

Maternal Child Health Block Grant Needs Assessment



Family Survey 2024



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New Hampshire Family Voices (NHFV) was asked to engage family perspectives as part of the Title V Five-Year Needs Assessment. In planning for engagement efforts NHFV staff worked closely with the Bureau of Family Centered Services to ensure their desired topic areas for inquiry were addressed.

The primary means by which NHFV ultimately obtained family input was a survey, using Survey Monkey. While virtual focus groups were also offered, they yielded few participants. A concerted effort was made to align both the survey and focus group questions, where possible, with the Blueprint for Change and the National Survey of Children's Health.



Access to Services



Paying for Services



Quality of Life

The number of questions necessary to ascertain the desired information resulted in a lengthy survey. In an attempt to reduce burden respondents were asked to choose one of three priorities, and answer questions related just to the area chosen - access to the services needed for their child, paying for services needed for their child, or quality of life and well-being for their child and family. Families were provided the option to include their contact information if they wanted to provide additional input.

NHFV's goal was to reach a broad range of caregivers having a CYSCHN under the age of twenty-one. NHFV relied on the Maternal and Child Health Bureau definition of children and youth with special health care needs (CYSHCN), as children who "have or are at increased risk for a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that is required by children generally" in determining the target audience.

Survey Distribution

In addition to attempting to address survey length and ensuring wide-spread distribution, protecting response integrity and reducing infiltration by "bots" were important final considerations. Multiple collectors were created to allow for distribution tracking, and to provide the ability to shut down a single collector if it became compromised. A difficult decision was made to not include an offer of an incentive in any marketing, to reduce the likelihood of bots. While this likely decreased participation, it did prevent false responses via bots.

Internally, NHFV utilized social media (Facebook) as well as email to distribute the survey. As NHFV is part of the Parent Information Center (PIC), we had the opportunity to amplify distribution via their social media, and the combined PIC / NHFV *Pass It On* newsletter list.

NHFV also worked with partners to distribute the survey. BFCS emailed the link to all families currently enrolled in services, as well as those who had been discharged in the past year. MCH included a link to the NHFV family survey in their survey. Other community agencies, while notified via email of the survey, were more inclined to share the social media post than to distribute the survey via email directly to families.

Focused Outreach

Additionally, NHFV hired two per diem staff to conduct community outreach in order to obtain input from families unlikely to be reached via the survey. Both staff members are parents with lived expertise, have native languages other than English, and are connected to communities of families who have come from other countries. They were supported to obtain input in whatever manner worked best for their community-hosting focus groups, attending existing meetings, facilitating survey completion or conducting interviews.

They employed a variety of outreach methods, such as phone calls, interviews, distributing flyers in the community, and attending community meetings. They connected with about forty individuals, and obtained an additional fourteen complete survey responses. They also reported back common threads they heard during their outreach. As trusted members within their respective communities they were able to engage families whose perspectives might not have otherwise been captured.

Opportunities for Additional Feedback

In addition to the efforts of the per diem staff, outreach was conducted to the sixty-eight survey respondents who had identified a willingness to provide additional feedback. The individuals were contacted and provided three additional options to participate. Twelve provided additional responses to the survey (completing a different priority area); and four participated in interviews. In addition, virtual focus groups were set up over a span of two weeks, with varied times, and advertised via NHFV social media. In addition, the focus group flyers were shared with all participants who indicated an interest in providing additional feedback. Six people registered to attend a focus group via zoom, and of those, only three attended. An additional six families confirmed intent to participate in a 1:1 interview, and of those, only two attended.

Data Analysis

In preparing to write the report, data was reviewed by three individuals, three staff within NHFV and a LEND intern, to identify key themes among open-ended responses. Coding of “other” responses to ensure accurate counts within graphs was conducted by one NHFV staff member and a LEND intern.

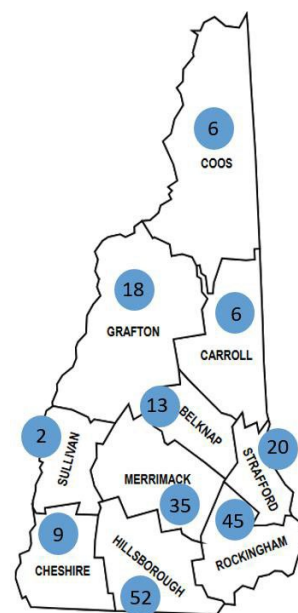


Figure 1: Responses by county N=206

251

Responses included
in analysis

As of the date of analysis, 308 people had entered the survey. Of this fifty-seven were ultimately excluded, as the respondent had either only answered the first question, identified themselves as a professional rather than caregiver, or identified that their child was over the age of twenty-one.

Responses were received from all counties in New Hampshire, at higher rates than shown in the map. Unfortunately, of the 251 responses included in further analysis, forty-five did not identify their county. These were all early respondents, and partly as a result of an oversight to make the county field mandatory, an error that was caught when reviewing responses after the first day of launch. We had purposefully not made the zip code mandatory to allow for increased anonymity where desired, but hadn't anticipated respondents would skip identifying their county.

RESPONDENTS



Children Represented

The children of respondents were varied in age, race, ethnicity, and chronic health condition and / or disability, providing a small but diverse sample of children with disabilities in New Hampshire.

Gender: 57% of the children were identified as male, 36.2% as female, 1.5% as non-binary or gender diverse, and 5.3% not identified – as parent preferred not to answer.

Age: 12.4% of the children were under the age of three; 23.9% were between the ages of three and six; 17.4% were between the ages of seven and ten; 8.0% were between the ages of eleven and thirteen; 25.9% were between the ages of fourteen and seventeen, and 12.4% were between the ages of eighteen and twenty-one.

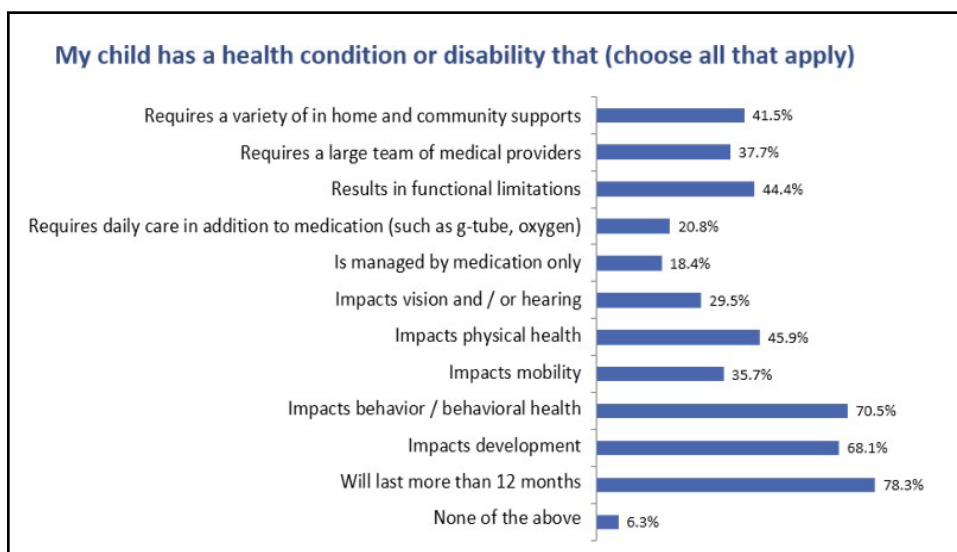


Figure 2: Child's health condition or disability **N=207**

Of the 210 families who responded to the question regarding their child's overall health, thirteen replied that their child had "none of the above", fifty-eight chose between one and three options, seventy-nine chose between four and six options and sixty respondents chose seven or more of the above options.



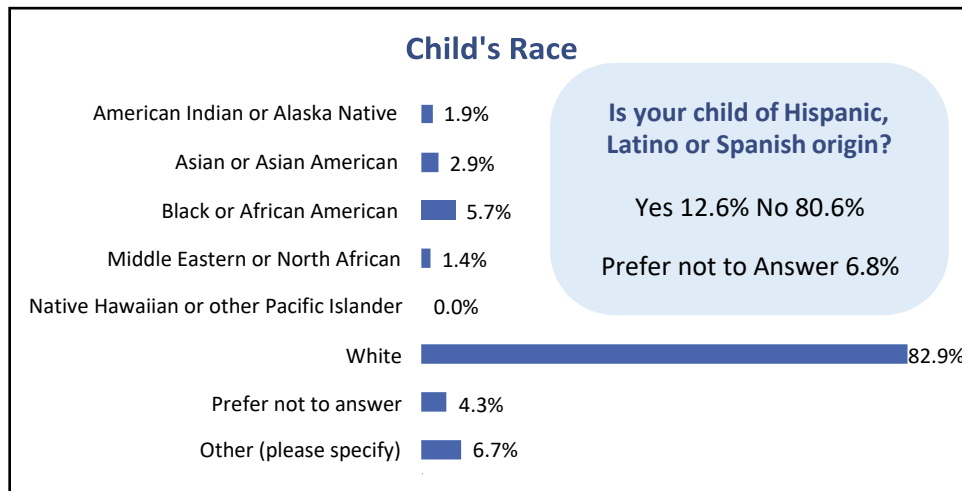


Figure 3: Child's Race N=220

Respondents were able to choose more than one option. The 6.7% “other” responses included Brazilian, Lebanese, as well as mixed race answers.

Additionally, the children were covered by a mix of health care funding options, and utilized a variety of services, again providing a diverse snapshot of children represented.

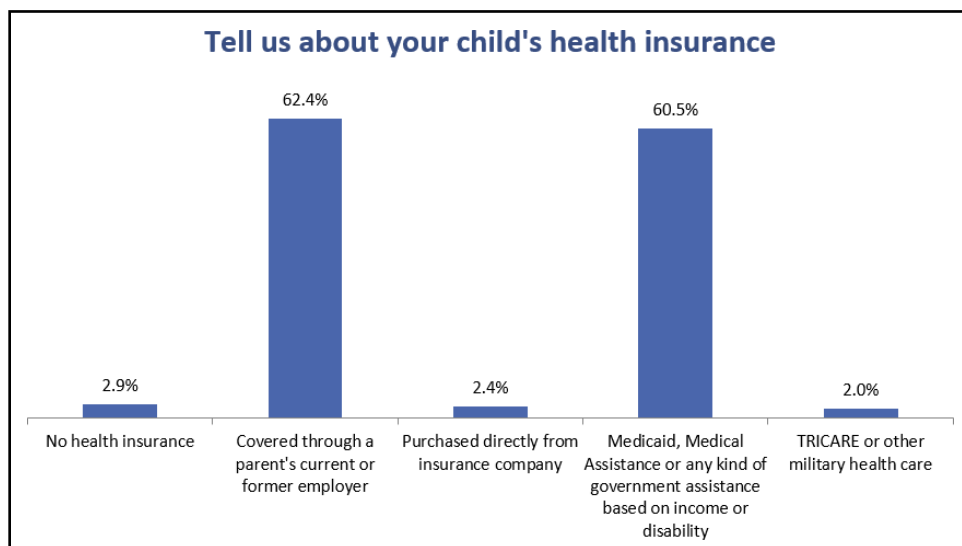


Figure 4: Child's Health Insurance N=205

Respondents were able to choose all insurance options that applied for their child. Of the respondents, 65 had Medicaid only, 77 had insurance through a parent’s employer, purchased from insurance company, or TRICARE only, and 57 respondents had Medicaid in addition to other coverage, and 6 who were uninsured.

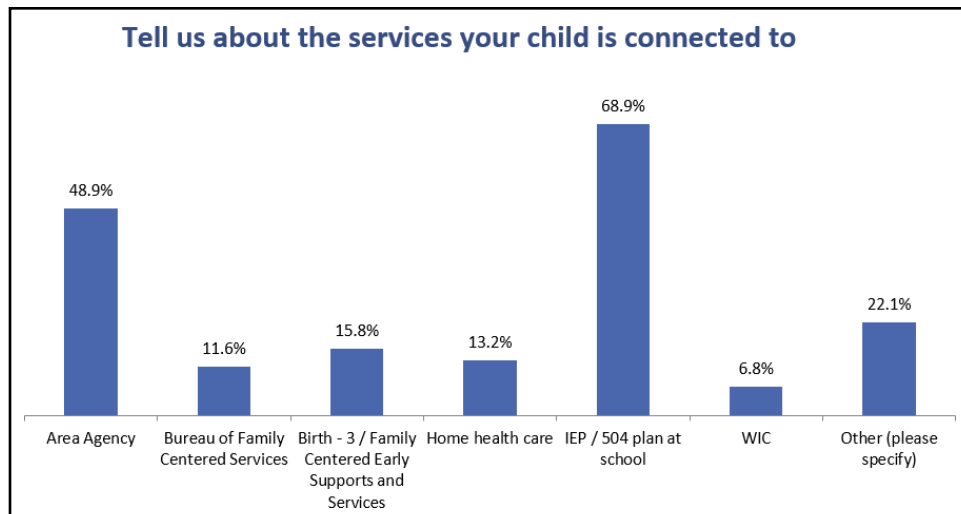


Figure 5: Services child is connected to **N=190**

“Other” responses included Mental Health services, DCYF, therapies such as PT, OT, and ABA, the Complex Care Network, Health Care Coordination / PIH, Fast Forward, Wrap Around, START, GSIL, and Vocational Rehabilitation. Some comments reflected they were not connected to any services.



Respondents identified accessing a number of community resources to meet the needs of their family.

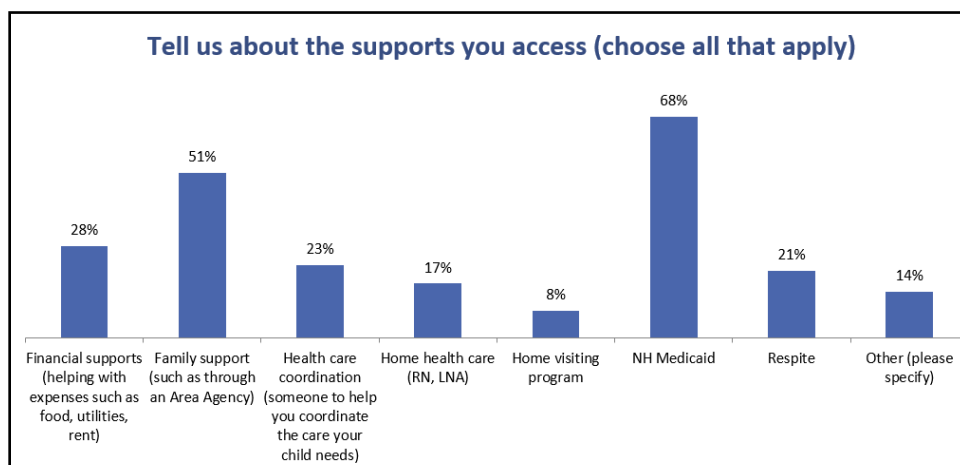


Figure 6: Supports family accesses N=155

“Other” responses included peer support, school, grants, case management, and Vocational Rehabilitation. Some comments reflected denials and a lack of support.

Families identified that meeting the health needs of their child has a significant impact on employment in their household.

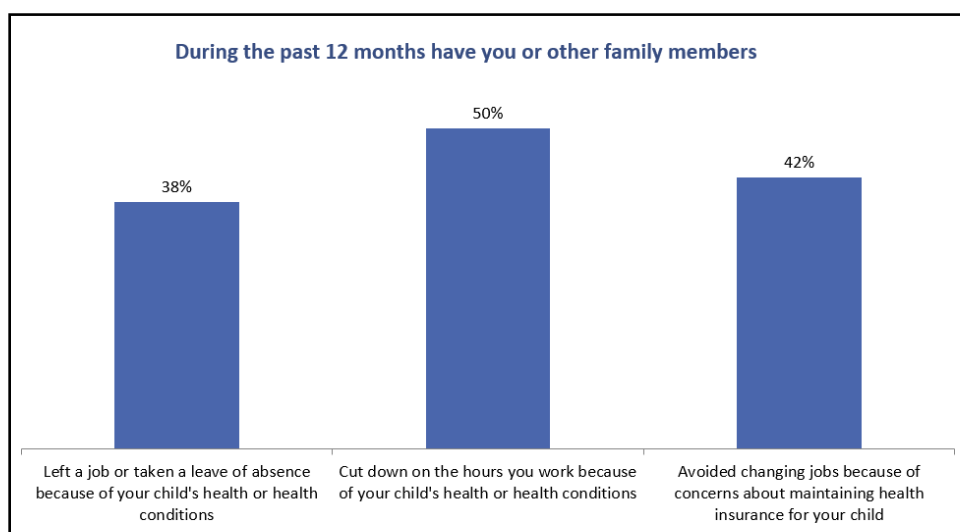


Figure 7: Impact on employment during past 12 months N:131

“It was financially difficult to find a job around my children being home from school sick and my husband’s work schedule. Lack of appropriate and trustworthy PCA’s is a huge factor.”



As touched upon at the beginning of the report, respondents chose one priority and answered questions related to that area. More than half of the respondents chose to answer questions related to access to services, demonstrating how vital these services are to their child and family. Just over a quarter chose to answer questions regarding quality of life and well-being, and the remainder answered questions regarding paying for needed services for their child.

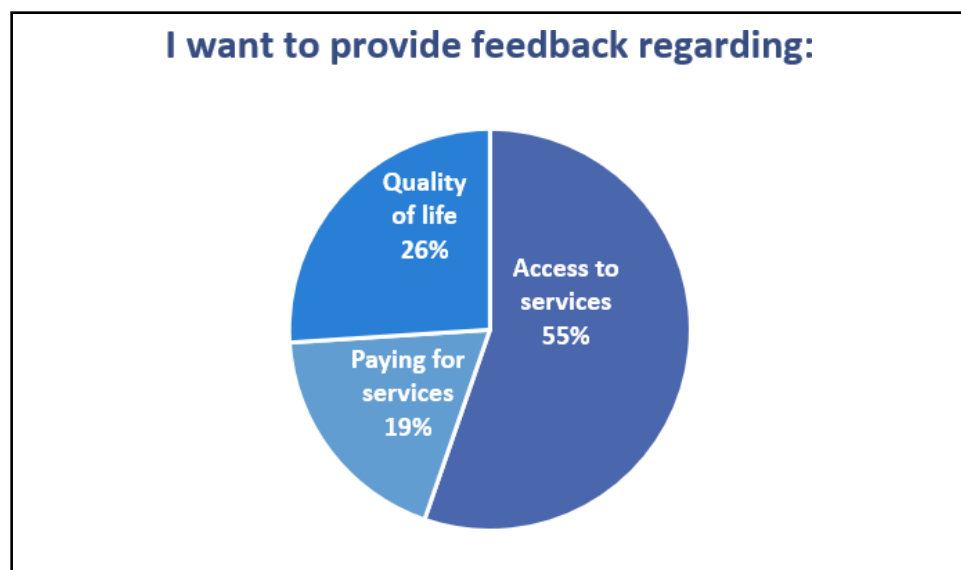


Figure 8: I want to provide feedback regarding N=251

We want to note that respondents were very generous with their time, with many providing detailed comments where possible throughout the survey. This report will highlight key themes and include de-identified comments where appropriate to illustrate the breadth of the feedback provided, but will not include all comments in entirety.

As we reviewed the data, we also took a deeper look into whether the presence or absence of factors impacted answers. As an example, did families who reported having access to care coordination respond differently than those who did not? Did families who reported having commercial or private insurance report differently than families who have Medicaid? Comments regarding any observations to these inquiries are included following the corresponding questions and graphs. It should be noted that these are observations made based on small numbers; but may be important for ongoing needs assessment work.





Health Care

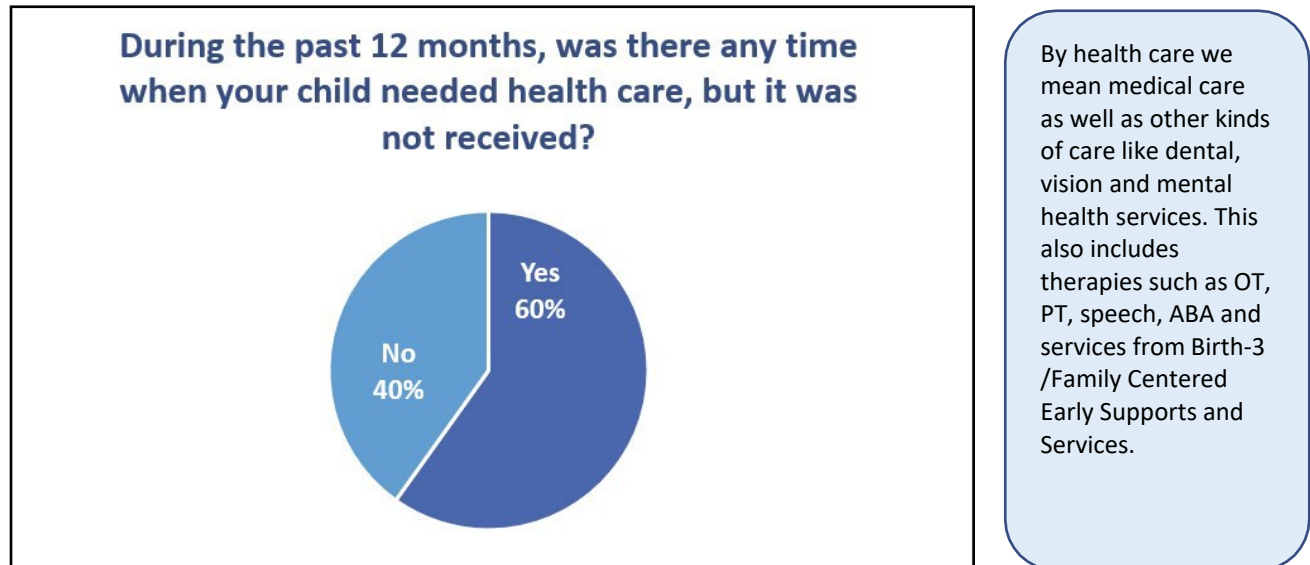


Figure 9: Child needed health care, but it was not received **N=147**

Those with and without access to care coordination responded nearly the same to this initial access question.

Those with Medicaid answered that needed care had not been received at a higher rate (65%) than those with commercial insurance (53%).

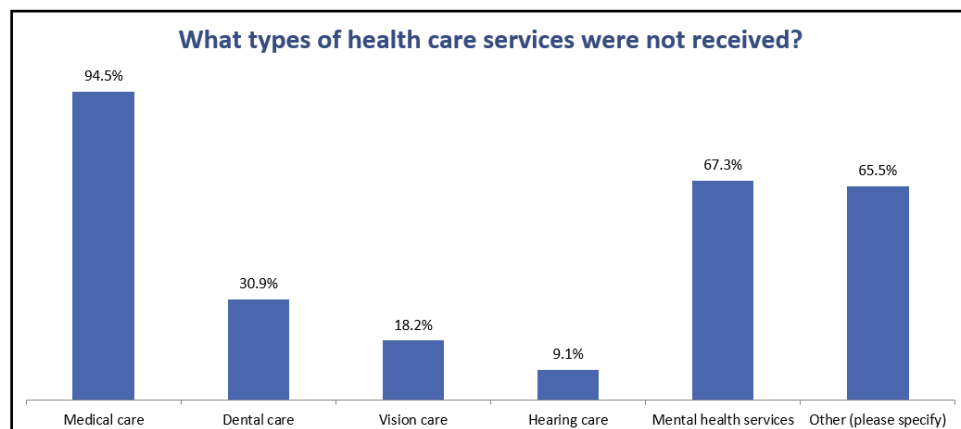


Figure 10: Health care services not received **N=55**

Most prevalent “other” responses included Occupational Therapy (OT) /Physical Therapy (PT) /Speech Language Pathology (SLP), Applied Behavioral Analysis (ABA), Nutrition and feeding services. Other responses included school-based services, developmental screening, Birth-3 / Family Centered Early Supports and Services, family support, and caregiver training.

The types of health care services not received reported differed based on whether the family had access to care coordination.

Those with care coordination identified an inability to access medical care (35%) and mental health services (60%) slightly less often than those without care coordination (medical care 42%; mental health services 68%).

Those with care coordination identified an inability to access dental care at a higher rate (40%) than without care coordination (26%).

The types of health care services not also received differed based on insurance coverage for the child. Those with Medicaid reported an inability to access dental and vision care at higher rates than those with commercial insurance. Those with commercial insurance reported an inability to access medical care and mental health services at a higher rate than those with Medicaid.

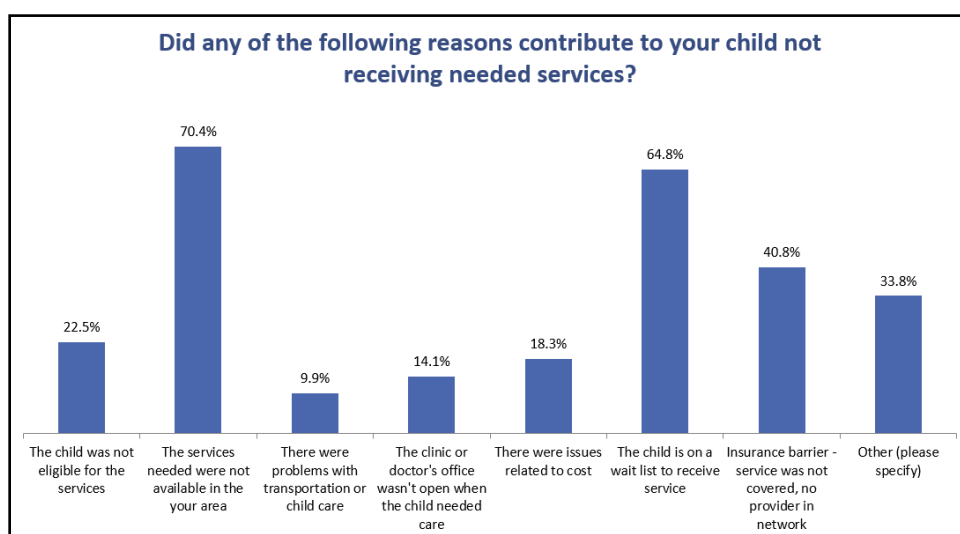


Figure 11: Reasons contributing to child not receiving needed services N=71

“Other” comments provided detail that reflect capacity issues –lack of available providers, appointments when needed, insurance contractual barriers and limitations, Medicaid transportation limitations.

The barriers identified by those with and without care coordination differed.

Respondents who reported having access to health care coordination more often identified the child was not eligible for the service, or the services needed were unavailable. Those without care coordination identified wait lists and insurance barriers at significantly higher rates.

Respondents who reported their child’s coverage being Medicaid reported the child not being eligible, issues with transportation, and insurance barriers at much higher rates than those with commercial insurance. Those with commercial insurance reported wait lists at much higher rates than those with Medicaid.

When we asked families to “tell us more” about the needed medical care they were not able to obtain for their child, many of the comments focused on behavioral health, school-based services, and access to ABA. Across services the long wait lists and insurance were identified as significant barriers to care. Challenges with transitions to adult care and service delivery systems were also identified.

"His PCP referred us to have him tested for developmental delays, we received and filled out paperwork for them and turned it in within a few weeks. We recently received a letter from them saying that the wait list is over a year and that we are in line. This is what we have been told by almost all of his doctors and any place that they refer us to for extra help."

"Feeding and Speech therapy have been very disjointed and not consistent. He was seen at an outpatient facility and released once one goal was achieved. We then had to get multiple referrals afterwards, waiting 3 months each time to be seen."

"My son needs epigenetic testing that [MCO] won't cover and Boston Children's has no alternative funding for. We don't have 50k+ to pay out of pocket. He also needs behavioral therapy but there are no providers that take [MCO] and are accepting new patients. He needs dental work too, but there are no dentists that take Medicaid and will work with his needs. He also needs to see a developmental pediatrician, but again there are no providers available."

"Unable to find an eye wear provider that will honor glasses coverage. We see an out of state provider (Boston Children's) and I can't find anyone in NH that will allow me to use their Rx to buy glasses, so I always have to pay out of pocket! Wish you'd allow reimbursement for online providers!"

"My son lacks social skills and has defiance and behavior issues which makes home life very challenging. I have tried two other parent training therapists but have now been referred for RUBI training but I am on a wait list. We tried home ABA without success and now want to try ABA at a clinic with his peers but the wait has been over 1 year and still waiting."

"Behavioral analysis was not available due to a shortage in NH. Early intervention was key and we had to pay for a neuropsychological eval in Boston. The regular eval would have been covered by insurance but neuropsychological was not."

"Later we needed occupational therapy to include hand writing. Insurance pays for general occupational therapy but nothing that would help a child learn to write. The reason provided is that they can get this through the school district. This is not true. You only get this if your child qualifies for services. My school district refuses so my 8-year-old write with reversals and his penmanship is illegible. I can't afford the therapy or the lawyer needed to challenge the school."

"Many pediatric providers (such as PT OT SLP) end on 18th birthday and then you feel as if you are in a black hole to get the needed services for your "adult child."



“[The community mental health center] will not schedule admission appointments in advance for new patients. Instead, a new patient must show up before they open in the morning, to wait in line hoping to be lucky enough to get one of the handful of new patient appointments available that day. I had to get my disabled adult child there at 7:30 am, before they opened at 8:00 am, to line up standing outside their locked door. (The bathroom was also locked, making the wait very uncomfortable.) A few minutes before 8:00, a receptionist handed out numbers to those of us waiting in line. As the first in line, we were able to get one of the FOUR new patient appointments available. This was our second attempt at getting a new patient appointment. All of this effort was required just to get an interview with an admissions counselor. After a two-hour interview, we were told the next day that there were no providers with experience with autism who could help my child, and he was referred to [Area Agency] for services.”

“For the last month, even with the help of his case management team, we have been unable to find a mental health provider who does medication management, who accepts [MCO], and who is accepting new patients. My son is stable and not aggressive on medication. Without medication, he is a threat to himself and others. The medical care my child needs was not only difficult to access, it is totally unavailable!”

We then asked respondents to discuss medical care their child had received in the past year, but that had been difficult to obtain.

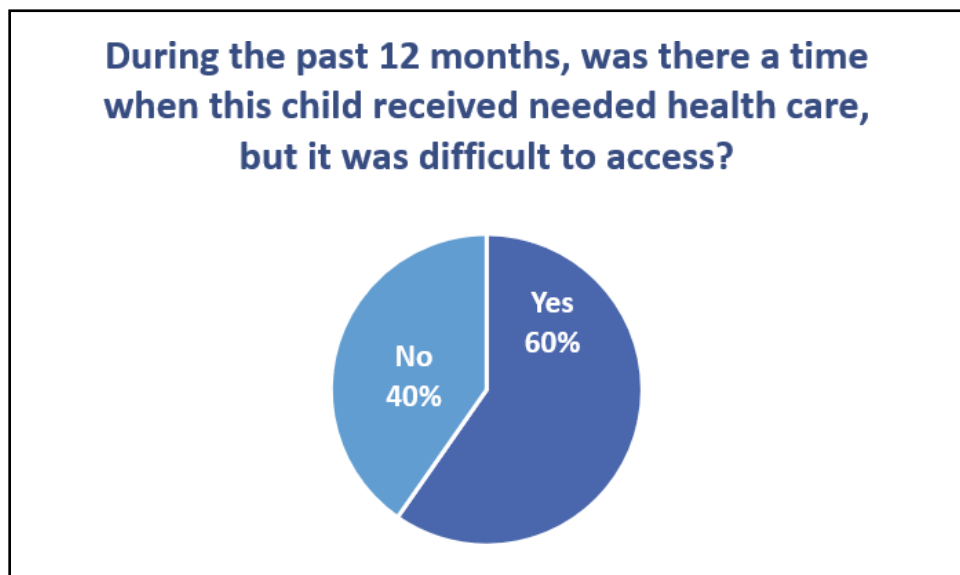


Figure 12: Difficulty receiving needed health care **N=134**

Those with and without access to care coordination responded nearly the same to this question, with those without care coordination responding 3% higher.

Those with commercial insurance and Medicaid responses were close, with those with commercial insurance responding 5% higher.

Health Care Received but Difficult to Access

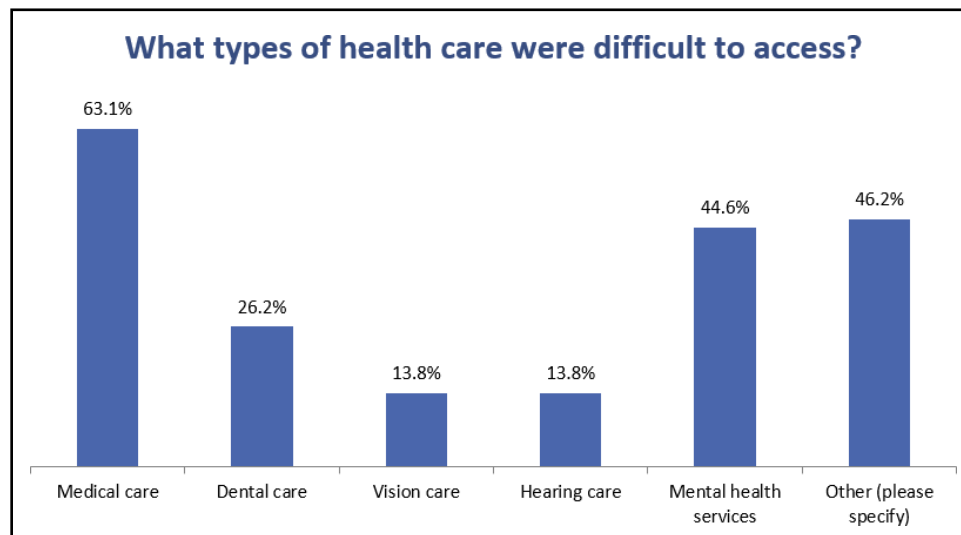


Figure 13: Types of health care difficult to access N=65

“Other” comments were largely medical, with families reporting difficulty with access to OT/PT/SLP, ABA, and Nutrition services, in order of frequency. Access to developmental screening and evaluation, access to specialists, DME/medication, and school supports were also noted.

As in the case of medical care families were unable to access, the types of care reported as being difficult to access differed based on access to care coordination.

Families with access to care coordination continued to report access to dental care at much higher rates than those without (39% to 20%).

Those without access to care coordination reported difficulty accessing mental health services at significantly higher rates (50%) than those with care coordination (26%). Difficulty accessing medical care came in slightly higher (55%) for those without care coordination than for those with access to coordination (48%).

Those with Medicaid reported access to dental care as an issue more often (29%) than those with commercial insurance (22%), while those with commercial insurance reported access to hearing services higher (17%) than those with Medicaid (9%).



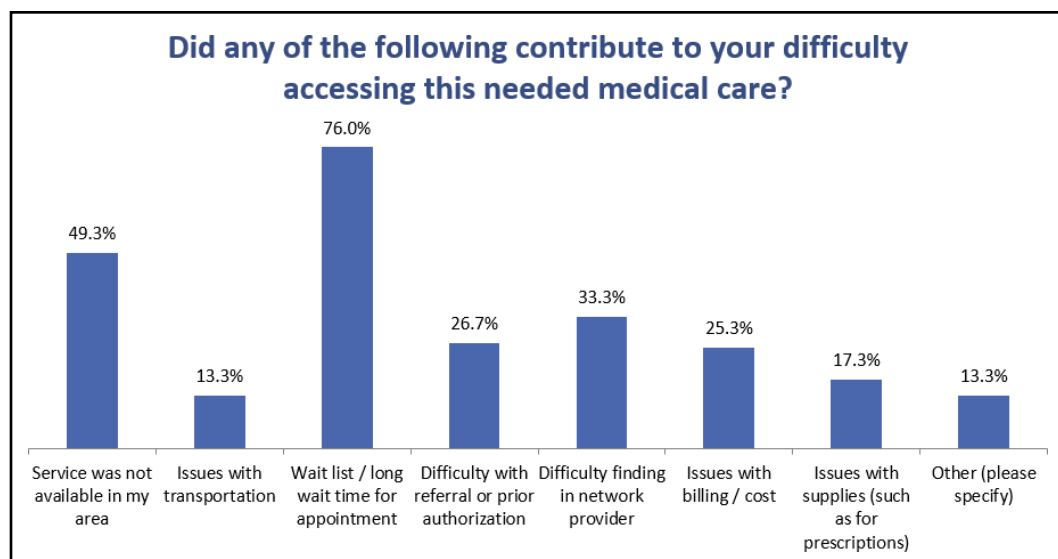


Figure 14: Reasons contributing to difficulty accessing needed medical care N=75

Families that were able to access OT/PT/SLP, ABA, and Nutrition services did indicate they were difficult to access. Additionally, they indicated that developmental screening and evaluation, access to specialist, DME/medication and school supports were difficult to access. Families also provided commentary on difficulty accessing care due to staffing issues, eligibility, issues with identifying appropriate providers, and navigating insurance coverage.

Families with access to care coordination identified transportation as a barrier far more often (20%) than those without care coordination (6%). Families with care coordination also identified issues with referrals and prior authorizations (33%), issues with supplies / DME (25%) more often than families without care coordination.

Families without care coordination identified wait lists at significantly higher rates (82%) than those with care coordination (67%). Families without care coordination also more often identified a lack of available providers than those with care coordination.

Families with Medicaid more often identified transportation, issues with referrals or prior authorizations and billing.

Families with commercial insurance more often identified the service not being available in area.

Wait lists were identified as a barrier at high rates across all insurance types on this question.

When we asked families to “tell us more” about the medical care that was difficult to access in the past year, families continued to describe poor access to mental health services, delayed approvals for and challenges with insurance coverage, and long wait lists for a variety of specialty care. Issues accessing occupational therapy, dental care, vision care, and medications were also raised. Transportation difficulties, which included large distances to see network providers, were highlighted.

“There are limited options for intensive outpatient programs, PHPs, and other group therapy opportunities specifically for adolescents AND within reasonable geographic distance AND geared toward LGBTQ+ teens.”

“There are no hospitals in the area that will provide the dental support in the operating room that is needed due to his complex airway. We waited 2+ years for the procedure at Boston Children’s to be scheduled and it still hasn’t happened. He has two cavities that have needed to be taken care of for 2+ years.”

“Had to change GI doc in Boston. Now on third GI doc. Difficulty scheduling therapy appointments, booking months out. Difficulty getting medication (prior authorization process is a nightmare).”

“I had to advocate for her to get to a specialist to and then for her to have swallow study. After swallow study the specialist recommended we get referral to ENT. Pediatrics office said she wasn’t aspirating and said she didn’t need ENT. I had to go back to specialist... I had to go through the Mass General to get referral to ENT. Due to the delay my daughter doesn’t have her first appointment until December. We got to the first specialist in Jan/Feb so almost a full year for us to get to the right dr.”

Insurance Adequacy

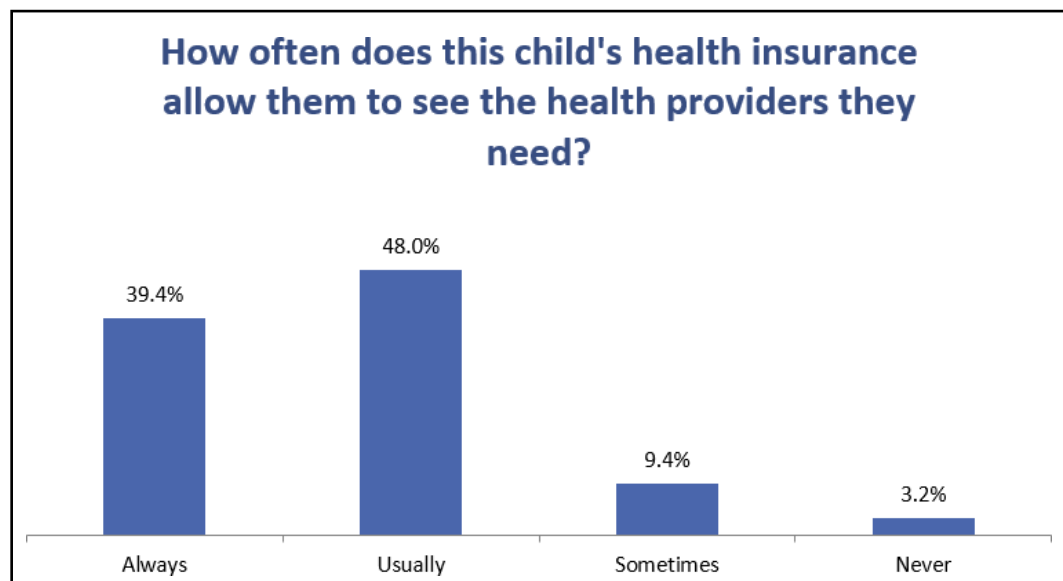


Figure 15: Frequency child's health insurance allows them to see providers they need **N=127**

Those with and without access to care coordination report nearly equal rates of “always + usually” being allowed to see needed providers. This is true across insurance types as well.



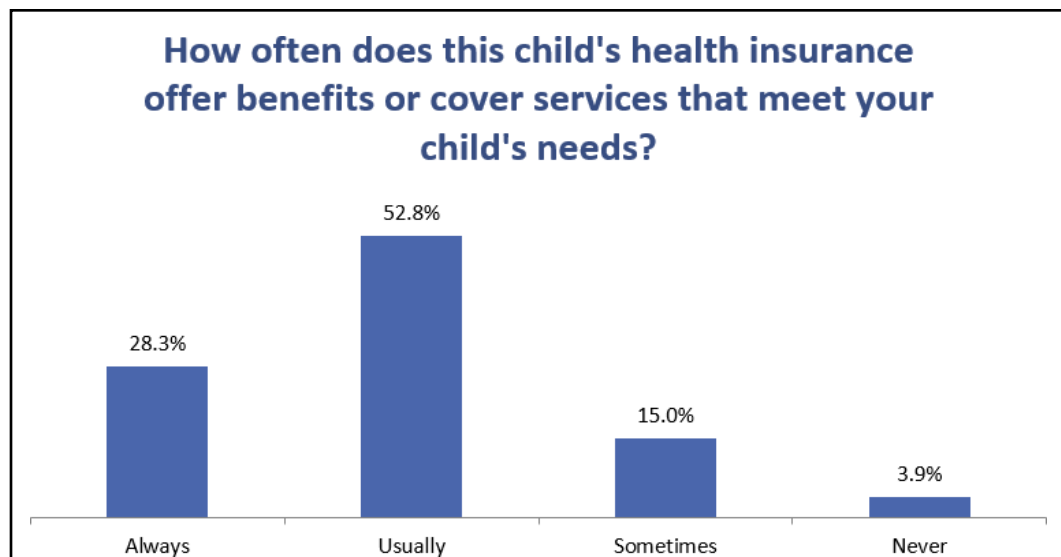


Figure 16: Frequency child's health insurance covers child's needs N=125

Those with care coordination are far more likely to identify that their child's insurance "always + usually" covers needed services than those without care coordination (82% vs 59%).

Those with Medicaid are more likely to report that their child's insurance "always + usually" covers needed services than those with commercial insurance (78% vs 67%).

When asked to "tell us more" about access through insurance, many respondents indicated that the services they need are covered. However, they also identified a number of obstacles to obtaining needed services. These included finding covered/ network providers, distance to those providers, and finding providers who do not have a long wait list. A number of respondents reported that having secondary insurance has been helpful for dealing with the high costs of care, but not all those who needed it were able to get it.

"Our insurance will often "cover" services but typically the services we need like intensive outpatient programs, evaluations or hospital stabilization go toward our deductible which means we are paying thousands of dollars out of pocket for these "covered" services. A recent DBT program cost us over \$4000, a neuropsychological evaluation cost us \$5000 since insurance doesn't cover most of it, and a recent night in the hospital cost us \$1500."

"Dental, pediatric, and vision services are all offered, though finding quality providers that accept Medicaid is a challenge."

"Our network is limited to NH-based providers, though in her medical emergency our insurer offered to cover hospitalization out of state. However, other preventative services we could have accessed that were not available to us in NH were not covered, and therefore were not an option to us."

"I have private health insurance. NH Medicaid picks up as secondary. Coordination of benefits is a nightmare for pharmacy coverage."

Community Services

Services Not Received

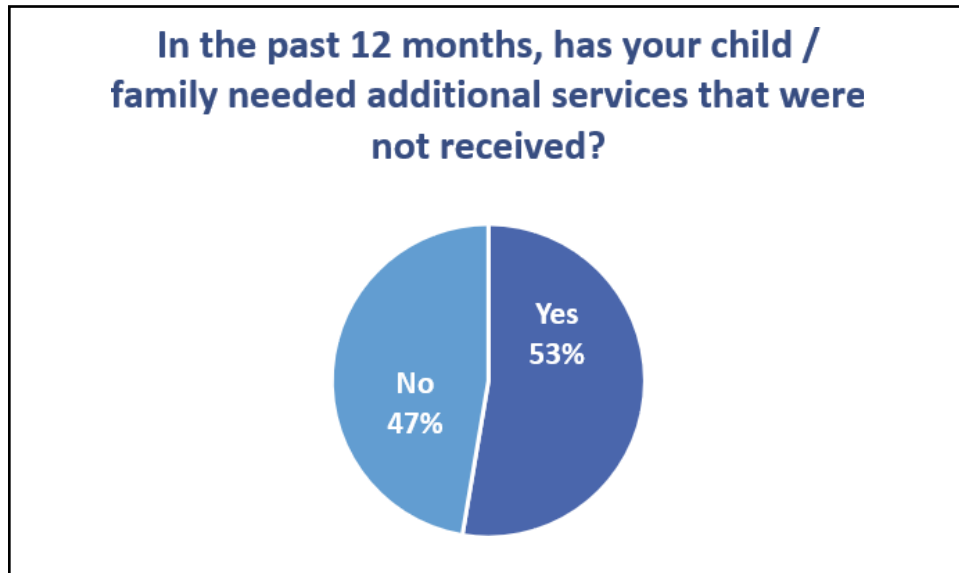


Figure 17: Additional services needed that were not received **N=131**

Families with access to care coordination were slightly less likely to report needing but not receiving additional community services (46%) than those without care coordination (52%).

Families whose child was covered by Medicaid were more likely to identify having needed, and not received, additional services (59%) than those with commercial insurance (42%).

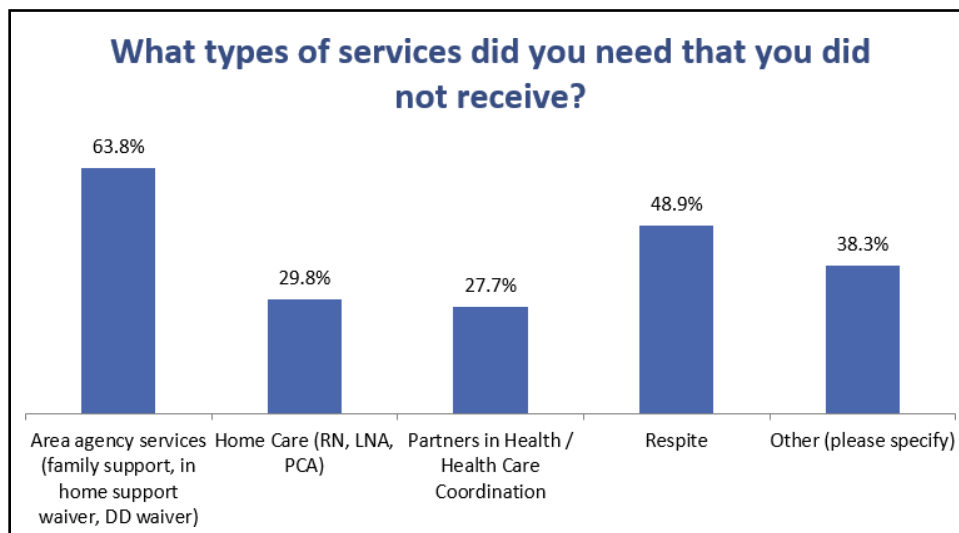


Figure 18: Services needed that were not received **N=47**

“Other” responses included comments about screening and Birth-3 / FCESS, adult services, alternative school placements, special education services, medical services such as OT, PT, SLP, urgent care, and DME.

Families without access to care coordination reported slightly higher rates of not receiving Area Agency services, and home care. There were larger differences regarding respite (48% of those without as compared to 33% of those with care coordination) and access to Partners in Health / Health Care Coordination (36% of those without as compared to 13% of those with care coordination).

Families with Medicaid identified needing but not receiving home care, Partners in Health / Health Care Coordination and respite at higher rates than those with commercial insurance.

When asked to “tell us more” about the services needed that were not received, a majority of respondents commented that they were unable to get in-home support services such as respite due to either being denied eligibility for it or due to a lack of available staff. Respondents also mentioned long waits for approval for services and described the need for improved case management. Others identified barriers to accessing services, such as paperwork and juggling appointments with employment and child care.

“Prior to his high school graduation, my son had support from an in-home mentor and our family had respite services. Post-graduation, and for five months, he had no services whatsoever, because his adult application sat unprocessed until complaints were filed and his case was expedited. It was not because of poor planning on our part. The necessary applications for services (Social Security, Medicaid, Adult Disability) began a year before he graduated.”

“We were denied for Katie Beckett which would have allowed us to apply for In-Home Support. We aren’t sure why we were denied as he has 24/7 monitoring needs, as well as epilepsy. We had IHSS in California for him from a young age when we lived there.”

“We need home staffing but have not been able to get it - perhaps more on a staffing issue side than coverage side. We are exhausted and need help at home in order to keep her out of an institution.”

“It’s hard to get afterschool care coordinated with paperwork and accessing WIC as I need to take time off and bring my two younger children with me.”

“They are difficult to maintain, lots of paperwork, and difficult to access help or services when enrolled. I have given up on PIH and most state services.”

“Still waiting on waiver to be finalized by area agency. Approved through state. No case managers in area for partners in health.”

“I have access to respite but no one to provide it.”

“Homecare staffing (LPN or RN care) despite having flexible open hours and intakes open with 3 nursing agencies.”

“We are eligible for In Home Support, however have not had a DSP since May, so no support and no respite.”

Services Received but Difficult to Access



Figure 19: Difficulty in receiving needed services for child **N=117**

Families with access to care coordination reported “yes” 42% of the time, only marginally better than the 46% reported by those without care coordination.

Families with Medicaid reported “yes” 48% of the time, as compared to families with commercial insurance (42%).

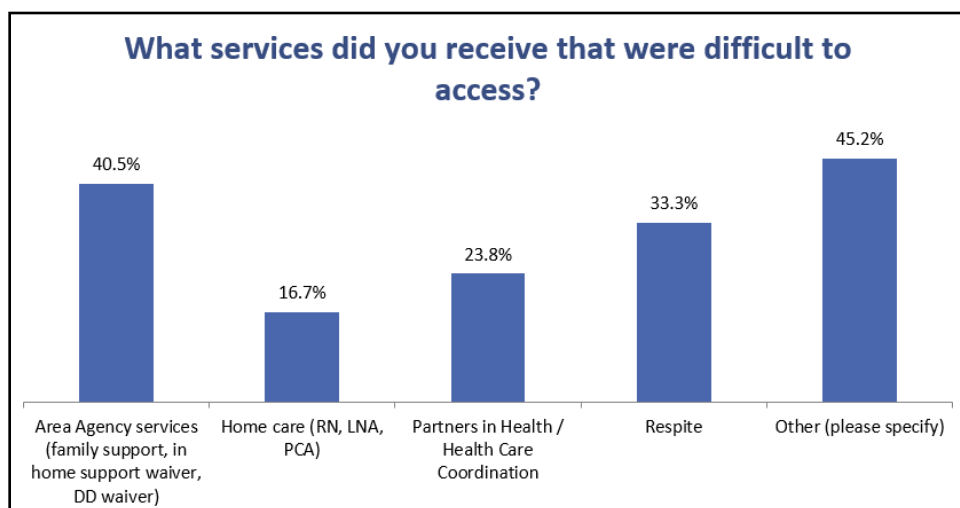


Figure 20: Services received but were difficult to access **N=42**

Families reported difficulty in accessing mental health services, OT/PT/SLP, dental, school supports, and support with transitioning to adult services.

Families with care coordination identified Area Agency, home care and respite more than those without care coordination. Those without coordination identified Partners in Health / Health Care Coordination more often than those with coordination.

Families with Medicaid reported difficulty with all of the above at higher rates than those with commercial insurance, with the highest difference noted in Area Agency and Partners in Health / Health Care Coordination.

When asked to “tell us more” about services they received, but were hard to obtain, respondents continued to describe difficulty with finding in-network providers and with long wait lists. Barriers to state services included the complexity of the application process and lapses in coverage. Several respondents mentioned that they ultimately paid out-of-pocket for the care that was needed because they could not receive it otherwise.

“Behavioral health took a year to call us. We gave up after 6 months and paid \$3000 out of pocket for a neuropsychologist, which was more than what was needed but without answers we could not seek services and early intervention through services is key.”

When asked to “tell us more” about access to the services they needed, and whether any agencies or programs had been helpful, many respondents indicated that their PCP or area agency was instrumental in helping them to navigate care. Others identified the need for more assistance with paperwork and navigating services, and understanding what services their child needs.

“We needed access to the nutrition feeding and swallowing team. [OT from AA] arranged the initial visit as well as setting up speech therapy coming up next month. [AA] is wonderful to work with and everybody truly cares about the kids and their families.”

“It’s really hard to navigate all the resources, and I need to know about them first. I wish it wasn’t so hard to get my kid the help she needs to be successful in her life.”

“The trouble is that we don’t know what we don’t know. We have been trying to figure out what our son needs and the doctors have been steering us in directions they think will help. We know that he needs speech and food therapy, but we need to get an evaluation done for if he has some developmental delays/bigger diagnoses. There has not been a liaison that has worked with us to get us in anywhere or to coordinate anything aside from regular referrals from the PCP and waiting for them to be answered.”

“I need someone to be a link between all the providers and making sure all different pieces get done.”

“I used [care manager] at [MCO] anytime I had questions regarding NH health insurance coverage and she was extremely easy to work with and she always had the info I needed.”

“We have used [Area Agency] and love our case worker. She shows up at IEPs and has been very helpful. But there are things she can’t assist us with and we need additional help.”

“I am the case manager for my child, and there is very little coordination between her providers.”

“My PCP’s office has been very helpful with referrals to specialist.”

Coordination of Services

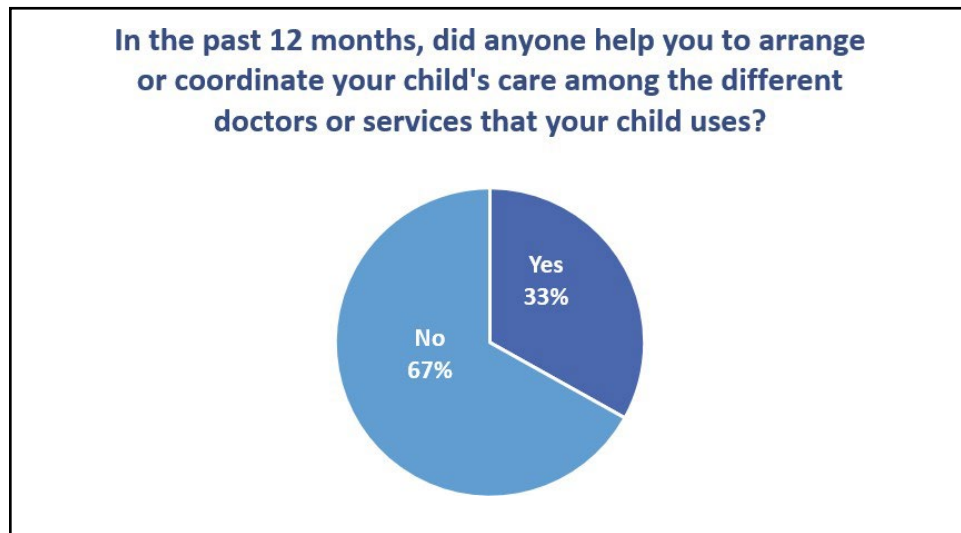


Figure 21: Support coordinating child's care **N=117**

Only 33% of respondents indicated they had anyone to help them to arrange or coordinate needed care for their child. Only minor differences were reported related to access to care coordination by insurance type, with slightly more covered by Medicaid saying yes, and slightly fewer covered by commercial insurance saying no.

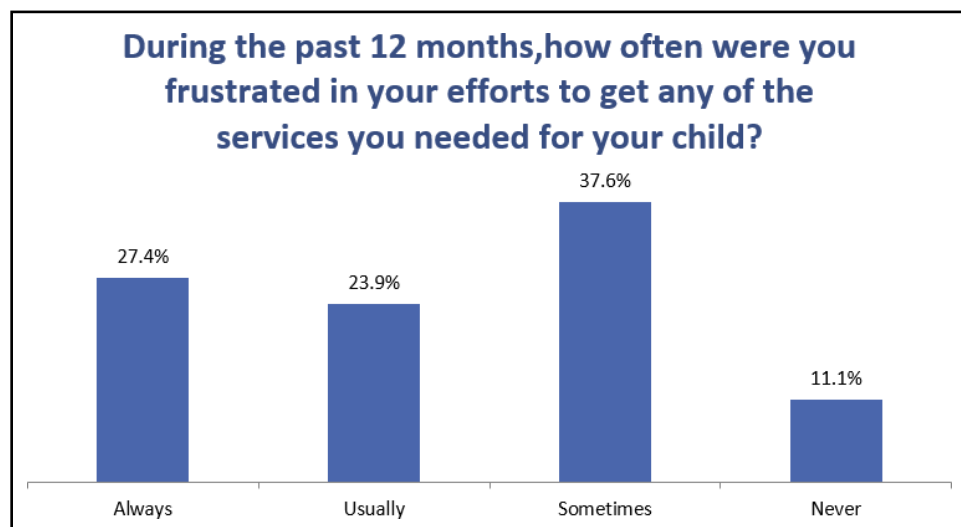


Figure 22: Frustration in efforts to get child services needed **N=117**

Access to care coordination appears to reduce caregiver levels of frustration in efforts to obtain needed service, as those with care coordination answered that they were “always” frustrated less often (18%) than those without care coordination (33%).

Families whose child was covered by Medicaid chose “always” frustrated more often (32%) than those with commercial insurance (23%).

Families with care coordination

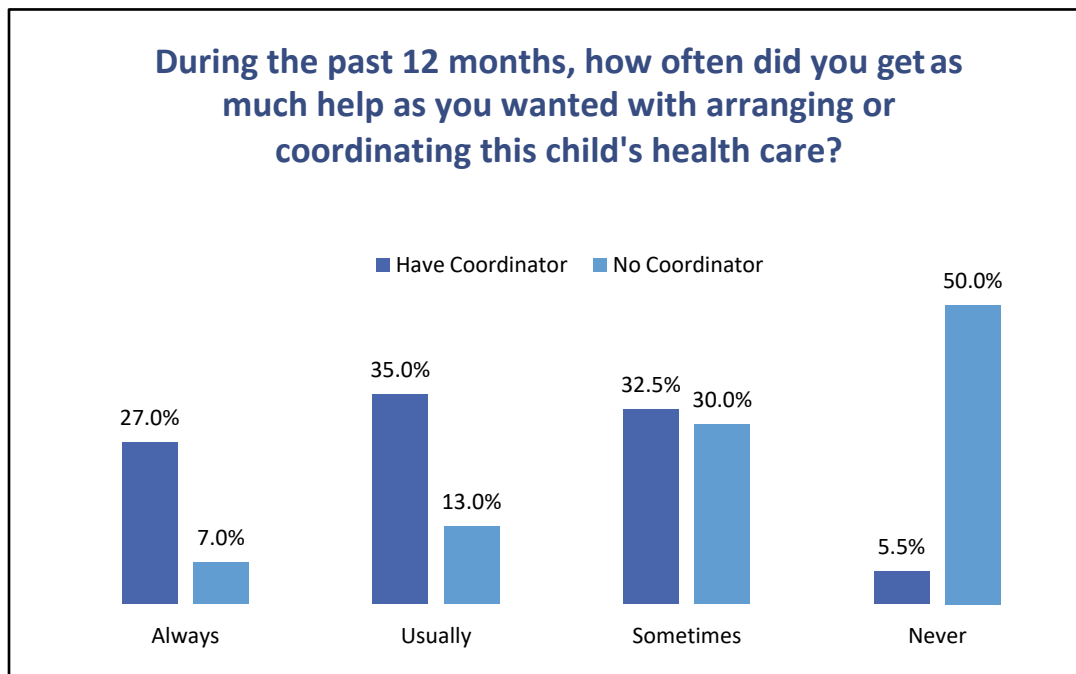


Figure 23: Frequency of getting as much help as wanted **N=111**

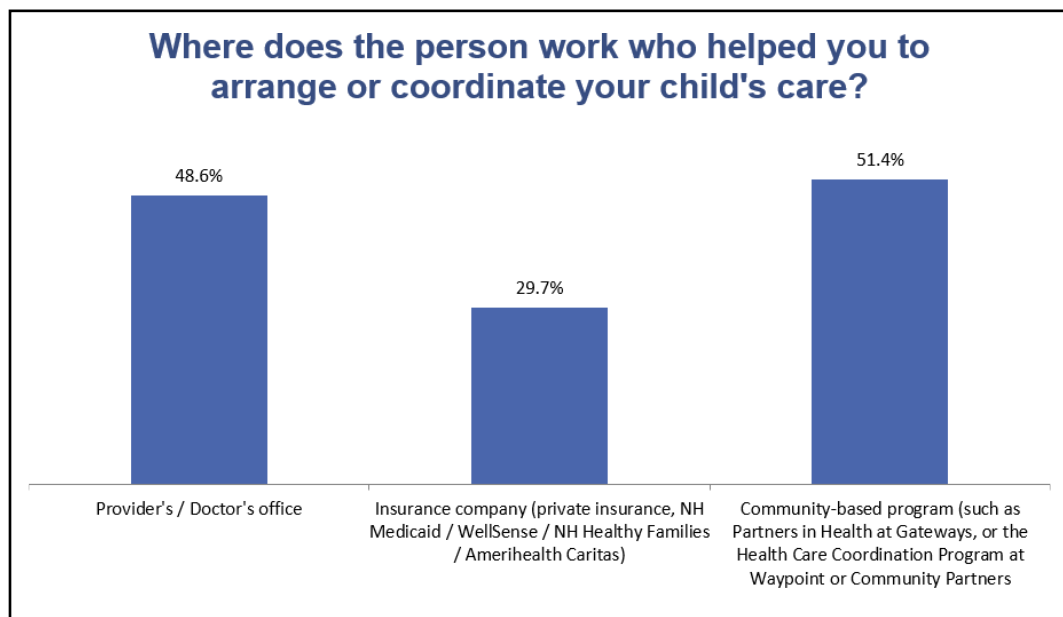


Figure 24: Where person that helped arrange child's care works **N=37**

“Other” comments were moved to existing categories, and “other” option deleted from graph. Most were community-based agencies, including identifying an area agency or Birth-3 Program, the Complex Care Network, a residential school nurse. One response identified a social worker in an acute care setting.

Families covered by Medicaid identified provider's office and insurance company more often than families with commercial insurance. Families with commercial insurance identified community-based program more often.

Paying for The Services



Health Care Coverage

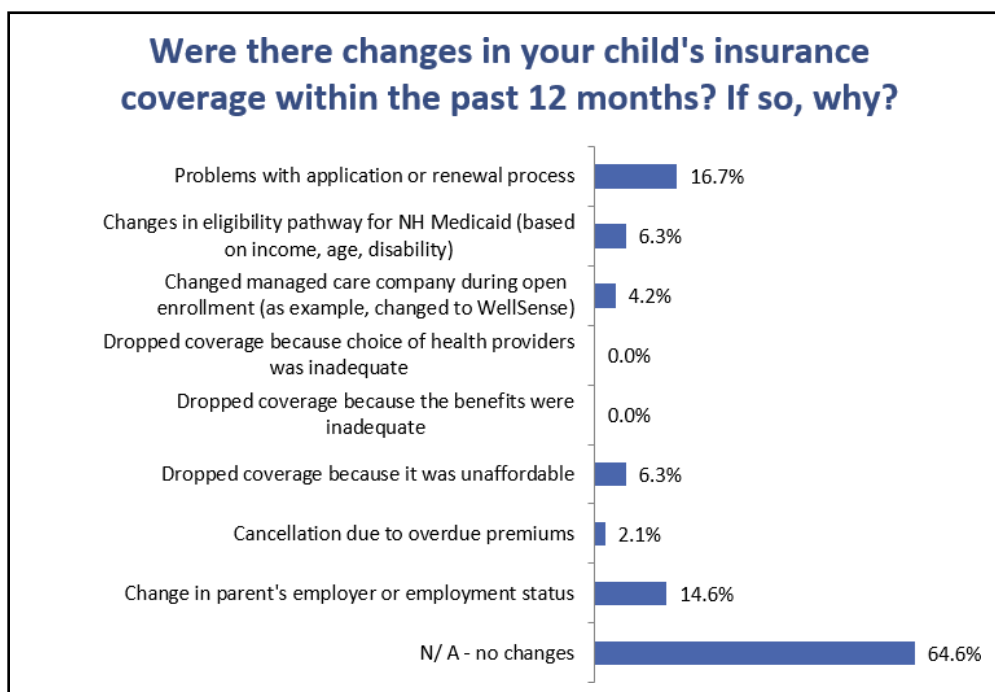


Figure 25: Changes in child's insurance coverage **N=48**

There was not an option to choose “other” on this question, however respondents did leave comments including challenges in applying for HC-CSD, ineligibility due to the child not being an US citizen, and needing support to navigate insurance coverage.



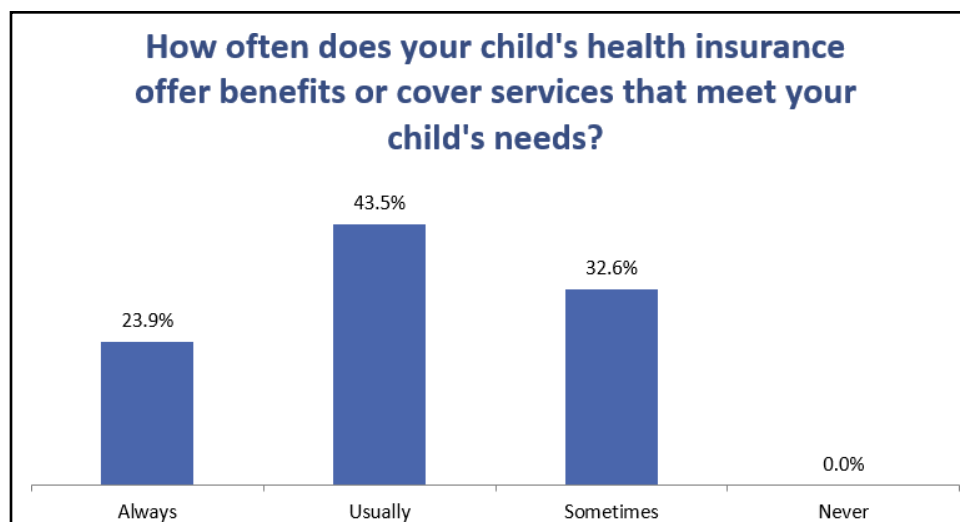


Figure 26: Frequency child's insurance covers needed services **N=46**

Families answered “always” nearly equally across insurance types. Families with Medicaid answered “usually” more often than families with commercial insurance, and families with commercial insurance answered “sometimes” more often than families with Medicaid.

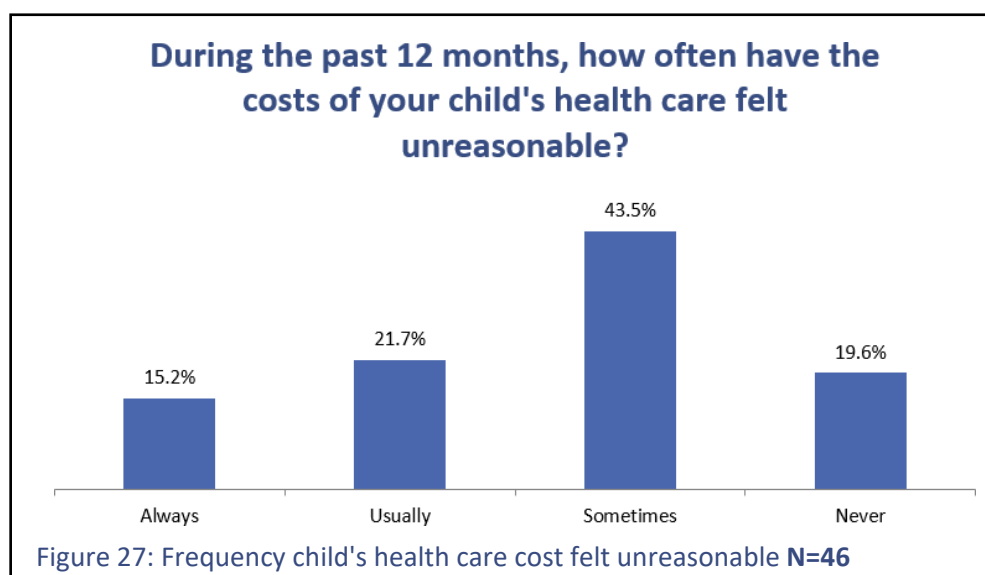


Figure 27: Frequency child's health care cost felt unreasonable **N=46**

Families with commercial insurance are more likely to answer that costs are “always” unreasonable. Likewise, those with Medicaid are far more likely to answer costs are “never” unreasonable than those with commercial insurance.

Health Care Costs

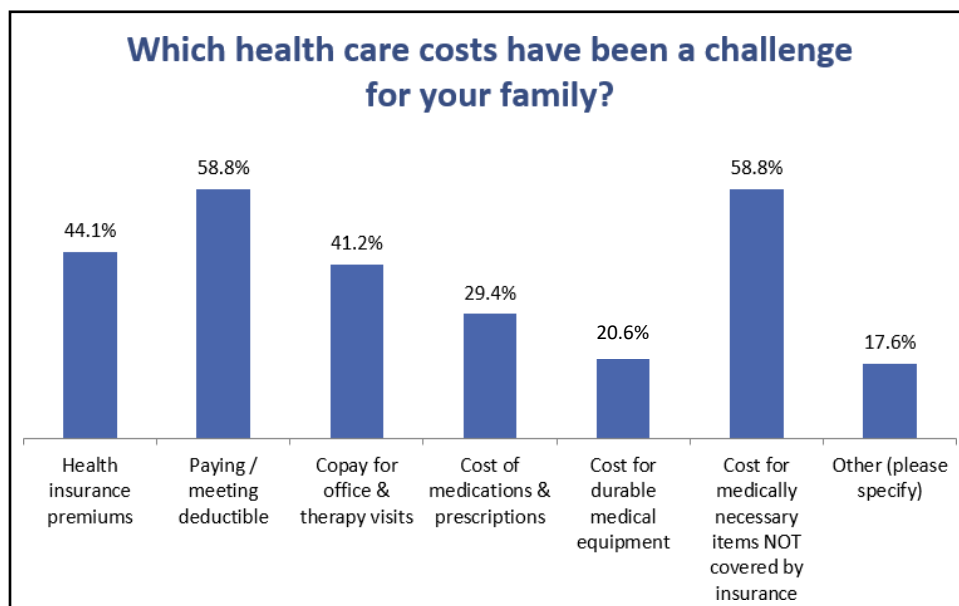


Figure 28: Challenging healthcare costs for family N=34

“Other” comments included paying for services beyond max allowable allotment, services by out of network providers.

Families with commercial insurance identified all but the “cost for medically necessary items NOT covered by insurance” as a challenge at higher rates than families with Medicaid.

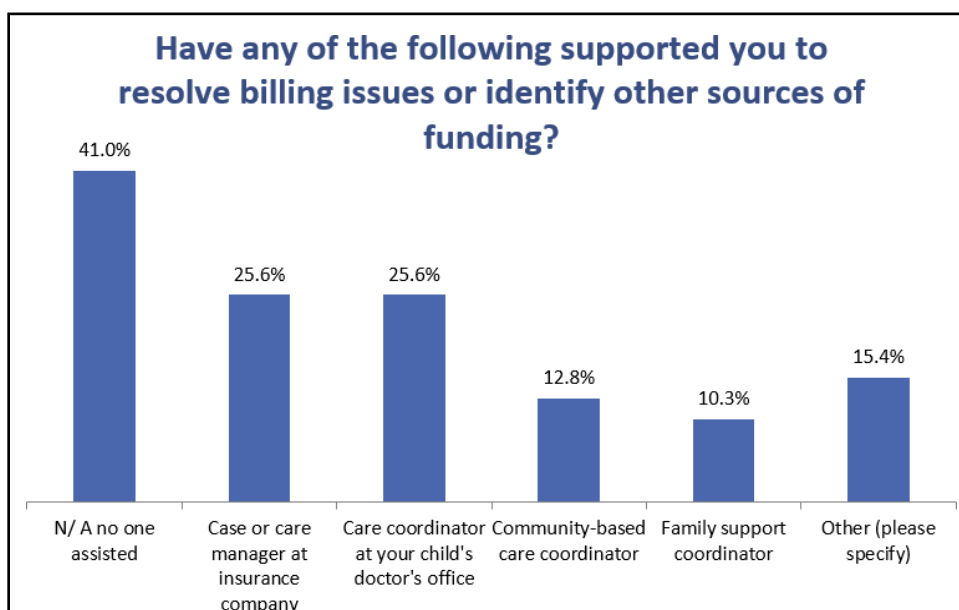


Figure 29: Who supported resolving billing or funding issues N=39

Other responses included individuals at community providers that may not have identified as care coordinators including OT, Nurse at Area Agency, DME agency. Some families responded they were the ones that resolved any billing issues.

Families with Medicaid more often report that someone at their child's provider's office or a family support provider helps them than do those with commercial insurance.

Families with commercial insurance more often identified community-based coordinators.

Billing Issues/Additional Funding Sources

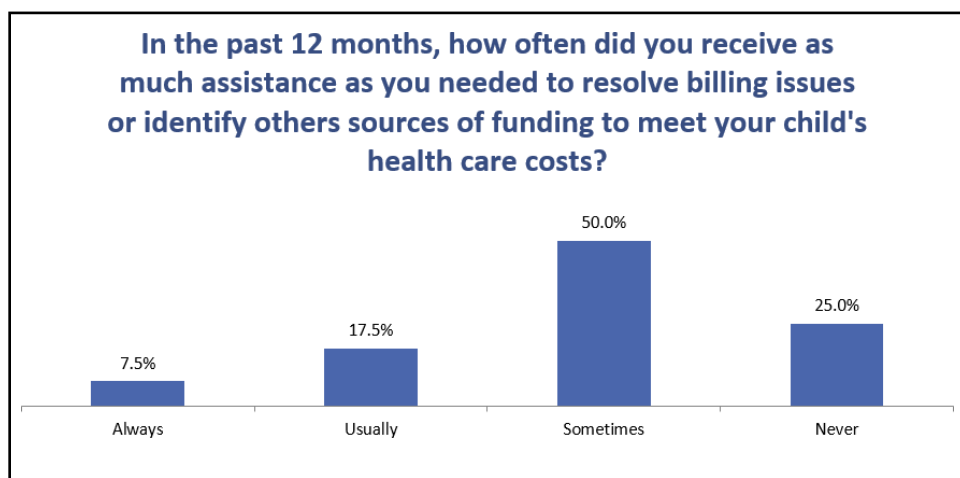


Figure 30: Frequency received needed assistance resolving billing or funding issue **N=40**

Families with Medicaid reported “always” and “usually” at higher rates than those with commercial insurance. Families with commercial insurance reported “sometimes” and “never” more often than those with Medicaid.

When asked to “tell us more” about the challenges experienced paying for needed services, many described having high out of pocket costs despite having health insurance. These costs were mostly associated with co-pays, deductibles, and health-related services, supplies and equipment not covered by insurance.

“My children have extreme dietary needs and the cost to feed them is oftentimes a challenge. I’ve gone without food for myself so that I could buy what they needed instead”.

“We often have to pay for medications, supplements, and other needs out of pocket. As a family with more than one child with special needs/medical needs, it is overwhelming. We’re paying insurance, co-pays, and still often need to pay for the remaining bills or uncovered expenses.”

“Our son is type one diabetic, so his DME is very pricey. He just went on a pump, which is life changing for him in the best way possible, but it's expensive. Even with insurance.”

"My son has autism, generalized anxiety disorder, and food allergies. He has visits with specialists including neurology, allergist, psychiatrist, and feeding therapy. All of these are a \$40 copay as we do not qualify for any additional assistance. It adds up very quickly and is a hardship."

"Our insurance struggles with accurately processing some of our child's medical needs so we are often stuck waiting for months before we can reorder medical supplies."

"My youngest has autism. She has had speech, OT, PT, ABA etc. and she was denied Katie Beckett. Our outstanding bills are too much for us to pay and services are still needed"

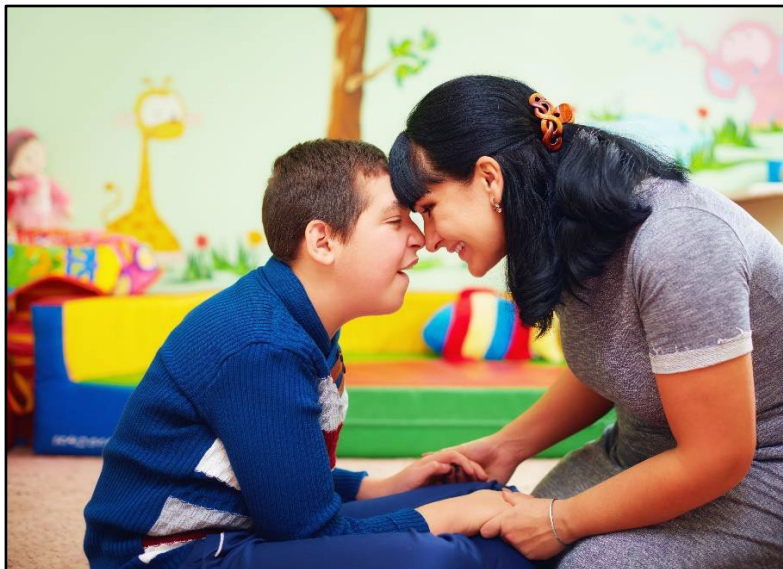
When asked to identify what supports had been helpful to them in either funding or locating funding for needed services, families specified that providers, health care coordinators, health insurance, grants, and area agencies had been somewhat helpful with acquiring needed services.

"Healthcare Coordination was able to help us apply for and be approved for health related funds, and those were able to pay a big chunk of bills toward the end of summer, but those funds are now tapped out until the next fiscal year starting in July. There are also flex funds, but we have used up those as well for this fiscal year. We are grateful for the help, and if there were more funding, it would go directly to healthcare costs that insurance does not cover."

"PCA program has been wonderful for our family. It allows me to work as my child's caregiver and provide her the care she needs and deserves, while not having to go to work or take away time from her medical care. Respite funds through local community has also been a blessing."

"We've had to tap into charities, and community funds when possible."

"We have a grant that reimburses us for our health insurance premiums, but it's ending in February and our insurance is expected to increase significantly this year."





Partnering in Care

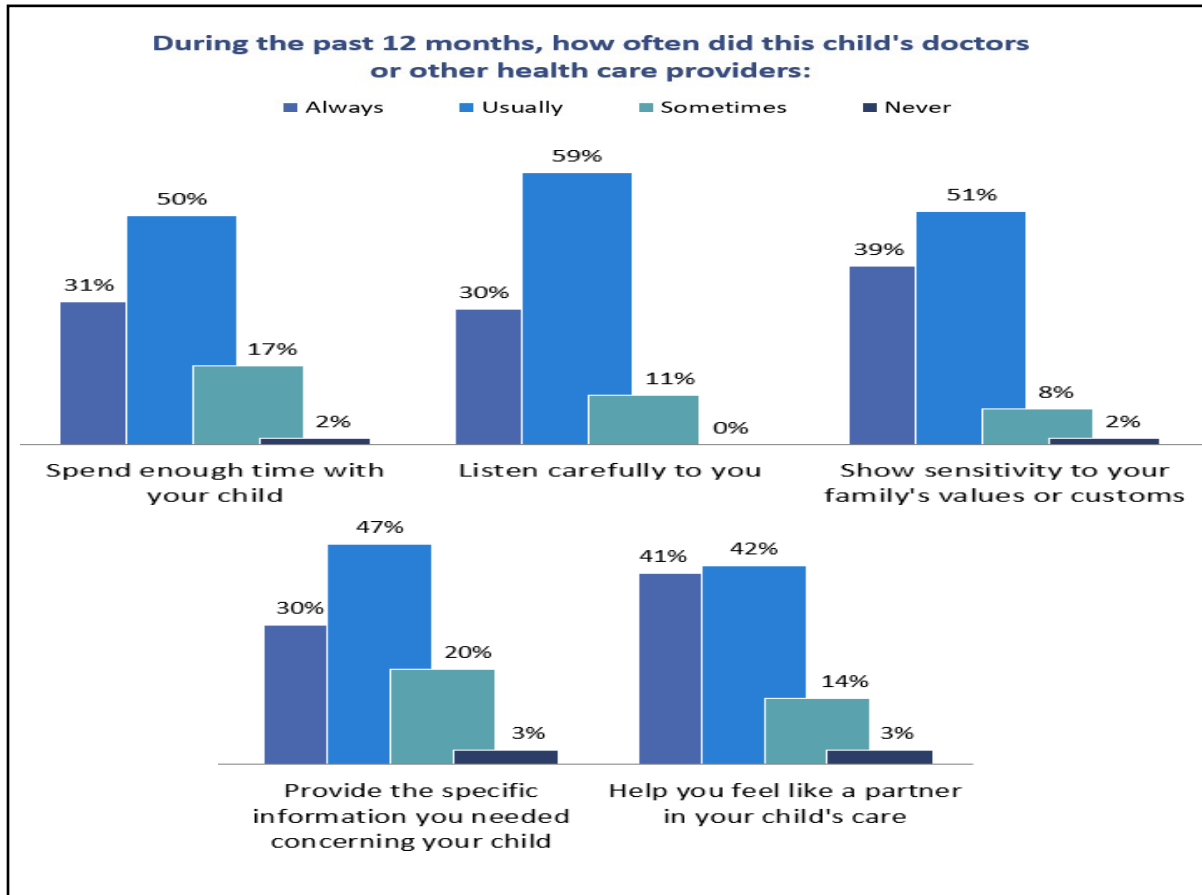


Figure 31: How often did health care providers partner N=64

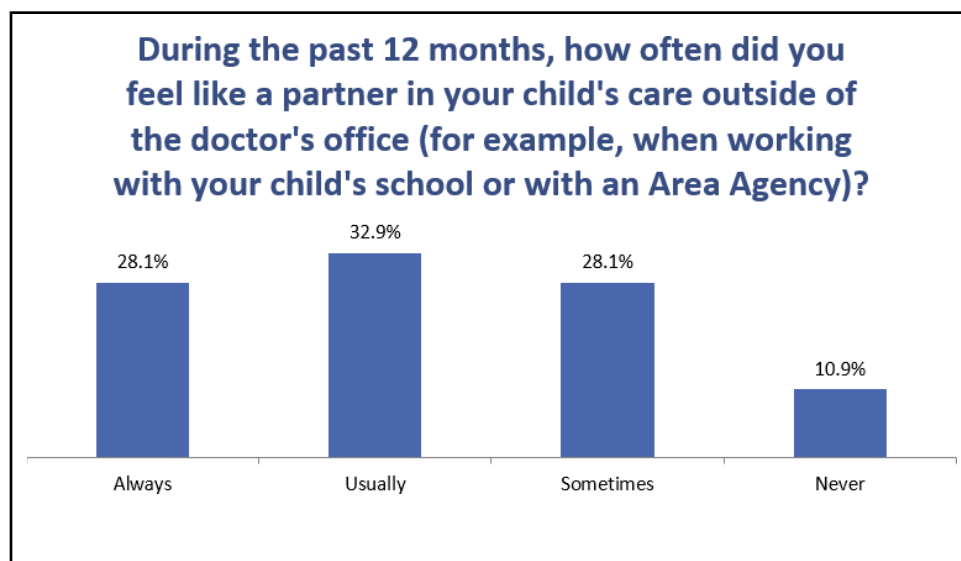


Figure 32: Partner in child's care outside of doctor office N=64

There were not major differences in these responses based on child's insurance coverage.

Support Services

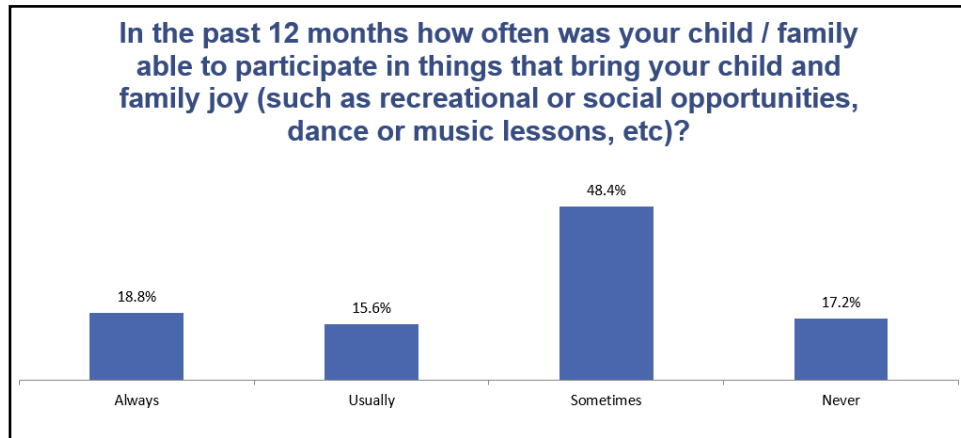


Figure 33: Participation in things that bring joy N=64

Families with Medicaid report “sometimes” and “never” more often than families with private insurance.

Families with commercial insurance report “always” and “usually” more often than families with Medicaid.

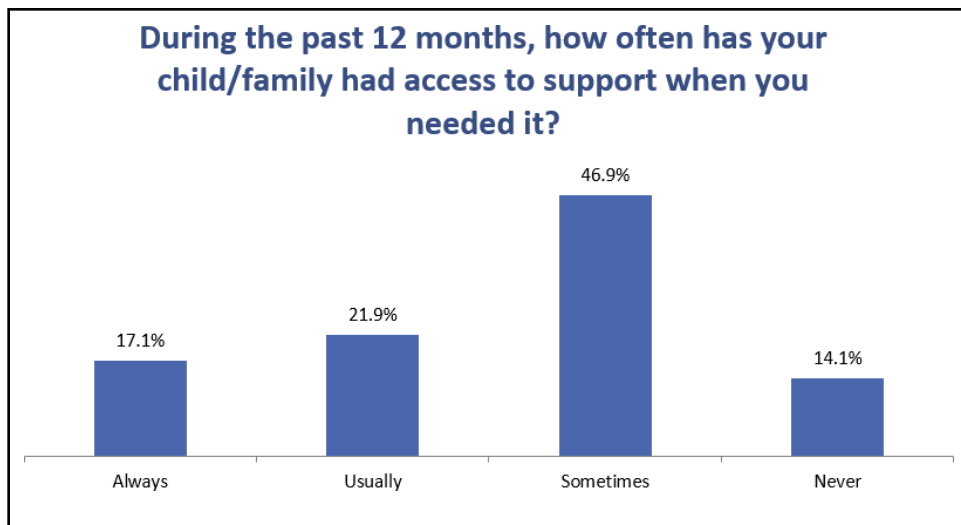


Figure 34: Access to support when needed N=64



When asked what other supports were needed, funding for and access to social supports and activities were identified as a need by many families. In-home support including respite and improved relationships with the school were also mentioned, as well as help navigating the transition to adult services.

“Services just don't exist in NH to help with hands-on solutions and support families with a single parent and multiple children with disabilities. Caring and advocating for my children has cost us our financial stability and I expect to be homeless with my three children in the next 12 months. I need help finding services that don't exist, like an in-home social worker to help me figure out how to care for the children, earn a living, provide social opportunities, and help manage family conflict between the children.”

“We need recreational activities and things to feel like a more “normal” family / kids would. We need connections with other families with similar situations.”

“Social opportunities for both kids and parents together and separately. Also, kids with 1:1 aides can't do after school activities without a parent. It's hard to be the cheerleader when you have to support your child through it as well.”

“Respite care. My child didn't have the “right” diagnosis to qualify for the needed services and so was denied access to many things he needed.”

We asked respondents to describe a good quality of life for their child and family. While access to health insurance and health care was identified, a most identified the opportunity for their child to participate in enjoyable activities with their family and within the community.

“We need inclusive activities, true parental support ([an organization that supports families] is overwhelmed and needs more staffing) and community centers like libraries that have medical needs in mind. For example, our local library doesn't have doors on the children's room, so our medical needs child with autism elopes every time we go.”

“One in which my children will usually wake up happy and excited for the days adventures and return at the end of the school day telling me about the wonderful things they learned that day and then go to sleep happy, content, and excited to do it again.”

“It's never going to be perfect, and it's never going to look the same from one family to the next and I know this. However, our life is filled with untraditional situations that don't fit most cookie cutter options. Flexibility when trying to access and work with programs is needed. In a good life, people are more willing to meet us halfway in the process of well, everything. A good life is not having to constantly fight to get a solution because our situation isn't part of the “normal” equation.”

Interviews and Community Outreach

The five families who participated in the interviews and focus groups shared diverse experiences accessing services for their child.

- One family had a five-year-old child in a full time ABA program, but wanted their child to be in the community school with peers. The school disagrees, stating the ABA program is more appropriate, citing concerns for the child's safety due to elopement. The family moved to NH just prior to the child turning three, and had received Early Intervention in another state. They were not yet connected to their local Area Agency, or to resources to improve parent's understanding of rights in special education process. They did report having Medicaid, and that they had not had issues with it covering needed services.
- One family had a medically complex child. This parent expressed concern regarding her child's future, and stated she is working hard to ensure her child's success. Connection to community and peers for her child, and in person support for herself, were priorities. She described that the MCO care manager had been helpful, but that obtaining needed items such as formula were time-consuming for the care manager. The parent reported being connected to the Area Agency and is funded as paid caregiver through the GSIL program.
- Another family with a medically complex child described the impact of hospital mergers, as some hospitals had discontinued pediatric programs as result of mergers. Her child sees over twenty specialists, with the majority out of state. She identified that while there are people to help coordinate appointments, they are not able to access the appointments at satellite locations, as reportedly those locations have such limited appointments her wait times would be longer. She described the support of her area agency case manager as "giving phone numbers to call." This parent also expressed concerns about school, citing that while her school is committed to her child and has adequate staff to do so, this is not true across districts. This parent also accesses a paid caregiver option. This affords her the ability to participate in her child's school experience, ensure community connections. Her child is covered by commercial insurance as well as Medicaid, and she described navigating coverage as "trial by fire".
- One family had a teen with a diabetes, who requires constant monitoring. Due to the other parent's work schedule this falls to mom. Clinic offered a short term group for teens with diabetes that mom felt was helpful. Mom reported difficulty obtaining glucose sensor that would allow teen to participate in preferred sport, as it was not deemed "medically necessary".
- One family has a teen with OCD, and felt that it was difficult to obtain the proper diagnosis. They found an out of network specialist via a national group and obtained coverage from their insurance for the provider. They were given approval for one year, and are currently trying to extend coverage as they are still on a waitlist for an in network provider. The parent expressed the wait lists seem to get longer. The family also reported that when in crisis, a child gets medication, and a list of therapists who are mostly not accepting new patients. No tools. No resources. The family wishes their teen had connections to other youth. Family also wanted respite, and more consistent specialized services to minimize the strain on families. The family reported doing all the coordination, and not being connected to any services.

The per diem staff doing outreach shared the following feedback from their discussions with members of their communities.

- Autism is completely unfamiliar in some communities. As such, there is sometimes a sense of distrust of providers regarding this diagnosis.
- There is stigma or shame connected to disability in some communities, and a tendency to keep children at home.
- There is a lack of awareness of resources. What resources exist? Who is eligible? How and where does one apply?
- There is a need for support around working with schools. Some families felt what their child with autism was getting in school wasn't enough, and felt there should be specialized programs for children with autism.
- Families echoed long wait lists for therapies – speech, OT, ABA.
- Some families had no access to ABA other than at school due to lack of eligibility for Medicaid.

A Well-Functioning System Is....

The final two questions of the survey provided an opportunity for respondents to identify what a well-functioning system of services would look like for their child and family. According to a majority of families, a well-functioning system would include easily accessible and highly qualified providers, health care coordination, affordable services, and good communication between all those involved in a child's care.

"All services would be working together, talking to each other, and making sure that my child was receiving adequate care in all areas."

"A provider or nurse manager who is able to manage all of the providers to make sure they are on the same page."

"Fewer roadblocks and red tape within agencies"

*"Less paperwork. More support other than reminders to complete paperwork.
Help with finding staff for direct support."*

"Seamless, rapid access to exactly what our child needs, when she needs it. This includes home-based mental health supports, in consort with her therapeutic school care team."

"In home/in community supports to help us thrive as a family in the care of our thriving child."

"Good communication between providers and convenient access to providers without long waitlists. Knowing what providers would be best for our child without having to go through multiple providers to find the right one."

"Person centered team meetings. Not a question of "if we can do it" but instead, "how do we do it." Respite opportunities, full staff, additional funding for more staffing hours."

"It would be a system where a family doesn't need to fight insurance to cover the cost of their child's care. We have had to fight with insurance more times than I can even count to cover parts of my child's cancer treatment and now the equipment he needs for day-to-day life. A system where the patient and doctor's decisions for care are put above money. Families like ours bear the heavy burden of caring for a sick child and worrying about mounting medical debt that just grows every year."

"A system that is affordable and provides financial help to people who have children with disabilities and are above the income limits but don't make enough still. Parents like us have to leave our jobs to care for kids, spend a lot of money on therapies, specialized sensory equipment, medications, and so forth that seems to be overlooked by the system."

When asked to respond to the question "I want the services my child and family needs to be..." the majority of the majority of the 213 families responding chose "accessible", closely followed by "patient and family centered", as depicted by the word cloud below.

Families also indicated they wanted services to be affordable. Some families again commented on challenges around access to needed educational, community, and health care services.

Accessible
Patient & Family Centered
Comprehensive Equitable Coordinated

One comment summed it up: *"All are important: I want them to exist! And then be available to us."*



There were respondents who indicated that the system of care is working well overall for their child and family. However, the majority of respondents identified substantial challenges in accessing the care and services needed for their child.

1. Wait lists. There are apparently more children in need of a variety of services than there is current capacity to meet them, with mental health and therapeutic services (OT, PT, SLP, ABA) as well as delays mentioned for providers, including developmental pediatricians, developmental screening and evaluation (for ASD), and specialists such as neurology.
2. Coordination. Despite the number of service coordinators, care managers, case managers, care coordinators who may be involved in some manner with families, only one third of respondents identified that had anyone who was assisting them in coordinating care for their child. Families who reported access to care coordination were less frustrated, felt more supported and had improved access in some areas.
3. Continued workforce shortages. In addition to access to providers, families continue to report difficulty hiring staff for home and community. (Home care, direct support professionals, respite). This is the first survey in a number of years that respite has been identified as a need at this level.
4. Transitions. Improved coordination and systems collaboration to eliminate gaps in service delivery. Families more often identified this as a challenge in the move to adult services, but there were also comments on gaps prior to preschool special education.
5. Systems level issues. Families commented on a number of these, including delays in Medicaid approvals, program application burden, challenges with prior authorizations, pharmacy and DME benefits, as well as changes in programs and access to services. There were families whose child required intensive home and community supports due to primary behavioral health needs who wished for level of supports available to other children (ABA, In Home Support).

Families identified that they want a system that provides access to the services they need for their child and family, in a more efficient and supportive way than they are currently experiencing.

“This mother does it all. Coordinates everything from 50+ doctor’s appointments a year and care for two children with chronic illnesses that impact daily life. There is no financial help, just lost hours of sleep and having to reduce hours worked due to my own exhaustion as a caregiver with zero support or help.”

And this desire for improvement is true of all families, regardless of their child’s health needs or disability. A comment made by a mom who didn’t identify that her child had a chronic health conditions or disability (had checked “none of the above”) could have been made by any parent:

“I have access, but most times I’m referred to urgent care on days when my doctor’s office is unable to help. When we do get in, it’s the fastest service ever and as a first-time mom I don’t always feel heard or that my questions are answered. It’s scary leaving like that.”

It’s important to note that respondents whose children did not have disabilities didn’t always feel like a partner, didn’t always have access to the support or community recreation opportunities they desire. Their experiences also identified opportunities for improvement in our system of care, including a need for improved access to child care, healthy food, parks and recreation.



- Consider an environmental scan of accessibility of / capacity for services cited as having long wait lists.
- Consider assessment of capacity for existing care coordination / care management services. Are family responses indicative of awareness, connection and / or capacity issue?
- Explore impact of paid family caregiver options on need for respite.
- Contemplate means to monitor and address systems level barriers. Is there a central place for these to be collected and addressed, rather than mitigated on an individual basis? (Upstream thinking)
- Ongoing monitoring of impact of health care financing changes on access to needed services.
- Monitor for impact of case management options as result of conflict free case management.

