



Chartbook:
2018 – Special Medical Services
Satisfaction & Needs Assessment
Survey

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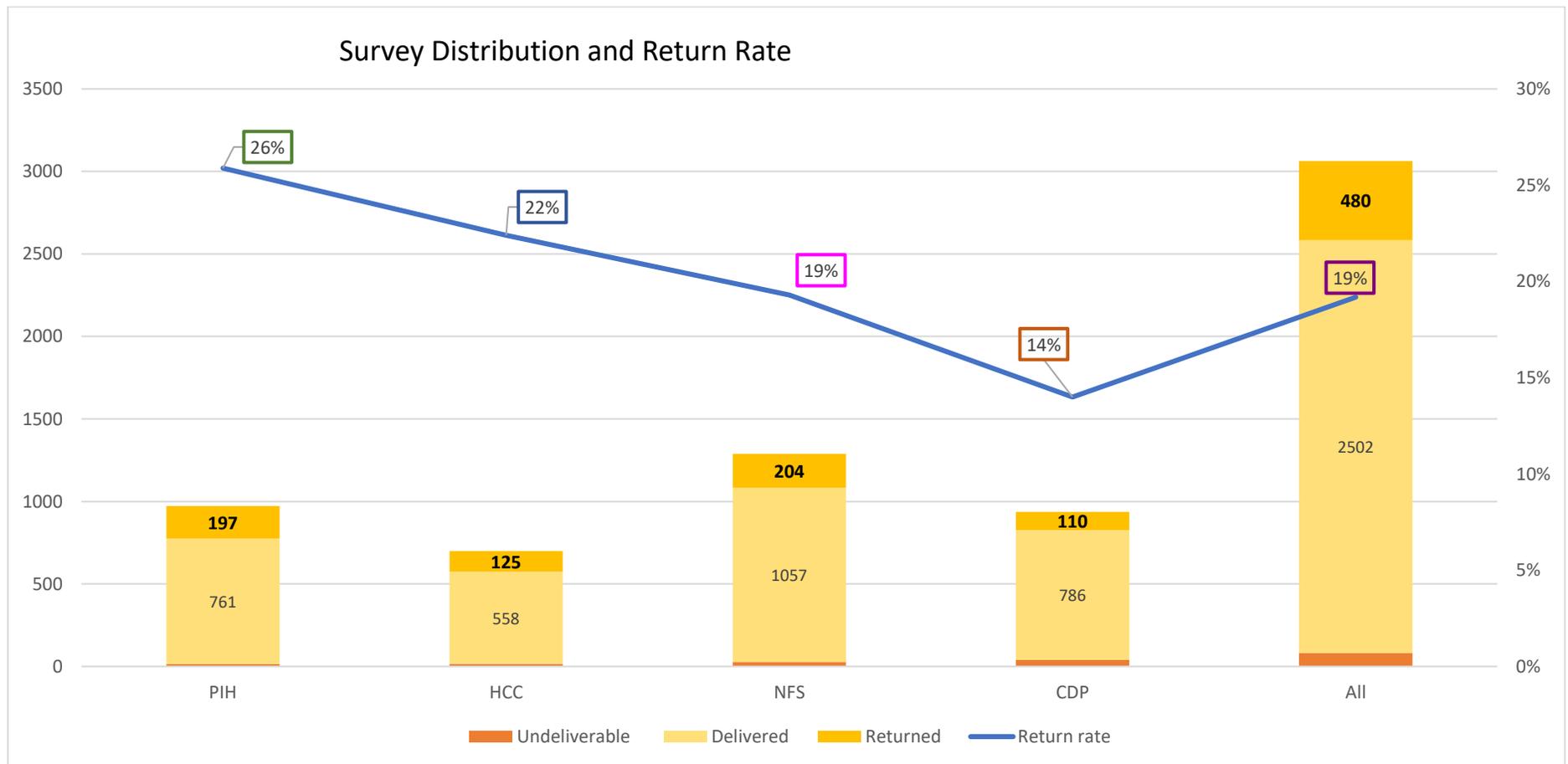
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SURVEY DESIGN & ADMINISTRATION

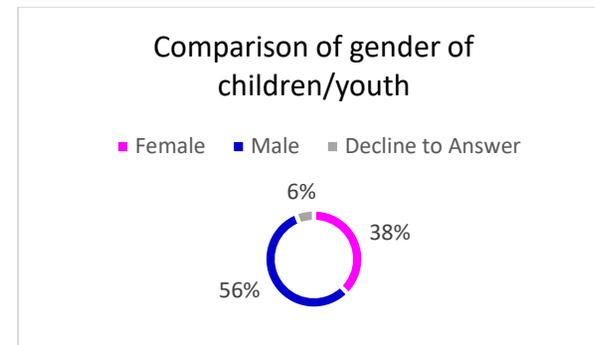
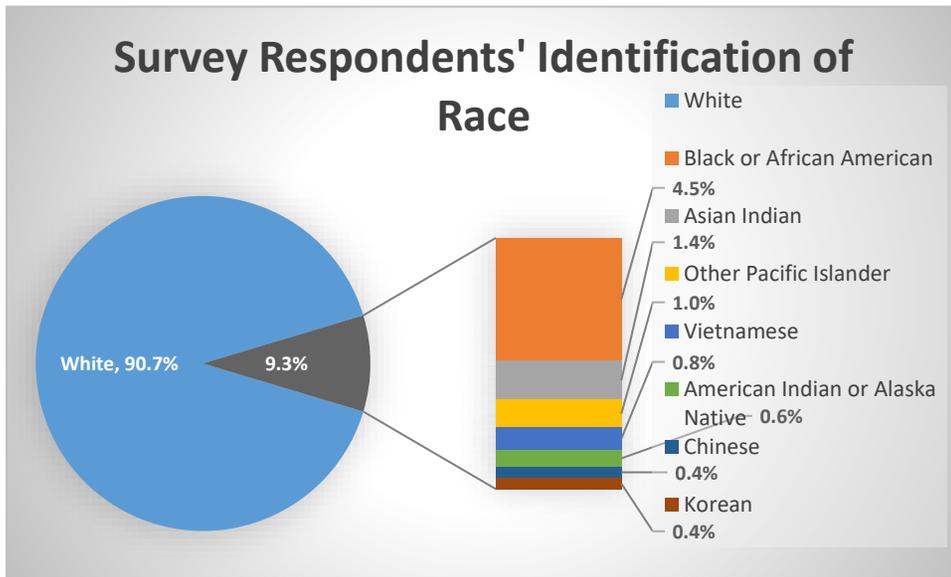
New Hampshire Special Medical Services offers services and supports to children and youth with special health care needs (CYSHCN), ages 0-21, and their families:

- Partners in Health (PIH): Family Support Coordination
- Health Care Coordination/Neuromotor Clinic (HCC)
- Nutrition and Feeding & Swallowing Consultation (NFS)
- Child Development Program (CDP)

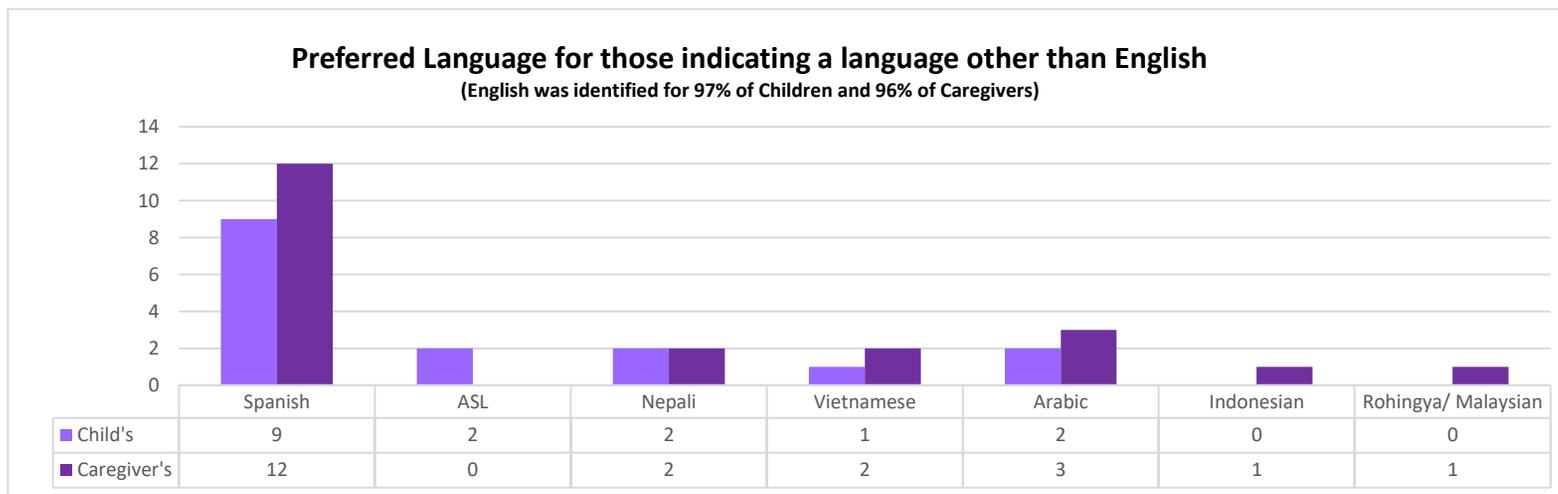
SMS conducted its biennial Satisfaction and Needs Assessment Survey of 2502 unduplicated enrolled families in February 2018, responses were received across all programs with an overall response rate of 19%.

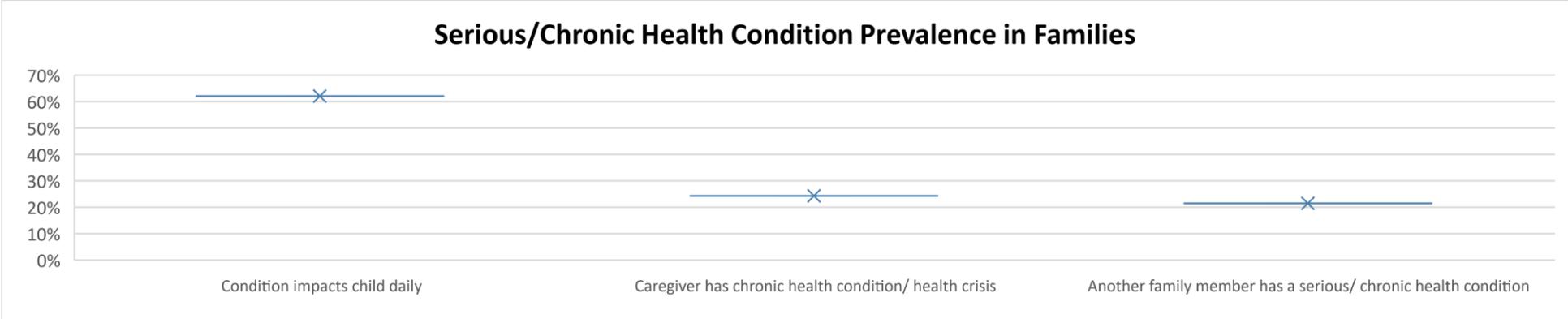
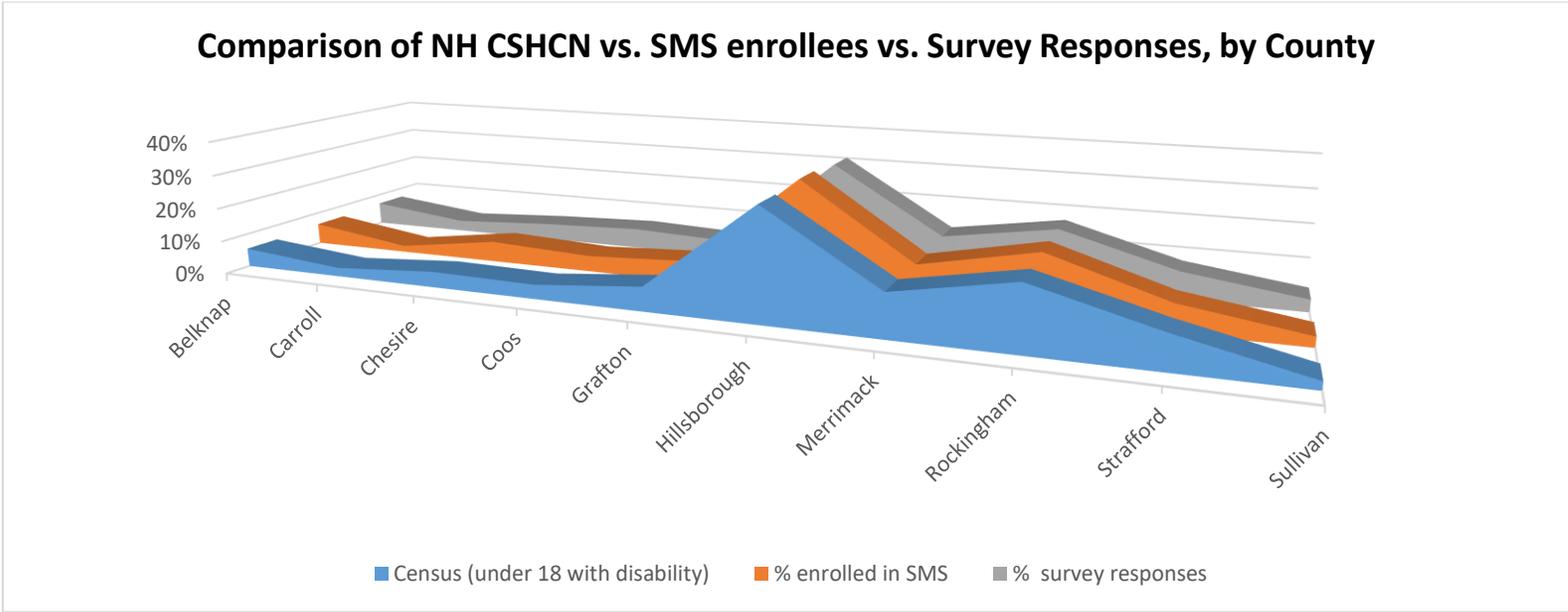


RESPONDENT CHARACTERISTICS



Overall, the demographics of survey respondents were consistent with statewide and SMS enrollment statistics. Respondents predominantly identified as White with English as their preferred language. In addition, the other preferred languages identified were those that were anticipated. Gender distribution is similar to that of CYSHCN as identified in the National Survey of Children’s Health (NSCH). When comparing the NH Census data, SMS enrollment data and SMS survey respondent data it is notable that all reflect the same geographic distribution. This indicates that there are not any obvious barriers to SMS services based solely on geography and that the survey responses are representative of SMS enrollees.

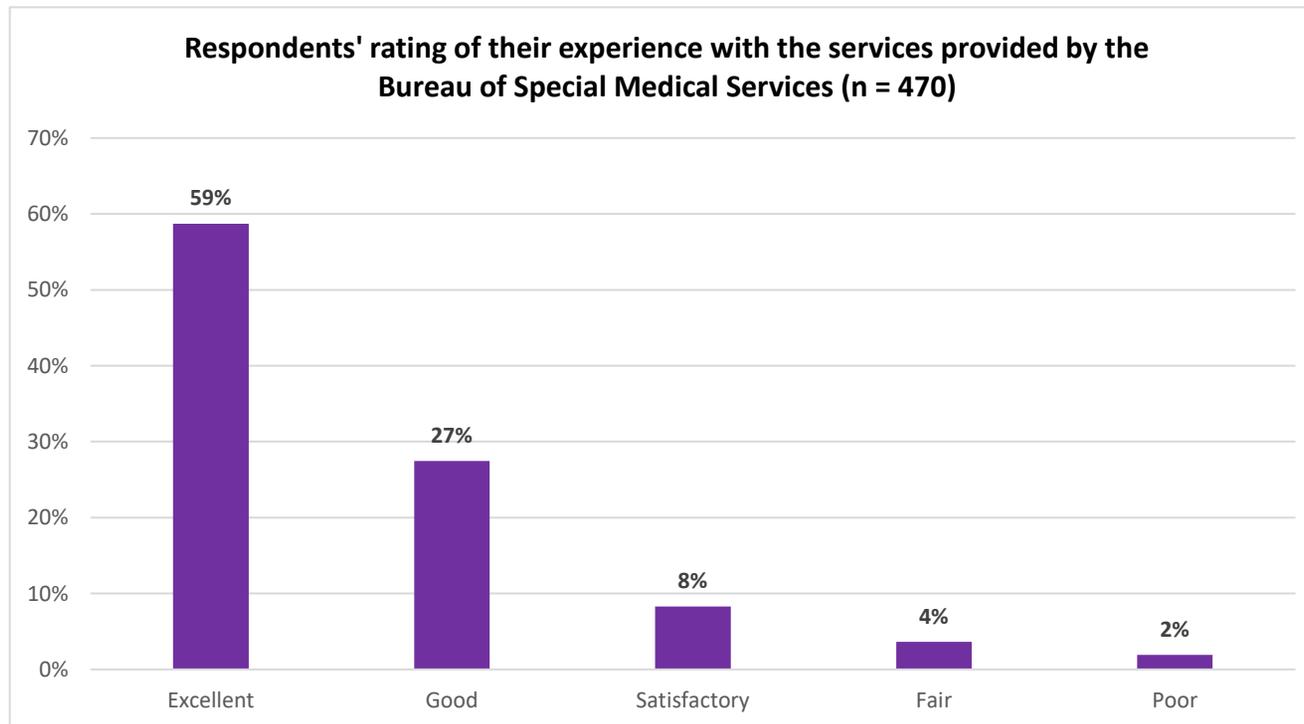




This information about the extent of caregiving that families are managing, on a daily basis, is significant. Of the 480 caregivers responding to the survey 24% of them have a chronic health condition or health crisis themselves while 62% are caring for a child/youth whose special health care need impacts them on a daily basis and 21% of them are also caring for another family member who has a serious or chronic health condition.

OVERALL SATISFACTION

In 2016, New Hampshire adopted the Standards of Quality for Family Strengthening and Support (Standards) for use with Partners in Health. Since then, the Standards certification training has been offered to all Partners in Health Coordinators & Supervisors and many Area Agency staff who provide family support services. In the Bureau of Special Medical Services, the Standards are used as a tool for planning, providing and assessing quality of services for CYSHCN and their families. The SMS Biennial Survey is the primary method of evaluating areas of program strength, as well as areas for further development, in order to guide continuous quality improvement and achieve positive results for families¹.

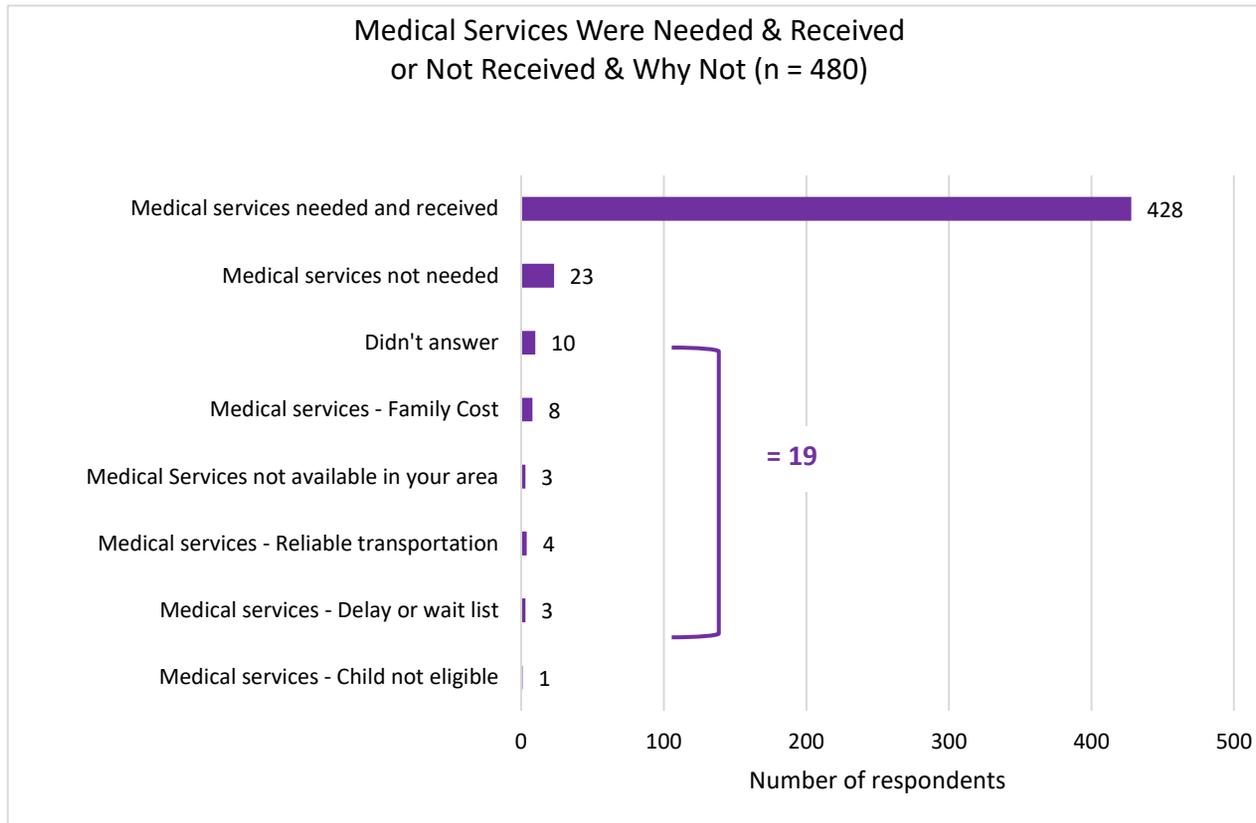


According to respondents to the 2018 Survey, 86% rated their experience with SMS as Good/Excellent. Of the remaining respondents, 6% indicated services were less than Satisfactory.

¹There are no sources in the current document.

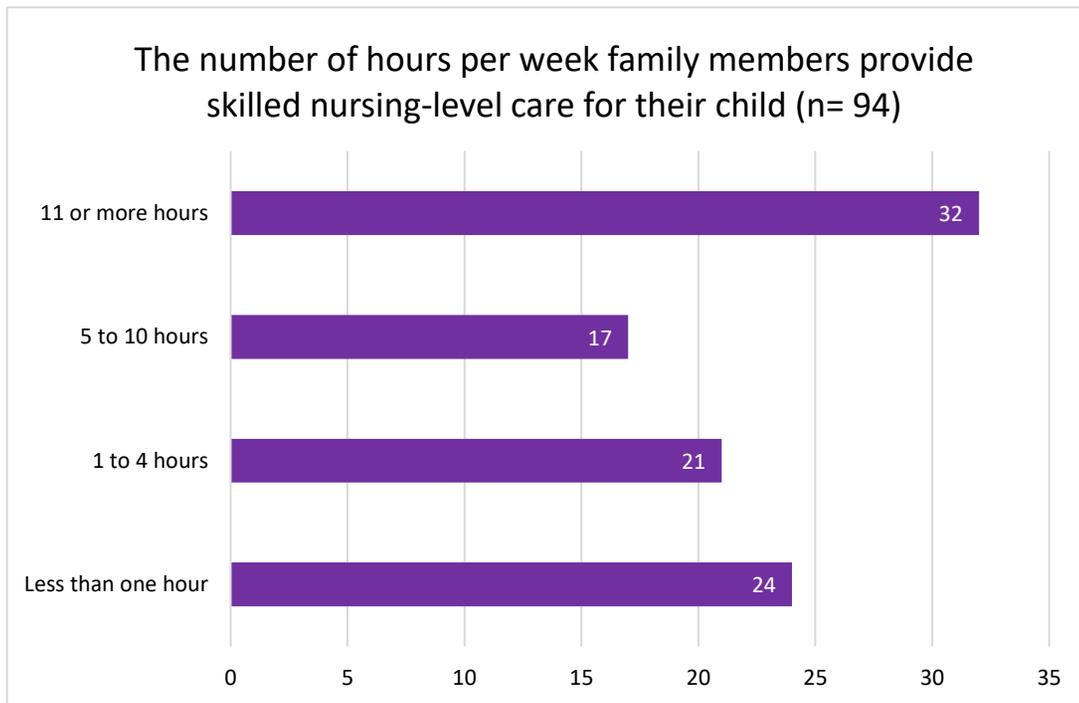
ACCESS TO CARE

One of the needs identified in the New Hampshire 2015 Title V Needs Assessment, was access to needed healthcare services for all populations, including CYSHCN. With that in mind, the Survey Team developed questions to assess progress toward improving families' access to medical services when needed by including the reasons for why services were not accessible.



The 2018 SMS Survey results were consistent with this data, indicating that more than 89% of families who needed medical services reported they were able to access them. Of the 19 respondents who reported inability to access services when needed, the reasons included family cost (42%), services not available in the area (16%), reliable transportation (21%), delay or wait list (16%) and child not eligible (5%).

Family-provided health care represents a critical component of the health care system for CYSHCN. To further understand the needs of caregivers, SMS included a survey question about the extent of skilled nursing (such as wound care, trachea care, vent care, IV's etc.) that caregivers are providing for their child in the home.



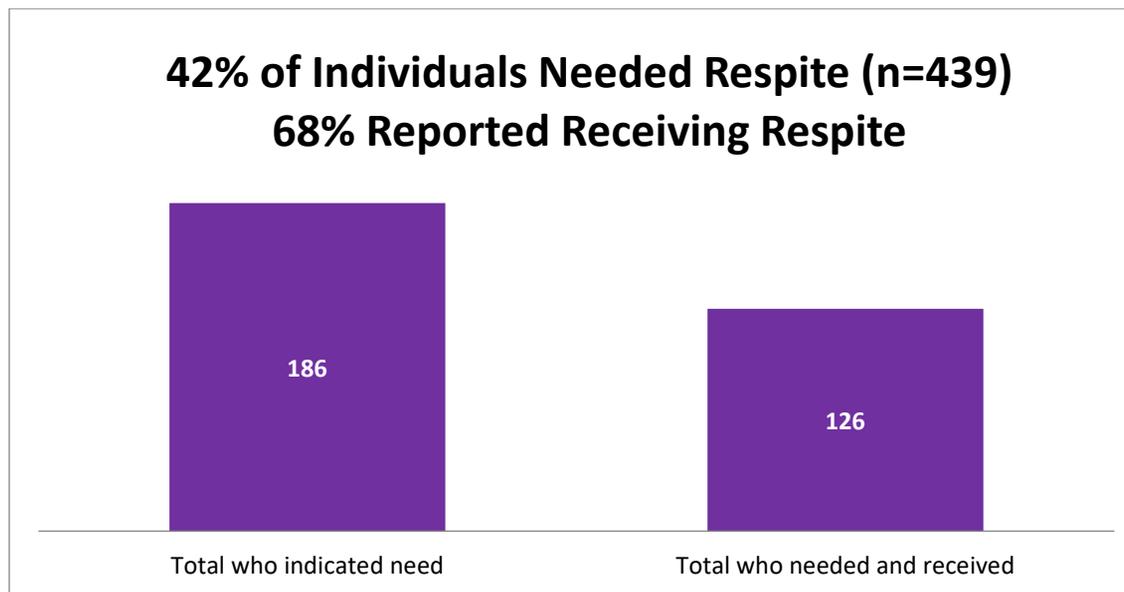
Nearly 20% of respondents indicated they provide skilled nursing-level care for their child with special health care needs in their home. Of these caregivers, 34% provide 11 or more hours, 18% provide 5 – 10 hours, 22% provide 1 – 4 hours, and 26% less than one hour.

The data demonstrates that home nursing services continues to be identified by families as a significant area of need. This is consistent with the limited capacity in NH to meet the need for Home Nursing services. SMS will continue to edit the biannual survey to solicit pertinent input to assess the need for CYSHCN and their families.

RESPITE

SMS provides a wide range of Family Support services and activities that assist families in developing and maximizing their ability to care for individuals with disabilities. SMS identifies and integrates supports that assist families, providers, and communities to meet the unique challenges of CYSHCN.

Families continue to indicate difficulty accessing respite care when needed, both anecdotally and in their responses to the 2018 SMS Satisfaction Survey-Needs Assessment. Of the 42% of respondents who identified respite as a need, 68% indicated they had received respite.



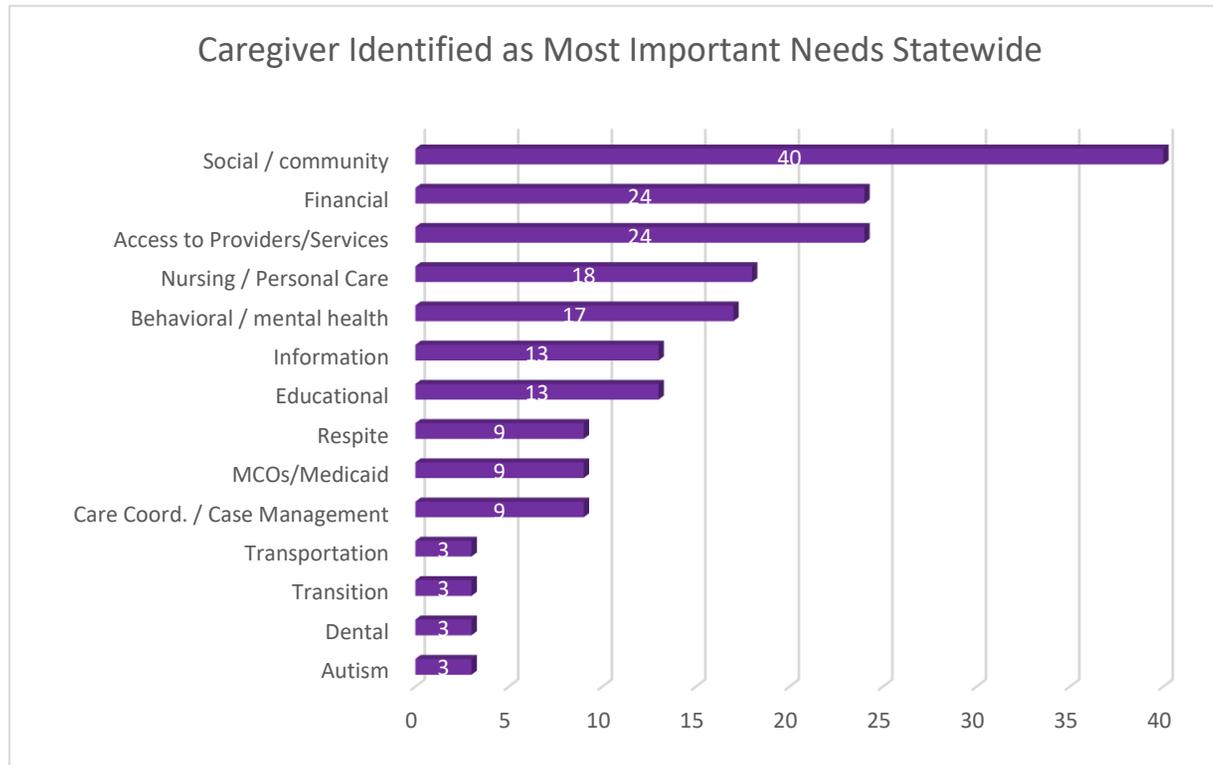
Summary:

SMS will continue to address the areas identified as “unmet needs” for respite through flexible funding options, designated campership/respite funds, and the exploration of family strengths and community supports. The lack of a trained and well-compensated workforce continues to be a significant problem for families seeking respite from the day-to-day requirements of caring for a child with special health care needs. SMS will continue to support the NH Lifespan Respite Provider Certification training through Relias™ Learning and to promote options for respite by referring to Servicelink and working with partners across DHHS to develop strategies to address this need.

Needs Assessment

The biennial SMS Satisfaction & Needs Assessment Survey is an integral component of Title V's activities to assess barriers to care and emerging trends/gaps in service delivery. To assist with that process caregivers were asked to share:

"What you would identify as the most important needs and services for children and youth with special health care needs, in New Hampshire, that you believe are currently unavailable or inadequate."



Overwhelmingly, caregivers think that there is a need for more opportunities for CYSHCN to be connected to their communities and peer groups. They also think that caregivers need more: connection to peer/support groups; information; and access to services/providers for their children.

Responses that highlight these needs include:

"More opportunities to meet other children with similar disabilities to form friendships to prevent depression (feeling alone)."

"More programs for grandparents that are or have guardianship of their grandchildren. We need more help."

"Having more information available to families about services that are available. Being provided with educational information is extremely helpful and helps families to be more knowledgeable in

ways they can benefit their children with special needs."

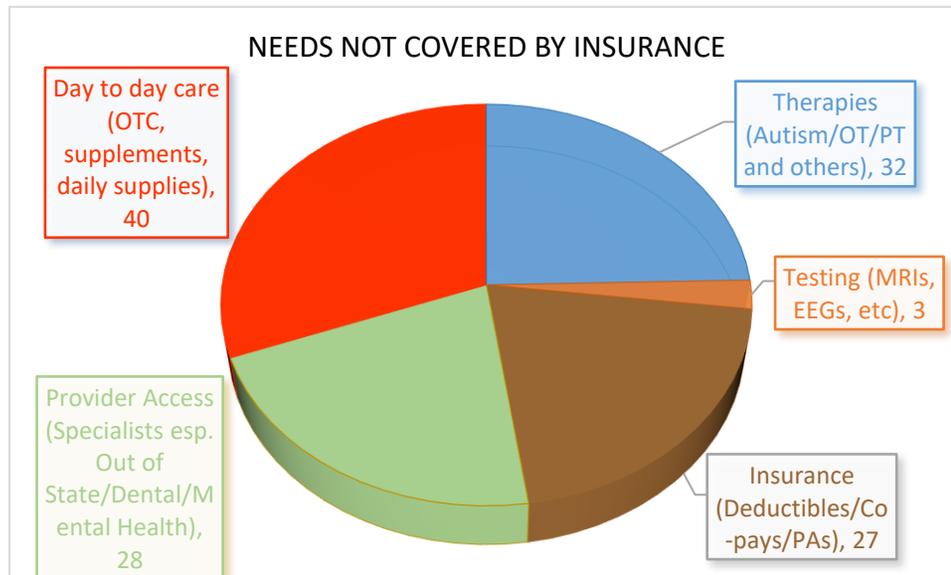
"Financial assistance for the lower middle class who had difficulties making ends meet but do not qualify for any services"

"Health services and insurance both need to be able to adjust rules and regulations and wait times for children with disabilities"

"Funding for parents who have to quit working to take care of their special needs child. Especially those who are drowned in student loan debt from college"

"Allowing NH children that are medically complex to go to Boston Children's. Providing dental services for over 21."

Concerns about the adequacy of Insurance coverage were collected by asking caregivers:



“Does this child's health insurance offer benefits or cover services that meet his/her needs? Please list types of expenses that are NOT covered by insurance”.

The responses were categorized and most frequent type of service that was not covered fell into the category of supplies for day to day management of the child's condition which includes items such as over the counter medication, vitamins & supplements, g-tube supplies, durable medical equipment etc.

Additional responses to questions in the survey also shine a light on barriers and gaps.

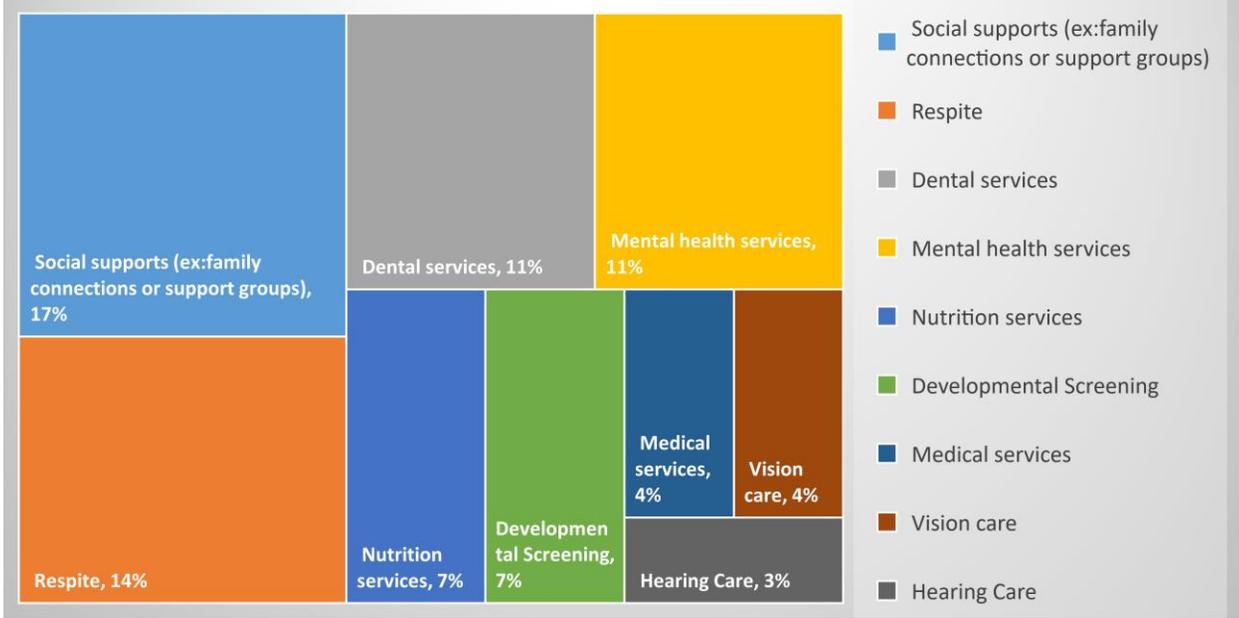
Need for “more dentists accepting Medicaid, also more orthodontists accepting Medicaid”

“There is no adequate care for the rare condition my daughter suffers from. We have to travel to receive treatment she needs out of state”

“Core mandatory education of individual health care and chronic health care issues and conditions within school districts without discrimination”

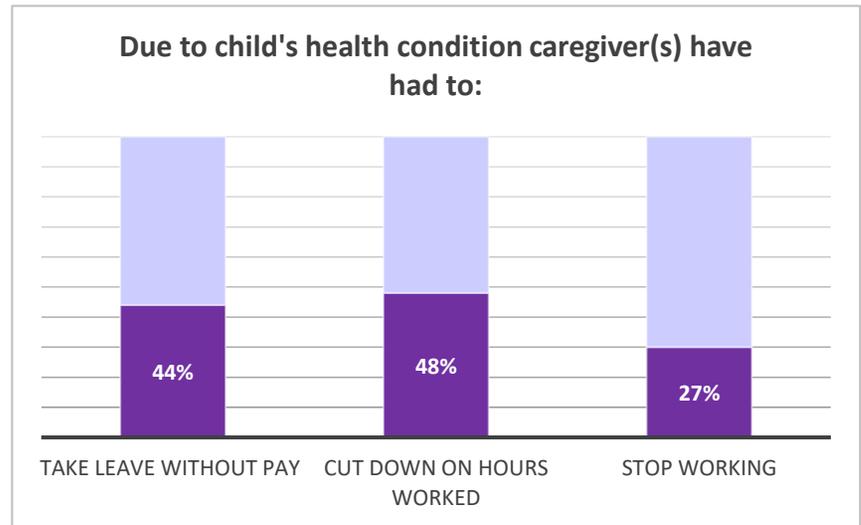
“LNA's. NH pays them so little ... and they barely have enough for all the families in need. It's been 8 months since I had one and have been paying out of pocket for care for my son

Individual - Unmet Health Care & Social Support Needs



Caregivers were presented with a list of specific service areas and were asked to identify their own unmet needs in those areas. The unmet needs that were most commonly identified fell under the social supports category, including respite and family supports such as parent connections and support groups. After that dental and mental health services were noted to be an area of concern followed by nutrition, developmental screening, medical, vision and finally hearing services

Respondents also shared information regarding the impact of caregiving on their families' employment and economic stability. The data is compelling and reinforces the need for enhanced caregiving supports in the community such as personal care assistance, home nursing and school based care so that they can attain and successfully maintain employment that grants them an equitable opportunity to financially provide for their families.



HEALTH CARE COORDINATION (HCC) & FAMILY SUPPORT COORDINATION (FSC)

Health Care Coordination is a Title V program that is comprised of a team of professionals consisting of registered nurses, social workers and parent navigators. There is at least one Health Care Coordinator assigned within each county in New Hampshire who works with families and their child(rens) health care providers, community agencies and schools to assist with obtaining access to needed health care and related services. This is accomplished by reviewing the child's health status and developing an individualized health care plan based on needs and priorities of the child and family. Health care coordinators also offer support in helping families find and apply for services including medical, educational, social as well as financial. They coordinate follow up care with families and medical providers. They work to problem solve and provide guidance about chronic illness and /or disability including transition to adult providers for teens.

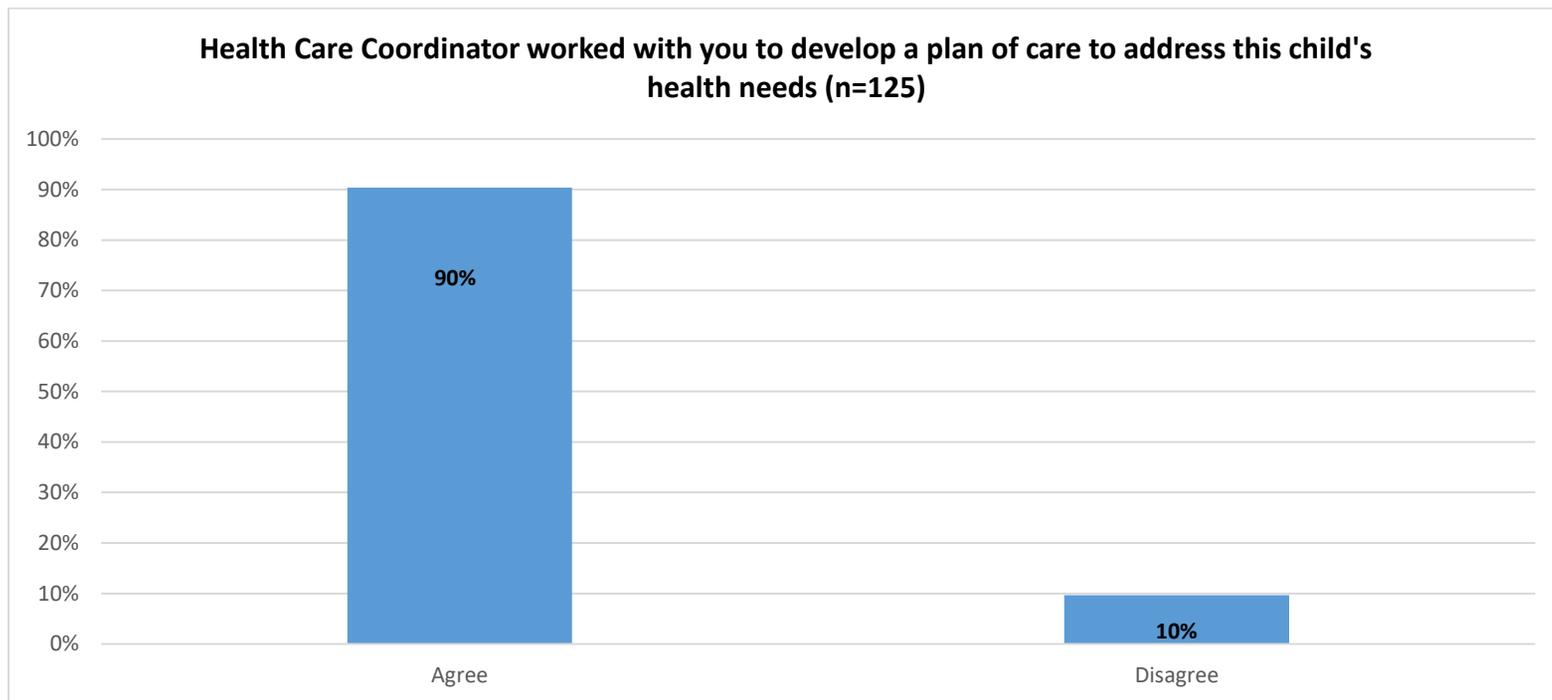
PIH Family Support Coordination is a program comprised of social services trained coordinators who work with families on self-identified goals to assist them to manage the impact of the child/youth's chronic health condition on the family. Family Support Coordinators provide social supports and assist families to navigate, access, and build related community resources. They also partner with family leaders to assess community inclusion needs & assets and provide community-organizing opportunities.

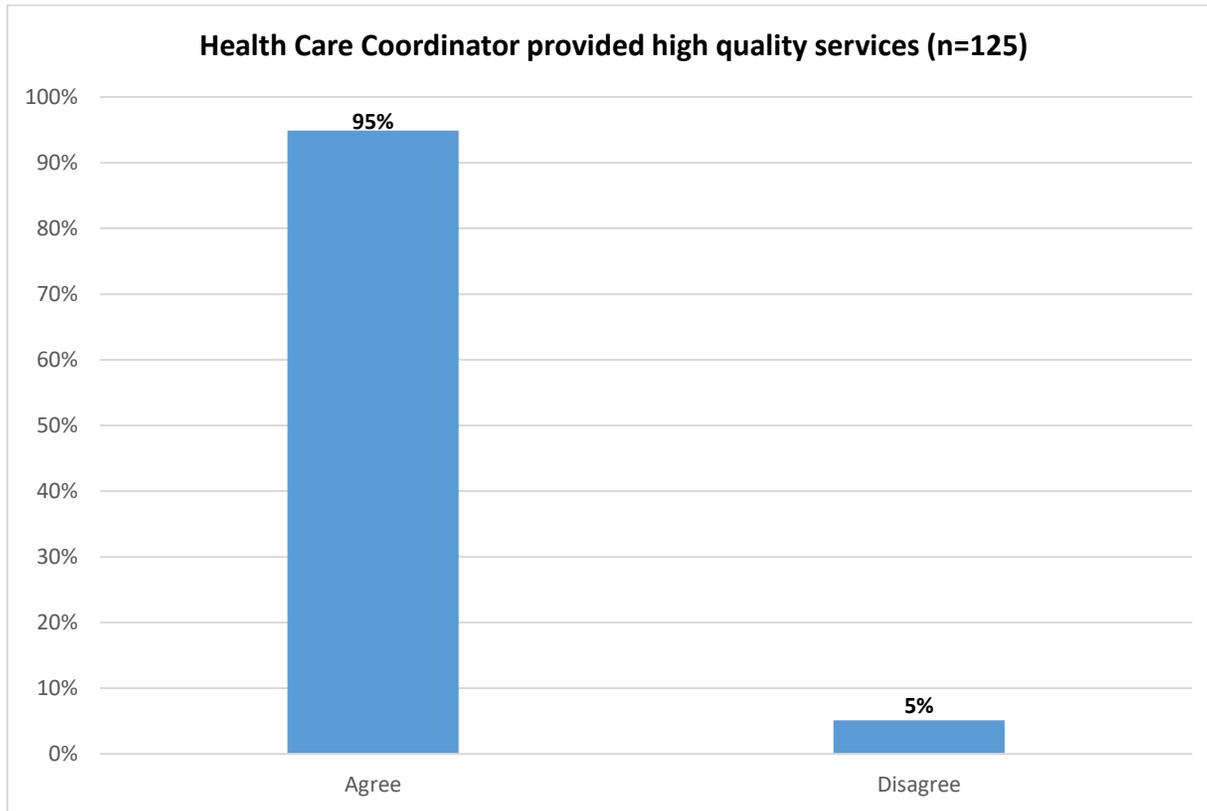


HCC/ Plans of Care

Ninety percent (90%) of the 125 caregivers surveyed reported that their assigned health care coordinator worked directly with them to develop a plan of care to address their individual child's health care needs. Ten percent (10%) indicated that this was not the case for their child, it is possible that these plans were not yet completed at the time of the survey or had not been reviewed by the family. The small percentage of individuals who disagreed unfortunately cannot be broken down for further analysis and in the future the question may benefit from the addition of a 'comment box'.

There were a number of responses left blank (11) this may indicate the families' own interpretation of the term "plan of care" and may represent confusion between this term, educational plans, physician recommendations and the like.



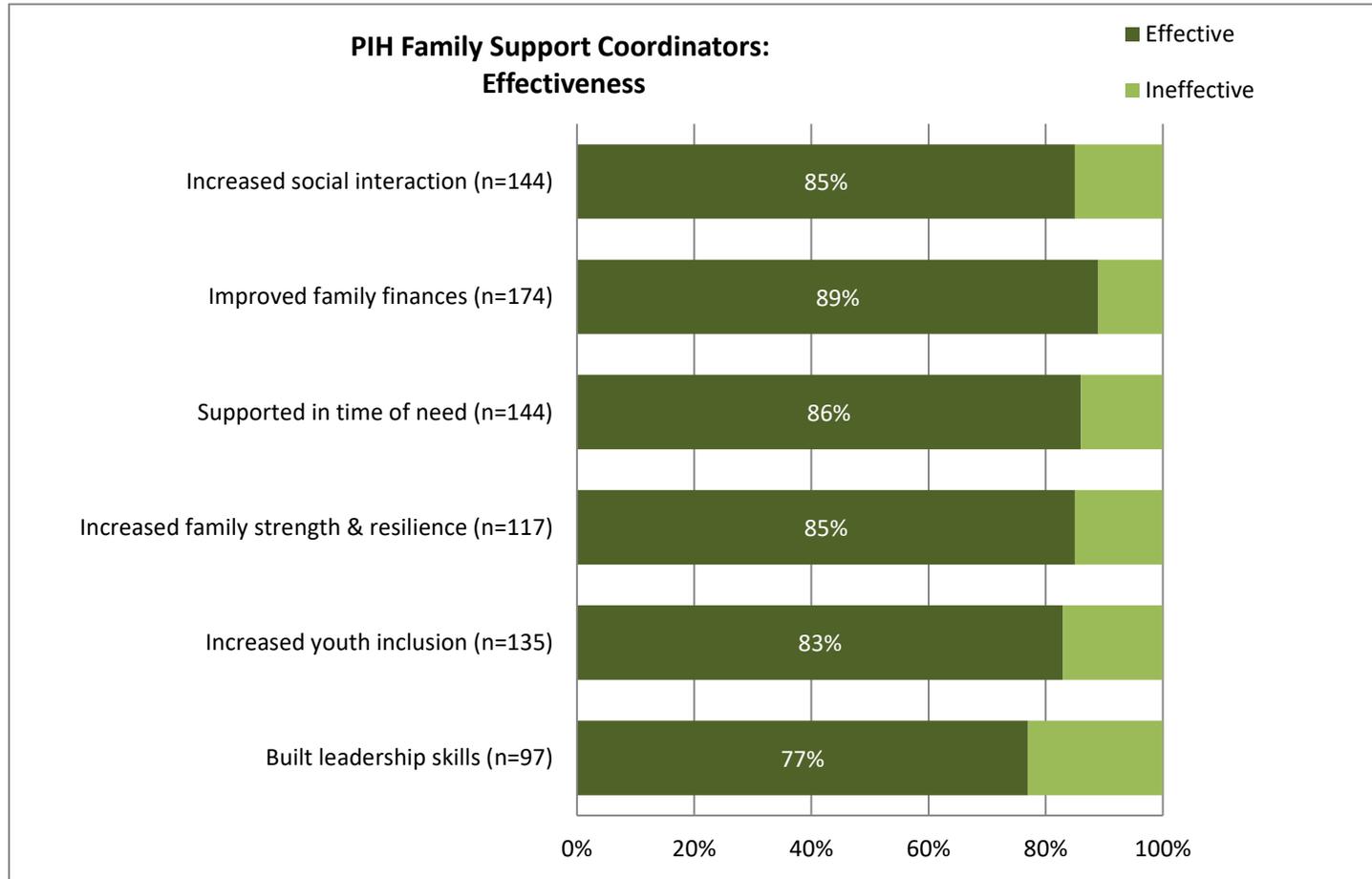


The results of 125 responding caregivers indicate that ninety five percent (95%) believed that the SMS Health Care Coordinators provided high quality services when working with their child and/or family. Six caregivers (5%) disagreed and it is difficult to determine the reason for their dissatisfaction. In the future, to identify the actual causes it would be helpful to craft the survey question in a way that extracts the information separating the performance from the final results.

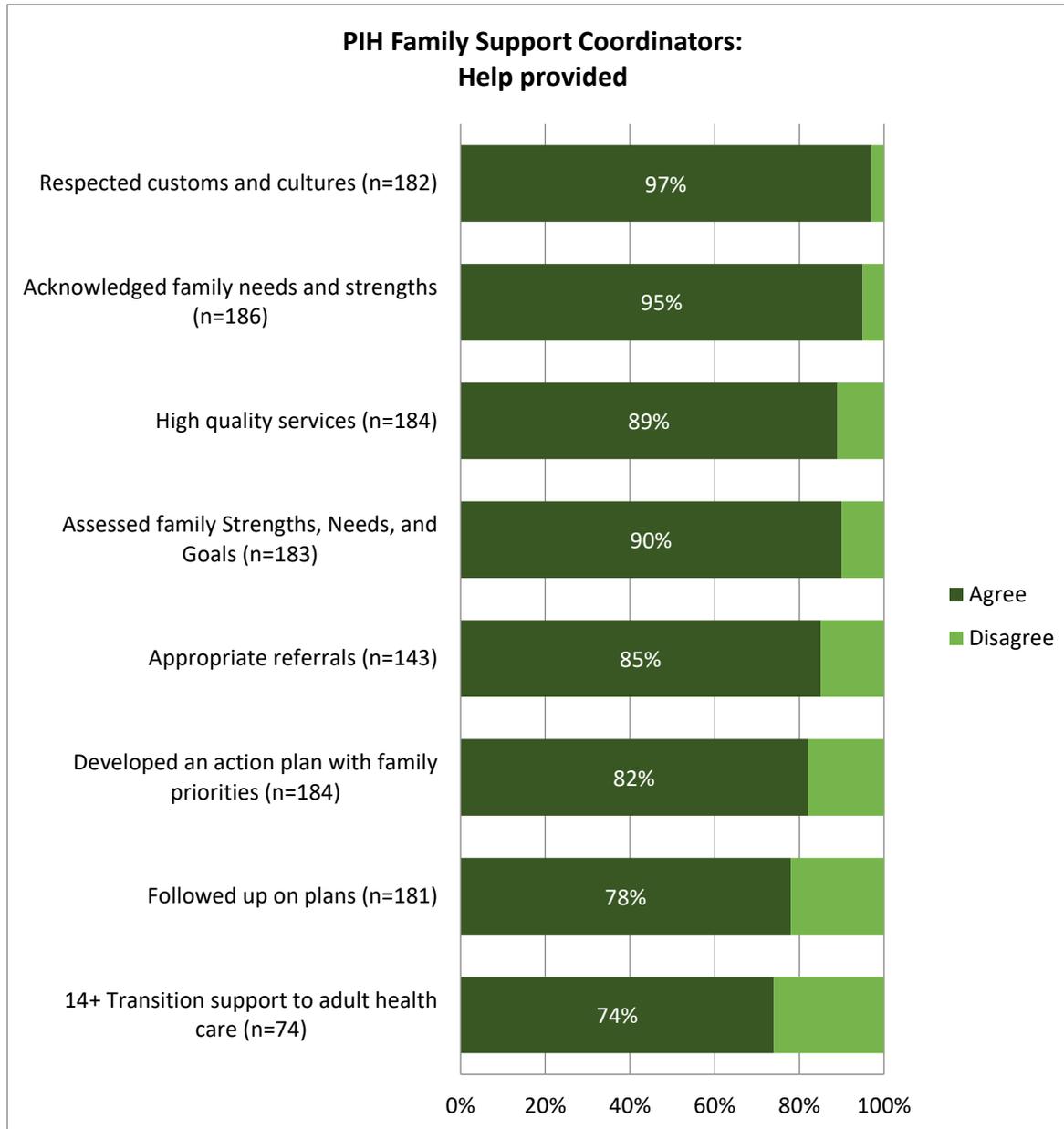
FSC/ Effectiveness

Family Support Coordinators showed effective supportive services across all domains.

PIH offers family support activities through home visits, access to respite, and financial assistance. Support for community connection includes fostering camp and recreational activities, family social activities, and referrals to local resources. PIH also offers support for the development of caregiver leadership/advocacy skills and understanding of educational planning.



FSC/ Services Provided

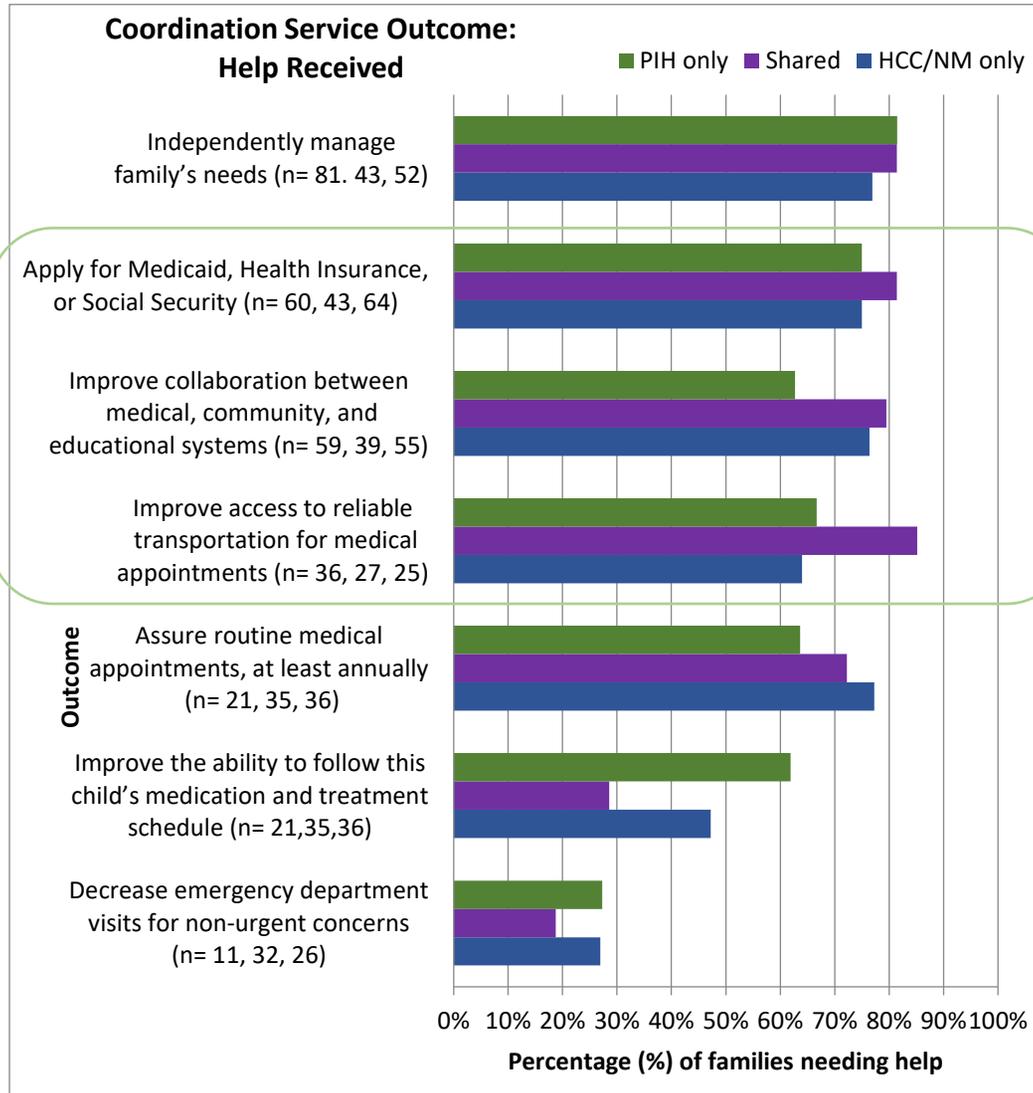


PIH strives to reach consumer satisfaction as a family centered program and looks for opportunities for improvement in areas that need further development.

More recently, PIH has introduced new initiatives with the utilization of an annual youth completed Transition Readiness Assessment Questionnaire (TRAQ), which started in 2016. Although fairly new, further improvements can be made to support families regarding transition services.

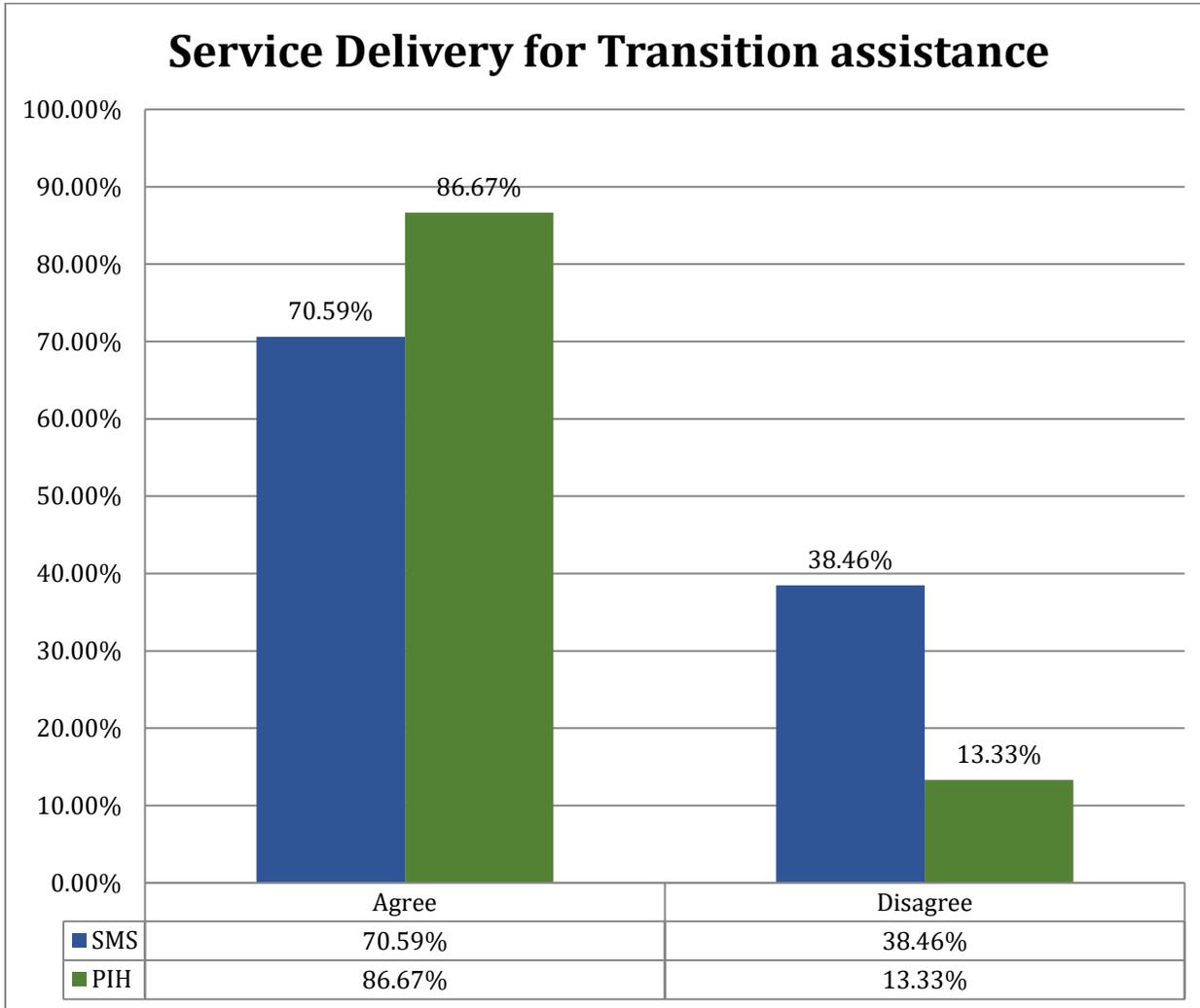
PIH Quality Improvement includes further review of services provided in areas below 85%. Family Support Coordinators meet monthly to review service coordination and provide annual improvement plans to improve services to families.

Outcomes for PIH Family Support Services, SMS Health Care Coordination (HCC) Services and Combined (shared) Coordination Services



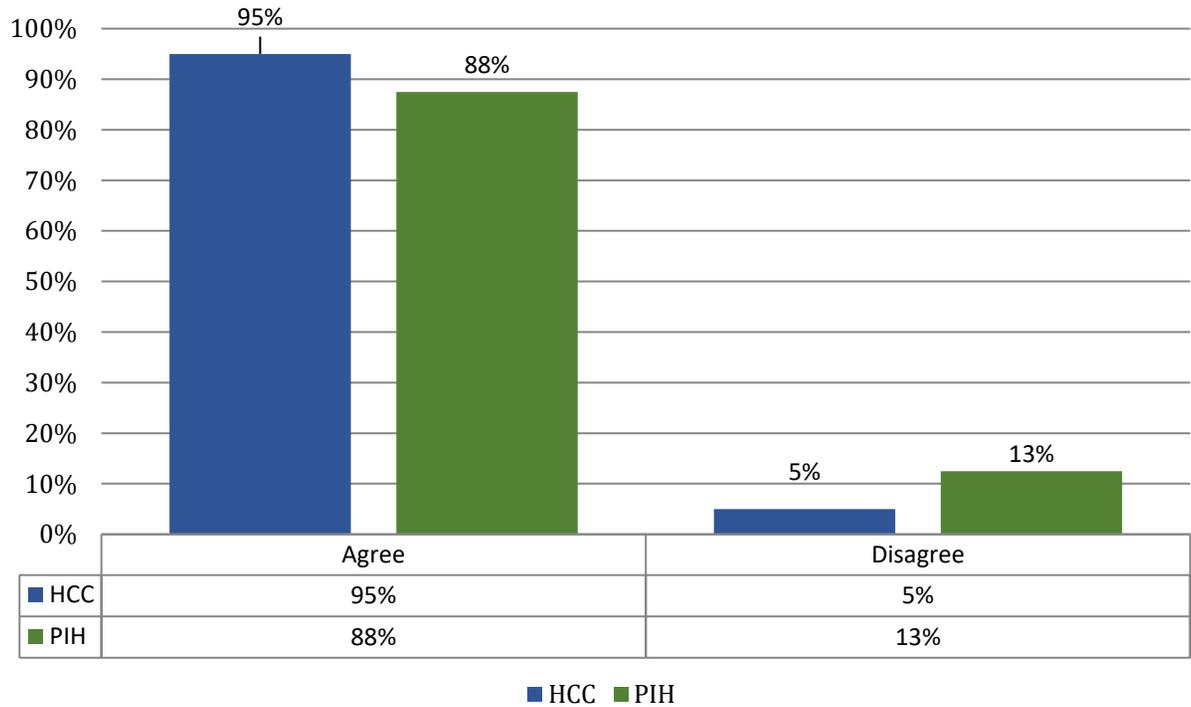
When PIH and HCC mutually serve a family (Shared), families report that services are more effective than either service alone. Eighty percent or more of shared respondents reported effective community referrals, application & transportation assistance, service provider collaboration, and coordination for families.

More than sixty percent of Partners in Health (PIH) respondents reported effectiveness in each of the core services. Core services are related to the impact of a chronic health condition on a family.



Both PIH and Health Care Coordination strive to support and guide youth over the age of 14 to prepare for the transition to adult health care services. This includes administering the Transition Readiness Assessment Questionnaire (TRAQ) and follow up discussions about what the youth may need to help reach their individual transition goals.

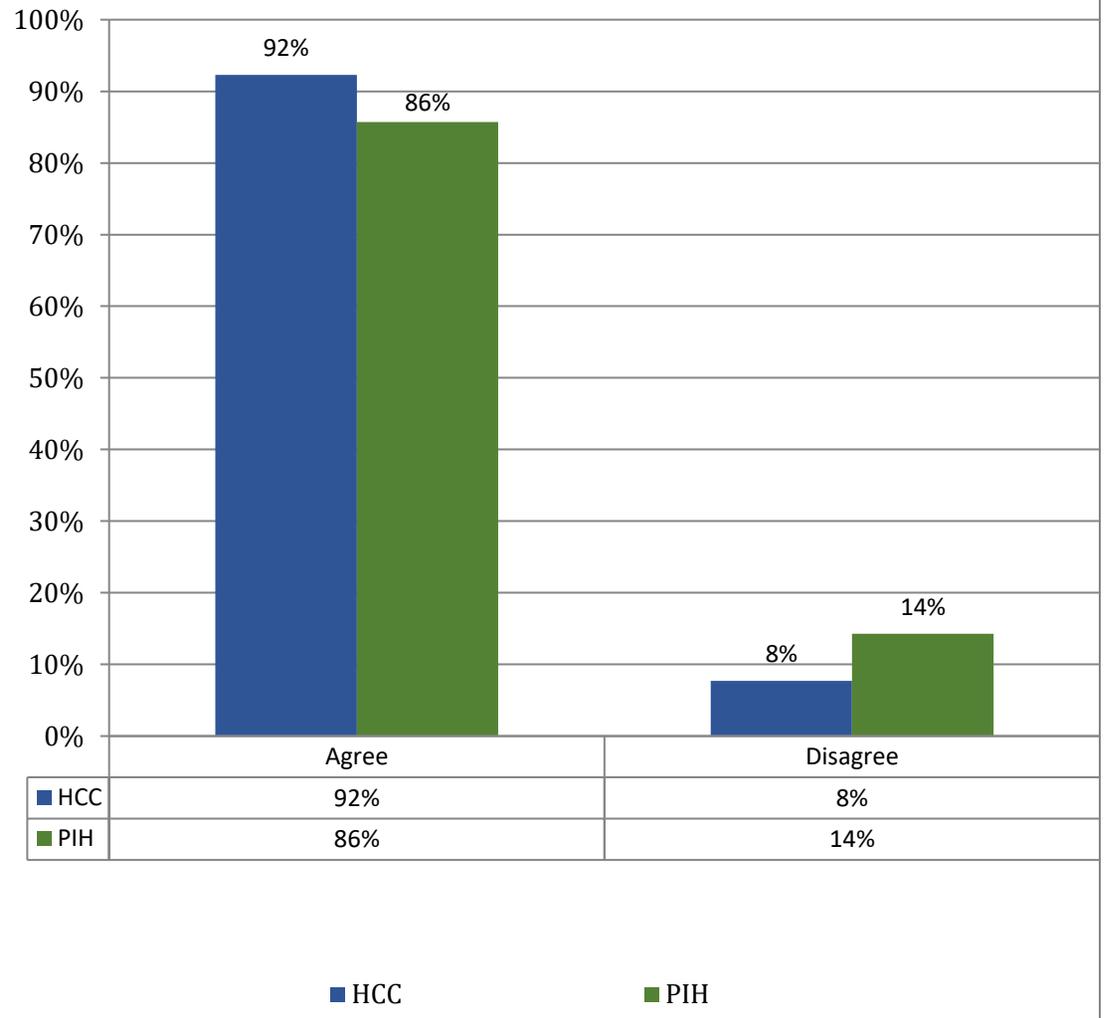
Coordination regarding concerns, needs and priorities in the plan of care



PIH and HCC both provide family centered care by continually supporting families and clients in goal setting that address the identified current needs. These goals and plans are developed to help them attain best outcomes. Clients and their families receive follow up and consultation services regarding issues as they arise and during annual or more frequent assessments. The corresponding graph indicates that participants felt that their communicated needs were addressed and recognized as their specific priorities.

PIH Family Support Coordinators and the Health Care Coordinators assist families with locating resources and making connections and referrals to support children with special health care needs within their communities. The Coordinators have extensive networks and experience, thus making these connections possible. This graph indicates the majority of respondents are receiving appropriate referrals to resources and services as were identified in their plans of care.

Appropriate referrals made by coordinators (n=44)



Summary

FSC/ HCC

- ✓ Transition planning is the area where the most opportunities exist for improved effectiveness.
- ✓ The majority of respondents agreed their cultures and customs are respected.
- ✓ Overall, families reported high satisfaction regarding the effectiveness of Coordination services.
- ✓ Respondents agree that coordinators recognized that families best know their own needs and strengths.

It is the combined belief of the coordinators serving in Partners in Health and Health Care Coordination, that better outcomes for clients and families are achievable when team players work together. Recognizing and acknowledging the priorities of those served, providing assistance during times of transition, and making appropriate referrals to agencies and programs all help families feel listened to and supported. Additional available data proves that health care access and educational/medical partnerships are improved and transportation options are more available for medical appointments. When families are provided joint services through Health Care Coordination and Partners in Health they report a high level of satisfaction with the coordination efforts.

CHILD DEVELOPMENT CLINIC



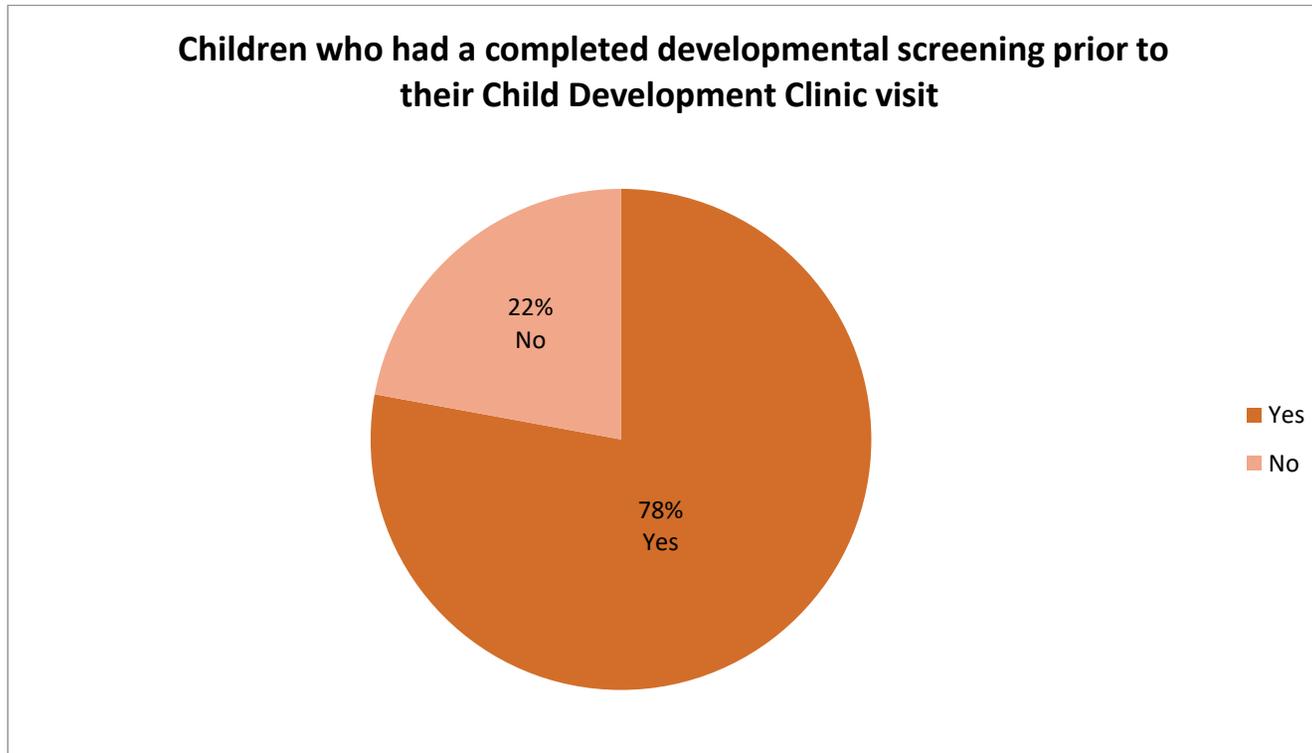
educational need. Services were family centered and culturally sensitive. Families may refer themselves, or can be referred by a health care professional or an early childhood professional.

This survey was received by 786 families, whose children had been evaluated by a Title V funded Child Development Clinic, and had 110 respondents.

The Manchester, Keene, and Laconia Child Development Clinics, in addition to the Lancaster and Community Partners site, comprised the network of five Title V supported diagnostic clinics in the State of New Hampshire. In fiscal year 2018, there were 92 clinics were held in Manchester, 9 in Keene, 12 in Laconia and 12 in Strafford County.

These clinics provided a one-time comprehensive diagnostic evaluation to assist families who have children with developmental/ behavioral concerns/ difficulties. Clinic evaluators assisted families in making informed decisions regarding medical, developmental and

Completed Developmental Screenings



The State of NH has focused on having children through the age of developmentally screened early and often at no cost to families. This survey provides evidence that developmental screening was the first step in receiving appropriate referrals to the Child Development Clinics. Of those surveyed, 78% of children had completed a screening prior to attending Child Development Clinic. Virtually all families (97%) said that they had shared the results from the screening with their child's Primary Care Provider(s).

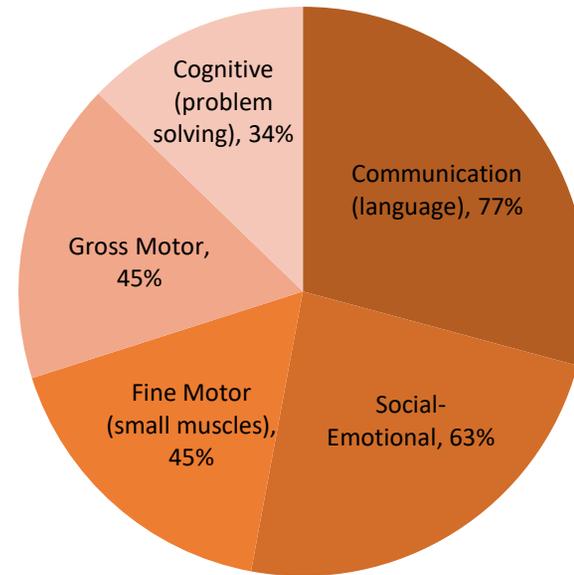
According to the National Survey of Children's Health (2017), 35% of NH Parents self-reported that they completed a standardized, validated developmental screening tool, which was slightly higher than the national response of 32%. This confirms that additional efforts are needed to assure that developmental screening, which is an important first step in identifying children who need further evaluation, is consistent and universally available.

Caregiver Identified Areas of Concern

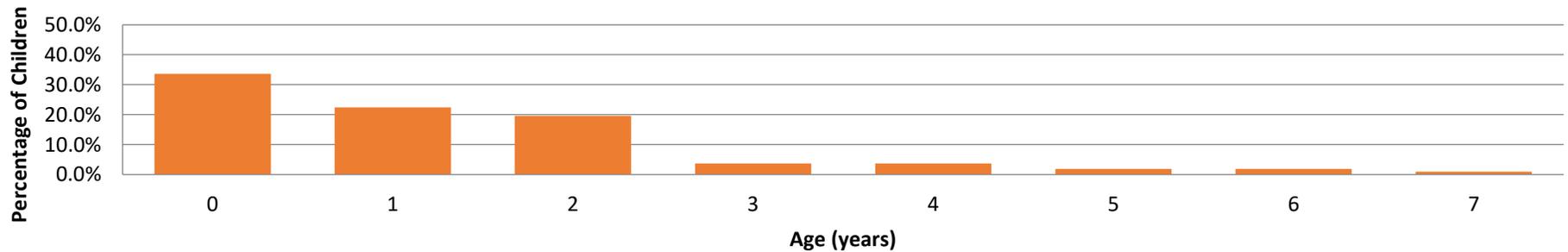
When asked about their developmental concerns for their child, the top two areas were communication (77%) and social emotional needs (63%). This is consistent with national reporting.

According to the survey, for the majority of caregivers, concerns originated when their child was under the age of three. This reinforces the importance of early and frequent developmental screening. This allows families/providers to identify delays as they emerge and to facilitate referrals for further evaluation, in a timely manner.

Areas of Concern for Child Development Clinic

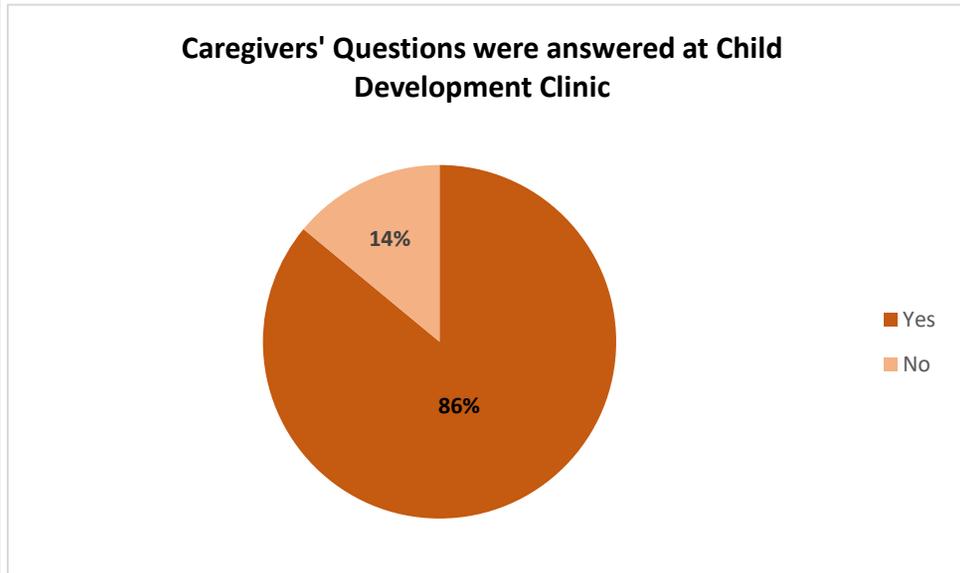
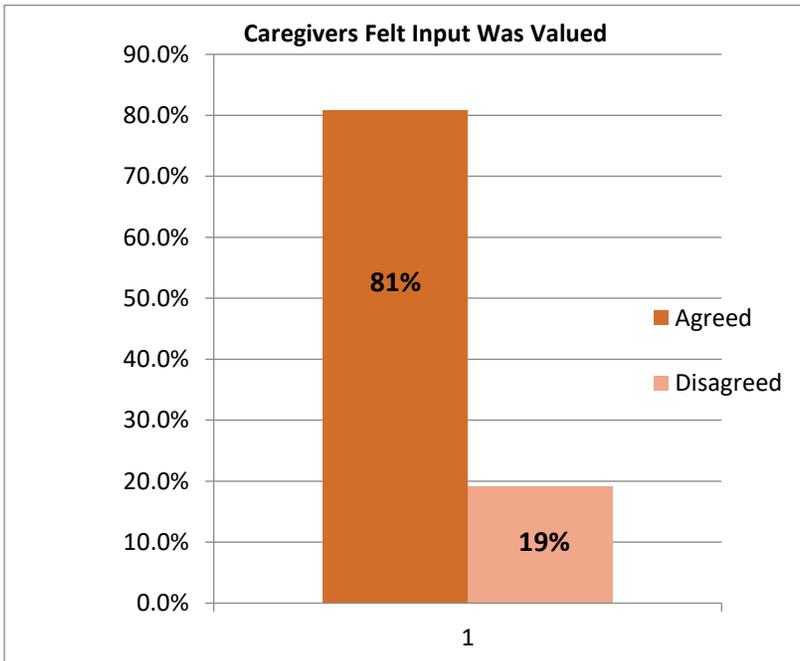


Age of First Developmental Concern



Family Experience at Clinic

Family centered care is a focus for NH, families know their children best and their input is invaluable to their child’s care. Families should be involved at every level of the comprehensive diagnostic evaluation process. An overwhelming majority (81%) of Respondents reported that their input was valued.



While not every child received a diagnosis as a result of the Clinic evaluation, 86% of caregivers felt that the Child Development Clinic Team was able to answer their questions regarding any concerns that they had for their child.

Summary

Family Concerns

- ✓ There was a significant difference by gender (child's) noted for the top two areas of concern:
- ✓ Communication deficits as the top area of concern were 72% (57) male, 19% (15) female with 9% (7) opting not to identify gender.
- ✓ Social Emotional deficits were 80% (51) male, 17% (11) female with 3% (2) opting not to identify gender. This reflects the national trend of more boys than girls being given diagnoses, related to social emotional delays, such as but not limited to autism.

Diagnoses

Caregivers reported that 73% of the children who attended Child Development Clinic received a diagnosis. Since young children have variable developmental trajectories the remaining 27% who did not receive a diagnosis may have been given a recommendation to pursue a follow up evaluation in the future if indicated.

Services

Consistent with caregiver-identified areas of concern and clinic diagnoses, the top four services that children received post clinic were:

- Speech and Language
- Occupational Therapy
- Family Centered Early Supports and Services (Part C Early Intervention)
- Physical therapy

Caregivers reported (23%) that wait lists and lack of providers resulted in service availability issues, particularly for autism spectrum disorders.

NUTRITION and FEEDING & SWALLOWING CONSULTATION

SMS supports a network of nutritionists and feeding & swallowing providers to offer nutrition and feeding and swallowing services to children birth to 21 years of age (and their families) in communities across the state.

The nutritionists are Registered Dietitians and the feeding and swallowing providers are all masters' level Speech Language Pathologists or Occupational Therapists. All providers have specialized competencies in delivering family-centered services to children and youth with special health care needs (CYSHCN).

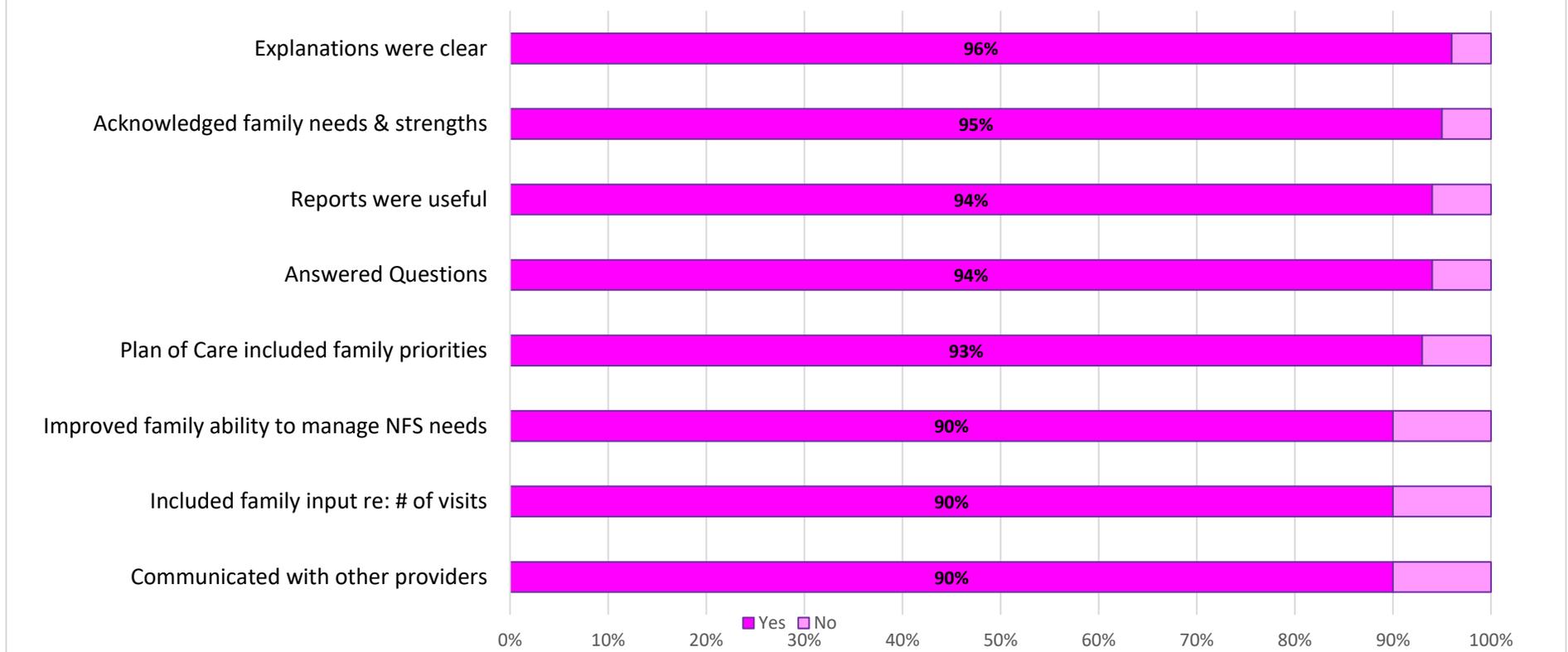
Nutrition, Feeding & Swallowing Services (NFS) include:

- * Initial nutrition and feeding and swallowing evaluations and follow up consultations are held at a location of family choice (i.e. home, school)
- * Close collaboration with Early Supports and Services, Head Start. Primary Care and school teams.
- * Develop safe eating plans and special meal prescription forms for daycare and school meal programs
- * Conduct swallow studies at six hospitals statewide as recommended from team
- * Join families at medical appointments and specialty clinics when requested by families
- * Insurances are billed with family permission; there is no charge to families.

Referrals may come from families, primary care providers, family centered early supports, parents, schools and specialty clinics. Families complete the SMS application; medical records are requested and reviewed for eligibility. Parents are then contacted to schedule the initial appointment.

The NFS program has consistently had the highest enrollment among the various SMS programs

Impact of NFS Services and Provider Effectiveness

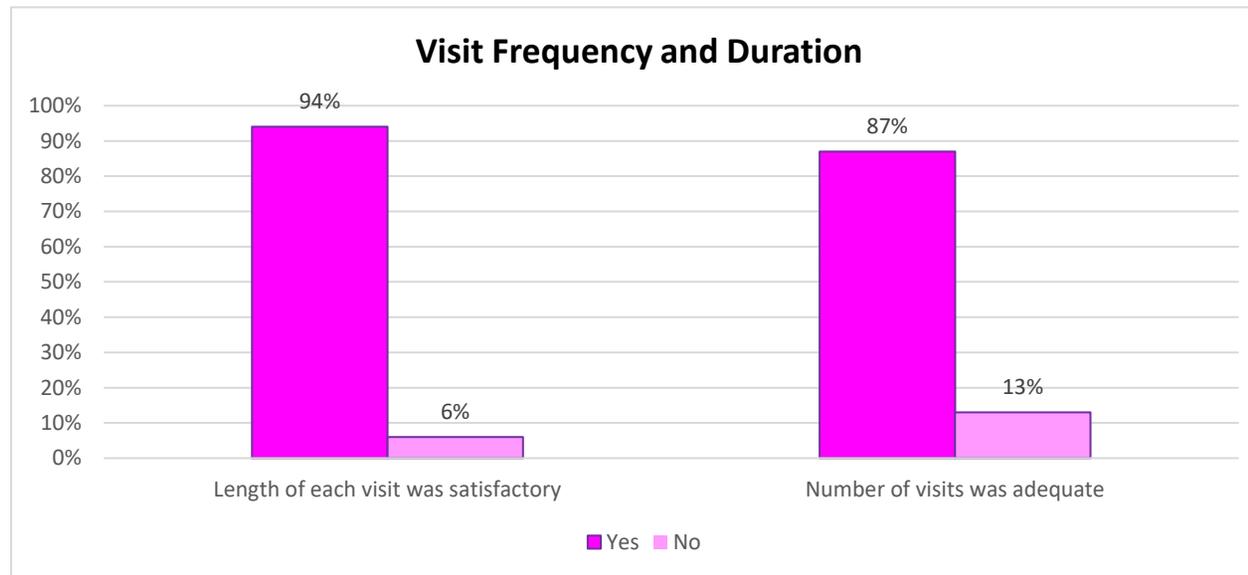


The survey respondents overwhelmingly reported that NFS services have a beneficial impact. Each component that was identified was rated as having been helpful for 90% - 96% of the families, including the overall goal that caregivers are more confident in managing their child(ren)'s needs independently.

Summary

The Nutrition, Feeding and Swallowing Program continuously seeks ways to:

- Improve services to families through a tight collaborative effort between Special Medical Services and the vendor programs at Amoskeag Health & SERESC;
- Strengthen collaborative efforts with other agencies to improve current service delivery;
- Expand service options; and
- Contribute to the advancement of pediatric nutrition, feeding and swallowing care by attending and contributing to advanced training.



The number of children in need of NFS services has been increasing, as has the acuity of their conditions and the social complexity of their families. The NFS Program has prioritized new evaluations and high risk children. One of the consequences of this change is that it has hindered the program's abilities to provide follow-up services to families and to connect with community service providers, as frequently as planned.

The responses from the survey reflect this reality. Caregivers are twice as likely to report that the number of visits was inadequate as they are to identify a need for more time with each visit. This reinforces the feedback that caregivers are highly satisfied with the services they receive while still indicating an overall issue with the NFS program's capacity.