

DELAWARE FAMILIES WITH CHILDREN WITH MEDICAL COMPLEXITY SURVEY

FINAL REPORT



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INTRODUCTION

NATIONAL CONTEXT

Children with medical complexity (CMC) have significant chronic health conditions impacting multiple organ systems, substantial functional limitations, increased health service utilization, and in some cases the need for medical technology. Nationally, CMC account for about 3% of the pediatric population, yet 40% of Medicaid spending for children (Lucile Packard Foundation for Children’s Health, 2018¹). Research on this population has increased in recent years with a focus on identifying and caring for these children. Findings show that existing health care models have difficulty meeting the care needs of CMC (Cohen, et. al, 2011)². Unmet needs are documented at significantly higher rates for CMC as compared with children without medically complex needs (Kuo, et al., 2014)³. The state of Delaware has focused on CMC since 2017 with the goal of supporting the well-being and health of children and families in this vulnerable population.

DELAWARE’S COMMITMENT TO CMC

Delaware passed legislation in 2017 with instructions for the Department of Health and Social Services to “develop and publish a comprehensive plan for managing the health care needs of Delaware’s children with medical complexity.” To develop the plan, the CMC Steering Committee was launched in November 2017 and held bi-weekly meetings for about six months. A group of highly involved parents were at the heart of the steering committee as was a diverse group of stakeholders including individuals from Delaware’s Division of Medicaid and Medical Assistance (DMMA), Nemours/AI DuPont Hospital for Children, Bayada Pediatrics, Highmark Health Options, AmeriHealth Caritas, Delaware Family Voices, Community Legal Aid, Division of Prevention and Behavioral Health Services, Division of Management Service/Birth to Three Programs, and the Division of Public Health. Families presented their care maps and experiences in caring for their children at the beginning of each meeting to ensure that discussions were grounded in families’ lived experiences.

¹ <https://www.lpfch.org/publication/measuring-population-health-children-medical-complexity>

² Cohen, E., Kuo, D. Z., Agrwal, R., Berry, J. G., Bhagat, S. K., Simon, & T. D., Srivastava, R. (2011). Children with medical complexity: An emerging population for clinical and research initiatives. *Pediatrics*, 127 (3).

³ Kuo, D. Z., Goudie, A., Cohen, E., Houtrow, A., Agrawal, R., Carle, A. D., & Wells, N. (2014). Inequities in health care needs for children with medical complexity. *Health Affairs*, 33 (12).

The committee's goals were to clearly identify this population, assess access to services, evaluate models of care, and analyze the relationships between insurance payers. The CMC Steering Committee defined CMC as a subset of children and youth with special health care needs because of their extensive health care utilization. For Delaware's plan, a child is considered medically complex if they fall into two or more of the following categories:

1. Have one or more chronic health condition(s) associated with significant morbidity or mortality;
2. High risk or vulnerable populations with functional limitations impacting their ability to perform Activities of Daily Living (ADLs);
3. Have high health care needs or utilization patterns, including requiring multiple (3 or more) sub-specialties, therapists, and/or surgeries;
4. A continuous dependence on technology to overcome functional limitations and maintain basic quality of life.

The steering committee made substantial progress in documenting the barriers and challenges that families face when accessing care for their medically complex children. Delaware's 2018 Plan for Managing the Health Care Needs of Children with Medical Complexity can be found [here](#).⁴ The plan delineates several recommendations to continue supporting CMC and their families, including:

- Keeping the CMC Steering Committee in place to assist the state in strengthening Delaware's ability to adequately meet the healthcare needs of CMC.
- Strengthening the network of home health providers for CMC.
- Strengthening systems of care for CMC by supporting models of care that are patient and family centered.
- Developing/strengthening existing resources for parents/caregivers, providers, and the community.
- Performing comprehensive research and analyses to identify the population of CMC in the state of Delaware and understand clinical and service utilization parameters to help identify service gap among other priorities.

The work of the legislatively mandated CMC Steering Committee was transitioned to an advisory council, led by the DMMA Medicaid Director, in order to oversee the implementation of the priorities identified in the 2018 Plan. The Children with Medical Complexity Advisory Committee

⁴ https://dhss.delaware.gov/dhss/dmma/files/de_plan_cmc.pdf

(CMCAC) continues to meet on a quarterly basis, supported by topic specific workgroups which meet on a bi-monthly basis. The work described in this report responds to the Plan's recommendation to engage in comprehensive research and has been conducted with guidance and support from the Data Workgroup.

STUDY DESIGN

Vital Research was contracted to facilitate the work with the CMCAC to design and implement a state-wide survey to better understand a broad range of families with CMC's experiences accessing and receiving health care and supports for their children.

Research questions that guided this study were:

- What are families with children with medical complexity experiences with care and services provided by the state of Delaware?
 - Access: How do families access services? How do families learn about service options? What are the barriers that families experience in accessing services?
 - Quality: What are families' perceptions of the quality of care received?
- What additional support and care needs do families have? What can DMMA do to better support families with children with medical complexity?
- What contextual factors contribute to variability in families with children with medical complexity experiences with care and services?

Prior to the COVID-19 pandemic, the intent was to meet with families, in person, via a series of small focus groups, in order to gain important information regarding family experiences to use in developing the family survey. The pandemic required a pivot to a different approach. Data were collected in two phases to ensure broad participation and representative results. In the first stage of data collection, Vital conducted in-depth interviews with parents and caregivers across the state of Delaware in June and July of 2020 to better understand the diverse needs and challenges families face. Details about the interview phase of this project can be found in Appendix A. This information was used to develop a survey that was disseminated to all families in the target population in January 2021.

TARGET POPULATION

All families with CMC under 18 and individuals with medical complexity ages 18-21 living in the state of Delaware were included in this study. Participants were Delaware Medicaid or CHIP program participants and must have been receiving services within the 12 months prior to data collection. Delaware's state systems do not identify and track CMC. As such, the 3M Clinical Risk Groups (CRG) analysis was used to identify families and their children who were eligible for study participation. Children with a CRG score of 5b or higher were included in the sample. Because the CRG analysis was conducted in 2018, a second analysis was done utilizing proxy indicators (e.g., eligibility for the Delaware Children's Community Alternative Disability Program [CCADP]) to capture additional children who entered the Medicaid program and could be considered to have medical complexity. These children are identified in the sample as having medical complexity, yet they do not have a score that indicates the severity of their condition(s) as the CRG scores do.

SURVEY DEVELOPMENT + ADMINISTRATION

Findings from the 11 open-ended interviews, existing research tools, and information gleaned from participation in the CMCAC all informed the first draft of the family survey. DMMA provided feedback on the first draft and then families involved in the CMCAC provided feedback and edits in second and third rounds of edits. Some sections were removed due to concerns with survey length (e.g., insurance coverage, approvals, denials, etc.) and additional detail was added to the services accessed section as well as the care coordination section. The following sections were included on the final survey (Appendix B):

- Your Child and Your Child's Services
- Challenges in Accessing Services
- Home Health Providers
- Care Coordination
- Primary Medical Provider
- Family Needs and Supports
- Demographics

An invitation letter and the survey were sent to 4,055 eligible participants within the target population with options for mail-in or on-line survey completion. Paper copies of letters and surveys

were sent in English or Spanish, based on DMMA's records regarding language preference, and postage paid return envelopes were provided. A unique access code and URL was included in the invitation letter to English-speaking families for on-line completion. For individuals aged 18-20, the invitation letter was sent directly to them and noted that families were invited to participate only if the individual agreed to have a family member or guardian respond on their behalf. A postcard reminder was sent to the full sample approximately one week after the initial survey mailing. Approximately one month later, a second reminder postcard was sent to everyone in the sample who had not completed the survey on paper or online to increase response rates. The survey deadline was extended in order to promote additional survey completion.

ANALYSIS PLAN

Paper-based surveys were formatted for electronic scanning using Remark OCR software to reduce data entry errors and expedite data processing. Data from paper-based and electronic surveys were merged and analyzed using the Statistical Package for the Social Sciences software program (SPSS). Basic descriptive statistics were calculated to understand response patterns by groups of interest and across the full sample. Inferential statistics to understand if differences among groups of interest are statistically significant and therefore expected at the population-level, were also conducted.

SURVEY RESPONDENTS

The survey was mailed to 3,035 families with CMC under the age of 18 and to 1,020 families with adult children between 18 and 21 years old. All recipients were provided the option to complete the survey online. Of the 4,055 surveys mailed, 393 respondents attempted the survey (100 online and 293 paper) for processing and analysis, representing an 9.7% response rate.

SCREENING FOR MEDICAL COMPLEXITY

Because a large portion of sample list members were included based on data that was approximately three years old, there was potential for a family's situation to have changed. To "screen" for eligibility to complete the survey, a series of items were developed using the Delaware definition for medical complexity (see below). Family members were asked a series of items at the beginning of the survey and instructed to proceed or discontinue based on their responses. All families were asked if

they considered their child to have medically complex needs, and then they were asked about specific aspects of their child’s health including risk of requiring hospitalization or dying, inability to perform activities of daily living (ADLs), seeing specialists, or requiring technology to maintain basic quality of life. If respondents answered ‘Yes’ to two or more items from the definition screener, they were asked to proceed and complete the survey. Otherwise, they were instructed to return the survey to Vital Research.

CMC SCREENING CRITERIA

1. Do you consider your child to have medically complex needs?
2. Does your child have one or more health conditions that puts them at risk of getting very sick (to the point of requiring hospitalization) or dying?
3. Does your child’s medical condition affect their ability to perform activities of daily living (ADLs) such as walking, feeding, dressing, bathing, toileting, or moving from one body position to another?
4. Does your child spend a lot of time seeing specialists or in the hospital due to their medical condition?
5. Does your child’s medical condition require technology (e.g., ventilators, feeding tubes, oxygen, etc.) to help them maintain a basic quality of life?

If families responded YES to two or more questions for items 2 – 5, they were instructed to continue the survey. If they answered NO or DON'T KNOW to three or more for items 2 - 5, families were asked to stop and mail the survey back to Vital Research in the postage-paid envelope.

Of the 393 survey attempts, 207 qualified based on the CMC definition screening criteria.

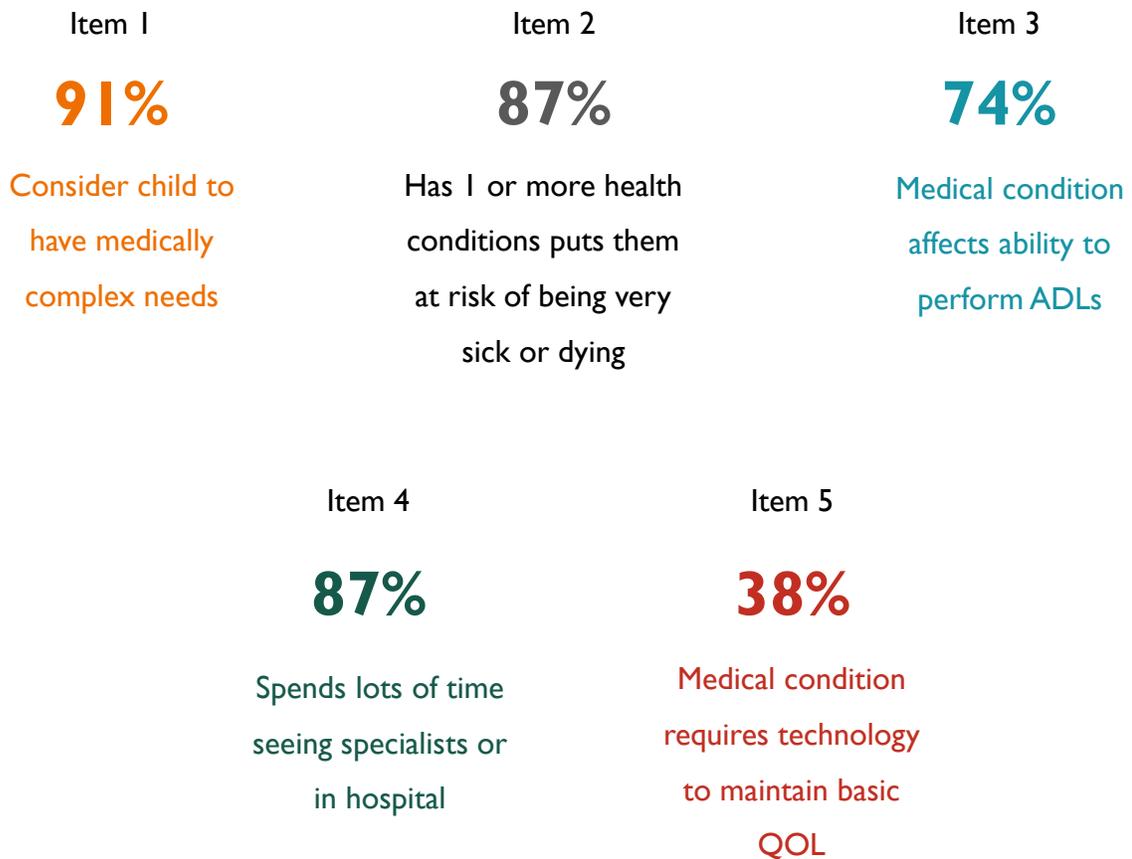
Three-quarters of the responses were received via mail using the paper survey format, and one-quarter were completed online.

TABLE I. SURVEYS RECEIVED FROM FAMILIES WITH CMC WHO PASSED SCREENER

MODE	NUMBER OF SURVEYS
Paper survey returned via mail	154 (English) 2 (Spanish)
Online	51
TOTAL	207

Almost all respondents (91%) considered their child to have medically complex needs. Most respondents reported their children had a health condition putting them at risk of illness or mortality, conditions that impacted their ADLs, and/or spent time seeing specialists or in the hospital. Fewer respondents, 38%, had children who required technology to maintain a basic quality of life.

FIGURE I. PERCENTAGE OF RESPONDENTS WHO ANSWERED 'YES' TO EACH OF THE FIVE CMC SCREENER ITEMS



CHILD DEMOGRAPHICS

Delaware provided the date of birth for children identified as being part of the target population. With this information, the ages of the children were calculated as of May 1, 2021. Approximately 15% were under five years old, nearly two-thirds (65%) were between the ages of six and 17, and 20% were over the age of 18. Surveys were received from all three Delaware counties, with 54% (n=112) from New Castle, 21% (n=44) from Kent and 25% (n=51) from Sussex. The genders of the children were 55% male and 45% female. Like the race/ethnicity of the parents, the majority were identified as White (62%), followed by Black/African American (26%), Latina/o/x or Hispanic (11%), Asian/Asian American (6%), American Indian/Alaska Native (3%), and Middle Eastern, North African or Arab American (1%).

TABLE 2. CHILD DEMOGRAPHICS OF SURVEY RESPONDENTS

DEMOGRAPHIC	FREQUENCY	PERCENTAGE
Age		
0 – 5 years	31	15%
6 – 17 years	135	65%
18+ years	41	20%
Gender		
Male	114	55%
Female	93	45%
Race/Ethnicity		
White	125	62%
Black or African American	53	26%
Latino/a/x or Hispanic	23	11%
Asian or Asian American	12	6%
American Indian or Alaska Native	7	3%
Middle Eastern, North African or Arab American	1	1%

NOTE: Race/Ethnicity was "Select all that apply" therefore total exceeds 100%

To a large extent, respondents' children were comparable to the full sample of eligible participants along key demographic characteristics. For example, while 62% of respondents' children were White, 60% of eligible children in the full sample were White. While 26% of respondents' children were Black or African American, 37% of children in the sample were Black or African American. The gender split was the same when comparing respondents' children to the full sample. Respondents lived in Delaware's three counties at similar rates as all eligible respondents found in the sample list. Finally, respondents' children were distributed across age groups similarly to the distribution of the full sample. A slightly lower percentage of respondents were in the 18–21-year-old age range (20%) as compared with the sample (25%) and more respondents were in the 6–17-year-old age range (65%) as compared with the sample (58%).

PARENT DEMOGRAPHICS

About 90% of survey respondents were female and the majority identified as White (64%), followed by Black/African American (20%), Latina/o/x or Hispanic (8%), Asian/Asian American (5%), American Indian/Alaska Native (4%), and Middle Eastern, North African or Arab American (1%). Survey respondents were mostly employed, with 44% employed full-time and 20% part-time, however, **one of three reports being unemployed (30%).** Educational attainment for the survey respondents varied, with one-quarter (26%) having a high school diploma or less, 30% an associate degree or some college, 17% a bachelor's degree, and 28% a graduate level degree.

HOUSEHOLD CHARACTERISTICS

Families were asked to report annual household income. **More than half of the families (55%) earn less than \$50,000 annually,** with 22% earning between \$25,100 and \$50,000 and 33% reporting incomes of less than \$25,000 per year. Forty-two percent of respondents were the sole parent or caregiver involved with the child's care. Of the 55% of respondents who did have two parents or caregivers involved, 24% lived in different homes.

42%
Of respondents
were the sole
parent/caregiver

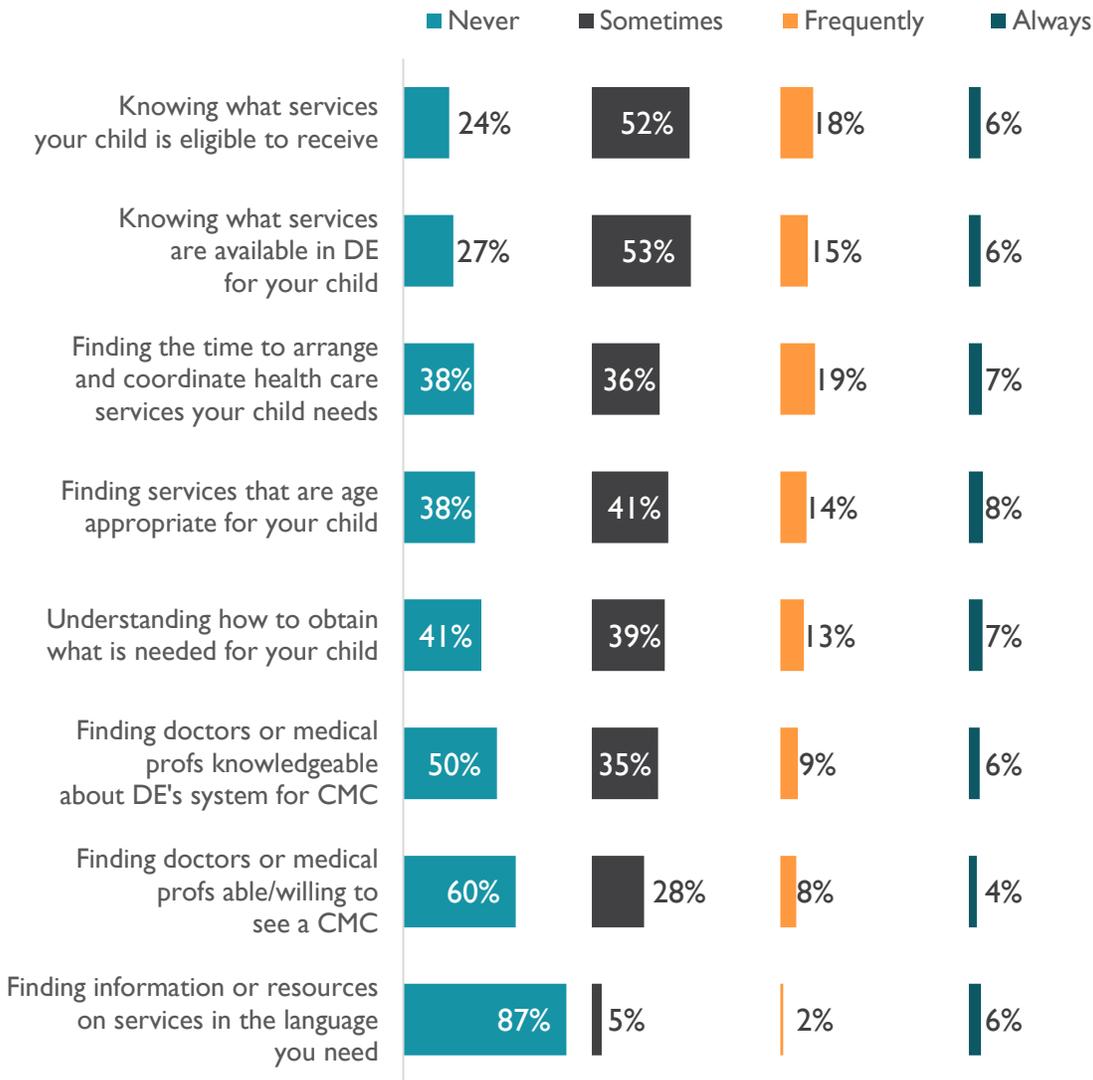
Household size varied substantially within the respondent population with a minimum of one individual living in the household and a maximum of more than eight living in the home. Fifty-nine percent of respondents reported 3-4 people living in the household.

RESULTS

CHALLENGES WITH ACCESSING SERVICES

Survey participants were asked to indicate how often they run into specific challenges when getting health services for their child with medically complex needs. **The most common issues are knowing what services their child is eligible to receive (24% ‘Frequently’/‘Always’), knowing what services are available (21% ‘Frequently’/‘Always’), and finding time to arrange/coordinate services (26%).**

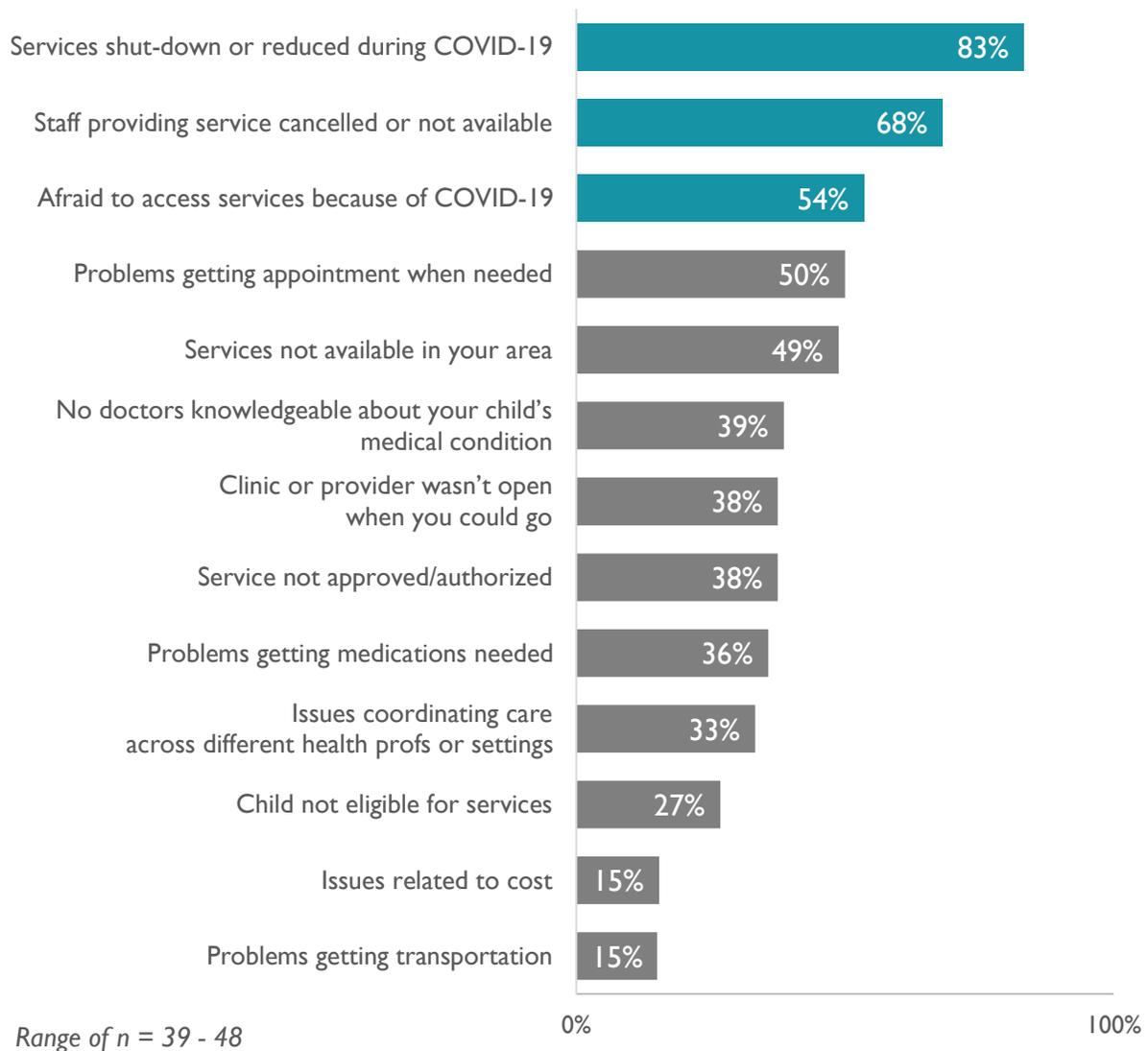
FIGURE 2. CHALLENGES WITH ACCESSING SERVICES IN LAST 12 MONTHS



Range of n = 188 - 193

Approximately 1 of 4 survey respondents (22%) reported there was a time their child needed health services in the last year and did not receive them. The most common reasons that contributed to not being able to access health services were related to the COVID-19 pandemic when services were shut-down or reduced (83%), staff cancelled or were not available (68%), or families were afraid to access services due to COVID-19 (54%). Families had issues getting the appointment (50%) and said services were not available in their area (49%). Nearly 38% said they did not get the health service because it was not approved/authorized, and 27% said their child was not eligible for the services they needed. Only 15% said their child did not get health services due to cost or problems with transportation to access those services.

FIGURE 3. REASONS CHILDREN DID NOT RECEIVE NEEDED HEALTH SERVICES IN LAST 12 MONTHS



ACCESS & SATISFACTION WITH SERVICES

MEDICAL SERVICES

Survey respondents were asked which medical services their child received in the last 12 months and their satisfaction with each service. Almost all (96%) had received preventative care, followed by dental care (75%) and vision care (59%). Approximately three percent (3%) of respondents did not receive medical services in the past year. Satisfaction with medical service types was high, with 97% of respondents 'Very Satisfied' and 'Satisfied' with preventative, dental, and vision care. Average satisfaction scores for medical services were 3.60 and greater (Rating Scale: 1=Very Dissatisfied to 4=Very Satisfied).

TABLE 3. ACCESS & SATISFACTION WITH MEDICAL SERVICES

MEDICAL SERVICE	ACCESS	SATISFACTION* 'Very Satisfied' + 'Satisfied'	SATISFACTION Average
Preventative Care	96%	97%	3.63
Dental Care	75%	97%	3.62
Vision Care	59%	98%	3.60

*NOTE: SATISFACTION are combined frequency percentages for 'Very Satisfied' and 'Satisfied' responses.

THERAPIES

In the past 12 months, over half of the respondents utilized occupational therapy (60%), physical therapy (56%), or speech therapy (54%). Fewer respondents accessed psychological/mental health therapy or behavioral therapy for their children with medically complex needs. One in ten respondents (13%) reported their children received none of the therapies listed. Satisfaction with

therapies were also high, with at least 9 out of 10 respondents ‘Very Satisfied’ and ‘Satisfied’ and average scores greater than 3.30 (Rating Scale: 1=Very Dissatisfied to 4=Very Satisfied).

TABLE 4. ACCESS & SATISFACTION WITH THERAPIES

THERAPY	ACCESS	SATISFACTION* ‘Very Satisfied’ + ‘Satisfied’	SATISFACTION Average
Occupational Therapy	57%	93%	3.37
Physical Therapy	56%	96%	3.47
Speech Therapy	54%	94%	3.42
Psychological/ Mental Health Therapy	34%	97%	3.38
Behavioral Therapy (incl. ABA for Autism)	25%	94%	3.37

**NOTE: SATISFACTION are combined frequency percentages for ‘Very Satisfied’ and ‘Satisfied’ responses.*

MEDICAL SPECIALISTS

Survey respondents were asked to select the types of medical specialists their child with medically complex needs has seen in the last year. The most frequently selected were neurologists (54%), orthopedists (49%), pulmonologists (37%), gastroenterologists (33%), and cardiologists (27%). Families reported high satisfaction with each of the top five medical specialists, with all average satisfaction scores greater than 3.50 (Rating Scale: 1=Very Dissatisfied to 4=Very Satisfied). For any specialist not listed, respondents were asked to write in the medical specialty their child visited. The most frequently referenced other types of medical specialists seen by children with medically complex needs include: ophthalmologists (n=17), ear, nose and throat (n=16), audiologists (n=10),

urologists (n=10), and nephrologists (n=10). Four percent indicated their child did not see any of the types of medical specialists provided.

TABLE 5. ACCESS & SATISFACTION WITH MEDICAL SPECIALISTS

SPECIALIST	ACCESS	SATISFACTION* 'Very Satisfied' + 'Satisfied'	SATISFACTION Average
Neurologist	54%	93%	3.58
Orthopedist	49%	96%	3.63
Pulmonologist	37%	97%	3.74
Gastroenterologist	33%	96%	3.62
Cardiologist	27%	97%	3.79

**NOTE: SATISFACTION are combined frequency percentages for 'Very Satisfied' and 'Satisfied' responses.*

SERVICES & SUPPORTS

In the last year, most respondents indicated their child with medically complex needs received prescription medications (89%) and over half (55%) received durable medical equipment (DME) (e.g., wheelchairs, walkers, braces, ventilators, oxygen equipment, feeding pumps, etc.).

Approximately 40% received disposable supplies (e.g., suction catheters, urine catheters, diapers, feeding bags, etc.), and nearly 20% used augmentative or alternative communication devices. Slightly fewer received intravenous equipment (16%) or utilized emergency or non-emergency transportation (11% each, respectively) and approximately 6% reported they did not use any service or support listed. Satisfaction for services and supports were somewhat lower on average than for medical

services, specialists, and therapies, but all were above 3.20 (Rating Scale: 1=Very Dissatisfied to 4=Very Satisfied).

TABLE 6. ACCESS & SATISFACTION WITH SERVICES & SUPPORTS

SERVICE/SUPPORT	ACCESS	SATISFACTION* 'Very Satisfied' + 'Satisfied'	SATISFACTION Average
Prescription Medicine	89%	93%	3.44
Durable Medical Equipment (DME)	55%	92%	3.38
Disposable Supplies	40%	89%	3.28
Augmentative or Alternative Communication Devices	20%	93%	3.34
Intravenous Equipment	16%	97%	3.48
Non-Emergency Transportation	11%	91%	3.23
Emergency Medical Transportation	11%	100%	3.54

**NOTE: SATISFACTION are combined frequency percentages for 'Very Satisfied' and 'Satisfied' responses.*

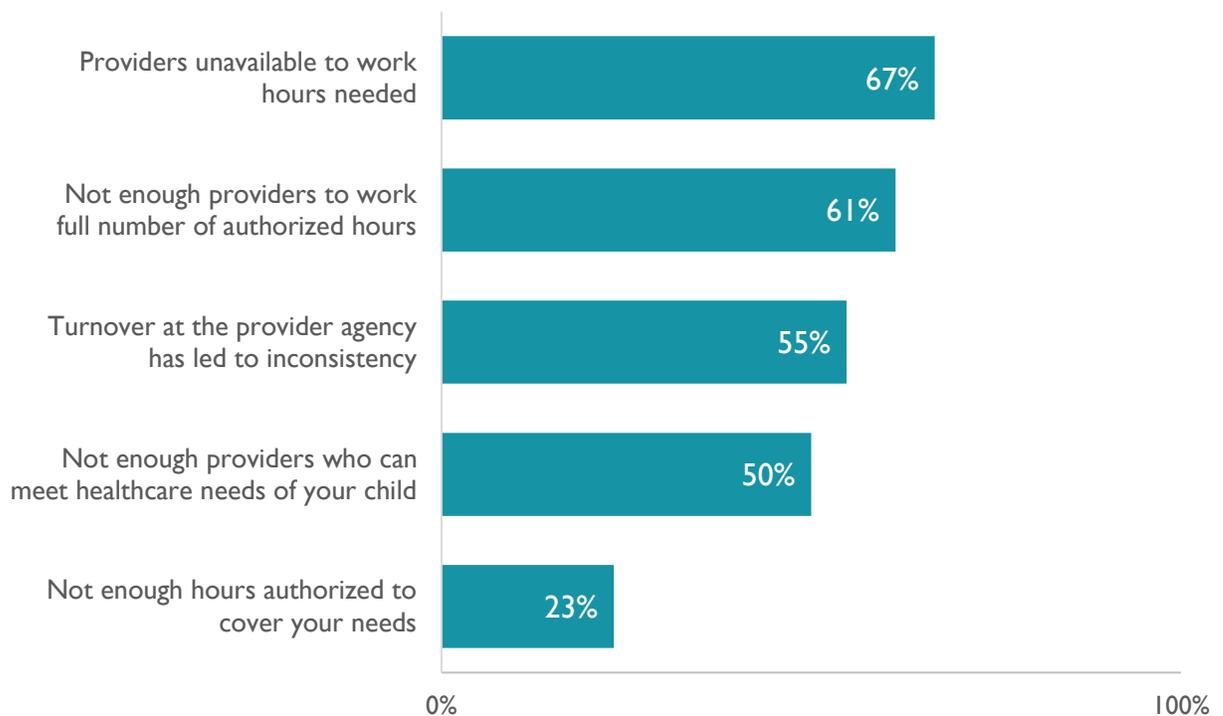
PRIVATE DUTY NURSES

Private Duty Nursing (PDN) services are nurses or other trained health professionals who provide medical care at home for CMC. Almost one-third (29%) of survey respondents were eligible for PDN, and nearly the same number of respondents said they did not know if they were eligible

(28%). Nearly half (44%) of the survey respondents said they were not eligible for PDN services. Of the respondents who were eligible, approximately 70% receive PDN services in their homes. Overall, parents who receive PDN (n=41) report high satisfaction with the quality of care provided by their providers, with 38% 'Very Satisfied' and 36% 'Satisfied'. On a rating scale of 1 to 4, the average satisfaction was 3.02, which is somewhat lower than other satisfaction scores associated with medical providers and specialists.

For families who receive PDN, the majority (64%) have a nurse for 40+ hours per week. Over two-thirds of the families with skilled home health providers receive services during the day shift (71%) and over half (52%) have nurses working the night shift in their homes. During the COVID-19 pandemic, 78% of families with PDN authorized for school hours said they came to their homes to provide medical care during school closures. When asked about challenges with PDN over the last 12 months, families experienced a dearth of providers available to work with their families.

FIGURE 4. CHALLENGES WITH PRIVATE DUTY NURSING IN LAST 12 MONTHS



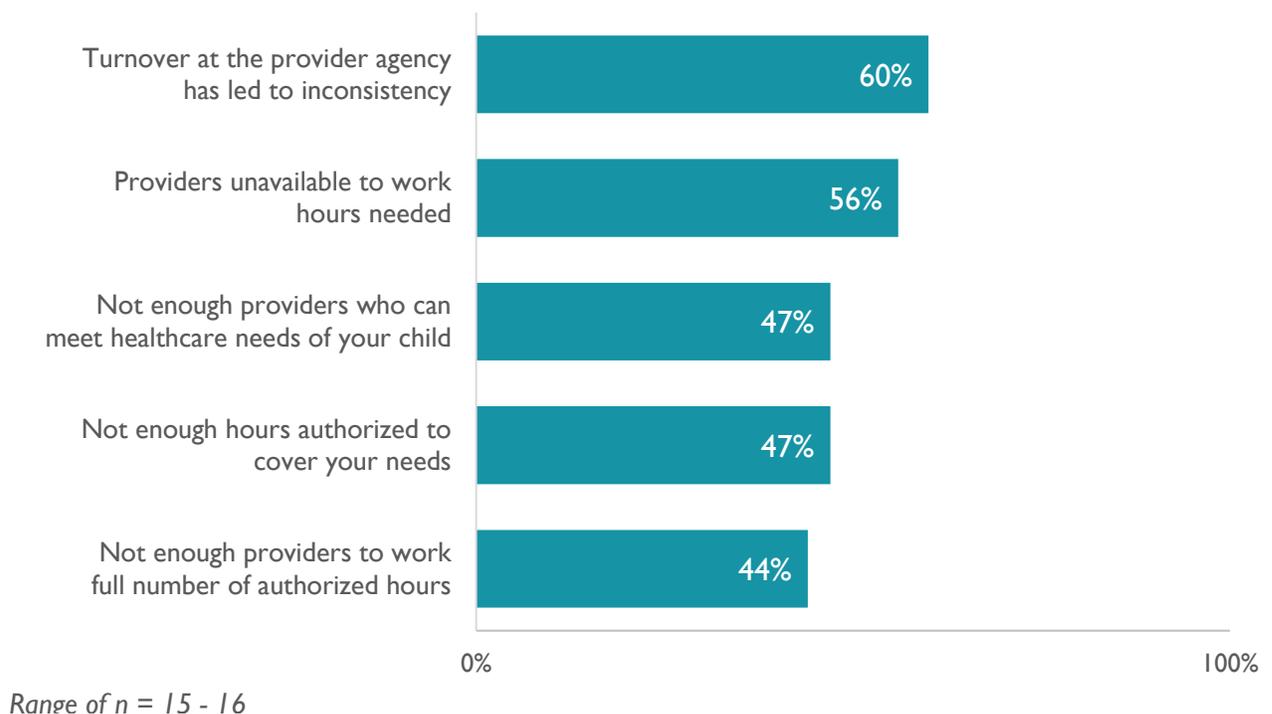
Range of n = 42 - 44

HOME HEALTH AIDES

Home health aide services are provided by non-nurses or non-medical care workers who assist with activities of daily living (ADLs) in the home or school environment. Only 17% (n=34) of families with CMC report being eligible for home health aide services, 44% were not eligible, and 39% said they did not know their eligibility. Of those who are eligible, 43% receive this service. Overall, two-thirds of parents who have home health aide services report high satisfaction with the quality of care, with 33% 'Very Satisfied' and 33% 'Satisfied'. However, one out of three families with home health aides report being dissatisfied (27% 'Dissatisfied' and 7% 'Very Dissatisfied'). On a rating scale of 1 to 4, the average satisfaction was 2.93.

During the COVID-19 pandemic, 75.0% of families with home health aides authorized for school hours said home health aides came to their homes to provide non-medical care during school closures. When asked about challenges with home health aides over the last 12 months, parents felt turnover and availability were key issues.

FIGURE 5. CHALLENGES WITH HOME HEALTH AIDES IN LAST 12 MONTHS



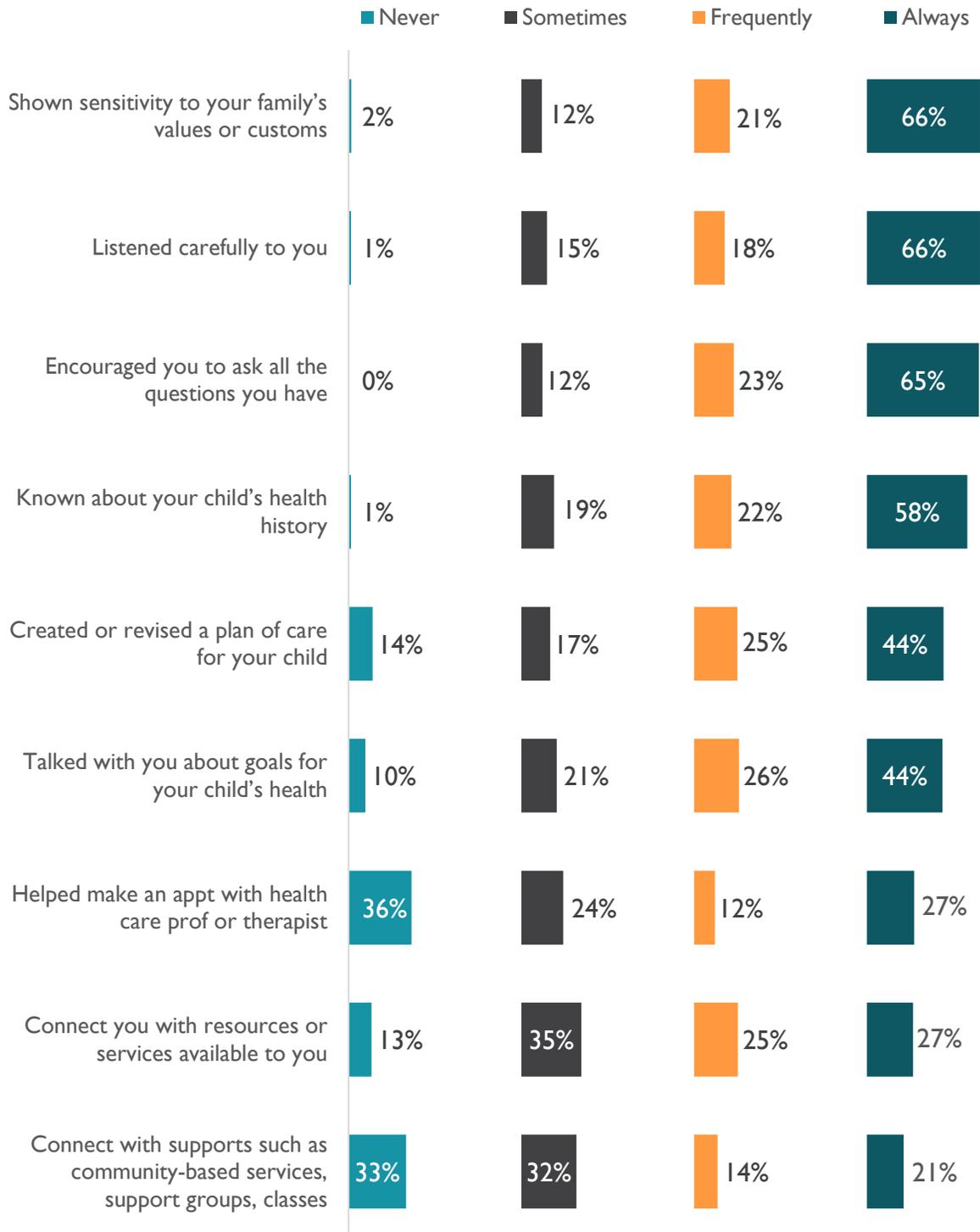
CARE COORDINATION

CARE COORDINATORS

Families with CMC in Delaware may be provided a care coordinator to assist with their various care needs. Care coordinators would be assigned by their managed care organization (MCO) AmeriHealth Caritas or Highmark Health Options. Approximately 40% of survey respondents have a care coordinator, 35% do not have one, and 26% do not know if they have an assigned care coordinator. Of those who have a care coordinator (n=80), over half (51%) say their care coordinator is involved in their child's case 'A Great Deal' and 47% are 'Somewhat' involved. For families with involved care coordinators, 57% said they are 'Very Effective' at supporting their child's case, followed by 33% 'Somewhat Effective,' 8% 'Somewhat Ineffective' and 3% 'Very Ineffective'.

Families were asked to reflect on the last 12 months and their interactions with an assigned care coordinator. Overall, care coordinators were sensitive to family values and customs, listened to families, encouraged questions, and were knowledgeable about their assigned child's health history.

FIGURE 6. SURVEY RESPONDENTS' ASSESSMENT OF CARE COORDINATORS

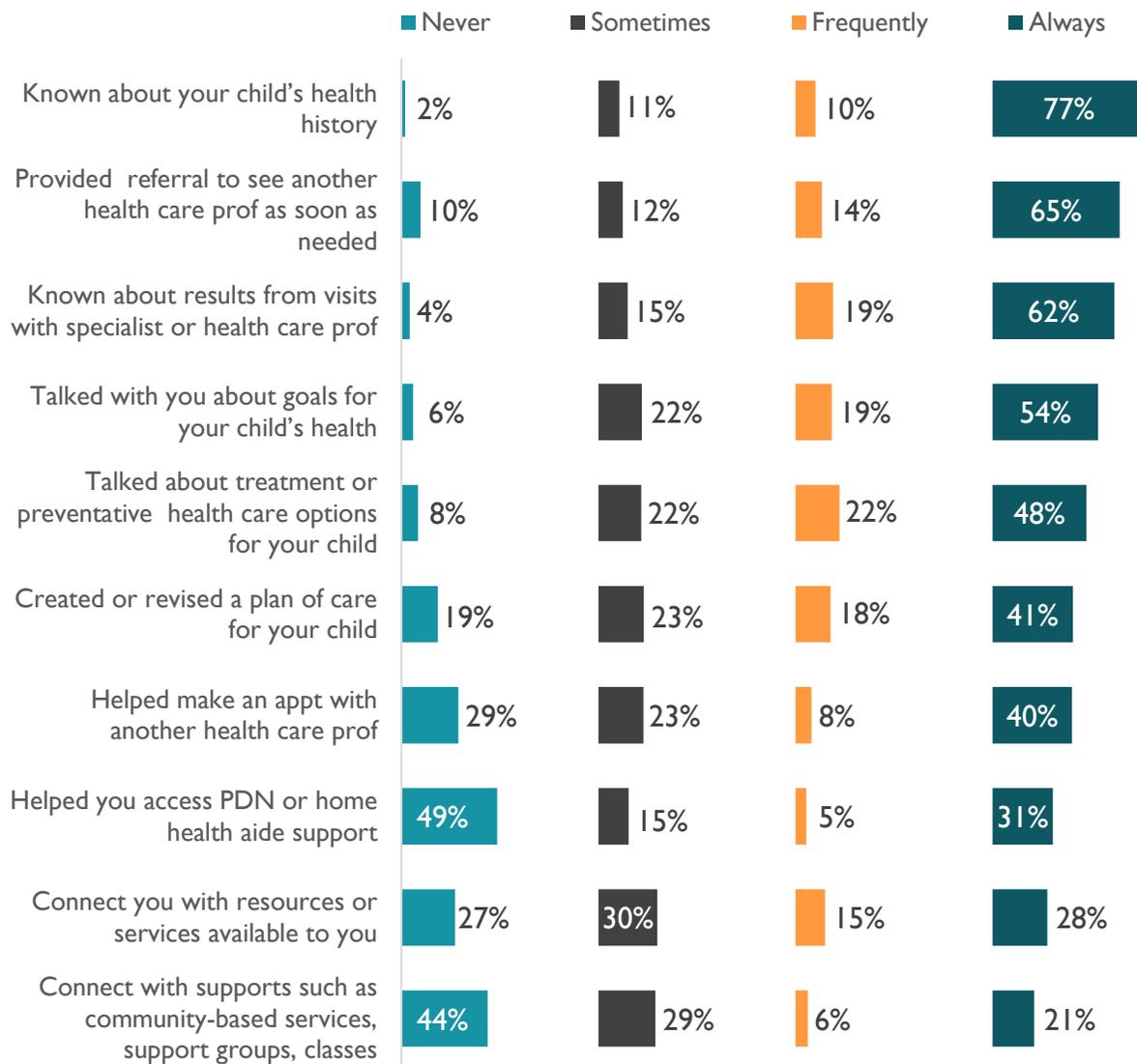


Range of n = 67 - 76

PRIMARY MEDICAL CARE PROVIDERS

Survey respondents were asked to think about their primary medical care provider over the last 12 months and assess their role in effectively communication and coordinating the care needs of the child. In general, primary medical providers ‘Always’ knew about the child’s medical history (77%), provided families with referrals as soon as they were needed (65%), and knew results from appointments with other specialists (62%). Primary medical providers connected families with additional resources in DE and with community-based supports with less frequency.

FIGURE 7. SURVEY RESPONDENTS’ ASSESSMENT OF PRIMARY MEDICAL CARE PROVIDERS

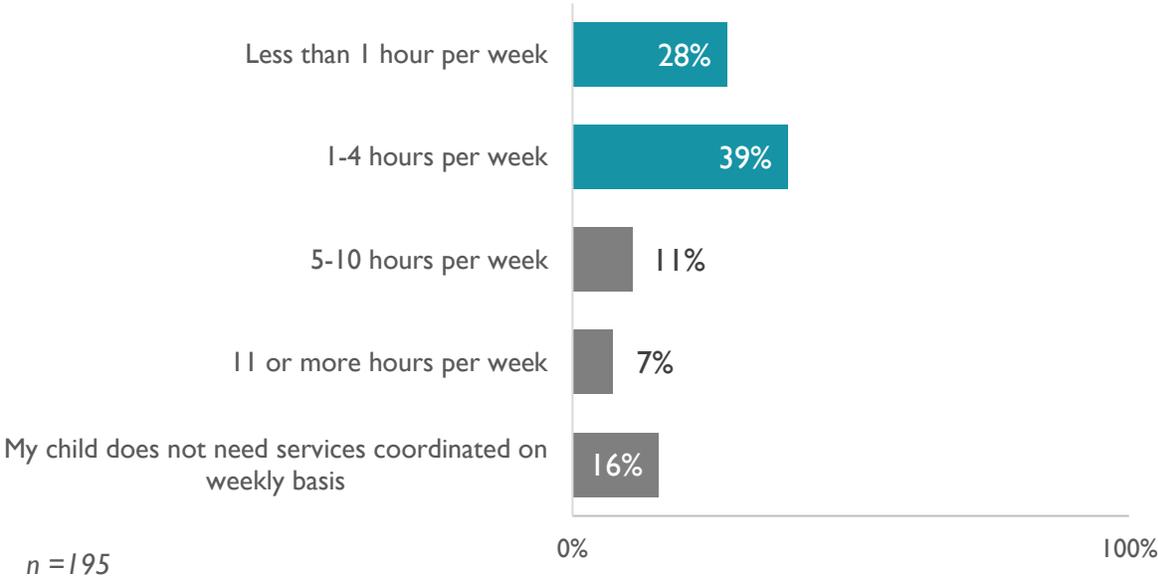


Range of n = 112 - 169

FAMILY NEEDS & SUPPORTS

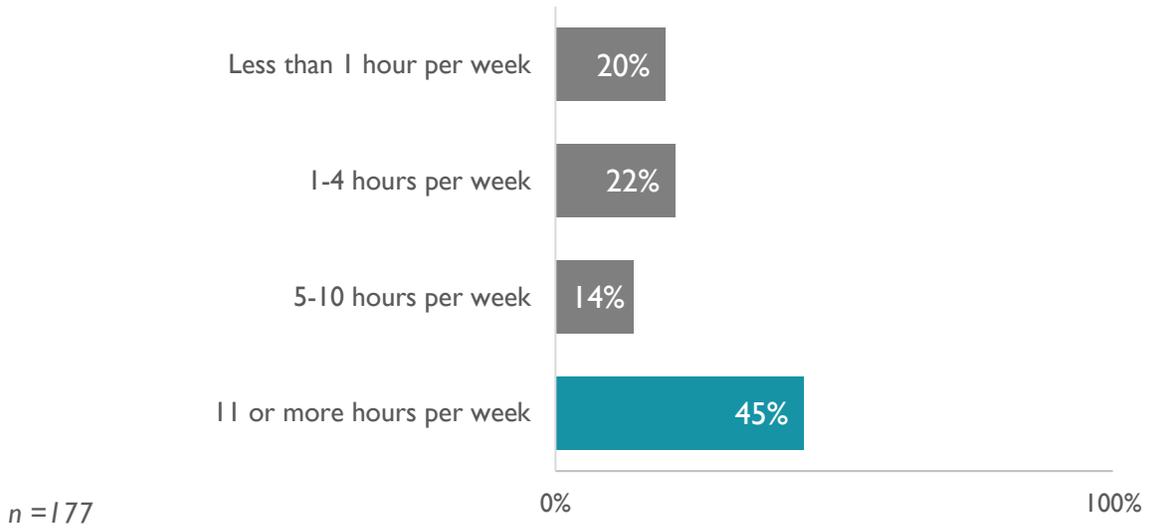
In an average week, two out of three families (67%) report spending less than 1 hour or up to 4 hours per week arranging or coordinating health care or other needed services for their child. Only 7% of families with CMC report spending 11 or more hours per week arranging/coordinating services. Nearly 16% of survey respondents said their child does not need care coordinated on a weekly basis.

FIGURE 8. AVERAGE TIME FAMILIES SPEND PER WEEK ARRANGING OR COORDINATING CARE



In contrast, almost half of families (45%) spend 11 or more hours per week providing health care in the home, such as giving medication or therapies, care of feeding or breathing equipment and changing dressings at home for their child. Sixteen respondents indicated their child did not need health care at home.

FIGURE 9. AVERAGE TIME FAMILIES SPEND PER WEEK PROVIDING HEALTH CARE IN HOME



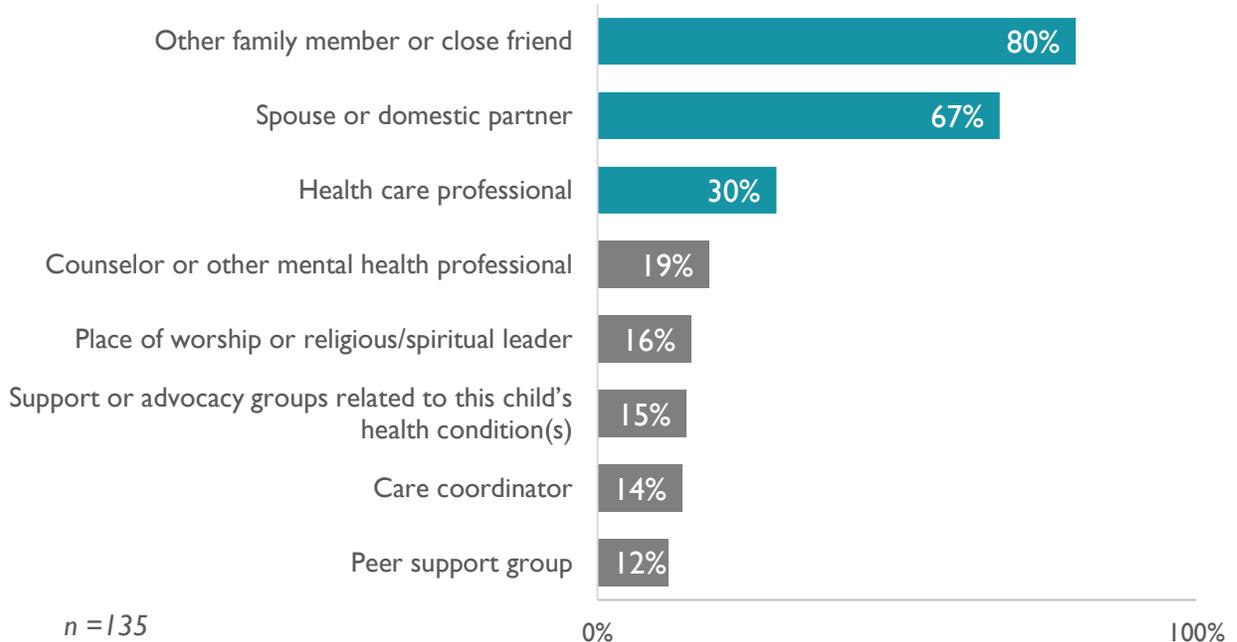
Survey respondents were asked to rate their health over the last 12 months. In general, they were more likely to rate themselves as ‘Good,’ ‘Very Good,’ or ‘Excellent’ than ‘Fair’ or ‘Poor’ on emotional, mental, and physical health.

FIGURE 10. SURVEY RESPONDENTS SELF-REPORTED HEALTH



In the last 12 months, approximately 68% of families with CMC report having someone they could turn to for day-to-day emotional support on parenting or raising their child with medically complex needs. One in three (33%) parents did not have that support. When asked who they received support from, parents heavily relied on other family members or close friends (80%), spouses/domestic partners (67%), or their healthcare professionals (30%).

FIGURE 11. SELF-REPORTED SUPPORT SYSTEMS FOR PARENTS OF CMC



RESPIRE CARE

Respite care is a service designed to give parents/caregivers a break from taking care of an individual with special needs to do different things such as visit family, go shopping or maintain their own health. Some, but not all, children with medical complexity are eligible for respite care services. Survey participants were asked if they used respite care benefits in the last 12 months. Of those who were knew they were eligible for respite care, only 14% reported using this benefit and 21% indicated they were eligible but did not use it. For those eligible but not using respite care, 50% said their needs changed with the onset of COVID-19, 38% reported not being able to find a qualified caregiver, and 15% said qualified caregivers were not available when needed. Other reasons listed for not using respite care despite eligibility included: fear about COVID-19 and exposure (n=4), full-time care provided by stay-at-home parents (n=2), receiving respite care from other entities (i.e.,

Easter Seals and DE Autism Program) (n=2), the process for payment/reimbursement being too complicated (n=2), lack of clarity around cost/reimbursement (n=1), and inability to afford co-pay (n=1). Almost half of the survey respondents (48%) did not know if they were eligible for respite care benefits, and 17% indicated they were not eligible.

RESULTS BY POPULATION SEGMENTS

Additional analyses were conducted to examine whether results regarding access to and satisfaction with services varied as a function of child gender and age, parent socioeconomic status (SES), whether the family was eligible for PDN, and the county families lived in. **No systematic differences in results were detected when comparing these segments of the population:**

- Families whose children were ages birth to five, 6-17, or 18 and older
- High versus middle versus low-income families
- Parents with differing education levels comparing those with a high school degree or less with those with some college, college degrees, and those with graduate level degrees
- Children who were male versus female
- Families residing in each of the three counties in Delaware

Given the relatively small number of responses within the population segments that were compared and the lack of systematic differences, discrete items that did reveal significant differences are reported in Appendix C.

CONCLUSIONS

HEALTH SERVICES: SATISFACTION + ACCESS

In general, families with CMC who responded to this survey were satisfied with the medical and therapeutic services they receive in Delaware. Families' average satisfaction with their primary care and specialty physicians was high as was their satisfaction with different therapies received. Families were also generally satisfied with additional services and supports such as DME or prescription medication.

Accessing services did present many challenges to families with CMC. Approximately 1 of 4 survey respondents (22%) reported there was a time their child needed health services in the year prior to completing the survey but did not receive them. The most prevalent challenges families faced in accessing services were knowing what services their child was eligible for, knowing what services are available in Delaware and finding the time to arrange or coordinate those services.

PDN

PDN services were highlighted in this survey and, at the time of this report, were being explored in-depth through several research activities conducted by the University of Delaware. Findings from this study should be considered together with the findings of this forthcoming work. One key finding from this survey was that many families who responded to this survey did not know if they were eligible for PDN services. Not all families with CMC are eligible for PDN services, however, there is also risk that some families who would be eligible for PDN do not know if this service is available to them.

On average, satisfaction with PDN services was lower than for other health services such as preventative and specialty medical care. Half or more than half of respondents who receive PDN services experienced challenges with providers in terms of availability, turnover, or shortages in the workforce. Similar findings were observed for home health aides. Additional information resulting from the PDN workforce studies should reveal clearer implications for how to address the challenges families face.

CARE COORDINATION

The majority of families with CMC are eligible for care coordination in Delaware. However, of survey respondents, more than a quarter did not know if they were eligible for this support. It is likely that some families who are eligible for this service do not know they are and therefore do not seek it out.

For those respondents who did have an assigned care coordinator and for whom the care coordinator was involved with their child's case, care coordination was perceived as quite effective. These families felt care coordinators respected their family's values and traditions, listened to them,

and encouraged them to ask questions. Additionally, families reported that primary care physicians typically provided frequent care that supported a coordinated approach to their child's care. For example, families reported that physicians frequently or usually knew of their child's medical history, had access to test results from specialty visits and provided referrals when needed.

FAMILY NEEDS

Respondents were asked about the time they invested in coordinating and providing care for their child with medical complexity. In general, many families spent 11 or more hours providing care to their child at home and relatively few families spent as much time coordinating or arranging for care. Respondents reported on their own physical, emotional, and mental health and 22-30% of respondents rated these three kinds of health as 'fair' or 'poor'. Finally, approximately one third of respondents did not have an individual in their lives who they could turn to for support daily.

APPENDIX A.
OPEN-ENDED INTERVIEWS WITH FAMILIES

INTERVIEW SAMPLE

A random subset of approximately 80 families were invited to participate in open-ended, qualitative phone interviews. Mailed invitation letters were sent to each of the 80 families with information regarding how to schedule interviews and written consent forms. VISA gift cards for \$100 were provided to participating families. Several families returned their consent forms right away and interviews were scheduled. Additional families were recruited via phone call follow-up for a total of 11 participating families. Families were from each of the three counties in Delaware and the children's ages ranged from two to just over 18 years old. Five children were male and six were female. Ten interviewees were the child's mother, and one was a child's father. Two interviews were conducted in Spanish.

INTERVIEW PROTOCOL

Prior to developing the interview protocol, Vital conducted informational interviews with DMMA staff, a representative of a managed care organization (MCO) and a parent, all of whom were members of the CMC Steering Committee. Results from the informational interviews coupled with findings from key documents and a literature review informed the interview protocol, found below:

Interviewee ID: _____ Date: _____

Hi [insert name.] Thank you for joining us on this call today to share a little about your family and your child who has medically complex needs. Is now still a convenient time to conduct the call?

Yes No New date/time: _____

As you know, we are working with the Delaware Division of Medicaid & Medical Assistance (DMMA) to conduct interviews to learn more about families' experiences accessing services for their children with medically complex needs. What we learn from these interviews will also help us develop a survey that will be distributed to all families with children with medical complexity to learn how well services are supporting all families.

Do you have any questions before we start?

Is it OK if I audio record our conversation to make sure I get accurate notes?

Yes No

1. First, we want to check in and ask how you are doing now considering the COVID-19 pandemic and civil unrest which is impacting families' routines dramatically.
2. Next, we are interested in hearing a little of your family's story. Would you share a little background about your child and one of your favorite things to do with your child?
3. Next, let's talk about caring for and getting services for your child. Tell me about the different services you access for [child's name].

PROBES:

- Transportation
- Durable medical equipment and supplies
- Support services like private duty nursing (PDN)
- Respite care
- Primary care
- Availability of knowledgeable providers including specialists and therapists
- Medications and availability at nearby pharmacies

We know there are many challenges that families face in accessing services, so we want to ask you about some of these common challenges and understand if/how you experience similar challenges.

4. What key challenges have you faced in accessing different services for [child's name]?

PROBES (as relevant for services mentioned previously):

- Transportation
- Durable medical equipment and supplies
- Support services like private duty nursing (PDN)
- Respite care
- Primary care
- Availability of knowledgeable providers including specialists and therapists
- Medications and availability at nearby pharmacies

5. What has been your experience with care coordination? [Probe: For example communicating with different providers across different systems, coordinating appointments, etc. To what extent are different services integrated and coordinated as opposed to separate and fragmented?]
6. Lastly, what have been some challenges with insurance such as authorizations, appeals, and paperwork?

7. Turning to some successes, what have been some highlights that you can share regarding accessing services? [PROBE: Are there people who are particularly helpful, resources, support groups, etc.?.]
8. In your opinion, what services/resources are missing? [Probe: For example, services that the child needs and is not getting because they are not available, services the child needs and are available, but that the child cannot access? Resources that might help families navigate the system?]
9. My last question is, if you could ask the state to do one thing to support children with medical complexity, what would it be?

Those are all the questions I have. Is there anything that we did not cover that you'd like to share with me?

FINDINGS

Each family member of a child with medically complex needs told a story that was truly unique. The complex constellation of CMC's shifting needs meant that parents were constantly providing care, researching resources, coordinating among providers, communicating among providers, and advocating for their children. The most significant factor related to families' access to services and care for their children was the level of medical complexity the child experienced. The challenges faced by families whose children had multiple diagnoses or rare conditions that may have been progressive were dramatically more intense than the challenges faced by families whose children had less complex medical needs.

Some **success factors** that parents mentioned were related to acquiring the right services for their children included **socioeconomic status** (SES) including parental education and professional training, was related to families' abilities to secure the care needed for their children. For example, one family, despite having a young child with dramatic health needs, had the education level, professional training, and flexible work schedule to allow them to recruit, train and retain home health aides. A few families mentioned **the ability to advocate** for their children as important in ensuring the appropriate care and services were in place for their children. One parent lamented what it would be like for a child in a family that did not know how to advocate for them. Finally, a few interviewees mentioned **individuals who supported them** and helped them navigate the health system. Often, this individual was a specialty medical doctor such as a neurologist who could point the family to additional resources and help to integrate care and coordination with other providers.

Families also expressed **challenges** they faced including **transitions** from early care to elementary school or from pediatric to adult care were particularly challenging for these families. One mother whose daughter had recently transitioned to adult care was frustrated with the stark differences in mental health programming for adults, which focused on substance abuse, as compared with child/adolescent programs, which offered the social supports her daughter needed. Her daughter's needs did not change when she turned 18, but the programs changed entirely and left a gap in her daughter's services. Transitions among medical providers was also challenging for a few families. For some families' **language barriers** were a challenge they faced in securing care for their children. Language barriers were not only present when a family spoke a language other than English, but also in appealing coverage denials by insurance which requires specific, technical language. One mother described the impact that her middle child's health situation had on her other children saying, While each family's story was unique, common elements emerged as potentially promotive of children's well-being and as challenges that might hinder service acquisition and therefore full support for the family. Several families described challenges in **applying for Medicaid** and in the renewal process. Applications were cumbersome with extensive documentation required and long wait times were involved before getting approval. Finally, the **COVID-19 pandemic** had different impacts on families. Challenges arose when school-based services were suspended due to school closures. Similarly, with skilled home health aides, staffing was even more challenging. Some families were accustomed to being somewhat isolated yet for others this was new and having to be socially distanced and wear masks when out of the house was difficult for some children.

IMPLICATIONS

The conversations with families were valuable in helping to draft the first version of the survey and ensure that relevant areas were covered. The topic areas that interviewees mentioned did not differ from what key areas identified by the CMC Steering Committee. However, because of the interviews, a robust set of demographic items was included in the survey to capture potential promotive and risk factors associated with children and families' well-being. Additionally, items regarding insurance coverage, denials and appeals were included in the first survey draft with greater clarity around possible response options. Care coordination was a key component of the first survey draft as well, thanks to conversations with families. In general, the interviews with families supported the draft of actual items within topic areas and response options for different items.

APPENDIX B.
FAMILY SURVEY INSTRUMENT

Thank you for taking the time to fill out this survey. Your participation is voluntary, and your services will not be impacted if you do or do not complete it. Your privacy is very important to us. Your individual responses to this survey will be confidential, meaning the information you share will only be seen by the research team at Vital Research, an outside research company.

Questions are divided into five sections: Your Child and Your Child’s Services; Home Health Providers (including Private Duty Nurses); Care Coordination; Family Needs and Supports; and Demographic Items. Please read items and instructions carefully. Depending on how some questions are answered, you may be asked to skip ahead. Most items will ask you to reflect on the last 12 months. If you have any questions, use the contact information found in the letter sent with this survey to reach out and ask questions.

For identification purposes, please enter the date of birth below for the child named in the accompanying letter. We refer to this child as ‘your child’ throughout the survey.

(__ __ / __ __ / __ __ __ __)
(MM / DD / YYYY)

Use pencil or pen (blue or black ink). Like this: ● Not like this: ○ / ○~~X~~

	Yes	No	Don't know
1. Do you consider your child to have medically complex needs? (Select one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Does your child have one or more health conditions that puts them at risk of getting very sick (to the point of requiring hospitalization) or dying? (Select one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Does your child’s medical condition affect their ability to perform activities of daily living (ADLs) such as walking, feeding, dressing, bathing, toileting, or moving from one body position to another? (Select one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Does your child spend a lot of time seeing specialists or in the hospital due to their medical condition? (Select one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Does your child’s medical condition require technology (e.g., ventilators, feeding tubes, oxygen, etc.) to help them maintain a basic quality of life? (Select one)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***** For items 2 - 5, if you answered YES to two or more questions, please continue the survey. If you answered NO or DON'T KNOW to three or more of questions 2 - 5, please stop here and send this survey back to Vital Research in the enclosed envelope.*****

Section 1: Your Child and Your Child's Services

This section includes items about the services your child receives. **Although your child may receive therapies and medical care services from numerous providers at different locations, this survey is focused on your "overall" level of satisfaction associated with different types of care.**

6. Which of the following medical care services has your child received in the last 12 months? (Select all that apply)

- Preventative care (e.g., child well visits, immunizations, developmental screenings)
- Dental care
- Vision care
- None of the above **(skip to question 8)**

7. For each medical care service your child has received in the last 12 months, please rate your overall satisfaction. (Select one)

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Not Applicable
Preventative care	<input type="radio"/>				
Dental care	<input type="radio"/>				
Vision care	<input type="radio"/>				

8. Which of the following therapies has your child received in the last 12 months? (Select all that apply)

- Physical therapy
- Occupational therapy
- Psychological/ Mental health therapy (e.g., counseling, group therapy sessions, etc.)
- Behavioral therapy (including Applied Behavioral Analysis (ABA) for Autism)
- Speech therapy
- None of the above **(skip to question 11)**

9. For each therapy your child has received in the last 12 months, please select if they are received in the home, at school or in childcare, in the hospital or doctor's office, and/or in other place. (Select all that apply)

	Home	School or Childcare	Hospital or Doctor's office	Other	Not Applicable
Physical therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychological/ Mental health therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Behavioral therapy (including ABA)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. For each therapy your child has received in the last 12 months, please rate your overall satisfaction. (Select one)

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Not Applicable
Physical therapy	<input type="radio"/>				
Occupational therapy	<input type="radio"/>				
Psychological/ Mental health therapy	<input type="radio"/>				
Behavioral therapy (including ABA)	<input type="radio"/>				
Speech therapy	<input type="radio"/>				

11. Which of the following types of medical specialists has your child seen in the last 12 months? (Select all that apply)

- Cardiologist (focuses on heart and blood vessels)
- Endocrinologist (focuses on hormones and metabolism)
- Hematologist (focuses on blood disorders)
- Immunologist (focuses on immune disorders)
- Gastroenterologist (focuses on digestive organs)
- Geneticist (focuses on genetic disorders)
- Neurologist (focuses on brain, head, and nervous system)
- Orthopedist (focuses on bone disorders)
- Pulmonologist (focuses on breathing and respiratory issues)
- Rheumatologist (focuses on diseases in joints, muscles, bones)
- Not listed (please specify)

- None of the above (**skip to question 13**)

12. For each type of medical specialists your child has seen in the last 12 months, please rate your overall satisfaction.
(Select one)

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Not Applicable
Cardiologist	<input type="radio"/>				
Endocrinologist	<input type="radio"/>				
Hematologist	<input type="radio"/>				
Immunologist	<input type="radio"/>				
Gastroenterologist	<input type="radio"/>				
Geneticist	<input type="radio"/>				
Neurologist	<input type="radio"/>				
Orthopedist	<input type="radio"/>				
Pulmonologist	<input type="radio"/>				
Rheumatologist	<input type="radio"/>				
Not listed (please specify)	<input type="radio"/>				

13. Which of the following services or supports has your child received in the last 12 months? (Select all that apply)

- Durable medical equipment (DME) (e.g., wheelchairs, walkers, braces, orthotics, ventilators, oxygen equipment, feeding pumps and supplies)
- Disposable supplies (e.g., suction catheters, urine catheters, urine bags, feeding tube extensions, feeding bags, diapers)
- Intravenous equipment (e.g., nutrition, valves, IV poles, pole pouches, dressings)
- Augmentative or alternative communication devices
- Prescription medication
- Non-emergency transportation (e.g., Logisticare)
- Emergency medical transportation
- None of the above **(skip to question 15)**

14. For each of the services or supports your child has received in the last 12 months, please rate your overall satisfaction with each service. (Select one)

	Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Not Applicable
Durable medical equipment (DME)	<input type="radio"/>				
Disposable supplies	<input type="radio"/>				
Intravenous equipment	<input type="radio"/>				
Augmentative or alternative communication devices	<input type="radio"/>				
Prescription medication	<input type="radio"/>				
Non-emergency transportation (e.g., Logisticare)	<input type="radio"/>				
Emergency medical transportation	<input type="radio"/>				

15. In the past 12 months, was there any time when your child needed health services, but they were not received? (Select one)

- Yes **(Continue to question 16)**
- No **(Skip to question 17)**

16. Did any of the following reasons contribute to your child not receiving needed health services in the past 12 months? (Select 'yes' or 'no' for each item)

	Yes	No
Your child was not eligible for services	<input type="radio"/>	<input type="radio"/>
The services were not available in your area	<input type="radio"/>	<input type="radio"/>
The service was not approved/authorized	<input type="radio"/>	<input type="radio"/>
The staff providing the service cancelled or were not available	<input type="radio"/>	<input type="radio"/>
There were problems getting the appointment when it was needed	<input type="radio"/>	<input type="radio"/>
There were problems getting transportation	<input type="radio"/>	<input type="radio"/>
The clinic or provider wasn't open when you could go	<input type="radio"/>	<input type="radio"/>
There were issues related to cost	<input type="radio"/>	<input type="radio"/>
There were no doctors who were knowledgeable about your child's medical condition	<input type="radio"/>	<input type="radio"/>
There were problems getting medications your child needed	<input type="radio"/>	<input type="radio"/>
There were issues coordinating care across different health professionals or settings	<input type="radio"/>	<input type="radio"/>
Services were shut-down or reduced during the COVID-19 pandemic	<input type="radio"/>	<input type="radio"/>
You were afraid to access services because of the COVID-19 pandemic	<input type="radio"/>	<input type="radio"/>

17. In general, how often have you run into any of the following challenges when getting services for your child?
(Select one)

	Never	Sometimes	Frequently	Always
Finding doctors or medical professionals who are knowledgeable about Delaware’s system of care for children with medical complexity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding doctors or medical professionals able/willing to see a child with medical complexity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing what services are available in Delaware for your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Knowing what services your child is eligible to receive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding services that are age appropriate for your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding information or resources on services in the language you need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding how to obtain what is needed for your child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Finding the time to arrange and coordinate health care services your child needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please specify) _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 2: Home Health Providers

This section addresses two types of home health providers that may work with your child and family:

1. Private Duty Nurses, often called skilled home health providers, and
2. Home health aides (non-nurses/non-medical care workers).

Although your child may receive home health care services from numerous providers at different agencies, this survey is focused on your “overall” level of satisfaction associated with home health care services. If your family receives services from Private Duty Nurses (skilled home health care providers), a more in-depth survey will be mailed to you from the University of Delaware soon.

Private Duty Nurses (Skilled Home Health Providers)

18. Is your child eligible for Private Duty Nursing services (nurses or other trained health professional who provide medical care at home)? (Select one)

- Yes (Continue to question 19) No (Skip to question 25) Don’t know (Skip to question 25)

19. Does your child receive Private Duty Nursing services? (Select one)

- Yes (**Continue to question 20**) No (**Skip to question 25**)

20. How many hours per week do Private Duty Nurses come to your home? (Select one)

- 1 to 10 hours
 11 to 20 hours
 21 to 30 hours
 31 to 40 hours
 40+ hours

21. What hours do Private Duty Nurses typically work in your home? (Select all that apply)

- Day Shift (approximately 7 AM to 4 PM)
 Evening Shift (approximately 4 PM to 12 AM)
 Night Shift (approximately 10 PM to 8AM)
 Not listed (please specify) _____

22. If your Private Duty Nurse is authorized for school hours, did they come to your home to provide medical care while schools were closed due to the COVID-19 pandemic? (Select one)

- Yes
 No
 Not applicable, my skilled home health provider is not authorized for school time
 Not applicable, my child is not in school

23. In the last 12 months, has your family experienced any of the following challenges associated with Private Duty Nursing providers? (Select 'yes' or 'no' for each item)

	Yes	No
There are not enough hours authorized to cover your needs	<input type="radio"/>	<input type="radio"/>
There are not enough providers to work the full number of hours that are authorized (i.e., shortage of providers)	<input type="radio"/>	<input type="radio"/>
Providers have been unavailable to work the hours needed	<input type="radio"/>	<input type="radio"/>
Turnover at the provider agency has led to inconsistency in who provides care in your home	<input type="radio"/>	<input type="radio"/>
There are not enough providers who can meet the specific healthcare needs of your child	<input type="radio"/>	<input type="radio"/>

24. Overall, how satisfied are you with the quality of care provided by your Private Duty Nursing providers? (Select one)

- Very Satisfied Satisfied Dissatisfied Very Dissatisfied

Home Health Aides

25. Is your child eligible for home health aide services (non-nurses/non-medical care workers typically assisting with activities of daily living (ADLs) in the home or school environment)? (Select one)

- Yes (**Continue to question 26**) No (**Skip to Section 3, question 30**) Don't know (**Skip to Section 3, question 30**)

26. Does your child receive home health aide services? (Select one)

- Yes (**Continue to question 27**) No (**Skip to Section 3, question 30**)

27. If your home health aide is authorized for school hours, did they come to your home to provide non-medical care while schools were closed due to the COVID-19 pandemic? (Select one)

- Yes
- No
- Not applicable, my home health aide is not authorized for school time
- Not applicable, my child is not in school

28. In the last 12 months, has your family experienced any of the following challenges associated with home health aides? (Select 'yes' or 'no' for each item)

	Yes	No
There are not enough hours authorized to cover your needs	<input type="radio"/>	<input type="radio"/>
There are not enough aides to work the full number of hours that are authorized (i.e., shortage of aides)	<input type="radio"/>	<input type="radio"/>
Aides have been unavailable to work the hours needed	<input type="radio"/>	<input type="radio"/>
Turnover at the agency has led to inconsistency in who provides support to your child	<input type="radio"/>	<input type="radio"/>
There are not enough aides who can meet the specific care needs of your child	<input type="radio"/>	<input type="radio"/>

29. Overall, how satisfied are you with the quality of care provided by the home health aides? (Select one)

- Very Satisfied Satisfied Dissatisfied Very Dissatisfied

Section 3: Care Coordination

This section includes items on care coordination. Care coordination is defined as effective communication and management of the care and services your child needs. Care coordination can include different people, such as an assigned care coordinator from the Managed Care Organization (MCO) or the primary medical provider whom your child sees most frequently. In many cases, you or another family member may also be providing care coordination for your child.

30. In an average week, how many hours do you or other family members spend arranging or coordinating health care or other needed services for your child? Examples include making appointments, arranging for skilled home health nursing or home health aide coverage, and locating services. (Select one)

- Less than 1 hour per week
- 1-4 hours per week
- 5-10 hours per week
- 11 or more hours per week
- My child does not need health care or other services coordinated on a weekly basis

Care Coordinator

The MCO to which your child is assigned (AmeriHealth Caritas or Highmark Health Options) may provide a care coordinator to assist with the needs of your child. The following items are focused on care coordinators and their role in effectively communicating and coordinating care needs for your child.

31. Do you have a care coordinator assigned to your child? (Select one)

- Yes (**Continue to question 32**)
- No (**Skip to question 35**)
- Don't know (**Skip to question 35**)

32. In your opinion, how involved is the care coordinator in your child's case? (Select one)

- A great deal
- Somewhat
- Not at all (**skip to question 34**)

33. How effective is the care coordinator in supporting your child's case? (Select one)

- Very effective
- Somewhat effective
- Somewhat ineffective
- Very ineffective

34. In the last 12 months, how often has the care coordinator... (Select one)

	Never	Sometimes	Frequently	Always	Not Applicable
Listened carefully to you?	<input type="radio"/>				
Shown sensitivity to your family's values or customs?	<input type="radio"/>				
Encouraged you to ask all the questions you have?	<input type="radio"/>				
Known about your child's health history?	<input type="radio"/>				
Talked with you about goals for your child's health?	<input type="radio"/>				
Created or revised a plan of care for your child?	<input type="radio"/>				
Helped you make an appointment with a health care professional or therapist?	<input type="radio"/>				
Helped connect you with additional resources or services available to you in Delaware?	<input type="radio"/>				
Helped connect you with additional supports such as community-based services, support groups, classes, etc.?	<input type="radio"/>				

Primary Medical Care Provider

The following items are focused on your child's primary medical care provider and their role in effectively communicating and coordinating care needs for your child.

35. In the last 12 months, how often has your child's primary medical provider... (Select one)

	Never	Sometimes	Frequently	Always	Not Applicable
Known about your child's health history?	<input type="radio"/>				
Known about results from any visits with a specialist or health care professional outside of their office?	<input type="radio"/>				
Talked with you about goals for your child's health?	<input type="radio"/>				
Talked with you about different treatment or preventative health care options for your child?	<input type="radio"/>				
Created or revised a plan of care for your child?	<input type="radio"/>				
Provided you with a referral to see another health care professional as soon as you needed it?	<input type="radio"/>				
Helped you make an appointment with another health care professional outside of their office?	<input type="radio"/>				
Helped connect you with additional resources or services available to you in Delaware?	<input type="radio"/>				
Helped connect you with additional supports such as community-based services, support groups, classes, etc.?	<input type="radio"/>				
Helped you access skilled home health providers (private duty nurses) or home health aide supports?	<input type="radio"/>				

Section 4: Family Needs & Supports

This section includes items about your family's experiences providing care for your child and supports or services you may need or currently receive to address emotional, physical and financial needs that arise.

36. In an average week, how many hours do you or other family members spend providing health care (e.g., giving medication or therapies, care of feeding or breathing equipment, changing bandages, etc.) at home for your child? (Select one)

- | | |
|---|--|
| <input type="radio"/> Less than 1 hour per week | <input type="radio"/> 11 or more hours per week |
| <input type="radio"/> 1-4 hours per week | <input type="radio"/> My child does not need health care at home |
| <input type="radio"/> 5-10 hours per week | |

37. In the last 12 months, have you used respite care benefits through the Delaware Division of Developmental Disabilities Services (DDDS)? Respite care is a service designed to give parents/caregivers a break from taking care of an individual with special needs to do different things such as visit family, go shopping or maintain their own health. (Select one)

- Yes (**skip to question 39**)
- No, I am eligible but have not used respite care (**continue to question 38**)
- No, I am not eligible for respite care (**skip to question 39**)
- I don't know if I am eligible for respite care benefits (**skip to question 39**)

38. Please indicate why you have not used respite care benefits. (Select all that apply)

- We could not find a qualified caregiver
- Qualified caregivers were not available at times we needed
- With the onset of the COVID-19 pandemic our needs changed
- Other (please specify) _____

39. In the last 12 months, was there someone you could turn to for day-to-day emotional support regarding parenting or raising your child? (Select one)

- Yes (**Continue to question 40**)
- No (**Skip to question 41**)

40. Please select the persons or groups you received emotional support from in the last 12 months. (Select all that apply)

- Spouse or domestic partner
- Other family member or close friend
- Health care professional
- Care coordinator
- Place of worship or religious/spiritual leader
- Support or advocacy groups related to this child's health condition(s)
- Peer support group
- Counselor or other mental health professional

	Excellent	Very Good	Good	Fair	Poor
41. In general, how is your physical health? (Select one)	<input type="radio"/>				
42. In general, how is your mental health? (Select one)	<input type="radio"/>				
43. In general, how is your emotional health? (Select one)	<input type="radio"/>				

44. What suggestion(s) can you offer to the Division of Medicaid and Medical Assistance-often referred to as DMMA, to improve access to and the quality of services for children with medical complexity?

Section 5: Demographics

This section includes demographic items that are important to help the Division of Medicaid and Medical Assistance (DMMA) better understand the diverse qualities of families who have children with medical complexity. **Your privacy is very important to us and your individual responses will be confidential. Each demographic question has the option 'prefer not to answer.'** However, responses to these items will help provide critical information about who has access and who does not have access to different services in Delaware. Your services will not be impacted if you do or do not answer the demographic items.

45. What is your child's race or ethnicity? (Select all that apply)

- American Indian or Alaska Native
- Asian or Asian American
- Black or African American
- Latina/o/x or Hispanic American
- Middle Eastern or North African or Arab American
- Native Hawaiian or Other Pacific Islander
- White or European American
- Not listed (please specify) _____
- Prefer not to answer

Household Characteristics

46. Including yourself, how many people currently live in your household? (Select one)

- | | |
|-------------------------|--|
| <input type="radio"/> 1 | <input type="radio"/> 6 |
| <input type="radio"/> 2 | <input type="radio"/> 7 |
| <input type="radio"/> 3 | <input type="radio"/> 8+ |
| <input type="radio"/> 4 | <input type="radio"/> Prefer not to answer |
| <input type="radio"/> 5 | |

47. Of the people living in this household, how many are under age 18? (Select one)

- | | |
|----------------------------|--|
| <input type="radio"/> None | <input type="radio"/> 3 |
| <input type="radio"/> 1 | <input type="radio"/> 4+ |
| <input type="radio"/> 2 | <input type="radio"/> Prefer not to answer |

48. Is there more than one parent/family/household caregiver (unpaid) involved in your child's care? (Select one)

- Yes (**Continue to question 49**) No (**Skip to question 50**) Prefer not to answer (**Skip to question 50**)

49. Do all of your child's parents/family/household caregivers (unpaid) live in your household? (Select one)

- Yes No Prefer not to answer

50. Please select the category that tells us your approximate total household income for 2019. Consider all sources of income including earnings, welfare cash assistance, child support alimonies, support from other members of your household who regularly contribute, etc. (Select one)

- | | |
|---|---|
| <input type="radio"/> Less than \$10,000 | <input type="radio"/> \$75,001 - \$100,000 |
| <input type="radio"/> \$10,001 - \$15,000 | <input type="radio"/> \$100,001 - \$150,000 |
| <input type="radio"/> \$15,001 - \$25,000 | <input type="radio"/> More than \$150,000 |
| <input type="radio"/> \$25,001 - \$50,000 | <input type="radio"/> Prefer not to answer |
| <input type="radio"/> \$50,001 - \$75,000 | |

Parent or Family/Household Caregiver Characteristics

Your child may have multiple parents or family/household caregivers (not paid nurses or aides) who assist in their care. Please complete the following questions about yourself as the primary household caregiver, and up to one other person (parent or family/household caregiver) who is involved in caring for your child.

Parent or Family/Household Caregiver 1 (YOU):

51. What is your relationship to your child? (Select one)

- | | |
|---|--|
| <input type="radio"/> Biological or Adoptive parent | <input type="radio"/> Other relative |
| <input type="radio"/> Step-parent | <input type="radio"/> Other non-relative |
| <input type="radio"/> Grandparent | <input type="radio"/> Prefer not to answer |
| <input type="radio"/> Foster parent | |

52. What gender do you identify with? (Select one)

- Female
- Male
- Transwoman
- Transman
- Genderqueer
- Not listed (please specify) _____
- Prefer not to answer

53. What is the highest degree or level of school you have completed? If you're currently enrolled in school, please indicate the highest degree you have *received*. (Select one)

- Less than a high school diploma
- High school degree or equivalent (e.g., GED)
- Some college, no degree
- Associate degree (e.g., AA, AS)
- Bachelor's degree (e.g., BA, BS)
- Graduate degree (e.g., MA, MS, Med, MD, Ph.D.)
- Prefer not to answer

54. What is your current employment status? (Select one)

- Employed (including self-employed) full time (40 or more hours per week)
- Employed (including self-employed) part time (up to 39 hours per week)
- Not employed
- Not listed (please specify) _____
- Prefer not to answer

55. How do you identify racially and ethnically? (Select all that apply)

- American Indian or Alaska Native
- Asian or Asian American
- Black or African American
- Latina/o/x or Hispanic American
- Middle Eastern or North African or Arab American
- Native Hawaiian or Other Pacific Islander
- White or European American
- Not listed (please specify) _____
- Unknown
- Prefer not to answer

*****If there is a second parent or family/household caregiver (unpaid) for your child, please continue to question 56. If you are the only caregiver for your child, please stop here and send this survey back to Vital Research in the enclosed envelope. *****

Parent or Family/Household Caregiver 2:

56. What is Parent or Family/Household Caregiver 2's relationship to this child? (Select one)

- Biological or Adoptive parent
- Step-parent
- Grandparent
- Foster parent
- Other relative
- Other non-relative
- Prefer not to answer

57. What gender does Parent or Family/Household Caregiver 2 identify with? (Select one)

- Female
- Male
- Transwoman
- Transman
- Genderqueer
- Not listed (please specify) _____
- Prefer not to answer

58. What is the highest degree or level of school Parent or Family/Household Caregiver 2 has completed? If Parent or Family/Household Caregiver 2 is currently enrolled in school, please indicate the highest degree *received*. (Select one)

- Less than a high school diploma
- High school degree or equivalent (e.g., GED)
- Some college, no degree
- Associate degree (e.g., AA, AS)
- Bachelor's degree (e.g., BA, BS)
- Graduate degree (e.g., MA, MS, Med, MD, Ph.D.)
- Prefer not to answer

59. What is Parent or Family/Household Caregiver 2's current employment status? (Select one)

- Employed (including self-employed) full time (40 or more hours per week)
- Employed (including self-employed) part time (up to 39 hours per week)
- Not employed
- Not listed (please specify) _____
- Prefer not to answer

60. How does Parent or Family/Household Caregiver 2 identify racially and ethnically? (Select all that apply)

- American Indian or Alaska Native
- Asian or Asian American
- Black or African American
- Latina/o/x or Hispanic American
- Middle Eastern or North African or Arab American
- Native Hawaiian or Other Pacific Islander
- White or European American
- Not listed (please specify) _____
- Unknown
- Prefer not to answer

Thank you very much for completing this survey!

Please mail the survey back to Vital Research in the postage-paid envelope that was included with this mailed survey. If the envelope has been misplaced, mail the questionnaire to:

**Karilyn Mauerman
6380 Wilshire Blvd., Suite 1700
Los Angeles, CA 90048**

****You may also call 1-888-848-2511 (Toll Free) to request a free replacement envelope.****

APPENDIX C.
ITEM-LEVEL DIFFERENCES BY RESPONDENT POPULATION
SEGMENTS

ANNUAL HOUSEHOLD INCOME LEVELS

Statistical analyses were conducted based on the categorical demographic variables associated with reported annual household income levels. Categories were collapsed into the following groups:

- Less than \$25,000
- \$25,001 - \$50,000
- \$50,001 - \$75,000
- \$75,001 - \$100,000
- More than \$100,001

Item	Pearson Chi-Square Value*	P value	Relationship Detected
For each of the services or supports your child has received in the last 12 months, please rate your overall satisfaction: Disposable Supplies	23.443	0.024	Middle- and higher-income respondents (\$50,001- <\$100,000 annual household income) selected 'dissatisfied' more than other income groups. High-income respondents (>\$100,000/year) selected 'satisfied' more than other respondents and 'very satisfied' less than other respondents.
In general, how often have you run into the following challenges when getting services for your child... Knowing what services are available in Delaware for your child?	22.227	0.035	Higher-income respondents (>\$75,001 annual household income) selected 'sometimes' more than lower-income groups. Lower-income groups (<\$50,001) selected never more than other income groups.
In the last 12 months, how often has your child's primary medical provider known about the results from any visits with a specialist or health care professional outside of their office?	23.659	0.023	Middle- and lower-income respondents (<\$75,001 annual household income) selected 'always' more than higher-income groups.

Item	Pearson Chi-Square Value*	P value	Relationship Detected
In the last 12 months, how often has your child's primary medical provider created or revised a plan of care for your child?	26.807	0.008	Lower-income respondents (<\$25,000 annual household income) selected 'always' more than higher-income groups. Higher-income (>\$75,001/year) and the lowest income (<\$25,000/year) selected 'never' more than middle-income groups.

* The Pearson Chi-Square test is used to test the independence of two categorical variables. It tests for association, but not causation.

HIGHEST PARENT/CAREGIVER EDUCATION LEVEL

Statistical analyses were conducted based on the categorical demographic variables associated with reported highest parent/caregiver education levels. Categories were collapsed into the following groups:

- High school or less
- Some college or an AA degree
- BA or BS degree
- Graduate degree

Item	Pearson Chi-Square Value*	P value	Relationship Detected
For each therapy your child has received in the last 12 months, please rate your overall satisfaction: Behavioral Therapy	19.020	0.004	Respondents with a graduate degree selected 'dissatisfied' more than other education levels. Respondents with a high school degree or less and some college or an AA degree selected 'very satisfied' more than higher education groups.
For each of the services or supports your child has received in the last 12 months, please rate your overall satisfaction: Disposable Supplies	17.252	0.045	Respondents with a graduate degree selected 'dissatisfied' more than other respondents. Respondents with a bachelor's degree selected 'satisfied' more than others. And respondents with a high school degree or less selected 'very satisfied' more than others.
In the past 12 months, was there any time when your child needed health services, but they were not received?	11.713	0.008	Respondents with a graduate degree or some college or an AA degree said 'yes' more while respondents with a high school degree or less or a bachelor's degree said 'no' more.
In general, how often have you run into the following challenges when getting services for your child? Finding the time to arrange and coordinate health care services your child's needs	34.620	<0.001	Respondents with a high school degree or less selected 'never' more than others. Respondents with a bachelor's degree selected 'frequently' more than others.

Item	Pearson Chi-Square Value*	P value	Relationship Detected
Is your child eligible for Private Duty Nursing services?	13.381	0.037	Respondents with a graduate degree or some college or an AA degree said 'yes' more while those with less than a high school degree or those with a bachelor's degree said 'no' more.
If your private duty nurse is authorized for school hours, did they come to your home to provide medical care while schools were closed due to the COVID-19 pandemic?	12.774	0.005	Respondents with a graduate degree or some college or an AA degree said 'yes' more, while respondents with a high school degree or less or a bachelor's degree said 'no' more.
Do you have a care coordinator assigned to your child?	25.793	<0.001	Respondents with a graduate degree said 'yes' more and respondents with a high school degree or less said 'no' more.
In your opinion, how involved is the care coordinator in your child's case?	20.009	0.003	Respondents with some college or an AA degree said 'a great deal' more and said 'somewhat' less than other respondents.
In the last 12 months, how often has your child's primary medical provider talked with you about goals for your child's health?	20.459	0.015	Respondents with a high school degree or less or some college or an AA degree selected 'always' more often than others.
In the last 12 months, how often has your child's primary medical provider talked with you about different treatment or preventative health care options for your child?	26.485	0.002	Respondents with a high school degree or less selected 'always' more than respondents from higher educational backgrounds. Respondents with graduate degrees or some college or an AA degree selected 'frequently' more than others.
In the last 12 months, how often has your child's primary medical provider created or revised a plan of care for your child?	20.406	0.016	Respondents with a high school degree or less or some college or an AA degree said 'always' more often than others.

Item	Pearson Chi-Square Value*	P value	Relationship Detected
In the last 12 months, have you used respite care benefits through the Delaware Division of Developmental Disabilities Services?	22.719	0.007	Respondents with a graduate degree said 'yes' more than respondents with a high school degree or less or some college or an AA degree.
In general, how is your physical health?	22.318	0.034	Respondents with a high school degree or less or some college or an AA degree said 'fair' more than other respondents.
In general, how is your mental health?	22.196	0.035	Respondents with a high school degree or less or some college or an AA degree said 'poor' more than other respondents. Respondents with a bachelor's degree said 'very good' more than others.
In general, how is your emotional health?	21.548	0.043	Respondents with a high school degree or less or some college or an AA degree said 'poor' more than other respondents. Respondents with some college or an AA degree or a graduate degree said 'good' more than others. Respondents with a bachelor's degree said 'very good' more than others.

* The Pearson Chi-Square test is used to test the independence of two categorical variables. It tests for association, but not causation.

PRIVATE DUTY NURSING

Statistical analyses were conducted based on the categorical demographic variables associated with reported eligibility for private duty nursing. Respondents selected ‘yes’ or ‘no’ for eligibility.

Item	Pearson Chi-Square Value*	P value	Relationship Detected
Do you consider your child to have medically complex needs?	11.424	0.022	Respondents who were eligible for PDN said ‘yes’ more.
Does your child have one or more health conditions that puts them at risk of getting very sick (to the point of requiring hospitalization) or dying?	12.195	0.016	Respondents who were eligible for PDN said ‘yes’ more.
Does your child’s medical condition affect their ability to perform activities of daily living?	20.624	<0.001	Respondents who were eligible for PDN said ‘yes’ more.
Does your child’s medical condition require technology?	48.808	<0.001	Respondents who were eligible for PDN said ‘yes’ more.
In the past 12 months, was there any time when your child needed health services, but there were not received?	6.247	0.044	Respondents who were eligible for PDN said ‘yes’ more.
In general, how often have you run into the following challenges when getting services for your child? Finding the time to arrange and coordinate health care services your child needs	23.738	<0.001	Respondents who were eligible for PDN said ‘frequently’ and ‘always’ more while respondents who were not eligible for PDN said ‘never’ and ‘sometimes’ more.
In an average week, how many hours do you or other family members spend arranging or coordinating health care or other needed services for your child?	35.042	<0.001	Respondents who were eligible for PDN said ‘5-10’ and ‘11 or more hours per week’ more while ineligible respondents said ‘<1 hour’ or ‘1-4 hours per week’ more.
Do you have a care coordinator assigned to your child?	84.287	<0.001	Respondents who were eligible for PDN said ‘yes’ more, while ineligible respondents said ‘no’ more.
In the last 12 months, how often has the care coordinator listened carefully to you?	19.310	0.004	Respondents who were eligible for PDN said ‘always’ more and ineligible respondents said ‘frequently’ more.

Item	Pearson Chi-Square Value*	P value	Relationship Detected
In the last 12 months, how often has the care coordinator shown sensitivity to your family's values or customs?	17.437	0.008	Respondents who were eligible for PDN said 'always' more and ineligible respondents said 'frequently' and 'sometimes' more.
In the last 12 months, how often has the care coordinator encouraged you to ask all the questions you have?	22.659	<0.001	Respondents who were eligible for PDN said 'always' more and ineligible respondents said 'frequently' more.
In the last 12 months, how often has the care coordinator known about your child's health history?	15.159	0.019	Respondents who were eligible for PDN said 'always' more and ineligible respondents said 'sometimes' more.
In an average week, how many hours do you or other family members spend providing health care at home for your child?	55.524	<0.001	Respondents who were eligible for PDN said '11 or more hours per week' more and ineligible respondents said '<1 hour' or '1-4 hours per week' more.
In the last 12 months, have you used respite care benefits through the Delaware Division of Developmental Disabilities Services?	47.963	<0.001	Respondents who were eligible for PDN said 'yes' and 'no I'm eligible but have not used respite care' more while ineligible respondents said 'no I'm not eligible' more.
In general, how is your physical health?	22.118	0.005	Respondents who were eligible for PDN said 'fair' and 'good' more and ineligible respondents said 'excellent' more.
In general, how is your mental health?	17.441	0.026	Respondents who were eligible for PDN said 'fair' more and ineligible respondents said 'excellent' more.
In general, how is your emotional health?	23.625	0.003	Respondents who were eligible for PDN said 'fair' more and ineligible respondents said 'excellent' more.

* The Pearson Chi-Square test is used to test the independence of two categorical variables. It tests for association, but not causation.

AGE OF CHILD WITH COMPLEX MEDICAL NEEDS

Statistical analyses were conducted based on the categorical demographic variables associated with reported age of the child. Categories were collapsed into the following groups:

- Birth to 5 years old
- 6 to 17 years old
- 18 to 21 years old

Item	Pearson Chi-Square Value*	P value	Relationship Detected
For each therapy your child has received in the last 12 months, please rate your overall satisfaction: Physical Therapy	16.534	0.011	Respondents with younger children (ages birth to 5) were 'very satisfied' more than other respondents.
For each therapy your child has received in the last 12 months, please rate your overall satisfaction: Occupational Therapy	14.644	0.023	Respondents with younger children (ages birth to 5) were 'very satisfied' more than other respondents.
For each therapy your child has received in the last 12 months, please rate your overall satisfaction: Speech Therapy	9.529	0.049	Respondents with younger children (ages birth to 5) were 'very satisfied' more than other respondents.
In general, how often have you run into any of the following challenges when getting services for your child? Finding doctors or medical providers able/willing to see a child with medical complexity	23.391	<0.001	Respondents with older children (age 18-21) said 'sometimes' more than other respondents.
In general, how often have you run into any of the following challenges when getting services for your child? Finding services that are age appropriate for your child	12.878	0.045	Respondents with older children (age 18-21) said 'frequently' more than others. Respondents with children under age 18 said 'never' more than respondents with children aged 18-21.
In general, how is your mental health?	16.190	0.040	Respondents with children under age 18 said 'very good' more than respondents with children aged 18-21. Respondents with young children (birth to age five) said 'excellent' more than others.

* The Pearson Chi-Square test is used to test the independence of two categorical variables. It tests for association, but not causation.