

**Private Duty Nursing Workforce Capacity Study
Impact of COVID-19 on Access to
Private Duty Nursing Services for
Children with Medical Complexities**

Authors:

Mary Culnane, MSN, MS
Sue Giancola, PhD

Funding Agency:

Delaware 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

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. (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.

Impact of COVID-19 on Access to Private Duty Nursing Services for Children with Medical Complexities

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 administered to PDNs, Family Caregivers, and Agency Representatives in the state of Delaware on how the COVID-19 pandemic has impacted access to private duty nursing services for CMC. In addition, this report addresses to what extent private duty nurses, family caregivers, and agencies are using telehealth during the pandemic. Select findings include:

- Agency Representatives said the pandemic exacerbated the already difficult task of recruiting PDNs, due to the added challenges of limited face-to-face outreach events; lack of COVID-19 hazard incentive pay; and attrition related to other higher paid COVID-19 related nursing opportunities.
- Families added that gaps in care due to the pandemic-and related challenges continue to affect coverage 12-15 months into the pandemic.
- Nurses altered shifts during the pandemic due to additional family obligations and concerns over COVID-19 exposure and spread; nurses also missed shifts, sometimes for up to one month, after being exposed to and/or diagnosed with COVID-19, thus contributing to gaps in care.

- Some Family Caregivers a) did not want new nurses to fill shifts; b) decided to limit the number of PDNs coming into the home to provide care; c) accepted only vaccinated nurses; and d) elected to cancel private duty nursing coverage altogether during parts of the pandemic.

All stakeholder groups shared their concerns regarding the pandemic:

- PDNs remain concerned about a) bringing the virus home to their own families and friends; b) the development and spread of virus variants; and c) increased exposure as more and more families circulate.
- Family Caregivers remain concerned about the a) unknown effects of COVID-19 if their child becomes infected; b) exposure to new variants; c) possibility of care rationing if a viral surge occurs; d) number of PDNs who come into their home; and e) unvaccinated nurses.
- Agencies Representatives remain concerned about the a) shortage of nurses compared to pre-COVID-19 levels; b) increased number of shift openings; c) number of PDNs who are not vaccinated; d) effect of COVID-19 on business practices; and e) costs and business impacts associated with the pandemic.

Experiences with telehealth were mixed:

- While some families had a positive experience with telehealth and felt it saved travel time, others did not have a positive experience due to technology issues and feeling like they were asked to make clinical assessments they are not trained to do.
- PDNs believe that about half of all homes they work in do not have the necessary technology to participate effectively in telehealth visits.

See the full report (T21-028) for a list of recommendations based on these findings.

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
LIST OF TABLES	6
LIST OF ASSERTIONS	7
INTRODUCTION	8
STUDY OBJECTIVES AND QUESTIONS	9
ORGANIZATION OF THE PDN WORKFORCE CAPACITY STUDY REPORTS	9
METHODS: COVID-19 AND TELEHEALTH SURVEY AND INTERVIEWS	10
SURVEY AND INTERVIEW INSTRUMENTS	10
IDENTIFYING THE STUDY SAMPLE, SURVEY DISTRIBUTION, INTERVIEW SELECTION AND PARTICIPANT CHARACTERISTICS	10
REPORT ORGANIZATION	10
FINDINGS A: IMPACT OF COVID-19 ON THE SUPPLY OF PDNS	10
RESULTS AREA 1: FACTORS IMPACTING THE NUMBER OF PDNS ON AGENCY ROSTERS	10
FINDINGS B: IMPACT OF COVID-19 ON SHIFT COVERAGE	12
RESULTS AREA 2. SHIFT COVERAGE PRIOR TO COVID-19 COMPARED TO DURING COVID-19	12
RESULTS AREA 3: NUMBER OF PDNS WORKING PRIOR TO COVID-19 VERSUS DURING COVID-19	13
FINDINGS C: FACTORS THAT CONTRIBUTE TO GAPS IN CARE DUE TO COVID-19	14
RESULTS AREA 4: ALTERED WORK SCHEDULES DUE TO COVID-19 PANDEMIC.....	14
RESULTS AREA 5: PDNS EXPOSED TO AND/OR TESTED POSITIVE FOR COVID-19.....	16
RESULTS AREA 6: FAMILY CAREGIVERS EXPECTATIONS.....	18
FINDINGS C: ONGOING CONCERNS ABOUT THE COVID-19 PANDEMIC AND IMPACT ON GAPS IN CARE	23
RESULTS AREA 7: CONCERNS OF PRIVATE DUTY NURSES.....	23
RESULTS AREA 8: CONCERNS OF FAMILY CAREGIVERS	24
RESULTS AREA 9: CONCERNS OF AGENCY REPRESENTATIVES	26
FINDINGS D: USE OF TELEHEALTH DURING COVID-19 PANDEMIC	28
CONCLUSIONS: IMPACT OF COVID-19 ON PRIVATE DUTY NURSING SERVICES FOR CMC	32
<i>Findings</i>	33
<i>Recommendations</i>	34
ACKNOWLEDGEMENTS	36
APPENDIX A. PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: REPORT LISTING	37

LIST OF TABLES

Table 1. Number and percent of shifts not covered in the six months prior to the pandemic compared to January-June 2021 as reported by family caregivers of CMC.....	12
Table 2. Difficulty in securing PDNs for CMC care as reported by family caregivers	13
Table 3. Shifts worked prior to the COVID-19 pandemic compared to during the current pandemic as reported by PDNs.....	13
Table 4. Reasons PDNs altered their work schedules during the current pandemic.....	14
Table 5. Number and percent of family caregivers informed by agencies that PDNs caring for their child tested positive for COVID-19	17
Table 6. Number and percent of family caregiver respondents' agreement regarding access to PPE.....	20
Table 7. Number and percent of family caregivers refusing PDN assignments in late spring/early summer 2021	21
Table 8. Number and percent of PDN respondents' interested in working but not offered an assignment	23
Table 9. Number and percent of family caregiver respondents' agreement that agency listens to their concerns about COVID-19.....	26
Table 10. Number and percent of family caregivers using telehealth during the current pandemic.....	28
Table 11. Frequency of telehealth visits in the past 12 months by family caregivers for CMC care.....	28
Table 12. Number and percent of telehealth visit types reported by family caregivers.....	29
Table 13. Benefits of telehealth reported by family caregivers.....	29
Table 14. Technology limitations in the home as reported by PDNs.....	31

LIST OF ASSERTIONS

Assertion 1. Agency Representatives said recruiting for PDNs was challenging prior to the COVID-19 pandemic. The current pandemic has made recruitment even more difficult given the lack of face-face outreach with potential PDNs during job fairs and other outreach events; lack of COVID-19 hazard incentive pay; attrition related to higher paid COVID-19 related opportunities in the community (such as vaccination units); and nursing jobs in other settings offering sign-on bonuses.	10
Assertion 2. Family Caregivers reported COVID-19 exacerbated gaps in care they were already experiencing for their children prior to the pandemic, and continues to affect coverage 12-15 months into the pandemic at the time of data collection.	12
Assertion 3. PDNs altered schedules during the pandemic for a variety of reasons, including: additional family obligations that prevented them from working; concerns about exposure to COVID-19 in <i>high risk</i> households; limits they set on the numbers of CMCs they cared for over concerns about contracting and spreading COVID-19; and other personal decisions.	14
Assertion 4. Nurses missed shifts, sometimes for up to one month, after being exposed to and/or diagnosed with COVID-19, thus contributing to gaps in care.	16
Assertion 5. Some Family Caregivers a) did not want new nurses to fill shifts; b) decided to limit the number of PDNs coming into the home to provide care; c) accepted only vaccinated nurses; and d) elected to cancel private duty nursing coverage altogether during parts of the pandemic.	18
Assertion 6. PDNs remain concerned about a) bringing the virus home to their own families and friends; b) the development and spread of virus variants; and c) increased exposure as more and more families circulate.	23
Assertion 7. Family Caregivers remain concerned about the a) unknown effects of COVID-19 if their child becomes infected; b) exposure to new variants; c) possibility of care rationing if a viral surge occurs; d) number of PDNs who come into their home; and e) unvaccinated nurses.	24
Assertion 8. Agencies Representatives remain concerned about the a) shortage of nurses compared to pre-COVID-19 levels; b) increased number of shift openings; c) number of PDNs who are not vaccinated; d) effect of COVID-19 on business practices; and e) costs and business impacts associated with the pandemic.	26
Assertion 9. Some families had a positive experience with telehealth and felt it saved travel time, others did not have a positive experience due to technology issues and feeling like they were asked to make clinical assessments they are not trained to do.	30
Assertion 10. PDNs believe that about half of all homes they work in do not have the necessary technology to participate effectively in telehealth visits.	31

Private Duty Nursing Workforce Capacity Study

Impact of COVID-19 on Access to Private Duty Nursing Services for Children with Medical Complexities

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 surveys and interviews administered to PDNs, Family Caregivers, and Agency Representatives on how the COVID-19 pandemic has impacted access to private duty nursing services for CMC. In addition, this report addresses to what extent private duty

nurses, family caregivers, and agencies are using telehealth during the pandemic. 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 overall 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 hoped 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: COVID-19 AND TELEHEALTH SURVEY AND INTERVIEWS

SURVEY AND INTERVIEW INSTRUMENTS

Subsections of the PDN, family caregiver, and agency instruments (surveys and interviews) were designed to collect data about how the COVID-19 pandemic impacted: a) the ability of the private duty nurse workforce to provide services, and b) families' ability to access needed services. In addition, data were collected about how telehealth was used during the pandemic to access services. The survey questions 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. In-depth interviews across all study populations elucidated the survey findings.

IDENTIFYING THE STUDY SAMPLE, SURVEY DISTRIBUTION, INTERVIEW SELECTION AND PARTICIPANT CHARACTERISTICS

For a detailed description of the PDN, family caregiver, and agency study populations used in this analysis, refer to additional reports from the Private Duty Nursing Workforce Capacity Study. See Appendix A for a full list of reports.

REPORT ORGANIZATION

This report is organized into four sections. The first section addresses the impact of the COVID-19 pandemic on the supply of PDNs. The second section focuses on how the COVID-19 pandemic affected shift coverage. The third section speaks to how COVID-19 is related to gaps in care for CMC. The last section focuses on the use of telehealth during the pandemic from the perspective of the three study populations.

FINDINGS A: IMPACT OF COVID-19 ON THE SUPPLY OF PDNS

Assertion 1. Agency Representatives said recruiting for PDNs was challenging prior to the COVID-19 pandemic. The current pandemic has made recruitment even more difficult given the lack of face-face outreach with potential PDNs during job fairs and other outreach events; lack of COVID-19 hazard incentive pay; attrition related to higher paid COVID-19 related opportunities in the community (such as vaccination units); and nursing jobs in other settings offering sign-on bonuses.

RESULTS AREA 1: FACTORS IMPACTING THE NUMBER OF PDNS ON AGENCY ROSTERS

The study populations identified several factors that directly impacted the number of PDNs on agency rosters due to the COVID-19 pandemic. Three areas are discussed below: recruitment challenges; lack of COVID-19 hazard incentive pay; and PDN attrition for other higher paying COVID-19 related positions.

First, although recruitment is hard “*whether we have a pandemic or not*”, PDN recruitment by agencies lagged due to the COVID-19 pandemic. Prior to the pandemic, some agencies depended on recruiting face-face at job fairs, held open houses (mostly at schools), and posted flyers. With COVID-19, recruitment strategies changed to online scenarios, social media, and television ads. However, not all agencies reported having the ability to finance costly recruitment efforts such as television ads. Some agencies initiated various innovations such as offering monetary incentives to previous employees to rejoin the PDN workforce.

[Agency Representative said] “Recruitment has been a concern for a really long time for [multiple reasons]...whether we had a pandemic or not.”

[Agency Representative said] “One thing that hurt the recruitment process this year is the fact that COVID-19 hit us and we couldn't get out to the schools because they didn't allow us...we didn't get to do all the open houses that we normally do with the schools to get more people to come into home care.”

[Agency Representative said] “We sent out emails to previous nurses who were employed by us...if they do reactivate, we have a reactivation bonus.”

Second, Agency Representatives noted nurses were likely discouraged to join the PDN workforce given that COVID-19 hazard incentive pay was not offered to PDNs, while it often was offered to nurses in other health care settings during the pandemic.

[Agency Representative said] “The main thing with trying to recruit nurses is we can't pay them what they're paid in a hospital. During COVID-19, they were paid a lot more. They were given hazard pay and we could not afford to do that.”

[Agency Representative said] “Other states were able to give hazard pay...we may have gotten some money but that went towards PPE...but that's something that other nurses have asked about, because we're in the tristate area...people have friends that work in other states...Pennsylvania offered hazard pay...and nurses [in Delaware] were saying, ‘Well, what about our hazard pay here.’”

[Agency Representative said] “Regardless of COVID-19, the lack of reimbursement is making it less attractive to be a PDN which creates a larger shortage for our patients especially with trach/vent qualified nurses.”

Aside, for those PDNs who continued to work during the pandemic, some were disgruntled and felt underappreciated about the lack of hazard pay.

[PDN said] “As a PDN working in a pandemic, I think it's disgraceful that...we have been asked to report to work throughout the entire pandemic with no incentive given to the nurses. I feel very underappreciated as a nurse. We deserve more compensation.”

[PDN said] “Nurses did all of this [work] and still got lousy pay and no hazard pay.”

Third, some PDNs left the field during the pandemic due to concerns about their and/or their families' health. Others left to work for higher paying, COVID-19 related jobs, such as working at vaccination units. Others simply left the workforce.

[Agency Representative said] "Nurses are leaving...to go work at a COVID-19 unit making 50 bucks an hour, not at the hospital. They will be giving COVID-19 shots making 50 bucks an hour."

[Agency Representative said] "I would say that some nurses in home health left the workforce when COVID-19 came out, because of their own fear, either of family members or their own personal health risks if they contracted COVID-19. COVID-19 would have been a significant risk to them or their family members. So some of them...just stopped working altogether."

FINDINGS B: IMPACT OF COVID-19 ON SHIFT COVERAGE

RESULTS AREA 2. SHIFT COVERAGE PRIOR TO COVID-19 COMPARED TO DURING COVID-19

Assertion 2. Family Caregivers reported COVID-19 exacerbated gaps in care they were already experiencing for their children prior to the pandemic, and continues to affect coverage 12-15 months into the pandemic at the time of data collection.

Families were asked about coverage prior to COVID-19 in comparison to the most recent six months from the time of survey and interview data collection. Prior to COVID -19, three-quarters of Family Caregivers (24/31; 77.4%) reported shifts were *usually* covered; in the most recent six months during COVID-19 (January-June 2021), the proportion of shifts *usually* covered dropped to two-thirds (19/28; 67.9%). The difference in those who reported shifts were covered about *seldom* or *never* increased from 3.2% (1/31) before COVID-19 to 10.7% (3/28) during COVID-19. See Table 1 for details.

Table 1. Number and percent of shifts not covered in the six months prior to the pandemic compared to January-June 2021 as reported by family caregivers of CMC

Family Caregivers reported...	All of the time	Usually	About half of the time	Seldom	Never
When I think about the 6 months PRIOR to COVID-19, I would say my child shifts were covered...(n=31)	0	24	6	1	0
	0	77.4%	19.4%	3.2%	0.0%
When I think about the last 6 months DURING COVID-19, I would say my child shifts were covered...(n=28)	0	19	6	2	1
	0	67.9%	21.4%	7.1%	3.6%

Note: Percentages may not add up to 100 due to rounding.

Family Caregivers reported COVID-19 magnified the gaps in care at the height of pandemic and continued to affect coverage 12-15 months into the pandemic, at the time of data collection for this study. In some cases, multiple shifts were not covered; in other cases, partial shifts were covered.

[Family Caregiver said] "Well, this year especially...COVID-19 really put a strain on staffing. We have months now where we'll have at least five or six days or seven where we don't have a nurse scheduled."

[Family Caregiver said] "One of the nurses that has been sent to our house only works 6 of the 8 hours that my child is approved."

During COVID-19, families reported agencies simply did not have PDNs to fill the shifts. The following exemplar provides a snapshot of issues related to coverage during the worst of the pandemic.

[Family Caregiver said] "We didn't have any day nurse at all...they didn't work for a good three months or so right at the height of the lockdown. So we didn't have any nursing at all. But they [the agency] also didn't have anybody else. So, it was a combination I think of us being worried, but also [the agency] literally having no one to supply to us, because the nurses weren't working and they couldn't find any new ones."

Three-quarters of Family Caregivers (20/27; 74.1%) continue to report it is difficult to secure PDN service. See Table 2 for details.

Table 2. Difficulty in securing PDNs for CMC care as reported by family caregivers

Family Caregivers reported...	Never	Rarely	Sometimes	Most of the time	Always
It is hard to secure PDNs for my child shifts (n=27)	1	6	11	3	6
	3.7%	22.2%	40.7%	11.1%	22.2%

Note: Percentages may not add up to 100 due to rounding.

RESULTS AREA 3: NUMBER OF PDNS WORKING PRIOR TO COVID-19 VERSUS DURING COVID-19

Of PDNs that worked in the home in late spring/early summer, two-thirds of PDN respondents (87/131;66.4%) reported they were currently working about the same amount of hours caring for CMC in the home as they did prior to COVID-19; however, some PDNs reported working more hours (28/131;21.4%) and some less (16/131;12.2%). See Table 3 for details.

Table 3. Shifts worked prior to the COVID-19 pandemic compared to during the current pandemic as reported by PDNs

PDNs reported....	Frequency (n)	Percent
I am working more hours caring for CMC in the home than I worked prior to COVID-19	28	21.4%

I am working about the same amount of hours caring for CMC in the home as I worked prior to COVID-19	87	66.4%
I am working less hours caring for CMC in the home than I did prior to COVID-19	16	12.2%
Total	131	100.0%

Note: Percentages may not add up to 100 due to rounding.

FINDINGS C: FACTORS THAT CONTRIBUTE TO GAPS IN CARE DUE TO COVID-19

Factors contributing to gaps in care for CMC are explored in this section including: decisions made by PDNs to alter shifts worked; PDNs missing shifts after being exposed to or testing positive for COVID-19; and family expectations about scheduling assignments.

RESULTS AREA 4: ALTERED WORK SCHEDULES DUE TO COVID-19 PANDEMIC

Assertion 3. PDNs altered schedules during the pandemic for a variety of reasons, including: additional family obligations that prevented them from working; concerns about exposure to COVID-19 in *high risk* households; limits they set on the numbers of CMCs they cared for over concerns about contracting and spreading COVID-19; and other personal decisions.

PDNs working in the field made several decisions during the pandemic that affected the number of PDNs available to cover open shifts. PDNs reported they: a) didn't work as much as they wanted to due to personal family obligations (49/130; 37.7%); b) refused to take shifts because they perceived a particular home to be a higher COVID-19 risk (20/131; 15.3%); c) were concerned about contracting COVID-19 (29/124; 23.4%); and/or, d) made personal decisions to cut back on their usual number of shifts at various times during the pandemic (24/122; 19.7%). See Table 4 for details.

Table 4. Reasons PDNs altered their work schedules during the current pandemic

PDNs reported...	Never	Rarely	Sometimes	Most of the time	Always
My personal family obligations prevented me from working as much as I wanted (n=130)	50	31	35	8	6
	38.5%	23.8%	26.9%	6.2%	4.6%
I refused to take some shifts because I perceived the family environment to be a high COVID-19 risk (n=131)	94	17	15	4	1
	71.8%	13.0%	11.5%	3.1%	0.8%
I refuse to take an assignment because I'm concerned about contracting COVID-19 (n=124)	62	33	23	2	4
	50.0%	26.6%	18.5%	1.6%	3.2%

I made a personal decision to cut back on my usual number of shifts due to COVID-19 (n=122)	84	14	18	4	2
	68.9%	11.5%	14.8%	3.3%	1.6%

Note: Percentages may not add up to 100 due to rounding.

PDN survey respondents and interviewees offered further insights into these decisions and other reasons PDNs altered their schedules.

First, PDNs reported they cut back to fewer patients because they were concerned about going into multiple households and potentially exacerbating COVID-19 spread:

[PDN said] "I cut down to two patients because of COVID-19. I don't want to spread [myself] around if somebody had COVID-19."

[PDN said] "There was a little while where I was afraid of bringing COVID-19 into a home because in the beginning, we didn't know how long it was between contraction and infection and showing symptoms."

Second, some PDNs chose their assignments based on their perceptions as to whether the home was a "low risk" home environment where families observe COVID-19 safety protocols, or "high risk" where family members have "risky lifestyles," including those who are vaccine hesitant. Interviewee exemplars offer descriptions of both low and high risk environments and capture why PDNs elect to take a shift or not:

[PDN said] "I personally haven't had any issues with going into the home because the family has been very smart about not going all over the place. Especially when it was bad. They weren't going anywhere. They were worried about their child...[some] families were going out and doing all these things that they shouldn't have been doing...Luckily, I didn't have that issue."

[PDN said] "[I elected not to take a shift because there are] family members who are either unable to get vaccinated or are refusing to get vaccinated or they live a risky lifestyle where they are around people who are not vaccinated."

[PDN said] "My major thing was coming into contact with somebody that I basically have no control over being around because I'm there to take care of somebody in their family and they're just coming and going as they please and they don't really adhere to the policies that were set in place by the CDC."

Aside, some Family Caregivers were aware some PDNs judged them as a "high risk" household; in turn they felt the nurses were not a good fit.

[Family Caregiver said] "For a long time, we kind of felt like maybe our nurses might be judging us a little bit on our socialization. If we had friends over or, if we decided to go somewhere. I felt definitely like some of our nurses were like, 'they're too social. COVID-19 is real and they should stay home'... to which we were just kind of like, 'if this isn't the placement for you, you kind of have to make it [work], because this is our home, this is as personal as it gets.' But that has gotten better."

Some nurses cancelled shifts if the CMC was feverish, leaving Family Caregivers without coverage.

[Family Caregiver said] "As soon as we said they weren't feeling well, [the PDNs] vanished...it happened several times. You're basically saying, 'Oh, your patient is sick, so I'm not going to come to work.'...so that's something that we also run into during COVID-19, and they blamed COVID-19 for that."

While some PDNs made decisions to cut back on shifts as noted above, other PDNs took on extra shifts during the height of the pandemic.

Nurses who worked during the pandemic increasingly found themselves encumbered with additional roles and responsibilities given that outside activities were cancelled and/or changed to a virtual format for the child. This included supervising school and therapies being directed by an online teacher or therapist. Some PDNs felt increasingly exhausted due to the multiple hours.

[PDN said] "During COVID-19 we became the physical therapist, occupational therapist, teacher and we're shut up in the home for 9-12 hours while wearing full PPE. We had to learn to log into multiple school sessions and perform therapy while being directed by the on-line teacher/therapist. Our nursing duties for the child were increased as doctors and hospitals were at their capacity."

[PDN said] "Our load has become greater... my whole body is exhausted...I just wanted fresh air. Because of this, my family suffered and my physical and mental health suffered."

RESULTS AREA 5: PDNS EXPOSED TO AND/OR TESTED POSITIVE FOR COVID-19

Assertion 4. Nurses missed shifts, sometimes for up to one month, after being exposed to and/or diagnosed with COVID-19, thus contributing to gaps in care.

In addition to the four factors listed in Table 4, two additional factors limited the number of shifts filled including some PDNs a) stopped working for a period of time after they were exposed to, tested positive, and/or were symptomatic for COVID-19; and b) could not take their usual PDN shifts because they were busy filling shifts at their fulltime job in the hospital.

The following exemplars capture the challenges to fill open shifts as it relates to testing, contact tracing, positive COVID-19 test results.

[Family Caregiver said] "COVID-19 threw a loop into some things, because a few nurses had COVID-19...they would be out for a month or more...that was hard, but we really don't have new nurses that much. If we bring on a new nurse, then somebody [would need] to train them."

[Agency Representative said] "If you have a positive [exposure] for a PDN, [you] have to wait to go get tested and get results and be cleared to return to work...this put a dent in the workforce. [It] also made it challenging for staffing as well, and dealing with the satisfaction of a caregiver of being able to cover their case, because then they couldn't go to work if we couldn't show up."

[PDN said] "If you did have any COVID-19 symptoms, [the agency] had a COVID-19 team that would contact you. Everyone was contacted anytime there was any question whether there might be a COVID-19 situation."

Note that it is unclear how agency policies changed overtime with respect to COVID-19 exposures and the effect such policies had on shift coverage. Approximately 7/32 (21.9%) families reported that their agency informed them that a PDN taking care for their child tested positive for COVID-19. See Table 5 for details. Family Caregivers appreciated the transparency of the agencies, however, also noted occupational health policies changed overtime. For example, initially an agency's policy was to wait until the nurse tested negative, however Family Caregivers said that policy, and others continued to change overtime.

[Family Caregiver said] "Recently we had a nurse who was symptomatic. The manager of private duty called before their shift began and [explained the situation] ... I would say [the agency] has done a good job with handling COVID-19 [testing] and being transparent."

[Family Caregiver said] "They didn't know what the heck to do [when a PDN tested positive]. They had no idea. When one nurse got COVID-19, they were like, 'oh, okay, she's not allowed to come back until it's negative.' But then that procedure went by the wayside. I feel like with COVID-19 nobody knew what to do...we were all just figuring it out as it came [along]."

While Family Caregivers were told if their nurse tested positive for COVID-19, Family Caregivers didn't necessarily know if their nurse was exposed to COVID-19 in other work settings or homes.

[PDN said] "The family knew this isn't the only house I work in...but [we were told] by the agency that it was a HIPAA violation to tell other families."

COVID-19 funds were available for PDNs who became infected with COVID-19, however accessing funds was a challenge according to PDNs as described below:

[PDN said] "They have a COVID-19 fund...and it is [available] if [exposure] could be directly traced only to a patient who had COVID-19...but the way it worked, the [agency] would say, 'Were you wearing your N95? Were you wearing your gloves? Were you wearing your goggles?' And if you say 'yes' to all the PPE questions...the [agency] says, 'Okay, we consider you have not been exposed.' If you said 'I didn't have my goggles on', then they would say, 'Well, then you didn't comply with our regulations, so we can't give you any assistance because you are non-compliant.'"

Table 5. Number and percent of family caregivers informed by agencies that PDNs caring for their child tested positive for COVID-19

Family Caregivers reported...	No	Yes	I prefer not to answer
	24	7	1

Has your agency ever notified you that a PDN who has taken care of your child has tested positive for COVID-19 (n=32)	75.0%	21.9%	3.1%
---	-------	-------	------

Note: Percentages may not add up to 100 due to rounding.

RESULTS AREA 6: FAMILY CAREGIVERS EXPECTATIONS

The COVID-19 pandemic altered Family Caregivers expectations about how assignments were made, creating challenges for agencies to back fill shifts.

Assertion 5. Some Family Caregivers a) did not want new nurses to fill shifts; b) decided to limit the number of PDNs coming into the home to provide care; c) accepted only vaccinated nurses; and d) elected to cancel private duty nursing coverage altogether during parts of the pandemic.

Early on in the pandemic, many Family Caregivers asked agencies to work with them to have consistent staff who were oriented and trained on their child’s case so as to limit the number of PDNs coming into the home. In addition, as vaccines became available, some families requested all nurses assigned to care for their child be vaccinated. Last, in some cases, families elected not to have nurses come into the home. The following exemplars capture types of Family Caregiver requests and the rationale for the request(s).

Families requested stable, consistent care from PDNs who are oriented and trained on their child’s case.

[Family Caregiver said] “We would like to be the first case of [the PDN’s] day, because they have to travel case to case...[PDNs] can work for multiple different agencies... they could be coming from a different case to yours...that’s something that we wanted right away not to have happen.”

[Family Caregiver said] “I didn’t eliminate nursing, but I restricted a little bit for [my child’s] exposure....and with that being said, that cuts me back on who’s trained to come here...and how many times I want somebody to come here. During COVID-19, I would have one nurse one night, a different nurse another night, a different nurse another night. And it was like, I had too many people coming in and out of the house that could possibly bring COVID-19 to [to my child].”

[Agency Representative] “Most parents do not [want someone new/unfamiliar], especially with COVID-19...they want it to be someone that they had at a meet-and-greet and was oriented [and trained].”

Families expected nurses to have personal protective equipment.

Families were concerned about nurses coming into their home without personal protective equipment (PPE).

[Family Caregiver said] "As far as what they were doing to help protect us once we did get nursing back in, not a thing, not a thing. They never provided any masks. I have provided every single mask that every nurse has ever worn in this house. They don't provide gloves. They don't provide sanitizer. They don't provide crap. I provide it all...and even when masks were a \$100 for a box of 50 at that height of the pandemic, instead of \$8 for a box of 50, I still paid that. Because I felt like it had to be done in order to have somebody in this house."

Although families wanted nurses to come to the home with adequate PPE, early in the pandemic it was difficult to access supplies. PDNs reported supplies were prioritized to hospital settings first and home health care agencies were the last to receive supplies. In the meantime, PDNs were asked to wear the same mask across all cases for multiple days in a row. Some PDNs purchased their own supplies.

[PDN said] "Unfortunately in the very beginning, we did have a mask shortage where we had to use the same mask for several different clients over several different days. And for somebody that only has one patient, that might be okay. But I sometimes see a different client every day. So infection control, that was not very good, but there was no other choice because there just weren't supplies."

[PDN said] "Supplies went to the hospitals where COVID-19 was, but there were no supplies that went to home health agencies...and it was something that I heard about not just from my co-workers, it was across the United States that home health agencies were just forgotten about. So I actually [purchased supplies] out of pocket...I order [masks] online so that I could maintain safety measures."

[Agency Representative said] "I think the worst part was not having enough supplies at times, and that was an overall...it was a world problem where there weren't enough pieces of PPE to protect everyone the way we would like to have done. So they're reusing masks when we would prefer to not have done that."

[Agency Representative said] "In the beginning when we gave surgical masks out, we gave one surgical mask and a paper bag. We said, 'This is your mask until indefinitely. We don't know how long you're going to have to use it for.'"

Later in the pandemic, some PDNs noted their agency(ies) had adequate supplies, communicated frequently with staff, were always available to address concerns, were proactive with vaccine dissemination efforts, and instituted wellness checks at the beginning of the shift.

[PDN said] "[My agency] called each of the nurses personally to ask if they had any concerns...offered to help...made sure that everyone had masks when masks were in short supply...[made sure] supplies were at the home...conducted daily briefings through a YouTube channel to explain the CDC recommendations...answered any questions...I've always been able to call them with anything."

[PDN said] “They [the agency] were calling us pretty often. We'd get text messages every day, asking us if we have any symptoms. Making it so that we can be open and have an open communication about if you were exposed or if you're having symptoms...they couldn't have been any nicer about everything and calling to check on me and making sure that I was okay and that kind of thing.”

Although Family Caregivers noted PDNs had access to PPE, different agencies appeared to have access to different types of PPE and different policies for use.

[Family Caregiver said] “Shortly [after COVID-19 hit] it seemed like there was a little bit of a ramp up and people started wearing masks and face shields...and there, I noticed some differences amongst the agencies. So some only required a mask and some required the mask and the face shield. I don't think at the beginning, but somewhere in there, they also started doing [screening] calls [for symptoms]. And they still do this to this day”

[Family Caregiver said] “They had PPE that they brought in. I mean, I'm sure it was a kind of fly by the seat of your pants of trying to figure it out at the time. So there were some changes along the way, but they all came with personal PPE that they were supposed to wear like face shields, masks, eye glasses and that kind of stuff...[sometimes] one agency needed their people to wear an N95 or some sort of higher PPE.”

At the time of the data collection for this study, a majority of Family Caregivers (22/27; 81.5%) reported their agency provided all of the necessary COVID-19 protection supplies, however, 5/27 (18.5%) Family Caregivers noted supplies were sometimes/rarely provided by the agency. See Table 6 for details.

Table 6. Number and percent of family caregiver respondents' agreement regarding access to PPE

Family caregivers reported in late spring/early summer	Never	Rarely	Sometimes	Most of the time	Always
My child agency provides all of the necessary COVID-19 protective supplies such as masks and gloves for the PDNs who provide care for my child (n=27)	0	4	1	3	19
	0.0%	14.8%	3.7%	11.1%	70.4%

Note: Percentages may not add up to 100 due to rounding.

Some families elected to stop private duty nursing care in 2020 and/or 2021 due to COVID-19 pandemic.

When stable, consistent nursing care was not available and/or families were concerned about multiple people coming into the home, some families elected to stop private duty nursing care altogether. Agency representatives observed this sometimes placed excessive burdens on the families leading to “burnout, frustration, anger.”

[Family Caregiver said] “We pulled nursing...all of our nurses just quit...except one... and they only worked one or two shifts a week instead of more...but they stopped nursing for a couple months as well...we really had no one else [all of last year].”

[Agency Representative said] "Some families, because of the fear and already being that the patient is compromised health wise, some families took the stance, 'We'll take care of this, because we don't want to bring COVID-19 to our loved one.' And then they do it for a while...and they're experiencing burnout, frustration, anger."

In late spring/early summer, over two-thirds of Family Caregivers (19/27; 70.4%) accepted PDNs assigned to their child's case; however, there were still times when Family Caregivers refused to accept the PDN assigned due to concerns about exposure to COVID-19 (8/27; 29.6%). See Table 7 for details.

Table 7. Number and percent of family caregivers refusing PDN assignments in late spring/early summer 2021

Family Caregivers reported...	Never	Rarely	Sometimes	Most of the time	Always
I have refused to have some PDNs provide care for my child because I was concerned about exposure to COVID-19 (n=27)	17	2	5	1	2
	63.0%	7.4%	18.5%	3.7%	7.4%

Note: Percentages may not add up to 100 due to rounding.

Some families request vaccinated nurses only.

Gaps in coverage occurred when families requested vaccinated nurses be assigned to care for their children.

[Family Caregiver said] "I had two nurses and they were the only two I had at the time. I had to let them go because even though they were both very good, but they were never going to be vaccinated. They were on the anti-vaccine train. I was shocked our agency did not tell us that they do not require nurses to get the vaccine...They never told anybody, 'Hey, ask your nurse if they're going to be vaccinated because we do not require it'...we pulled them...and were several weeks without nurses [as we waited for new nurses]."

In order to meet the demand for vaccinations, some PDNs reported their agency(ies) was proactive in offering vaccinations and information about how to access the vaccine(s).

[PDN said] "They jumped hoops to get everyone vaccinated...anyone who wanted to get vaccinated...we were constantly getting, 'There's such and such. You can go to this place or that place,' ...as soon as we were able to get vaccinated...[the agency] offered rides and were willing to take nurses [to be vaccinated]."

One agency reported providing monetary incentives for their PDNs to get the COVID-19 vaccine in order to meet demands, protect staff and clients, and cut back on shifts missed due to illness.

[Agency representative said] "[Our agency] is paying if you receive a vaccine, you get one, you get \$50. You get two, you get \$100...[we] are paying, [we] feel we are paying for the time that it may take them away from their job."

Agencies are challenged to find nurses that meet family expectations.

Sometimes when a PDN left a case(s) or cut back hours, it was difficult for agencies to find PDNs trained on the case as well as to honor other Family Caregivers requests, such as only wanting PDNs who did not have young children at home or nurses who were vaccinated. When Family Caregivers elected not to have PDNs in the home, agencies found it stressful to maintain the necessary revenue flow to cover business expenses. The following exemplars capture some of the challenges from the agency point of view:

[Agency Representative said] "I will say COVID-19 has been a big deterrent for us in regards to backfilling shifts at times, because families didn't want multiple caregivers in and out of their home with the COVID-19 situation."

[Agency Representative said] "A lot of parents are very selective with the nurses. We have a lot of unfilled hours now because of COVID-19. Parents don't want certain people ... They're very selective."

[Agency Representative said] "Especially since COVID-19, the [caregiver] does not want a nurse that has kids."

[Agency Representative said] "The family may have some real specific requests...like right now, some families are only taking vaccinated nurses."

[Agency Representative said] "It's been very stressful trying to maintain family caregiver/CMC clients, because some clients didn't want to have a nurse come into their home."

[Agency Representative said] "Families feel like we should be in control of where these nurses work and we're not...I always have to say to them, 'I don't know if they have another job' because that's not what we do. We don't ask our nurses, 'Hey, are you working at the nursing home? I mean because the [family] doesn't want you if you worked at a nursing home because they feel that you may get COVID-19,' so I think that's one of the downfalls in home care right now."

The usual procedures some agencies use to orient and train nurses prior to coming into the home was interrupted due to COVID-19.

[Agency Representative said] "Before COVID-19, we could send nurses to the hospital and meet the family, and meet the kids in the hospital. We can't do that now with COVID-19."

Some agencies reported nurses were available to work, however creating schedules to accommodate a family caregiver's expectations and concerns was challenging.

[Agency Representative said] "Nothing changed with availability...but restrictions that COVID-19 brought, yes...they were still available to work, but some clients took the stance that, 'No, it's okay. We'll handle this'...the [family caregivers] wanted the same nurse...I had to actually start telling nurses, due to COVID-19, the family doesn't want [them]...they don't want too many nurses [in the home]."

[Agency Representative said] "Nurses were available...but families themselves were fearful and backed off."

This finding may explain why some PDNs reported they wanted to work, but their agency did not have enough shifts for them (26/123; 21.1%). See Table 8 for details.

Table 8. Number and percent of PDN respondents’ interested in working but not offered an assignment

PDNs reported...	Never	Rarely	Sometimes	Most of the time	Always
I wanted to work but my agency did not have enough shifts for me (n=123)	76 61.8%	21 17.1%	20 16.3%	6 4.9%	0 0.0%

Note: Percentages may not add up to 100 due to rounding.

FINDINGS C: ONGOING CONCERNS ABOUT THE COVID-19 PANDEMIC AND IMPACT ON GAPS IN CARE

At the time of data collection, study populations were asked to reflect on concerns as they relate to the COVID-19 pandemic, and in particular those that are likely to impact the health and wellbeing of CMC and results in gaps in care. Concerns are shared below by study population.

RESULTS AREA 7: CONCERNS OF PRIVATE DUTY NURSES

Assertion 6. PDNs remain concerned about a) bringing the virus home to their own families and friends; b) the development and spread of virus variants; and c) increased exposure as more and more families circulate.

As of late spring/early summer, PDNs remain concerned about the COVID-19 pandemic, even though they use PPE when working in the homes. They are concerned about the development and spread of virus variants and the increased exposure as more and more families began to circulate outside of the home.

[PDN said] “We’re [using] all the PPE that we’re supposed to but we may be in the home when they’re having company over [and they don’t use masks]...that’s my biggest concern now just because I’m vaccinated so I feel pretty safe but that’s probably my biggest concern.”

[PDN said] “Especially right now today with everybody going out in public now not masked and not necessarily vaccinated, that the parents who aren’t vaccinated or family members who are not vaccinated, families having more gatherings, that there might be more exposure. There’s actually a higher risk of exposure than there might’ve been prior to this when everybody was staying home or using masks and things like that.”

[PDN said] “I’m as safe as I can be in [the home], but there’s no telling if I’m bringing it out with me.”

[PDN said] “I feel like things are being laxed but we’re really not where we should be to be laxed yet. We don’t have immunity yet. We’re dropping a lot of precautions in public... so that’s my biggest concern.”

[PDN said] "Bringing it out to my family. I mean, you wear your PPE, but there's so much unknown in terms of COVID-19 and the variants, and if you're really safe or not and if people have been vaccinated or not. That's my fear, just spreading it to someone else."

[PDN said] "Thankfully, all of my clients have received the vaccine, one cannot because of their age. So it at least puts me a little bit more at peace that they're fully vaccinated."

Agency Representatives agreed PDNs have ongoing concerns about exposure in the home, in spite of having PPE and following other public health guidelines.

[Agency Representative said] "I'm not necessarily worried about the safety of my staff, because I feel like we've been through this long enough that we're at a point where we have the proper PPE now. We have the masks. We have the mandates. We tell people what to do. However, I feel like the [nurses] are still hesitant sometimes to be in a patient's home where you don't know who's in and out of that home and who they're exposed...and that is still a concern for in general."

RESULTS AREA 8: CONCERNS OF FAMILY CAREGIVERS

Assertion 7. Family Caregivers remain concerned about the a) unknown effects of COVID-19 if their child becomes infected; b) exposure to new variants; c) possibility of care rationing if a viral surge occurs; d) number of PDNs who come into their home; and e) unvaccinated nurses.

Exemplars specific to each of the issues noted in the assertion above are provided below.

Family Caregivers worry their child may become infected with COVID-19 or a variant.

Family Caregivers reiterated they worry about the health and safety of their child and the unknown consequences if their child became infected with COVID-19, as captured by the following exemplars:

[Family Caregiver said] "The biggest thing, ideally, is we'd like to make sure that COVID-19 doesn't come into the home...we are vaccinated...most of the nurses come in with their mask on. The few that I've had concerns with, I've let them know directly and I've also reached out to their manager and said, 'They're not masking appropriately.' I think any of us that have a medically complex child, we don't know how they would respond or react or how their bodies would deal with COVID-19. That's the unknown part."

[Family Caregiver said] "[My concern is] probably the same as everyone else's. My child is medically complex. I mean...I don't have any frame of reference, so it's kind of just the unknown...we are vaccinated...but we have [another child]...can they give it to their sibling? At this point, we kind of got to deal with it."

[Family Caregiver said] "I'm worried that there are all these new COVID variants that seem to be popping up now...And it doesn't seem like there's a great understanding of whether we're all going to need to be re-vaccinated annually or maybe it needs to be more often than that...I'm just worried that it's going to keep lingering on and it's going to be sort of a continual issue where I'm worried that [my child] is going to get infected."

[Family caregiver said] "[I'm worried about] a variant...and another variant that we have to deal with."

Family Caregivers worry health care rationing will impact the care their child receives if their child becomes sick.

A fear that won't go away for some caregivers is the notion that if their child becomes sick and needs acute care, will there be care rationing similar to what was reported in the news.

[Family Caregiver said] "Care rationing is my biggest concern...I find that terrifying...like what happened in Italy and what started to happen in California, where they do triaging based on your likelihood of survival, right? If it came down to my kid versus a healthy kid getting a ventilator, would they skip my kid [and give it to] the healthy kid? Who's more likely to survive?"

Family Caregivers remain concerned about multiple nurses coming into their homes.

Family Caregivers hope the PDNs who come into their home are "being responsible." They continue to remain concerned about multiple nurses coming into the home, particularly as activity restrictions are lifted across the state.

[Family Caregiver said] "You just have to trust that [the PDNs] are being responsible out in the world and not be coming in situations where they're going to be infected. But with all the restrictions being lifted, now it's almost scarier than it was a year ago. Because at least a year ago everybody really thought they were going to die if they breathed anybody else's air. So nobody went anywhere, nobody did anything, and now everything's open and everybody's going everywhere and going and doing everything with no mask. And you know, it's a little bit scary."

[Family Caregiver said] "My biggest concern in terms of COVID-19...is exposure to many different staff. That's a really, really important part of transmission obviously. And we all know that the less contact that you have with multiple individuals, the better statistically you will be in terms of contracting the virus...multiple staff members have multiple patients...and then those multiple patients have multiple family members, so it is a compounding effect. So really consistency of staffing I think is really important."

[Family Caregiver said] "So, we worked really hard in making sure that [my child] stayed negative with COVID-19. And for [my child] to possibly get it now is an actual shame if they do get it, because we worked so hard in preventing it for them."

[Family Caregiver said] "My biggest concern right now, is that as tired as we all are of being stuck inside and wearing masks, that it's just not time yet to start treating this as business as usual, which is really how it feels, starting to feel now."

Family caregivers remained concerned that unvaccinated nurses might be assigned to care for their children.

Family Caregivers remain concerned about unvaccinated PDNs assigned to care for their child. Some Family Caregivers believe a COVID-19 vaccine should be mandatory for all PDNs.

[Family Caregiver said] "It's too big of a risk to have nurses in the home that are not vaccinated...at a time when two new variants of COVID-19 are coming around the country."

[Family Caregiver said] "The [agency] doesn't tell me necessarily if anybody has or has not been vaccinated. I don't think that's information that they can really share, but most of the nurses personally have shared with me that they have been vaccinated, when they were or they were going through the process or whatever. They've all been pretty forthcoming with that. I think, maybe, we've only had one or two people that are like, 'Nah, I don't think I'm going to do it,' and then I think they ended up doing it anyway."

[Family Caregiver said] "Vaccination rates...that's my biggest fear is that there's too much misinformation about vaccines out there, and so the vaccination rate is just not high enough. So, that being said, are we ever going to get to a place where it's truly safe again? Like they've had this change in the mask policy lately, where if you're vaccinated you don't have to wear your mask, and it seems to me that that means the vaccination rate must be at least 90%, because most people aren't wearing their masks anymore. But I know that the data says that's not true... that is just open season for this virus to get another foothold, and it's only a matter of time before [the virus] evolves the means to fight against the vaccines that are in place."

[Family Caregiver said] "Nurses should be required to receive the COVID-19 vaccine."

Although they have multiple concerns, two-thirds of Family Caregivers (18/27; 66.7%) acknowledged their agency listens to their/their child's concerns about COVID-19 and tries to work with them. See Table 9 for details.

Table 9. Number and percent of family caregiver respondents' agreement that agency listens to their concerns about COVID-19

Family Caregivers reported...	Never	Rarely	Sometimes	Most of the time	Always
The agency listens to my/my child's concerns about COVID-19 (n=27)	1	1	7	8	10
	3.7%	3.7%	25.9%	29.6%	37.0%

Note: Percentages may not add up to 100 due to rounding.

RESULTS AREA 9: CONCERNS OF AGENCY REPRESENTATIVES

Assertion 8. Agencies Representatives remain concerned about the a) shortage of nurses compared to pre-COVID-19 levels; b) increased number of shift openings; c) number of PDNs who are not vaccinated; d) effect of COVID-19 on business practices; and e) costs and business impacts associated with the pandemic.

The following exemplars capture Agency Representatives' concerns in each of the areas.

Shortage of nurses compared to pre-COVID-19 levels and number of shift openings.

First, Agency Representatives shared that there is a shortage of nurses compared to pre-COVID-19 levels, resulting in increased shift openings.

[Agency Representative said] "This has been...the worst nursing shortage I have seen in years. COVID-19 has changed people's mindset with where they want to work."

[Agency Representative said] "There are still numerous clients out there that don't get services for one reason or another whether they're not in school or their primary caregiver's home because they're not working."

[Agency Representative said] "As of this time [i.e. May and June 2021] we're still not 100% staffed, in the field...we have more openings than we have ever had."

Shift openings may be related to a shortage of PDNs, however, Agency Representatives note shift openings are also related to Family Caregivers who remain selective about the PDNs who are assigned to care for their child.

[Agency Representative said] "Parents don't want a ton of nurses, and I think that's going to stay with us for a while. I don't think that's going to change, which is unfortunate. But I'm hoping things get back to normal as the summer [progresses]."

Challenges to have nurses vaccinated.

Agencies feel they are in a bind to ask if their PDNs are vaccinated given HIPAA regulations, even though Family Caregivers want to know if the PDN assigned to their child's case is vaccinated.

[Agency Representative said] "The biggest concern I think I have now for home care is the change that has come about with people not wanting that many nurses in their homes due to COVID-19 or people asking if the nurses are vaccinated."

[Agency Representative said] "You give information about vaccines...but with HIPAA you can't ask PDNs without permission...that is my biggest concern...the number of nurses that still don't have a vaccine or don't want them, I think that was a little alarming and a little challenging."

Continued costs and business impacts associated with the pandemic.

There are continued costs associated with COVID-19 that impact recruitment efforts and wages agencies can offer to PDNs.

[Agency Representative said] "We do have vaccines for our PDNs...and there are plenty of other people that may be vaccinated in the home, that's the good side of it. We are still doing screenings and say, 'Do you have a fever or you have a little head cold? Do you have allergies acting up, because you're going to fail a screening and we're not going to be able to staff.' So there's still that precaution that's going on out there...We still are wearing masks, N95s and so on, and taking all those PPE precautions...that has not changed...there is that expense and cost."

[Agency Representative said] “We are going to be feeling the residual effects...for a long time. Business costs and loss impacts the ability to invest in recruiting...it's kind of like a domino effect...and our ability to pay nurses.”

[Agency Representative said] “[Working] has been very stressful...we have rebounded somewhat, [but] not enough.”

Continued fear of spreading and or contracting COVID-19 will continue indefinitely.

According to Agency Representatives, the fear of spreading and/or contracting COVID-19 has not changed overtime and will likely continue indefinitely. As with other study populations, Agency Representatives also remain concerned about possible variants.

[Agency Representative said] “You're taking care of a very fragile and vulnerable population, that if they contracted COVID-19, they very well could die...and so that has been a great fear of many of the [PDNs] who are providing the care directly, and it's a great fear of the family members.”

[Agency Representative said] “Now people are going back to work and I think there's still a fear out there whether you get the shot or not or...it's a fear, and I think fear is a terrible thing to have. You can't run your life.”

[Agency Representative said] “I am concerned about the other strains, concerned about what are we looking at in the fall? Are we looking at another upsurge?”

FINDINGS D: USE OF TELEHEALTH DURING COVID-19 PANDEMIC

This study also examined to what extent and in what ways private duty nurses and families of CMC utilized telehealth services during the pandemic.

Nearly three-quarters of family caregivers (23/32; 71.9%) used telehealth to access services for their child since the COVID-19 pandemic began in March 2020. Of those, about half used telehealth at least once a month or more (11/23; 47.8%). See Tables 10 and 11 for details.

Table 10. Number and percent of family caregivers using telehealth during the current pandemic

Family Caregivers reported...	No	Yes
Have you or your PDN used telehealth services for your child since the COVID-19 pandemic began in March 2020? (n=32)	9	23
	28.1%	71.9%

Note: Percentages may not add up to 100 due to rounding.

Table 11. Frequency of telehealth visits in the past 12 months by family caregivers for CMC care

Family Caregivers reported...	Frequency	Percent
Every day	1	4.3%
Several times a week	3	13.0%

Several times a month	2	8.7%
About once a month	5	21.7%
Several times a year	8	34.8%
Other, please specify	4	17.4%
Total	23	100.0%

Note: Percentages may not add up to 100 due to rounding.

Telehealth was used most frequently by Family Caregivers with their children for consultations with physicians/nurse practitioners/physician assistants (21/74; 28.4%), followed by consultation/care provided by therapists (17/74; 23.0%), and assessments by case managers associated with insurance companies (15/74; 20.3%). Telehealth was used less frequently for care team meetings, case reviews by agencies, and/or consulting staff regarding test results (e.g., laboratory or clinical tests). See Table 12 for details.

Table 12. Number and percent of telehealth visit types reported by family caregivers

Family Caregivers reported...	N	Percent of Responses
Participating in a care team meeting	9	12.2%
Consulting a MD or nurse practitioner/physician assistant	21	28.4%
Consulting a therapist for my child (e.g., speech, physical, occupational, other)	17	23.0%
Consulting staff regarding test results (e.g., laboratory or clinical tests)	5	6.8%
Assessment by my case manager from Highmark or AmeriHealth	15	20.3%
Care review by the nursing supervisor from my child agency	6	8.1%
Other	1	1.4%
Total	74	100.0%

Note: Percentages may not add up to 100 due to rounding; multiple response variable.

The majority of Family Caregivers agreed/strongly agreed there are benefits to using telehealth, including decreasing their own anxiety when caring for their child (21/31; 67.7%) and acknowledging telehealth may reduce the need for their child to be hospitalized (22/31; 71.0%). See Table 13 for details.

Table 13. Benefits of telehealth reported by family caregivers

Family Caregivers reported...	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
	7	3	9	12

Access to telehealth may lessen/lessens my anxiety when caring for my child (n=31)	22.6%	9.7%	29.0%	38.7%
Telehealth could potentially reduce/has reduced hospitalizations for my child (n=31)	5	4	14	8
	16.1%	12.9%	45.2%	25.8%

Note: Percentages may not add up to 100 due to rounding.

For some, the telehealth experience was positive. During consultations, staff were thorough and took their time.

[Family Caregivers said] "I being able to really sit there and talk [with the health care provider] and have a conversation. And I didn't feel like the next person was waiting in line, so I better hurry up. It was nice. You can have like a good conversation."

Some Family Caregivers indicated they had wanted to use telehealth in the past (prior to COVID-19) but insurance companies didn't always cover telehealth visits.

[Family Caregivers said] "I wanted telehealth before [COVID-19], especially since a lot of the time that I went up there, it was to have a visit where they said, 'Oh, he's okay. You can go home now.' And I'm like, 'I wasted an hour and a half coming up, an hour and a half going back, a half an hour in there so that you can tell me what I already know.' And they weren't using telehealth, because they said that insurance wouldn't pay for it."

More than one family agreed they would use telehealth visits in the future if the option was offered. Families noted that telehealth saved the family from driving a long distance for care visits.

[Family Caregivers said] "I found them to be very thorough and obviously it saved me a three-hour commute that day. So it was less stressful for myself, less stressful for my child. And I really felt like they were able to take more time with us."

Assertion 9. Some families had a positive experience with telehealth and felt it saved travel time, others did not have a positive experience due to technology issues and feeling like they were asked to make clinical assessments they are not trained to do.

Some families did not have a positive experience due to technology issues.

[Family Caregivers said] "Half the time we can't see the provider. They could see us, but we couldn't see them. So we're trying to show them our kid, and they're telling us go left, go right, but we can't see them on the screen."

Other Family Caregivers were asked to perform clinical assessments they did not feel comfortable with and for this reason, felt it is important to see the provider in person.

[Family Caregivers said] "The physicians asked us to feel our child's abdomen and look for different things...I just have no idea what I'm feeling for or anything...I would rather them be able to examine my child in person and just have the peace of mind that way."

During COVID-19, some PDNs working in the homes observed how telehealth was used for CMC care, particularly for therapy visits. In some cases, the PDNs worked with the child during the therapy sessions. While PDNs felt telehealth was often the best option during the height of COVID-19, many did not feel children were getting the services they needed.

[PDN said] "It can be very frustrating and I don't think necessarily the children are getting the best experience and getting their OT, PT, and speech needs met the best."

[PDN said] "The other big thing was not being able to have therapies in the house. We had to do it via telehealth. With a young child and a parent who works ... Yes, his parents were home, but they couldn't be there every time...having to use my phone to try to do telehealth with a child who walks and is moving around constantly and trying to do it, it's just so hard. I didn't feel as though all therapists were great about it. They understood. Some of them weren't. It just depended on the therapist."

PDNs that were involved in service delivery for various therapies were thankful they were no longer responsible for therapy.

[PDNs said] "Now that they're coming in the home, it's so much better and I feel like it's actually doing something for them whereas I felt like telehealth, I don't know that it was doing anything for them...Especially with OT and PT...I don't know if I was doing those stuff right...You're telling me how to do it, but I'm not an OT or a PT."

Not all PDNs participated in telehealth therapy sessions. Some were asked by their agencies not to serve in that role and the session required the parents' involvement.

[PDNs said] "I've actually enjoyed and thought it was good to have the therapies by Zoom like physical therapy and occupational therapy. I really think that works really well by Zoom for the patients. The parent has to be there to do it with them. I'm not allowed to do it with them, but I think that's a really good thing. And I think maybe if the nurses were allowed to participate in the therapy, that would be good as well."

Assertion 10. PDNs believe that about half of all homes they work in do not have the necessary technology to participate effectively in telehealth visits.

Access to technology is an important requirement for effective telehealth. PDNs believed about half of all homes they worked in (61/135; 45.2%) did not have adequate technology. See Table 14 for details.

Table 14. Technology limitations in the home as reported by PDNs

PDNs reported...	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
In the homes of CMC where I work, access to technology limits (or would	35	39	50	11
	25.9%	28.9%	37.0%	8.1%

limit) the use of video conferencing (n=135)				
---	--	--	--	--

Note: Percentages may not add up to 100 due to rounding.

Some agency representatives saw benefits to using virtual appointments with families for the required agency supervisory visits and recertification visits.

[Agency Representative said] “Our ability to complete re-certification visits and supervisory visits virtually helped immensely. I feel [the family] felt more comfortable [rather] than a nurse clinical supervisor doing a visit who has been in multiple homes...it kept [family caregivers] from worrying they were going to bring something from one home to another. I believe that helped a lot because we were able to just get on a telehealth visit, talk through whatever was going on, and then not have to be physically in the home...that was a huge plus.”

[Agency Representative said] “Parents who did not want our clinical managers even to come into the home. So the clinical managers would do a virtual telehealth visit, observing the client and the nurse in the home and asking questions, doing their assessments that way... It was very helpful to at least be able to touch base virtually.”

On the other hand, some agencies did not feel comfortable conducting virtual visits and continued to conduct in home visits during COVID-19. They feel it is necessary to see the patient, the home, and the chart.

[Agency Representative said] “During COVID-19 we went out to see everybody. We continued to go out, we did not stop going out [to the homes]. I can't use telehealth...How do we know [what is going on] about our patient if we're using telehealth? That kind of messed up a lot of people with this telehealth.”

[Agency Representative said] “I liked it, and I don't like it...a lot can be hidden on a Zoom call, because you can only see what I show you. So, that's part of it...and we don't get to see the actual chart...we're looking at it through a screen versus actually being able to flip through. For scheduling purposes, we can grab families when they're available, and it helped in that aspect.”

Aside, some Agency Representatives believe virtual platforms are an efficient mechanism to work with PDNs. Other than signing paperwork and completing competency reviews, everything can be done virtually with PDNs including interviews, orientation, and most trainings.

CONCLUSIONS: IMPACT OF COVID-19 ON PRIVATE DUTY NURSING SERVICES FOR CMC

This study provides a snapshot of challenges in providing care for children with medical complexities during the ongoing COVID-19 pandemic from the perspective of Family Caregivers, PDNs, and Agency Representatives. Specifically, the study offers insights into how the COVID-19 pandemic impacted the ability of agencies and PDNs to offer services and family caregivers to access care for CMC over the last 12-15 months.

This study asked participants about their experiences in the midst of the COVID pandemic while state-wide containment efforts were enacted (and continually changing) including stay at home policies, social distancing policies, guidance for travel, healthy business operations, and hazard assessments. While some Family Caregivers, PDNs, and Agencies Representatives look forward to transitioning toward normalcy, there is little indication, based on the findings of this study, that PDN services and the ability to access care for their children have returned to pre-pandemic levels.

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

⇒ Shortages of PDNs during the pandemic are attributed to:

- ✓ Challenges in recruiting given the lack of face-face outreach with potential PDNs during job fairs and other outreach events;
- ✓ Lack of COVID-19 hazard incentive pay for PDNs;
- ✓ Higher paid COVID-19 related jobs in the community (such as vaccination units); and
- ✓ Nursing jobs in other settings offering sign-on bonuses.

⇒ Gaps in care during the pandemic are attributed to several factors including:

- ✓ Nurses missing shifts, sometimes for up to one month, after being exposed to and/or diagnosed with COVID-19.
- ✓ PDNs cutting back on their schedules during the pandemic for a variety of reasons, including:
 - Family obligations that prevented them from working;
 - Concerns about exposure to COVID-19 in “high risk” households;
 - Desire to limit the numbers of CMCs they cared for; and
 - Other personal decisions.
- ✓ Family Caregivers deciding to:
 - Limit the number of PDNs coming into the home to provide care; and
 - Accept only vaccinated nurses.
- Issues related to vaccination including:
 - Lack of approved vaccine(s) for children;

- Persistence of vaccine hesitancy by PDNs and families; and
 - Emergence of new variants.
- ⇒ In some cases, family caregivers elected to cancel private duty nursing coverage altogether during parts of the pandemic.
- ⇒ Agencies were challenged to cover CMC care needs and accommodate the concerns of family caregivers.
- ⇒ Agencies monitored state and local public health communications about COVID-19 and provided information to PDN staff including:
- Safe work practices;
 - Cleaning and disinfections;
 - Use of masks and PPE;
 - Testing; and
 - Vaccination access and policies.
- ⇒ PDNs remain concerned about a) bringing the virus home to their own families and friends; b) the development and spread of virus variants; and c) increased exposure as more and more families circulate.
- ⇒ Family Caregivers remain concerned about the a) unknown effects of COVID-19 if their child becomes infected; b) exposure to new variants; c) possibility of care rationing if a viral surge occurs; d) number of PDNs who come into their home; and e) unvaccinated nurses.
- ⇒ Agencies Representatives remain concerned about the a) shortage of nurses compared to pre-COVID-19 levels and number of shift openings; b) number of PDNs who are not vaccinated; c) effect of COVID-19 on business practices; and d) costs and business impacts associated with the pandemic.
- ⇒ Experiences with telehealth were mixed. While some families had a positive experience with telehealth and felt it saved travel time, others did not have a positive experience due to technology issues and/or feeling like they were asked to make clinical assessments they are not trained to do.
- ⇒ PDNs believe that about half of all homes they work in do not have the necessary technology to participate effectively in telehealth visits.

RECOMMENDATIONS

- ⇒ Brainstorm across all stakeholder groups about innovations needed to meet the care needs of CMC as the competition for nurses skilled in home care continues to gain momentum with increased emphasis on home and community care models and movement away from hospital and facility care.

- ⇒ Consider the option of allowing parents, on a voluntary basis, to be paid to provide care to their own children at home, as suggested by Family Caregivers.
- ⇒ Use the Medicaid dataset(s) to understand how CMCs utilized care in the past 15 months, including number of hours scheduled, charged, and missed as well as other services utilized such as primary care and specialists visits, emergency room visits, admissions, diagnostics, and use of therapeutics. These data will offer valuable insights into the impact of COVID-19 on access to care, including access to PDN services, and can be compared to pre-pandemic levels.
- ⇒ Literature reviews and further studies of preferences of family caregivers of CMC with respect to telehealth, as well as in home limitations are needed as health care delivery policymakers, technology companies, and some consumers continue to advocate for the use of telehealth. (See Janice Nevin, CEO ChristianaCare, 10/22/2020 <https://news.christianacare.org/2020/10/christianacare-builds-one-of-the-first-alexa-skills-in-the-u-s-exclusively-for-home-health-patients>).

ACKNOWLEDGEMENTS

This study was a collaborative effort. CRESP 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 private duty nurses, family caregivers, and agencies leads who took the time to respond to the survey and/or 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. (September 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.