

2019

# Medical Home in New Hampshire



A needs assessment conducted by  
the Medical Home Project through  
New Hampshire Family Voices



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## Background

NH Family Voices currently implements a Medical Home Project via contract through the NH Department of Health and Human Services, Special Medical Services, using funds from the Title V Maternal and Child Health Services (MCH) Block Grant.

Each state chooses at least five of fifteen available national performance measures (NPM). NH has chosen access to a medical home, for children with and without special health care needs, as a measure for a number of years. As a result of this focus, Special Medical Services has long supported medical home initiatives.

Historically NH has performed well on surveys, such as the National Survey of Children's Health, on measures regarding medical home. In the 2017-2018 survey, over 47% of children with special health care needs received care in a manner that met the medical home standard on that tool, a full 5% over the nationwide rate.<sup>1</sup> And yet, we knew that there was more to the story than these data points. Through the current Medical Home Project, NH Family Voices conducted a needs assessment in order to inform future activities to further implementation of the medical home concept. NH Family Voices sought to tease out the story behind the data, to determine what is working in New Hampshire, and where opportunities for improvement still exist, particularly for families who have children with special health care needs.

In addition to the individuals who answered surveys or attended focus groups, NH Family Voices owes its gratitude to the members of the Medical Home Project Advisory Committee for their role in the development of the needs assessment process, and to NHTI intern Suzanne Keays, whose willingness to learn and to participate was matched by her professionalism. Their contributions were critical to this endeavor.

## Methodology

Planning for the needs assessment began in May of 2018 with the Medical Home Project Advisory Committee. Members engaged in an activity which resulted in the identification of target audiences for data collection, as well as key questions and recommended methods of outreach for each group. Of note, this activity validated the need for diverse perspectives in advisory groups, with membership representative of the target audiences. During the activity, all non-youth members chose "survey" as a method to reach youth. The youth member emphatically voted against a survey, suggesting a focus group as a much more appropriate way to garner youth feedback.

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<sup>1</sup> Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [04/03/2020] from [www.childhealthdata.org].

As a result of this activity, the following outreach methods were chosen for each target audience:

	Parents	Youth	Providers
Outreach Method(s)	Focus Group / Interviews Survey	Focus Group	Focus Group / Interviews Survey

## PARENT ENGAGEMENT EFFORTS

**Survey:** To develop the parent survey, project staff and intern Suzanne Keays conducted a thorough review of several existing surveys, including the National Survey of Children's Health, Consumer Assessment of Healthcare Providers and Systems Survey, Pediatric Integrated Care Survey for Parents / Guardians Version 1.0, and Family Experiences with Coordination of Care measure set. This effort was undertaken to identify the types of questions routinely asked of families around experiences of care for their children. Once key topic areas were identified and question formats developed, the survey was created in Survey Monkey. A careful review and test were then conducted by members of the Medical Home Project Advisory Committee. Once finalized, the survey was marketed via the NH Family Voices Facebook group, a closed group of over 800 members. In addition, it was emailed to community-based health care coordinators and family support coordinators to share with families. Collection was ongoing during March of 2019. Additional outreach was conducted via NAMI NH to reach families having children with primary behavioral health needs. Participation was incentivized via an offer of fifty gift cards, with one \$50 and forty-nine \$20 gift cards available by drawing.

**Interviews / Focus Groups:** To gather additional parent feedback interviews were conducted with parents remotely via Zoom, and in person through focus groups in the months of March-May and August of 2019. A moderator's script was developed and utilized for both the interviews and focus groups.

As NH Family Voices had never used Zoom in this manner, the first two virtual groups were completed with seasoned parent partners. They were gracious not only in providing the input necessary for the needs assessment, but also in helping us to "work out the bugs" regarding the use of Zoom for this effort. Their feedback resulted in the development of a set of instructions on the use of Zoom, which was sent to all future participants.

NH Family Voices conducted outreach to the family support coordinators with Partners in Health, a program serving children and youth with chronic health conditions, to organize the in person focus groups. Two focus groups were subsequently held at Partners in Health sites to gain access to the perspective of families enrolled in that program.

An additional outreach method was conducted via NAMI NH, in an attempt to reach families whose children had primary behavioral health concerns.

## YOUTH ENGAGEMENT EFFORTS

### Focus Group

Following the recommendation of the youth member of the advisory committee, Medical Home Project staff and intern Suzanne Keays attended the YEAH Council meeting in March of 2019 to gain input from youth. The YEAH Council (Youth for Education, Advocacy and Healthcare) is comprised of youth who experience diverse health care needs. The script designed for use with parents was adapted to allow youth to speak to their own, versus parents speaking to their child's, experiences. While a very small sample, the honest, forthright input of youth to this process proved invaluable, as youth identified different areas of priority than parents.

## PROVIDER ENGAGEMENT EFFORTS

### Focus Groups

Two in person focus groups were held with providers, leveraging existing partnerships. NH Family Voices offered to provide lunch and to host the groups during their existing lunch break. One group was held with staff at a small, private pediatric practice, and another with staff at a larger clinic. Both groups contained professionals having diverse practice roles; physicians, practice managers, nurses, care coordinators and schedulers. Their varied roles allowed for unique insight into how components of the medical home concept were being implemented at their clinic site.

### Survey

In 2008 Special Medical Services conducted a survey of adult primary care providers. The survey included questions to ascertain their comfort with a variety of pediatric onset health conditions. At that time, no survey was conducted of pediatric providers regarding their thoughts on health care transition, or their comfort with said conditions.

Using the previous survey as a basis, new surveys were crafted for both pediatric and adult practitioners as part of this needs assessment. The decision was made to include the questions regarding comfort levels in caring for youth with special health care needs in the pediatric practitioner survey order to compare their response to those of adult practitioners. Additional questions were added to the surveys to address components of medical home, with a focus on access, family-centered care, and care coordination.

As with the parent surveys, the questions were entered into Survey Monkey, and reviewed by the Medical Home Project Advisory Committee. Once edits were complete, committee member Lisa Plotnik, MD wrote an introductory email to accompany the survey link. The survey was distributed via email lists managed by the New Hampshire Medical Society. Respondents to either the adult or pediatric provider survey were entered into a lottery to win one of five \$50 Visa gift cards, with odds doubled for responses received in the first week.

## Results

### PARENTS & CAREGIVERS

123 parents responded to the survey, and an additional 19 participated in focus groups, either virtually or in person. 135 of the 142 respondents provided the town in which they live, allowing us to identify that all but one county (Coos) was represented. The percentage of returns from Carroll, Hillsborough and Merrimack counties was higher than relative population for those counties, and lower in all others.<sup>2</sup>



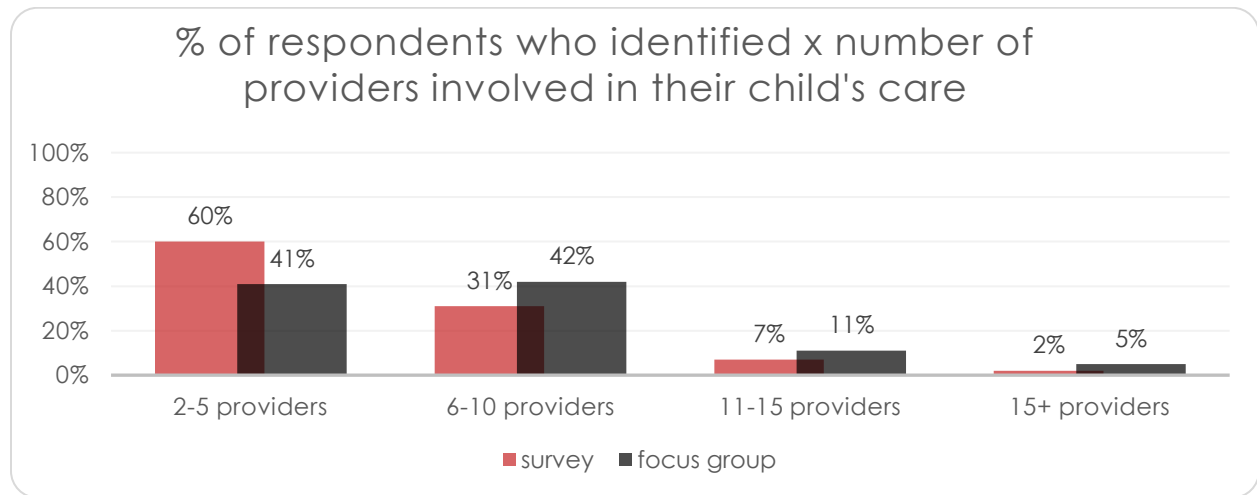
County	% of total responses	% of NH Population
Belknap	2%	4.5%
Carroll	16%	3.6%
Cheshire	3%	5.64%
Coos	0%	2.33%
Grafton	2%	6.62%
Hillsborough	40%	30.61%
Merrimack	17%	11.14%
Rockingham	15%	22.79%
Strafford	4%	9.59%
Sullivan	1%	3.18%

Most of those who provided feedback have children with special health care needs. The strong majority (80%) of survey respondents and *all* of the focus group participants identified that their child has needed or used more medical care, mental health or education services in the past year than is used for most children of the same age. They further identified that their child experienced these needs at varying levels of complexity. Complexity was stratified by the number of providers families stated were involved in their child's care, not through the collection of specific health information.

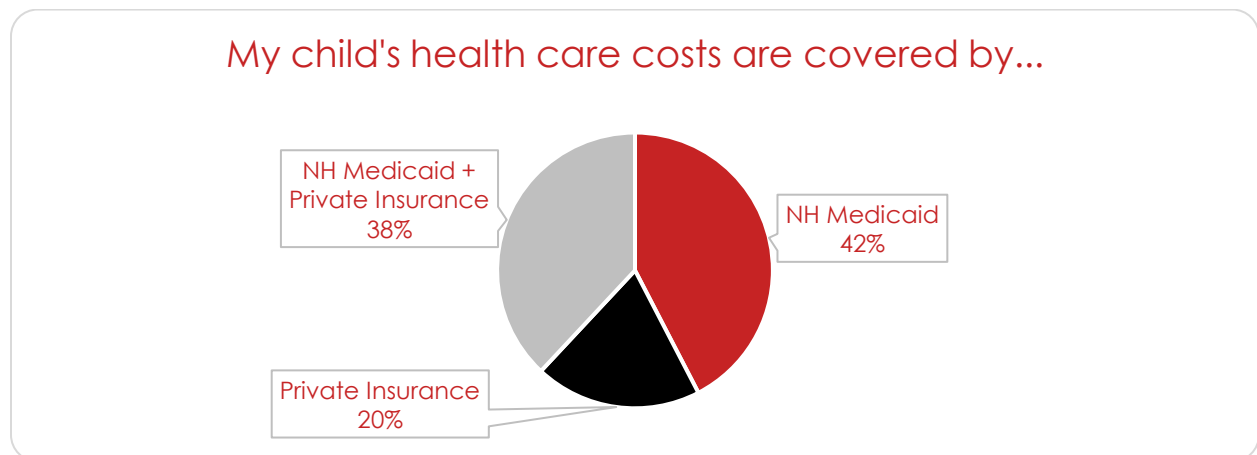
<sup>2</sup> New Hampshire Population. (202-02-17). Retrieved 2020-04-02 from <http://worldpopulationreview.com/states/new-hampshire/>



Given the frequency with which these families interact with the health care system in order to access needed services, their feedback provided valuable insight into how well the system is currently working to meet those needs.



Survey respondents represented a mix of health care financing experiences. All parents identified a source of coverage, with fairly even amounts covered solely by NH Medicaid as were covered by both private insurance and NH Medicaid, and about half as many covered solely by private insurance.



*What did parents and caregivers tell us about their understanding of “medical home” and their experiences with health care?*

Family members remain largely unfamiliar with the term “medical home”. When participants in both the survey and focus groups were asked if they were familiar with the term, only 33% responded “yes”. However, when provided a definition, the majority (61%) felt their child's practice provided care in a manner that met the identified components of a medical home. Interestingly, the families least likely to report being familiar with the term were those who reported their child was covered solely by NH Medicaid (only 23% were familiar).

In contrast, families who reported private insurance coverage only were the most likely to be familiar with the term (47%), but the least likely to identify their child's practice as a medical home (53%).

Families were asked, in both the surveys and focus groups, to provide feedback on a number of key components of the medical home concept; namely **access** to care, **continuity**, **comprehensiveness** and **coordination** of care, as well as **family-centeredness** and **cultural competence**. They were also asked to rate the importance of the individual components. Focus groups allowed for follow up questions, identifying why families rated some components higher than others, or why they felt their child's practice did not meet the definition of a medical home. The key components discussed are utilized as a framework to present data gathered regarding their experiences of care in this report.

### Access to Care

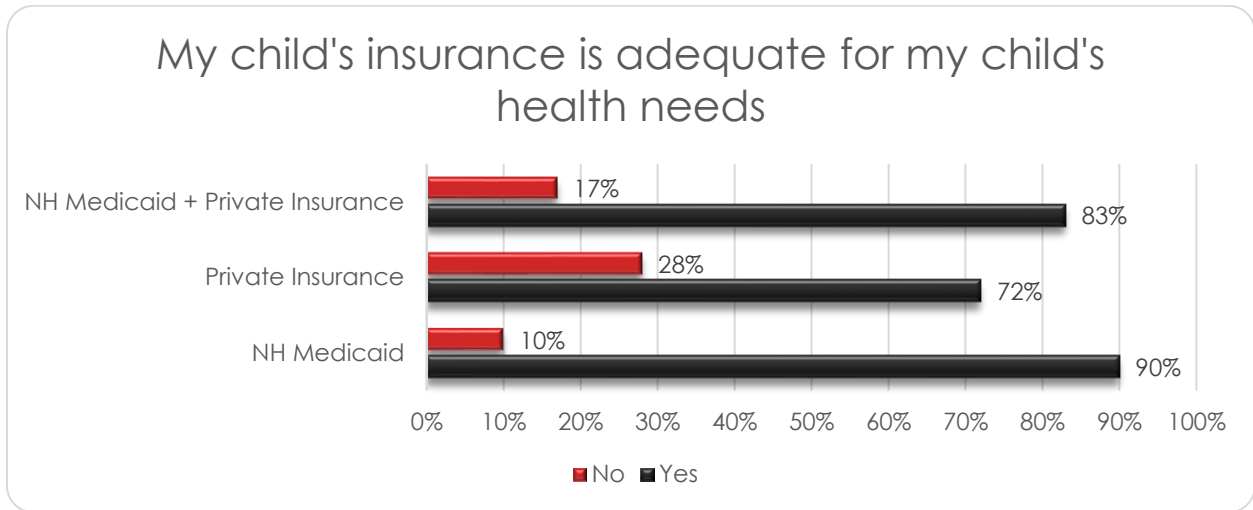
When asked to rank the components of medical home in order of importance, the majority of parents and caregivers rated access, defined as the ease of being seen by a provider, getting an appointment when needed, as most important. Not surprisingly, conversation with focus group participants revealed that ranking was often associated with previous challenges in that area. For example, families who had experienced the most challenges in access ranked it highest, whereas families who had recently struggled with continuity of care ranked that component as most important.

Overall, families identified having providers of record for their child. Nearly all survey respondents (97%) indicated that they had one person they thought of as their child's primary care provider, defined as the provider who knew the most about their child's health and was in charge of their child's care overall. Of these, 96% identified this was their child's provider of routine preventative care, while the remaining 4% identified a specialist. 88% of families said this provider was located within 30 minutes of their home, and most often (73% of the time) practiced in a hospital owned or affiliated practice.

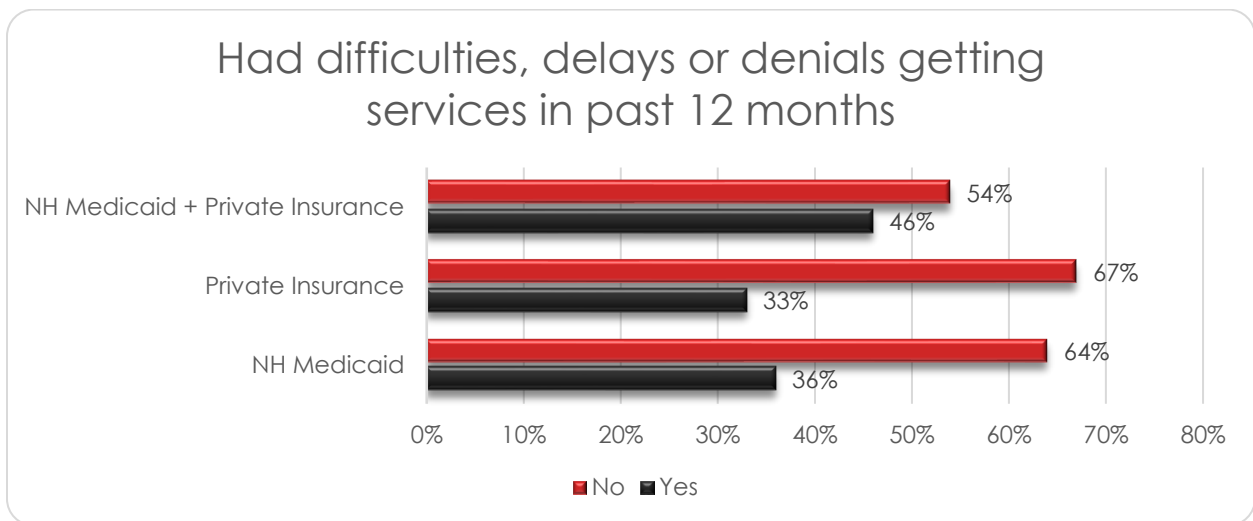
Of note, there were differences in access to primary care providers based on reported health insurance coverage. Children covered solely by NH Medicaid had a primary care provider who was the source of routine care 90% of the time, as compared to 100% of children covered solely by private insurance.

The adequacy of coverage to cover the health care costs for a child is an additional factor impacting access to care. While the majority of families completing the survey identified that insurance was adequate to meet their child's needs, there were differences based on type of coverage.

Families of children covered solely by private insurance were the *least likely* to identify coverage as adequate, while those covered solely by NH Medicaid were most likely to state coverage was adequate.



Between 33% and 46% of families reported difficulties, delays or denials in getting medical or social services for their child in the previous twelve months, with the lowest rate experienced by those with private insurance, and the highest rate in those with both private and NH Medicaid.



28% percent of survey respondents had filed an appeal or grievance, with a notable difference in coverage. Of those who had done so, 13% were covered by NH Medicaid only, 33% covered by private insurance only, and 40% covered by both NH Medicaid and private insurance. One focus group member summed up the experience of working with insurance in this way; "Every day I have an obstacle. I pay out of pocket for something. Every day we choose whether to do battle over payment."

Some additional challenges regarding access were identified during focus group discussions:

- **Access to primary care providers:** Three caregivers shared that their 19-20-year old young adults were without identified providers as a result of provider retirements more than a year ago, and as a result two were without maintenance medications. Another family member shared a struggle locating a provider in the area currently accepting patients. One shared “I feel like a lost ship on the ocean. We are back at square one.” Several participants also cited challenges accessing existing practices via phone. “It is hard to get a call through; you wait and wait and wait.” “There must be a secret code to get to speak to a nurse now. They take a message, and call you back... eventually.”
- **Accessibility:** Families who have children who use a wheelchair expressed concerns regarding accessibility and availability of their child to obtain a comprehensive evaluation during appointments. Families expressed challenges navigating small rooms with wheelchairs, and transferring their child manually to an exam table well beyond when it was safe or comfortable for them to do so due to the lack of available lifts. One parent shared this concern was the primary reason for changing practices, and that her child now receives care in a practice where this is not an issue.
- **Variable access to practice – use of walk-in or urgent care:** While many families identified that extended hours were available at their practice, they also reported using walk in or urgent care locations to meet their child’s health care needs. Some expressed that they were directed to do so, even during office hours. Others shared they had chosen to go in order to get care in the time frame they felt was needed, or for matters of convenience or reduced cost. One family reported that extended hours were no longer available at her practice, as a walk-in clinic had been developed in the same hospital system. Four families (from three separate areas in the state) shared experiences of using walk-in clinics within their same hospital system, where the providers had access to their child’s health information. Two shared frustration that providers didn’t read it, while a third excitedly exclaimed “They not only had her information, they READ IT.”
- **Access to specialists:** Multiple families cited challenges accessing specialists, specifically citing long wait times. One parent commented “I better not forget to make an appointment, or she might not get one for nine months.”
- **Some limitations regarding the use of telehealth:** While families appreciated the use of telehealth both for the improved access to specialists and the reduced travel it afforded, one family cited concerns about the inability to access visit notes from a telehealth visit in the patient portal, another cited concerns posed by the inability to do some of the same functions via telehealth if the same equipment was not available at the originating site.

## Continuity of Care

Continuity of care, which was defined as being able to see the same provider at each visit, was the component families identified as most important to them following access to care. One participant commented "It is better to wait months for a well child visit than to see a provider sooner who doesn't know your child." While the majority of families identified that a consistent provider had been available for well child visits, one focus group participant stated that at their child's practice, it is the norm to see a different provider all the time, regardless of visit type.

Families did recognize that it wasn't always possible to see the same provider for a sick visit, but felt strongly that the provider who saw their child should know their child. Focus group participants shared examples where this was happening;

- "I was really nervous when she was little, but the providers read her chart, they were knowledgeable, friendly. We have now seen all the doctors at least once, but we usually see the primary care doctor."
- "They all brief themselves ahead of time. I never have to tell the whole story."
- "I think as far as well child and sick visits, I wanted her primary care provider most of the time. But if another walked in, and I know her primary care provider signed off, I was comfortable. Being able to message her primary care provider, is a new kind of access; it makes seeing someone different easier if I have to."
- A parent of a child with complex needs described the process of selecting a new provider when their child's previous pediatrician left the area. Their confidence in the practice they chose was further enhanced by the new provider proactively discussing their daughter with other providers over a working lunch, to be sure that anyone who saw her was familiar with her needs.

And also provided examples of where it was not;

- "They don't read the chart, I am left to tell the story, while my son tears the room apart."
- "I can't tell the whole story; it sets my daughter off. If they don't read it, they don't know, they see her as defiant, when it is anxiety."
- "When providers don't know my kid, I end up at specialist appointments when they are not needed."

While the survey and focus groups defined continuity of care as access to the same provider, the process of health care transition impacts continuity of care in a broader sense. The need for a health care transition to occur to an adult provider of care is a reality for youth whose medical home is a pediatric practice. Whether this transition occurs in a planned manner or not impacts a youth's likelihood to access care in a continuous manner, without a gap in needed services. In NH, survey responses and national data both reflect there is room for improvement in this area.

In our survey, 61% of respondents identified that their child's primary care provider is in a practice that only provides care for children.

Of the 46% who identified that their child was at least 14 years of age, only 22% reported having discussions of how or when transition to an adult provider would occur. This is consistent with the 2017-2018 National Survey of Children's Health data for NH, which identified that 21.5% of children with special health care needs received services necessary for transition (defined as having time alone with a provider, a conversation of the transition to occur, and actively working to address needed skills).<sup>3</sup> At the time of this needs assessment activities were occurring across all Dartmouth-Hitchcock primary care practices to develop a universal process to address health care transition. Efforts were also occurring within populations served by NH's Title V Agency for children and youth with special health care needs, Special Medical Services to engage families in conversations regarding health care transition and to assess youth readiness. These activities will hopefully impact this measure in future surveys.

Four of the nineteen focus group participants identified that health care transition was being addressed in some way within their child's practice, with one identifying a clear process and efforts to engage her teen in building skills to manage her own care. One participant cited the work being done within the Partners in Health and Special Medical Services programs as the only transition preparation they had experienced.

In addition, focus group participants shared challenges, and missed opportunities regarding health care transition. Three families, previously referenced in the report, identified that their young adults were currently without identified providers, two due to the retirement of two different providers. All three young adults were currently experiencing gaps in care, and two were without maintenance medications. One family shared that they could not locate adult specialty providers that would provide care for a patient with her daughter's profile. These experiences provide examples of what happens when a planned transition fails to occur. Families shared the following comments;

- "Biggest gap in transition is that there is no connection between the person who cared for my child her whole life and knows her so well and the new provider."  
(Parent whose child had recently transitioned to adult care provider)
- "We didn't want to talk about it" (so the conversation didn't happen)
- "They (practice) can't keep up with affordable health care, how to navigate insurance, navigate the health care system. How can they help with transition to adult care?"
- "There is a lot going on at once. Transitioning medical. Transition at school. I am more worried about the specialists. Our pediatric office is working on primary care."

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<sup>3</sup> Child and Adolescent Health Measurement Initiative. 2017-2018 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [04/03/2020] from [www.childhealthdata.org].

It is important to note that preparation to depart a pediatric practice is only one part of the health care transition story. The effort to complete a successful transition of a youth with special health care needs is sometimes further complicated by the challenge in locating an adult health care provider who is comfortable taking on their care. Adult providers were surveyed as part of this needs assessment, and those responses are detailed in a later section of this report.

## Comprehensiveness of Care

This component was defined as having one provider manage and coordinate care, through a whole patient approach. This component was chosen as most important by only 4% of survey respondents, but received the highest number of #1 ratings among focus group participants (26%).

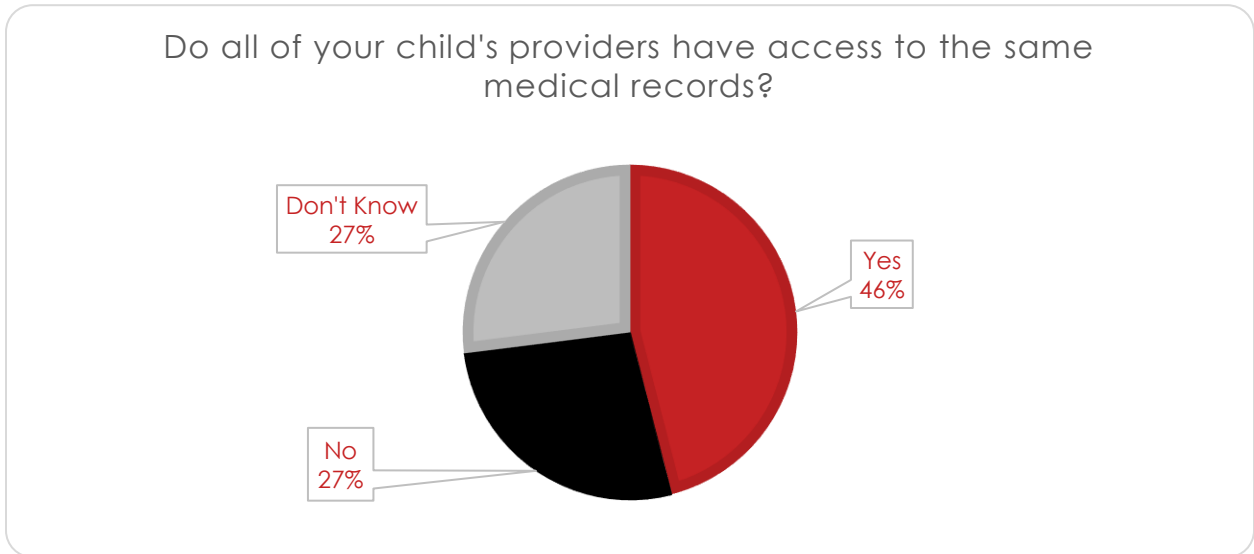
While some focus group participants felt providers treated their child in a holistic manner, such as asking about behavioral health and educational needs, others shared different experiences.

- "Visits are focused on the issue of the visit, not centered on my daughter as a whole patient."
- "They don't ask about my granddaughter's behavioral health needs, or about the side effects of any medication. They confirm the medications she is on. That's the closest they get to discussing behavioral health."
- "Comprehensive? That's a great idea. I've never experienced it."

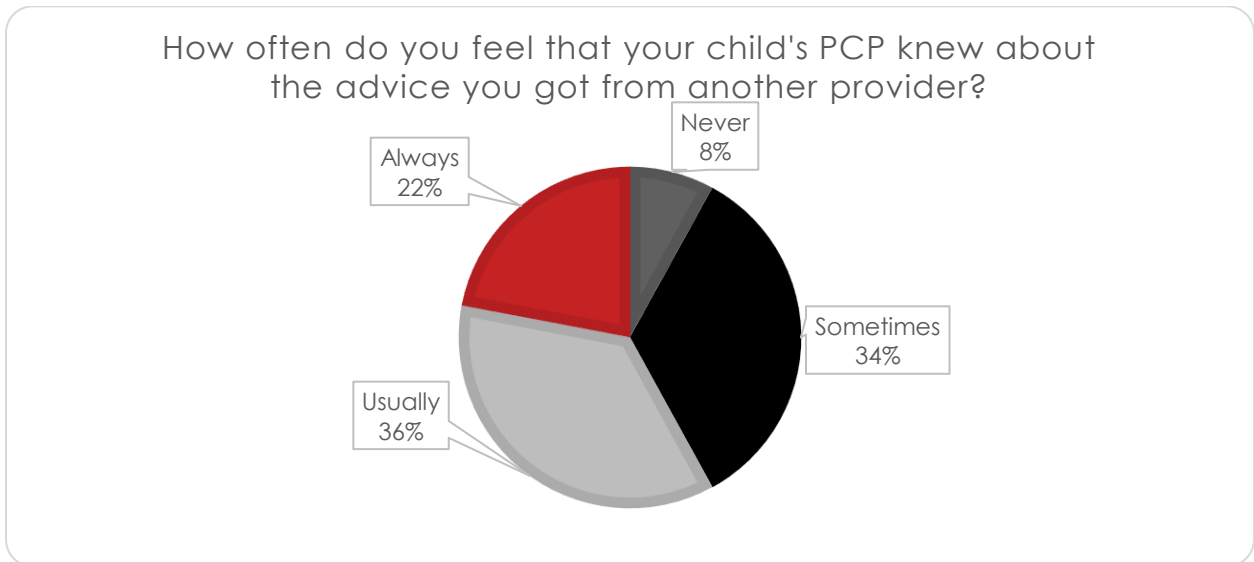
Of note, focus group participants who felt their child's practice *did not* meet the definition of a medical home more often cited communication challenges as the reason, not access or coordination, as we may have anticipated. This was not something that would have been clear in reviewing the survey data.

Families' comments during focus groups regarding this component often focused on whether providers had access to the information that would allow for care to be provided in a comprehensive manner. There was a recognition that while access to electronic health records *should* eliminate this information barrier, the experiences they shared suggested otherwise.

Survey responses indicated that less than half of parents were aware if their child's providers had access to the same medical records.

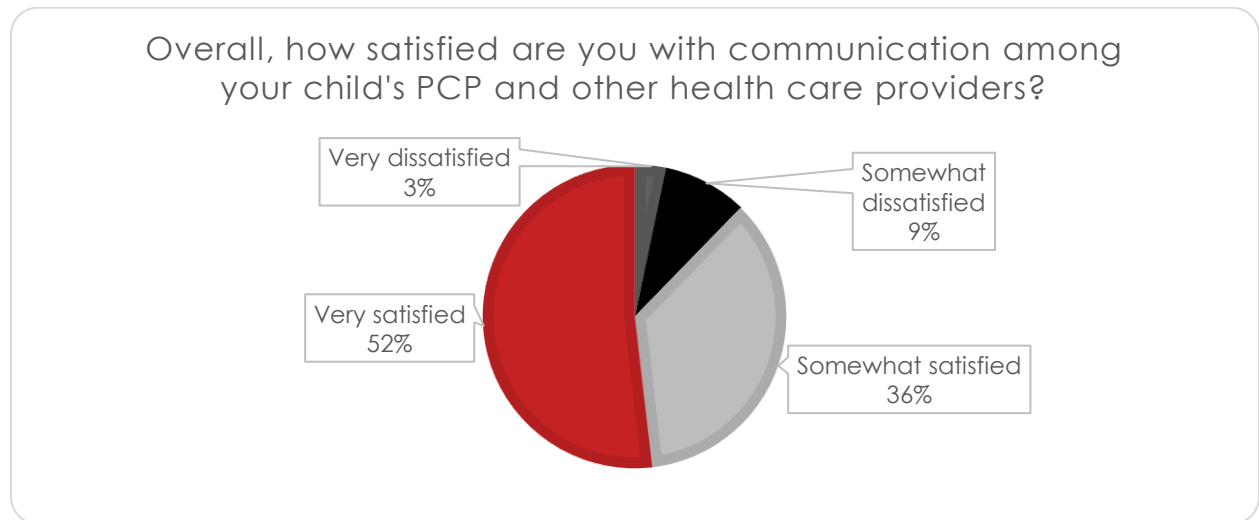


Regardless of whether providers shared access to medical records, families were asked how often they felt their child's primary care provider was aware of recommendations they had been given by another provider.

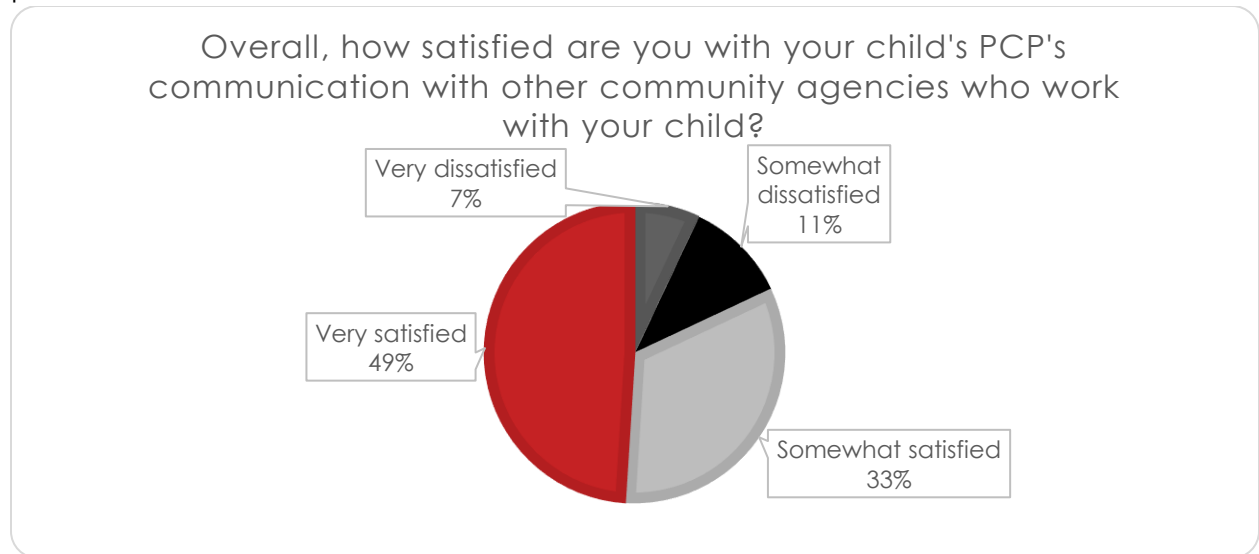




Families were also asked to identify their overall satisfaction with communication between their child's primary care provider and other health care providers. Over half are very satisfied, and all but 12% were at least somewhat satisfied.



Survey respondents were also asked how satisfied they were with communication between their child's primary care provider and other community agencies that work with their child. For those for whom this was applicable, families were a bit less satisfied with this communication than they were with communication among health care providers.



While survey data suggests that most families are at least somewhat satisfied with communication, focus group participants provided clear examples of what experiences led them to feel otherwise.

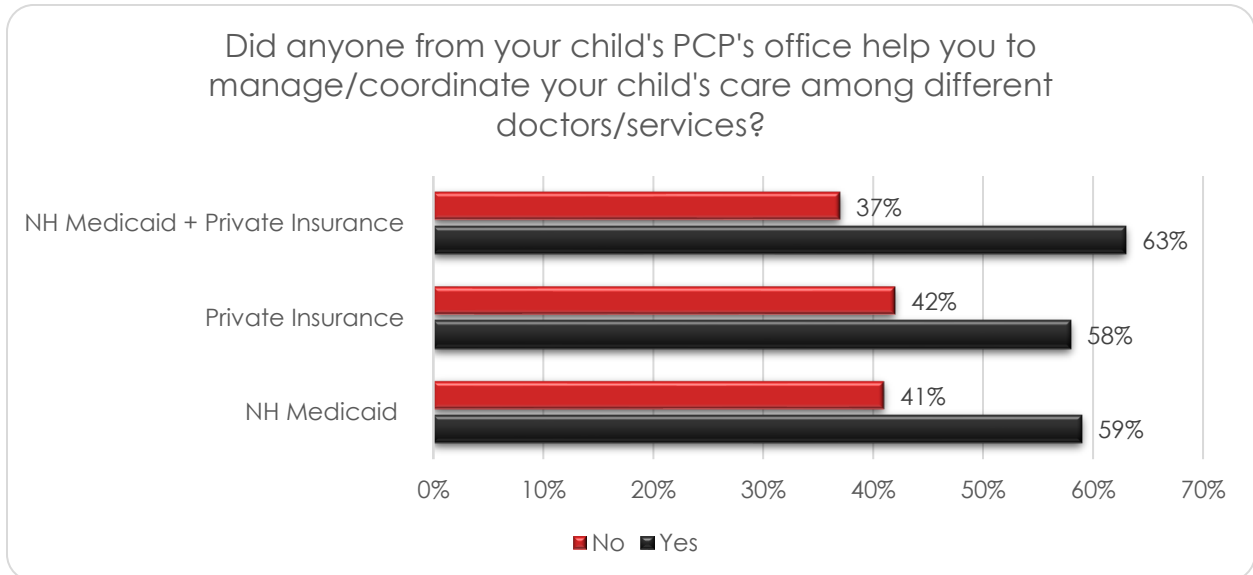
- “They ask me, ‘What did they say? Did you go to the appointment?’ It’s so frustrating! Can’t they take five minutes to read the report?”
- “I have tried to use providers in the same system, and am still asked ‘what did they say?’ Can’t they make time to read the report from the other doctor? I go there, even if it isn’t where I want to take my son, because I thought it would be easier.”
- “The challenge is getting the information from all of the specialists to primary care. It doesn’t happen automatically like you think it would. Primary care is not up to date with those specialists, especially if there is a large amount. Some records seem to never catch up. I think this does make it hard for them to have a whole person approach.”
- “Sometimes the providers have differing opinions. Who should I listen to? I know they all want the best for her. It’s not a bad thing, but I am like, you’re the ones who went to school. Then they send us off for another specialist visit. We walk into the room and you could just see “why the hell are you here?” You could see it in their faces. It was such a waste of time.”
- “Give me a HARD copy of records so I can take it. You know damn well it isn’t going to get there otherwise.”
- “We are the ones informing them, keeping them in the loop. The tech is there, but the logistics and the time to do that in advance of the appointment is challenging.”

The communication challenges the focus group members shared relate directly to another important component of medical home, coordination of care.

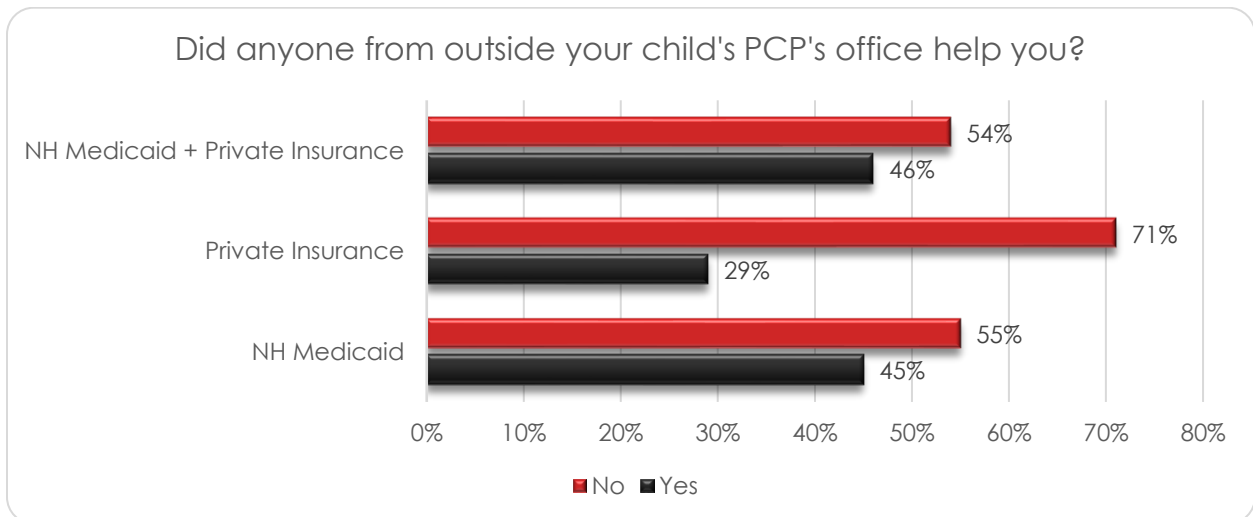
## Coordination of Care

Care coordination and case management are regarded as widely available to families in NH, through a variety of systems. However, feedback from families suggests varying experiences with and access to this support in managing their child’s care. It is important to remember that 80% of survey respondents and 100% of focus group participants had children with special health care needs, utilizing multiple providers of care. 67% of the survey respondents indicated a need for a referral to see a provider or access services within the past twelve months. Survey respondents identified whether anyone helped them to manage or coordinate their child’s care, as well as the location of and adequacy of that support to meet their needs in a series of questions. As a difference in access to support was noted in one area based on insurance identified, graphs reflect the data by child’s insurance status.

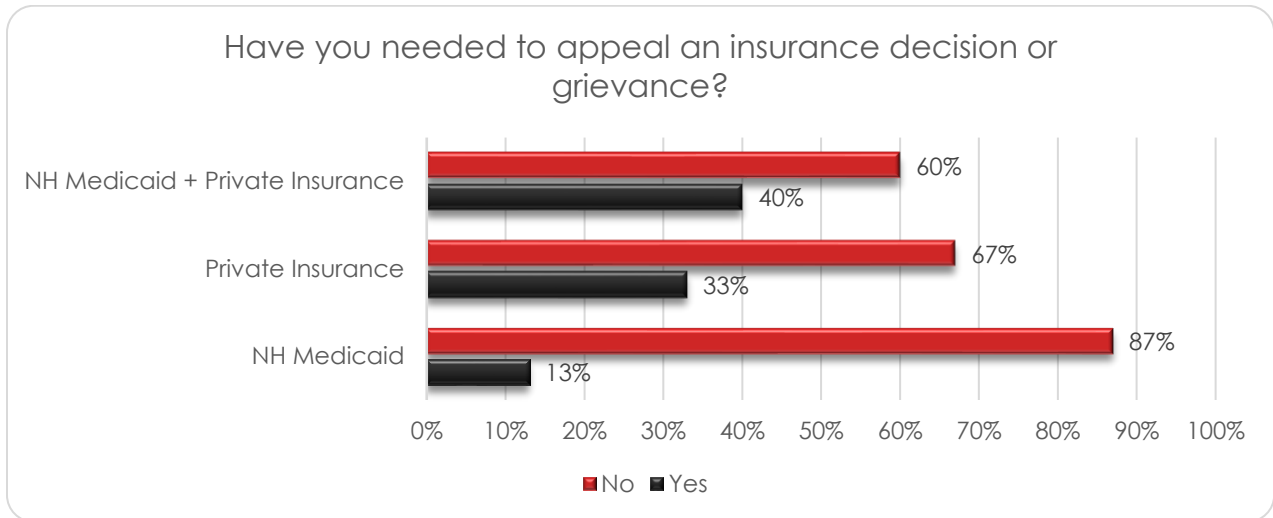
Access to care coordination within their child's primary care practice was comparable among all insurance groups, and reflected access for 58% of families in total.



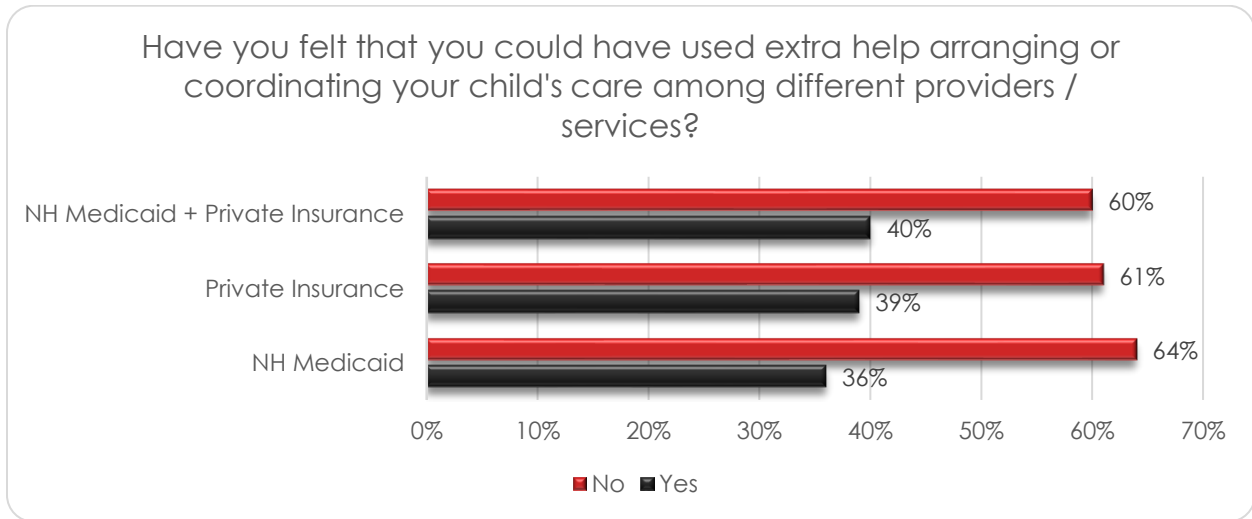
Families who identified they *did not* have access to support from within their child's primary care office were asked if they had support elsewhere. Overall, 40% of families reported access to external support. Families whose child was covered only by private insurance reported far less access to this support.



Interestingly, those who reported their child was covered solely by private insurance reported higher rates of filing appeals or grievances, and yet, had less access to support to do so.



This reported difference in access to support is important to note, as families whose child was solely covered by private insurance reported similar challenges accessing needed services, and identified a similar need for additional support.



In looking at factors other than insurance coverage among those caregivers who identified a need for more support, the complexity of their child's health care needs appears to be an additional driver. 100% of families who identified that their child used 11-15 providers identified a need for more coordination, whereas only 40% of families who identified their child had 6-10 providers did so, despite similarly reported access to coordination services between these two groups.

Survey respondents were also asked to provide additional feedback about the person who helped them to manage their child's care, regardless of whether that person was located within or external to their child's primary care practice. Families felt the coordinator was informed, and supportive of their decisions. And while most indicated receiving help, 10% reported never receiving assistance with appointments, and 16% reported never getting help with needed equipment.

Did the person who helped you with managing your child's care:				
	Always	Usually	Sometimes	Never
Know the important information about your child's health care needs?	58%	38%	2%	2%
Seem informed and up to date about the care your child got from other providers?	62%	27%	9%	2%
Support your decisions about what is best for your child's health and treatment?	75%	21%	2%	2%
Help you to get appointments with other providers?	59%	22%	9%	10%
Help you to get special medical equipment your child needed, like a special bed, wheelchair or feeding tube?	65%	10%	9%	16%

An interesting note: A small number of families in our survey identified a specialty practice as their child's medical home. They were more likely to identify that they never received assistance with getting appointments with other providers (16.7%) or obtaining medical equipment (33%) than those who had identified a primary care practice.

Focus group participants shared varied experiences with care coordination, reflecting a full range of access to and involvement with the support;

- "We serve as our own care coordinator. Our family is in this on our own."
- "I don't know how practices without coordinators could provide comprehensive care. How could that happen effectively?"
- "It wasn't helpful – another person I had to talk to, another thing I had to do – another coordinator to coordinate!"
- "I am my child's coordinator"
- "Having a care coordinator, that would be GREAT!"
- "I know my practice has some, but I don't know who they work with."
- "I am not sure if my practice has one. I have never been offered one."
- "For us, it is just easier to coordinate. Nobody is going to give it the same attention. She is our daughter."

- “I think we have one that is non-existent. Met her once a year ago, but never have contact. It’s me or my husband fighting with the insurance company.”
- “Our care coordinator deals with prior authorizations every six months. She has been really good at it. Pain for her, but she has been really good. We haven’t had any issues. She has been a huge help, and the one before her. I wouldn’t have survived the beginning without her.”
- “We had a team, a nurse coordinator, a care plan before. It doesn’t seem as central to their practice now.”

## Family-centeredness & Cultural Competence

Survey respondents answered a series of questions regarding their interactions with their child’s primary care provider, painting a picture of how families felt about the nature of these interactions. Survey responses in this area demonstrated little need for improvement.

During the past 12 months, how often did your child's primary care provider:				
	Always	Usually	Sometimes	Never
Listen carefully to you?	82%	15%	3%	0%
Spend enough time with your child?	77%	21%	2%	0%
Explain things in a way that was easy to understand?	83%	16%	1%	0%
Show sensitivity to your family's values and customs?	83%	13%	4%	0%
Show respect for what you had to say?	85%	13%	2%	0%
Provide the specific information you needed concerning this child?	78%	17%	5%	0%
Understand your child's medical, behavioral, or other health conditions impact on your child's day to day life?	71%	20%	8%	1%
Help you feel like a partner in care?	80%	17%	3%	0%
Discuss with you the range of options to consider for his or her health care or treatment?	67%	24%	6%	3%
Make it easy to raise concerns or disagree with recommendations for this child's health care?	73%	22%	3%	2%
Work with you to decide together which health care and treatment of choices would be best for this child?	73%	22%	5%	0%

Survey respondents were not asked to identify race or ethnicity, but we are aware that none indicated a primary language other than English. The lack of engagement of families who have a primary language other than English is a known gap in these results.

Focus group respondents indicated that while some families feel respected as partners in their child's care, others clearly do not. Had we not conducted focus groups; we would have missed this important feedback.

- "They could improve at partnering with families."
- "I make sure my priorities and his needs are forefront, and it's been welcomed at primary. The emergency department has not been friendly, especially for children. My son was in the ED for five days. The hospital needs help with this. That is the big black cloud for children with mental health needs, the emergency room."
- "I have had to fight. I will state a concern, where I want him to go, but get sent in another direction. I wanted to him to see a sleep specialist. He got sent to ENT, had his adenoids removed. It has done NOTHING. He is still not sleeping."
- "I feel like a partner, but I tell them what to do. I remember being a terrified mom. It took me a long time to get there. I feel like they hear my concerns and take them seriously."
- "I feel respected, and recognized as central to my daughter's care."
- "I rated cultural competence low on my priority list because of my own identity; but this sure as heck better be an addressed well for others!"
- "Some things have been a struggle. We hit speed bumps in certain things that as parents we wanted to do, but weren't necessarily how they do it, how it's done. We blend her diet. We don't do formula. It was kind of like 'Why do you want to do this?' But we didn't get too much push back because we said we are doing this."
- "You need to build a team where people can see eye to eye and not fight against each other."
- "You know, even if you don't agree with it, understand this is what we want or what works for our family."
- "I don't want to feel like a number. You know, hurry up, and get to the next patient. Not my problem. We deserve the time to ask all the silly questions we have, or whatever it is we want to talk about. Even time to have the conversation to say, I don't like this, or this isn't working for our family."
- "Her saying she didn't have all the answers was huge. I wish others would say that to their parents. Because when you are going through it, you think they are supposed to know. They are the ones that went to school. She admitted she'd never had a patient like my daughter before, but that she would find the answers with me. That make me feel okay, I can't be mad she doesn't know, I shouldn't have put that on her."

## YOUTH

The sole source of youth feedback in this effort were members of the YEAH Council, a youth advisory group comprised of youth. This in person focus group was conducted as a result of the input from the youth member on the Medical Home Advisory Committee. Youth were engaged in a discussion regarding their familiarity with the concept, how well their practice met each of the components of a medical home, and to identify which component was the most important to them.

The youth members were more familiar with the term medical home than parent respondents, as project staff had previously attended a council meeting and presented the concept. Five out of seven in the group reported being aware of the concept, and six out of seven felt that their practice provided care in a manner consistent with the components.

### Access to Care

In contrast to parent respondents, youth did not identify access to care as the most important component of medical home. We noted that the component parents identified as most important was the one which had been a challenge. Youth did not perceive access as a challenge, with six out of the seven indicating they were able to get an appointment with their primary care provider when needed. All of them stated that their practices offered extended hours. One indicated being able to be seen within a three-day window, and felt that was acceptable. Four identified having used urgent care, but did not relate this as an access issue.

Not surprisingly, the YEAH Council members were aware of issues related to accessibility, and did identify barriers in some specialist offices such as lack of ramps or elevators, narrow doorways, or rooms too small to maneuver a wheelchair. The one member most familiar with navigating these challenges identified the primary care practice as being accessible. The importance of this as a component of access to all members of this group, however, was evident.

### Continuity of Care

All members felt they had continuity of care, and at the same time, indicated they didn't expect it. Youth seemed less troubled by the practice of seeing a different provider, or seeing someone who was not knowledgeable about their health needs. They indicated that they were accustomed to relaying information to providers, and educating them about their needs when they saw someone unfamiliar. Where families identified this as something they wished were different, youth seemed to accept this as business as usual.



## Comprehensiveness of Care

Youth rated comprehensiveness as the most important component of medical home. This choice was impacted by a strong desire to be treated as a whole patient, and the successes and challenges they had experienced.

In this regard, it was similar to the parents and caregivers who identified access as the most important component as a result of experiencing access challenges. Youth shared experiences where a provider expressed hesitation treating a young woman's reproductive health needs as a result of a chronic health condition, or where a mental health provider more frequently addressed the patient as a whole person than primary care. For youth it was paramount that primary care engaged them and were aware of their "outside world", as they felt strongly that their health impacted everything in their lives. Several of the youth identified duration of appointments as a barrier to providing comprehensive care.

## Coordination of Care

Five out of seven youth felt that their primary care provider tries to coordinate their care, where others do not. None of the youth were aware if their primary care practices offered support with care coordination.

In a manner similar to parent respondents, communication was identified as an area of challenge. One youth shared frustration that three providers not only in the same system, but in the same building, seemed to have difficulty communicating. Another youth shared frustration that a primary care provider made an *assumption* that the youth had *not* gone to a specialty appointment, when in reality the appointment had occurred, but the information hadn't been shared by the provider.

## Patient / Family Centeredness & Cultural Competence

When engaged in a conversation about patient and family-centeredness, youth immediately identified trust as the most important factor in their relationship with a provider. They also identified that trust was something providers earned over time.

Five out of seven of the youth felt they were actively engaged in decision-making with their provider. As mentioned earlier, several of the youth identified the time limits and frequency of appointments with primary care providers as a barrier, expressing that they didn't have a sufficient opportunity to address everything they wished to discuss. Youth who saw specialists more often said the frequency of those interactions led to the sense that these were the providers who knew them best, not the primary care provider, a feeling shared by some parents as well.

When asked about issues around culture, youth questioned whether signage and phone messaging systems were in multiple languages, but otherwise had little experience or insight in this area given the current make up of the group.

## PROVIDERS

Results reported below are a compilation of the feedback received from the 95 providers who responded to the adult and pediatric provider surveys, and the nineteen staff members of varied professional roles, who participated in the two focus groups.

One focus group was held at a large hospital-affiliated practice, with sixteen staff members representing diverse professional roles in attendance (practice manager, providers, schedulers, care coordinators, nurses). Another focus group was held at an independent pediatric practice, with three staff members in attendance (practice manager, provider, and nurse). We note that these results represent a small sample of practitioners.

When the same question was asked on the two surveys, results are reported in the same graphic where possible, and identified as separate when required.

Of the 40 pediatric providers who responded, the majority were pediatricians. Of the 55 adult providers who responded, nearly all were family physicians.

<b>What sort of practitioner are you?</b>			
<b>Pediatric</b>		<b>Adult</b>	
Family Physician	0%	Internist	5%
Med / Peds	27.5%	Family Physician	95%
ARNP	2.5%	Med / Peds	0%
PA	0%	ARNP	0%
Pediatrician	70%	PA	0%

<b>Years in Practice</b>		
	<b>Pediatric</b>	<b>Adult</b>
1-5	15%	18%
6-10	2.5%	9%
11-15	22.5%	6%
16-20	20%	11%
greater than 20	40%	56%

Practitioners in both pediatric and adult care reported a range of years of experience, with the highest percentage of respondents in both groups reporting greater than twenty years in practice.

Practitioners in both pediatric and adult care reported practicing in diverse care settings, with the highest percentage of pediatric practitioners identifying multi-specialty clinics, and almost the same percentage of adult practitioners identifying being located in either a community health center or clinic.

<b>Type of Practice</b>		
	<b>Pediatric</b>	<b>Adult</b>
Private / Solo	2.5%	6%
Private / small group	10%	6%
Community Health Center	10%	25%
Clinic	20%	25%
Multi - specialty clinic	27.5%	10%
Academic clinic	15%	4%
Hospital	15%	24%

37% of pediatric and 48% of adult practitioners identified that their practice had pursued recognition or certification as a medical home. 52% of pediatric and 40% of adult practitioners believed there was a value in this identification. Of the focus groups, the larger practice had previously sought and attained recognition as a medical home,

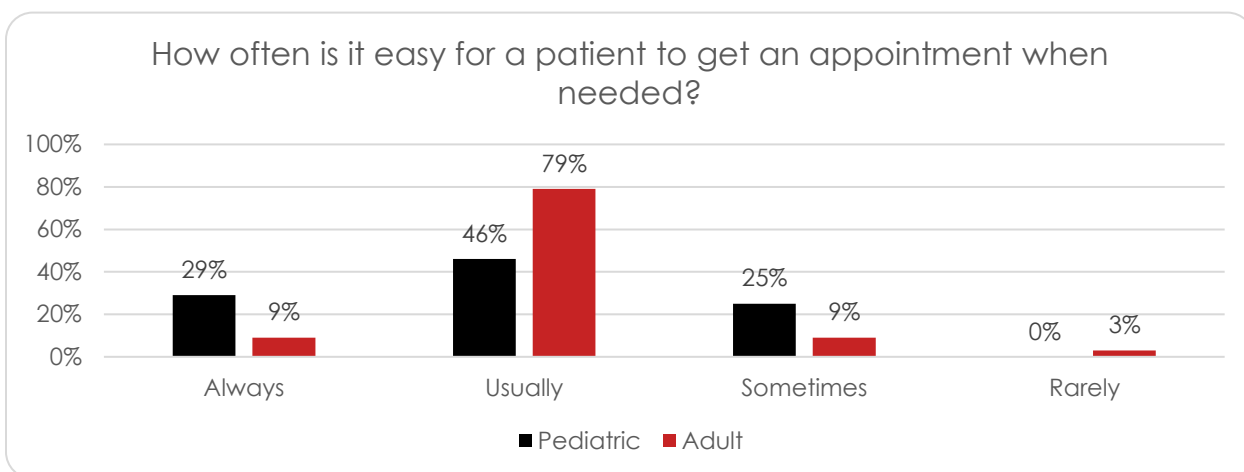
but had not maintained it. The smaller practice had never pursued recognition. Survey respondents were asked to share the value of medical home identification, and the barriers to pursuing it. While a number stated they believed there was a value in identification, comments largely identified barriers, with multiple comments identifying additional time, staff, and expense in excess of reimbursement gained.

- "We were accredited. The process was so cumbersome the organization decided not to continue."
- "I think having the services is more important than the designation."
- "Don't know whether it truly makes much difference."
- "The limited incentives from insurance do not support the additional efforts to get the designation. We perform the same supports and services."
- "Patients still don't know what it means, hospitals don't really care if we have it. If there's any extra funds available, they're minimal. Lots of work to recertify."
- "I think most people don't know what this is or care."
- "More extraneous useless requirements that eat up my time and energy"
- "I would need to significantly increase staff and cost in order to be defined as a Medical Home."
- "The necessary hoops to jump through to receive an official "designation." We provide a medical home to our patients, but applying for a designation seems unnecessary and cumbersome in a rural small practice setting."
- "If processes are in place to take best care of patients and transition appropriately, checking off boxes to "certify" as a medical home is additional work, no value added."
- "High cost of having more employees and the inevitable large amounts of paperwork"
- "We are too small to meet the criteria for being a medical home, especially since we cannot provide extended hours."
- "Too costly and time consuming for the reimbursement"
- "Don't think we have significant barrier in practice although sometimes recognition requirements are difficult and not representative of what is actually happening"
- "Lack of resources and staff"
- "Additional personnel needed"
- "Paper / documentation requirements"
- "LOTS of regulatory requirements and hurdles"
- "Data management"
- "Cost"
- "Certification and reporting measures"

From a practical standpoint, all primary care sites are addressing components of the medical home concept in some way in their care delivery model. As had been the approach with parents and youth, providers were asked questions in both the surveys and in the focus groups that relate to these components, and their answers are reported using the components as a framework.

## Access

Providers were asked how often patients were able to get an appointment when needed in their practice. While pediatric providers indicated patients were always able to get an appointment more often than adult providers, when combining the always and usually responses, a higher percentage of adult providers indicated patients were usually or always able to do so than was reported by pediatric providers.



Extended hours were reported in the majority of respondents' practices, with 74% of pediatric providers and 66% of adult providers indicating that weekend or evening hours were offered by their practice in order to support access.

The focus group participants echoed survey results. Both practices felt they met this component well, and acknowledged it required effort to do so. Both practices cited that they work to match the number of urgent care appointments with demand, with the smaller practice stating this was constantly reassessed, and the larger practice working toward more full utilization of the scheduling capability of its EMR to improve access. Both practices offered appointments at night and at least one weekend day, either via on call or extended hours. The independent practice reported that the local emergency department reported seeing fewer of their patients than patients from other practices.

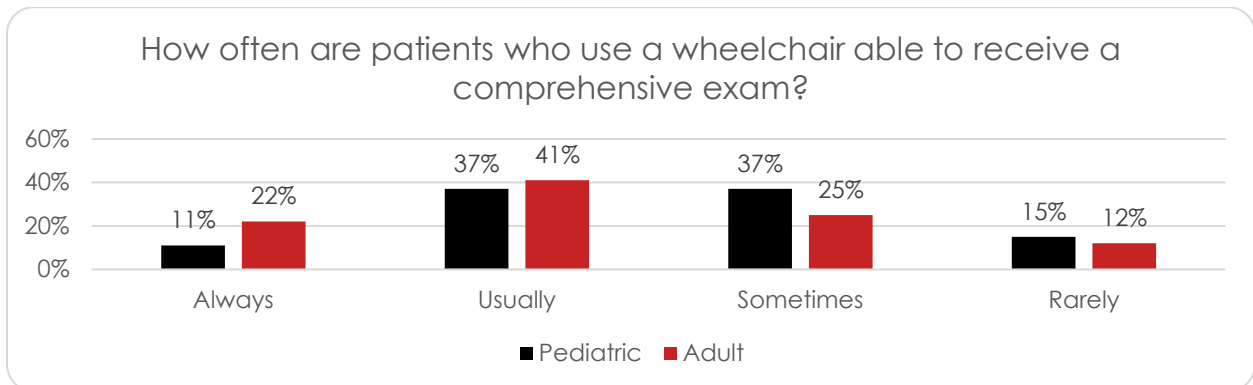
Despite efforts to ensure access, both survey respondents and focus group participants indicated that patients sometimes are seen in urgent care or other treatment sites such as Convenient MD, due to a lack of sick appointments. In the surveys, fewer pediatric providers (44%) indicated this occurred than adult providers (64%). In the focus groups, both practices noted this occurred, and identified a number of factors. They felt that

sometimes this was as a matter of convenience to the family, either proximity to home, or timing, if the appointment offered by primary care was not soon enough for the comfort level of the family, or at a time that was compatible with their schedule.

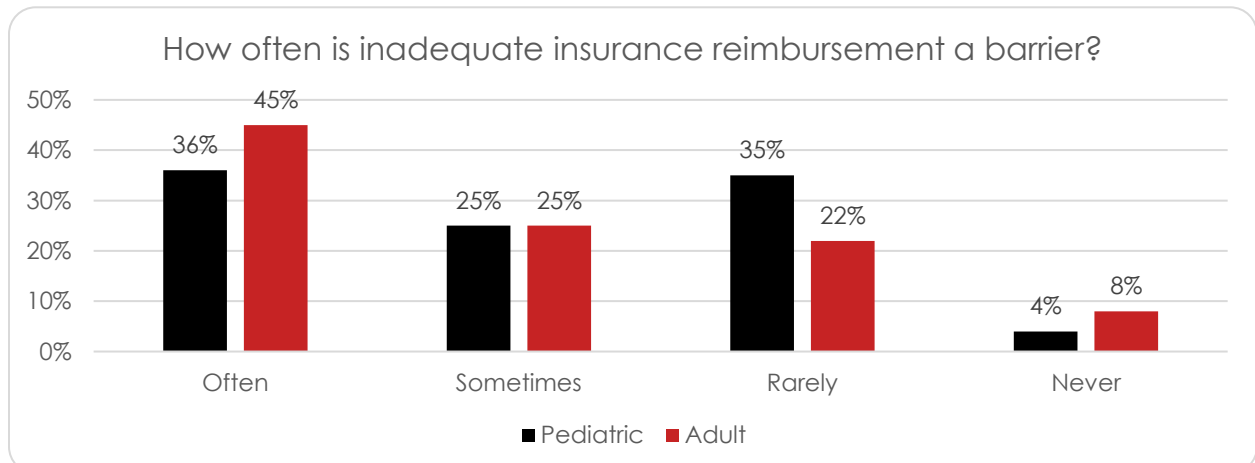
This matches what parents shared and was previously reported.

- "Parents who can only come to an appointment after 4pm, or on Saturday, may feel access is a problem. They will have to wait longer than if they have flexibility."
- "Staffing has also impacted access. We had more trouble for a couple of months when we were down an ARNP. It's not a problem now."

In addition to access to appointments, the accessibility of them was discussed with both family members and providers. Providers were asked to identify how often patients who use wheelchairs were able to receive comprehensive exams, such as being weighed or transferred to exam tables. Consistent with family reports, results from both pediatric and adult providers indicate some opportunities to improve in this area.

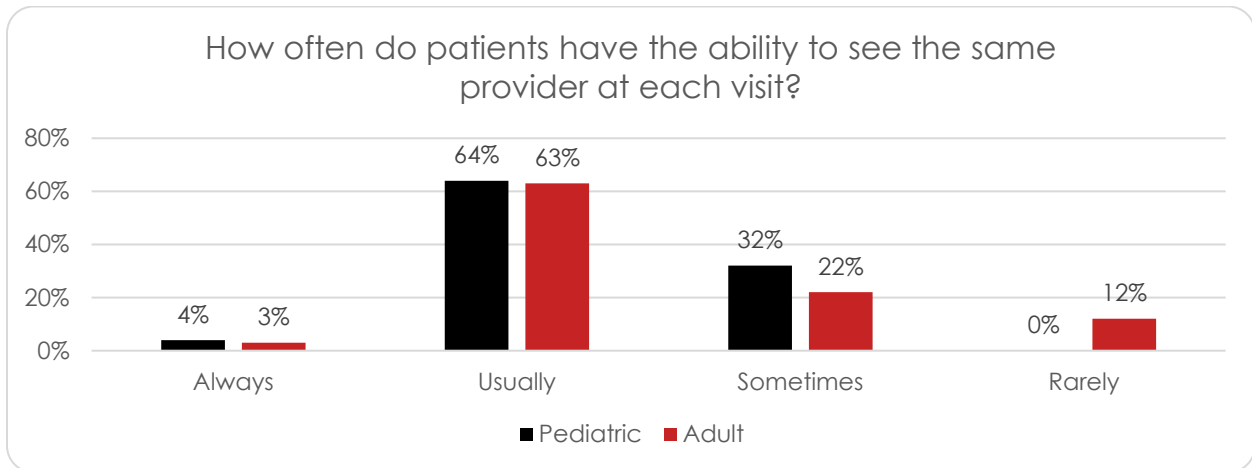


Lastly, providers identified insufficient insurance reimbursement as a barrier to providing care for youth with special health care needs, which may well impact access, as well as other components of medical home.



## Continuity of Care

In the survey pediatric and adult providers identified how frequently patients were able to see a consistent provider at each visit. Results were quite similar in the “always” and “usually” options. However, 12% of adult providers indicated this was rarely the case, where no pediatric providers made this choice.



In focus groups, both practices cited processes to assure that patients were either seen by the same provider, or that the alternate provider had the information needed to see the patient. Within the smaller practice more complex patients were identified by a “yellow chart”, alerting providers who were unfamiliar with the patient and allowing them to prep a bit before entering the room. These patients were also routinely scheduled for longer visits, and received a faster return call from the RN. Within the larger practice, where there are multiple teams of providers, patients are prioritized to their PCP, and next to a member of that team, and lastly to another team. This practice also cites efforts for that provider to become more familiar with the patient in advance of the appointment to ensure continuity of care. The larger practice noted that this is a process that addresses their more complex patients, and may not occur for the “typical” child.

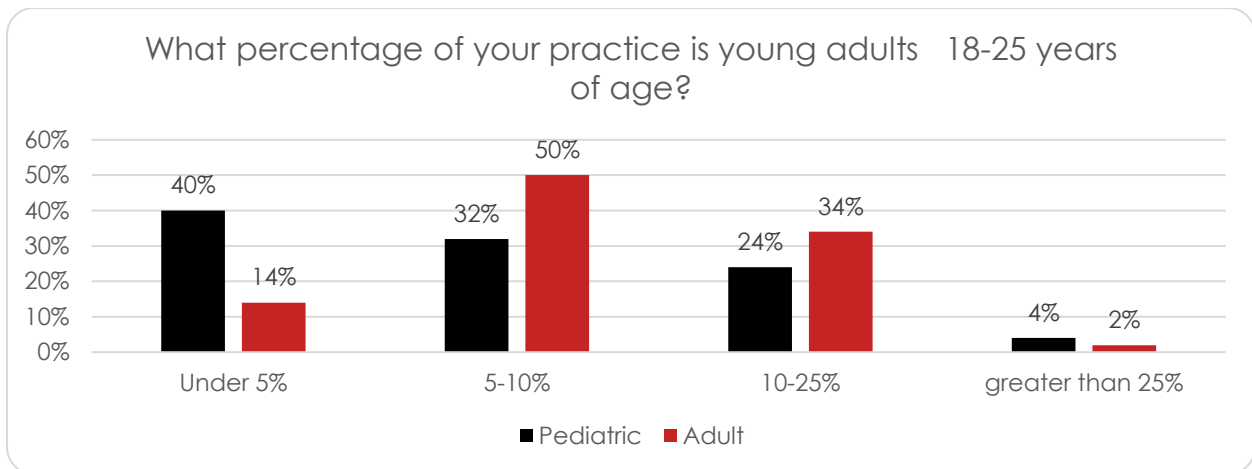
Having processes such as these, and having them consistently followed, are both critical to preventing some of the challenges parents identified regarding continuity of care that were previously reported.

Efforts to address health care transition impact access to care, and continuity of care in a broader sense than consistency of provider, and as such could be reported under either component. We are reporting results regarding health care transition in this section, to be consistent with previous sections of the report.

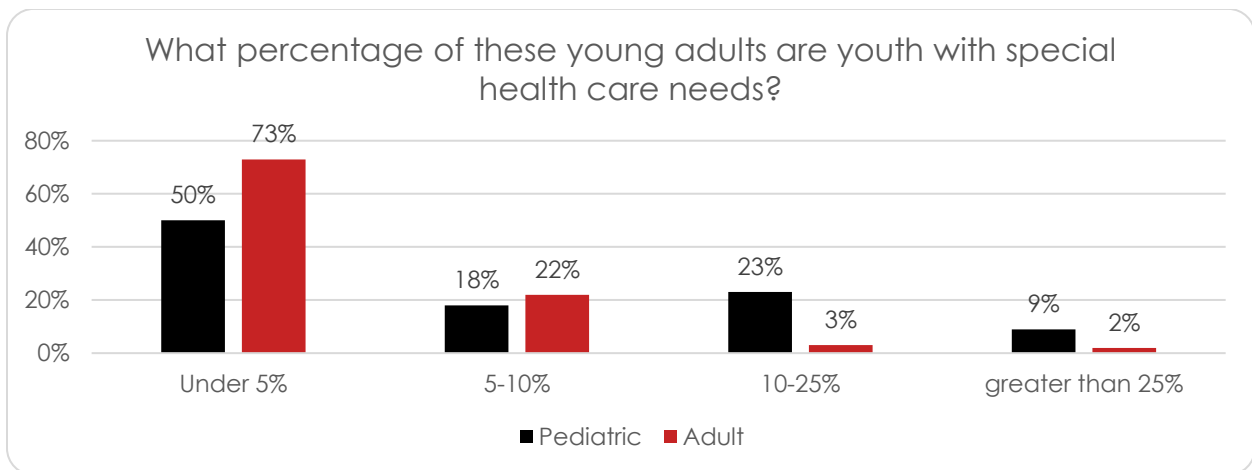
A health care transition policy is recommended for all practices, whether it outlines the transition of care from a pediatric practice to an adult practice, or from a pediatric model of care to an adult model of care within a family practice setting.

40% of pediatricians reported having a transition policy at their practice, with only 7% of adult providers reporting one. Of those who report having one, 56% of pediatricians and 33% of adult providers believe everyone in the practice is aware of the policy, and 83% of pediatric providers and 33% of adult providers believe it is used. This data matches previously identified opportunities for improvement in the area of health care transition identified by families.

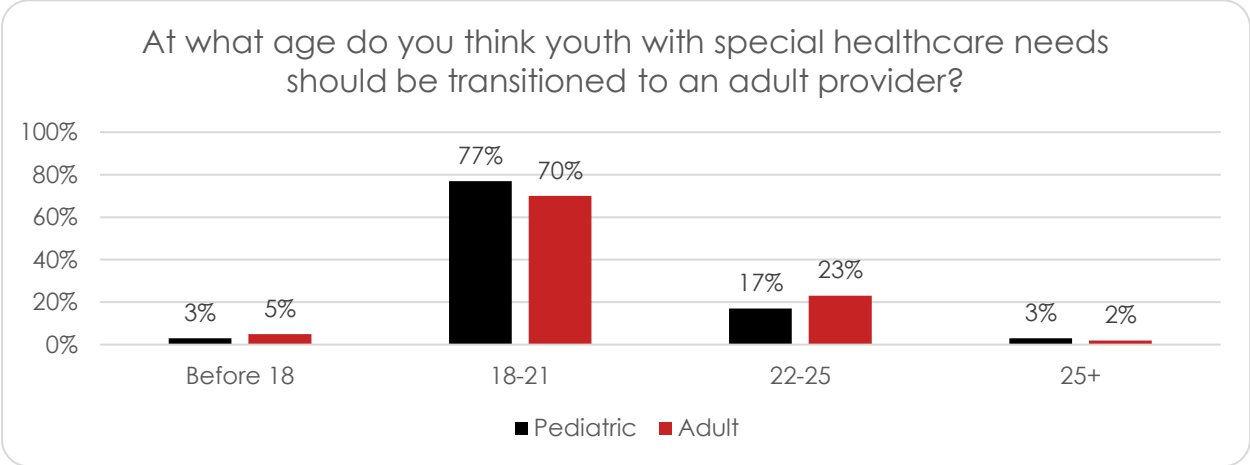
Of the providers surveyed, 77% of pediatric providers and 93% of adult providers indicated that their practice sees young adults between the ages of 18 and 25 years of age.



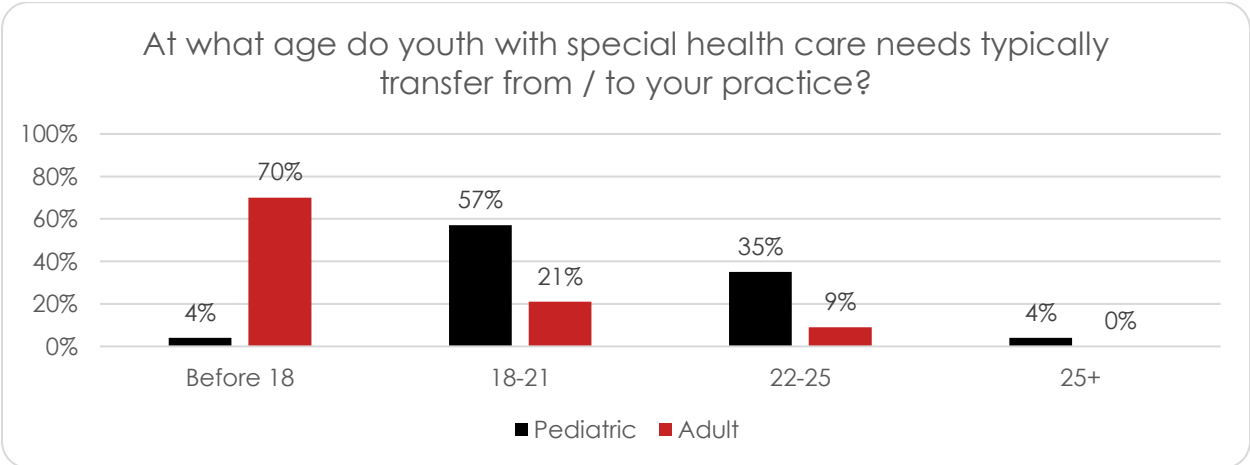
Pediatricians report that young adults with special care needs made up a higher percentage of their panel than adult providers report, consistent with family reports of delayed health care transitions for youth with special health care needs.



The majority of providers, both pediatric and adult, identify the ages of 18-25 as the time period in which health care transition should occur. More pediatricians feel such transitions should occur between the ages of 18 and 21 than do adult providers, with adult providers choosing between 22 and 25 years of age more often than pediatricians.

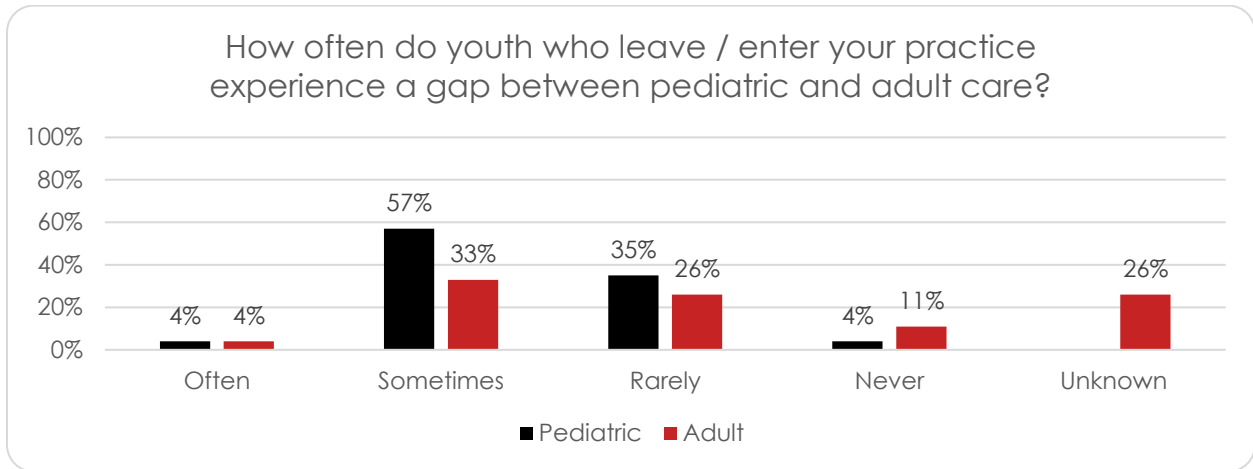


Adult providers report youth with special health care needs entering their practice before the age of 18 at much higher rates than pediatricians report them leaving their practice. This number reflects responses from family practice practitioners, who had the youth in the practice already.

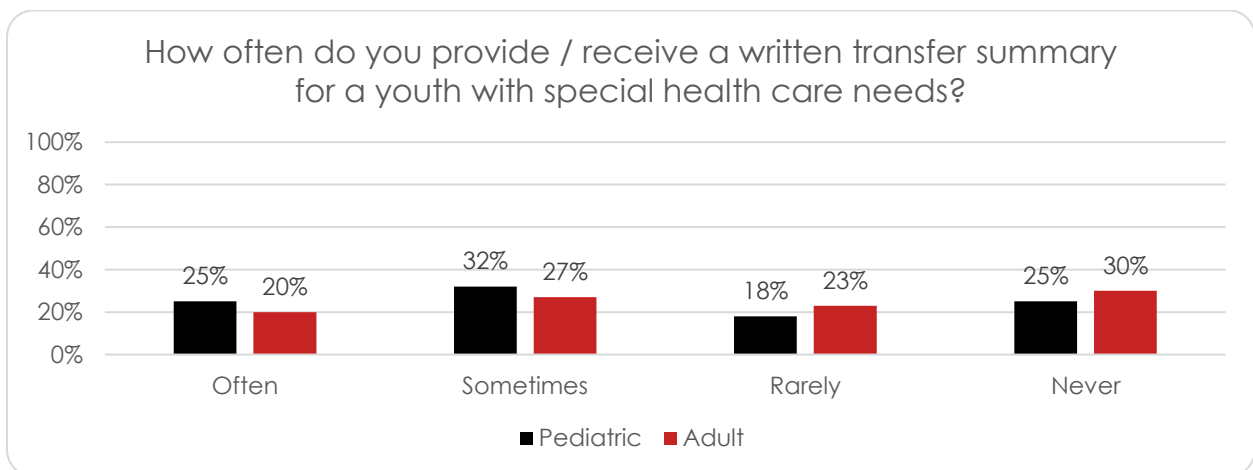




Four percent of pediatric and adult providers felt youth often experienced gaps in care during health care transition. Pediatricians otherwise felt this gap occurred more often than adult providers, although over one quarter of adult providers reported this as unknown.

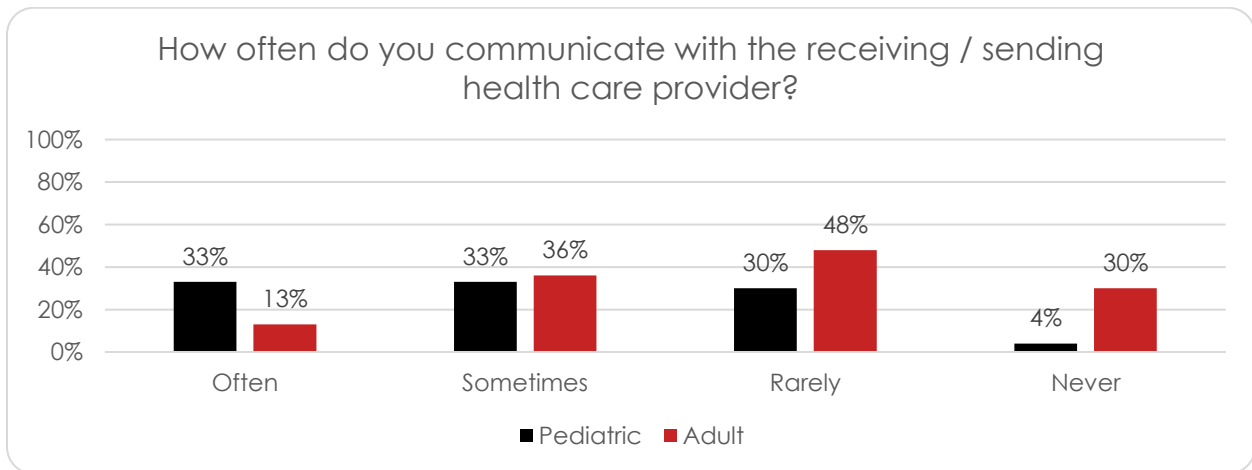


Communication between sending and receiving providers is also a recommended component of health care transition. Sending and receiving providers identified whether they prepared, or received, written transfer summaries for youth with special health care needs, or communicated with the other provider.

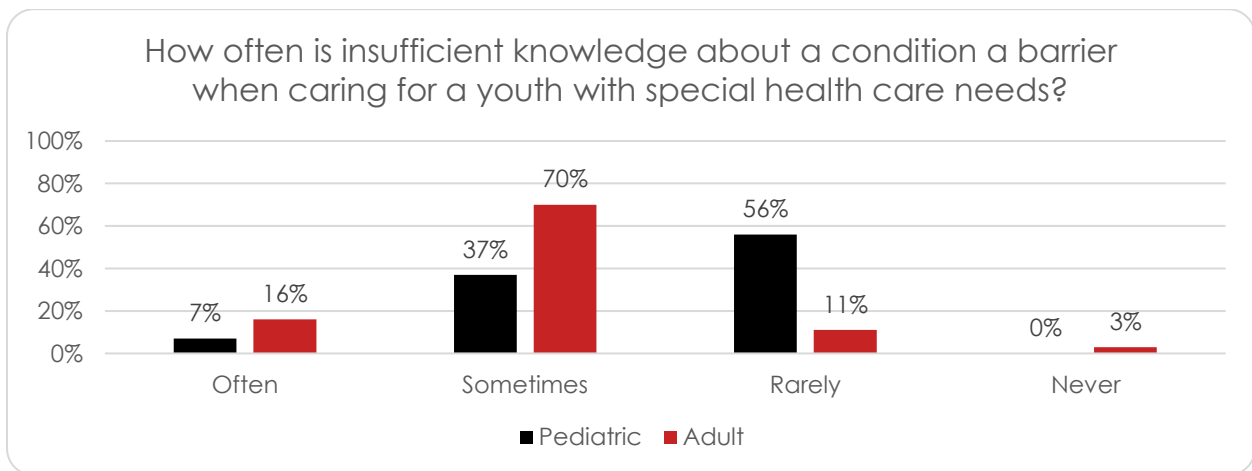


Reports of creating and receiving summaries are fairly consistent, but adult providers report far less communication with pediatric providers than pediatric providers report with adult providers.

Of note, 83% of adult providers identified a written transfer summary with patient-specific information as *very important* when caring for a youth with special health care needs.

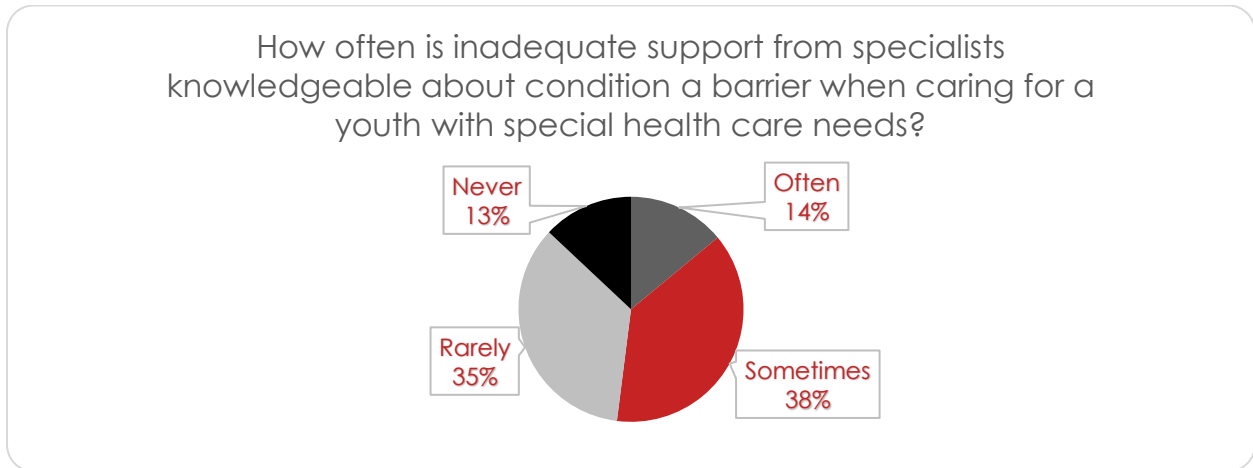


51% of adult providers identified conversations with prior health providers as very important, and an additional 37% identified as somewhat important. The desire for communication is evident, and the need is noteworthy in light of adult providers' reports regarding knowledge of conditions being a barrier to care.



The majority of adult providers report that inadequate support (from specialists knowledgeable about a condition) is a barrier to providing care to youth with special health care needs at least some of the time.

This is important to note, as 94% of adult providers identify this support as very important to providing care.

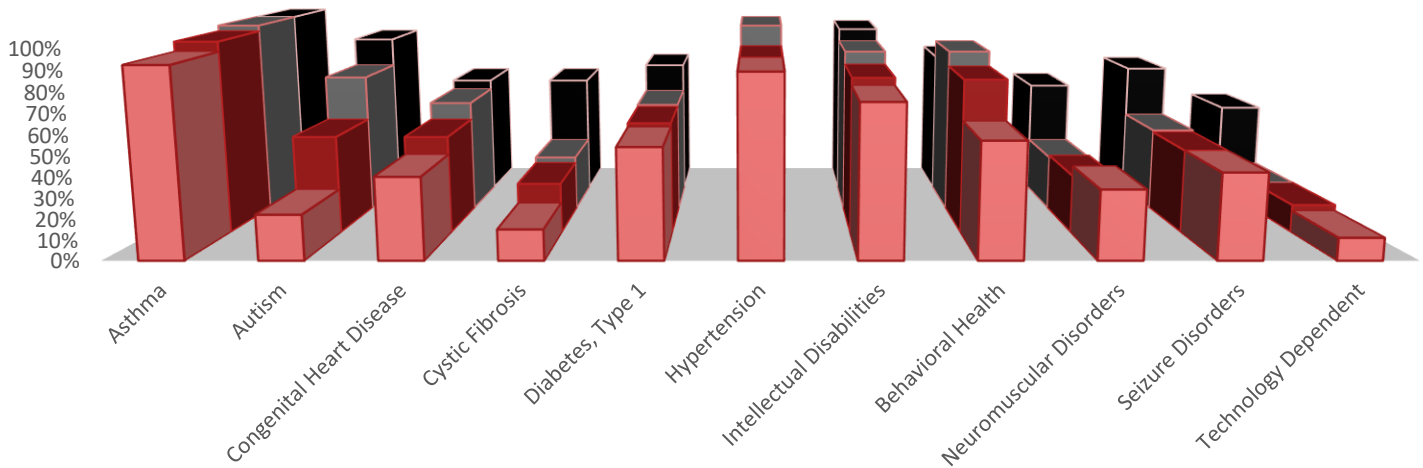


Adult providers also report differing levels of comfort in caring for those conditions, likely related to knowledge and access to support. A survey of adult providers, conducted in 2008 by Special Medical Services, assessed provider's relative comfort levels in caring for patients with a number of identified conditions. The survey was both mailed to all adult care providers in the state, and distributed via email listserv, resulting in 180 responses. Additional communication from sending providers was identified as something that would be helpful in the 2008 survey, and as such, the current responses indicate an area of continued need for improvement.

The current 2019 surveys were distributed solely by email, to both adult and pediatric providers, and yet resulted in far fewer total responses. 55 adult providers started the survey, but only 37 answered questions regarding comfort caring for patients with identified conditions. 40 pediatric providers started the survey, with only 30 answering this question. As a result of such low responses, a word of caution must be noted regarding interpretation of the results.

However, it is interesting to note that while responses are similar for adult providers across most conditions, the survey indicated improved levels of comfort in caring for patients with autism or behavioral health needs.

## Provider Survey - % Who Comfort Level With Identified Conditions

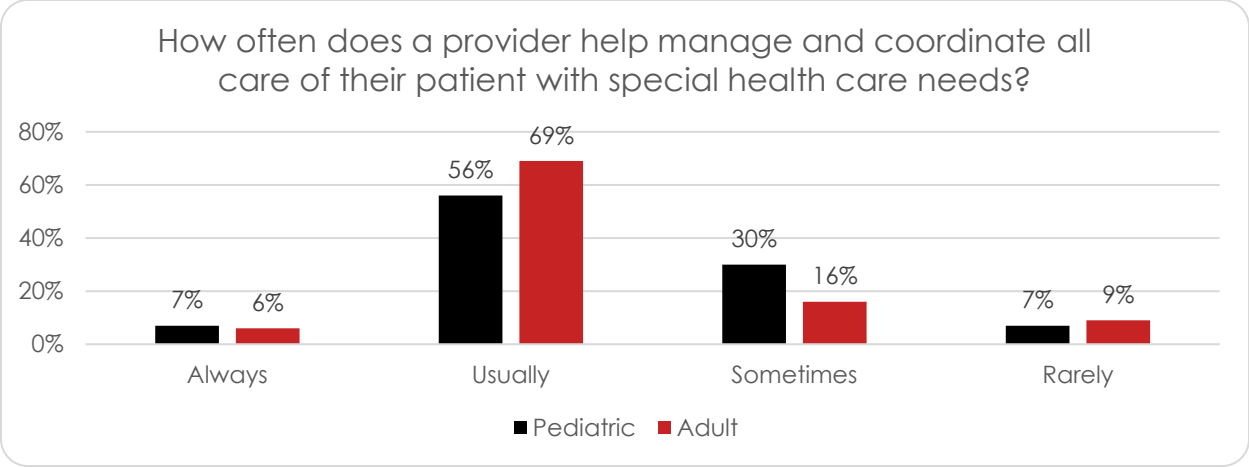


	Asthma	Autism	Congenital Heart Disease	Cystic Fibrosis	Diabetes, Type 1	Hypertension	Intellectual Disabilities	Behavioral Health	Neuromuscular Disorders	Seizure Disorders	Technology Dependent
■ Adult Provider 2008	92%	22%	40%	15%	54%	89%	75%	57%	34%	42%	11%
■ Adult Provider 2019	97%	49%	49%	25%	56%	89%	79%	78%	29%	42%	14%
■ Adult Provider 1-5 yrs in practice	100%	72%	58%	28%	57%	100%	86%	86%	28%	43%	14%
■ Pediatric Provider 2019	100%	87%	63%	63%	72%	36%	93%	77%	60%	70%	47%

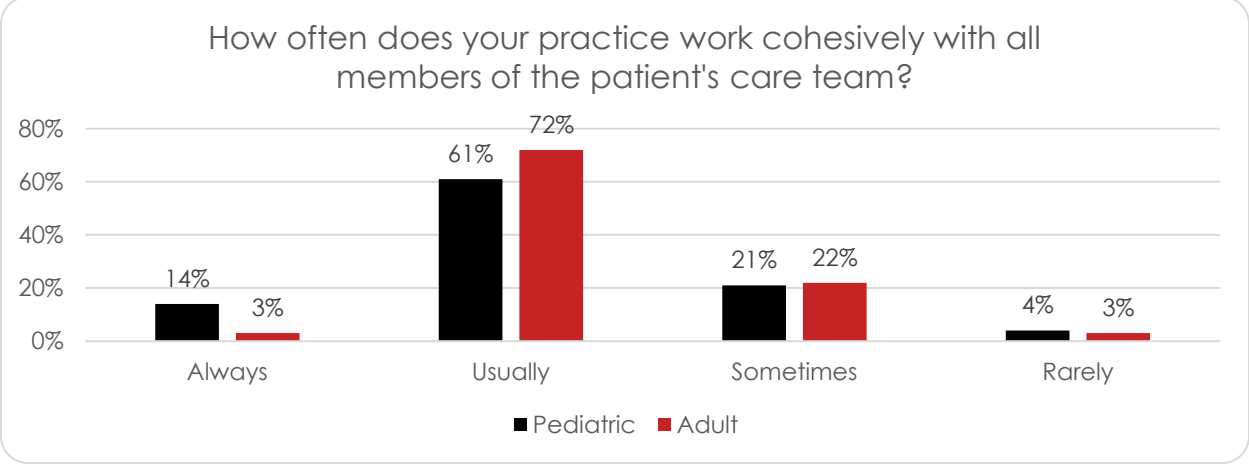
It is also interesting to note that providers with one to five years in practice reported higher comfort levels than those who had been in practice longer.

### Comprehensiveness of Care

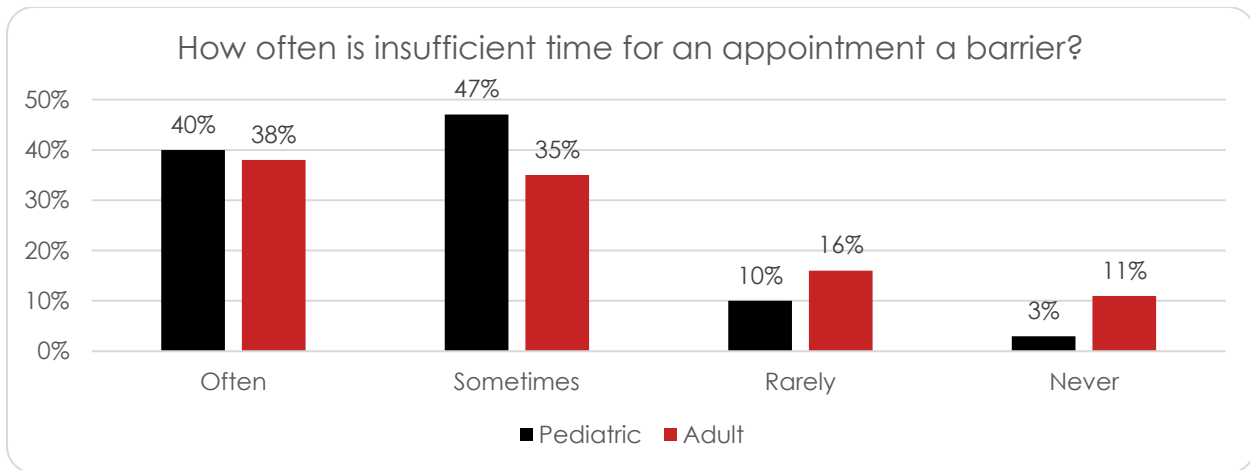
In the survey practitioners were asked questions to ascertain whether they were able to manage and coordinate *all* care for patients with special health care needs, and to identify how frequently the practice worked cohesively with all members of a patient's care team. 75% of adult providers responded that they usually or always managed and coordinated all care for their patients, as compared to 63% of pediatric providers.



Adult and pediatric practitioners reported nearly identical results regarding their ability to work cohesively with all members of a patient's care team to address a patient's needs, with 75% identifying this happened usually or always.



Pediatric providers more often identified that insufficient time at an appointment was a barrier to provision of comprehensive care, with 87% of pediatric practitioners identifying this was often or sometimes a barrier, as compared to 73% of adult practitioners. Adult practitioners chose the option "rarely" or "never" at higher rates as well.



In the focus groups, both practices felt they did well providing comprehensive care, but noted this was a component that relied on a complex system, and was also impacted by appointment times. They identified that within the scope of a well visit, there is time to provide comprehensive care, but in a quick acute care visit, things may need to be followed up on rather than addressed immediately. The identification of appointment time being a barrier to the provision of comprehensive care by pediatric providers in the focus groups is consistent with what was reported by pediatric providers in the survey.

The larger practice noted that the ability to do e-consults within the larger health system, and their capacity of care coordination allows for most questions to be resolved within 48 hours. They reported having a more medically complex panel of patients compared to the rest of the state, and were proud of their ability to provide this level of care. The smaller practice echoed the comments regarding consults, or searching for missing consult notes in order to provide this level of care. They noted issues whether providers shared an EMR or not, and cited access to mental health notes as a challenge. They shared the situation where a caregiver had called their child's psychiatrist for over a week trying to refill a medication, with no return call, and called the PCP for assistance. The nurse in the office was able to resolve the issue.

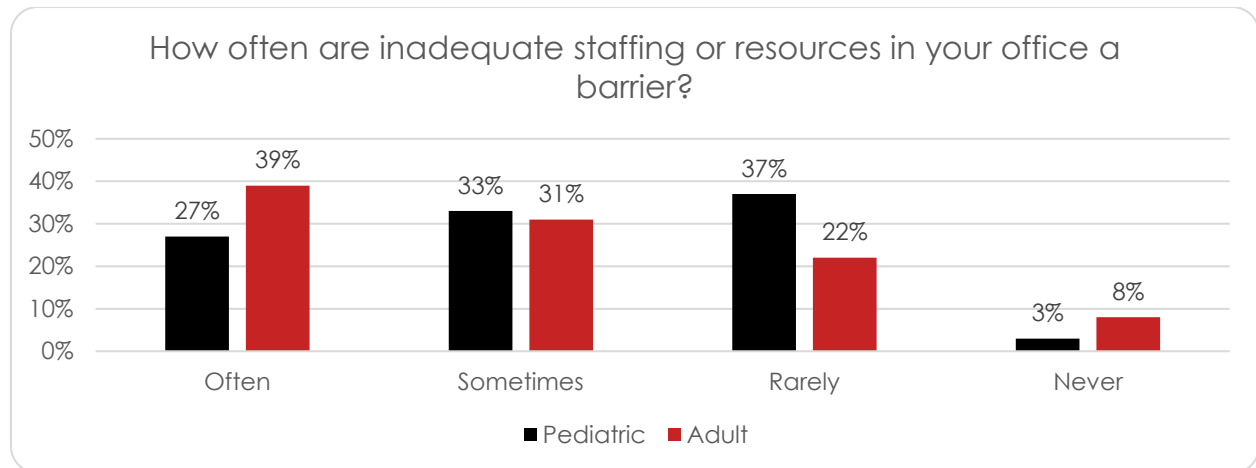
It is worth noting that the results indicating that access to information, and having sufficient appointment time to address care in a comprehensive manner, is in line with what both caregivers and youth reported.

### Coordination of Care

Interestingly, where parents identified access as the most important component of medical home, a pediatrician from the focus group representing the larger practice identified care coordination as *the* most important factor in a medical home. "If you don't do this well, you don't have a medical home."

A specific question regarding capacity for practice-based care coordination was not included in the provider surveys, but several other questions touched on this component.

Within the surveys, providers were asked to identify some of the barriers and relative importance of items such as staffing, resources and insurance reimbursement in caring for children and youth with special health care needs. Care coordination was identified as an example of staffing and resources within a practice. Interestingly, both adult and pediatric providers identified inadequate staffing as a barrier to caring for individuals with special health care needs as often as they identified inadequate insurance reimbursement.



When asked to rate the importance of having more care coordination and higher insurance reimbursement to care for individuals with special health care needs, a higher number of adult providers rated more care coordination as very important (51%) than did those who identified obtaining higher reimbursement (44%). Pediatric providers rated both aspects, having more care coordination and higher reimbursement, as very important equally as often (60%).

One additional survey question related to a practice's capability to provide care coordination. The ability to proactively provide care coordination has been associated with a practice having a means to identify patients within the practice who have special health care needs. In the surveys, 39% of adult providers and 73% of pediatric providers reported having a method for such identification.

Focus group participants identified differing capacity for care coordination between the two practices, but both reported providing this support. Within the larger practice, full time positions dedicated to care coordination exist. These coordinators manage large panels of patients (300 at time of focus group), who have been referred to them by providers. All of the patients have special health care needs. Within the smaller practice, care coordination support is provided in response to a parent request for assistance or if a need arises. This is not a support provided routinely to an existing panel, nor is it a dedicated role for this nurse.

Both practices noted that providing this support is very time consuming. The coordinator in the larger practice reported spending twelve hours on one out of network referral for a patient who needed to access care out of state. This coordinator expressed a need

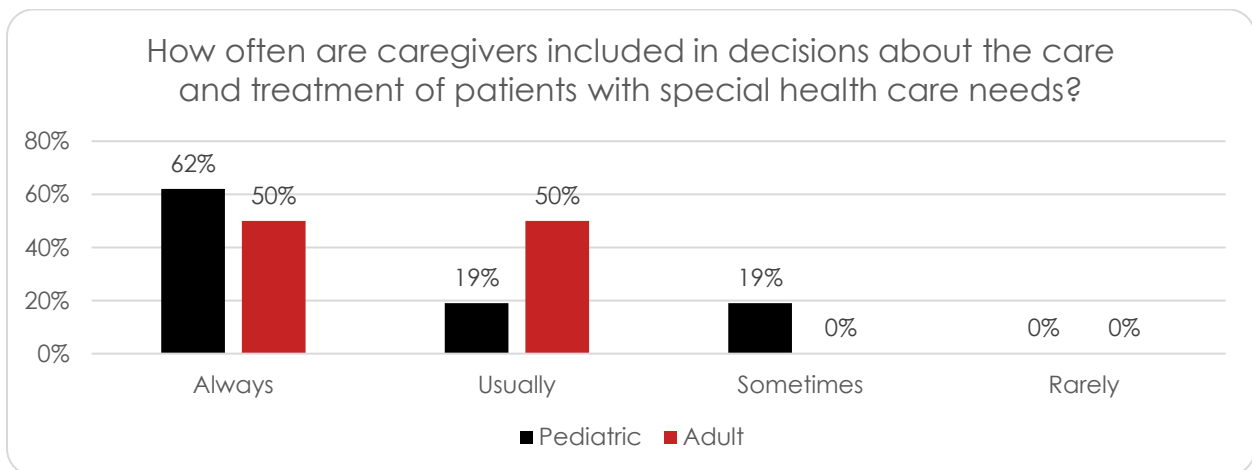
for more coordinators, echoing survey responses regarding staffing. She stated that in her practice providers and team nurses are also now spending more time on medication approvals; citing constant changes in insurance lists of preferred medications as a challenge. These formulary changes result in the need to either get the existing medication approved, or change the medication, update care plans, and contact others who care for the child. The nurse in the smaller practice echoed similar frustrations, citing rule changes (“prior authorization not needed one day, but needed the next”) and insurance responses (“send in a very detailed request and get a ludicrous response”) as additional challenges.

Families who reported partnering with care coordinators were very appreciative of the service. However, some families reported being totally unaware of the service. This lack of awareness may be explained by variable access in practices, and a dependency on either provider referral or parent request. Likewise, if the capacity for care coordination, whether dedicated or not, is similarly stretched in other practices, this may also explain some of the less positive experiences shared by caregivers.

### Patient / Family Centered & Cultural Competence

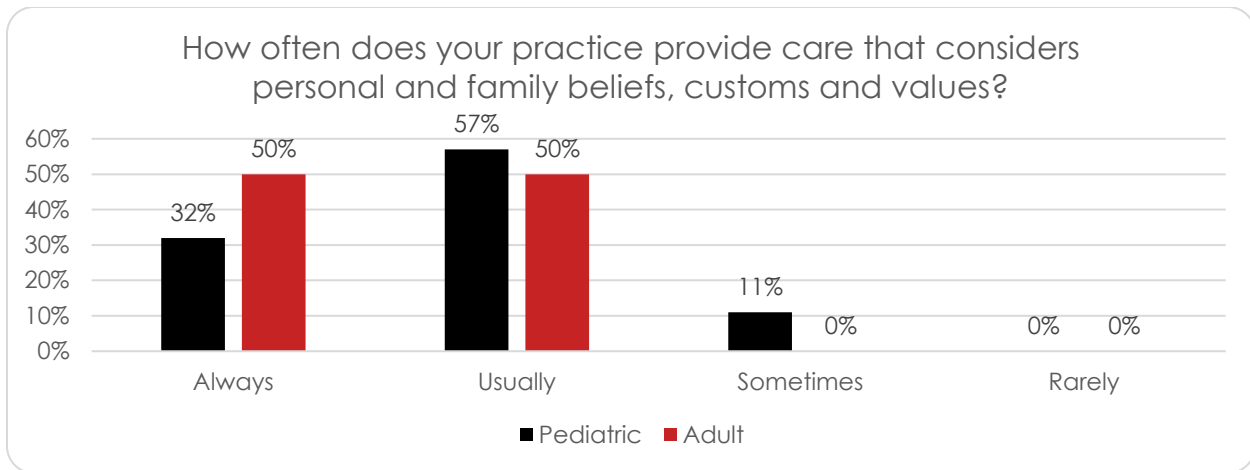
Within the surveys, two questions addressed elements of patient / family-centered care and cultural competence. The focus groups provided an opportunity for more rich discussion in this area.

The first question asked how frequently caregivers were engaged in decision-making. Somewhat surprisingly, 100% of adult providers reported this happened usually or always, with 19% of pediatric providers indicating that it happened “sometimes”.



The second question asked how frequently care was provided in a manner consistent with personal and family beliefs, customs and values of patients and families. Again, all adult providers indicated that this happened “usually” or “always”, while 11% of pediatric providers chose “sometimes”.





Of note, previously reported parent survey results reflect that parents rated their experiences regarding partnership, shared-decision making and respect more highly than providers.

Within the focus groups, both practices felt they were patient and family-centered, and at the very least, culturally aware.

- “Shared decision making is heavily done here.”
- “Large staff makes it work for us. It’s who we are. Building compassion.”
- “We let the family take the lead. Try to respond to their need, coordinate them with providers when we can. We meet them where they are. It may not be where we want them to be, but it’s where they are.”

Neither practice identified receiving any training specific to patient and family-centeredness. The larger practice identified training and processes to de-escalate difficult conversations, as well as training in cultural competence. They expressed a recognition of the varying senses of urgency regarding follow up care that may occur within and amongst families. They also shared a sense of confidence that they knew their families well enough to plan appropriately to meet their needs. The practice identified a number of capacities of the EMR to identify preferences, beliefs, identity, but acknowledged a gap in the patient portal not being visible in multiple languages, even if a variety of materials could be translated. They felt overall they were doing well, but could still do better. Staff identified that additional training around patient and family-centeredness and bias may be beneficial.

The smaller practice demonstrated an awareness of the differing needs of families, acknowledging that their partnership model may leave families who want more direction and specific recommendation from providers less satisfied. They also cited challenges working with divided families who hold different opinions regarding the course of a child’s treatment. They identified they would benefit from more training regarding diversity and bias, and expressed a hope that they were doing well in these areas for all families.

The sense that practices have of doing well in this area is supported by the results on our parent survey. The opportunities for improvement are likewise supported by some of the experiences shared by members of the focus group, demonstrating that perhaps some of the trainings the practices have identified for themselves may be beneficial.

## Summary

While not particularly surprising, perhaps the most striking feedback garnered through this process relates to the medical home concept itself. For the most part families remain unfamiliar with the concept. However, it was not the unfamiliarity that was so striking; it was the difference between those who understood and those who did not in terms of their expectations of and experience with care.

Those family members who were aware of the concept demonstrated support for its full implementation and value. A family who reported that her child currently receives care within a practice she would describe as a medical home shared a challenging experience when with another practice; "If we had a medical home early on, none of this would have happened. I wish I knew what a medical home was a long time ago. I would have looked for one." Several other families in focus groups shared success stories with a current practice, whether they had been in the practice continuously or had interviewed practices to "find the right one" for their family. One parent familiar with the concept lamented changes over time, citing that "medical home doesn't seem as central to practice" at it had previously. All of these families demonstrated that they had an expectation of the manner in which care should be delivered.

And for other families, it was very apparent that the notion that care should be delivered in a manner that meets the needs of their family requires a mind shift. "Sometimes you feel like you don't have a right to ask these things. You take what you can get." Addressing this feeling with patients and families is critical if we are to achieve the sense of partnership inherent in the concept.

However, regardless of level of awareness of the concept, patient and family members demonstrated strong opinions about the components that underpin a medical home. When asked to rate components of medical home in order of importance, patients and family members identified the component they most often had difficulty with as the most important. For parents this was access; obtaining an appointment when needed for their child was critical. For youth, this was comprehensiveness of care; being treated as a whole patient, with attention paid to their full life, was critical to their feeling a sense of trust and satisfaction with provision of care.

Communication issues were identified as a barrier to the realization of the medical home concept by both youth and family members who participated in focus groups. Caregivers cited communication challenges as *the* reason their child's practice did not meet the definition of a medical home.

Practices appear committed to implementation of various components of medical home, even if not universally convinced that pursuit of formal recognition as a medical home is an undertaking currently worthy of the effort required. Practice members who participated in the focus groups clearly articulated some of the challenges practices face day to day, including adequacy of staffing and insurance reimbursement. Not surprisingly, practitioners identified some of the same challenges as patients and

families; from communication issues, to limited appointment duration. Despite challenges, practitioners also shared examples of efforts to improve patient access, as well as to provide continuous and coordinated care.

Both family and provider surveys identified health care transition as an area in need of improvement. Adult providers also reported lower levels of comfort with a number of pediatric conditions; something that may be addressed by providing additional information and increased access to knowledgeable specialists as part of the transition process.

In summary, the information so generously shared by patients, family members and providers painted a picture of a health care delivery system working well in many aspects, and opportunities for growth in others. We can't help but hear the voice of the parent who lamented that "medical home didn't seem as central to practice" any longer. In the evolving landscape of healthcare, it seems apparent that for families, practice in accordance with the components, regardless of what it is called, is key.

## Recommendations

### 1. IMPROVE AWARENESS REGARDING MEDICAL HOME

#### Practice Level

- **Explain practice goals for care delivery.**
  - Family members suggest the medical home concept be part of the conversation with practice staff; specifically, what it means for delivery of care in the practice.
  - In addition to conversation, posters, new patient packet materials, and evening workshops by office staff were suggested.
- **Invite patients and family member feedback regarding their experience.**
  - Family members suggest being asked “How is this working for you / your family?” periodically, *not* via survey, but in discussions over time.

#### Community Level

- **Disseminate information regarding medical home to improve awareness, increase expectation of care and activate patients as partners.**
  - In addition to practice-based education, caregivers recommend using short, web-based videos or virtual training modules.
  - Youth recommend using YouTube, and conducting outreach to community providers to help spread awareness to other youth, such as school nurses.

### 2. IMPROVE AWARENESS OF RESOURCES

#### Practice Level

- **Ensure awareness of internal resources.**
  - Family members noted that practices often offered supports not all family members were aware of, such as care coordination, or extended office hours.
- **Ensure connection to external resources.**
  - Family members felt that primary care providers could help to address the disparities of awareness of and access to community-based resources faced by families sharing similar needs if primary care offices took a more central role in sharing this information.

#### Community level

- **State and community-based organizations collaboration with practices.**
  - Partner with practices to maintain up to date resource repositories, but also to supplement practice-based services and supports (such as external care coordinators, family support coordinators).

### 3. ADDRESS CAPACITY OF PRACTICES TO MEET COMPONENTS

#### Practice Level

- **Continue efforts to maximize access to appointments when needed.**
- **Establish processes to identify patients with complex needs and to ensure that alternate providers within practice are familiar with patient.**
- **Ensure access to comprehensive care**
  - For patients who use a wheelchair (larger rooms, access to lifts).
  - For patients who may require extended appointment times to address all needs.
- **Address communication**
  - With families (provide live vs. recorded answer, increase use of secure messaging via patient portal)
  - With external providers, whether medical or community-based. Access to information should be timely, and allow time for provider to review. *Important given increased utilization of walk in clinics such as Convenient MD.*
- **Establish health care transition processes to ensure patients make a seamless transition to adult providers of care.**
  - Develop transition policies
  - Engage youth and families in transition process
  - Provide adult practitioners access to information requested and support identified to increase their capacity to provide care for youth with complex health needs.
    - Transition summaries
    - Access to specialists knowledgeable about conditions(s).
- **Maximize access to care coordination.**
  - Either via practice-based resource or in collaboration with external coordinators.
- **Staff training.**
  - Consider staff self-assessments and training regarding patient and family-centeredness, cultural competence, implicit bias as part of ongoing staff development.

#### Community level

- **State and community-based organizations collaboration with practices.**
  - Partner with health care systems regarding payment reform and reimbursement to ensure adequacy of funding for service delivery in accordance with medical home principles.
  - Support training and utilization of patient and family members as advisors in ongoing quality improvement initiatives to further medical home implementation.

The Medical Home Project, and its funder, Title V's program for Children with Special Health Care Needs, remain committed to supporting patients and families in their full understanding of the medical home concept, and to the practices dedicated to meeting primary health care needs. As such, we are available to provide information and / or technical assistance to realize the partnership needed to fully realize this model of care.

In closing, we again note that the sample size for each target audience was small, and as such, provides just a glimpse of the medical home experience in the state of NH in 2019. The effort, and the findings do however provide the Medical Home Project with additional areas of interest for future inquiry. Additionally, as the majority of the survey questions are captured in graphics, a decision was made to not include copies of the three surveys or the focus group script in this report. If interested in reviewing these materials, please contact NH Family Voices to request them.

