New Hampshire
Medicaid Care Management

MEMBER SEMI-STRUCTURED INTERVIEWS
SUMMARY REPORT
FALL 2024

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Contents

Acknowledgments.....i

Executive Summary.....2

Introduction.....4

Methodology.....*4*

Sample Size and Composition.....4

Participant Recruitment.....4

Data Collection Process.....5

Data Analysis and Validity.....5

Description of Participants.....5

Resources and Support.....*7*

Housing.....7

Food security.....7

Mobility Equipment and Physical Access to Care.....7

Mobility Equipment.....*8*

Prior Authorization Experience.....9

Timing for Receiving Mobility Equipment.....9

Mobility Equipment Repair.....12

Transportation Challenges.....*13*

Experience with Medicaid Transportation.....14

Experience with Physical Access to Providers.....15

Experience with Medicaid Managed Care.....17

Understanding of Health Plan.....*17*

Support from MCO.....*18*

Limits on Care.....*19*

Positive Experiences with MCO.....*21*

Challenging Experiences with MCO.....*22*

Understanding of the MCO Complaint Process.....*23*

Case Management.....*24*

Access to Information.....25

Source of Information.....*25*

Written Information from MCO.....*26*

Internet Access.....*27*

Use of Technology for Communication.....*28*

Quality of Well-Care.....28

Access to Well-Care *29*

Positive Experiences with PCP *30*

Challenging Experiences with PCP *31*

Mental Health Evaluation *32*

Mental Health Recommendations 33

Specialist Care *34*

Medication *35*

Challenges Getting Answers 35

Challenges Getting Medications 36

Additional Comments 38

Recommendations 39

Appendix 1. Recruitment Letter 41

Appendix 2. Interview Guide 42

Appendix 3. MCO-Specific Recommendations for EQRO.01 Report 46

ACNH *46*

NHHF *46*

WellSense *48*

Appendix 4. Research Staff 49

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Executive Summary

The New Hampshire Department of Health and Human Services (DHHS) conducted an independent qualitative study of adults and guardians of children enrolled in the Medicaid Care Management (MCM) Program who had a claim for durable medical equipment for a mobility aid.

Horn Research[1] interviewed 31 individuals between December 18, 2024, and January 10, 2025. The study explored five points of inquiry: Description of Participants, Mobility Equipment and Physical Access to Care, Experience with Medicaid Managed Care, Access to Information, and Quality of Care.

Study participants mirrored the sample population in all demographic characteristics explored, with the exception of young children and older adults being slightly over-represented in the study participants as compared with the total sample. All participants reported having safe housing. A third of participants reported worrying about not having enough food.

Participants used a range of mobility equipment from canes to wheelchairs. Just under half of participants said they use multiple pieces of mobility equipment. Wheelchair users reported extensive wait times for their equipment. Prior authorization, assessments, and manufacturing time all contributed to the delays. Participants said getting repairs for their mobility equipment was equally long and burdensome. Wheelchair users noted the lack of backup mobility equipment exacerbated the challenges associated with both replacement and repair delays. Participants reported poor experiences with the Medicaid transportation program, including late and no-show drivers causing missed appointments. Physical access to healthcare providers was generally easy, but some participants said a lack of wheelchair-accessible parking was a problem. Other challenges to physical access included insufficiently powered chairlifts, exam rooms that are too small to accommodate mobility equipment, a lack of a proper ramp at home, and a lack of wheelchair-accessible scales at healthcare providers offices.

Participants reported sufficient understanding of their health plan and easy access to support from their MCO. About half of participants said they had experienced limits on the types and amount of care they felt they needed, including access to medication, in-home nursing care and respite care, imaging, and specific health care providers. Participants said they like that their insurance covers their healthcare needs, appreciated the MCOs' customer service, ease of use, and access to needed equipment and medication. The most challenging experiences participants reported with their MCO included denials of coverage, a lack of coverage for specific needs, and delays with prior authorization. The vast majority of participants did not have any knowledge of their MCO's complaint process, but felt able to navigate any potential grievances. Case management services were available to nearly half of participants, the bulk of whom reported positive experiences. Participants frequently said their case managers were integral in helping them to access to needed mobility equipment and medication.

Most participants said they contact a medical provider if they have questions about their health. About a quarter of participants reported barriers with information they receive from their MCO. Issues included not comprehending specific wording, delays in receiving information about denials, and documents not being provided in an accessible format. The vast majority of participants said they have access to the internet, but half experience challenges. The primary difficulties identified included problems with connectivity, a lack of technological skills, and cost. About half of participants said they use telehealth to

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

support their access to healthcare, and an equal number use their providers' online portals to facilitate communication.

Participants nearly universally reported access to well care. They appreciated their PCPs' friendly manner, persistence, communication skills, and knowledge. The most frequently noted challenges associated with primary care were a lack of available and timely appointments. The majority of participants said their PCP regularly evaluates their mental health, the bulk of whom said the evaluation *was thorough and helpful. A significant portion of participants said the wait time to access specialist care was a barrier. Most participants did not report any challenges getting their questions about* medications answered. Transportation, prior authorization delays, and formulary rules were the primary challenges participants said they experienced getting their medications. For the most part, participants did not have challenges taking their medications.

Based on the experiences and feedback interview participants reported, the findings from this report generated six recommendations for the MCOs.

Improve access to wheelchairs

Participants who require wheelchairs frequently noted the long wait to receive their equipment. The delays were attributed to prior authorization timelines and denials, pre-authorization assessments, and the time to manufacture their equipment. To ensure timely access to wheelchairs, the MCOs should streamline the prior authorization process, and establish clear communication channels with providers and users. Several participants reported experiencing initial denials and reversals on appeal, which delayed access to critical mobility equipment. MCOs should review historical denial and reversal data to improve initial decision-making. Participants also noted that some denials were due to not having specific language included in the prior approval process. MCOs should improve the support providers receive to complete prior authorization paperwork effectively and minimize delays. Participants said the time it took to get an assessment for the prior authorization was unduly long. MCOs should expand their network of assessment providers to address these delays.

Improve the process for wheelchair repair

Participants noted long waits for wheelchair repair. MCOs should consider eliminating prior authorization requirements for repairs, increasing the reimbursement rates for repairs, providing coverage for preventative maintenance, and consider policies that allow for self-repairs of certain components when appropriate; all while ensuring timely access to necessary repairs for wheelchair users.

Provide adequate backup mobility equipment

Some participants had either no or inadequate backup mobility equipment. MCOs should ensure beneficiaries have appropriate and effective mobility equipment during wait times for initial receipt, replacement, and repair through immediate access to appropriate loaner equipment.

Expand access to case management for vulnerable populations

Participants with case managers reported that the support provided eased their access to needed mobility equipment and medication. People with mobility disabilities are particularly vulnerable to difficulties accessing proper healthcare and equipment. MCOs should consider expanding case management to these vulnerable populations proactively to facilitate access to mobility equipment, medication, and care.

Provide additional support for food security
A significant portion of participants reported frequent concerns about having enough food. MCOs should consider developing additional program supports to ensure beneficiaries have sufficient access to nutritious food. MCOs could facilitate and support beneficiaries to access programs such as Meals on Wheels and Supplemental Nutrition Assistance Program (SNAP), and partner with food pantries and food banks to develop ‘Food as Medicine’ programs.

Provide access to medication through delivery or transportation support
Several participants reported challenges accessing their medications due to transportation challenges. MCOs should support beneficiaries to receive their medication through the mail, delivery services, and/or expanding Medicaid transportation to include trips to pharmacies.

Introduction

To support an external quality review of New Hampshire's MCM Program, Horn Research gathered qualitative data from adults and caregivers of minor children with the following criteria:

- Eligible for Medicaid as of 11/22/24.
- Had a durable medical equipment (DME) claim for an identified mobility aid code between 08/1/23-10/31/24.
- Had either a physical disability code (PHD) or, if under 18, were eligible for Katie Beckett, SSI/SSDI or SMS.
- Not in a nursing home or dually enrolled with Medicare/Medicaid as of 11/22/24.

The sample population included beneficiaries from across New Hampshire. Horn Research conducted telephonic qualitative interviews between December 18, 2024, and January 10, 2025.

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

- Description of Participants
- Mobility Equipment and Physical Access to Care
- Experience with Medicaid Managed Care
- Access to Information
- Quality of Care

Methodology

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

Sample Size and Composition

DHHS provided a population list (N=261) of Medicaid beneficiaries in the MCM Program, who met the sampling criteria. The study sample included all beneficiaries on the population list.

Participant Recruitment

Horn Research sent the initial sample of members a letter (Appendix 1) on December 12, 2024, that explained the project, asked for participation, and offered participants a $50 gift card. Members were encouraged to participate in the study through email and text message. Participants completed the interviews between December 18, 2024, and January 10, 2025.

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 31 interviews out of a goal of 30 interviews. The completed 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 note-taking. The Interview Guide (Appendix 2) directed the conversations to address the Key Points of Inquiry. The interviews lasted approximately 20 to 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 were 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. Still, they should not be assumed to represent the total 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

The facilitator asked participants a series of questions about themselves and the resources available to them.

Demographic Details

Study participants represented all three MCOs at nearly equal rates as the full sample (*Table 1*).

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

County	*Interviewed Participants*		*Sample*
	Number	**Percent**	**Percent**
ACNH	3	10%	8%
NHHF	13	42%	42%
WellSense	15	48%	50%

For beneficiaries under the age of 18, the beneficiary's parent or guardian participated in the interview on their behalf. Half of study participants were guardians of the identified beneficiary (*Table 2*) which was similar to their proportion of the full sample. However, young children and older adults were over-represented in the study participants as compared with the total sample (*Table 3*). The gender of the Medicaid beneficiary was similar between participants and the sample (*Table 4*).

Table 2. Number of Beneficiaries

Age Group	*Interviewed Participants*		*Sample*
	Number	**Percent**	**Percent**
Self	15	48%	54%
Guardian	16	52%	46%

Table 3. Number of Participants and Percent of Population by Age

Age Category	*Interviewed Participants*		*Sample*
	Number	**Percent**	**Percent**
Under 5	5	16%	9%
5-11	6	19%	20%
12-17	4	13%	17%
18-55	5	16%	35%
55-64	10	32%	19%
Mean age	31		28

Table 4. Number of Participants and Percent of Population by Gender

Gender	*Interviewed Participants*		*Sample*
	Number	**Percent**	**Percent**
Female	14	45%	43%
Male	17	55%	58%

Household size ranged from a single person living alone to up to seven in the household (*Table 5*). One beneficiary lived in a rooming house. Half of participants said no children were living in their homes (

Table 6).

Table 5. Number of Participants by the Number of People in the Household

Number in Household	*Interviewed Participants*	
	Number	**Percent**
1/Living Alone	9	29%
2	4	13%
3	7	23%
4	5	16%
5	4	13%
6 +	1	3%
Rooming house	1	3%

Table 6. Number of Participants by the Number of Children in the Household

Number of Children	Interviewed Participants	
	Number	Percent
0	15	48%
1	4	13%
2	7	23%
3	4	13%
5	1	3%

Resources and Support

The interviewer asked participants a series of questions about their housing and food security.

Housing

All participants said they had a safe, stable place to sleep and store their possessions. However, one participant said that the home he had been living in for the past four years was no longer a suitable home for him physically. He said, *"I have my own place, but I'm looking to move. I lost my leg last September. I've been in and out of the hospital every month since then. I have to go up and down steps in this home, and it's not safe for me."*

Participants reported living in their home for an average of six and a half years. Nine participants had lived in their home for two years or fewer, and four had lived in their home for over ten years.

Food security

Twelve participants said that within the past 12 months, they worried about whether their food would run out before they had money to buy more. Half of these participants experienced this very often or all the time. The other half of participants said it occurred occasionally. Seven participants said they received food assistance from a food pantry or other charity. Three other participants said they receive food stamps, though they noted the monthly benefit amount did not cover their needs. One participant said he tries to spread his benefit across the month, and he does not feel he should go to a pantry if he's receiving SNAP benefits. Two participants said they received Meals on Wheels. Two participants said they had received help with food from a service provider.

Mobility Equipment and Physical Access to Care

The facilitator asked participants to describe their experience with obtaining and maintaining mobility equipment as well as any physical barriers they experience in trying to access care. Participants reported using a range of mobility equipment. Participants, particularly wheelchair users, said they had to wait months for their equipment. Prior authorization, assessments, and manufacturing time all contributed to the long wait times. Participants said getting repairs for their mobility equipment was equally long and burdensome. Wheelchair users noted the lack of backup mobility equipment exacerbated the challenges associated with both replacement and repair delays. Participants reported poor experiences with the Medicaid transportation program. Physical access to healthcare providers was generally easy, but some participants said a lack of wheelchair-accessible parking was a problem. Other challenges included insufficiently powered chairlifts, exam rooms that are too small to accommodate mobility equipment, a lack of a proper ramp at home, and a lack of wheelchair-accessible scales at healthcare providers.

Mobility Equipment

All but one participant reported using some sort of mobility equipment. Study participants represented a wide range of equipment needs from those using a cane only and those needing multiple equipment types. One participant who uses only a cane noted that while he could use a wheelchair, his room was not large enough to accommodate one. The largest group of participants (N=12) said they use multiple mobility equipment items, including wheelchairs, walkers, gait trainers, and canes.

Table 7. Number of Participants by the Type of Mobility Equipment Used

Mobility Equipment Used	***Interviewed Participants***	
	Number	**Percent**
Cane only	5	16%
Walker and cane	3	10%
Walker only	1	3%
Adaptive stroller	4	13%
Wheelchair only	5	16%
Multiple equipment needs	12	39%

Twenty-two participants said their MCO had paid for all of their mobility equipment. Six participants said that some pieces of their mobility equipment were paid for by their MCO while other pieces were borrowed, donated, or paid for out-of-pocket. Some participants indicated that higher-level mobility devices were acquired from their MCO. One participant said her insurance had paid for *“just the electric wheelchair. I had to pay for my manual wheelchair, a rollator, and a cane. My church friends helped.”* Another participant who has needed a cane, walker, wheelchair, and knee scooter said, *“I got most of the equipment from lending closets, but I got my wheelchair through NHHF. It's through a rental program. If I have any issues with it, they send the company out. I've had to have the chair switched out a couple of times. I got my knee scooter through my physical therapist.”* One other participant said her MCO had paid for her wheelchair, but initially had denied the walker she needed. She said, *“They wouldn't do a walker when I needed one. My practitioner at the time requested one for me, and they denied it. But it's supposed to be coming now.”* One other participant said that they had to pay out-of-pocket for a wheel cover for her child’s wheelchair, but the chair itself had been covered by the MCO.

Other participants were only provided lower cost mobility equipment by their MCO and had acquired wheelchairs and scooters from friends. One participant said, *“The insurance got me a walker. I had a friend who had a wheelchair, and he got it to me right away, so I never bothered trying to get any assistance with a wheelchair. I also had a cane from my mother, who passed away.”*

Another participant said she had not been able to get all the mobility equipment she felt she needed covered by her insurance, and as a result, she felt unsafe with the equipment she has. She explained, *“My doctor has tried to get a wheelchair or a scooter from insurance, but it's been denied. If they came out to my house and saw me walk, they would give me one. I have an electric wheelchair I use in the world that I got from some lady, but it’s dangerous feeling. I put weights in the back so I don't tip forward. I got it from a friend of a friend. I also have a scooter which I got from a friend. I use a cane to go to my scooter, and I sit because I can't walk very far. My cane and rollator were paid for by insurance. I also need a four-prong cane, but I haven't asked the doctor for it.”* She said not having the proper equipment was stressful for her. She said, *“My balance isn't very good, so I can't really use the rollator. In the wheelchair, I've gotten stuck in the middle of the crosswalk. It just died. We unhooked the* *batteries and set it back up. Also, it doesn't recline. The correct one would be good. With this one, I'm always fearful. I'm also grateful I have it. If I didn't have that, I wouldn't be able to go out."*

One other participant said that she did not have her MCO pay for her walker because she got one from a neighbor. She said, *"Fortunately, the lady on the next floor over gave me one. I couldn't do anything unless I had this walker. [The insurance] would have tried to get me one, but the lady overheard me and brought it over to me. It works well for me. If I need to sit down and take a break because of the stroke, it's good to have."*

One participant did not know who paid for his walker. He said, *"I don't know who paid for it. I just know I didn't pay. I don't know if it was charity or what. I didn't argue with them. I really needed it."*

Prior Authorization Experience

Twenty-two participants said their insurance company had required prior authorization before they received their mobility equipment. The other six participants said they did not recall whether prior authorization was required.

Timing for Receiving Mobility Equipment

Half of participants (N=15) said they did not receive their mobility equipment as soon as they needed it. Seven participants said at least part of the delay was because their MCO initially denied coverage for the equipment, and they had to go through the appeal process. One parent who needed an adaptive stroller for her child said, *"It took way too long to get it. The prior authorization took a really long time. It was denied at first, and so we went through the appeal process. I had a case manager from NHHF help me."* Another parent whose child requires leg braces said, *"I think we fought with the insurance for six months to get the braces. It was all the prior authorization."*

Three participants noted that there were delays in getting the assessments required for the prior authorization. One parent said, *"The biggest delay for the stroller was getting the assessment done. It took probably three months to get the assessment. After that, it happened fairly quickly."*

Wheelchairs were the equipment that was most likely to be delayed. Two-thirds (N=11) of participants who needed a wheelchair (N=17) said they did not get their equipment as soon as they needed it. One parent said, *"It was eight months before we got it. It felt like it took forever. The manufacturing timeline was the longest. The approval came pretty quickly. I don't know who to talk to about getting a bath chair and toilet seat topper. I'm just now understanding that we will need more as she's growing up, and I don't know if it's the physical therapist or pediatrician that I should be talking to."* This parent noted that they were able to get other mobility equipment for her daughter through the physical therapist at her school. She said, *"A gait trainer, a stander, and a mini wheelchair for the bus was provided by physical therapy at school. They also supplied us with a stroller. That's honestly why I haven't had to reach out to insurance. I didn't go through the process of requesting it because she already had it available to her.*

Another parent noted her child's wheelchair took seven months to receive because of a denied prior authorization. She said, *"It was really hard to take him out in public. In the grocery store, he can't sit in the cart because that top belt doesn't go far enough. There are only some that have a special car seat."*

One other parent noted that the wheelchair provider caused delays and challenges with billing. She said, *"It was a delay to get it initially on the vendor's side. He's had the chair now for two years, and it's still a* *hairy, prickly process. It went through, and he was approved for both the chair and the power mechanism. But from my understanding, the power mechanism was not billed in a timely manner and they tried to bill me for the portion of the power piece. To the best of my knowledge, it's still pending."*

Another participant who is paralyzed said she experienced significant delays with the prior authorization, assessment, and manufacture time for her wheelchair. She shared, *"It took a whole two years to get the power wheelchair. I was left in a bed for two years, unable to get out of bed. I was very abused. I thought getting a wheelchair would open up my life, but it really doesn't. I can't leave the house in it. It won't go travel on any flooring other than hard wood flooring. It's very difficult. It made it that I can get out of bed, but I can't even leave the porch. I begged for help, but they wouldn't cover a manual chair. They said I couldn't have both. If I was going to have one, they couldn't give me the other. The first year, they were denying the prior authorizations, and I would have to go back and get another evaluation. And then people were quitting their jobs, and my information wasn't passed along. The assessment is supposed to be the first thing you do, but that kept getting changed because I couldn't get it done. Then, they referred me out to another place in Manchester, and they had a hard time getting out here to do the home evaluation. It seemed like it wasn't very important that I didn't have working legs. Once they did their jobs and did the order, then it was another year for the process of doing the evaluation and getting the measurements done at the hospital and building the chair and getting it to come here. The chair is meant for me size-wise, but it does not have the ability to withstand me. Structurally, it won't last. When I got evaluated, I was told it would have these features that would help me. I put too much stock in that, but then I figured out what it really was. I'm not ungrateful. It's given me a lot of mobility in my room, but I just know it could be better. I see other people with the same insurance that have a lot better equipment, and they can go out in the snow. I see people drive down the road in wheelchairs. It doesn't make sense that I can't."* She noted that she faced significant isolation as a result of the delays in getting her mobility equipment. She said, *"I'm not able to leave home. My life is very depressing, and there's not much quality of life. The only people I see are from church and Meals on Wheels. It's quite a sedentary and quiet, depressing life."*

Another participant said he had significant challenges in getting a wheelchair that fit him and was structurally sound. He said, *"I got the wheelchair while I was still in the hospital going through rehabilitation. I got it two days before I was discharged, but they gave me one that was too big. It took that one falling apart before I got the new one. When I called about getting the right size, I was no longer going to the rehab and I couldn't get a referral for the right one. Once that one broke, they sent out the right one. It took about six or seven months. The new one is brand new. The one I had before was used. It had damage when I got it."*

One participant noted her child's doctor failed to do the prior authorization in a timely fashion, which led to delays getting her son's leg braces, walker, and adaptive stroller. She said, *"The pediatrician's office is the slowest on the planet. They are short-handed. When we were trying to get the medical equipment, I thought I was going to have to go down and do it myself. I have a case manager, and she and I were talking about it for a long time."*

Another participant said his provider also did not fill out the prior authorization paperwork delaying his access to his cane. He said, *"I went to the doctor, and we established that I didn't have the right balance that I needed and my hand wasn't stable enough. I needed the cane. He wrote the prescription, and said I just needed to go to the durable medical equipment facility with the piece of paper, and I'd be able to get the cane right then on the spot. But they said I needed prior authorization. The doctor didn't do any of the things he needed to do. I stayed for three hours getting fitted and I couldn't even get it. It took two* *weeks to get the prior authorization through, and then they didn't even tell me. I called, and they said it went through three days earlier."* He said as a result of the delay he was unable to leave his home. He said, *"I have chronic distal adnexal neuropathy in my left leg. I have no sensation from my thigh to the tip of my toe that comes and goes. I had a lot of issues where I wasn't able to get my stance right. I wasn't able to get out and do the things I needed to do because I didn't have the appropriate equipment."*

One parent said the convoluted process for getting her son's medical equipment has been unduly difficult. She said, *"The problem is there's not enough communication among the different agencies. The doctor, insurance, and vendor all say different things, and I'm stuck trying to translate. We ordered a new gait trainer back in August, and we still haven't seen it. It definitely varies between who is at fault. I think there's very specific wording and verbiage needed for the insurance company to approve something. If something is not specifically included by the doctor, the insurance denies it. There are a lot of runarounds between all of them. In this case of his wheelchair, I believe there is a delay from the manufacturer. It took eight months. And now, it's down and not working. Even just for bolts, we have to go back through the entire approval process with the doctor and insurance before we can get the new parts, which are on back-order. I do find that it's a system issue with all the involved organizations. And there is no support in borrowing equipment. I just bit the bullet and bought a pediatric travel wheelchair, and I will try to fight it on the back end because they can't give me a timeline on that. You never know who to call or who to start with. My son has a case manager, and she's helpful, but she doesn't seem to be equipped with the right information. Or she has different information than what the DME vendor is telling me."*

Another parent had a similar experience and shared, *"It was not the easiest thing. There are a lot of moving parts. With the wheelchair, the physical therapist had to evaluate her needs, the doctor had to do the prior authorization, and then the developmental pediatrician had to get involved. But when they did the wheelchair, they were not thinking of our needs inside the house. My daughter has hypotonia and doesn't have great muscle strength in her stomach. They wanted to deal with the tilt of the wheelchair so she could be out in the world, but this wheelchair is not easy to maneuver inside the house. We can't get it through the doorways. It took about six months to get the chair, but if we have an emergency, it would be bad. She can barely walk now. They said we can't get another wheelchair for five years. She needs a wheelchair to get her from the couch to the bathroom. I'm trying to figure out how to get that piece of equipment. I haven't gone through the process yet. The physical therapist is still trying to figure out what kind would be best given her diagnosis and her decline over the past year. She has some rare things. One is a disease that only 250 people in the world have. They don't know what will come. Some people decline differently. I spoke with the case manager at WellSense who said that because we got the wheelchair last year, the likelihood is not good for another one. She said we could try, but they would want a lot of reasons why, and it could take a lot of time to obtain it. Her walker/rollator got approved rather quickly. It only took a couple of months because it was a different type of mobility device and it's cheaper."* This parent noted the dangers associated with not having the appropriate equipment for her daughter. She said, *"I have multiple sclerosis and my husband has stage IV cancer and a neurological condition caused by the cancer. I can't pick up my daughter. She outweighs me by 70 pounds, and my husband isn't strong enough to pick her up anymore. She can't walk to the bathroom anymore, and she has accidents. She has a swallowing problem and obstructive sleep apnea, so she had to get a hospital bed. The doctor had to submit it three times to get that bed approved."*

Fourteen participants said they had not experienced significant delays in getting their mobility equipment. One parent said her daughter's manual wheelchair had come quickly. She said, *"The wheelchair was custom made, so it took a little longer than normal. She's weaker on one side than the* *other, and they had to attach certain things so it would fit her the way she needs it. It took a little while, but it came. Probably a month at the most."* Another parent noted, *"It's funny because NHHF said you can't get a new stroller for five years. But we have two now. We just got the new one a year ago. For some reason, he got it before five years. We needed it because he grew. When I decided we needed a new one, I wanted to get a basket because he still wears diapers and is on a feeding tube. The girl said they don't usually do that, but we got one! He had one already, so the wait wasn't a problem."*

Mobility Equipment Repair

Thirteen participants said they had their mobility equipment repaired. Eleven of these participants said their MCO had paid for the repairs.

Participants also noted long waits for service. Eight participants said they had to wait too long to receive repair services for their equipment. One parent said the wait time for repairs made it very difficult to allow her daughter to have mobility. She said, *"It took a long time. It was two and a half months without her wheelchair. It's hard for me. I need to push her, and she's heavy. When she's older, I'm not sure if I'm going to be able to help with the manual wheelchair. I'd like her to have an electric wheelchair. We haven't tried to get that yet. It's a long process, and it depends on how old she is and how old the chair is before we can apply for the new one. They will only approve them after a certain number of years."* Participants said there were often significant delays in getting repairs made on mobility equipment. One parent said, *"My son is growing out of his wheelchair. We are waiting to get a new back and seat. We don't need a whole new chair. This was before Christmas, and I haven't heard anything yet. The prior authorization has been submitted."* Another parent indicated the delay was caused by her son's pediatrician. She said, *"We had gotten a larger pair of braces because he grew, and a replacement for the walker because a piece broke off getting on and off the bus. If he tips it backwards, the piece keeps him from falling over backwards. It's sturdy, but it gets beat up. That took a long time, and it was dangerous without having that piece. He did fall backwards, but luckily, I was behind him and caught him. I don't know why it took so long for the repair. The company called me every couple of weeks to update me. I think the problem was the doctor again. It finally got down to them trying to call the doctor to get the prior authorization. I thought they would be able to put the old part back on, but it wouldn't have been safe. It took over two months for something I could have picked up if I had known what to get."*

One parent said in the past, her daughter's wheelchair took a long time to be fixed, but more recently, the repairs had happened more quickly. She said, *"With her first wheelchair, there were a lot of issues. The brakes kept breaking. I was buying bike cables to replace the brakes. It took forever to get brakes for it. This wheelchair she's had now, they've been good about fixing anything that needs repaired."*

Another participant said it took nine months to receive an adaptive piece for her son's wheelchair to accommodate his tracheostomy tube. She indicated that it was a delay on the vendor's supply chain.

One other participant said she was not offered any information on how long it would take to get her wheelchair repaired. She said, *"I'm waiting for them to do something on it. We didn't know what was wrong with it. It stalled at the top of the hill with me on it. I can get a new one next year. They have to make an appointment, and they don't have many people out to come. I'm still waiting to get it repaired after two months. It will drive a little, but it makes a grinding noise. They've had to replace the batteries. I'm doing without right now. They are paying for the repair for the wheelchair, but I'm not kept up-to-date on when it will happen. It's been two months since they were supposed to come out. They haven't given any sense at all of when they are coming to fix it. I'm afraid it's going to break down, so I don't* *want to go far on it. I use my wheelchair more than my walker. I can't use the walker if I'm feeling lightheaded."* This participant noted the impact of not having her wheelchair was substantial. She said, *"I can't do much without it. It's limited my ability to go out into the world."*

Another parent noted that beyond just the time to get equipment repaired, the lack of backup mobility equipment is difficult for her son. She said, *"We are still in the process. The wheelchair has needed ongoing repairs. He has significant involuntary movements, and none of the equipment is made to accommodate his movement. It needs regular maintenance as a result. We just had to put in another order for a lateral support because the metal frame ripped through the pad. That's now happened twice. We ordered the new one a month and a half ago, and we won't see it until January. It has to go through every process. Usually a tech is sent out to us, but it depends on what the item is. The other thing is because my son has different mobility needs, I've been told that insurance should cover a backup piece of equipment in case his current one is broken. They consider his gait trainer as his backup equipment. His old wheelchair is broken and we can't use it. And he can only use the gait trainer for ten minutes at a time. Their definitions are off."* This parent noted that she had paid out-of-pocket for a backup wheelchair and borrowed a pediatric stroller to ensure that her child had access to the equipment he needed. She said the impact of the delay in getting his wheelchair fixed quickly and the lack of a backup option was significant for her son and family. She said, *"It's compounded because he splits his time between me and his dad. He has a lot of transitions with transportation. If you take the wheelchair out of it, it's harder. A friend gave us a pediatric stroller, but it takes away his independence. And now, they're very concerned about atrophy of his muscles. The stroller won't hold up to his needs. It keeps him safe, but limits his access. With his wheelchair, he has access to his classroom and table. The lack of a proper wheelchair has eliminated that access. I would say I'm relatively intelligent, but it's a constant battle, and I see why people fall through the cracks. They give up."*

Three participants said they were currently waiting for the prior authorization to be approved for repairs on their equipment.

Transportation Challenges

Seven participants said they experienced challenges with their transportation getting to their healthcare providers. Three participants said their primary challenges were associated with the Medicaid transportation program not being effective.

One participant said she could not leave her house, in part because she does not have a ramp that will accommodate her wheelchair, but also because public transportation does not come to her location. She said, "*If I had a way to attach my wheelchair to a vehicle, or a ramp that would get it to a car, I could get out into the community. I thought I could do that, but that's not happening. They don't have public transportation that comes out to where I live. I'm just out of the catchment area for public transportation. They have a handicapped bus, just a mile a way, that takes people to Walmart or grocery store. But I can't do that."*

One participant said his car was unreliable. He said, *"My car is not good, and the tires aren't good for the winter, so sometimes, that's a problem."*

Another participant said he does not have a driver's license despite having access to a vehicle. He also noted that public transportation was non-existent in his area. He said, *"I have a vehicle that my mother gave me, but I don't have a driver's license. Previously, I was in Massachusetts, and there was public transportation everywhere. But now, in central New Hampshire, there's not a lot of public transportation* *and not a lot of sidewalks. I rely on family members and medical rides. The good news is I went to a driving school. I just need to get my license. It's a very imperfect system."*

One parent said the primary barrier to transporting her son to healthcare providers was the need for nursing staff to accompany them in the car. She said, *"The challenge is finding nursing staff to get in the back of the car. He needs respiratory and toileting."*

Four other participants said that while they are able to get to their healthcare appointments, they experience transportation challenges in other ways. One participant said the cost of gas created difficulty with transportation for him. Another participant said it was hard to get her wheelchair in the car, and a parent said if there were several people in her car, her daughter's wheelchair had to be broken down to fit properly. One other participant said having to take her daughter to a specific provider covered by the insurance was a challenge because of the distance. She said, *"At first, it was a little bit of a challenge. The insurance was only paying for Dartmouth for her cerebral palsy. It was too far to have continuity of care. That was a challenge, but her neurologist there referred her to the Boston Children's cerebral palsy clinic, which is closer for us."*

Experience with Medicaid Transportation

Twenty-six of the 31 participants said they were aware of the Medicaid transportation program. Nine participants had never used the transportation benefit, seven of whom said they did not need transportation support. One participant who did not know about the program said, *"I didn't know there was any transportation help. That would have been nice today. I have an appointment at 3:30 in Manchester, but I had to cancel because I can't get there."*

> *"They just didn't show up. I can't even deal with them any more. I work with a case manager at NHHF. When I have problems with the transportation, I call and they take care of it. It's been brutal since day one."*

Participants frequently said they received poor service through the Medicaid transportation program. Five participants said they had experienced drivers not showing up despite scheduling the rides appropriately, and one participant said she had experienced a last-minute cancellation by the service. One participant detailed, *"They use MTM and they have the most horrible reputation in the industry. The vendors that provide the rides tend to be the local taxi services. The taxi drivers are just awful. I've had so many bad experiences. They weren't showing up, or they couldn't find me rides. Where I live now is not a huge city. They have three taxi providers in town. The main one that would do most of the rides had a falling out with MTM. So, I had no rides. I had to contact NHHF, and they gave me a liaison between myself and MTM. They put me on a special program called a managed member list. They will call you Lyfts and Ubers. If you have an appointment at 9 AM, they book the Uber or Lyft the previous day. Sometimes, you wake up in the morning and that person has decided not to pick up that ride. Or the morning ride would pick you up, but because there's not enough people that use the service locally, you won't get a return ride. I'd go to the hospital and ring for Lyft and MTM would say there are no rides in the area. It's been very challenging."*

Other participants commented on the impact of late drivers and no-show drivers. One participant shared, *"Recently, the driver called me and said he was ten minutes away, but I only had five minutes to get to the appointment. That was ridiculous. Especially since I had to have a CT scan on my lungs at that appointment. And he no-showed!"* One other participant said, *"I had a very important meeting to see a doctor for diabetes and they canceled. I had to cancel the appointment an hour before."*

Three participants reported customer service challenges with the Medicaid transportation program. One participant shared, "*I've had a couple of times where I've gotten representatives put me on hold and never come back. Other than that, that's the only problem. It seems to be the same person."*

Three participants said the process for obtaining rides or receiving reimbursement was burdensome. One parent said, *"Typically, I don't ask for reimbursement from the CTS because it's not timely and the process is burdensome. It's such a small window to send the information in. You have to call 24-hours before the appointment. It isn't necessarily a smooth process to call, get authorization, and stay on the phone while they call the doctor's office. Financially and fundamentally, it's a great concept, but when you call CTS, they're rude and keep you on the phone too long. Finding time is hard for me."*

Two participants noted that scheduling return trips was difficult. Another parent said, *"I always forget to do the reimbursement. For the rides, you have to do it ahead of time, but you never know how long the appointment is going to be."* Another participant said, *"I used to use it a lot. The only negative I found is that sometimes when they would drop you off at an appointment, they would want to know when to pick you up. And you'd guess, and then you'd sit there for an extra hour waiting for a ride. It's hard when it's very cold out or you have other appointments. My roommate purchased a vehicle, so I'm able to borrow that."*

One participant said the drivers and vehicles were not safe. She said, *"I used it one time, but the car was very old and was not safe for my daughter. I don't want to use it again. The seatbelt was not healthy for my daughter. I went to Boston, and the whole time I had to grab her wheelchair because it was not safe. I said never again. It was scary for me."*

Four participants reported good experiences with the transportation program. One participant said, *"The reimbursement works fine. I paid for the gas, and they reimbursed me ten days later. It works out. I go to so many appointments every week, so it's helpful."* Another participant said, *"I'm thankful for the mileage reimbursement. That's a good thing they do. Her neurologist is in Boston, so that's quite the drive. I haven't had any challenges using it."*

Two participants said they/their child was homebound and could not use the transportation program.

Experience with Physical Access to Providers

Twenty-one participants said they had experienced no challenges physically accessing their providers. Three participants said the distance walking from the parking lot or within a hospital could be a difficult for them. One participant shared, *"When I was using the walker, it could be hard if it was a really long walk. Sometimes, I wish they would have somebody at the hospital to get you in a wheelchair. At the time, I was very heavy. Walking into a gigantic hospital, you might have to walk really far. That's the only time that it was daunting. I was trying to offload pressure on my foot."* Another participant said, *"I used to go to a Manchester facility that was a ranch style hospital building. They closed down, and I had to go to the main hospital with a bad leg. It's a long walk from the parking lot through the hospital. It's a* *quarter mile from your vehicle to where you're going. I think they pretty much tell you to plan ahead. They didn't offer any support with a wheelchair. It was up to me to figure it out."*

Two participants said their healthcare providers' parking lots were not accessible. One parent said, *"Sometimes, the parking lots do not have ramps to the sidewalk."* Another participant said, *"The only challenge is if they don't have wheelchair accessible parking. Like the orthopedic doctor, they only have four spots and it's a major practice. It's too far to walk. You have to get there super early."*

One participant said a clinic's chairlift was not safe or strong enough to carry him with his wheelchair. He said, *"The only place I have an issue is at the methadone clinic. I'm not able to access the interior of the building. They have a chair lift, but it's small, and I'm a bigger guy. One time, I almost fell out. They come out and bring me my medication."*

One parent said her child was homebound due to agoraphobia, but her providers worked closely with her to ensure she had healthcare appointments virtually. She explained, *"My daughter can't leave. WellSense put things in place where they do her appointments virtually. When the doctor needs information, he sends the paramedic out, and he does the exam while on a virtual connection with the doctor. We have visiting nurses that come out. That was pretty easy to obtain. Getting physical therapy was easy. Occupational therapy was easy. We haven't had a lot of issues doing those virtually. It mostly started because my daughter's doctor was on vacation, and his office reported us for medical neglect. The state came and did an investigation. I was angry at first, but I get it. I told them I've had eight encounters with the developmental pediatrician this year, 35 with the primary care, and a lot with Boston Children's Hospital. There was plenty of data showing I was not like that. That's when the team decided to put my daughter in palliative care. No matter what they do, we know our daughter's time is limited because of her diagnosis. There is no test that's going to fix it. It gives her too much anxiety and there is nothing they can do to fix it. The only thing we can do is keep her strength up and doing what she can do. Nothing is going to change anything. We even have connections with Boston Children's Hospital that works virtually. It's been since before the pandemic that she's gone in person."*

One participant said the lack of a proper ramp at her home and insufficient mobility equipment prevented her from leaving her home to get to most of her providers. She said, *"My mom drives me in my vehicle, but it's a challenge. This wheelchair won't go down the ramp I have because it's too steep. It won't move. You can't even put it in a manual mode. They put me in a wagon, and I get down to the ramp so I can get in the car. My mom and my sister's boyfriend take my arms to be safer. I can't transfer with the walker. I have a manual chair I bring with me. It's held together with duct tape, but it gets me in to the clinic. To be pulled out of the car into the wheelchair and into the building was so embarrassing. I'm a big woman. Everyone just thinks I'm fat and lazy. My doctor thinks I'm making choices I don't have to make. I totally get everyone else thinks I can do it, but I have no money, and both of my caregivers have mental illness. It may sound like I'm making excuses, but there are definitely a lot of barriers. I haven't been offered any ideas of what I could do, or what's out there to help me. This ramp came about when it was an emergency. My house did not have a ramp, and I couldn't get in. My dad's friend came here, and he built me this ramp very quickly. He just matched it up to the porch where the stairs were. He built it the way he could, but it's dangerous. If I had money, I could build from the other side, but I can't do that. The only thing I've been told about is the program through the government called Choices for Independences. I applied for that, and I was denied because I refused to say that they could take my home if I died. It's a duplex, and my mom and sister live in the other side. I'm not leaving them homeless and me dead. That's too much for me."*

One parent noted that at times exam rooms were insufficiently sized to accommodate her child's wheelchair and attachments. She also reported a lack of accessible changing tables. She said, *"He has 12 specialists in Boston, and some of the clinics aren't necessarily accessible because of his high complex medical needs. Some of the rooms are smaller and not accessible for a larger stroller with medical equipment. Oftentimes, I end up asking the nurse for something like oxygen hookup if his portable nebulizer runs out or his oxygen runs out. Those are the challenges. Also, not having accessible changing tables is common."*

One other parent said her challenge was primarily a lack of scales that could consistently and accurately record her son's weight. She said, *"Generally speaking, most locations are accessible. What's not accessible are the scales. It depends on the location. It's a big deal because he has a G-tube, and we're needing to monitor his weight closely. We get a completely different number based on where we are. Sometimes, they have a scale for a wheelchair, but we've gotten three different weights for chair. Sometimes, I hold him. Sometimes, they use the infant scale, but it's really inaccurate. As he gets older, this is going to be a problem."*

Experience with Medicaid Managed Care

The facilitator asked participants to describe how well they understood their health plan and their experience of soliciting and receiving support from their MCO. In addition, the facilitator asked them to explain 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. The facilitator asked about whether the participant received case management services from their MCO and to provide an assessment of those services. The bulk of participants said they understand their health insurance plan well enough. Participants generally relied on their insurance company's main number or a case manager to answer their questions. Participants said they like that their insurance covers their healthcare needs, appreciated the customer service provided, ease of use, and access to needed equipment and medication. The most challenging experiences participants reported with their MCO included denials of coverage and a lack of coverage for specific needs and delays with prior authorization. About half of participants said they had experienced limits on the types and amount of care they felt they needed, including access to medication, in-home nursing care and respite care, imaging, and other health care providers. The bulk of participants said they did not know about their MCO's complaint process, but indicated they could figure it out. Nearly half of participants had access to a case manager, the bulk of whom reported positive experiences.

Understanding of Health Plan

Twenty-four participants said they understand the health insurance plan to a degree. One participant said, *"I think I understand OK. I have a lot of people who help me with services. They explain a lot to me."* A parent said her son gets the care he needs, and that is enough information for her. She said, *"He gets what he needs. It's all covered."* One other parent said denials of care can be confusing. She said, *"I understand it until something is not approved, then I don't understand. I get it for the most part. We get the member handbook, and I look through that. Certain components are harder than others, specifically mobility equipment."* One other participant reported not understanding all the rules of his insurance. He said, *"I would say I understand it about 65%. I know all about the All Scripts and prior authorization, but I know there are still billing things I don't understand. Like, how some things need prior authorization, and some don't. And why I can go to one practice for a shoulder injection without prior authorization, but need one for a different provider? Things don't add up."* One other participant said he understands that insurance has paid for his hospital bills. He said, *"They mailed me a handbook, and I've looked through* *some of the things. I really can't answer whether I know it. If I'm sick, I just go to the hospital. I don't worry if there's a bill or not a bill. I used to have employer paid insurance. WellSense has been my insurance since 2020. They have never said no to me. They have paid for 15 inpatient 28-day programs for me. I have a medical care nurse that's personally assigned to me from WellSense. I can call her right now, and she'll call me back the same day."*

Six participants said they did not understand their health insurance plan, but most were unconcerned about the lack of knowledge. One participant shared, *"I don't understand it very well, but I have a case manager who helps me out if I have a problem with anything my daughter needs. She's there, and she's great."* Another parent shared, *"We don't really have a problem with it. They're pretty good at covering what the primary insurance doesn't cover."* One other participant shared, *"I don't understand it very well at all. If I have an issue, I call them. They have been extremely helpful in that respect. I have a lot of trouble with any kind of paperwork."*

One parent reported feeling frustrated by the lack of consistent information about her son's coverage. She said, *"I don't understand it all. I have had problems with it. We are trying to get respite through the Moore Center, and they're saying we need different insurance. But the insurance says we already have the waiver. It's been a big cluster, and I've not been able to get it resolved."*

One parent said she understands the health insurance plan very well. She said, *"I understand it extremely well. There are very excellent parts, and parts that are frustrating."*

Support from MCO

When asked how they get support from their MCO when they have questions, 14 participants said they call the main number on their insurance card. One participant reported, *"I call them and they get back to me within 24-hours. I call the main number, and it connects me to a switchboard. If they don't answer, I can leave a message to relay to them, and they usually get back to me the next day."* Another participant said, *"I call the 800 number. They've always been extremely helpful."* One other participant shared, *"I've called. All Scripts has gotten me to understand them a lot better, but other than that, I haven't gotten much out of WellSense when I've called. They're always calling to offer to help and convince me to do cooking classes, but they don't help with the insurance."*

Thirteen participants said they call their case manager from the MCO when they have questions. One participant said, *"When I was in the hospital, they sent up a transition care manager. She was a liaison between me and the health insurance. She was the one who got me on the list for transportation. They went to bat for me and filed grievances. That was a night and day difference. They also got me a care manager. She was excellent. She would call and check on me. She sent me emails on exercises. I got healthy food boxes delivered to me from NHHF."* Another participant noted, *"I have a care person I reach out to for stuff with my son, like getting the car seat. She's also helped me get diapers. That's who I go to if I have questions."*

One participant said they either call the main number or their case manager. Three participants noted they had often reached out to their case manager, but the case manager had recently stopped contacting them. One participant said, *"Generally, I contact the case manager. I don't know where she went, though. I usually have monthly check-ins with her, but it's been a few months. She's been great when it comes to his prescriptions. It's a special order, but you can't order it until the insurance says so. When it's not in stock, he has to go without it for a few days."*

One participant said she typically speaks with her child's pediatrician, initially. She said, *"I go through his pediatrician's office who goes through the insurance company for me. But I have called the number before and got what I needed as well."*

One parent said she had only contacted her insurance company once by calling the number that was included in a denial letter.

One participant said they call a case manager they have through another organization.

Limits on Care

Sixteen participants said they had not experienced any limits on the types or amounts of care needed. One parent shared, *"He has everything he needs. The school has physical therapy and speech therapy. They're getting him equipment at the school. The bus transportation has the lift, and they pick him up personally. They're going to build a handicapped playground."* One participant said that at one point she thought her son needed additional screenings and was being limited, but it was actually a lack of information from the insurance company. She said, *"I think he's had access to everything he needed. I didn't necessarily understand everything at first. He's missing a large portion of the white matter in his brain. They told me they couldn't stop it from receding. I wanted follow-up MRIs, but you have to wait to see if there's a difference. A beginning explanation would have made it a lot clearer and easy to understand. That's not necessarily anybody's fault. The providers said the insurance wouldn't pay for another MRI for another two years. I asked the case manager, and we figured out it might take that long to see whether there were any changes. I couldn't figure out why I couldn't get more testing for him because there were no details on how often he could get one."*

Five participants reported limits on the types of medications they had access to through their insurance. One participant said, *"Once I got insurance, I found that everything wasn't being covered. I had to change all of my medicine. And only certain doctors see me, and only certain pharmacies take it. That was a big struggle to switch all my medications."* Two participants noted the lack of coverage for weight-loss medications. One participant shared, *"The only thing that I've ever been denied is medicine. I broke my leg, and I put on a lot of weight when I was off my feet. I'm pre-diabetic, and they came out with all these weight-loss drugs. I talked to my physician, and we were going to try to get me on Ozempic, but they denied that. She tried another request for Trulicity, and they agreed to that. I had a weird adverse effect from that. So, I stopped taking it. I decided to try to do it the hard way through diet and exercise, but trying to eat healthy is very expensive. When the prices went high, it made it harder to eat decent foods, like vegetables and fruits. You end up eating cheaper foods, like pastas, and processed foods, rather than something healthy for you. You end up eating what you can afford, and it doesn't help you with your health problems."* Another participant shared her challenges in getting her pain medication. She said, *"I just went to the doctor last week for pain management. She put a prescription in, but she's only in once a week. It's frustrating because I can't get it approved because of the holiday. I called NHHF yesterday to see if they could help get it through. I'm not getting anywhere because it takes time. Every day is a struggle for me. The prior authorization is delayed. The pharmacy had to order it, and it came in, but they're waiting for approval from the insurance company so I can pick it up. It's a new medication and I need it. I've been waiting for six months to get into the doctor, and then I've got this as a setback. I don't know if it's waiting for the doctor or the insurance. That's bothering me a lot right now."*

Three participants said there were limits to their at-home nursing care. One participant said the insurance would only cover three days per week of in-home nursing care instead of the one day he actually needed. One parent said her biggest challenges were around the insurance company's rules for home care. She said, *"Four years ago, it came to head, and we had to fight it. Let's say we had our nights covered, and we had a nurse to pick up an eight-hour or ten-hour shift. That would mean we'd have 18 hours of support in 24 hours, and then the next day it would be 10 hours of care. Rather than looking at authorized hours over the week, they would look at the day. They ended up denying payment to the home care provider. We had to fight it. I told them I would go to court for it after the peer-to-peer denial. They ended up resolving it within a 48-hour period. We've had home care for seven years, and I can't tell the number of hours I've been in an unsafe situation because I couldn't get home care. It might look like I have 18 hours in a day, but you have to look at the week. Staffing home care has been very challenging because of his high medical needs. It's hard to bring in nurses and get them to stay because of his high demands. The rigidity of the rules, and his need for more complex care, has been a barrier for us."* Another participant said, *"I had home health care, but then was told to do an appeal. I didn't think I needed to do the appeal because I had the service. But then it got canceled because of that. I'm fighting right now to get it back in. I need the help."*

One participant reiterated the challenges of accessing respite care and noted she was in the process of getting ABA (Applied Behavior Analysis therapy) approved for her child. She said, *"Just the respite, so far, in terms of limits. He's going to the public preschool, and they say he needs more support. I'm trying to get him into ABA, but the insurance takes a long time to approve it."*

Two participants said their insurance had limited imaging recommended by their provider. One participant had a significant health issue as a result of a denied MRI. She said, *"The doctor recommended some kind of X-ray of my head or something like that, and they denied it. And then, I ended up in Lebanon Hospital having a heart attack and a stroke. At that point, I got the MRI, but if I had it the two or three weeks prior when the doctor wanted, he might have prevented the heart attack and stroke."* One participant said, *"There were a couple of times I needed a CT scan. My pulmonary doctor likes to have me have a CT scan once a year to check for cancer. One time, I think he tried to get another one, but they wouldn't cover that. It was not a problem because I had had one three months later."*

Two participants said their child was denied ABA for their child. One parent said, *"The ABA took a lot of working around. There were only certain ones they were going to allow me to work with. We needed the same ABA person because they started with us, and it needed to be parent-coached or my daughter would have shut down. That was a barrier, and it took months to handle."*

Two participants said they were limited in the amount of care allowed from specific providers. One parent said, *"I've had limits on physical therapy and occupational therapy. Also, her speech therapy was reduced. The occupational therapy was definitely needed. We had to do appeals to get more visits. Sometimes, I feel like I have to be very involved. We don't always get notices from the insurance until the appeal timeframe has gone by. I have to be very on top of it to make sure everyone is on the same page."* Another parent said she would like her insurance to cover social work or case worker support. She said, "*Sometimes, I need more help with my daughter. For example, to help her find a job, or to find more opportunities for her to enjoy, and to get her involved in the community more. I think the kids need that."*

One participant said her child has been limited in the visual equipment he can access through the insurance. She said, *"There's nothing for kids with a TBI (traumatic brain injury). When I have his eyes checked, he needs a specialty person, but I can't find anyone for that. He goes to three different types of therapy, but they don't know what else to do. He needs other equipment. In the school, he has equipment. It would be nice to have it at home so he can practice more."*

Positive Experiences with MCO

Participants were asked to describe the positive experiences they had with their MCO. Participants commonly (N=9) reported liking that their healthcare costs were covered. One parent said, *"For the most part, they're pretty quick with things, except the prior authorization for the leg braces. Aside from that, the authorizations go through within a week or two. They've covered everything. I don't have to pay out-of-pocket for anything."* Another parent said, *"When I found I was having a baby with spina bifida, they took me up to specialty care up in Maine, and they covered it immediately. For his first surgery, they took care of everything. He had emergency brain surgery, and they covered everything."* One other participant shared, *"I love the fact that if I'm sick, I can walk into a MedStop or call my doctor. I don't have to worry about what I'm going to lose trying to pay my bill. It takes so much stress out of your life. Money is very precious. If I didn't have that, I'd be very sick."*

> *"The people who work for them are really excellent and good people with good hearts. They've stuck by me and from what I'm hearing out there, not all health insurance companies do that. They aren't driven by a bottom dollar. They care about their people."*

Seven participants said they liked their MCO's customer service. One participant said, *"I like the fact that I'm not on hold too long and, also, when I called about needing the wheelchair, it wasn't a hard process."* Another participant said, *"They always get back to me as soon as possible with an answer or with a resolution to any issues I do have."*

Four additional participants said they valued the support they received from their case manager. One parent shared, *"The case manager is my favorite thing. Before she was my person, it was difficult and confusing. He has a health plan that I have no paperwork for. Mine, I can pick up my book and look things up. The website is not necessarily my friend either, but I also live in rural New Hampshire with inconsistent internet. I like to have a good old-fashioned book I can go through. I requested one, but I didn't get it. I have bigger problems, so I never think of it until I want it, which is usually 11 o'clock at night."* Another parent said, *"Our case manager is extremely responsive. She helps give information on prior authorizations, denials, and appeals. If I have a barrier to getting medication in a timely manner or the formulary doesn't cover it, she explains why and helps me with the process of getting it approved."* One other participant said, *"I love her case manager. Without her, we wouldn't be able to navigate half of what we have. It offers some good benefits."*

Two participants said they appreciated that their medications were paid for through their insurance. One participant shared, *"They make sure that I'm able to cover my medications. I have HIV, so I'm on two anti-viral medications. Some of my medications are really expensive. I appreciate everything they do."*

One parent said she liked how easy it is to use the health insurance. She said, *"I'd say the ease is what I like best. I really don't feel like I get tons of paperwork or emails. And thus far, the communication has been straightforward."*

> *"I have good access to medication, referrals, and second opinions."*

One parent said she appreciated the availability of equipment for her son through his MCO. She said, *"I feel like things work well when they finally go through. We got the AAC (augmentative and alternative communication) device, and that helped a lot. They helped with diapers, so that helps too. Getting the wheelchair has helped. It costs a couple thousand dollars, and I'd never be able to pay for that out-of-pocket."*

Three participants had only general positive comments about their MCO. One participant simply said, *"I've been very blessed."*

One participant liked that the insurance was based in New Hampshire. She said, *"I like that they're local. I know that the case manager lives in New Hampshire and understands our state."*

Two participants said they liked the rewards available through their MCO. One participant said, *"I like the zero co-pay for prescriptions and the over-the-counter rewards card that they reload over the course of the year that you can use on medical supplies. I think they changed it this year to a VISA card. It says you can use it on utility bills now, so that's cool. If I run low on food, I can use it on that."*

Two participants appreciated the transportation benefit. One participant shared, *"I would say the rides are the best. I have a ride every morning to take me to the methadone clinic. I go every morning, and he's here at 6:00 AM on the dot every day. That's so handy."*

Challenging Experiences with MCO

When asked about their most challenging experiences with their MCO, ten participants said they had experienced no difficulties. One parent said, *"I have not experienced any major problems. I'm sure there are hiccups, as with any other insurance plan out there. But for the most part, I don't think we've had any problems."*

Thirteen participants mentioned the lack of coverage and denials of coverage for specific needs as their primary challenges. One parent said the medical reviewers at her son's MCO were excessively denying equipment and were not following federal rules requiring coverage. She said, *"He has both medical and behavioral complexity. I find the medical reviewers at WellSense are not flexible and deny things that are not covered as part of the plan, rather than responding from an EPSDT (Early and Periodic Screening, Diagnostic, and Treatment) standpoint. They are rigid. I've found that disheartening. They deny things that aren't aligning with the state plan."* Another participant said, *"I just feel like nothing I need is covered, like leg braces and shoes. They won't pay for that because I'm in an electric wheelchair. I still have to be in braces, and the braces require shoes. I just give up. When you're hurt and sick and your body is broken into pieces, and no one is helping you, you can't fight for yourself anymore. I'm done fighting. I don't have it left in me."*

One participant mentioned the lack of coverage for over-the-counter medications as a problem. He said, *"The doctor prescribed me Vitamin D. But AmeriHealth says they won't cover the over-the-counter supplements. Where am I going to magically get the money for that?"*

Another participant reiterated the challenges with denials for imaging and prescriptions. She said, *"The biggest problems were the denial of the MRI and the Ozempic. I have diabetes, and I need it. They sent an explanation that I don't have kidney disease, but that doesn't make sense. I gave it to the doctor who reached out to the insurance, but the doctor said they denied it. The doctor said I should talk to the diabetes doctor. Maybe they will listen to her."*

Eight participants said delays with prior authorization were difficult for them. One parent noted that the amount of effort required to get prior authorization was hard. She said, *“You have to be the squeaky wheel and be proactive to get things to go through.”* Another parent said the wait times and complicated process for approval were a challenge. She said, *“The wait for the wheelchair was a long time. And, we need prior authorization for things like physical therapy. It's a very complicated process to approve. Sometimes, they don't approve the supplies that she needs. For example, she needs the medication to put in her colostomy, but it's not covered.”* One participant noted the delays in approval for medication and imaging were difficult. She said, *“Sometimes, getting medications approved is hard. This afternoon, I have to go to the medical center for a CT scan on my heart. It took two or three months to get it approved. And then, when it came through, it only gave me a week to get it done. I just got the letter last weekend. I called them and told them I need a couple of days' notice because I need to get the Medicaid transportation. The nurse at the scanning place pushed it through for me to make sure I could get the scan.”* Another parent said confusion with prior authorization resulted in a significant challenge getting her child’s prescription. She said, *“I would say prescriptions are one of the biggest frustrations. I ended up having the pharmacy and insurance company telling me to go to an emergency room to get an emergency order because they couldn’t get the prior authorization figured out. I had to pack up my two kids in the car on a Sunday. I get that these individuals are trying to do their job and following policy, but there needs to be a human-first approach. Sometimes, that's lacking, and I know policies drive that.”*

Two participants reiterated their problems with Medicaid transportation as the challenges they had experienced.

One participant mentioned the case manager was a problem for him, initially, but the issues were resolved. He said, *“They just assigned me a new case manager. She came in a little hot. Everyone has a different personality. The other one took a new position, so they sent me a new case manager. There are some nurses who are patient, and some who are no nonsense. If I'm giving her answers, she cuts me off. We rubbed each other wrong for the first few minutes, but we got to know each other better.”*

One parent said getting answers to her questions was the biggest challenge she had experienced. She said, *“Honestly, anything I've ever done, without going through the case manager, has been a struggle. I had to go through person after person to get an answer.”*

Understanding of the MCO Complaint Process

Twenty participants said they knew nothing about their MCO's complaint process. One other participant said, *“I know I can make one, but I haven't needed to, so I don't know much.”*

Six participants said they feel confident in their ability to file a complaint if needed. One participant said, *“I'm pretty sure the information is at the end of every statement I get.”*

> *“I'd call the number on the back of the card. I don't know if there's another way. I'd probably open my book to see what number to call. Like I said, I've never had any negative thing so I've never thought about it.”*

Four participants said they were aware of their MCO’s complaint process. One parent said, *“I haven't used it, but I know about it. I've been such a strong advocate to get our needs met through the process of doing the appeal, getting denied, and the peer-to-peer process. I'm not a parent who takes no for an answer* *when I know it comes under EPSDT law. I have found that, over the years, WellSense is often not compliant with EPSDT. They don't have the urgency to deal with things in a timely manner."* Another parent who had used the complaint process said it had worked fine for her. She said, *"I had to do something. They called it a complaint. For one of the medications she has, I have to give her more if she has a seizure, and I've had to pay out-of-pocket. It was pretty quick. It was within four weeks that I got the reimbursement."* Other participants reported feeling retaliated against as a result of complaining. One participant said, *"My experience with complaints is that you get treated worse. I was nervous about doing this interview, but the confidentiality switched my mind, so hopefully something will change."* One other participant shared, *"The only experience I have with that is the grievances we'd file against transportation. I had a liaison at the health insurance. I would contact and let them know about the no show, and they would file a grievance. That's worked sometimes, but it also got me blacklisted. They retaliate."*

Three participants said they knew about the appeal process, but did not necessarily know about the complaint process. One participant said, *"I know if they deny something, if you want, you can appeal, but that's all I know."*

Case Management

Fourteen participants said they had access to case management services through their MCO. Six others said they had in the past, but the service was discontinued. One of these participants said, *"I liked it because if I couldn't resolve something, I could ask her, and she could do something about it."* One parent said they have a case manager, but had not had any contact or information from the case manager. Three participants said they receive case management support from a different organization. Three participants said they did not know if they had a case manager through their MCO.

Ten participants said they appreciated that their case managers are helpful, particularly in resolving issues with prior authorization and denials of coverage. One parent said, *"She helps to get things through and advises me. If I have questions, she helps me find out the best way to find out the answer to that question if she can't figure it out on her own. I was talking with her about the car seat, and she got the ball rolling and told me to go to the doctor to get the prescription. She is very helpful, as opposed to the toll-free number and having to go through the whole menu. I can just email her or call her. She's very responsive. She'll find out the answer or direct me in the right direction."* Another parent said, *"She calls every month and any issues I have, she helps me resolve. She is the one I spoke to initially about the medication. She told me about the process. She's great."* Another participant shared, *"It's a total gift to have her. She's extremely knowledgeable. Just to give you an idea, I'm not prescribed anything except one medication to help me sleep. When they called in my prescription, my pharmacy said I'd have to pay $74. I called her and gave her the name of the medication. She called me back in 20 minutes. She had done the research and found out the drug was the same, but the manufacturer was different. The manufacturer that WellSense covers was at a different pharmacy in Nashua. If she hadn't told me, I would have gone without. I called the one here in Manchester and it wasn't covered. I'm not sure why it wasn't cross-referenced."*

> *"She's like a unicorn. I wish the other MCOs had the capability to staff her at all of them."*

Four participants said their case manager was responsive and easy to contact. One parent said, *"The case manager is really easy to get a hold of. I have her phone number and email. Usually, she answers me* *within a day. I can't say enough good things about her. She has helped facilitate my daughter getting services. ABA was really hard to get it in place, but she helped facilitate it. The insurance has been pretty good in that respect, especially when you have a case manager on top of things. She even inserted herself into the nutritional supplements issues we were having when they weren't covering it. My daughter has autism, and the swallowing specialist and case manager were the driving force saying this is what has to happen. She was a great advocate, and she made it happen."*

Three participants said their case manager is caring and supportive. One parent said, *"I know that the case manager lives in New Hampshire and understands our state. Oftentimes, when I'm calling the DME companies, I get a call center. The case manager is really supportive and makes me aware of things I didn't know about, like his diapers. I know that I can call her if I need something. She doesn't always have the information, but she's usually OK at getting back to me."*

One parent noted appreciating the case manager was knowledgeable about her son's issues. She said, *"Instead of sitting on hold and getting through to somebody, I can call her. And she knows about him. She cares and knows specific things about him that would be hard to explain to someone else."*

Ten participants said there was nothing they disliked about their case manager. One parent said her son's case manager has been integral in getting equipment for her son. She said, *"Everyone is always asking me how I'm getting all this equipment. A lot of people struggle to get what he is getting."*

One parent said the case manager was lacking information and did not follow-up appropriately. She said, *"I feel the level of education and knowledge is insufficient. I should be able to ask a question, and they should be able to connect with me. And just the follow-up is sometimes lacking, depending on what it is. If she knows, she'll call, but if she doesn't, I won't hear back until I call five times."*

One participant said the turnover in case management staff is a challenge, and another participant said they wished the case manager could resolve their transportation issues. One participant reiterated that his new case manager was not very friendly.

Access to Information

Participants were asked who they contact if they have a question about their health, whether they experience any challenges with written information from their MCO, if they have access to the internet, and their use of technology to support their healthcare. Most participants said they contact a medical provider if they have questions about their health. About a quarter of participants reported barriers with information they receive from their MCO, including not comprehending specific wording, delays in receiving information about denials, and documents not being provided in Braille. The vast majority of participants said they have access to the internet, but half of them said they experience challenges with their internet access, including difficulties with connectivity, a lack of technological skills, and cost. About half of participants said they use telehealth to support their access to healthcare and an equal number use their providers' online portals to facilitate communication.

Source of Information

When asked who they contact when they have a question about their health, the bulk of participants (N=26) said they reach out to a medical provider. PCPs were the most commonly (N=14) reported as the first line of contact. One participant shared, *"I contact my PCP, or I use my hospital app and write to her, so I'm not on hold for an hour."* A parent shared, *"Typically, I would contact our medical home and reach* *out to the PCP. But we also have a team that's staffed from Boston that manages his airway needs. It's a small team with 24/7 staffing. I do the on-call or portal for messages."*

Eight participants said who they contacted would depend on which doctor the issue was related to. One parent said, *"He has so many doctors, so it depends on what's going on. I make the first decision to figure out what's going on, and I'll call the correct doctor."* Another parent shared, *"She has many health problems, and she sees a doctor for each one of them. Neurology, pulmonology, urology, it depends on what my concern is, and I would go to that doctor."*

Two other participants said they would likely contact a nurse at the PCP's practice. One participant said, *"I have a nurse assigned to me from Dartmouth-Hitchcock through my PCP. I can call this woman if I have any questions about how I'm feeling. This summer, I wasn't breathing well after I had been hospitalized. I told the nurse I wasn't feeling well, and she told me I probably had pneumonia and to go to the emergency room."* A parent shared, *"I'll call his doctor's office. There's a nurse there. She knows everybody and is super helpful."*

One parent specifically noted she would contact her child's developmental pediatrician. She said, *"My first person is usually the developmental pediatrician because she's the missing piece to all of it. She's been in my daughter's corner since she was two years old, and she has the most history. She will tell me who to reach out to next and help me navigate where to go. Sometimes, depending on what it is, I might have to reach out to someone different."*

Another parent said she would talk with her child's physical therapist if she had questions. She said, *"I would inquire with her physical therapist. She sees her every week and is in tune with her."*

One parent said she would contact her daughter's case manager. She said, *"I call the case manager for NHHF. They have one lady that has helped me. She answered my questions."*

One participant said her first call would be to her daughter. She said, *"I contact my daughter first. When I have a problem with what I need to get done, like the testing today, my daughter is aware of it and looks it up and explains it to me. For anything else, I call my primary and the nurses call me back."*

Two participants shared that they typically check the internet for information. One participant said, *"Generally, I Google first, followed by my PCP if it's serious. Or my specialists."*

One participant said she didn't know who she would talk to. She said, *"Not every doctor wants to explain things to you. I don't think I have an answer."*

Written Information from MCO

Participants were asked whether they had experienced any barriers to receiving or understanding written communication from their MCO. Two-thirds (N=22) of participants said they did not have any barriers. One parent shared, *"I either get approvals or denials. If I do get a denial, I just call the case manager, and she explains it. Usually, all it needs is a prior authorization. I understand everything else. I get letters all the time, and they all say the same thing."* Another parent said, *"I have no trouble understanding, and it comes to us fine. I do wish they would mail out the member handbooks automatically, so people could have a better sense and not have to go online to get it. They send out a paper notice that says it's available if you call."*

Five participants said they had difficulties understanding the information they receive. One parent said, *"I can read fine, but sometimes I can't comprehend some of the things it's saying. I get support by calling and asking for an explanation."* Another parent said, *"Sometimes, I don't understand it. If it's not highlighted, I don't know if I'm supposed to send it back or not. Sometimes, it just doesn't make any sense."* One other parent said, *"I understand most of the time, but I usually will take it to my parents and ask my mom to explain it to me. Then, I can understand it. They use big words I don't understand."* One participant said their attention deficit disorder made it difficult for them to concentrate and understand what is sent.

> *"It's hard for me to understand a lot of things. I have to take it and let it sink it. I might have to have it interpreted another way. WellSense has been helping me with that."*

One participant noted there were often delays in receiving information about denials of coverage and, at times, the wording was difficult to understand. She said, *"There are delays in getting the letters. Most of it's understandable, but sometimes the denial letters are very confusing. The wordage on why they're denying it can be confusing."*

One participant said the volume of information sent is too much to read. She said, *"I never read it. I get overwhelmed with the packages. I just prefer dealing with the case manager."*

One participant noted her blindness made it impossible to read the information on her own, and that she relies on support to read and understand the documents. She said, *"I find someone with normal eyesight to read it to me. I have a caseworker from another agency that I deal with too. Anything from the state, I can go to her and she can help me."*

Internet Access

The qualitative interviews also explored participants' access to the internet. All but two participants confirmed internet was available to them, but eight participants said they or the person they care for do not use it. (*Table 8*). Nearly all (N=26) participants reported access to the internet through their cell phone. Ten participants said they use a computer, and four participants said they have a tablet. Eleven participants said they accessed the internet through more than one device. One participant said he can access the internet through his voice-activated assistant (Alexa) only, and one other said he has internet access, but does not know how to use the computer.

Table 8. Number and Percent of Participants by Access to the Internet

Regular access to the internet	Number	Percent
Phone	26	84%
Tablet	4	13%
Computer	10	32%
Other	2	6%
Do not have	3	10%

Fourteen people said they had challenges with their online access. Five participants said connectivity was an issue. One participant said, *"We have connectivity issues from being in a rural area. It's not* *constant. I do better in the car and the Walmart parking lot. I've done many Zooms in the parking lot."* Another participant said, *"We lose Wi-Fi frequently at the house due to the rural nature of where we live and power outages. Thankfully, I have a cell plan I can use the data for."*

Four participants said they struggled with having sufficient technology skills to use the internet effectively. One participant said, *"I don't know how to get things from my email. I have to have somebody print it out and fill it out. I don't have a printer either."* Another participant said, *"I don't do a whole lot. I know they have all the websites. I pretty much will go to the main office, and if they have paperwork, I'll do that and bring it there or mail it back."*

Two participants said the cost of internet service could be burdensome. One participant said, *"Once the data runs out, I can't get more. I try to just use it for medical stuff."*

Use of Technology for Communication

When asked what kinds of technology participants used to facilitate communication and access to healthcare providers, 14 participants said they have had good experiences with telehealth. One parent shared, *"We've done telehealth a few times for his Maine providers. They usually do the simple updates over telehealth. Some of his doctors send us right to Portsmouth to get MRIs here."* Another parent said, *"We use the portal and telehealth. Especially with Boston Children's rather than having to go there. We alternate appointments."* Another participant said, *"I've used telehealth. I think it's awesome. I used it during COVID and when I had a broken leg. It was a very good service."*

Fourteen participants said they use their healthcare providers' portals to communicate with doctors with mixed results. Some participants did not have good experiences with the portals. One parent said, *"I use the portal, but sometimes they can be very difficult. My biggest gripe is because my daughter is 16, I couldn't access the portal. That became a huge barrier, and I had to jump through hoops so it could be handled. I talked to both the PCP and the developmental pediatrician to figure out what to do. They each wrote letters on why I needed to access the portal. I feel like that is a huge problem. It's a disconnect for people with children that are developmentally disabled."*

Others had good experiences with their portal. One participant shared, *"I have a portal to send a message right to the doctor, and they get back to me."*

Twelve participants said they do not use any technology. One parent said, *"We go wherever we need to go. I know the speech therapist has a telehealth option, but it's better for him if he's right there. I will do whatever I need to do for the best for him."* One participant said using telehealth was not an option because insurance would not pay for it. Another participant said, *"They have that patient portal, and I haven't been able to figure it out. They say call the helpline, but that doesn't necessarily work. I still haven't been able to get on it."*

Quality of Well-Care

The interview questions included asking study participants to describe the quality of their well-care, including their relationship with their PCP, their access to well-care and specialist care, and their experience with mental health

> *"I use telehealth if the kids have visits in Boston so I don't have to drive there. I definitely use the internet for health related things.*

evaluations. In addition, the facilitator asked participants to describe any challenges they faced in getting and taking their medications as prescribed and how they get information about their medications. Most participants said they had access to a well care exam within the past year and two-thirds said they receive care from their PCP when they need it. Some participants noted they may see another provider in the office or go to urgent care if they were unable to see their PCP. Participants were largely positive in their opinion of their PCP, remarking on their friendly manner, persistence, communication skills, and knowledge. Challenges with PCPs reported by participants included a lack of available and timely appointments, being unsupportive, not understanding specific needs, and not following through effectively. The majority of participants said their PCP regularly evaluates their mental health, the bulk of whom said the evaluation was thorough and helpful. A significant portion of participants said the wait time to access specialist care was a barrier. Most participants did not report any challenges getting their questions about medications answered. Transportation, prior authorization delays, and formulary rules were the primary challenges participants said they had getting their medications. For the most part, participants did not have challenges taking their medications.

Access to Well-Care

Nearly all participants (N=27) said they had a well care exam in the past year. The four participants who had not had a well care exam reported varying reasons for not accessing that care. One participant noted that she is unable to leave her home due to her disability. She said the lack of proper mobility equipment, such as a sturdier wheelchair and ramp, had prevented her access to a well care exam. One other participant said he sees his healthcare providers frequently for blood tests, and is asked about his health then. One other participant said she has not been able to access regular screenings and well care exams due to open wounds and chronic infections. The fourth participant said she does not go for well care exams because they do not seem important. She said, *“When you go to the doctors, they just listen to your heart and lungs and that's it. They don't suggest anything.”*

Twenty-one participants said they generally receive care from their health care provider when they need it. One parent said, *“They take him right in. I can even call on the weekends and they'll call me right back.”* Another parent said, *“They're very good. If she's sick or having issues, they're very good at getting her in, usually the same day or a day later.”* One parent noted her daughter could see the PCP when needed, but specialists were a different matter. She said, *“She has what she needs. Sometimes, she might need a referral to a specialist, and that can take a long time. The rest is OK.”* Another parent noted it could be a challenge if she could not get care when her son needs it. She said, *“It’s tough. It depends on what it is. If it's an emergency thing, the emergency rooms around here struggle to understand his disorder because it's so rare. They don't necessarily listen to what we have to say before they make decisions about his care. But if I need to get him support or help, I can get him there after some frustrations.”* One participant reported being able to get regular care, but often was not able to get sick care when needed.

Five participants said that they can get care when they need it if they are willing to see another doctor in the practice. One parent said, *“I'm fine with her seeing the physician’s assistant or other doctors on staff. If they can get me in, and she's sick, I'm happy with it.”*

Two participants said they frequently go to urgent care rather than their PCP. One parent said, *“If they can't see him, they suggest I take him to urgent care. They give me the option to wait, but I want him to get quick care.”*

Two participants said they were not able to get care when they need it. One participant said, "*There are some delays. The doctor is young and overworked.*" Another participant said, *"I have to wait two months when I ask for an appointment. I went to the emergency room several times. After the emergency room, they will make an appointment for me to see a primary care doctor."*

One participant said she does not go to doctor's appointments as a result of being house-bound.

Positive Experiences with PCP

Interview participants had many positive opinions about their PCPs. Nine participants said their PCP is approachable, friendly, and caring. One parent said, *"She's very personable. She gets down on the kids' eye level. She's fabulous. My kids are relaxed around her. She asks good questions, and she listens to their long answers. She'll answer any questions."* Another parent said, *"She's amazing. I love her to death. She's really good with me and my kids, and she attends to them and their needs. If anything is a concern or there is a need, she goes out of her way to make sure my kids are taken care of. She is amazing."*

Twelve participants said they appreciated that their PCP follows through and is persistent and proactive in determining the best course of action. One participant said, *"She's known me right from the start. She calls me to check in, sometimes, to see how he's doing. She goes out of her way for me and my son. She's clued in for what's going on. PCPs don't usually know much about the brain and spine. They're just the sick doctor. But she can make referrals and she speaks with his neurology team. I told her I thought he had a UTI. She listened to me and did the testing. She takes what I say and talks with the other doctors."* Another parent said, *"I like that anything I call about or send a message about, I get a response really quickly. I wouldn't change her. Any concern, she's right on top of it."* One other parent shared, *"When my son was born, he wasn't a normal baby doing the normal things. The pediatrician advised us to see a genetic doctor. He basically told us we had to go. He was very persistent and straightforward. He also recommended a new specialist when I didn't like the first one. I'll be sad when my son can't see him anymore."*

Nine participants said they liked that their PCP listens to them, communicates clearly, and is attentive to their thoughts and ideas. One parent shared, *"She's the only doctor I've had for him. She's really understanding and listens, and doesn't rush you along. And she is not one to argue when I ask for a referral. She goes with the 'you know your kid best' theory, which is my favorite part."* Another parent said, *"He listens. He actually thinks about my daughter first. He knows that things aren't always going to be done in the fashion he'd like them to happen. He's good at pivoting. He gets back to me in a timely fashion. He's a good doctor. She's one of the patients he's waiting to age out before he retires."*

Seven participants said their PCP is knowledgeable about their conditions. One parent said, *"She really understands him. If I need something, she gets me in contact with what I need for him."* Another participant said, *"I would say she's very thorough. She's new to me, but she's on top of everything. If one of my levels is running high, she will deal with it. A lot of what's going on is obesity related. I have diabetes and issues with my kidneys. When you have that, you have to watch your levels. If my potassium is high, she'll call me and tell me to go to the emergency room. She's very thorough."*

Six participants noted their PCP had been their provider for a long time and knew them well. One parent said, *"He was recommended to us when my son was born. The pediatrician has been with him since he was born. He does his check-ups and follow-ups, and he makes recommendations for specialists. So far, we haven't had any problems with him."* Another participant said, *"She's an extremely nice lady. I feel* *she genuinely cares for me. She cared for me when I was actively doing drugs. I'd make appointments and not show up. She believed in me, and she never harped on me. When I was in the hospital, she was checking on me every week. I didn't realize that until I got out and went to see her. That says something about her as a person."*

Three participants said they appreciated that their PCP was available to provide care. One parent said, *"They're very good. If she's sick or having issues, they're very good at getting her in the same day or a day later. They're very nice, and she explains everything and asks all the questions. She always wants to keep on top of what plans the team at Dartmouth is coming up with."* Another participant said he likes the convenience of the care he receives. He said, *"They come to my place. Not very many doctors do that anymore. It's healthcare for the homeless. They have an outreach program. My daughter also goes through them. They'll go to her place."*

Challenging Experiences with PCP

Two-thirds (N=20) of participants said there was nothing they disliked about their PCP.

Four participants noted challenges with availability to see their provider. One parent said, *"Sometimes, I get a different provider because he's not available. I don't like that. I don't think they understand my child as well."* Another parent noted that in addition to not being available, her son's pediatrician did not always understand her child. She said, *"Sometimes, I don't like how hard it is to get in there for a sick appointment. Also, she's not the best at dealing with his autism and special needs. She doesn't know how to deal with his behaviors that typical kids don't have. Like, having a hard time getting his ears checked, or temperature taken, or blood taken."*

One participant said his biggest challenge is the physical distance between providers. He said, *"I wish they had all my doctors in the same hospital. But my diabetes and kidney doctors are across the street from the hospital, and my primary care is at a totally separate office. When I was at Tufts, everything was within a three-minute walk. I have a prosthetic leg, and it's hard to get around."*

One participant said they felt their provider did not explain very well or respect their opinion. She said, *"I don't invest that much emotion for him. I went to a urologist for the first time in my life. She talked to me and wanted to know who I am. She asked questions about my lifestyle, what I eat, and don't eat. She talked to me like a psychiatrist. She wanted to know her patient. Every doctor should do that. The PCP doesn't talk like that. He doesn't like to answer questions about how I'm going to be in the future with nerve damage and my eyes. He doesn't like to answer questions, and he doesn't like to explain things to me about medicine. Maybe he'll tell me about side effects, if I ask, but he doesn't tell me about my illness or what's going on. I think that he thinks I'm stupid. Maybe it's because of my English skills that he thinks I'm stupid."*

One other participant said her PCP was unsupportive. She said, *"My last hospital stay was for double pneumonia, and my entire leg was infected. I went to her first before going to the emergency room. She didn't even look at me. I said I feel like I'm dying and she said, 'I guess I'll order a chest X-ray and bloodwork'. By the time I got home, I found out I needed to go to the hospital. She thinks I'm a hypochondriac. My pneumonia had not gone away. The doctor at the hospital wanted to know why my PCP wasn't helping me. And then the PCP was mad because she was being reprimanded. She's threatened me that if I won't do the things she wants, she won't be my provider any more. I've only been with her since the car accident. Before that, I was relatively healthy. No one knows what to do with me.*

Maybe I need to go to Boston. There needs to be some kind of plan. I don't feel like anyone is doing anything. I take these pills, and nothing helps."

One participant said the provider speaks too fast. She said, *"She's a go-go-go lady. I'm not sure that's a bad thing. Sometimes, she's fast talking."*

One parent reiterated her concern that the provider was giving too much agency to her daughter. She said, *"I like more information, but here they include the children more. I want to be more involved. I think it's not right that they push for the children to be independent."*

One participant said her provider did not follow through. She said, *"We've been talking about me being tested for ADD (attention deficit disorder) for over a year now, and I'm still waiting to get an appointment. She wants me to go talk to them. She thinks it might be something else. My mom and aunt had Alzheimer's. It runs in the family."*

One participant said the PCP's office was understaffed, which resulted in delays. She said, *"It's a huge office and they only have one person answering the phones. They are much better now than they were six months ago, but, for a while, I wanted to rip my hair out. It's hard to get mad at people who are doing their best, but they didn't get the prior authorizations through in a timely manner. They are always training people."*

One participant said the provider had not adequately documented her child's issues and the care provided, which resulted in a medical neglect complaint. She said, *"He went to part-time hours, and he hadn't conveyed to the staff about my daughter. Things weren't put in her chart about her agoraphobia, or that he had agreed to do virtual visits. That drove the state investigation because it wasn't in the chart. He was out of the office, and she was out of her diabetic medicine with no refills. His office staff said we had to come in. I said we can't. They said I was being medically neglectful and called the state. That was a bad thing."*

Mental Health Evaluation

The facilitator asked participants to describe their experience with their PCP evaluating their emotional health. Twenty-three participants said their PCP regularly evaluates their mental health.

One parent shared, *"She's been really supportive of that. I appreciate that she's having those conversations early. As he hits full-time school, she is talking about how to handle emotions. She's been very supportive. My son can get frustrated if his movements get bad. She's given us options for different therapies and referrals."* Another parent said, *"We just saw her to get a referral. She immediately put in a request for Elliot Behavioral, and they called me right away. She's been having emotional meltdowns. After I had the IEP (Individual Education Plan) team meeting at school, they mentioned reaching out to Boston's cerebral palsy (CP) clinic to find out if there's someone that would be more appropriate for her with CP. It might be better to have that specialized."* Another parent said, *"It is important, especially with her autism and seizures. She does a complete and thorough assessment. She's always on top of everything."* Another participant shared that her discussions with her PCP about mental health are ongoing and integrated into her visits. She said, *"I usually tell her. She knows everything about me. Like I said, she listens and understands me. We've known each other for a long time. She's really good."*

Four parents noted that the evaluation is completed by asking them questions rather than the child. One parent said, *"He has autism. When he was one-and-a-half, I called early intervention, and they started* *working with him."* Another parent said, *"They ask questions about it, but he's not really there yet. He's little."*

Three participants said that while their PCP does a mental health evaluation, it is not thorough or helpful. One parent said, *"It's a really quick questionnaire, and it's not very detailed. It's probably not very effective. It happens only at the once a year visit. We rely more on the developmental pediatrician."* Another participant said, *"I've talked to her about it. My doctor out in Colorado was very upfront and on the ball with that. Maybe that's why I think the doctor I have now is lacking because the other was very on the ball. With the one right now, I have to keep reminding her."*

Eight participants said the PCP does not evaluate their or their child's mental health.

Two parents noted their child was too young to be effectively evaluated. One parent shared, *"It's not really done. He's pretty little, and he has a disability. He's a happy child. He plays with toys and they watch. They used to have someone that made the recommendations for the speech therapy and physical therapy. It was perfect on both counts, but she quit. We know he's developmentally delayed. We're working with him. They're working with him at school. He just started speaking some words in July. Before that, he was non-verbal. He has a tablet to communicate, as well."*

Two participants said they receive their mental health evaluation from mental health care professionals. One parent said, *"He sees specialty care for that. He has a lot of doctors."*

Two participants said that their PCP does not evaluate their mental health, but does monitor their mental health medications. One participant said, *"He'll do a check-in to see how my medications are working with my psychiatrist. We don't really talk about mental health."*

One participant said that while her PCP does not do a formal mental health evaluation, they frequently have conversations about her emotional health. She said, *"She asks me because I told her about my situation here. My boyfriend is a little bit abusive. I told her about that. She asked if I feel safe. I said I just deal with it because it's all I can do. I don't want to see him homeless. He sleeps in the bedroom. I sleep in the living room."*

One participant said she does not talk with her PCP about mental health at all, but believes she needs support. She said, *"There is nothing about mental health. I told them that I needed to see a psychiatrist after the heart attack, but they did not make an appointment. It's up to me. I think they made a referral for me. I wanted to see a psychiatrist because I thought that I would die in the by-pass operation. But right now, I don't need the operation. I'm seeing the heart doctor in April. I think I'm in denial. I'm hoping I won't ever have to have the operation. I don't think I'm strong enough to survive it."*

Mental Health Recommendations

Fifteen participants said their provider had made mental health recommendations. Six participants were referred to counseling. One parent said, "*She sees a psychologist for a therapy once a week."* Another participant said, *"She did some testing for ADD, but now she wants me to go talk to somebody else. I never got any follow-up information on who it was."* Another participant said, *"She recommended I might want somebody to talk to me, but I said I don't need it."*

Four participants were provided with medication. One participant shared, *"I'm on anxiety medication."*

Two participants were referred to both counseling and medication. One participant said, *“I have medications. They have me set up to start going to a mental health facility to see a counselor, but it takes forever to get into those places.”*

Two participants were given referrals to other types of therapy. One parent said, *“We have a few referrals out now. The PCP collaborates with his developmental pediatrician at Dartmouth-Hitchcock. We had done ABA. Now, we have a referral out for physical therapy and hippotherapy.”*

Specialist Care

Sixteen participants said they did not experience any challenges accessing specialist care, and one participant said they had not needed specialist care. One parent shared, *“They're all from the same place. They come together to make it as easy as possible to get appointments on the same day, so I don't have to make multiple trips. They work with me.”* Another participant said, *“I've gotten referrals in the last year to go to neurology, endocrinology, a spinal doctor, and a shoulder doctor. I got an appointment in less than two weeks. For neurology, I got really lucky with that one. I think it was because it was at the end of the year, and people were canceling appointments.”*

In contrast, twelve participants said the wait time for getting specialist care was a barrier. One parent said, *“The doctors are always booked for the next century. He was supposed to have surgery in October. A couple of days before the surgery, the hospital called and said the anesthesiologist team refused to sedate him because he has seizures. The only place that will do it is at Dartmouth, and we're at ground zero with them. They want to do their own evaluation of him.”* Another parent said, *“It was a nine and a half month wait for Boston. But I’m just grateful to have the team.”* One other parent said, *“There's a waiting list for the developmental pediatrician. We had to wait two years to get in, and the doctor has taken random leaves of absence. We have to reschedule appointments frequently. When I've asked to switch doctors, they've told me I can't. I've just had to deal with the changing of appointments.”* Another parent shared, *“My son had an eye surgery in 2020, and there are only two providers in that department to do that surgery. I asked for a second opinion. The PCP had to do three separate referrals because I never got responses from the ophthalmology department. It was disheartening that we had three referrals, and it took two years to get a response.”* One other participant said, *“Sometimes, it's prolonged. The doctor wants me to get different tests done. She'll put it through, and she'll send me to the right doctor. Then, I have to get that approved. It's a process, but it works out. Sometimes, it takes a while. I have to stay on top of it. I have to keep checking up.”*

One parent said there had been challenges getting specialists to agree on a treatment plan. She said, *“I’ve been battling with them for a year, trying to get them on the same page about a procedure that would benefit her. Finally, they are. I told them I felt she needed to be more independent and this would help. They met with the team, discussed their thoughts, and they all got on the same page.”*

> *“He sees several specialists. It can take three months to get in unless there's a cancellation. If we had to get a different provider, then we would have to wait even longer.”*

One parent said it was difficult to get specialists to do virtual visits. She said, *“Because it needs to be virtual, some of that care has been a challenge. She can access the team in Boston. We've been able to keep her GI doctor. There are other specialists that she could use, such as a neurologist, to maintain her seizure medication. For now, her PCP manages* *all her medications. Some specialists can't do telehealth because they can't practice over state lines. The PCP is managing her diabetes, seizure disorder, and genetic disorder. The developmental pediatrician manages her other stuff. She lost her cardiologist and nephrologist because of her limitations."*

Medication

Nearly all (N=28) participants currently take medication.

Eleven participants said they ask their PCP if they have questions about their medications. One participant said, *"I will discuss medicines with my PCP. If it sounds like something good to try, she'll prescribe it. The printout for the medicine always has the information on adverse effects and information on the drugs, and I read that. Sometimes, I'll go online and Google it to see what the internet says about it. I really do care because what I'm putting in my body is already aggravating my skin. I don't want any more hardship."* Two other participants said they would contact the nurse at their PCP.

Ten participants said they ask the doctor who prescribed the medication if they have questions. As one parent noted, *"It depends on who prescribes the medication. I ask the doctor who prescribes."* Another parent agreed. She said, *"Usually, I ask his PCP, but also, some of the other specialists. They sometimes prescribe, and if we have an issue, we'd contact that doctor as well."*

Seven participants said they would ask their pharmacist. One participant said, *"Usually, I ask the pharmacist. When I get a new medication, they talk to me then."*

One participant said she would ask her friend. She said, *"My best friend is a registered nurse at the Veteran's Administration, so I ask her questions."*

One participant said she looks information up online. She said, *"I'm pretty smart. Before this, I was an LNA (licensed nursing assistant) and a medical technician. I have a lot of experience. I go online. I have medical books. I just figure out the answer on my own."*

One parent said she would call the case manager if she was not able to get information from the prescriber or the pharmacy. She said, *"I contact the prescriber and the pharmacy. If I'm having difficulties with approval, the case manager is responsive in getting back to me. If it's not a formulary coverage issue, it's typically Walgreens not billing it correctly."*

One participant said she does not have any questions. She said, *"I have been on them so long, I don't have any questions."*

Challenges Getting Answers

Twenty-three participants said they did not have any challenges getting answers to their questions about medications.

Two participants said they look information up online if they do not have enough information. One participant said, *"Usually, I look online if I don't understand or to see side effects."*

Two participants said they have difficulties with their PCP. One parent said she has to be very proactive in getting her son's PCP's attention. She said, *"When I talk to the doctor and have concerns, I have to really reach out and make sure that they're listening."* One participant said, *"I had an unpleasant* *experience at the primary care office. I wanted her to change a medicine to three times a day instead of twice a day. I was complaining I was having anxiety in the middle of the day, and that I was suffering. She said I had to go to a psychiatrist because it was a psych drug. She said if I don't like it, I can call some other doctor or go to an emergency room. I don't want to go to the emergency room for medicine. I'm not looking for drugs."*

One parent noted that sometimes the answers are not in-depth enough. She said, *"I find a lot of the answers, specifically from the pharmacies, are rehearsed."*

Challenges Getting Medications

Thirteen participants said they did not have any challenges getting their medications.

Six participants said transportation issues made getting their medications a challenge. One participant said public transportation was not very efficient to the pharmacy. He said, *"My challenge is just the distance from me to the pharmacy. That takes a bus ride, and then you have to wait an hour to get back."* One participant mentioned affordability as an issue for getting their medication in addition to transportation issues. He said, *"Affordability is a challenge if it has a co-pay. And transportation getting it is hard. The insurance company only offers rides to and from appointments, not to get your medications."* Two participants with transportation challenges mentioned that their pharmacy would not deliver opiates, which presented difficulties for them. One participant said, *"They deliver to me from the drugstore if I need it, but they don't deliver any kind of opiate. Sometimes, I have transportation difficulties, and I can't get them. My sister lives right around the corner. She helps me out as much as she can."*

Four participants said the prior authorization process presented barriers to getting medications. One parent said her son's pediatrician was the primary barrier. She said, "*The doctor sometimes forgets to send a prior authorization. It's very frustrating. I'm calling back and forth for two weeks. It gets done, eventually."* Another parent said, *"There's always a disconnect when we have to re-do a prescription with a prior authorization. There was a time he went without for two weeks because of problems with the prior authorization. The providers and health insurance don't talk to each other. I have to be the go-between."*

Two participants said their medications were occasionally unavailable. One participant said, *"I have diabetes. When I was taking my weekly medication, Ozempic, they couldn't get it. It was popular. They couldn't get it. I now have a diabetic doctor. He suggested the Mounjaro. They have no problems getting that."*

Two participants said the insurance's formulary rules presented challenges with getting needed medications. One parent said the limit for a 30-day refill was a challenge for getting her son's medications. She said, *"I would say the only thing that gets in the way is they only fill it 30-days a time. Even with auto-refill, I'm waiting for the day insurance will pay for it. It's compounded because he's on so many medications and the pharmacies are overburdened. Many times, I've had to call the pharmacy and say we are out. But they won't have it in stock, and I've had to call around and have the prescription transferred. The 30-day fill is really challenging. I think our barrier is we have a primary insurance plan in place. I have to find a pharmacy that takes our insurance plus WellSense."* Another parent said she had consistent challenges getting with daughter's medications due to formulary limits. She said, *"She has had acid reflux her whole life, and she needs a specific drug for it. The insurance has only wanted to pay for a once-a-day dose, but she needs twice-a-day. We sometimes have to pay and use a Good Rx card.*

That has, historically, been an issue. She also has a skin condition and needs doxycycline prescribed monthly. It's not typically a managed drug because it's an antibiotic. This is something she needs daily and consistently, and they keep denying it. There have been fights about them covering certain medications."

One parent said sometimes the pharmacy does not communicate well with her. She said, *"There have been one or two instances where the pharmacy didn't send the notification. My daughter was without the medication for the whole weekend. They didn't let us know there were no more refills, and it needed prior authorization, which made it take a little longer."*

Challenges Taking Medications

Twenty-one participants said they did not have any challenges taking their medication. Three parents said their child has a G-tube (gastrostomy tube) the medication goes through. Another parent said, *"She's good about it. She's done it her whole life. She started having seizures when she was so young, and she doesn't know anything different."* Other participants (N=5) noted they have a process set-up to remember taking their medications. One participant said, *"I have one of those pill boxes that I set up for the week."*

Two participants said the only challenge they had with their medication was remembering to take them.

One parent noted her son had experienced adverse reactions, and also the insurance did not pay for needed syringes. She said, *"We've definitely had adverse reactions from switching manufacturers. One of them he was on for several years was discontinued. Getting WellSense to cover the replacement from that manufacturer was challenging. We had to contact the prescriber and pharmacy to go over the adverse reactions and have it documented. It was challenging to get WellSense to cover that. The regimen goes ok, but we have occasionally lost doses of the medications. In the past two or three years, the whole system for administering medication has changed to syringes, and that's challenging. There are medications that get lost because of how we're trying to administer it. I've never been able to get the medication syringes covered. I've had to buy them on Amazon. I've heard that from other families."*

One parent said her son had difficulty swallowing his medication. She said, *"It's hard for him to swallow a pill. The way we do it is we use a little bit of applesauce on a spoon, and he can swallow the whole thing."* Another parent said her child did not like the bitter taste of his medication. She said, *"He's four years old, and he doesn't want to take them. There's only one that doesn't taste good. He'll make his opinion known, and then he'll take it."* One other parent said the only challenge was her child being difficult at times.

One participant said she was scared to take some of her medications because of side effects. She said, *"I have a fear of taking some of them. I don't like taking my nighttime medications because I'm a hard sleeper, and I can't hear because I need hearing aids. It's hard to hear anybody knock on the door. My nighttime medicine knocks me out more."*

Additional Comments

The facilitator offered participants the opportunity to provide any additional comments.

Five participants said they were happy with their insurance and health care. One parent said, *"I believe he has everything he needs. I'm satisfied and happy with his care and insurance. I haven't had any problems."*

One parent said she wished there were better services for pediatric vision. She said, *"I wish there were more services for kids that have vision problems. That would be awesome. Providers don't take the insurance."*

One parent appreciated the opportunity to provide feedback and noted the challenges she experienced managing her primary care insurance along with Medicaid managed care. She said, *"I appreciate getting the opportunity to be heard, and it will hopefully make a difference. The biggest challenge we had was when I originally got NHHF for my son. I kept him on my private insurance. It's a lot easier to not do that, but no one told me. Making NHHF his primary was an absolute nightmare. They kept trying to charge my private one. I think it was a mix of both the health care providers and NHHF."*

One parent said she wanted the insurance company to improve the peer-to-peer process. She said, *"I would love to see some improvements to the medical decision making for peer-to-peer reviews at WellSense. It's not timely, and we've run into so many formulary and durable medical equipment coverage issues. Those are the pieces that have been challenging for us. It's not the case management. I love WellSense, but that is the piece that is so time-consuming for me as a parent. I'm doing twenty to thirty hours a week of care coordination to make sure I have everything in my house that I need. The biggest barrier for us has been how the medical providers at WellSense are making decisions and denying even after a peer-to-peer review. The lengthy documentation and back and forth is extremely burdensome on families and doctors. They should honor EPSDT more. There was guidance to recognize that. WellSense needs to do a better job in recognizing that guidance for the institutional patients living in their homes. I would love to be able to give feedback again in the future about the lack of neuropsychologist providers in network. They need to contract with neuropsychologist providers so kids aren't waiting 12 to 24 months for evaluations. There are providers that have a three-month wait list."*

Another parent emphasized the importance of continued telehealth options for her child. She also reiterated the need for better access to both prescribed and over-the-counter medications and durable medical equipment. She said, *"I think it is important for the state to realize that there are people who really need telehealth for a multitude of reasons. It's vital in the life of my daughter to not take that away. Without it, she wouldn't get the care she needs. She would fall through the cracks. She can't even step over the threshold of our house. That's how scared of the outside she is. She's not the only one in the state of New Hampshire who is like that. I hope they keep telehealth in place. Also, they should make it easier to obtain the drugs people need. If the doctor is saying they need it more than once-a-day, they do. Just because it's not the 'norm'. People are not always in the norm. Also, there should be an easier way to obtain DME. If they could make that easier to navigate, it would be better. When someone declines, they may need more and different equipment. Obtaining equipment is critical. Sure, there are reasons for a cap on expenses, but maybe there are reasons why there should be an exception to that cap. Another example is that the insurance will cover only a certain thickener. She needs nutritional supplements and needs a thickener for her food. It's really hard to obtain, and it's expensive. One container is $30, and it lasts a week. That is a huge burden on a family, especially when you can't even* *get it with a co-pay. That's something they should look at. She's not the only person with a swallowing disorder. Most thickeners won't work with nutritional supplements. They need to help families to obtain them. My husband has cancer and needs Boost, but it's not covered. We sometimes have to make the choice between my child's thickener or my husband getting nutrition. They should think about that. I can use xanthan gum for her apple juice, but it won't work in her supplement."*

One participant was happy with his insurance, but took issue with the recertification process through DHHS. He said, *"The health care is very good, but Health and Human Services needs to be fixed. During COVID, you got some extra EBT money. They sent the letter about it two weeks later. The cost of that doesn't make sense. Why send a letter to thousands of people two weeks late? Also, when you re-certify every year, they ask you the same things in triplicate. Why do they need so much information if you're volunteering the information yearly?"*

One participant reiterated her concerns about prior authorization for medications. She said, *"I just want to emphasize the issue of trying to get the approval for the medication so I can go get it. When my doctor gives me a prescription, it has to go through that process. It's frustrating. When you need it, you need it."*

One participant said she likes the reward program available through her MCO.

Recommendations

Based on the experiences and feedback interview participants reported, the findings from this report generated six recommendations for the MCOs.

Improve access to wheelchairs
Participants who require wheelchairs frequently noted the long wait to receive their equipment. The delays were attributed to prior authorization timelines and denials, pre-authorization assessments, and the time to manufacture their equipment. To ensure timely access to wheelchairs, the MCOs should streamline the prior authorization process, and establish clear communication channels with providers and users. Several participants reported experiencing initial denials and reversals on appeal, which delayed access to critical mobility equipment. MCOs should review historical denial and reversal data to improve initial decision-making. Participants also noted that some denials were due to not having specific language included in the prior approval process. MCOs should improve the support providers receive to complete prior authorization paperwork effectively and minimize delays. Participants said the time it took to get an assessment for the prior authorization was unduly long. MCOs should expand their network of assessment providers to address these delays.

Improve the process for wheelchair repair
Participants noted long waits for wheelchair repair. MCOs should consider eliminating prior authorization requirements for repairs, increasing the reimbursement rates for repairs, providing coverage for preventative maintenance, and consider policies that allow for self-repairs of certain components when appropriate; all while ensuring timely access to necessary repairs for wheelchair users.

Provide adequate backup mobility equipment
Some participants had either no or inadequate backup mobility equipment. MCOs should ensure beneficiaries have appropriate and effective mobility equipment during wait times for initial receipt, replacement, and repair through immediate access to appropriate loaner equipment.

Expand access to case management for vulnerable populations
Participants with case managers reported the support provided eased their access to needed mobility equipment and medication. People with mobility disabilities are particularly vulnerable to difficulties accessing proper healthcare and equipment. MCOs should consider expanding case management to these vulnerable populations proactively to facilitate access to mobility equipment, medication, and care.

Provide additional support for food security
A significant portion of participants reported frequent concerns about having enough food. MCOs should consider developing additional program supports to ensure beneficiaries have sufficient access to nutritious food. MCOs could facilitate and support beneficiaries to access programs such as Meals on Wheels and SNAP, and partner with food pantries and food banks to develop ‘Food as Medicine’ programs.

Provide access to medication through delivery or transportation support
Several participants reported challenges accessing their medications due to transportation challenges. MCOs should support beneficiaries to receive their medication through the mail, delivery services, and/or expanding Medicaid transportation to include trips to pharmacies.

Appendix 1. Recruitment Letter

December 2024

Dear Medicaid Member,

The New Hampshire Department of Health and Human Services is asking for your help with a project about New Hampshire Medicaid. The Department hired Horn Research to gather opinions from individuals like you to better understand your experience with your health care and health plan.

We would like to invite you to participate in a **telephone interview** where you can share your experience about your providers 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 **December 2024 – February 2025.** 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 benefits or health care in any way. No one from Medicaid will see your individual answers. Your 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**, text at **(607) 247-0712** 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 PROGRAM
INTERVIEW GUIDE – FALL 2024

Introduction
The goal of this interview is to try to understand your experience with (insert name of MCO) 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 Program. We want to know about your experiences. Your participation will not affect the benefits and services you receive through the Medicaid Program. All the information you provide will be kept completely confidential. At no point will your name or any other identifying information be released.

Thank you for participating in this interview.

I. General information

1. Your current age *(Years)*

2. 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?

3. 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.)

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. Mobility Equipment and Physical Access to Care

1. Do you use/require any equipment to assist you with mobility (e.g. cane, walker, rollator, manual wheelchair, electric wheelchair, scooter)? If so:
   a. Did (insert name of MCO) pay for the (name of equipment)? If yes,
      1. Did (insert name of MCO) require a referral or prior authorization to get (name of equipment)?
      2. Did you get (name of equipment) as quickly as you needed it?
      3. Did (insert name of MCO) pay for repair or replacement services for your (name of equipment) if needed?
      4. Tell me about any barriers you experienced receiving or maintaining this equipment?
   b. If (insert name of MCO) did not pay, were you able to obtain the equipment you needed?

        1. If yes, how did you obtain this equipment (e.g. borrowed, paid out-of-pocket)
        2. If no, what is the impact of not having the equipment you need?

2. Have you experienced any transportation challenges getting to your healthcare provider?
    a. If yes, tell me more about that.
    b. If yes, are you aware of Medicaid transportation assistance?
    c. If you have used Medicaid transportation, have you had any challenges? *For example, not having access to a wheelchair (W/C) van, lift not working properly on the W/C van, etc.*

3. Have you experienced any challenges physically accessing your medical provider? *For example, not having access to a ramp to get into building, not having access to an elevator to get to your provider office, not having access to automatic doors, not having access to a low exam table, etc.*

III. <u>Experience with Medicaid Managed Care</u>

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

2. How do you get help from (insert name of MCO) if you have questions? *(Prompt: Have you had any trouble getting your questions answered? Do you use the member handbook for understanding your health plan?)*

3. Tell me about the access to care such as primary care, behavioral health, physical therapy, you have through (insert name of MCO)?
    a. Have you experienced any limits on the types or amounts of care you feel you have needed?

4. What do you like best about (insert name of MCO)? (prompt: Can you tell me about a good experience you've had?)

5. What are the most challenging experiences you've had with (insert name of MCO)? (prompt: Can you tell me about any problems you've had?)

6. What do you know about (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 health care process in which a medical professional helps the client and their family navigate the health care system by connecting them to healthcare providers, resources, and services so that the client gets appropriate care when they need it. Do you receive case management services from (insert MCO name)? What do you like best about these services? What do you like least about these services?

IV. Access to information & services

1. When you have a question about your health, who do you contact for information?
   Probe: doctor, nurse, pharmacist, community health worker, health plan, other

2. Tell me about any barriers you experienced receiving or understanding written communication from (insert name of MCO)

3. 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? What kinds of technology or apps do you use to help with language or access barriers?)

Next, let's go into some more specific areas related to your recent health care visits.

V. Quality of Care- Well Care (Physical and/or Preventive Screenings)

1. What do you like best about your primary care provider?

2. What do you like least about your primary care provider?

3. Did you receive care as soon as you thought you needed it? If not, please explain why.

4. Have you had a well-exam (physical) in the past year? If no, why not? (i.e. can't get an appointment with your doctor, transportation issue, childcare issue, etc.)
   a. If you didn't have a well exam in the past year, when was your most recent well care exam?

5. Describe your experience with your primary care provider (doctor) evaluating and discussing your mental or emotional health. Did your provider ask you how you are feeling mentally? (i.e. if you are feeling sad, etc.)
   i. Did your doctor make any recommendations?
      i. If yes, tell me about that.

6. If you needed to be seen by a specialist (including Behavioral Health) in the past two years, tell me about your access to that specialist. Did you receive that care as soon as you thought you needed it? If not, please explain why.

7. Do you take medication? (IF NO SKIP TO NEXT SECTION)

8. If yes, how do you get answers to questions about your medications? Who do you ask? What has been difficult about getting answers to your questions about medications
   Probe: Who? (pharmacist, nurse, doctor, care manager, health plan)

9. Are there things that get in the way of getting your medications as prescribed?
   Probe: affordability, transportation, language/communication barriers

10. Are there things that get in the way of you <u>taking</u> your medications as prescribed?
    Probe: difficult/complicated regimen, side effects, difficulty opening pill bottle or pill pack

VI. Final Comments

1. Lastly, is there anything else about your 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 9 lists opportunities for improvement from the Member Qualitative Interview Report to include in the EQRO.01 report for ACNH.

Table 9. 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-2024Fa-EQRO-SSI-01	*Improve access to wheelchairs* Participants who require wheelchairs frequently noted the long wait to receive their equipment. The delays were attributed to prior authorization timelines and denials, pre-authorization assessments, and the time to manufacture their equipment.
2	ACNH-2024Fa-EQRO-SSI-02	*Improve the process for wheelchair repair* Participants noted long waits for wheelchair repair.
3	ACNH-2024Fa-EQRO-SSI-03	*Provide adequate backup mobility equipment* Some participants had either no or inadequate backup mobility equipment.
4	ACNH-2024Fa-EQRO-SSI-04	*Expand access to case management for vulnerable populations* Participants with case managers reported the support provided eased their access to needed mobility equipment and medication. People with mobility disabilities are particularly vulnerable to difficulties accessing proper healthcare and equipment.
5	ACNH-2024Fa-EQRO-SSI-05	*Provide additional support for food security* A significant portion of participants reported frequent concerns about having enough food. MCOs should consider developing additional program supports to ensure beneficiaries have sufficient access to nutritious food. MCOs could facilitate and support beneficiaries to access programs such as Meals on Wheels and SNAP, and partner with food pantries and food banks to develop 'Food as Medicine' programs.
6	ACNH-2024Fa-EQRO-SSI-06	*Provide access to medication through mail, delivery, or transportation support*

NHHF

Table 10 lists opportunities for improvement to include in the EQRO.01 report for NHHF.

Table 10. 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-2024Fa-EQRO-SSI-01	*Improve access to wheelchairs* Participants who require wheelchairs frequently noted the long wait to receive their equipment. The delays were attributed to prior authorization timelines and denials, pre-authorization assessments, and the time to manufacture their equipment.
2	NHHF-2024Fa-EQRO-SSI-02	*Improve the process for wheelchair repair* Participants noted long waits for wheelchair repair.
3	NHHF-2024Fa-EQRO-SSI-03	*Provide adequate backup mobility equipment* Some participants had either no or inadequate backup mobility equipment.
4	NHHF-2024Fa-EQRO-SSI-04	*Expand access to case management for vulnerable populations* Participants with case managers reported the support provided eased their access to needed mobility equipment and medication. People with mobility disabilities are particularly vulnerable to difficulties accessing proper healthcare and equipment.
5	NHHF-2024Fa-EQRO-SSI-05	*Provide additional support for food security* A significant portion of participants reported frequent concerns about having enough food. MCOs should consider developing additional program supports to ensure beneficiaries have sufficient access to nutritious food. MCOs could facilitate and support beneficiaries to access programs such as Meals on Wheels and SNAP, and partner with food pantries and food banks to develop 'Food as Medicine' programs.
6	NHHF-2024Fa-EQRO-SSI-06	*Provide access to medication through mail, delivery, or transportation support*

WellSense

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

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

WellSense EQRO Findings/Recommendations for Improvement to be Included in the EQRO.01 Report		
Member Qualitative Interview Report		
1	WS-2024Fa-EQRO-SSI-01	*Improve access to wheelchairs* Participants who require wheelchairs frequently noted the long wait to receive their equipment. The delays were attributed to prior authorization timelines and denials, pre-authorization assessments, and the time to manufacture their equipment.
2	WS-2024Fa-EQRO-SSI-02	*Improve the process for wheelchair repair* Participants noted long waits for wheelchair repair.
3	WS-2024Fa-EQRO-SSI-03	*Provide adequate backup mobility equipment* Some participants had either no or inadequate backup mobility equipment.
4	WS-2024Fa-EQRO-SSI-04	*Expand access to case management for vulnerable populations* Participants with case managers reported the support provided eased their access to needed mobility equipment and medication. People with mobility disabilities are particularly vulnerable to difficulties accessing proper healthcare and equipment.
5	WS-2024Fa-EQRO-SSI-05	*Provide additional support for food security* A significant portion of participants reported frequent concerns about having enough food. MCOs should consider developing additional program supports to ensure beneficiaries have sufficient access to nutritious food. MCOs could facilitate and support beneficiaries to access programs such as Meals on Wheels and SNAP, and partner with food pantries and food banks to develop 'Food as Medicine' programs.
6	WS-2024Fa-EQRO-SSI-06	*Provide access to medication through mail, delivery, or transportation support*

Appendix 4. Research Staff

Table 12. 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 high-quality research and evaluation services for non-profits, academia, and government agencies. Ms. Horn has expertise in 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 various methodologies, including surveys, focus groups, round tables, and interviews. She has sub-contracted with HSAG since 2014.