himself, and you never know what's going to come out of his mouth. The PCP freaks out, tries to counsel him, and talks to me. They want to be helpful, but they don't see the big picture. Yes, talk with him independently, but know all these other supports are in place. Don't always trust what he says in the moment. There's a new* *learning curve with a new PCP. And my son likes to dramatize and enjoys an audience. If you really have questions, let us hook you up with people at the state to get the full story."*

Mental Health Recommendations

Six participants said their child's PCP had made a recommendation about their child's mental health. Five participants said the PCP made a referral for mental healthcare. One participant said it was a challenge following through with the referrals. She said, *"He tries to makes referrals, but you can't get in. We are in the process of trying to get another referral sent, but it's like pulling teeth."* Another participant said they had been referred to *"someone to create a more advanced safety plan. My child has complicated triggers. We have an appointment coming up with her."*

One participant said their child's PCP recommended continuation with therapy.

One participant said she did not want the PCP to provide any recommendations. She said, *"I try to keep them separate - medical and mental. I don't want to have different opinions from the person she's already working with."*

Medication

All participants said their child was taking medication regularly. Eleven participants said they had received suggestions before or while taking the drug.

Three participants said they had been recommended to try therapy for their child.

Two said they had tried dietary changes. One participant said, *"Diet suggestions were made that were not helpful. I hate giving my kids medicine, but he really needs it. His aggression got so bad he smashed two televisions and doors. He's only eight. We needed to do something. The suggestions would not feasibly have any impact."* The other participant shared, *"My son, with his ADHD, we always talk about the diet that can go with that. I'm aware and try to monitor."* She noted that her daughter, who also takes medication and was part of the original sample list, was recommended a different intervention rather than medication. She said, "*With my daughter, we are doing EMDR* [Eye Movement Desensitization and Reprocessing therapy]. *We are trying to go about it to get to the heart of the problem instead of just medication."*

Two said the providers had recommended specific coping skills for their child. One participant said, *"We talk a lot about developing coping skills. He thinks the medicine cures him, but we tell him it's not a cure. It's a tool. He finally got an IEP at school after seven years. So, he gets support at school from a counselor to work on those coping skills. Especially because he struggles in large groups such as recess and gym class. She helps him work on his peer relationships. The doctor reinforces that. And a lot of what we talk about now is that you have to eat food in order to grow."*

One participant said the provider had recommended staying on schedule with the medication, which was critical. She said, *"Staying on schedule with his sleep medication. And making sure he's going to bed at the same time and taking his meds at the same time every day. We had a thing at school where they were giving them at the wrong time. The psychiatrist wrote a note that said he had rebounding ADHD. They calculated the right times when he needs his medication."*

One participant reported receiving parenting advice. She said, *"It's more of just a matter of providing stability and staying on top of things, and not backing down. Not saying, 'You can't have the computer,' and then giving him the computer. It's more about parenting advice. It's a respectful conversation."*

One participant said they had tried several alternative therapies before starting ADHD medication with her child.

One participant said they had tried alternative medications to good effect. She said, *"I refused to put him on anything in the same umbrella as Ritalin. So, he made sure he wasn't on those types of meds because I wouldn't allow it. He's on something in a different family that helps with his squirminess. It's not like how those other drugs are. I didn't want him on that. They completely understood and found an alternative. I was quite pleased with that."*

Medication Counseling

Seventeen of the 28 participants said they received ongoing and consistent medication counseling for their child. One participant shared, *"We check in monthly and see how he's doing and see if his needs have changed if it's still working. He's growing like a tree, so we've adjusted due to his height and weight. He was six when we got him, and now he's ten."* Another participant shared, *"Definitely. He's been so stable and doing so well that we've bumped it out for psychiatry check-ins every two months. But if I had questions, I could call."*

Two participants said their child was started on medications while in residential care and, thus, were not informed about any aspect of the medicine, side effects, or effectiveness. Both said that since being home, they were better informed. One participant shared, *"She went to a school in Vermont, and they took her off the medication her current psychiatrist had her on and put her on something else. I wasn't aware. They were taking blood once a month. Every time I would protest putting her on another medication, they would say I wasn't taking her mental health seriously. That's why her doctor here was so concerned. She was so incredibly overweight. We had to give her a vitamin D supplement. [When she came home], we changed all the medication. Took her off all the things she was on and put her on another medicine that doesn't gain weight. I don't get to go to the appts because I work full-time. He leaves me a voice mail."* The other participant shared a similar story. She said, *"Now I'm getting good information. He did spend some time in a facility in Vermont. I'm not sure if that's where he was originally put on the medications. He was put on Seroquel at Hampstead Hospital. We have a family history of addiction, heart disease, and diabetes. He's already overweight. While he was in Vermont, they upped his meds way too much, even when we said we didn't feel comfortable with it. I said I read the side effects, and they said not to use the medication with our family history. But they continued to up his meds. He's currently around 300 pounds, which makes activity a struggle. We are trying to bring the Seroquel down, but it's very addictive. It's been incredibly difficult."*

Three participants had experienced challenges with the medication counseling they received with their child. One participant said, *"They give good information and check-in, but there were challenges in being in touch when they took something away. He metabolizes stuff very fast, and he could be on something for months, and things will go very well, but then I don't give it to him, and then that's a bad decision."* Another participant who had experienced a lot of turnover with providers for her child said there was a significant challenge with the constantly changing medications for her child.

Four participants said their child had been on the medications for a long time. One of whom noted they needed to find a new prescriber. She said her child was on the same dosage since he was 10 but was now 16. She reported having challenges finding a new psychiatrist. Another participant said, *"The PCP is just keeping the prescription going and doesn't want to change anything. He just wants to keep what was prescribed until she can get into mental healthcare. My daughter was hospitalized, and her psychiatrist dropped her. It's all behavioral. She went to school and said some things to another child for attention. That child went home and told their mom. And it went from there."*

One other participant said the PCP is currently managing their child's medication as they are trying to find a new psychiatrist.

One participant said they received consistent medication counseling for her child's psychiatric medications but not her other medications. She said, *"Yes, at least with her psychiatry because that's where most of her medication is. But I would not say any of the other providers do."*

Access to Other Care

Nearly all (N=26) participants said their child had access to other primary care services, such as sick care, as soon as they needed it. One participant said, *"It depends on the issue. We use urgent care if something happens all of a sudden. I usually can get in pretty quickly to the PCP. And the same with the other behavioral support. I know I could get in touch if I had to."* Another participant said that since COVID-19, the practice her child goes to has a particular time and location for sick care.

One participant reported difficulty getting an appointment at the primary care for sick care and had to utilize urgent care instead. She said, *"She had been throwing up constantly for two days, and the pediatrician could not get her in. They fill up really fast for appointments. I've had to wait a full day, get on the list for the next day, or take them to urgent care. If I don't call at 8 am, I might not get an appointment for that day."*

One other participant said COVID-19 created a challenge for sick appointments. She said, *"COVID*[-19] *was tricky. That was the only point that was frustrating. We couldn't get an appointment because they were triaging for COVID*[-19]. *But it was understandable, and we tried to be flexible."*

QUALITY OF BEHAVIORAL HEALTH (BH) CARE

Participants were asked to describe their child's access to and the quality of BH care. Over three-quarters of participants said their child received care from a BH care provider. Overall, participants reported positive appraisals of the BH care providers, but some reported limited effectiveness, varying levels of competency, and challenges with provider turnover. Over half of participants said their child's BH care provider had changed within the past year. The reasons for the change included the provider not meeting the child's needs, turnover within the practice, retirement, and a return from residential treatment. Many participants reported long waitlists for care, a general lack of providers and services, and specifically, a lack of providers covered by insurance. As a result of the lack of available care, nearly half of participants said their child had not received care soon enough. Two-thirds of the children receiving BH care support said their child's PCP was knowledgeable about that care. For the most part, participants without coordination of care were not concerned.

Access to BH Care

Twenty-two of the 28 participants said their child received BH care support from another provider.

One participant said her child needed BH support. She said, *"He's not receiving any care at this time. It ended in January or February. There is such a black hole in providers. We've exhausted the only therapists there are. There's no connection, no incentive to work with anyone. There are so few providers, and they are overloaded and have waiting lists. He was hospitalized three times, and they didn't do a medication wash at those time either. This was a year and a half ago. We're overloaded. In the past 30 days, he was hospitalized for nine days, but they needed the space. They felt he was stable enough to go home, but he ended up in juvenile detention after that. They didn't do a psych evaluation or medication check-in juvenile detention, but he was getting really great care. But he just got released from there, too."*

Another participant said her son had seen a variety of providers in the past but was doing well now. She described, *"He doesn't anymore. He did for a while and saw a variety of people based on availability and urgency. He saw a psychiatrist first who did not take insurance, so we were paying out of pocket. We basically worked with him to get diagnosed, and he did the prescription and medication visits. It got really expensive, and I didn't particularly like his therapeutic style. Eventually, we got into Dartmouth psychiatry, and it was all telehealth. She did a little bit more. It was a study, so it was free. She did some therapy and modified his medication. After the study was completed, he saw somebody at Community Partners in Dover. That was when he had some pretty significant behavioral challenges about anger and impulse control. We stuck with that guy for a while, but he also was not a good match for our son. Then, his primary care said he could start managing his medications and my son had some other support in the school environment. He had a really great therapist when he was young who took Medicaid, and then the pandemic hit. For a kid with attention issues, doing therapy over Zoom was not great. He's really stable right now and has been for a while, so he doesn't have a therapist right now. We are going to see how it goes with this new PCP. Puberty seems to have had a profound impact. He has done a lot of hard work to manage his impulses and big feelings. We know when big changes are coming that might fuel some stuff for him, so we do a lot of work to prepare - if it's a change that we can anticipate."*

Quality of BH Care

Overall, participants had positive reviews of the quality of care their child received from BH providers. One participant shared, *"She's amazing. He has come from being uncontrollable to completely wonderful. He came up with a cup of coffee for me this morning. When I got him, he was throwing toys and buckets, and I didn't know how to deal with it. Together with the therapist, I learned things, he learned things, and now he's amazing. It's a complete 180. We barely see the therapist now. We just keep them as a safety net. We do see her once a month because we want to maintain that connection. We had an incident when DCYF came about one of the homes he was in, and it set him back about a year. And recently I had a serious accident. I was in a coma. We were very worried that would impact him negatively. He had a few bumps at school while I was in the hospital but bounced back like a champ. What we're doing is working."*

Another participant said the quality of care her child received was excellent, but it could be a challenge getting access to the psychiatrist. She said, *"I absolutely love his counselor. She's been with us from the get-go. She was his case manager at first, then became his counselor. The only issue I have is sometimes getting in touch with them. For example, his psychiatrist took him off a medication, and things started backsliding, and he got very aggressive at school. I wanted to give it back to him, but she's on vacation.*

She's also the director of mental health, so she's a very busy woman. I am amazed at the progress she's made with his medication, but it's slow going because she is so busy. She's hard to get a hold of."

Two participants said that while their child had received extensive support, they had seen very little results for their child's BH. One participant said, *"She sees two therapists and a psychologist once a month. Therapy is twice a week, and I just don't feel like it's done anything. I don't really know what they do. She hasn't changed at all. She's a hard kid. Nothing has helped in her day-to-day life. Medication has helped some. I think the child manipulates the whole situation. I don't know what they're talking about. She's been [in therapy] for years. You would think a little something would be happening."* Another participant shared, *"He has a psychiatrist and a counselor. The counselor does no good. We have to see the counselor once a month to get the psychiatric medication from the psychiatrist. My son won't join in and won't talk. And the providers have said that it's not doing any good and tried to get rid of him, but we said we can't get the medication if he doesn't do the counseling. It bothers me sometimes because it's a waste of money. But it's the only way we can get the meds. His psychiatrist is good. It's been the same one for ten years."*

Two participants reported different experiences in quality depending on the provider. One participant shared, *"There's a mixed bucket here. For the last five years, things have been really awful. CLM [Center for Life Management] seems to be a place where there is a lot of turnover. Always someone new and inexperienced, and the lack of experience didn't enable them to understand my daughter 100%. They would get it wrong, and we're wasting time doing some strange exercises or conversations or tasks. My daughter was way more capable than all of that. I think that set her back in getting better. Also, being on a lot of medications she didn't need to be on. Earlier, we had someone who was spot on, and they shifted us. One person didn't talk much. We would leave, not knowing what to do next. It was weird and awkward. We asked to change to someone else, but the new person was brand spanking new, and we lacked confidence in that person. Suddenly, we were on a merry-go-round of trying new things. My kid is not a guinea pig. We finally got back to the original doctor three years later and got back on track with the right medications. We discovered that two of them shouldn't have been taken together. But then something occurred again where CLM changed again to provide a team of people. They want to do this Assertive Community Treatment (ACT) thing, and she has to be part of a team and has to lose that therapist. I just got this person back, the one who could always pinpoint what was going on with her since she was 10. Why can't we keep her? The people who were the best for my daughter, we couldn't have. That was infuriating. They called CPS* [child protective services] *on me. I don't know why I can't question my kid's health and what you're trying to provide. They claimed I was trying to get in the way. They said my daughter was dangerous, but she was doing well with the right people and medication. I feel they're trying to run us through a checklist so they can write us off. They're trying to constantly recycle certain people in certain offices. Now, they want to send her away. Why would I? She would have no support. That was the worst thing anyone could say. Again, it's mixed because there were two people there that were fabulous. They were sometimes not accessible, but they understood kids. The rest were all new and created problems and issues for me. They called CPS on me. I don't live with anyone. I go to work and I come home. I try to have fun with them. My whole life has just been them, and still is. But to call CPS was really hurtful. They wanted CPS to say we need to remove her for the better and take her to Easter Seals and let her grow up there. Some new person told me this in the hallway. They were constantly saying send her to the ER* [emergency room]*, or we will call CPS. They called the hospital to make sure she went. They just weren't capable of handling it. They should have admitted it. I would have tried to find somebody else."* This participant noted that her daughter was consistently cycling through hospitalizations and providers, which severely limited her ability to stabilize her mental health.

Two participants remarked specifically on provider turnover and the challenges posed to their child's care. One participant said, *"She's on a waiting list for a psychiatrist through her therapist's office. It's Manchester Mental Health. I'm not really a fan of them. She's been with them on and off since she was 3 years old. I feel like they just get her a little bit stable and then boot her out the door. She doesn't have an assigned counselor just yet. She sees the one that did the intake. She's on a waiting list to be assigned to one."* Another participant said that while the care was good, the turnover was challenging. She said, *"My daughter has attachment issues, and the turnover has been really hard for her. Overall, I think they keep a really good track and are available for emails and calls. They respond quickly.*

One participant said she previously had negative experiences with the quality of care her child received but currently was receiving excellent care. She said, *"She has a psychiatrist, a home support person, and a therapist. Now, it's great, but in the past, it's been awful. My family has used our community mental health agency for at least 13 years, and this is the first time we have had decent therapists. Because what happens to us is all the really skilled, highly specialized therapists don't take NHHF. We were forced into community mental health. That was the only way we could get psychiatry. Most psychiatrists are private pay. That was another reason we switched to NHHF. My daughter's other therapist stopped taking Well Sense because the reimbursement rate was so poor. But she kept NHHF. In general, we have a hard time finding skilled mental health providers. We get providers that are getting their licensure, but after a year or two, they leave, and we start all over again. And the licensed therapists aren't taking Medicaid. Only the community mental health facilities are taking it."*

Another participant said her daughter was currently hospitalized. She said, *"She's currently at Hampstead Hospital. I'm not sure how she's going to do. She was seeing a therapist and psychiatrist from Manchester Mental Health. I don't think they were super helpful. None of it was very helpful. She was not getting better services in residential either."*

Positive Experiences with Behavioral Health Providers

When asked what they liked best about their child's BH provider, participants provided various responses. The most common answer (N=6) was that the providers listened and consulted with the parent. One participant said, *"I like the fact that they respect that I know my child the best, and they listen to my advice as well. I'm not necessarily your average parent with mental health providers. I have a strong background in education. I've done a lot of research. The providers respect that and listen to what I have to say and talk it through."* Another participant said, *"I like that they're readily available for questions. All I have to do is call, and they get right back to me."*

Five participants said they liked that their child was comfortable with the provider. One participant shared, *"He's very comfortable with her and can totally be open with her. Same with us. She listens very well."* Another parent said, *"I like her ability to communicate with my child in a very effective way. Any time I propose a change in medication because something isn't right, she is on board with me. We have follow-ups if we do change a medication. I can reach out at any time through e-chart."*

> *She is awesome. I wouldn't want another therapist. She is the best therapist he's had.*

Five participants remarked on the high quality of care they believe they received from the providers. Another participant said, *"His psychiatrist takes the time to connect with my son. He's been through so many medication trials and neuropsychiatric trials. This psychiatrist is very laid-back and approachable. My son doesn't resist going. The doctor goes step by step, focused on talking with my son and leaves it* *up to him to fill him in or not. He's totally focused on my son but looks up at me and raises his eyebrows to check in. He puts my son first in all those discussions, which makes him feel like he's being heard and will go. We begged him to stay on his caseload even while my son was in-patient. He agreed and stayed available to us."* Another participant said, *"Their section that deals with high-need autism functions really well. They have a team with a medical prescriber, and their monthly/quarterly plans are usually spot on. They come to our IEP meetings to help support the school and my child. They are helpful at making sure the kids get functional help out in the community. Talk therapy isn't great for them, but having hands-on help out in the community is great. We have had the therapists with my kids for two years or longer. We have four providers. They'll switch providers within our family and rotate through that way. That's less transition for kids, but they get to generalize the skills they're providing."*

Three participants said they liked that the provider worked hard at connecting with their child. One participant said, *"She's so great with him. She gets things done without him even realizing he's getting therapy. They'll play games. If you do that with him, he's in. She'll make therapy into a game and also provide mental care while making it fun for him."*

Two participants said their favorite thing about the provider was that they were caring and compassionate. One participant said, *"I like their attentiveness to my children and wanting to be part of the solution. They really care. They have totally different personalities, but absolutely both want to help the kids."*

One participant said she liked nothing about her child's BH care provider.

Challenges with BH Care Provider

When asked what they liked the least about their child's BH providers, 12 participants said nothing was noteworthy. One participant shared, *"I've worked very hard to get him into places that are on top of things. He was somewhere else; it was a cluster, and I was spinning my wheels. That's why I shopped around after his last hospital stay to find this psychiatrist."*

One participant said it was difficult to reach the provider. One participant said the provider was "difficult to read." She said, *"He has a poker face. Trying to read him is hard."*

One participant reiterated her concern that despite the counseling not working, they had to continue the process to access the psychiatrist and medication.

One participant said she did not like that the appointments were virtual instead of in-person. Another participant did not like the office's policies. She said, *"I don't like that I have to be 20 minutes early for appointments. I actually have been turned away and not been seen. I've sat there and waited plenty of times."*

One said they felt their child was receiving poor quality of care. She said, *"They don't give her the proper treatment that she needs."*

One remarked on the turnover in providers.

One said the providers were rude. She said, *"They're really rude. They canceled appointments on us and then blamed us. Somehow, that gets put on us that we're missing appointments."*

One participant said the provider was new and no particular issues were noted yet. One participant reiterated that the care her daughter was currently receiving was in the hospital.

Changed Provider

Over half (N=13) of the 22 participants who reported their child received BH care said they had changed their provider in the past year.

Six participants said the change was due to the provider not meeting the child's needs. One participant shared, *"He was seeing a female therapist, and it wasn't working. There were some serious breakdowns in communication."* Another participant said, *"Last summer, she had a therapist, but my daughter called up and said she didn't want to see them anymore. She cancelled the services herself, and they allowed her to."* Another participant shared, *"We didn't like the providers. We had a psychiatrist at the other place blaming me. It's a big shift with the new providers. Just having his clinical mental health provided through school has been so helpful on a daily basis."*

> *He was seeing a therapist, but his school provided him with better counseling. We didn't think he needed it anymore.*

Five participants said their child had changed providers due to turnover at the practice or clinic where the child was receiving services. One participant said, *"We have been with this team for about a year. We just recently lost her first therapist, so we started a new therapist three months ago. I quit my job because I needed to take care of my kids, so we lost the insurance. I couldn't get them in-home supports without being on Medicaid. Also, she has language disorders, but we couldn't get speech therapy. It's not seen as an acute condition. It's a rough trade-off because we are limited in skilled providers and location, and my older daughter has pretty severe mental health needs. Before she went residential the first time, we couldn't find anywhere that would take her in-state. They wouldn't even consider her. New Hampshire only has one pediatric psych facility in the state. My experience is that kids are not kept safe there."* Another participant said, *"He had some other counselors who were ok. This guy is new. This is the fifth one. They switched us because people left. The fourth one we didn't like at all. We were glad when that switched. She wanted to take him off his medications. We went through so much trying to get him on medications, and we had to really fight for it. And finally, he got on it, and it helped. The one here at first was really good. It was that person after that who was terrible. I was so glad when they got rid of her."*

One participant said the provider had retired, and another said the change was part of a planned transition.

One participant said her child was returning from residential treatment and shifting to a new provider.

Challenges Accessing BH Care

Fifteen participants reported challenges accessing BH care for their child.

> *There is a lot of waiting for mental healthcare. You can't just call and get in somewhere. There are waiting lists.*

Eight participants noted wait lists for care as a significant challenge in accessing care for their child. One participant said, *"The waiting time is an issue. The same with the evaluation with Dartmouth-Hitchcock for a second opinion. Even that is a year and a half behind."* Another participant said, *"The whole system of getting an appointment is a nightmare. That's not the providers as much as the people* *who fund the providers. I know a lot of them, and they're really trying, but they're understaffed and underfunded. They don't have the means to meet all the needs of the area. There's a huge need. They deserve so much more than what they're getting."* Another participant shared, *"We are still figuring it out. It will take three to six months for an intake appointment. That's a long time. There's no actual services for kids. It's limited. You get therapy, you get doctors, but when it comes to the nitty gritty about residential or hospital stays, there isn't much. Some intervention when she's angry would be helpful. We don't have immediate response types of support."*

Seven participants said one of the challenges they experienced was a lack of providers and services. One participant said, *"The system is broken. There is no health parity. We assume that if a child is struggling, he wants to give us a hard time. He's having a hard time. When you look at trauma, you see it affects the way a child behaves. If you look at them as what happened to you rather than what is wrong with you. They said they set up a crisis team, but there isn't one. The police come instead. There is a big, big hole for somebody to respond when a child is escalated. These kids who have mental health challenges are off the rails. They don't want to do it. They need somebody to be chill with them, and they need follow-up. We are losing beds, no psychiatrists, no therapists in the state. And the whole country. Honestly, I think there should be some serious incentives for therapy and psychiatry. It's very hard work. Nobody stays. I'm looking everywhere - Maine, Massachusetts, NYC, trying to get help. We just had a psych evaluation in Boston. They offer outpatient psych services, but we have to be in Massachusetts. I know people who will drive across the line to have those weekly visits. My son stopped going to school in April, and he's in such a deep depression. For the residential program, we are waiting for school approval. They have rolling admissions. As long as we have a way to pay for him, they would take him. They focus on kids with adoption issues, like my son, and have a focus on his primary diagnosis. I was going to call insurance to see if we could do the 'Get Started Plan,' but what if we can't afford it? The school district is already out of compliance with special education laws. They have yet to respond. We have to hire another lawyer to sue the school. There's no timeline for decision-making because everybody quit. The district is 15 positions down in the special education department alone. In order to get the school budget passed, they had to cut all sorts of services."*

Another participant noted the relationship between waitlists and the lack of providers. She said, *"We took the one that had the first opening, and it still took us months to get into that one. I was stuck at that point. There's no discharge plan for her at this point. Her care from the clinic hasn't been cut yet, and we're hoping she's going to go to residential at Easter Seals. That has yet to be determined as well. I think we're just waiting at this point. There aren't enough providers. There are not enough people in the mental healthcare system, which has been the main barrier. It's just a lack of people and low-quality care."*

A participant shared the connection between lack of providers, lack of coverage by health insurance, and lack of knowledge about services. She said, *"Psychiatrists are not covered. The systems in New Hampshire are pretty abysmal. Literally, the only way my son could get help was to be arrested. The Juvenile Probation and Parole Officer (JPPO) was able to get us into services, and the police chief was pushing the judge to write an order to get him eligible for services. We didn't even know that NFI North existed. He's been in the wards, and they're trying to push you to Manchester Mental Health. They don't even know about the other programs. The program he's in, NFI North, is new. We are one of a few families to access it. It's really a shame hospitals don't know about it. I am employed in a non-profit, and even working in this world, it felt like I was hitting my head against a wall trying to get services. When we were recommended to get on Medicaid, I kind of knew what Katie Beckett was and knew sort of about it. We don't have enough money to place him in residential out of pocket. We can't afford it, but* *also, he was not eligible for it until he got arrested. Then, that got the ball rolling to get the services. That's the last thing you want to do with a kid like him. That was really sad before. We had tried for quite a while on our own to get different counselors and pull a team together, and we just couldn't. The first appointment to call for a psychiatrist is in December, which isn't going to help. There is a complete lack of knowledge of what's available, and there is not enough available. NAMI [National Alliance for Mental Health] is trying to help, but it's still sketchy out there."* Another participant mentioned the lack of crisis support available. She said, *"Our kids were initially with DCYF, so they got pushed to the front, and that was helpful. The only issue we had was with our other child, who needed a crisis team. The school called, and it was going to take the team about an hour to get to the situation, which the school said was too long."*

Two participants said they could not find a provider covered by their child's health plan.

One participant said there needed to be better information available on providers who could provide the care her daughter needed. She said, *"One thing about NHHF they were not able to help me find providers. The website is not up to date, and that was really frustrating. I did go to the website and call someone to find someone else. We desperately needed someone more capable. It was destabilizing. CPS isn't necessarily bad for you to admit. You can get additional help from them. I've discovered the people who have been super helpful and super nice. They're not saying I'm a bad person and are trying to help us get other help. I said we need better mental healthcare, and they referred me to Youth Villages. They stay with you for about a year and a half, and they really deep dive into what my daughter needs. This is where the progress actually came from. It was a godsend that they sent me to CPS, I guess. I love NHHF for our insurance, but as far as being able to provide customers really good advice where else they can go, they are incapable."*

Received Care Soon Enough

Thirteen participants said their child had not received BH care as soon as they thought their child needed it. Seven participants reiterated the challenges with waitlists. One participant said, *"It did take time to find an alternative therapist once we realized the therapist wasn't working. It wasn't just because of staffing. My child was in and out of the hospital. It was a combination of circumstances on both ends that led to the delay. The delay that really upsets me was the delay in getting him into the hospital. They made him board at home after a legitimate suicide attempt until they had space for him. I'm glad they're passing that law that people are going to need to get in within six hours. I don't know how long they have to implement that."* Another participant said, *"It was quite a long time ago when she first started having therapy. We had switched a few times because people had left. She was at the ER a couple of years ago for depression and suicidal ideation. I told Community Partners that she wasn't allowed to come home from the hospital until they had something set up and on board. We've had the same people ever since."*

Five participants said the delay was due to a lack of providers and services. One participant said, *"It's the economy we live in. There just are not enough providers in our rural area. We only have one for the whole valley."* Another participant said, *"There was a delay because we couldn't find a provider. The other thing is that our son is multi-racial, and it is incredibly hard to find providers of color, whether it's primary care or mental health support. We were trying at least to get some men so he had some kind of male support. We figured out it mattered more about the connection he made with him. I still every so often do searches for therapists of color who take Medicaid."*

One participant said her child had complex needs, which created delays. She said, *"They absolutely try, but we don't always succeed. It's always a crap shoot. He's not a typical kid. He's very complex."*

One participant reiterated that there was a lack of information about services available, which delayed her child getting services.

Four participants who said their child had received services as soon as needed provided some context for their responses. One participant said her family "got lucky," but it is clear that she had to make a significant effort to get care for her child. She described, *"It was not as big a gap as it could have been. I got extraordinarily lucky. I must have called or reached out to 10 or 15 different providers and was on a waitlist for maybe six of them who were saying it would be six weeks to six months before they would have an opening. One office got back to me and told me that all their current therapists were full but had a new therapist starting soon and would be filling slots as quickly as people responded. She suggested I program their number into our phone, and if they called, I should answer. I did, and it took probably about a month to get seen."*

One other participant said her child had a Person in Need of Supervision (PINS) case open, which made it easier for him to get services.

One participant said having her children already established as patients made accessing care quickly easier. She said, *"Originally, years ago, there was quite a delay that was frustrating. I find that because they're patients, we get support much more quickly."*

One other participant said that having access to telehealth during the pandemic made it possible for her child to receive care more quickly. She said, *"We got him on Valentine's Day, and then on March 2nd, the pandemic hit. The first year was really rough. We did Zoom, which was hard because a physical connection hadn't been made yet, but it really helped teach me on how to deal with a child with these issues. It helped our family adjust even though it was Zoom."*

Coordination of Care

Fourteen of the participants said their child's PCP was knowledgeable about the BH care their child was receiving. One participant said, *"I agree when it's a psychiatric case for the psychiatrist to handle it. They do inform each other when things change. They always make sure they update what he's on."* Another participant said, *"The PCP and therapist are well connected. I like us all to be in the loop. The school knows; everybody knows what's going on."* Another participant noted that her child's PCP was knowledgeable about the care he was receiving but also very happy to leave that care to the psychiatrist. She said, *"She's been very open about not being comfortable adjusting his meds. She is sending us to someone who is. That is a rare and wonderful trait. She has no ego to it."* One other participant said, *"It's all together. They're linked through Elliot. They look into each other's records and are very, very communicative all around. I like that. We all need to be on the same boat."*

Six participants said their PCP was unaware of their child's BH care. One participant shared, *"I am not against it, but I feel like a lot of PCPs don't want to get involved in that side. She was willing to call in refills until we got into mental health, but I got the vibe that she was going to let mental health deal with that, which makes sense. I get it."* Another participant said, *"I think she could be a little more informed. She always has a ton of questions when I come in. I would prefer they would talk to each other."* Another participant said, *"They don't connect. I am the connector person. I relay the information. I don't want them to connect."*

One participant said she did not know if there was coordination of care. She said, *"I don't know if they talk to each other. I know that if I have a problem getting certain medications for whatever reason and can't get a hold of the psychiatrist, the PCP will see him. I've had no problems getting his medication the other way. The only problem I've had is the pharmacy being out of medication."*

One participant said that currently, there was no need for coordination. She said, *"Changing providers has limited their understanding. I don't see the benefit of more engagement with the current psychiatrist's level of care and communication. If we lost the psychiatric care, we might want the PCP to understand more in navigating the meds. There's nothing prescribed from the PCP, so there are no interactions with that. Generally, we are okay right now."*

ACCESS TO INFORMATION

Participants were asked how and where they accessed information about their child's health, including information they received from their MCO. Participants rely on their child's healthcare providers to answer questions about their child's health. For the most part, participants did not have challenges getting their questions answered. A handful of participants said it was difficult to get in touch with their providers, and two said they continued to have challenges accessing mental healthcare for their child. Participants said they preferred to research independently and interact one-on-one with a provider when they are learning about health. Nearly all participants said they received information and reminders from their MCO, but a minority found the information useful. Only a handful said the information impacted their decision-making. Most participants reported using telehealth for their child, but half said their experience was not positive. Participants said it was difficult for their child to focus during telehealth visits, which limited the success of their mental healthcare appointments. Other participants appreciated the convenience of telehealth, particularly for providers far from their homes.

Resources Tapped for Information

Participants were asked who they talked to if they had questions about their child's health. All participants said they would visit their child's PCP or other healthcare providers. One participant shared, *"It depends on what the issue is. If it's basic health, it's PCP. Mental health, I turn to her psychiatrist. If it's anything neurological, I turn to her neurologist."* One participant noted that she will sometimes research an issue but generally relies on her son's PCP. Another participant said she discusses any problems with her husband first and then calls the PCP.

It depends on who's lane it is. But, generally a provider of some sort.

Problems Getting Health Questions Answered

Twenty-two participants said they had no problems getting answers to their questions. Three participants noted difficulty at times in getting in touch with their child's providers. One participant said, *"If they don't know, they do find out for me. His counselor is in some class, and she's using the kid for a case study because he's so complex. So, she's always asking her teachers questions. They're amazing, but they're just so busy, sometimes you can't get a hold of them."* Another participant said, *"This particular practice got bought up by a large hospital company, and it was incredibly hard to get through on the phone system. They have since made some improvements, but that was a pain. I would be sitting on hold for 45 minutes to an hour to get through to somebody. It hasn't been hard lately. And they also have an online portal. I never set it up for my kids. If I did that, I think that would be helpful."*

One participant said she had experienced challenges before but no longer had any problems.

Two participants reiterated significant challenges getting mental healthcare for their children.

Learning about Health

When asked how they preferred to learn about health, 20 said they liked to research independently. One participant shared, *"I like to arm myself with knowledge if possible. I'll get recommendations from the therapist. I stay away from WebMD. I usually get recommendations on sources that would be helpful."* Another participant said, *"I usually look it up. I'm working on my Masters in clinical mental health."*

Half of the respondents (N=14) said they liked one-on-one interactions, particularly with a provider. One participant said, *"Usually one-on-one with a provider because I ask a lot of questions."*

Three participants said they liked classes.

Three participants said they were open to any method of receiving information and training about their health. One participant shared, *"I feel pretty well-versed at this point. I would say, previously, reading and research. I've taken some classes in the past. I think a combo of conversation with provider, classes, and reading."* Another participant said, *"All of the above. If a doctor is suggesting a new medication, I'll go online and look it up myself. Any type of new diagnosis, I do try to do some research on it."*

Support and Information Received from MCO

Nearly all (N=24) participants said their MCO sent them information and reminders about well-care, immunizations, and prevention screenings. All participants said the information is easy to read and understand.

Only 9 participants said they liked getting information and reminders from the MCO. One participant said, *"Yeah, it's a nice reminder to make sure we get a check-up. Sometimes, if we miss a cleaning, it's a nice reminder."*

Twelve participants said they did not read the information and did not need the reminders because they were already well-situated with their children's appointments and care. One participant said, *"Most of the time I don't really need it because I keep up on everything. If I weren't the one making those appointments, a reminder would be good."* Another participant said, *"I rarely have time to read them. Most of them I don't open. And when I do, it just says, 'this is not a bill,' and I put it in a pile."* One other participant shared, *"Usually letters that say it's time for a dental check or it's time for annual check-ups. These things are always on the calendar. You make them at the time when you leave the last appointment. They are easy to read if I do it. As soon as I know what it is, it goes in the garbage. If we weren't one of those families, I'm sure it would be super helpful."*

Two participants said the information was repetitive and not helpful.

Two participants said the information was fine but not particularly useful.

Two participants said the information they received was not accurate. One participant said, *"It's not accurate. We get messages about being due for an appointment, but it's not correct. It might be because I switched insurance. If it were accurate, I would like it. Sometimes, it's hard with primary care. They* *don't have the schedule for a year ahead. So, you can't finish a physical and schedule one for the next year; you have to remember to call. It would be helpful to have that reminder. But don't call a couple of months ahead of time. It needs to be six months ahead of time."*

Six participants said the reminders and information received from their child's MCO impacted their decision on whether or not to seek care. These participants universally noted that the communications provided a nice reminder about appointments or screenings. One participant said, *"Yeah, it lets me know he's due for this or that and reminds me to check the portal."*

Five participants said the information sometimes had an impact, but generally, their family was on top of the care their child needs. One participant shared, *"We're a very privileged family in that we work, we have access to healthcare, we can take time off if we need to. We are in the habit of doing those things generally. When he has a well-child visit, we set up the next year's visit. Sometimes, the reward card might ring a bell. We do all our vaccines. It's more like a helpful resource and reminder. We're typically already on board with it."*

Telehealth

Participants were asked to describe their experiences with telehealth. Twenty-four interview participants reported having a telehealth appointment since March 2020.

Half (N=12) of those participants said their telehealth experiences were not positive, primarily because it was difficult to get their child to focus for mental healthcare in a virtual environment. One participant said, *"My kid can't sit in front of a computer doing telehealth and not play a game. So, we try stay away from that."* Another participant said, *"We haven't ever met the psychiatrist in person, which annoys me. I just feel like you really should meet her."* Another participant said, *"It can be difficult to talk about your child in front of them. That makes it different and more difficult. There are times I want to have a conversation with the psychiatrist by myself, but I can't because it can't be billed unless the child is there. If I'm on Zoom, she's going to hear what I'm saying. And, I've had to go to school pull her out of school to do a Zoom at the school which has been kind of strange. Some of timing has been tough. It's difficult to get appointments before school or after school."*

> *Telehealth is hard because he's not sitting with the person, so his concentration isn't there, so I have to do more in terms of paying attention and describing.*

Eleven participants reported positive experiences with telehealth, mainly because of the convenience. One participant said, *"Those are really good and convenient. It is so easy to do telehealth. She can get on her phone. It's been such a good thing."* Another participant said, *"It has been very helpful, especially with the psychiatrist from Dartmouth. I have a vehicle that literally has parts held on with painter's tape."* Another participant said, *"Most of her psychiatry is telehealth. Once a year, she has to go into the office. It's phenomenal. I set up the appointment at the end of a visit. Ten minutes prior, I log on, and then she's right there. It's not a shorter visit. It could be a half hour to an hour. I think telehealth enhances the care because my child is in her own surroundings. Sometimes, in the office, she's totally distracted by new things. She is acting like she's always acting at home through telehealth."* Another said, *"They work great. The psychiatrist is*

> *It worked very well, especially the ability to manage all the kids. To see everybody, but be at home, having a snack. That was really nice.*

an hour away from his school. It's nice not to drive all that way and nice to be able to hop on and do the appointment."

One participant said it depended on which type of care. She said, *"It goes back and forth. With the psychiatrist, it goes well, but counseling doesn't work. He shuts down."*

SUGGESTIONS FOR IMPROVEMENT

Participants were asked what improvements they would make to their child's well-care and BH care and what assistance they wish they could have received as parents to help meet their child's needs. Many of the suggestions centered on the availability of providers, particularly mental health providers, but also dental and vision providers and pharmacy options. Participants also remarked on the need for more residential treatment options, respite care, in-home supports, and better crisis response. Participants said there was a need for better information on the resources available and efforts to decrease stigma. Participants mentioned an opportunity for MCOs to be more proactive in providing support and resources for families in times of crisis and connection to other families experiencing similar challenges.

Well-Care Improvements

Participants had several suggestions for improvements to their child's well-care.

One participant said she would like more advice and guidance on the developmental milestones she should be looking out for with her daughter. She said, *"I think what's typical and developmentally appropriate in all the areas for her age. I have a lot of questions about my daughter's learning ability. She has an IEP, but it would be helpful to know about social development. Is it typical for her to self-isolate like she does? She seems to be younger than her peers socially. Her psychiatrist said I could have her tested for non-verbal autism, but the school will say they don't think so, probably because they don't want to provide services if there were some standard sheets on what is typical. After they're walking, you don't get them. I just feel like it would be helpful to know the basics of what they should be doing."*

One participant mentioned it would be helpful for families with older children to have information on the next steps for coverage and care as they become adults.

One participant said she would like a one-page summary of all available benefits. She said, *"I know we got the big booklet and access to it online, but you could send out a one-pager or something that was easy for people to read about benefits that could access through Medicaid. 'Do you know they can go to the dentist? Do you know you can get paid for driving them to appointments?' Especially if you have to drive your kid to Dartmouth or Lebanon, that's expensive, and it's easy to get that reimbursed. 'Did you know you can get a car seat/booster seat?' If you're a person who looks at what resources you can get, especially with some of our kids, that would be helpful. You can really show why it's good to be with Well Sense. We would have never qualified for Medicaid income-wise, but it was helpful to know that prescriptions would be covered. If you're a person who is on the fence about whether to apply, do I want the government in my life to know that your taxpayer dollars cover this, not as an entitlement, but something that is a benefit that you should take advantage of for your child? Your child will benefit in these ways. You can use your money in your monthly budget in these ways. It frees up worries and resources that are really helpful. It's not marketing, but communication of what is preventing people who should be on Medicaid from doing that."*

One participant remarked on wanting more covered vision care providers. He said, *"I guess it's mainly the vision. Even getting the appointments for them. There are only a few providers that will take the insurance. I can't get an appointment until October, and he needs them."*

One participant remarked on the lack of options for pharmacies. She said, *"One thing I do have a complaint about with Well Sense is that I'm only able to use one pharmacy for his prescriptions, Walgreens. My insurance only allows me to use CVS. And now we are running into this issue where we can't get his medication from Walgreens, and they also won't give us any information. I never had any problems before when getting it from CVS. To me, this is not life or death, and I'm not riled up. It's just ADHD medication. But it is really annoying that it's been months that he's been prescribed this medication, and I have no clue if he's ever going to get it. We can't even get the answer about why we are not getting the medication. I'm guessing it's from the shortage."*

One participant said she wished her provider had convenient hours. She said, *"They have such really good care, and our provider is so amazing, but obviously, as a working parent, scheduling is tricky. I would like more early evening hours. They do Saturdays, but only for acute cases."*

One participant said she would like an improvement made to the reward system through her MCO. She said, *"I really have to stretch to find an improvement. I'm pretty happy with his insurance. It would be nice to be able to use the rewards card at gas stations. It says fuel, but I only seem to be able to use it at Wal-Mart. It doesn't have super good instructions. I don't know what fuel options are available."*

Another participant said she would appreciate having more providers available through the plan. She said, *"I guess more options for providers. It's because our area is so small."*

One participant said she would like not to have telehealth as a requirement.

Eleven participants said they had no suggestions for improvements to their child's well-care.

BH Care Improvements

The bulk of recommendations for BH care improvements from participants centered around the availability of providers.

Eight participants said there was a need for more BH providers overall. One participant said, *"There need to be better choices to go to. More resources. There are not enough providers that take Well Sense."* Another participant said, *"Just have more providers, and providers stay longer. I think it all comes down to reimbursement rates. Providers are not taking NHHF because they don't get reimbursed, maybe the way private insurance reimburses. Also, they are allowed to bill for the interns, but you never see the licensed therapist. It would be nice that there would be a requirement that you have to see the licensed therapist at least some minimum number of times."* One participant recommended developing an incentive process to draw more people into the field. She said, *"I would have more people in college to be mental health providers if there were a way to have scholarships or loan repayment for kids going into college. If there was recognition that this is a governmental program and that Medicaid is covering this and it's a high need. It's like teaching fellows. If they had a mental health provider fellowship in some of the state schools and if they declared early and actually worked in the field, they could graduate debt-free. You would have more providers that come into the field and stay in the field and see it more as a vocation. Being proactive with high school seniors who can afford to go to a state school and offering a mental health fellowship would increase the number of providers."* One participant said, *"In an ideal* *world there would be more therapists of color. I work in higher education, and I understand it's a pipeline challenge. In an ideal world, there would be more men of color, particularly in the therapeutic environment."*

Two participants specifically said there was a need for more psychiatrists. One participant said, *"I guess it would just be nice if some of these psychiatrists would take the insurance. And improve the communication on who does take it. If you look up our psychiatrist's name, it says it takes Medicaid and Anthem, but if you go to the practice, they only do it when they are on-call at the hospital. Only at that location at that time."*

One participant said there was a need for residential treatment options and better support in getting into that treatment. She said, *"We have been trying for months to get him into residential treatment. He has acute suicidal episodes. The last one happened in the middle of the night. He needs the care, and it is urgent. Finding a place that fits is hard. We went through the Crisis Assessment Tool (CAT) assessment, and he got a level 3. Finding a level 3 facility is difficult. You can't just go into a search engine that will provide that information. We just have to go by word of mouth from therapists. By the time we got the name of the place we tried to apply for, the CAT assessment had expired. If it takes that long, maybe you should talk about how long the expiration dates are. The kid has gone to the hospital multiple times, having psychotic episodes. He loses touch with reality a bit."*

One participant said she would like respite options. She said, *"One thing that I do wish that I could get, and I've gone to many agencies, is respite. Because he has attachment disorder, I cannot get a break from him. A respite would be good. I've talked to different agencies, but he doesn't fall into the right category. He was on a waitlist for three years for a program. We were waiting and waiting to get him on respite. Finally, the paperwork was done, and they said he didn't qualify because he needed to be developmentally disabled. He hasn't changed other than getting worse. I don't understand. If the insurance covered the respite in any way, even one hour a week for somebody to do something. They do have community care through the mental health clinic, but if they misbehave, it's a safety issue, and they get kicked off. There's nothing in between."*

One participant remarked on wanting less turnover among providers, and another said there was a need for reduced wait times to see a provider.

One participant said she wanted better providers available for her child. She said, *"Listen to the parents. Take my concerns seriously. I feel like they're discounting me."*

One participant said that the BH care her child was receiving was not helping. She said, *"It hasn't really done anything. I think that is just a process in general. It's not anyone's fault."* One other participant said her child was resistant to participating in treatment, and she was unsure what would help.

Ten participants said they had nothing to recommend concerning their child's BH care.

Parent Support Recommendations

Four participants said they wanted access to respite care to help them better meet their child's needs. One participant said, *"Respite care program that was navigable for parents like me would be great. I have a family, but I don't talk to them because that's what led us here. I don't have a huge support. The only support I have is within the community. We do have the family resource center in Gorham, which has been a huge help. The respite would be very useful. One big problem with the respite care system is* *that it is a reimbursement thing. You have to have the money upfront or have someone willing to wait and lie and say you paid them. That's shaky ground. Also, there's no easy way to find someone. You have to find your own. They don't offer up a vetted list of providers."*

One other participant said there was a need for in-home support and care. She said she needed *"in-home support with actual direct service personnel support. You can only get the in-home support waiver if your child has a permanent disability. All of my kids do, but they might not have formal diagnoses. My son didn't get his autism diagnosis until he was 18, and I never got any in-home support. The reason I quit my job was the lack of those services. I wasn't able to pay for some in-home support without going through hoops. I have never been able to have a babysitter or a paid professional. I spent time with my case manager trying to figure out how to get in-home support for kids with disabilities that didn't require going through the waiver system because the kids didn't have a formal autism diagnosis yet. But their symptoms were so severe and functioning so impaired it was more than I could handle. We needed it 12 years ago. Caring for my kids put me in the hospital from burnout. That's why I quit my job. That would be exactly what I would need from insurance to help with that cost. If I had someone to help, I probably could still work. I think they pay for it, but only if you go a certain way and people don't know how to do it. I just found out about the waiver two years ago, and I've been involved with this for 13 years."*

One participant mentioned the need for crisis response for mental health. She said, *"We need crisis response - in person, not over the phone. You can call 988, but you never know who you will get. They have no context of regional resources."*

One participant said they would like better access to dentists and providers closer to their home. She said, *"I just wish they had doctors closer that took Well Sense. When they're that far away, I end up not calling them when I should. I wait until I have to. He needs a dentist."*

Two participants said there was a need to improve access to resources and information and to decrease stigma. One participant said, *"I have a lot of huge needs for the girls, but need more advice and support for what's out there. Someone who knows how I can better invest and maximize the insurance for my girls. I am sure there's more out there, but I haven't found anyone to help me find it. The woman I always speak with says there's more out there, but I go to the website, and there doesn't seem to be anything. Maybe there isn't anything out there, and maybe we need to add services."* Another participant agreed, saying, *"The programs that usually come along with Medicaid are helpful, but there's a real social stigma. How do you decrease the social stigma to increase the access to resources? That sense that we're all in it together rather than the perception of people 'sucking the resources.' How do we resolve that, especially when these are kids? I also think it's helpful when you're trying to recruit foster parents for them to know that they will be on Medicaid and tell them what that means. A lot of people who might be interested in being foster parents can be concerned about the cost to them in terms of medical care. If Medicaid said, 'we'll cover these needs,' there might be more interest."*

One participant said that providers should listen to parents more.

One participant said there should be more proactive outreach to families during crisis from the MCO. She said, *"I didn't reach out to Well Sense after my daughter's last hospitalization. I would like them to reach out to me. They see the bills when she's in the hospital, psych hospital, or residential. They should reach out and ask what they can do to help. They reach out other ways; this could be added."*

One participant recommended parenting classes. She said, *"Earlier parenting classes would have been helpful. My kid had been having problems since third grade, and if the counselors or staff at school were knowledgeable enough to get kids some help rather than waiting for parents to ask for help. My wraparound person before he went residential helped me find the classes I went to."*

One participant said she would like more connection with other parents and caregivers having similar experiences. She said, *"When he was first diagnosed with ADHD, I was looking very quickly for support from other caregivers because I felt we were out on an island. Social media helped fill that in. Maybe it would have been helpful if we could have connected with other parents/caregivers in New Hampshire, but I know there are HIPAA* [Health Insurance Portability and Accountability Act] *restrictions."*

One participant noted she had challenges with DCYF and wished she had other recourse. She said, *"I had problems with DCYF, and I don't even know who I would talk to about for assistance. I was pushed to do things very quickly, not with this child, but with another grandson. I lost him in the system. I thought I was pushed toward letting them adopt. I was overwhelmed. My daughter had just passed, and the child was abused, but I couldn't take both of them. I left him in care. If I had more time, I could have taken him. And that's hard. You're not in a state of mind to be able to make a life-changing situation in the midst of the pandemic and grief. I felt they were really pushy and weren't willing to slow the process down. They used the analogy of a puppy mill. They said they would take a picture, and he'd be snatched up. He was in a safe place, and this child was out of control. I wish I could go back and do it over. The adoptive family won't let us have any contact with him. The children were supposed to be able to connect. She's blocked me on social media. I know where she lives, but I'm not going to stalk her. The younger one doesn't realize he has a brother, but my son does."*

Fourteen participants did not report any support they wished they had or could receive to help them with their child's care.

Additional Comments

Ten participants had additional comments they wanted to share.

Four participants remarked on a lack of available providers. One participant reiterated her concerns about a lack of mental health providers and limited pharmacy options. Another participant said she could not find a dental provider who accepted Medicaid for her 16-year-old child.

One participant reiterated his concerns about vision care. He said, *"Like I said, his PCP and dentist, we never have any issues. Vision: I'm sure we won't have issues, but we will have to pay out of pocket. I have insurance with my wife and Medicaid. The place I found that had the least expensive stuff required paying $100 out of pocket."*

Another participant noted challenges in finding providers covered by the insurance, including dental and vision care and trauma-informed mental healthcare. She said, *"Dental was the same problem as the eye doctor, in terms of finding someone. At first, it was very hard to find a dentist that you really trusted. There are a lot of holes in the wall that will do teeth. I was not happy with the results. They did too much unnecessary work. It was more of a scam thing. It was concerning until I found this dentist. The same with psychiatric care. There have been times I've gone and looked for specialty psychiatric care. Both kids had trauma and needed trauma specialists, and that can be very, very hard to find anyone that will accept NHHF or Well Sense. The current counselor is trauma-informed, but she's not an expert. At one* *point, we needed that next level and couldn't find it. That was very frustrating. It's either not available, or they didn't take Medicaid. There are so many kids that need it; they're overwhelmed in the industry."*

Two participants said they had difficulties accessing their child's ADHD medications. One participant noted challenges with shortages of ADHD medications. She said, *"He does take a medication for ADHD, and there is a shortage of those meds, and I don't get it. It's not the provider, pharmacy, or Well Sense. I don't understand how we have a shortage of medication. That is a constant thorn in my side every month. I have to chase down medicine. Sometimes, I have to drive over an hour to get his medicine. I have to call pharmacy after pharmacy to see who has it in stock. I think it's a manufacturer's problem. I just know it's nobody's fault. And his brother is on similar medicines, and it's a double whammy. You panic because these are not medications that can be stopped abruptly. And you can't get any ahead of time. You get your one-month supply, and that's that."*

Another participant had difficulties with her son's ADHD medicine. She said, *"The thing that is often the hardest is getting his ADHD medications because it's a controlled substance. The pharmacy won't fill it until there are only a couple left. There have been days that he has had to go a few days without because it was literally impossible to get it filled up and to him in time. That's hard to navigate as a family. He needs it every day. Part of it was we were relying on him to use his executive functioning to tell us when he was getting low to empower him. It was compounded when I couldn't get in touch with the doctor right away and put on hold. If I was at work and couldn't call back that day, we couldn't get it. I take some responsibility for it. I think I could have opened his online account that is connected with healthcare for the kid. I think that maybe would have been helpful. I think initially, the only way we could do a refill was to call and there were a couple of times there was a holdup. It may have been on the doctor's office end with confusion over which pharmacy to use."*

One participant reiterated her desire for better case management. She said, *"It's finding out what families need and supporting them. Especially those with kids with disabilities. If a case manager could help with those things, it would be helpful."*

Another participant said she was pleased with the insurance coverage and care her adopted grandchild had received but reiterated the challenges she had experienced with DCYF and noted an additional issue. She said, *"His healthcare, mental care, dental care, all of it has been fabulous. My only state-involved issue is DCYF and how they handled the questioning about his foster family from before. It was a traumatic situation."*

One participant said she was *"very pleased with Well Sense. It's a phenomenal program."*

One participant said she would like the insurance company to be more cautious about using the word "important" in their emails. She said, *"There will be a message that says, 'There's an important message for you,' but it's not important. It's just the pharmacy. That's annoying."*

One participant noted how well her son was doing now. She said, *"He's doing really good. I'm happy because I don't have to worry about it anymore. His meds are adjusted just right now. In the beginning, it was hard to adjust his meds when he was in school. He would have these breakdowns in school, sometimes provoked by others. Some people didn't understand his ADHD, and that includes teachers. It was trial and error getting him on the right med. He's finally on what helps him. I don't have any worries. He even takes his meds on his own sometimes."*

Recommendations

Based on the experiences and feedback reported by interview participants, the findings from this report generated four recommendations for the MCOs and two recommendations for DHHS.

For MCOs:

Incentivize current mental healthcare providers to accept Medicaid

Participants reported that the lack of mental healthcare providers who accepted their insurance resulted in delayed care for their children. Finding ways to increase the number of current mental healthcare providers who accept Medicaid may result in reduced waitlists and greater access to care.

Participate in efforts to create a diverse pipeline of new mental healthcare providers

Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.

Provide respite care coverage and access to vetted respite care resources

Participants frequently mentioned the need for respite care. Programs that require beneficiaries to make upfront payments to respite care providers and wait for reimbursement significantly limit access to care for low-income families. In addition, requiring families to find appropriate and safe respite care options without guidance creates an additional burden that can prevent access to care.

Assess families' need for case management periodically and provide proactive support

Participants noted appreciation for the case management support they were currently and had previously received from their MCO and other agencies. Families with children with mental healthcare needs can have periods of relative stability followed by high-need times. MCOs should periodically assess a family's need for case management and provide support if needed. In addition, following up with families when a hospitalization or residential treatment has occurred to offer case management support could ease transitions back to community-based providers.

For DHHS:

Provide information on the benefits of Medicaid to prospective foster parents

Participants noted that concerns about care costs may prevent some families from participating in the foster care system. Providing information on Medicaid and other benefits available through the foster care system and adoption may increase the number of families interested and willing to participate.

Participate in efforts to create a diverse pipeline of new mental healthcare providers

Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.

APPENDIX 1. RECRUITMENT LETTER

June 19, 2023

Dear [FirstName],

The New Hampshire Department of Health and Human Services is asking for your help with a project about New Hampshire Medicaid Care Management. The Department hired Horn Research to gather opinions from parents like you to better understand your experience with your child's healthcare and health plan.

We would like to invite you to participate in a **telephone interview** where you can share your experience about [ChildName]'s providers, support services, and managed care organization.

We are only asking a small number of people to take part so **your participation is very important**. You will receive a ***$50 VISA gift card*** as a thank you for your time if you participate in a telephone interview.

We will be conducting the telephone interviews between **June 21, 2023 – July 24, 2023.** The interview will take about 25-30 minutes and we can schedule it at your convenience. We have a limited number of interview slots and they will be filled on a first come, first serve basis. All information you share will be kept completely private and will not affect your child's benefits or healthcare in any way. No one from Medicaid will see your individual answers. Your and your child's personal information will never be made public.

If you would like to schedule an interview, please call Horn Research toll-free at **(888) 316-1851** or email at Lisa@HornResearch.com.

Thank you for sharing your experience and thoughts about New Hampshire Medicaid Care Management.

Sincerely,

Susan Drown

Susan Drown, MBA, LICSW
Director, Bureau of Program Quality

APPENDIX 2. INTERVIEW GUIDE

NEW HAMPSHIRE MEDICAID CARE MANAGEMENT PROGRAM
INTERVIEW GUIDE – SPRING 2023

Introduction

The goal of this interview is to try to understand your experience with your child's managed care organization and the support you received during the past year.

Your feedback is very important and will help the State of New Hampshire evaluate the Medicaid Care Management Program. We want to know about your experiences. Your participation will not affect the benefits and services your child receives through the Medicaid Care Management Program and all the information you provide will be kept completely confidential. At no point will your child's name or any other identifying information be released.

I. Demographics / Context

1. Child's Current Age *(Years)*
2. Are you the custodial parent or guardian?
    a. Do you have other children? If so, how old are they?
    b. Do they all live in the same household as you? (If no, they may live with another parent, are away at school, live on their own, etc.)
3. Are you or your significant other in the household currently employed? If yes, is it FT, PT, temporary, etc.?
    a. Are you or your significant other in the household currently a student? If yes, FT or PT.
4. Do you have a safe, stable place to sleep and store your possessions? How long have you lived/ stayed there?
    a. How many people live with you? (i.e. spouse/partner, grandparent(s), roommates) How many of those are children?
5. Do you have access to childcare, including any informal childcare from relatives, friends, or neighbors? If no, why not?
6. Within the past 12 months, did you worry whether your food would run out before you had money to buy more?
    a. If yes, did you receive help obtaining food? (i.e. case manager, Managed Care Organization (MCO), food pantry, etc.)
7. Have you experienced any challenges with your transportation?
    a. If yes, tell me more about that.
    b. If yes, are you aware of Medicaid transportation assistance?
        i. If yes, have you had any challenges using Medicaid transportation?
8. Do you have access to a phone, tablet or computer with internet access? (specify which ones) (prompt: Do you have any challenges/difficulties with online access?)

Note to interviewer: Please refer the participant to NH's 211 resource if the interviewee expresses they would like help obtaining additional resources such as food, stable housing, or transportation.

II. Experience with Medicaid Managed Care

1. Can you describe how well you understand your child's health plan, such as what is covered and what isn't?

2. How do you get support from your MCO if you have questions? Do you feel the customer support services meet your families' needs and available when you need it?
   (prompt: Do you have someone you can call/contact if you have a question? Who do you call if you need help? If you did call, how easy has it been to get to answers or resolutions to issues or questions? Do you reference the member handbook for understanding your child's health plan? Have you had any trouble getting your questions answered?)

3. What do you like best about your child's Managed Care Organization (insert name of MCO)? (prompt: Can you tell me about a good experience you've had?)

4. What are the most challenging experiences you've had with your child's Managed Care Organization (insert name of MCO)? (prompt: Can you tell me about any problems you've had?)

5. Do you feel like you have had access to the care your child has needed, such as primary care, behavioral health, physical therapy, through your MCO? Have you had access when you needed it? What challenges or difficulties have you faced with that?

6. What do you know about your child's Managed Care Organization's (insert MCO name) complaint process? (prompt: Have you ever utilized the complaint process? If so, do you feel your concern was adequately addressed? If not, do you feel you could find this information if you needed it? Did you check the member handbook?)

7. Case management is a healthcare process in which a medical professional helps the client and their family navigate the healthcare system by connecting them to healthcare providers, resources, and services so that the client gets appropriate care when they need it. Does your child receive case management services from the MCO? What do you like best about these services? What do you like least about these services
   a. If their child does not receive case management through the MCO, does your child receive these services from another organization? What do you like best about these services? What do you like least about these services

Next, let's narrow our focus and go into some more specific areas related to your child's most recent healthcare visits.

<u>Quality of Care- Well-care</u>

1. How would you describe your relationship with your child's primary care provider?
   a. Do they understand your child's healthcare needs? Please explain your response.
   b. Does your child's provider explain things in an easy-to-understand way? Please explain your response.
   c. Does your child's provider treat you/your child with courtesy and respect? Please explain your response.
   d. How would you rate the quality of the care your child's primary care provider provides your child?
      1=very poor quality support and 5=excellent quality of support, why did you choose that score?
   e. What do you like best about your child's primary care provider?
   f. What do you like least about your child's primary care provider?

2. Has your child changed their Primary Care Provider (PCP) in the past year? If so, why?

3. Has your child had a well-child exam in the past year? If no, why not? (i.e. can't get an appointment with a PCP, transportation issue, childcare issue, etc.)
    a. If your child didn't have a well-child exam in the past year, when was your child's most recent well-care exam?

4. At your child's most recent well-care visit, the provider may have discussed a variety of topics associated with your child's weight, nutrition, and physical activity. Can you tell me about that discussion? (prompt: Did your provider discuss healthy eating habits, staying active)?
    a. Did the discussion change anything about your child's eating or physical activity habits?

5. Tell me about your experience getting vaccines (such as DTaP, Tdap, HPV, flu, meningococcal) for your child. Did the provider recommend any vaccines at your child's last well-care visit? Did your child receive all of the recommended vaccines at that same visit? If not, why not? Have you had any challenges in accessing any vaccines? If you chose not to have your child receive a vaccine(s), please explain why?

6. Describe your experience with your provider evaluating and discussing your child's mental or emotional health. Did your provider ask your child how they are feeling mentally? (i.e. if they are feeling sad, etc.)
    i. Did your child's doctor make any recommendations?
        i. If yes, what did they recommend? Did you follow those recommendations? If not, please explain why?
        ii. If the provider did not make any recommendations, do you wish they had? Please explain your response.
    ii. If your child received behavioral health support (i.e. counseling from a therapist, prescriptions from a psychiatrist, etc.), how would you rate the quality of the support your child received?
    1=very poor quality support and 5=excellent quality of support, why did you choose that score?
        i. Does the behavioral health provider (psychologist, psychiatrist, etc.) understand your child's needs?
        ii. Does the behavioral health provider explain things in an easy-to-understand way?
        iii. Does the behavioral health provider treat you/your child with courtesy and respect?
        iv. What do you like best about your child's behavioral health provider?
        v. What do you like least about your child's behavioral health provider?
        vi. Has your child changed their behavioral health provider in the past year? If so, why?
        i. Have you experienced any challenges accessing behavioral health support for you child? If so, please explain what challenge(s) you have had.
        ii. Did your child receive the behavioral support as soon as you thought they needed? If not, please explain why.

7. Is your child taking medication on a regular basis?
    b. Tell me about any suggestions your provider made to support your child's health either before trying or while taking the medication (e.g. therapy prior to medication, changes to environment to support asthma management). Were these suggestions helpful or did you have any challenges implementing them?
    c. Tell me about your experience with your child's provider's ongoing medication counseling (prompt: do they ask about how effective the medication has been, the impact of side effects on your child).

8. If your child was seen by a specialist (including Behavioral Health) in the past 6 months, do you feel that your child's PCP was knowledgeable about the care your child received from the specialist? Do you think your provider should work more or less with other providers to manage your child's care?

9. If your child needed primary care services other than their well-visit (such as sick care), did they receive that care as soon as you thought they needed them? If not, please explain why

Next, let us talk about your ability to access your child's health information.

V. General Access to information

1. If you had any questions about your child's health (includes physical health and behavioral health), who did you ask? *Prompt: doctor, nurse, health plan, friends, other*

2. Did you have any problems in getting your questions about your child's health answered?

3. When learning about your child's health, how did you like to get information?
   Prompt: website/online, magazine, group education class, one-on-one, group class, telehealth

4. Do you receive emails, texts, letters or other reminders from your child's MCOs (insert name of MCO) about well-care, immunizations, or prevention screenings? If so,
    a. Are they easy to read and understand?
    b. Do you like receiving this type of information?
    c. Do these communications impact your decision whether or not to seek care or get these screenings for your child?

Next, I would like to speak with you about telehealth.

VI. Telehealth

Telehealth is the delivery of healthcare and health education or health information in which the patient and medical provider have two-way communication remotely through audio or video (e.g., FaceTime, Skype, Doxy, etc.)

1. Has your child participated in a telehealth appointment since March 2020? Tell us about your experience.

Lastly, I would like to ask you a few questions related to suggestions for improvement.

VII. Suggestions for Improvements

1. If you were going to make one improvement to the well-care/preventative healthcare and support your child received during the past twelve months, what would it be? (If their child did

not receive well-care/preventative healthcare in the past twelve months ask the question replacing twelve months with twenty-four months)

2. If you were going to make one improvement to the behavioral healthcare and support your child received during the past twelve months, what would it be?

3. Is there support as a parent that you received or wish you had received from either the MCO or your child's healthcare provider in the past year that helped/would have helped you meet your child's needs?

4. Is there anything else about your child's health coverage that I did not already ask you that you would like to share with me?

APPENDIX 3. MCO-SPECIFIC RECOMMENDATIONS FOR EQRO.01 REPORT

ACNH

Table 10 lists opportunities for improvement from the Member Qualitative Interview Report to include in the EQRO.01 report for ACNH.

Table 10. EQRO Findings and Recommendations for Improvement from the Member Qualitative Interview Report to Include in the EQRO.01 Report for ACNH

ACNH EQRO Findings/Recommendations for Improvement to be Included in the EQRO.01 Report		
Member Qualitative Interview Report		
1	ACNH-2023Sp-EQRO-SSI-01	*Incentivize current mental healthcare providers to accept Medicaid* Participants reported that the lack of mental healthcare providers who accepted their insurance resulted in delayed care for their children. Finding ways to increase the number of current mental healthcare providers who accept Medicaid may result in reduced waitlists and greater access to care.
2	ACNH-2023Sp-EQRO-SSI-02	*Participate in efforts to create a diverse pipeline of new mental healthcare providers* Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.
3	ACNH-2023Sp-EQRO-SSI-03	*Provide respite care coverage and access to vetted respite care resources* Participants frequently mentioned the need for respite care. Programs that require beneficiaries to make upfront payments to respite care providers and wait for reimbursement significantly limit access to care for low-income families. In addition, requiring families to find appropriate and safe respite care options without guidance creates an additional burden that can prevent access to care.
4	ACNH-2023Sp-EQRO-SSI-04	*Assess families' need for case management periodically and provide proactive support* Participants noted appreciation for the case management support they were currently and had previously received from their MCO and other agencies. Families with children with mental healthcare needs can have periods of relative stability followed by high-need times. MCOs should periodically assess a family's need for case management and provide support if needed. In addition, following up with families when a hospitalization or residential treatment has occurred to offer case management support could ease transitions back to community-based providers.

NHHF

Table 11 lists opportunities for improvement to include in the EQRO.01 report for NHHF.

Table 11. EQRO Findings and Recommendations from the Member Qualitative Interview Report for Improvement to Include in the EQRO.01 Report for NHHF

NHHF EQRO Findings/Recommendations for Improvement to be Included in the EQRO.01 Report		
Member Qualitative Interview Report		
1	NHHF-2023Sp-EQRO-SSI-01	*Incentivize current mental healthcare providers to accept Medicaid* Participants reported that the lack of mental healthcare providers who accepted their insurance resulted in delayed care for their children. Finding ways to increase the number of current mental healthcare providers who accept Medicaid may result in reduced waitlists and greater access to care.
2	NHHF-2023Sp-EQRO-SSI-02	*Participate in efforts to create a diverse pipeline of new mental healthcare providers* Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.
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Well Sense

Table 12 lists opportunities for improvement to include in the EQRO.01 report for Well Sense.

Table 12. EQRO Findings and Recommendations for Improvement from the Member Qualitative Interview Report to Include in the EQRO.01 Report for Well Sense

Well Sense EQRO Findings/Recommendations for Improvement to be Included in the EQRO.01 Report		
Member Qualitative Interview Report		
1	WS-2023Sp-EQRO-SSI-01	*Incentivize current mental healthcare providers to accept Medicaid* Participants reported that the lack of mental healthcare providers who accepted their insurance resulted in delayed care for their children. Finding ways to increase the number of current mental healthcare providers who accept Medicaid may result in reduced waitlists and greater access to care.
2	WS-2023Sp-EQRO-SSI-02	*Participate in efforts to create a diverse pipeline of new mental healthcare providers* Participants reported high turnover in providers due to retirements, changing careers, and moving to new practices. Supporting and participating in efforts to create a pipeline for young people to gain training and education to become mental healthcare providers may reduce future pressures on the healthcare network and improve access to care.
3	WS-2023Sp-EQRO-SSI-03	*Provide respite care coverage and access to vetted respite care resources* Participants frequently mentioned the need for respite care. Programs that require beneficiaries to make upfront payments to respite care providers and wait for reimbursement significantly limit access to care for low-income families. In addition, requiring families to find appropriate and safe respite care options without guidance creates an additional burden that can prevent access to care.
4	WS-2023Sp-EQRO-SSI-04	*Assess families' need for case management periodically and provide proactive support* Participants noted appreciation for the case management support they were currently and had previously received from their MCO and other agencies. Families with children with mental healthcare needs can have periods of relative stability followed by high-need times. MCOs should periodically assess a family's need for case management and provide support if needed. In addition, following up with families when a hospitalization or residential treatment has occurred to offer case management support could ease transitions back to community-based providers.

APPENDIX 4. RESEARCH STAFF

Table 13. Research Team

Name/Role	Skills and Expertise
Lisa Horn, MILR *President/Owner, Horn Research LLC*	Ms. Horn has over 20 years of professional consulting experience providing non-profits, academia and government agencies high-quality research and evaluation services. Ms. Horn has expertise in the full scope of research and evaluation activities including project management, outcome modeling, methodology design, data collection, data analysis, data management and report writing. Her skills include organizing public input through a variety of methodologies including surveys, focus groups, round tables, and interviews. She has sub-contracted with HSAG since 2014.