

Private Duty Nursing Workforce Capacity Study: Family Caregiver Survey and Interview Results

Authors:

Mary Culhane, MSN, MS
Sue Giancola, PhD

Funding Agency:

Delaware's Department of Health and Social Services
Division of Medicaid and Medical Assistance

CRESP is committed to addressing education and social policy challenges with rigorous, relevant research.

The Center for Research in Education and Social Policy (CRESP) within the College of Education and Human Development at the University of Delaware conducts rigorous research, program evaluation, and policy analysis to help policymakers and practitioners in education, community health and human services determine which policies and programs are most promising to improve outcomes for children, youth, adults and families.

Founded in 2013, CRESP recognizes that poverty, educational achievement, and chronic disease prevention are intertwined in a complex social web that challenges communities and policymakers alike. CRESP's mission, values, and scientific priorities seek to inform program and policy development across local, state, and federal levels. We work alongside program professionals, academic leaders, and students to foster engagement in high-quality, practice-driven research and evaluation. CRESP researchers are trained in evaluation methodology, randomized field experiments, natural experiments, qualitative methods, statistical analysis, mixed-method evaluation and survey research.

Please feel free to contact us should you have any questions about us or our research.

Center for Research in Education and Social Policy
University of Delaware
Pearson Hall, Suite 107
125 Academy Street
Newark, DE 19716
cresp-info@udel.edu
(302) 831-2928

cresp.udel.edu

Twitter: [@udcresp](https://twitter.com/udcresp)

CRESP Leadership Team

Henry May, Director (hmay@udel.edu)
Allison Karpyn, Co-Director (karpyn@udel.edu)
Sue Giancola, Senior Associate Director (giancola@udel.edu)
Jeff Klein, Associate Director (kleinjef@udel.edu)

Suggested Citation

Culnane, M., Giancola, S. (October 2021). *Private Duty Nursing Workforce Capacity Study: Family Caregiver Survey and Interview Results* (Publication T21-027). Newark, DE: Center for Research in Education and Social Policy.

Private Duty Nursing Workforce Capacity Study: Family Caregiver Survey and Interview Results

EXECUTIVE SUMMARY

In 2018, the Delaware Children with Medical Complexity Advisory Committee (CMCAC) was formed under the auspices of the Delaware’s Department of Health and Social Services (DHSS), Division of Medicaid and Medical Assistance (DMMA). The CMCAC focuses on addressing system change across health programs in order to improve the care and well-being of children with medically complex needs.

A recurring concern of the CMCAC since its inception is whether the current private duty nursing workforce is sufficient to meet the needs of children with medically complex needs in Delaware. In 2020, the DMMA contracted with the University of Delaware Center for Disabilities Studies (CDS) and Center for Research in Education and Social Policy (CRESP) to conduct a study examining the capacity of the home health nursing workforce to serve CMCs. Survey and/or interview data were gathered from four stakeholder populations: agency providers, PDNs, family caregivers, and nurses not affiliated with the PDN CMC workforce. Findings are presented in a series of reports intended to address the private duty nursing workforce capacity in the state of Delaware. This report focuses on findings from surveys and interviews conducted with family caregivers of children with medically complex needs. Analyses are based on 34 survey respondents and 15 interviews with family caregivers. Select findings include:

- Three-quarters of respondents have no nursing coverage for their children multiple times a month.
- Family caregivers attribute the shortage of nurses to low wages, poor benefits, and unpredictable pay which in turn leads to inconsistent, transient staffing patterns and gaps in care for their children.
- Family caregivers report gaps in care occur when there aren’t enough nurses trained for high acuity cases; backup nurses are not oriented to their child’s case; PDNs and families are not a “good fit”; agencies triage care assignments; and PDNs cancel or do not show up for their assigned shifts.
- Family caregivers have little confidence shifts will be filled when there are cancellations, no shows, or open shifts; in turn, some family caregivers devote considerable time to communicating and coordinating PDN coverage for their children.
- Communication between agencies and families about open shifts and cancellations is subpar. Family caregivers attribute this to scheduling mix-ups at the agency; lack of

communication between agencies; staff turnover at the agencies; and/or ineffective use of call centers.

- Family caregivers report that only about half of new nurses arrive with adequate information about the particular disease processes or disability of the child and their care needs; less have information about the home environment.
- Family caregivers describe experiences where their child is put at risk because nurses do not have the necessary skill sets to: recognize clinical problems; respond appropriately to emergencies; or manipulate medical equipment used for the care of their child.
- Family caregivers appreciate nurses who initiate developmentally appropriate activities with their child, however, not all nurses appear skilled or interested in delivering holistic care.
- Desperate for care coverage, family caregivers sometimes struggle with weighing the costs and benefits of keeping on nurses to care for their child who are not trained appropriately.
- Gaps in care impact families in multiple ways and lead to emotional, physical, and mental stress.
- Family caregivers reported system operations and policies that affect access to quality care. For example:
 - Family caregivers report some MCO representatives are not informed nor forthcoming with information; in turn, families are left to navigate the system themselves and advocate for their children.
 - Family caregivers wonder why they hear from their PDNs that they want more hours and the agency won't assign them.
 - Authorization should allow for flex hours as well as options for respite care.
- Family caregivers suggest DMMA use quantitative data to document the numbers of PDN hours scheduled and covered, in addition to increasing oversight of the system. In turn, these data can be used by stakeholders to advocate as necessary.
- If a rate adjustment is approved for skilled nursing care, family caregivers believe the funds should go directly to the PDNs to increase their hourly base rates.

See the full report (T21-027) for a list of recommendations based on these findings.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
INTRODUCTION	10
STUDY OBJECTIVES AND QUESTIONS	10
ORGANIZATION OF THE PDN WORKFORCE CAPACITY STUDY REPORTS	11
METHODS: OVERALL PDN WORKFORCE CAPACITY STUDY	11
OVERALL INSTRUMENTATION.....	11
OVERALL ANALYSES	12
<i>Surveys</i>	12
<i>Interviews</i>	12
METHODS: FAMILY CAREGIVER SURVEY AND INTERVIEWS	13
FAMILY CAREGIVER SURVEY AND INTERVIEW INSTRUMENTS	13
IDENTIFYING THE FAMILY CAREGIVER SAMPLE	13
FAMILY CAREGIVER SURVEY SAMPLE AND DISTRIBUTION.....	13
SURVEY AND INTERVIEW RESPONSES	14
CHARACTERISTICS OF RESPONDENTS' CHILDREN	14
FINDINGS A: FACTORS THAT INFLUENCE THE SUPPLY OF PDNS	16
RESULTS AREA 1: DEMAND FOR PDNS EXCEED SUPPLY	16
RESULTS AREA 2: FAMILY CAREGIVERS' PERCEPTIONS AS TO WHY THERE IS A SHORTAGE OF NURSES.....	18
RESULTS AREA 3. ACCESSING DATA TO DOCUMENT DELAWARE'S PDN SHORTAGE.....	20
FINDINGS B: FACTORS THAT CONTRIBUTE TO GAPS IN CARE	21
RESULTS AREA 4: LACK OF NURSES TRAINED FOR HIGH ACUITY CARES	21
RESULTS AREA 5: BACKUP NURSES ARE NOT ORIENTED TO THE CMC CASE	21
RESULTS AREA 6: PDNS ARE NOT A GOOD FIT FOR THE CHILD AND FAMILY	22
RESULTS AREA 7: PDNS SCHEDULING PREFERENCES.....	22
RESULTS AREA 8: PDNS SEEK A PREDICTABLE NUMBER OF HOURLY SHIFTS.....	22
RESULTS AREA 9: AGENCIES TRIAGE ASSIGNMENTS BASED ON NEED	23
RESULTS AREA 10: CANCELLATIONS AND NO SHOWS.....	23
FINDINGS C: CHALLENGES TO ACCESSING QUALITY CARE	26
RESULTS AREA 11: FAMILY CAREGIVERS REFLECTIONS OF PDN CORE NURSING COMPETENCIES.....	26
RESULTS AREA 12: UNDERSTANDING THE GROWTH AND DEVELOPMENT OF CMC	29
RESULTS AREA 13: LACK OF CARE CONTINUITY	30
FINDINGS D: SYSTEM OPERATIONS AND POLICIES THAT LEAD TO GAPS IN CARE	32
RESULTS AREA 14: LACK OF INFORMATION TRANSPARENCY	32
RESULTS AREA 15: AUTHORIZED HOURS	34
RESULTS AREA 16: UNDERSTANDING THE BUSINESS MODEL	36
FINDINGS E: GAPS IN CARE AND IMPACTS ON FAMILY UNITS	36
FINDINGS F: WHAT IT LOOKS LIKE WHEN THE SYSTEM WORKS	39
SUMMARY STATEMENTS	40

CONCLUSIONS AND RECOMMENDATIONS.....	40
<i>Findings</i>	41
<i>Recommendations</i>	42
STUDY LIMITATIONS	43
REFERENCES.....	44
ACKNOWLEDGEMENTS	45
APPENDIX A. PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: REPORT LISTING	46

List of Tables

Table 1. Child's gender.....	14
Table 2. Child's Race.....	15
Table 3. Child's most recent hourly shift by a PDN.....	15
Table 4. Child's receipt of private duty nursing care before and during COVID-19.....	15
Table 5. Types of equipment used by CMC in the home for treatment and care needs	15
Table 6. Number and percent of respondents told there are no PDNs available to care for their child ...	17
Table 7. Number and percent of shifts not covered.....	17
Table 8. Number and percent of CMC who had a delayed hospital discharge due to lack of in home PDN coverage.....	17
Table 9. Family caregivers' confidence that cancelled and/or open shifts will be filled	23
Table 10. Family caregivers' perception that agencies communicate promptly regarding schedule changes	24
Table 11. Number and percent of family caregivers who contact PDNs to fill shifts	25
Table 12. Family caregiver satisfaction rating of agency activities and roles	25
Table 13. Family caregivers' perception of PDNs who arrive with adequate information about their assignments	26
Table 14. Family caregivers' perceptions of PDNs skills and expertise	27
Table 15. Family caregivers' perceptions of PDNs compassion and empathy	29
Table 16. Family caregivers' perception about continuity of care	31
Table 17. Family caregivers' satisfaction with number of hours authorized for their child	34

List of Assertions

- Assertion 1. Three-quarters of respondents have no nursing coverage for their children multiple times a month. _____ 16
- Assertion 2. Family caregivers attribute the shortage of nurses to low wages, poor benefits, and unpredictable pay which in turn leads to inconsistent, transient staffing patterns and gaps in care for CMC. _____ 18
- Assertion 3. Family caregivers believe if a rate adjustment is approved for skilled nursing care, the funds should go directly to the PDNs to increase their hourly base rates. _____ 18
- Assertion 4. Family caregivers believe PDNs join the workforce because they prioritize a flexible schedule over all other considerations. _____ 19
- Assertion 5. Family caregivers suggest DMMA use quantitative data to document the numbers of PDN hours scheduled and covered, in addition to increasing oversight of the system. _____ 20
- Assertion 6. Gaps in care occur when there aren't enough nurses trained for high acuity cases; backup nurses are not oriented to a case; PDNs and families are not a "good fit"; agencies triage care assignments; and PDNs cancel or do not show up for their assigned shifts. _____ 21
- Assertion 7. Family caregivers have little confidence open shifts or cancellations will be filled; in turn family caregivers devote considerable time to communicating and coordinating PDN coverage for their children. _____ 23
- Assertion 8. Communication between agencies and families about open shifts and cancellations is subpar. Family caregivers attribute this to scheduling mix-ups at the agency; lack of communication between agencies; staff turnover at the agencies; and/or ineffective use of call centers. _____ 24
- Assertion 9. Family caregivers report that only about half of new nurses arrive with adequate information about the particular disease processes or disability of the child and their care needs; even less have information about the home environment. _____ 26
- Assertion 10. Family caregivers describe experiences where their child is put at risk because nurses do not have the necessary skill sets to recognize clinical problems, respond appropriately to emergencies, or have experience working with medical equipment used for the care of their child. _____ 27
- Assertion 11. Family caregivers appreciate nurses who initiate developmentally appropriate activities with their child. _____ 29
- Assertion 12. Desperate for care coverage, family caregivers sometimes struggle with weighing the costs and benefits of keeping on nurses who are less than ideal in caring for their child. _____ 31
- Assertion 13. Family caregivers believe some MCO reps are not informed nor forthcoming with information; families are left to navigate the system themselves and serve as advocates for their children. _____ 33

Assertion 14. Family caregivers believe authorization polices should include options for flex hours and respite care. _____ 35

Assertion 15. Despite having been told there are no nurses to cover open shifts, family caregivers are told by their PDNs that they want more hours and the agency won't assign them. _____ 36

Assertion 16. Gaps in care lead to emotional, physical, and mental stress for family caregivers. _____ 36

PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: FAMILY CAREGIVER SURVEY AND INTERVIEW RESULTS

INTRODUCTION

In 2018, the Delaware Children with Medical Complexity Advisory Committee (CMCAC) was formed under the auspices of the Delaware's Department of Health and Social Services (DHSS), Division of Medicaid and Medical Assistance (DMMA). The CMCAC focuses on addressing system change across health programs in order to improve the care and well-being of children with medically complex needs. The Committee members represent government and non-government organizations and include policymakers, health care providers, payers, professionals, advocates, and parents. For the purposes of the Committee's work, a child is considered medically complex if she/he falls into two or more of the following categories: (a) having one or more chronic health condition(s) associated with significant morbidity or mortality; (b) high risk or vulnerable populations with functional limitations impacting their ability to perform Activities of Daily Living (ADLs); (c) having high health care needs or utilization patterns, including requiring multiple (3 or more) sub-specialties, therapists, and/or surgeries; and (d) a continuous dependence on technology to overcome functional limitations and maintain a basic quality of life.

A recurring concern of the CMCAC since its inception is whether the current private duty nursing workforce is sufficient to meet the needs of children with medically complex needs in Delaware. Anecdotally, families reported they were often left without nursing coverage for their child while agency providers reported difficulties recruiting and retaining private duty nurses (PDN). The CMCAC agreed data were needed to identify factors related to the lack of coverage to better understand the current situation.

In 2020, DMMA contracted with the University of Delaware Center for Disabilities Studies (CDS) and Center for Research in Education and Social Policy (CRESP) to conduct a study examining the capacity of the home health nursing workforce to serve CMCs. CDS and CRESP designed the study during fall 2021 and winter 2021. CRESP conducted the study from March through June 2021.

This report focuses on findings from a survey administered to and interviews conducted with family caregivers of children with medically complex needs in the state of Delaware and is one of several reports intended to address private duty workforce capacity. See Appendix A for a full list of reports that are part of the Private Duty Nursing Workforce Capacity Study.

STUDY OBJECTIVES AND QUESTIONS

The objectives of the Private Duty Nursing Workforce Capacity Study were to better understand the extent to which gaps in PDN coverage exist for CMC and identify factors associated with those gaps.

The primary study questions included:

1. To what extent is the current workforce sufficient to meet the PDN nursing needs of CMC and to what extent are there sufficiently available RNs to serve CMC?
2. What are the factors that contribute to the perceived PDN workforce shortage in home care?
3. In what ways is the current workforce clinically and culturally competent?

Secondary objectives were related to the impact of the COVID-19 pandemic on PDN staffing and services, as well as the utilization of telehealth as an alternative to in-person care.

4. How has the current COVID-19 pandemic impacted the PDN workforce ability to provide services to CMC?
5. How has the current COVID-19 pandemic impacted families' ability to access needed services?
6. To what extent and in what ways are private duty nurses and families of CMC utilizing tele-health services during the pandemic?

By systematically gathering study data, the DMMA and CMCAC hope to identify factors related to a perceived private duty nursing shortage that in turn has led to gaps in care for CMC, as well as understand how families and PDNs have adapted during the COVID-19 pandemic.

ORGANIZATION OF THE PDN WORKFORCE CAPACITY STUDY REPORTS

PDN workforce capacity reports are organized by study population. In addition, a separate special topic report addresses the impact of the COVID-19 pandemic on service delivery, as well as opportunities and challenges associated with the use of telehealth during the pandemic.

Common methods applicable to instrument development, data collection, and analytic approaches are described in the next section. Detailed methods unique to each study population are described in the respective reports, including: sampling frame, study instruments; and processes for survey distribution and interview data collection efforts.

METHODS: OVERALL PDN WORKFORCE CAPACITY STUDY

Data were gathered from four stakeholder populations: agency providers, PDNs, family caregivers, and nurses not associated with the PDN workforce. The following sections outline the development of instrumentation used to collect data from these stakeholder populations, as well as the methods used to analyze data collected.

OVERALL INSTRUMENTATION

The University of Delaware's Center for Research in Education and Social Policy (CRESP) developed surveys and/or interview instruments for each of the stakeholder groups. Instrument

content was informed by informational interviews with key stakeholders (e.g., agency representatives, PDNs, family representatives, policy actors & advocates); observations and discussion themes from the CMCAC and the Skilled Home Health Nursing (SHHN) Workgroup meetings; DMMA documents and website materials (e.g., Delaware’s Plan for Managing the Health Care Needs of Children with Medical Complexity); and relevant literature.

Tools were finalized after iterative reviews by the CMCAC, SHHN Working Group; individual meetings with PDNs, agency providers, family caregivers, and leads of professional organizations; and internal reviews. Field testing was conducted with representatives of the study populations.

The study design and implementation plans were reviewed and approved by the Delaware Health and Social Services (DHSS) Human Subjects Review Board (HSRB). In addition, the study protocol was submitted to the University of Delaware Institutional Review Board (IRB) and the Board provided an exempt designation. All survey tools were made available in Spanish, Creole, and English. Survey instruments and interview protocols may be requested from CRESA.

OVERALL ANALYSES

SURVEYS

All survey data were collected using the Qualtrics platform. Survey responses were summarized using frequencies for categorical variables and mean and medians with interquartile range (IQR) for continuous variables. In addition, data were explored using the Chi-square (χ^2) test for association to compare categorical variables and ANOVA for comparison of means. *P* values <.05 were considered statistically significant. Analyses were performed using SPSS (v.28, IBM). Data for all items that included a multiple response and/or used the “other” option were reviewed, collapsed, and re-grouped by categories, if appropriate. Open-ended responses were reviewed, coded, and categorized by themes.

INTERVIEWS

All interviews were conducted over the phone and/or using the Zoom platform. Interviews lasted approximately 45-60 minutes. Audio recordings were made of all interviews and data were transcribed verbatim using the Rev.com transcription service.

After reading the transcripts, narratives were uploaded into Dedoose Version 8.12. Initial codes were developed a priori based on a brief review of the literature and emergent codes were developed based on analysis of the narrative content. The coding summary was reviewed and the exemplars within each code considered. Using an iterative process, response patterns and trends were organized into categories based on commonality of meaning and thematic content.

METHODS: FAMILY CAREGIVER SURVEY AND INTERVIEWS

FAMILY CAREGIVER SURVEY AND INTERVIEW INSTRUMENTS

The family caregiver survey was designed to collect data about the PDN workforce as well as characterize demand for services from the perspective of family caregivers and guardians caring for CMC authorized to receive PDN services.

- Factors that impact the supply of PDNs;
- Factors that impact gaps in care and challenges in receiving appropriate care for their child; and
- Assessment of the clinical and cultural competence of the PDN workforce.

The family caregiver survey included single-response and multiple-response questions, as well as matrix items. Respondents used open-ended text fields to provide comments, clarifications, and additional information, as appropriate. Given that data were collected in the midst of the COVID pandemic, participants were asked to respond to survey questions thinking about their experiences that were "usual" for themselves and their child, not those experiences that are unique because of the pandemic, unless otherwise noted.

At the end of the anonymous survey, family caregivers interested in participating in an interview with research staff were given an opportunity to provide their contact information via a separate data collection instrument. The semi-structured interview protocol explored the above topics in depth with volunteer interviewees.

IDENTIFYING THE FAMILY CAREGIVER SAMPLE

Family caregivers who met the study inclusion criteria were identified by DMMA and contact information was provided to CRESP. Duplicate listings, miscoded state information, non-Delaware addresses, and/or facility addresses were flagged. The final sample size included 291 unique child IDs matched to 282 unique family caregiver IDs; this sample included nine households with more than one child eligible for services at the same address.

In order to improve recruitment, notices about the survey and interview study with family caregivers were distributed to leads of advocacy/community organizations who support work in this area, as well as the admins of social media groups of family caregivers.

FAMILY CAREGIVER SURVEY SAMPLE AND DISTRIBUTION

Letters inviting family caregivers to participate in the survey were sent via regular post to all eligible family caregivers; families with more than one child eligible for PDN services (n=9) received separate invitations for each child.

Family caregivers were provided a link to access the PDN Workforce Capacity Survey website. From the website, family caregivers had options to access the survey in English, Spanish, or Haitian Creole. Unique PINs were provided to ensure that only one survey was filled out for each eligible child. Families who did not want to complete the survey using the electronic link were advised to call the CRESO offices to obtain a hard copy of the survey or participate via phone. Two survey reminder postcards (that included Spanish and Haitian Creole translations) were sent to all eligible participants. Family caregivers interested in volunteering for an in-depth interview were asked to complete a separate data collection form at the end of the survey. Families who volunteered to participate in the interview were contacted by CRESO research staff. All volunteers who completed the interview received a \$25 Amazon gift card. Families were assured survey responses were anonymous, interview participation was confidential, and participating in the survey or interview would not impact the private duty nursing services received now or in the future. The content of the invitation letter and website included English, Spanish, and Haitian Creole versions. Data collection closed on June 30, 2021.

SURVEY AND INTERVIEW RESPONSES

Of the 291 surveys mailed, 42 family caregivers (14.4%) accessed the survey. Of the 42 family caregivers who opened the survey link, 21.4% (9/42) did not complete the survey other than cursory information. The final analytic dataset was comprised of 34 survey respondents for a survey response rate of 11.7% (34/291). Valid responses by item ranged from 31-34 respondents, depending on the question. In addition to the survey, 15 interviews were conducted with family caregiver volunteers.

CHARACTERISTICS OF RESPONDENTS' CHILDREN

The majority of children of survey respondents were males (18/34; 52.9%) and nearly three-quarters were White (25/34; 73.5%). Most were actively receiving care in May or June 2021 (27/34; 79.4%) which coincided with the data collection effort for this study and had received care both before and during the COVID-19 pandemic. Children's age ranged from 1-20 years, with an average age of 8.4 years (S.D.+/-6.4), compared to an average age of 8.2 years in the sample list provided by the DMMA. Note: Family caregivers were asked to report age in years corresponding to the most recent PDN shift in the home. See Tables 1-4 for details.

Table 1. Child's gender

	Frequency (n)	Percent
Girl	16	47.1%
Boy	18	52.9%
Total	34	100.0%

Table 2. Child's Race

	Frequency (n)	Percent t
White	25	73.5%
Black/African American	3	8.8%
Hispanic	1	2.9%
Mixed Race	4	11.8%
Prefer Not to Tell	1	2.9%
Total	34	100.0%

Table 3. Child's most recent hourly shift by a PDN

	Frequency (n)	Percent
2018	1	2.9%
2019	3	8.8%
2020	3	8.8%
2021	27	79.4%
Total	34	100.0%

Table 4. Child's receipt of private duty nursing care before and during COVID-19

	Frequency (n)	Percent
My child received in-home PDN care <u>both before and after</u> the COVID pandemic started	26	76.5%
My child received in-home care <u>before</u> the COVID pandemic started but not after COVID started	7	20.6%
My child started receiving PDN in-home care for the first time <u>after</u> the COVID pandemic started	1	2.9%
Total	34	100.0%

When asked about equipment used in the home, feeding pumps (26/32; 81.3%), feeding tubes (24/32; 75.0%), pulse oximeters (25/32; 78.1%), and wheelchairs (20/32; 62.5%), or other mobility aids (20/32; 62.5%) were used most frequently. Approximately one-third (10/32; 31.3%) of children used a mechanical ventilator in the home. See Table 5 for details.

Table 5. Types of equipment used by CMC in the home for treatment and care needs

	Number of responses	Percent of Cases
Feeding pump	26	81.3%
Feeding tube	24	75.0%
Pulse oximeter	25	78.1%
Wheelchair	20	62.5%
Mobility aids (e.g., scooters, walkers, crutches, prosthetic devices, orthotic devices)	20	62.5%

	Number of responses	Percent of Cases
Oxygen	15	46.9%
Medical bed	14	43.8%
Mechanical ventilator	10	31.3%
Medical lifts	10	31.3%
Adaptive switches and/or utensils for motor skill (e.g., for eating, playing games, and accomplish other activities)	9	28.1%
Cognitive aids (e.g., computer or electrical assistive devices to help with memory, attention or other challenges in their thinking skills)	9	28.1%
Non-invasive mechanical ventilator [CPAP machine]	7	21.9%
Computer software and hardware (e.g., voice recognition, screen readers, screen enlargement applications)	6	18.8%
Hearing aids	6	18.8%
Infusion pumps	3	9.4%
Other	8	25.0%
Total	212	

n=32 respondents; multiple response variable - number and percent add up to more than sample

FINDINGS A: FACTORS THAT INFLUENCE THE SUPPLY OF PDNS

Findings are presented in the following sections. Participants were asked to respond to survey questions thinking about their experiences that were "usual" for themselves and their child, not those experiences that are unique because of the pandemic, unless otherwise noted.

RESULTS AREA 1: DEMAND FOR PDNS EXCEED SUPPLY

Assertion 1. Three-quarters of respondents have no nursing coverage for their children multiple times a month.

Family caregivers report they are allocated hours, but there are no nurses to cover them. Nearly all family caregivers (32/33; 97.0%) have been told at some point there are no nurses available to care for their child and almost three-quarters (23/31; 74.2%) said they have no nurses to care for their child multiple times a month. See Tables 6-7 for details.

Family caregivers are told repeatedly by agencies that shifts can't be filled because "*there are no nurses*", "*we have a staff shortage*"; "*there are too many patients and not enough nurses*"; "*there is a nursing shortage*"; and, sometimes family caregivers are told, "*there are not any nurses to hire right now.*"

Table 6. Number and percent of respondents told there are no PDNs available to care for their child

	No	Yes
Have you ever been told there are no nurses available to provide care for your child? (n=33)	1	32
	3.0%	97.0%

Table 7. Number and percent of shifts not covered

	Frequency	Percent
Every week	9	29.0%
Multiple times a month	14	45.2%
A couple of times a year	3	9.7%
Other, please specify	5	16.1%
Total	31	100.0%

In some cases, children cannot be discharged from the hospital until coverage is identified; this includes families who may be waiting to return home after the birth or hospitalization admission of a CMC who needs PDN coverage in the home.

“Until they find enough people to fill all of those shifts...so you're pooling from a small group of people and I think that's really why it was so difficult to come home from the hospital in the first place...there's a whole bunch of agencies and the hospital was great with trying to coordinate them [but] they all came back with the same thing. ‘We don't have enough people to fill those shifts.’”

“We were told that my child was ready to leave medically, but that we would not be discharged because there was no private duty nursing...and I'm like, ‘Excuse me? You mean to tell me my child is medically ready to go home and we can't leave until there's nursing and there's no nursing?’...that was rough...you kind of lose the sense of [it's your kid]...it's not really your kid...it's the medical field's kid and that was hard.”

“After surgery, nursing coverage was the main reason he couldn't come home [for three months].”

Of those family caregivers whose child was hospitalized in the past two years, over one-quarter (7/25; 28.0%) reported their child's discharge was delayed due to lack of availability of PDNs. See Table 8 for details.

Table 8. Number and percent of CMC who had a delayed hospital discharge due to lack of in home PDN coverage

	No	Yes
Remained in hospital because there was no PDN available (n=25)	18	7
	72.0%	28.0%

In addition, family caregivers shared that the demand for nurses can interfere with school attendance. That is, some children cannot attend school because of the nursing shortage.

“They would call me in the morning at 6:30 and say, ‘We have a nurse for you, or we don’t have a nurse for you.’ That was kind of troubling. That lasted a couple of months...and she can’t go to school without a nurse.”

RESULTS AREA 2: FAMILY CAREGIVERS’ PERCEPTIONS AS TO WHY THERE IS A SHORTAGE OF NURSES

Assertion 2. Family caregivers attribute the shortage of nurses to low wages, poor benefits, and unpredictable pay which in turn leads to inconsistent, transient staffing patterns and gaps in care for CMC.

Families attribute the shortage of PDNs almost exclusively to low wages, poor benefits, and unpredictable pay. They believe recruitment is hampered by competition from other health care settings that offer higher wages and affordable benefits. Low wages, poor benefits, and unpredictable pay lead to inconsistent, transient staffing patterns.

“I’ve had plenty of nurses say that they need benefits and they’re maybe not married or divorced, what have you, so they can’t go with their spouse’s benefits so they finally leave to get benefits. I would say most have left to work at a hospital...or a facility that the pay is higher.”

“The reimbursement rate [is low]...like one of our nurses, we were talking about, RN versus LPN. She’s like, ‘LPN stands for low paid nurse.’ And I think the pay is really poor.”

“Benefits are a problem – in some settings you are working full time but not considered a full-time employee. Some agencies don’t offer benefits at all. And those that do, the benefits are limited.”

“I hear from the nurses constantly that they make half of what they could make if they worked in a hospital setting. But then I always explain, ‘Right, but in a hospital you’re taking care of maybe 10 or 12 patients and here you’re taking care of one. And here you get to watch TV, use wifi and basically just monitor things while somebody is sleeping.’ So it’s a different set of responsibilities and the pay reflects that. But they definitely do not like the pay. So I think they are constantly looking for another job and then once that job comes available, they take it. So it always seems temporary [how long they work in our home]...like say three or six months. I think it’s pay that makes them go.”

Assertion 3. Family caregivers believe if a rate adjustment is approved for skilled nursing care, the funds should go directly to the PDNs to increase their hourly base rates.

Families don’t understand why PDNs are paid so little given the critical nature of the care they provide to CMC and hope that if reimbursement rates are adjusted, all of funds will be funneled to the nurses in the form of an hourly rate increase.

"If you can care for a person in the hospital for two weeks who is critically ill, then you're caring for a person in a home who's critically home, then you deserve the same pay."

"If the state's looking to adjust or improve reimbursement rates or anything, I feel really strongly there needs to be riders on that, with this reimbursement rate, 100% of the increase needs to go directly to the nurses. You cannot take it as overhead."

Other reasons there is a shortage of private duty nurses is the belief that the absolute numbers of CMC requiring care in the home is increasing; the difficulty attracting nurses interested in home care nursing; and the associated nuances of working in the home environment.

"We had a nurse that said that there were at least four patients [at the hospital], just this past month, that couldn't go home because there were no nurses to cover."

"So it is a lot of pressure sort of on one nurse to handle everything. And depending on how extreme the case is...I know others are a lot more intensive just by their nature...so I think some people have realized that it's a little too much and they don't like not having that [full] support system of other people."

"At home, PDNs take care of my child's physical therapy, occupational therapy, speech therapy. They're even the respiratory therapist. PDNs are the ones that have to put my child on the ventilator and monitor them and make sure that they got oxygen when they need it. At the hospital, you pick up the phone, and you call somebody when you need a respiratory therapist to come put that child on a vent. At home, you don't have that. At the hospital, you also have a CNAs who are doing vitals, who change diapers, who change clothes. Here at home, you don't have that. You are the CNA."

Assertion 4. Family caregivers believe PDNs join the workforce because they prioritize a flexible schedule over all other considerations.

Although pay, lack of benefits, and other issues may detract nurses from working in the field, family caregivers believe the primary reason most nurses work in the field is the flexible work schedule. PDNs want to choose when, and how often, to work. If a flexible work schedule is not important to a nurse, they may not be interested in working as a PDN.

"My impression is a lot of people like the private duty nursing sort of environment because they can basically set their own hours. I shouldn't say set their own hours, but kind of. They set their own schedule and if they need to call out sick this day, they call out, or take a day or whatever, they do that. And if they have a client and things are going well with that client, they stay on that case. But if they say, 'I don't want to work with this patient anymore,' then they move to another case. So I think there's a lot of freedom in that regard that you wouldn't have for example, if you were a hospital nurse."

"As far as we understand, and for even nurses that are at the hospital, their inclination is that a lot of nurses go to home care because of their flexible schedule. I think, is the biggest draw. But other than that, there really doesn't seem to be other things that draw them into it."

“They can choose their schedule, so they can continue to do school...they can work another job...and so, the way the system is set up, the pay isn't great, and the benefits aren't great, but they can really mold what they're doing around whatever else they're doing, and that keeps them here.”

Other than flexibility, family caregivers acknowledged some of their PDNs work in the field because they enjoy the 1:1 pediatric care; need a “filler” position until they can find a higher paying job; earn extra pay; or are at the end of their careers and don't want the “hustle and bustle” of the hospital and thus prefer the home setting. Some Family Caregivers said their PDNs are genuinely interested in interacting with the children and watching them grow and improve.

“The one-on-one care. That hospital setting you're always working multiple cases; you don't stay with the same person. Our PDN is somebody who's on my child's team...and wants to see them succeed and watch them grow and see them progress.”

“For some of them, the PDN nursing is actually kind of a side-gig...it's actually just for extra hours or for some extra money. Sometimes they'll pick up a weekend shift or a couple of hours here and there. We have another nurse who [has a fulltime job]...and she just does the private duty nursing for some extra cash on the side.”

A few family caregivers wondered if they work as PDNs because hospitals won't hire them, or the PDN simply couldn't “hack the hospital setting.”

“[I think] they choose private duty versus anything else because they can't handle nursing in any other environment. The majority of them, they can't handle it. They either have worked in a hospital and just can't handle the caseload or they have never stepped foot in a hospital and never done any sort of medical surgical experience ever.”

RESULTS AREA 3. ACCESSING DATA TO DOCUMENT DELAWARE'S PDN SHORTAGE

Assertion 5. Family caregivers suggest DMMA use quantitative data to document the numbers of PDN hours scheduled and covered, in addition to increasing oversight of the system.

Family caregivers suggest that DMMA work to expand and make available reports that include information about the number of PDN hours scheduled and covered. Findings can be used to assess discrepancies across the system, including analyses at a granular level, such as by family, child, and agency characteristics.

“There is a report that breaks down the uncovered hours and shifts across all of the families, that the agencies provide, but there's no breakdown. It's overall. What information, or what can you do when you have an overall group number. Where's your breakdown? Where's your breakdown of this family, these many families had an average of no coverage for X, Y, and Z? These families had all the coverage. So, how do you do that? Well, if you give data that breaks down those scenarios, then you might be able to catch [problems], and say, okay, what are we doing about this? But because it's overall [it is not helpful].”

"We hope that this [study] helps drive independent studies into this issue, because there's a lot going on."

In addition, family caregivers suggest increased oversight to protect children from PDNs who have demonstrated insufficient skills or care standards.

"There were a couple of things like, 'Oh, I don't want to put her on your case because she'll just fall asleep.' Well, then why is she working for you? You're going to send her out to somebody else's house?"

"We've let go of nurses for safety reasons...[we know of nurses who]...end up back on cases and really they shouldn't be. So, where is the oversight at the state level, making sure that these nurses aren't allowed to stay in the community."

FINDINGS B: FACTORS THAT CONTRIBUTE TO GAPS IN CARE

Assertion 6. Gaps in care occur when there aren't enough nurses trained for high acuity cases; backup nurses are not oriented to a case; PDNs and families are not a "good fit"; agencies triage care assignments; and PDNs cancel or do not show up for their assigned shifts.

Family caregivers report that nursing coverage for their child is unpredictable with frequent gaps in care due to multiple factors including, but not limited to, lack of PDNs available to take care of high acuity cases; limited PDNs available to match hours needed; triaged care decisions by agencies; nurses who are asked not to return to the home by families due to safety reasons; and cancellations, no shows, and shifts that were never assigned. Each of these factors are explored in this section.

RESULTS AREA 4: LACK OF NURSES TRAINED FOR HIGH ACUITY CARES

Gaps in care are often due to the lack of availability of nurses with appropriate skill sets for their children, particularly for those with high acuity care needs (e.g., tracheostomies, mechanical ventilators, or other multifaceted care needs).

"The community greatly needs more trach vent nurses for our kids."

"We always have holes in the schedule...the reason that I'm getting as an explanation for why there aren't more is that there aren't enough trach-vent nurses out there...and this is after two and a half years of trying to get nursing and having three agencies on board."

RESULTS AREA 5: BACKUP NURSES ARE NOT ORIENTED TO THE CMC CASE

Gaps in care occur because there are no backup nurses oriented to case. Family caregivers are anxious about new nurses coming into the home and wonder if "teams" of nurses can be oriented for each case.

"We never have substitute nurses...my child's needs are greater than having somebody just come in for one night...that typically leads to a lot of confusion between the nurse and my child...even if I said, 'Sure, send somebody'...they wouldn't have anybody to send. So no, there's never a new nurse in that respect."

"When there are more people involved in your case, that makes it better when somebody's on vacation or somebody calls out sick, that there are more options to rotate people in that are familiar with my child."

"I read somewhere about somebody saying there needs to be teams. So a team of five to ten nurses does meet and greets with a whole bunch of families. And then they're able to plug and play people as they call out...You can kind of move people around more."

RESULTS AREA 6: PDNS ARE NOT A GOOD FIT FOR THE CHILD AND FAMILY

Family caregivers report there are gaps in care when there is not a "good fit" between the PDN and the child and/or family. Regardless of the reason, finding a replacement is challenging and "it's often playing the waiting game to get restaffed."

"We installed cameras in my child's room and we have found more than one nurse, a couple of times, different nurses sleeping during the night shift when they're supposed to be taking care of him...so for all of those people, I have asked them not to return...that's happened several times."

"We've had a nurse who actually was a decent nurse, but I don't know if she was a smoker or somebody else, but clearly somebody in her household was a smoker and it was just very, very strong smoke smell on her and on her clothes...and we didn't want third-hand smoke...so I had to ask her not to come back to it."

"If our older child and the nurse don't get along...[we can't have here]."

RESULTS AREA 7: PDNS SCHEDULING PREFERENCES

Given the flexibility guaranteed with PDN work, family caregivers note there are open shifts because PDNs are not available for the hours and shifts families need. PDNs don't care for short shifts, and staffing for weekend and night shifts are particularly challenging with repeated cancellations.

"We need nurses here early...and a lot of the times they don't want to start until like 8:00AM...and a lot of nurses seem to prefer working three days a week, maybe four, 10 to 12 hour shifts. We can't offer that."

"Weekend nurses aren't committed, and fall through even though they get weekend incentive pay."

RESULTS AREA 8: PDNS SEEK A PREDICTABLE NUMBER OF HOURLY SHIFTS

Families acknowledge that if their child is hospitalized frequently, it is difficult to secure nurses.

"[A nurse] dropped us for a while because my child was hospitalized frequently...and sometimes we can't give them much advance notice because [it's a sudden admission]."

"I think honestly PDNs need a guarantee that they're going to have hours. I can't imagine how stressful it is if you're [already] not making great money, and then you're being called off all the time because your [case] gets admitted."

RESULTS AREA 9: AGENCIES TRIAGE ASSIGNMENTS BASED ON NEED

Families believe agencies triage cases and, depending on the situation, a nurse may be moved from one case to another case leaving the family caregiver with a gap in care for their child.

"PDNs who have more experience with a certain health issue may be pulled to take care of another patient since my child was not high needs."

"Triage may become necessary. One parent cannot safely provide more than 16 hours of paid or unpaid care per day, and so for children who need round-the-clock skilled awake supervision, at least one outside nursing shift per day must be an absolute priority for coverage."

RESULTS AREA 10: CANCELLATIONS AND NO SHOWS

Assertion 7. Family caregivers have little confidence open shifts or cancellations will be filled; in turn family caregivers devote considerable time to communicating and coordinating PDN coverage for their children.

When family caregivers receive their monthly calendar with open shifts, or they are told there is a change in plans and a nurse is not available, some families have never had a nurse fill in after a call in – *"it simply was never that option."* Family caregivers feel there is no urgency to scheduling open shifts or call outs, rather *"You get the attitude of 'it is what it is.'"* and wonder why the system works the way it does.

"There is no system or backup plan for when call outs/absences happen. Any other business/service has a way to cover last minute call outs."

"Nursing is stretched too thin covering multiple cases, so if for any reason we have a call out, there is no replacement."

From experience, family caregivers have little confidence shifts will be filled when there are no shows or cancellations (27/32; 84.4%). See Table 9 for details.

Table 9. Family caregivers' confidence that cancelled and/or open shifts will be filled

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I am confident the agency will find a replacement PDN when a shift is canceled (n=32)	19	8	5	0
	59.4%	25.0%	15.6%	0.0%

When there is a change in schedule, less than half of family caregivers (15/32; 46.9%) are consistently informed by their agency, while over half (17/31; 53.1%) are sometimes, rarely, or never informed. See Table 10 for details.

Table 10. Family caregivers’ perception that agencies communicate promptly regarding schedule changes

	Never	Rarely	Sometimes	Most of the time	Always
My child’s agency communicates with me promptly about any changes to my child PDN shift coverage (n=32)	3	3	11	9	6
	9.4%	9.4%	34.4%	28.1%	18.8%

Assertion 8. Communication between agencies and families about open shifts and cancellations is subpar. Family caregivers attribute this to scheduling mix-ups at the agency; lack of communication between agencies; staff turnover at the agencies; and/or ineffective use of call centers.

Family caregivers might hear about staffing or schedule changes from their PDN, or do not hear about these changes at all, and are left without coverage at the last minute. Overall, family caregivers said communication about cancellations and coverage is often subpar. It may be related to scheduling mix-ups at the agency; lack of communication between agencies; staff turnover at the agencies; and/or ineffective use of call centers.

“When we bring it up with the scheduler at their office, we get a response that says, ‘Oh my bad. We forgot to tell you that we switched that.’ And that’s typical. There’s simply no professionalism or accountability quite a bit of the time where something so simple as, ‘Hey, you have this person on the schedule you sent us, but now you’ve changed it and you’ve not bothered to tell us.”

“All of the agencies seem to have this issue where they use a call center for their call outs, and then we don’t get a phone call. So it’s very frustrating when the nurse just doesn’t show, then we come to find out later that they have in fact contacted their call center, but nobody forwarded that message to us.”

“I don’t really get very many call outs...but there is just so much turnover in the scheduling department that no one ever really seems to know what they’re doing...like a great example...[our PDN] took the day off... and told me that she told [the agency] two weeks before that she wasn’t going to be working...it was a scheduled day off...but the nursing agency told me just [three days before].”

“It is a constant struggle. Agencies do NOT communicate with one another.”

“Really the communication was just subpar. I mean, horrendous. I would never refer a person to that company ever. I don’t even trust that they would be safe.”

Some family caregivers (13/32; 40.6%) report they always/most of the time will try to find a replacement while waiting for the agency to fill the slot. See Table 11 for details.

Table 11. Number and percent of family caregivers who contact PDNs to fill shifts

	Never	Rarely	Sometimes	Most of the time	Always
I try to find PDNs myself to make sure my child shifts are filled (n=32)	10	2	7	8	5
	31.3%	6.3%	21.9%	25.0%	15.6%

Interviewees elaborated on the unprofessional conduct of some PDNs, the unpredictable nature of coverage, and the stress this placed on the family.

“A huge problem with nursing is private duty nurses seem to think that they’re doing us a favor coming. It’s like your friend doing you a favor, not actually an employee that’s been hired. And so they like to not show up or show up late. And I have had numerous nurses just not show up at all, not call, not show up, no call, no show. And you’re sitting around waiting for the nurse to come. You have other things that you’ve planned because you’re supposed to have a nurse and they just don’t come. And then if they do come, they sometimes show up, my nursing starts at nine o’clock at night and sometimes they’ll show up at midnight. No call, and then just show up unexpectedly.”

Family caregivers describe the agencies role as primarily related to scheduling and providing clinical reviews.

“So the agencies, they’re simply there to staff your case. They have nothing to do with the approval of your hours. And really, they’re not in charge of supplying families with durable medical equipment, for example, or finding resources. They’re simply staffing agencies.”

“They call me about scheduling most often, for sure. But the only other communication I really had with them is the nursing supervisor does, I don’t know what she calls it an assessment...she’ll just call and we go through all of her meds and make sure I have all the doses right and everything is in the nurses book the way it should be.”

When asked about overall satisfaction with agency roles and activities, family caregivers somewhat/strongly agreed the agency was responsive to their concerns (28/32; 87.5%). Three quarters of respondents believe the agency system allows them to give feedback as necessary (24/32; 75.0%) and felt comfortable in doing so (22/32; 68.8%). Family caregivers were satisfied with the agency clinical nurse manager (24/32; 75.0%) and slightly less satisfied with the scheduler they currently work with (20/32; 62.5%).

Table 12. Family caregiver satisfaction rating of agency activities and roles

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
	2	2	16	12

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
The agency listens to my/my child concerns (n=32)	6.3%	6.3%	50.0%	37.5%
The agency system allows me to give feedback (n=32)	3	5	13	11
	9.4%	15.6%	40.6%	34.4%
I am comfortable providing feedback to my child agency (n=32)	2	8	9	13
	6.3%	25.0%	28.1%	40.6%
I am satisfied with the agency scheduler I currently work with (n=32)	6	6	11	9
	18.8%	18.8%	34.4%	28.1%
I am satisfied with the agency clinical nurse manager I work with (n=32)	5	3	13	11
	15.6%	9.4%	40.6%	34.4%

FINDINGS C: CHALLENGES TO ACCESSING QUALITY CARE

RESULTS AREA 11: FAMILY CAREGIVERS REFLECTIONS OF PDN CORE NURSING COMPETENCIES

Family caregivers report that about half of PDNs new to their child’s care arrive with knowledge about the child’s care plan or condition (16/32; 50.0%); fewer PDNs arrive with information about the overall home environment (14/32; 43.5%%). See Table 12 for details.

Assertion 9. Family caregivers report that only about half of new nurses arrive with adequate information about the particular disease processes or disability of the child and their care needs; even less have information about the home environment.

Table 13. Family caregivers’ perception of PDNs who arrive with adequate information about their assignments

	Never	Rarely	Sometimes	Most of the time	Always
New PDNs have knowledge about my child status when they arrive to provide care (e.g., weight, mobility status, etc.) (n=32)	1	8	7	9	7
	3.1%	25.0%	21.9%	28.1%	21.9%
New PDNs have knowledge about our home environment when they arrive to provide care (e.g., no smoking, pets, etc.) (n=32)	3	8	7	7	7
	9.4%	25.0%	21.9%	21.9%	21.9%

Assertion 10. Family caregivers describe experiences where their child is put at risk because nurses do not have the necessary skill sets to recognize clinical problems, respond appropriately to emergencies, or have experience working with medical equipment used for the care of their child.

When asked about PDNs who have taken care of their child on a regular basis, family caregivers believe approximately one-quarter of PDNs don't have the skill set (8/32; 25.0%) or expertise with medical technologies (8/32; 25.0%) necessary to care for their child. In addition, families believe less than half of PDNs are able to recognize and respond to clinical problems quickly (13/32; 40.6%), including emergency situations (9/31; 29.0%). When on the job, family caregivers report that PDNs are not necessarily attentive and engaged with their child (8/32; 25.0%), or alert (9/32; 28.1%), particularly during the night shifts. Last, few PDNs are proactive and communicate frequently with the child's care team (21/32; 65.6%). See Table 13 for details.

Table 14. Family caregivers' perceptions of PDNs skills and expertise

	Never	Rarely	Sometimes	Most of the Time	Always
Have the skills to meet the needs of my child (n=32)	0	0	8	12	12
	0.0%	0.0%	25.0%	37.5%	37.5%
Have the expertise with the medical technology my child uses (n=32)	0	3	5	17	7
	0.0%	9.4%	15.6%	53.1%	21.9%
Recognize clinical problems quickly (n=32)	0	2	11	10	9
	0.0%	6.3%	34.4%	31.3%	28.1%
Are able to respond to emergency situations appropriately (n=31)	0	2	7	9	13
	0.0%	6.5%	22.6%	29.0%	41.9%
The PDN is attentive and engages my child in their surroundings (n=32)	0	2	6	15	9
	0.0%	6.3%	18.8%	46.9%	28.1%
The PDN stays alert on their shift (n=32)	1	0	8	13	10
	3.1%	0.0%	25.0%	40.6%	31.3%
Are proactive and communicate frequently with members of my child multidisciplinary team (other than PDNs) about my child care plan (n=32)	1	7	13	6	5
	3.1%	21.9%	40.6%	18.8%	15.6%

Interviewees reflected on experiences working with nurses who have inadequate preparation and skills. First, when a nurse arrives without information about the child, family

caregivers didn't know if the nurse was given background information "but [did] not read any of it." This includes nurses who came to the home for initial "meet and greets", as well as nurses who arrived for a shift assignment.

"The meet and greets are so essential and I've had nurses come in for a meet and greet, and they've had no background on my child. They don't know [anything about our home]. They don't know anything about [my child's condition]. I just thought, 'Wow, what is the agency telling them when they say, would you like to work with this child?' I was shocked. So now I just come in and expect that they're not going to know anything...so I think there's a missing link with meet and greets and the prep for a meet and greet. Also, I think a lot of parents don't know they have an option for a meet and greet. They don't just have to take the nurse that the agency gives them...now, obviously, if you're really hard up and you'll take anybody, then you don't need a meet and greet."

"So my experience has been that obviously there's a big issue with the lack of knowledge about [my child's] case. I found that staff usually is unprepared and that lends itself to not quite understanding the needs of my [child] and the family...because nobody really explained in full detail what the case would require."

Second, interviewees elaborated that some nurses assigned to their child's care lacked basic core competencies, whether it be working with medical equipment, conducting clinical assessments, or following care plans. In some instances, family caregivers were left to deal with an unsafe clinical dilemma for their child, and high anxiety for themselves.

"They came out, supposedly trach trained, but if there was any handling of the trach, they got me."

"A nurse changed my child's ventilator setting and didn't realize she had done that ...I came home and I could tell right away the ventilator didn't sound the same...she completed that shift while I sat in the room with her until she was done."

"[Nurses who do not] ask clarifying questions [like about medicines]...they are just kind of guessing, and then in the morning, I'm having to correct mistakes."

"We had a nurse say, 'Well, it's not my job to help do that'...'Okay, that might be. That probably is not a primary classification of being a nurse, however it's written into his documentations that you do that'...we said, 'You don't need to come back to our home again.'"

"I just sat up all night and watched the camera in [my child's] room... it was an uncomfortable situation. When she left, I did call the agency and asked them not to send her again...and they asked me a couple of reasons as to why...and I just said that she made me feel uncomfortable...she didn't really seem like she knew what she was doing. She just seemed like she had no clue what she was doing. I know she had to be a nurse, but I don't know how."

Family caregivers worry about their child's health and well-being when nurses are not engaged and fall asleep on their shift. In these situations, families often refuse to have the nurse come back into the home, again leading to gaps in care.

"We've experienced hearing the feeding tube beeping because it's clogged or something's happened, or one of his monitors is beeping. From my bedroom I can hear it beeping. And so I get up after, I'll sit there and count like 50 beeps. And then I'm like, 'Okay, it's beeped 50 times.' So I guess I'm getting up and I go in there and the nurse is sound asleep, never heard any of the beeping."

"I know [our PDN] was overworked and overwhelmed and she decided she was going to try and work the night shift even though I'm quite sure she didn't have the energy or the mindset to do it at the time...there was a lot of stuff going on, but you can't take that kind of gamble on my child. Just call out [if you can't stay alert]."

"I routinely woke up with the pump alarming and the nurse sleeping. Why should I have a nurse when I have to wake up the nurse and take care of the pump myself? I get it is a challenge of sitting in a dark room all evening. So the staying awake, being alert, being attentive to my child [is critical]"

RESULTS AREA 12: UNDERSTANDING THE GROWTH AND DEVELOPMENT OF CMC

Assertion 11. Family caregivers appreciate nurses who initiate developmentally appropriate activities with their child.

Caregivers described nurses as having dual roles when caring for their child - not only do the nurses need pediatric-specific clinical and technical skills, they also need to understand the growth and development needs of the children, as well as disability-specific approaches to care. Children need play time, age-appropriate interaction, and an emphasis on activities that help them grow physically and developmentally.

"It's not just about nursing care."

"We're not just talking about from a nursing skill set, we're talking about, again, the needs of the child, the needs to interact with the child, the needs to ensure that the child is receiving activities that are age appropriate."

"[I appreciate] a nurse that can understand and is willing to learn how to interact with my child's disability...someone who takes the time out of their schedule or whatever to learn about the disability and how they can interact better."

When asked to think about the PDNs who care for their child, the majority reported PDNs are dedicated to the care of their child (24/32; 75.0%); treat their child with compassion (30/32; 93.8%); and talk and interact with their child the same way they would with a typically developing child (23/32; 71.9%). However, there are outliers. See Table 14 for details.

Table 15. Family caregivers' perceptions of PDNs compassion and empathy

	Never	Rarely	Sometimes	Most of the Time	Always
Are dedicated to the care of my child (n=32)	0	1	7	11	13
	0.0%	3.1%	21.9%	34.4%	40.6%

The PDN treats my child with compassion (n=32)	0	1	1	14	16
	0.0%	3.1%	3.1%	43.8%	50.0%
The PDN talks and interacts with my child the same way they would interact with typically developing child (n=32)	1	0	8	11	12
	3.1%	0.0%	25.0%	34.4%	37.5%

Interviewees elaborated on what happens when nurses do not “listen, adapt, and understand and respect my child.”

“We had one nurse, and my child was crying one night, and she was just inconsolable, or so the nurse said. And she’s like, ‘I tried everything, I gave her Tylenol, I did this, I did that.’ And I walked in and I was like, ‘Well, did you pick her up?’ And she was like, ‘No’, she didn’t even try. And that’s all my child wanted, was just that snuggle, to be consoled.”

“Caring for a child also, it’s a very different role than caring for an adult with a disability. Obviously children want to play and not all nurses are ready for that role. It really is a dual role when you’re in pediatric care. So it takes a special kind of nurse to have the patience and the desire to care for our child...it really needs to be the holistic approach.”

Family caregivers observe days when their child receives appropriate clinical care, but is otherwise left to sit in front of a TV or simply playing with an iPad all day. Some attribute this to laziness on the part of the nurse, however, others note nurses may need more training on how to engage the child and support a holistic care approach to the child.

“It’s not just about clinical expertise. It’s about getting my child up and around. Caring about him developmentally.”

“Our last nurse would come here...and if I wasn’t directly supervising, my child would end up planted in front of a TV or on an iPad for hours on end. Really I would say that my takeaway from that is that some of these nurses do not understand the needs of a child, because they’re not childhood development experts or they’re not trained in that.”

“What is most important [is] getting him to engage in his surroundings, helping him grow physically and developmentally...you don’t have to stay in his room...we want him to be out and about the house and do everything that he wants to do...sit on the porch, go swing outside.”

RESULTS AREA 13: LACK OF CARE CONTINUITY

Family caregivers report frequent turnover in the PDNs who care for their child (19/32; 59.4%) See Table 15 for details. Lack of continuity causes anxiety for the family caregivers as described by one interviewee:

“They tend to push and hurry and orient somebody to the case in order to fill one hole for the month’s schedule and then you never see that nurse again...we’re told that they changed their availability or maybe they get pulled to another case, but that’s something that we’ve not been happy with...we want continuity. We don’t want somebody that doesn’t know how to take care of our kid.”

Table 16. Family caregivers' perception about continuity of care

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
My child's PDNs change frequently (n=32)	8	5	13	6
	25.0%	15.6%	40.6%	18.8%

Family caregivers see the importance of continuity for their child's care given the nuances that are often different case by case.

"There are so many nuances to providing care for a medically complex child. If you have somebody that comes in and they don't know your child and they're going to panic. 'Oh, my God, what am I supposed to do?' ... We love that idea of having that continuity of nurses because they are competent in providing care."

Assertion 12. Desperate for care coverage, family caregivers sometimes struggle with weighing the costs and benefits of keeping on nurses who are less than ideal in caring for their child.

When a shift needs to be filled, family caregivers prefer to have a nurse who knows their child, however, that does not always happen. Some families elect never to accept a new nurse who is unfamiliar with their child; whereas others will choose to accept a new nurse rather than not have coverage. At times, family caregivers, weigh the costs and benefits of keeping nurses who may be less than ideal.

"The agency that I've worked with...when we signed with them, it was, 'Oh, the nurse will come during the day at some point so that I can meet her or him, and then talk about coverage and then they would show up for their first shift' ... That has never happened. Any time that anybody new has come to my house, the first time I'm meeting them is when they're knocking on my door to come and do coverage in the evening."

"Yeah, out of fear and desperation, we take [PDNs we don't know]"

"Honestly we tell them to come anyway. If it's a new nurse, I usually talk to my boss and ask if I can work from home while the new nurse is here. One, because they have a million questions, trying to get settled with his routine and where all his stuff is...and also I just want to kind of hear what's happening."

"We usually tend to let people come.... because I feel like the worst thing that's going to happen is, two hours in, I call the agency and ask them to have them go."

"We had a situation with a PDN...our relatives were like, 'Oh my God, you're going to get rid of her right?' ... No. we probably won't be able to...she's super reliable and she also takes all [the hard to cover shifts]...it's medical, so people feel strongly that it shouldn't be a compromise...I think it's unacceptable...but [we need to compromise]."

"Over time, we have realized it is not good to allow nurses who have never been to our house before to do a shift on their own, so we don't permit it. So when there is an opening, it is because the few people who have been trained are not free."

Family caregivers assess the situation when a new PDN is assigned. If the new nurse arrives without appropriate competencies, family caregivers are often the ones to shadow and train the nurse. In some cases, they are left to essentially supervise the entire day.

"I have found in the past that when we have new staff, not everybody is aware of his disability and therefore they're not really prepared when caring for my child."

"I'm not sure what the agency's training process is like. I don't know what they, how they train, but typically the nurse comes in and the family is the one who does the training for their child...you are dealing with children who don't know their own care...so it's not like the patient can articulate to the nurse what they need."

"When I found out that most of them are trained on a dummy, and there's a whole lot of difference between being trained on a dummy and actually being trained on a child that's going to move. So, when they started sending nurses out to me, I no longer asked where they trained; I just said, 'You need to demonstrate your capability.'"

"I think on paper they have the skillset. Unfortunately, that doesn't always correlate to actual skill. For instance, G-tubes, you might on paper be okay to do a G-tube, when you come in, it's obvious you don't know how to run the pump, that's a little bit nerve wracking. I don't feel like I should be teaching you how to run his G-tube feed. I feel like if you know how to do a G-tube, you should know how to do it. And if you don't, you don't. You can certainly learn, but you're not going to learn on my child."

Depending on the agency, some nurses are properly trained via preceptorships and onsite training. In such cases, families are more comfortable and appreciative of the care their child receives, however.

"I just have so much more confidence in the training that they have that they can take care of an emergency with her at any given time. No matter what time of the day it is, they can handle it."

"The care quality is very dependent upon the agency...we've found that requirements, training, responsiveness and nursing skills vary widely across the agencies."

FINDINGS D: SYSTEM OPERATIONS AND POLICIES THAT LEAD TO GAPS IN CARE

Family caregivers identified system-wide issues that lead to gaps in care and affect the quality of care their child receives.

RESULTS AREA 14: LACK OF INFORMATION TRANSPARENCY

A recurring theme among family caregivers was lack of information transparency. In general, family caregivers are often confused about how the system works, what information they can and cannot have access to, and why some families' have access to services they don't.

"One of the questions that I had for one of the MCOs was how do they make the decision of who gets what? Because it seems it's like the Google algorithm, no one really knows how it works. There's no transparency. And when you ask these questions, you're given the run around. No one's really provided with the how are decisions being made as to who gets what?"

"I think everything about having a special needs child is difficult, and the system is definitely set up to make it as difficult as possible...overall, the systemic bureaucracy that goes with having a special needs child, there's a complete disconnect."

Assertion 13. Family caregivers believe some MCO reps are not informed nor forthcoming with information; families are left to navigate the system themselves and serve as advocates for their children.

Family caregivers struggle to find information. They report benefits booklets are not written clearly and MCO policies differ across the system, thus creating barriers to families being able to make informed decisions about how to address gaps in care. In some cases, case managers are not forthcoming with information, or they may not know themselves the services for which a child is eligible. Understanding policies and regulations can be a full time job for the family caregiver.

"Most families don't know what they're entitled to, don't know what benefits they could receive, because there's no statewide book of regulations, book of benefits that explains...the different MCOs have different policies and they work differently. So you have a lot of discussions between families of which MCO was better. Right. It should be a uniform booklet of benefits that special needs families are made aware of so that they can make informed decisions as to what am [my child and family] is eligible for and how can I fill in the gaps?"

"I have found [the insurance case managers] not very forthcoming with information. I have found things out that I was eligible for that, for nearly two years I had a case manager that told me I wasn't...they're an insurance company. They're not there to fight for the welfare of the families and the child."

"I think it's that [MCO coordinators] need to be proactive and maybe even oversharing information, especially with new parents...if the MCO rep isn't the right person they can maybe recommend who would be like a social worker for instance, or somebody else."

"[Insurance coordinators] need to guide parents...here are the questions you need to ask. Here's what I'm here for. Here's what I can help you with. But they kind of left it open-ended...and we didn't know that we were supposed to check in and ask them questions or that could have helped us navigate certain things with equipment or coverage or denials."

"If things could be translated into Spanish for the families that need that, that would probably be a service that's worthwhile."

In order to glean information, some family caregivers turn to, and appreciate, parent support groups. Without these groups, they feel they would be lost.

“Parents are the key. Veteran parents, the ones that have been doing this for a while are the ones that kind of know what to do more so than the agencies and that’s kind of sad. It should be that the people that are being paid to take care of our kids or to be MCO reps, they’re the ones who should be holding our hands and walking us through, hey, here’s what you do next. But I find it’s really not the case.”

“I don’t know anybody else that has private duty nursing...it’s really a whole new world for us...made some connections via social networks and ...Thank God for those ladies because we all ask questions. When we’re like, ‘Is anybody fighting this? Is anybody doing this? Has anybody’s kid been qualified as disabled?’ We definitely talk about these things.”

Beyond medical services, family caregivers are often searching for resources to meet other needs.

“With special needs kids and adults with disabilities, a lot of the services aren’t known to us. We have to go out there, and we have to look for them.”

“I had to go and find my own resources...now I try to share that with everybody that I can. If there’s a parent out there, I try to share that information.”

RESULTS AREA 15: AUTHORIZED HOURS

Approximately two thirds of all respondents (20/31; 64.5%) were satisfied with the number of authorized hours. However, a little over one-third (11/31; 35.5%) were not satisfied with the number of hours authorized for their child’s needs. See Table 16 for details.

Table 17. Family caregivers’ satisfaction with number of hours authorized for their child

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I am/was satisfied with the number of hours authorized for my child’s needs (n=31)	5	6	14	6
	16.1%	19.4%	45.2%	19.4%

Family caregivers expressed confusion and frustration regarding authorization policies that were based on the caregiver’s work and sleep cycles. Many family caregivers felt this policy was unrealistic.

“Because the agencies only cover working and sleeping, there is no time to do other necessary things to maintain a household, e.g. cleaning. The household is a place of work for the nurse. The 8 hours for sleep is not realistic because turn over before and after the shift is not accounted for.”

“My authorization states the only time I can have nursing in my home is when I am at work. What they fail to realize is that I do this day in and day out. There are days when I need help. Especially on days when we have appointments up at A.I. Hospital for Children.”

"Children don't qualify for an hourly shift if a family member is home from work for an employee holiday."

"If my daughter has to go to a dentist appointment and I take off work, that means I don't have a nurse for my child? That doesn't make any sense. We can't live our life. So just in taking care of ourselves and our child for basic needs, groceries, appointments."

"It's a hard balance because I'm sure there are plenty of people out there that take advantage of the system, but that makes it really difficult for the rest of us...we're trying to do what we need to do."

Assertion 14. Family caregivers believe authorization polices should include options for flex hours and respite care.

Family caregivers suggested that flex hours and respite care are needed.

"They'll give us a hard time about making up hours, but people called out. For example, they've said 'you can't make up a partial shift'...so if a nurse leaves four hours early, you can't make up those four hours, you can only make up a shift if it's the whole shift, like they called out the whole night."

"[I would] like more flex hours."

"There needs to be more flexibility when it comes to when us parents can utilize nursing. I can [give several examples]. These case managers need to be a little more empathetic to us as parents. This is beyond a full time job, this is a lifelong commitment to our special needs children, and we shouldn't have to jump through hoops just to get a little help. Caregivers need to be able to take care of themselves too."

"So I guess the only thing would have been like, before we had kind of worked out the flexibility of like, yes, you can go to a funeral, or if you're sick, you don't have to call off your nurse because you're home. Or if your other child is sick, you don't have to call off your nurse because you're home. That was really problematic. But now that we've worked out with them that that's acceptable."

"I'm like, until you live with a child with a tracheostomy and medically complex needs, you have no idea what you're talking about. So it's very frustrating. It's incredibly frustrating, the insurance situation and the nuances of one word on a paper that goes to whoever the approver is and he's like, mm, no."

"We don't have that option and I feel like I constantly need to make that point that I have haven't been out to dinner in two years because I literally can't. We're not out gallivanting around town. I'm not asking for nursing services so that I can go play. We both have a full-time job, we do have another child, we need to go grocery shopping, run a household...even if we have a nurse for a couple hours on a weekend so that we can take her somewhere with her parents is important."

"The bulk of [my child's] care falls on me...there is no school nursing...there is no respite care."

"There is no option for respite care, which is untenable."

"I don't understand why the State does not allow for respite care of children with medically complex needs. We are in desperate need for a trained individual; preferably one of our nurses, to be able to watch our child in order for the caregivers to take care of themselves."

Last, family caregivers wondered about the overall equity in the authorization process.

"I am very aware that there are many other families who have been or are 'approved' for more hours when their family member has less skilled nursing needs than my child does. There is no equity at all in this process."

RESULTS AREA 16: UNDERSTANDING THE BUSINESS MODEL

Assertion 15. Despite having been told there are no nurses to cover open shifts, family caregivers are told by their PDNs that they want more hours and the agency won't assign them.

Family caregivers are frustrated when shifts are open and they are told by nurses that they are not getting enough hours, or would like more hours.

"Even though I might be short a nurse, sometimes the companies won't let them work overtime because it takes money out of the company's pocket."

"They actually are told that there are no available hours to give them to get benefits, and the nurse leaves because of that...and they go into a facility or someplace that has more stable hours in care. But I know a ton of families have open shifts, we're one of them. But the agencies tell the nurses that we don't have any openings available for you."

"[I wonder] technically in a state of law, that if you work X, Y, Z, as many hours as you need, the organization, the business is required to provide these benefits. So, they may be telling nurses, no there's nothing available, but really they can't give any hours because then they would be required to give benefits. It could be just to keep them part-time employment."

They are also concerned about the lack of support and advocacy from MCOs.

"So I have found that most of the case managers at the MCO don't... How can I phrase this? They don't seem to necessarily be advocating for the patient and family...case managers working with the MCOs are looking for ways to cut benefits, not to offer more."

"We don't think the state is doing enough oversight, because...what happens with open shifts that we don't get covered? What happens to that money? Because it's a flat fee that these insurance companies get. Where is that money? It doesn't go back to the community. It doesn't go back to the state. The profit goes to the insurance company."

FINDINGS E: GAPS IN CARE AND IMPACTS ON FAMILY UNITS

Assertion 16. Gaps in care lead to emotional, physical, and mental stress for family caregivers.

Gaps in care impact the family unit. When a nurse is not available, the onus to care for their child falls on the family caregiver(s). Given the number of open shifts and/or “call outs”, families experience undue anxiety and hardships, and are concerned about longer term impacts on their children, as captured by the following exemplars:

“Caregivers are considered the fix for these problems [call outs] when that should not be the case. Regardless of notice given, the agencies are unable to find ways to cover vacations, planned time off and leave of absences (i.e. maternity leave).”

“Oh gosh. I mean, there’s just an emotional, physical, and mental strain when we don’t have a nurse.”

“My husband and I do not get to have any time together that is not involved in the direct one-o- one care for our child.”

“Our family is broken because of the stress. No mother should be in this position.”

“[Not having] nurses will have long term implications on the health outcomes of my child.”

“In the long run, my child will not be able to attend school if they don’t have a nurse. This is robbing them of their life. This is denying him the possibility of an education. Denying him friendships.”

When a shift is not covered, family caregivers discussed the impacts on employment, other family members, and their own well-being, compounded by lack of sleep. Open shifts and cancellations impact the day-to-day routines of all family members and contribute to exhaustion and fatigue that is further compounded for family caregivers who work.

“So if we have enough notice and nobody’s coming...it’s a stressful schedule and it’s not really as easy on those nights...we’ll both get maybe four hours of sleep in some sort of fashion and then just struggle through the next day...if it’s one night, we can do it. If it’s two or three nights, which we’ve done and that’s when you start to sort of lose your mind.”

“We have had many, many holes in our schedule, many nights where we go without a nurse...because of my child’s needs, it’s really hard to get sleep to get up early in the morning to go to work...you don’t sleep...so those nights that we go without, it can be a little stressful when you’re just exhausted the next day and trying to function at work.”

“I have scheduled days on my calendar where I do not have a nurse because the scheduler could not get coverage. And most of the time, that’s okay, because I can look at that, and I can say, ‘Well, okay, I’ll go to sleep, or I’ll take a nap and try to work it into my way.’ And if all else fails, in between medications...I’ll lay down on the floor with the pillow and take a nap.”

While some family caregivers are fortunate to have jobs where they are eligible for FMLA or whose employer allows scheduling flexibility when they have gaps in care for their child, many families are not so fortunate. Family caregivers shared that they are unemployed, have used all of their leave, lost significant portions of their incomes, have given up any hopes of career mobility,

and experience stress in their relationships. Some respondents said that the state should do more to investigate and document the impacts of the private duty nursing shortage for CMC on family caregiver employment, and to subsequently develop strategies to address the issue.

“When we don't have nurses and we don't work, our quality of life goes down, and we're forced into a situation of poverty, which affects my son's life. And ultimately what ends up happening is he doesn't get the best life that we can provide for him.”

“Well, for the day shifts...thankfully...at least I have decent vacation and sick coverage, so if it's necessary, if it's a day shift, sometimes I'll just take off or I'll take a half-day...and while they are taking their two or three-hour afternoon nap, I'll work during those hours...or I can flex my time and I'll go back and work some after they go to bed so I don't have to take a full day's leave.”

“It's a huge strain on the family, for sure. I am a single mother of a special needs child, and I'm essentially unemployable...most employers expect you to make up that time...so many of us in this community find ourselves just unemployable...no employer will tolerate five or six call-offs a month...and that may be due to the child's illness and also the issue with staffing in private duty nursing. No matter the reason, the outcome is the same.”

“We have used all of our leave...we lost [almost 15%] of our income from having to cover the open shifts we had or the cancellations.”

“And I've had to turn down job opportunities I would've really loved to have, because I knew I couldn't start someplace else and be calling out the way that I do with this job. So that's been really disappointing. And I know my promotion opportunities, even staying where I am, are pretty limited, because I don't have the capacity because I'm constantly having to call out.”

“There's so many things about this that are so complex. You look at the parents. Most of them are working. Not all. Maybe half. I don't know the numbers off the top of my head. But that's another challenge. A lot of these families, they have medically complex kids, but they're working these jobs where they do not have FMLA. They're doing hourly rates at McDonald's or somewhere and they don't get FMLA. So then they end up losing their job because they have to take all this time off because they have a sick child or a child that has a lot of medical needs and off they go to find another job. More than likely, they're going to end up at another place that doesn't have FMLA. So it's this vicious circle.”

“[Consider looking at] single parents, how many single parents are suffering through? And then have two parents. How many people are unemployed that are getting their shifts filled versus people who do work? You can break it down into groups and that's what I think they need.”

Last, family caregivers suggested that emphasis be placed on family-centered models.

“I just think a study like this should hear that when a kid is born with these complexities and we kind of know that length of life is shortened, then it really becomes about quality of life. And I just think the whole family has to be considered in that. And it's not just about hours for the parents, the siblings really need to be considered as well. There's healthy siblings that know what's going on, and they need their parents support too.”

One family shared how they appreciate the counseling they receive from an in-home visit by social workers and child life specialist.

"AI is wonderful. Nemours is great. So once a month, AI comes out with a social worker and a child life specialist and the child life specialist strictly works with our son. So she takes him outside or in the basement, and they play games and they talk about what it's like to have a sister with some special stuff. And that's great. And then the social worker basically has a counseling session with my husband and I. So that's wonderful because again, I'm all about the whole family and not just these little pieces of the puzzle."

FINDINGS F: WHAT IT LOOKS LIKE WHEN THE SYSTEM WORKS

Family caregivers acknowledge the system is not always "broken." When the system works, families have coverage and nurses demonstrate they are clearly engaged in multiple ways. For example, nurses ask for clarifications about care; troubleshoot and problem solve about care issues; provide care advice; interact in a developmentally appropriate style; develop rapport with their children; and are reliable and show up on time.

"I would just say that, overall, we have a wonderful team of nurses and they do a lot of really good work and it is a shame that there are those couple of outliers that sort of give a bad name to everybody else, but those couple of nurses [cause] very serious [issues]."

"So I would say 95% of nurses, have just been phenomenal people, let alone nurses. They really have good hearts. They will also admit, 'Huh? I'm not familiar with that. Please tell me what you mean.'"

"[My child's nurse]...we will talk in the evening sometimes before she goes in...we will bounce ideas off each other...she's invested in how my child is responding...and [the nurse] wants to see her improve and grow."

"Our day nurse she's wonderful...we want our child to be able to blossom and she certainly provides that for him every day...she gets our child up and they are smiley...they have the tablet...they go in the living room...they go in the playroom...they're all over the place...he actually cries when she leaves."

"Nurses who just read my child's general body language and gestures and things that they [my child] is not happy...or he needs you to back off and little things like that...other times my child has some certain sounds that they make when they are kind of afraid...or sudden movements and things like that...and I just see some nurses pick up on that stuff right away and they're like, 'oh, they didn't like that'...and other [nurses] just never seem to kind of catch on."

"For the most part, we have good, consistent coverage now. And I trust them and I don't bat an eye once they're here, I can sleep soundly in bed. And I'm not really worried about if they're not doing the right thing or if they're making a mistake or anything like that."

Some families have had a positive experience where agencies work to ensure nurses are highly skilled and competent, and MCO staff advocate for the children and demonstrate genuine concern.

“Our PDN agency provides competent, skilled, adaptable nurses. They provide more than medical care, they are also teachers, therapists, and at times friends to my child. They provide more for my child at home to ensure she has the best quality of life possible for her.”

“I will say that my insurance coordinator is wonderful, which is hard to say for an insurance company, but she's great. She checks in with me regularly...we have to regularly renew our letters of medical necessity. I just had to provide her updated work letters...that helps in determining how many hours we're getting for care and all that kind of stuff.”

“I was telling her that man, I really wish I had a bed like the hospital where I can raise it up, work on her and then lower it so she could get in and out of the bed as she needed. And she was like, well, let's call the doctor. Let's get an order put in. So she called the doctor, she got the doctor to put an order for a bed. And in like two weeks, there was a bed in my house. An electric bed. So it really was great. And I had to do nothing. I didn't have to call a doctor. I didn't have to. She did all of it for me. They came in here, they set the bed up for me and everything.”

SUMMARY STATEMENTS

Family caregivers note that to address the gaps in care, a “village” needs to work together to change the system. Information needs to be shared with policy makers at all levels of government to improve the system and decision-making needs to be informed by data and experiences.

“There's more kids and adults coming home with this stuff and they're pushing home care, and we're already broken. And they're just pushing more people into it. So, I think there's a lack of understanding, a lack of information...the law lawmakers don't understand what's going on. They need evidence, they need some type of facts.”

“I think advocating with legislators for whatever comes down the pipeline with the state budget is essential. As legislators are definitely impacted by the stories of parents and nurses when it comes to kids that require private duty nursing, whether it's under 21 or over 21. Until they hear the stories about how lives are impacted, they just don't know. So I would say if there's any way in your survey results to talk about how nursing agencies can share, ‘Hey, if you would like to make a difference in how nurses can work...If you want to be part of our advocacy team, here's what it could mean for you and your child.’ So I'd love that to be part of the conversation at some point with nursing agencies.”

CONCLUSIONS AND RECOMMENDATIONS

Based on the feedback from the study participants who completed the surveys and/or participated in the interviews, the research team provides the following summary of findings and recommendations. These recommendations emerged from the study data and should be discussed in the context of work that has been completed, or is ongoing/planned by DMMA, CMCAC, the SHHN Workgroup, or other stakeholder entities in the state.

FINDINGS

- Three-quarters of respondents have no nursing coverage for their children multiple times a month.
- Family caregivers attribute the shortage of nurses to low wages, poor benefits, and unpredictable pay which in turn leads to inconsistent, transient staffing patterns and gaps in care for their children.
- Family caregivers report gaps in care occur when there aren't enough nurses trained for high acuity cases; backup nurses are not oriented to their child's case; PDNs and families are not a "good fit"; agencies triage care assignments; and PDNs cancel or do not show up for their assigned shifts.
- Family caregivers have little confidence shifts will be filled when there are cancellations, no shows, or open shifts; in turn, some family caregivers devote considerable time to communicating and coordinating PDN coverage for their children.
- Communication between agencies and families about open shifts and cancellations is subpar. Family caregivers attribute this to scheduling mix-ups at the agency; lack of communication between agencies; staff turnover at the agencies; and/or ineffective use of call centers.
- Family caregivers report that only about half of new nurses arrive with adequate information about the particular disease processes or disability of the child and their care needs; less have information about the home environment.
- Family caregivers describe experiences where their child is put at risk because nurses do not have the necessary skill sets to: recognize clinical problems; respond appropriately to emergencies; or manipulate medical equipment used for the care of their child.
- Family caregivers appreciate nurses who initiate developmentally appropriate activities with their child, however, not all nurses appear skilled or interested in delivering holistic care.
- Desperate for care coverage, family caregivers sometimes struggle with weighing the costs and benefits of keeping on nurses to care for their child who are not trained appropriately.
- Gaps in care impact families in multiple ways and lead to emotional, physical, and mental stress.
- System operations and policies affect access to quality care. For example:
 - Family caregivers report some MCO representatives are not informed nor forthcoming with information; in turn, families are left to navigate the system themselves and advocate for their children.

- Family caregivers wonder why they hear from their PDNs that they want more hours and the agency won't assign them.
- Authorization should allow for flex hours as well as options for respite care.
- Family caregivers suggest DMMA use quantitative data to document the numbers of PDN hours scheduled and covered, in addition to increasing oversight of the system. In turn, these data can be used to by stakeholders to advocate as necessary.
- If a rate adjustment is approved for skilled nursing care, family caregivers believe the funds should go directly to the PDNs to increase their hourly base rates.

RECOMMENDATIONS

- ⇒ While this study, and the other Private Duty Workforce Capacity studies, provide detailed findings about the PDN workforce capacity in the state of Delaware, proposed solutions to meet the private duty nursing care needs of children with medical complexities will require careful and comprehensive program and policy research and deliberations. For example, while paying family caregivers a “caregivers allowance” is a possible solution, and one that is endorsed by some stakeholders, such policies that exist across various states are complex, and may have unintended consequences.
- ⇒ Consider planning for next steps by supporting groups of stakeholders from the CMCAC, SHHN Workgroup, and ad hoc members to review the five PDN Workforce Capacity Study reports. Prioritize findings and action items related to workforce shortages, gaps in care, and other issues raised in the studies.
- ⇒ Collect, analyze, and document quantitative information such on numbers of PDNs available to serve and discrepancies in approved private duty nursing hours versus provided hours for CMC care. Use these data to plan programs, policies, and advocate for the care needs of CMC and their families.
- ⇒ Consider expanding data collection efforts to include groups that are often part of marginalized communities, who may be less inclined to participate in research. In addition, for future studies and analyses, collect information on other variables that may also provide insights into gaps in care, such as socioeconomic status and geographic location.
- ⇒ Develop or adapt benchmarks for quality improvement measures that capture family caregiver’s and CMC experiences related to service supports, care, and PDN services, such as the “whole child, whole family” metrics developed by Barnett et al. (2019).
- ⇒ Consider developing and supporting care practice models not only for the children, but also for the family caregivers, particularly mental health supports and respite programs. For example, several models are discussed in a recent publication by Bayer et al (2021). The paper references

models such as the Chronic Care Model and Family Resilience Framework. (see Barr et al, 2003; Walsh, 2016) and other innovative health practices that have positive health outcomes for family caregivers, as well as the children (see Glassgow et. al., 2017; Law et. al., 2019).

- ⇒ Continue to emphasize a culture of open communication, transparency, and accountability across the system to ensure CMC have access to quality care and services.
- ⇒ Ensure information for special need families is readable and comprehensive and available in English, Spanish, and other languages, as necessary.
- ⇒ Consider providing honorariums for family caregivers who participate in best practice and policy committees.
- ⇒ Ensure PDNs are trained using a pediatric-specific holistic model that incorporates understanding the needs of CMC from a clinical, developmental, and socio-emotional context.
- ⇒ Continue to study existing models and/or proposed care models across other states for CMC, including cost-benefit analyses of continually recruiting and training new nurses versus bonafide rate increases.
- ⇒ Consider how systems of care operate for other populations who also require in home hourly shift work, such as the elderly and/or chronically ill populations. Incorporate programs, policies and lesson learned to the CMC system of care.
- ⇒ Consider how federal funds available to assist family caregivers with day to day household activities, such as household chores and grocery shopping, as well as provisions for counseling and respite care, can be allocated to family caregivers of CMC.

STUDY LIMITATIONS

The study has a number of limitations. First, the survey was only available electronically to family caregivers. Some family caregivers who do not feel comfortable with technology may have elected not to participate. Second, the survey and interview population may not be representative of the greater population of CMC family caregivers. This voluntary convenience sample represents just over 10% of family caregivers of CMC eligible for PDN care known to DMMA.

REFERENCES

- Barnert ES, Collier RJ, Nelson BB, et al. Key population health outcomes for children with medical complexity: a systematic review. *Matern Child Health Journal*. 2019;23(9):1167–1176.
- Barr VJ, Robinson S, Marin-Link B, et al. The expanded Chronic Care Model: an integration of concepts and strategies from population health promotion and the Chronic Care Model. *Hosp Q*. 2003;7(1):73–82.
- Bayer N D, Wang H, Yu J A, et al. A National Mental Health Profile of Parents of Children With Medical Complexity. *Pediatrics*. 2021;148(2):e2020023358.
- Glassgow AE, Martin MA, Caskey R, et al. An innovative health-care delivery model for children with medical complexity. *Journal of Child Health Care*. 2017;21(3):263–272.
- Law E, Fisher E, Eccleston C, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Syst Rev*. 2019;(3):CD009660.
- Walsh F. Family resilience: a developmental systems framework. *European Journal of Developmental Psychology*. 2016;13(3):313–324.

ACKNOWLEDGEMENTS

This study was a collaborative effort. CRESPP would like to thank all of the members of the CMCAC and SHHN Workgroup who assisted with the design of the study by participating in informational interviews, reviewing instruments, and providing guidance on the implementation logistics. Second, we would like to thank the stakeholders who field tested the instruments and the agency providers in Delaware who distributed the survey to the private duty nurses on their roster. Last, we would like to acknowledge and thank all of the family caregivers who took the time to respond to the survey and participate in the interviews.

APPENDIX A. PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: REPORT LISTING

Culnane, M., Giancola, S. (September 2021). *Private Duty Nursing Workforce Capacity Study: Private Duty Nurse Survey and Interview Results* (Publication T21-023). Newark, DE: Center for Research in Education and Social Policy.

Culnane, M., Giancola, S. (September 2021). *Private Duty Nursing Workforce Capacity Study: General Nurse Survey Results* (Publication T21-025). Newark, DE: Center for Research in Education and Social Policy.

Culnane, M., Giancola, S. (September 2021). *Private Duty Nursing Workforce Capacity Study: Agency Interviews* (Publication T21-026). Newark, DE: Center for Research in Education and Social Policy.

Culnane, M., Giancola, S. (October 2021). *Private Duty Nursing Workforce Capacity Study: Family Caregiver Survey and Interview Results* (Publication T21-027). Newark, DE: Center for Research in Education and Social Policy.

Culnane, M., Giancola, S. (September 2021). *Private Duty Nursing Workforce Capacity Study. Impact of COVID-19 on Access to Private Duty Nursing Services for Children with Medical Complexities* (Publication T21.028). Newark, DE: Center for Research in Education and Social Policy.