

Private Duty Nursing Workforce Capacity Study: Private Duty Nurse Survey and Interview Results

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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 a survey administered to and interviews conducted with private duty nurses in the state of Delaware.

All PDNs who provided hourly shift services for CMC in the home were eligible to participate in the PDN survey and interview if they 1) worked at least one hourly shift caring for CMC in 2019, 2020, or 2021, and 2) were currently licensed to work as an RN or LPN in the state of Delaware. Analyses are based on 146 survey respondents and 15 interviews with PDNs. Select findings include:

- PDNs observe most families have gaps in coverage; perceive there is an increase in the number of CMC; and are concerned factors related to the PDN shortage are not being addressed.
- Subpar wages and benefits likely contribute to workforce shortages.
 - Over three-quarters of PDNs believe their pay rate is not appropriate for the work they do.
 - The high cost of health insurance and lack of sick leave are two factors that make becoming a PDN an impossible career choice for some nurses.
 - PDNs believe unpredictable take home pay is another important reason why nurses leave the PDN workforce or elect to only work part-time or on a PRN basis.

- Having the flexibility to select shifts and cases is important to PDNs; for some nurses, flexibility was more important than wages and benefits.
- Many nurses choose to care for CMC because they want to work in pediatrics, enjoy the autonomy of the setting, or prefer 1:1 care with clients; these are some of the same reasons their colleagues elect to leave the field.
- Nurses said colleagues leave the field because they are concerned about losing clinical skill sets, workload demands, career advancement, and work culture.
- PDNs are selective in the assignments they take, thus contributing to gaps in care. The most common variables they consider include: location, travel time, home environment, shift timing, and clinical characteristics of the child that might affect their ability to care for the child (e.g., weight; acuity).
- Nurses value orientations, preceptorships, ad hoc trainings, and competency reviews. However, they observe some colleagues are undertrained; those that are undertrained may leave a case, creating a void in coverage.
- Nurses report barriers to delivering quality care including: insurance policies; clinical practice policies, lack of adequate supplies; challenges to care practices by family caregivers about the PDNs approach to care delivery practices; and care communication between PDNs and across agencies.
- PDNs said caring for a child in their home requires one to be sensitive to working in the personal spaces of the family; interacting with the whole family; and respecting and accepting diverse lifestyle and cultural norms.
- PDNs empathize with family caregivers who struggle with gaps in coverage.

See the full report (T21-023) for a list of recommendations based on these findings.

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PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: PRIVATE DUTY NURSE 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 private duty nurses 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 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: 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: PRIVATE DUTY NURSE SURVEY AND INTERVIEWS

PDN SURVEY AND INTERVIEW INSTRUMENTS

The PDN survey was designed to collect data about the PDN workforce and characterize demand for services from the perspective of the PDNs working in the field. In addition to information about the respondent's demographics, employment history, and years of experience working with CMC, survey questions explored:

- Factors that impact the supply of PDNs (e.g., such as the characteristics of nurses who choose to work as PDNs with CMC);
- Factors that impact gaps in care (e.g., challenges with scheduling and coverage); and
- Assessment of the clinical and cultural competence of the study population.

The PDN 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. Since this study was conducted in the midst of the COVID-19 pandemic, participants were asked to reflect on PDN work environment and culture that were "usual for you, not experiences that are unique or different because of the pandemic." Participants were asked about COVID in a separate section of the survey.

At the end of the anonymous survey, nurses 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 PDN SAMPLE

All PDNs who provided hourly shift services for CMC in the home were eligible for the study if they 1) worked at least one hourly shift caring for CMC in 2019, 2020, or 2021, and 2) were currently licensed to work as an RN or LPN in the state of Delaware.

The large majority of PDNs who care for CMC in the state are registered with agency providers. Agency providers have exclusive access to PDN characteristics and information, including email contacts. In order to identify the study sample, DMMA identified 11 agencies who employ PDNs to provide care for CMC in the home; of those, several had more than one office location across the state. Of the 11 agency providers, DMMA met with leads from 13 agency locations during several study outreach calls. During the calls, DMMA and CRESPP provided information about the study, and sought collaboration and cooperation from the agencies.

PDN SURVEY DISTRIBUTION

Following the DMMA:Agency calls, CRESA coordinated survey outreach, distribution logistics, and implementation with agency leads. All 13 agency locations were invited to participate in the study and asked to identify the PDN cohort from their rosters that met the inclusion criteria for the study across all agency locations. Each agency location received instructions about survey distribution, including invitation email template(s) with the survey link, as well as subsequent follow-up reminders to be emailed at specified intervals. Agencies who maintained PDN rosters at more than one location were asked to ensure the survey was emailed to all nurses affiliated with all agency locations.

Over the course of the study, CRESA followed up with all agencies via telephone calls and/or emails to encourage participation in the study, as well as clarify any questions about the logistics and process related to the PDN mailings.

As a safeguard, screening questions at the beginning of the survey filtered respondents who did not meet the inclusion criteria. In addition, since PDNs may be registered with more than one agency, a screening question filtered those PDNs who may have received and responded to the survey after receiving an invitation from another agency.

Data collection initially closed on May 31, 2021, however, in order to increase the PDN response rate, the survey was re-opened for an additional month. All agencies were asked to resend the survey link with additional reminders in June 2021. Data collection closed June 30, 2021.

Participation by agency providers to distribute the PDN surveys was voluntary.

SURVEY AND INTERVIEW RESPONSES

Invitations to participate in the PDN survey were sent from agency providers to the PDNs on their respective rosters. Participation by agency providers was voluntary and agencies were not asked for information about the total number of surveys emailed; thus, a response rate based on the number of surveys mailed cannot be calculated.

Over 200 PDNs (n=205) responded to the survey. Of the 205 PDNs who opened the survey link, 28.8% did not meet eligibility criteria due to incomplete consents or not meeting inclusion criteria. The final analytic dataset was comprised of 146 surveys. Valid responses by item ranged from 133-146 respondents, depending on the question. In addition, 15 interviews were conducted with PDN volunteers. Based on PDN responses regarding agency affiliation notations, PDNs were affiliated with 6 of the 13 agency locations that were represented on the DMMA:Agency outreach calls. Thirteen PDN respondents were registered with more than one agency. Of those, 12 were registered with two agencies and 1 was registered with three agencies.

RESPONDENTS' CHARACTERISTICS

GENDER, AGE, AND RESIDENCE

Most respondents were female (127/134; 94.8%) and half of all respondents were over 50 years of age (67/134; 50.0%). Approximately half lived in New Castle County (65/133; 48.9%), with the remainder living in Kent County (31/133; 23.3%), Sussex County (18/133; 13.5%), or outside the state of Delaware (19/133; 14.3%). See Tables 1-3 for details.

Table 1. Respondent's gender

	Frequency (n)	Percent
Female	127	94.8%
Male	4	3.0%
Prefer not to say	3	2.2%
Total	134	100.0%

Table 2. Respondents' age

	Frequency (n)	Percent
20-30 years	10	7.5%
31-40 years	23	17.2%
41-50 years	34	25.3%
51-60 years	39	29.1%
60+ years	28	20.9%
Total	134	100.0%

Table 3. Respondents' county of residence

	Frequency (n)	Percent
New Castle	65	48.9%
Kent	31	23.3%
Sussex	18	13.5%
Other	19	14.3%
Total	133	100.0%

LICENSURE AND EDUCATION

Equal numbers of survey respondents were licensed as RNs or LPNs. Of those licensed as LPNs, most reported graduating from an LPN diploma school (56/75; 74.7%). Of those licensed as RNs, nearly equal numbers graduated from an RN associate degree program or a Bachelor of Science program. See Tables 4 and 5 for details.

Table 4. Respondent's type of nursing license

	Frequency (n)	Percent
Licensed Practical Nurse	75	51.4%
Registered Nurse	71	48.6%
Total	146	100.0%

Table 5. Respondents' highest nursing degree

	Frequency (n)	Percent
Diploma - LPN	56	38.9%
Associate - LPN	19	13.2%
Associate - RN	31	21.5%
Diploma - RN	4	2.8%
Bachelor of Science in Nursing (BSN)	32	22.2%
Master of Science in Nursing (MSN)	2	1.4%
Total	144	100.0%

NURSING EXPERIENCE AND EXPERTISE WORKING WITH CMC

Over two-thirds of respondents reported working with CMCs for at least five years (101/145; 69.7%), while just under half (64/145; 44.1%) had more than 10 years of experience. When asked to rate their experience working with CMCs, the majority of respondents (137/146; 93.8%) described themselves as experienced or highly experienced. See Tables 6 and 7 for details.

Table 6. Respondents' length of time working as a PDN caring for CMC

	Frequency (n)	Percent
Less than 3 months	1	0.7%
3-6 months	4	2.8%
7-11 months	3	2.1%
1-2 years	16	11.0%
3-4 years	20	13.8%
5-10 years	37	25.5%
> 10 years	64	44.1%
Total	145	100.0%

Table 7. Respondents' experience in caring for CMC

	Frequency (n)	Percent
Highly Experienced	78	53.4%
Experienced	59	40.4%
Somewhat Experienced	9	6.2%
Little Experience	0	0%
No Experience	0	0%
Total	146	100.0%

EMPLOYMENT STATUS

Nearly all PDNs (137/146; 93.8%) reported they worked both before and during the COVID-19 pandemic and that their most recent shift was in 2021 (136/141; 96.5%). Of those whose most recent shift was in 2021, nearly all reported their latest shift worked was in late spring/early summer 2021 (133/136; 97.7%), i.e., at the time data were collected for this study. Current employment status varied, with over half of PDNs reporting that they worked full-time (85/146; 58.2%), some part-time (29/146; 19.8%), and a few PRN (16/146; 11.0%). See Tables 8-10 for details.

Table 8. Respondents' work history during the COVID-19 pandemic

	Frequency (n)	Percent
PDN worked both before and after the COVID-19 pandemic started	137	93.8%
PDN worked before the COVID-19 pandemic started but not after COVID-19 started	1	0.7%
PDN worked shifts after the COVID-19 pandemic started only	8	5.5%
Total	146	100.0%

Table 9. Respondents' most recent shift (Year)

	Frequency (n)	Percent
2020	5	3.5%
2021	136	96.5%
Total	141	100.0%

Table 10. Respondents' current employment status working as a PDN caring for CMC in the home

	Frequency (n)	Percent
Employed full-time greater than 30 hours/week	85	58.2%
Employed part-time, 20-30 hours/week	29	19.8%
PRN/casual, picking up hours now and then	16	11.0%
Not working as a PDN with CMC (PDN's choice)	1	0.7%
Not working, but looking for PDN CMC work	1	0.7%
Prefer not to answer	2	1.4%
Other, please specify	12	8.2%
Total	146	100.0%

FINDINGS A: Factors that Influence the Supply of PDNs

Findings from the PDN survey and interviews support anecdotal evidence that PDN care hours authorized for CMC in home care are not being met. This section addresses factors that influence the supply of PDNs in the workforce. Following a brief introduction with general observations by PDNs about supply and demand (results area 1), the following factors are addressed in results areas 2-8: monetary compensation, unpredictable take home pay, competitive flexible work schedules offered in other work settings, characteristics of nurses who choose to work in the home vs. other settings, concerns about losing clinical skill sets, workload demands, and career advancement and work culture.

RESULTS AREA 1: DEMAND FOR SERVICE IS GREATER THAN THE SUPPLY OF PDNS

Assertion 1. PDNs describe situations where it appears the demand for PDNs is greater than the supply, such as continually being asked to cover additional shifts.

When asked, most nurses agreed there is a shortage of PDNs to care for CMC in the home. PDNs report there is always a demand for PDNs to cover hourly shifts and that agencies frequently ask them to cover additional uncovered shifts. Some agencies, but not all, ask PDNs to work overtime and/or offer extra incentives to work more hours, special shifts, or with specific clients.

"You always will have an opportunity. There's always work available. There's always a need."

"I'm usually working 50 plus hours...I typically work probably about five to 10 hours of overtime a week."

"There's so many uncovered shifts that there's always work."

"[They] offer you some kind of incentive...\$10 an hour more...or a day off or whatever."

While some PDNs are able to take advantage of overtime pay and opportunities, others are exhausted from the continued requests.

"It's kind of rough...and they [agency] squeeze and squeeze, and then they tried to squeeze [more]... you can work only so much, you're one body...I spend so much time on [these shifts]; I cannot work these many hours."

PDNs perceive there are less nurses recruited and available to care for CMC. At the same time, PDNs believe the population is aging and more PDNs are retiring or working less hours.

"There's always nurses coming and going that I've worked with...but at the same time, it just seems like less and less nurses are being oriented."

"I feel that it's the older population is aging out and retiring."

Assertion 2. PDNs observe most families have gaps in coverage; perceive there is an increase in the number of CMC; and are concerned factors related to the PDN shortage are not being addressed.

PDNs perceive there is an increase in the numbers of CMC cases authorized to receive care. They also wonder if the number of hours are authorized in an equitable fashion.

“And there seems to be more and more children [coming home].”

“There are more and more children that are coming home with medical needs that need to have nurses take care of them and there’s not the overwhelming nurse population to be able to do that.”

“I would actually like to see some type of a review...And I can't really believe I'm saying this, but to just justify the level of care that is ordered. Because as I've said, I've been on a few cases where I didn't honestly feel that nursing care was needed, or at least not as many hours as was being ordered. On the flip side, I've seen other families that could really, really use more hours and they weren't being granted. The disparity is just kind of frustrating at times...for the most part...we don't have a real say in it.”

Nurses shared that most families have gaps in coverage.

“Every family that I worked for, every month, has holes in their schedule.”

“I don't think that I have a single case right now that is completely fully staffed...”

Nurses are concerned the shortage is going to become an even bigger issue for families unless factors related to the shortage are addressed.

“I just think it needs more attention. And I think it's going to become a bigger issue, even if something doesn't change soon. I am really concerned about the future of it as far as that goes.”

See Appendix B for exemplars from PDN interviews and open-ended survey responses that offer PDN perspectives on how gaps in care affect CMC and their families.

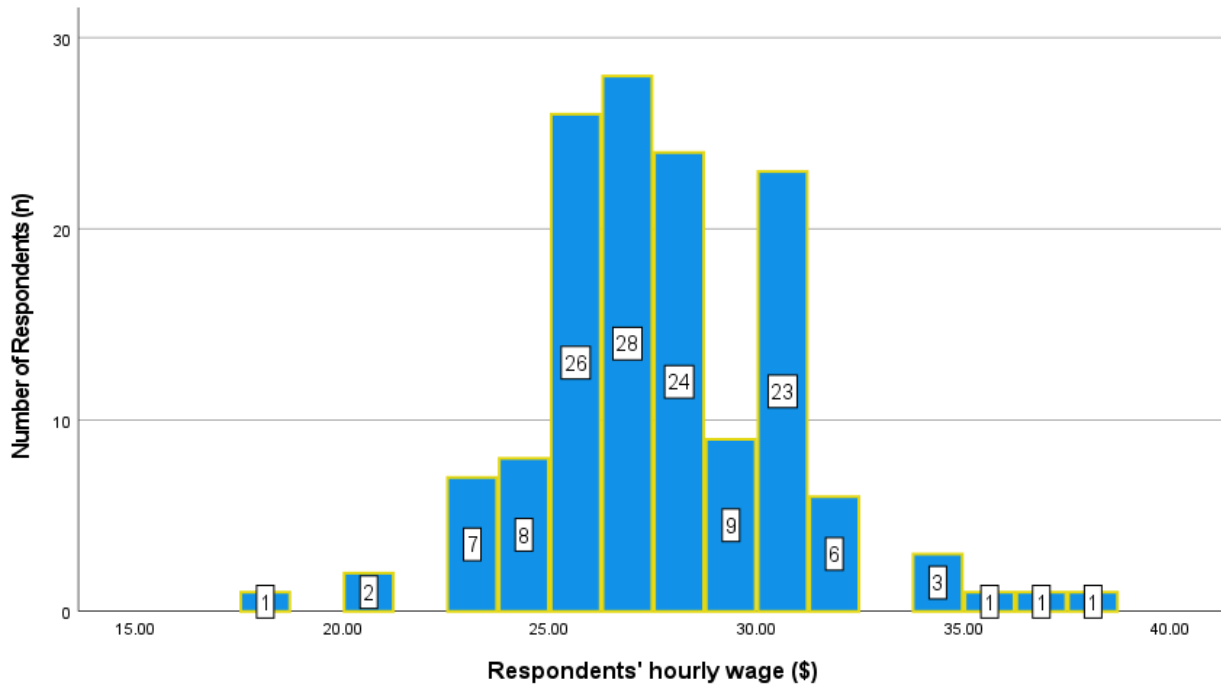
RESULTS AREA 2: COMPENSATION – WAGES AND BENEFITS

BASE WAGES

Hourly wages based on last shift worked, ranged from \$18/hour to \$38/hour with an average wage of \$27.61/hour (S.D. = 3.0). See Figure 1 for details.

Data revealed differences in average hourly wage by licensure status (RN versus LPN) as well as by level of education (data not shown). There were no differences in average hourly wage by age, county, employment status, length of time in years working with CMC, or how the respondent rated their expertise and experience in caring for CMC.

Figure 1. Hourly wage for all respondents



Assertion 3. PDNs report hourly wages ranging from \$18/hour to \$38/hour with an average wage of \$27.61/hour; over three-quarters of PDNs believe their pay rate is not appropriate for the work they do.

When asked how they perceived their hourly wage in light of the type of work they do, over three quarters of nurses (111/141; 78.7%) disagreed that their hourly wage was about right for work they do. See Table 11 for details.

Table 11. Respondents’ perception about wages

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
My hourly wage is about right for the work that I do (n=141)	70	41	25	5
	49.6%	29.1%	17.7%	3.5%

n=141; percentages may not add up to 100 due to rounding.

Of the RNs and LPNs (n=30) who agreed their wage was about right, 60% (18/30) were LPNs whereas (12/30; 40.0%) were RNs. Note: data were not collected on whether PDNs were receiving/referring to a per diem rate. See Table 12 for details.

Table 12. Respondents' agreement with hourly wage by licensure status

	My hourly wage is about right			
	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
Licensed Practical Nurse	33	19	15	3
	47.1%	27.1%	21.4%	4.3%
Registered Nurse	37	22	10	2
	52.1%	31.0%	14.1%	2.8%

n=141; percentages may not add up to 100 due to rounding.

Nurses had the opportunity to elaborate on their responses about wages and benefits using short answer responses in the survey and during the in-depth interviews.

As noted above, LPNs were more likely than RNs to say their wages were adequate for the work they did. One LPN agreed and noted specifically that they were satisfied with their per diem rate, that working as a PDN was a rewarding experience, and given the limited opportunities for LPN positions in the state, was grateful for their job.

"Yes. I think I'm fine [with my per diem pay]. As an LPN, I would say just the fact that it was something different than a nursing home, because in this state particularly LPNs have a very limited opportunity for employment. For me to be able to do this private duty as an LPN, I felt that I was paid well and it was very satisfying because I felt like I had an important job...I'm not a VP or an executive of some big company, but I'm making a big difference in this child and this family's life."

Nurses reported their pay is not competitive, raises are rare, and when a raise is offered, they are minute.

"I've gotten a quarter raise over the past three years, the total of a quarter...and they say well, because of the reimbursement rates for Medicare, that's what it is...That's ridiculous."

"We have kids that really do need that skilled care, and I hate to say it but when you're paying a McDonald wage, that's kind of what you're getting in a skill set, and that's not what these kids need. That results in higher hospitalization rates. It results in higher mortality rates. And that's just wrong all around."

PDNs observe nurses tend to leave the field due to low wages and the high cost of benefits.

"Money is a big issue."

"Another reason there is a shortage is because nurses can make a lot more money somewhere else and get benefits because it's not only that they don't make enough...they're paying so much more for their benefits."

"I have seen nurses that have been tried to be paid \$18 an hour. And considering how much some nurses pay for their degree to go through schooling to only be offered \$18/hour, I couldn't imagine being satisfied with that or being even just okay with that."

PDNs who currently work in the field said that they encourage their nursing colleagues to join the PDN workforce but it is a "hard sell" given the low pay and poor benefits.

"As far as the pay, no, it's very low paying. So in that regard, it's not meant for everybody. Which I think is the issue for the nursing shortage right now is, I know plenty of nurses that have come and gone and I've talked to trying to recruit them and that's always the detour."

"I do, but it's a hard sell. I do encourage them...you don't have the excitement of [the hospital setting] and you don't have the pay. The pay at the hospital's a lot higher, so to try to drag them from that is difficult."

"If [Medicaid] reimbursement would go up, because most of our pediatric kids are Medicaid, if reimbursement would go up then I think it would be more competitive. You'd have more nurses interested in doing [working as a PDN]."

"I really feel that the reimbursement rates need to change. but I really do feel that it's wages that pulls a lot of nurses away. There's just more benefits, more things that can be offered."

Nurses are often reminded that reimbursement rates have not changed in 15 years, that there is no money for wage increases, nor benefits such as PTO, sick leave, and education.

"Not only do you hear it about money for education, it's money for reimbursement for the nurses...PTO. Reimbursement hasn't changed in 15 years. And so there's not enough money to go out to the nurses for anything, for education, for nurses' salaries, for the purpose that other nursing jobs will give. It's just not there. So we get the shaft."

Although survey data revealed PDNs believe both agencies and families value their skill sets (see Table 13 for details), many PDNs believe their experience, education and contribution(s) are not respected by Medicaid, agencies and/or insurance companies and are reasons some plan to leave the field.

"To attract and retain nurses for home health care, it is vital Medicaid and Medicare reimburse agencies so they can provide higher wages to compete with health care institutions...Medicaid and insurance companies need to recognize the importance of elevating the role of PDN through wages and benefits to draw nurses into home health care."

“I am highly experienced due to the number of years of experience but due to reimbursement rates I no longer receive any raises in my hourly wage. This is disheartening and is causing me to [make plans] to move on from home care. This will be a loss to the families I care for. I cherish my job and the children I care for, but as time goes on the technological needs of CMCs is increasing requiring increased skill nurses, but we are not adequately compensated...we really should have the same compensation and benefits as long term care. If I don't work, I don't get paid. Nurses are the backbone of the agency but the office staff have better benefits and perks such as holiday gifts and parties, bonuses, sick pay and bonuses for not using their sick pay. As a home care nurse I feel like we are at the bottom of the barrel and we are not treated with the same dignity and respect and compensation and recognition as someone working in a facility.”

“Home care nurses are in high demand and play an essential role in keeping kids in the comfort of their home while they receive complex medical care so that they can live their best possible lives. Caregivers rely on home health agencies to staff and ensure competent nurses are filling open shifts so the best care is given following the doctor's orders. Home care nurses are independent and act as the eyes and ears of the healthcare team, providing medications and treatments as ordered and quickly assessing and identifying alterations in status so the client can receive the appropriate care before conditions worsen. Often, home care nurses can address issues quickly and prevent costlier hospital stays...Compensating skilled, licensed, insured nurses providing home care is important to prevent nursing shortages as nurses often ultimately choose to go to facilities where the pay is better. Home care nursing is different but very important, cost effective, and worth paying a competitive salary.”

“I don't think that they realize that we're like the nurse, the physical therapist, the CNA. I mean, we're bathing them, we're putting their braces on, we're doing range of motion and that type of stuff.”

“I almost wonder sometimes if the insurance companies feel that because a nurse is taking care of only one person, they should be paid less versus somebody who takes care of three to five patients...a person who takes care of more gets paid for more. But it's more therapeutic to keep somebody at home in their own environment that they're used to. It's been proven that clients see their family more when they're at home versus when they're in a facility...parent or caregiver are not going to see their child as much and they're not going to be as involved in their lives unless they're under the same roof.”

Table 13. Respondents' agreement regarding skills valued by agency providers and families of CMC

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
My agency values my nursing skill set (n=138)	5	3	30	100
	3.6%	2.2%	21.7%	72.5%
My skills are valued by the families of the children I care for (n=136)	4	2	19	111
	2.9%	1.5%	14.0%	81.6%

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

Interview data revealed nurses often discuss wages with colleagues and peers. From their experience and these conversations, PDNs report wages are higher compared to wages of PDNs caring for CMCs across multiple clinical settings, such as nurses working in hospitals, long term care facilities (including those for CMC), and adult home health care. They also compare their pay to workers in other fields and, again, given their experience and education, wonder why they are getting paid so little:

“I just feel like sometimes home care is overlooked as far as being... I don't think it's being given the credit it deserves. There's a real place for it, there's a real need for it.”

“I'm at approximately \$25 an hour....one of my friend's daughter works as a para-professional in the school district and gets paid more than me; she's getting paid \$35 an hour to work the summer program. I've been a nurse for nearly 30 years and I'm getting paid \$10 less an hour than her.”

Some nurses believe their wages differ by geographic region in the state. For example:

“I've known for a while that in the middle of the state, they don't pay as much as the upper and lower counties. That was the same when I was in office work too. For some reason, the middle of the state was a lot lower.”

INCENTIVE PAY

The majority of nurses (117/140; 83.6%) indicated they receive an increase in the PDN pay rate if they work on holidays. This confirms the policies of some agencies to offer pay increases for holidays as a means to help maintain coverage, as well as offering an increase in the hourly rate if nurses agree to work on weekends, cover specific shifts, and/or care for specific clients. See Table 14 for details.

Table 14. Number and percent of respondents who receive holiday pay

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
If I work on a holiday, I receive holiday pay from my agency (n=140)	11	12	37	80
	7.9%	8.6%	26.4%	57.1%

n=140; percentages may not add up to 100 due to rounding.

BENEFITS

When asked to list the top three job benefits that were most important to them, health insurance, sick pay, and holiday/vacation pay were mentioned most frequently. Travel/mileage reimbursement and on-call pay were also mentioned specific to PDN work. Benefits mentioned less frequently included: dental insurance, vision insurance, personal days, retirement, life insurance, education opportunities (e.g., CEUs etc.), and paid maternity leave.

Respondents reported that health care insurance is generally available from agency providers. Insurance plans and rates appear to be structured differently depending on the agency. For example, some plans and rates vary depending on employment status (e.g., part-time versus full-time). Nurses who access health benefits from the agency described their health insurance as expensive.

"Insurance-wise, they [the agency] did offer me insurance, but I got private insurance for less than it was going to cost me to get insurance through them."

Nurses believe lack of access to affordable health insurance rates discourages nurses from joining the PDN workforce and is prohibitive for a nurse looking for health coverage for their family due to the high cost of medical insurance.

"For a single person who is only having to support themselves and to pay for benefits for themselves, or if a person was covered with medical benefits under a partner's plan...it [is] good. But if you [are] a single parent or a head of household, it is not sustainable. Cost of benefits easily outweighed the paycheck in some cases."

"I've seen a lot of good nurses leave because of [pay and benefits] and they were nurses that were really dedicated and they really loved it, but a lot of times it was, they had a child and now all of a sudden their health insurance doubled, and they had to pay for childcare on top of that and they couldn't sustain it, or a spouse who they were previously covered under lost their job. That was one of the major things and it also affected recruitment. When they looked at the initial hourly wage they were like, 'Oh okay, that's pretty good. I get so much paid time off in the bank, that's good, that's good.' And here's the benefit package and they're like, 'Whoa, I can't do that. I can't pay \$800 a month for me and my kid.'"

Assertion 4. The high cost of health insurance policies through the agency and lack of sick leave are two factors that make becoming a PDN an impossible career choice for some nurses.

For some, the high cost of medical insurance makes it impossible for nurses to work as a PDN unless they have coverage from other sources, such as coverage by a partner's insurance, from a full-time position with another employer, and/or through a previous job/career. Nurses who are covered from outside sources feel fortunate they can work in the home care setting without having to worry about health insurance costs and empathize with nurses who need to secure costly medical insurance from the agency.

"I don't think I could keep insurance and keep everything [going] and work for the rate that I'm currently working. Like I said, I just happen to be lucky enough to have [benefits and secondary income]...If I had to rely just on my nursing income and have to pay benefits, I would not be able to be a home care nurse."

"I didn't take their benefits because they're more expensive. And my husband works...and I just go under his, because it's cheaper."

“For me, benefits are not an issue...but for other people who are doing home care nursing, it is a big issue because in general, the salaries are lower. Most of the agencies I know do offer benefits, but the cost of the benefits almost makes them prohibitive to taking them...if I had to pay for full medical benefits with the salary that I'm getting paid, I probably wouldn't do home nursing. I don't think I could afford it.”

When asked about paid time off/vacation and sick leave, approximately half of all respondents (75/141; 53.2%) somewhat or strongly agreed they receive paid vacation days, whereas very few (24/140; 17.1%) receive paid sick leave. See Table 15 for details.

Table 15. Respondents' agreement about benefits received (paid time off and sick leave)

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I receive paid vacation days from my agency (n=141)	47	19	44	31
	33.3%	13.5%	31.2%	22.0%
I receive paid sick leave benefits from my agency (n=140)	96	20	14	10
	68.6%	14.3%	10.0%	7.1%

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

Nurses clarified that agencies structure how vacation/paid time off (PTO) are accrued in a variety of ways. Some agencies structure vacation/PTO based on the number of hours worked. Other agencies do not offer vacation/PTO regardless of hours worked. Some have special programs that allow nurses to accelerate vacation/PTO depending on hours worked, and/or weekend or holiday shifts covered.

“Every hour that I work, I accrue so many points towards my time off...it just depends on how much you work per week, and how much it goes towards your paid time off.”

“We don't get vacation either unless we work above 40 hours.”

“[Agencies] don't have full time. Even if you were working 40 hours a week, you're not considered full time. It's just the beast of home care, I guess. That's generally been how they've always operated.”

“It doesn't matter how many hours I work...they don't call [you] full time, you are called the part-time...honestly, I think they do that so they don't have to pay the benefits.”

PDNs noted that if they don't accrue PTO as per the agency policy (or don't have any available to use), PDNs are not paid. Some nurses reported that working without sick time benefits can be a hardship and is one reason nurses choose not to work as PDNs.

“The paid time off is our sick time.”

“There is no sick time, so if you got sick with something and you had to call out, they would either take it out of PTO if you had it or you were shorted on your paycheck.”

“The fact that there was no sick time, there was no emergency bank, is catastrophic for some people.”

“If I don't show up, I don't get paid. There's no sick time in home care. There's no reimbursement for any time that you are not with that client. There's no before and after.”

“I would earn two hours of PTO per paycheck. So every month I'm earning four hours of PTO. So basically, it would take me all year to earn enough PTO, to go away for a week [on vacation]...then if you have patients that are hospitalized and you're missing shifts, well guess what? A lot of nurses have to use their PTO.”

RESULTS AREA 3: UNPREDICTABLE TAKE HOME PAY

Assertion 5. PDNs believe unpredictable take home pay is another important reason why nurses leave the PDN workforce or elect to only work part-time or on a PRN basis.

PDNs report that shifts are not guaranteed with home care. Further, they believe a key reason nurses leave the PDN workforce and/or cut back on hours is to take a more dependable and predictable full-time job.

“Anyone who works in-home care, it cannot be income-based, because you never know. You cannot depend on 40 hours with home care. So that's why a lot of nurses have full-time jobs and work in home care [part-time or PRN].”

When PDN shifts are cancelled, often at the last minute, a nurse's take home pay is impacted. For example, if the CMC they were scheduled to care for is admitted to the hospital, has a doctor's appointment, or the family elects to take a day trip, PDNs do not get paid.

“Unfortunately or fortunately, if I think that [the unpredictable hours] is the only thing...I'm not satisfied with my job.”

“We don't get paid if the client doesn't show up. There's got to be some kind of payment for when ... I know Medicaid has to pay for the child to be in the hospital, but if the family goes on vacation and the nurse is out a week's pay, that nurse may decide to go someplace else, and it's happened.”

PDNs try to protect themselves from cuts in take home pay by working with multiple cases, working for more than one agency so they can switch to other cases if need be, working overtime, and/or working additional jobs, including finding a fulltime job and switching to PDN work part-time. Without predictable take home pay, some PDNs struggle with bills (e.g., mortgages and utilities); others become anxious as they try to find additional hours to make ends meet.

“I have a full-time job where I receive medical and dental coverage.”

“They don't want to guarantee if a patient goes to hospital, or a patient expires, or they declined the nursing service, or a patient gets better, maybe they don't need any more nursing services. So whatever the reasons when you stop, you're losing hours, and when you don't work, you don't get paid.”

"I have been a PDN for [many] years and I still don't make enough to provide and save for my family. The only way I make enough is by working overtime. If for some reason I can't work my overtime my budget is blown. Health insurance is very expensive."

"When you had months where you might only get 12 hours a week and you have a mortgage to pay, it just wasn't sustainable. Many nurses end up working two or three different jobs just so they could have that security of having enough hours. If they didn't get it at one agency, they could go to another agency and try to pick up shifts there."

"I'm going to probably have to use my PTO potentially like on random days when I'm planning on working...like when I was called...and[cancelled]...that's it. So I didn't get paid. So I'm out. And for me it works, it's still okay. One, because I'm oriented to so many cases...I picked up other shifts and other cases. So I survived, but for two months...I really didn't know what my schedule was going to be because it was like, where can you put me? What can I do?"

"If the patient happens to go into the hospital where nursing care wasn't needed, that nurse [is] out of a paycheck that entire time that child was in the hospital...but those medical benefits have to get paid and so they take it out of your PTO balance, so then you'd essentially get no vacation."

Depending on the agency business model, if hours are not assigned, PTO hours must be used.

"If you were a benefited employee, you were expected to be available to work at least 30 hours a week ...and you are supposed to be scheduled at least 30 hours a week...but there were times [when I wasn't]...and the gap between required hours is pulled from my PTO."

Some PDNs accept that the unpredictable hours and paychecks are the nature of the job. Several exemplars capture the essence of this mindset:

"You cannot be guaranteed any hours with home care. You're lucky if you do. It's great when you do, because sometimes you get families who you stay with for eight, 10 years, and it's consistent and you know ... but that's not the norm for home care."

"You have to be flexible with your hours. You have to be flexible with ... you just got to roll with it so many times in homes. You show up and, 'Oh, we're going to a doctor's appointment.' or, 'Oh, we're going on vacation next week.' Or they're in the hospital or we're moving. There's so many things that you have to deal with that people who work a nine to five, Monday through Friday job do not have to deal with. And the pay does not reflect that, hence the trouble of finding nurses who are willing to do that."

"So we have cases that are either new cases or cases that for some reason they didn't get the schedule done properly so they had holes in the shift. You're looking through this going, okay is there anything I can pick up? Do I know any of these patients? Am I willing to drive an hour and a half down south to work a six-hour case to not have my PTO taken?"

"With home care, that's just part of the gig. If a child's in the hospital and a family goes on vacation, they move, they pass away, there's all kinds of dynamics that you have no control over."

Some families are aware that nurses do not get paid if they are not working and the families adjust their schedules so nurses are not faced with a reduction in pay.

"I've never had [the issue of no pay] because [my family] are actually very cognizant that not only am I helping to take care of their child, but this is my job. If I'm not working...I don't have paid time off. So if I'm not working, I'm not making money...They realize that that's the case...they try to be very cognizant about not calling and canceling because they know that that's somebody's livelihood."

Assertion 6. PDNs who don't worry about wages, benefits and take home pay are empathic when thinking about peers who do need to consider these factors when deciding whether a career as a PDN is sustainable.

Not all nurses worry about wages, benefits, or unpredictable take home pay, albeit, they are empathetic for those PDNs who need to consider what it means for them to accept a job with low pay, limited benefits, and unpredictable take home pay.

"I have some flexibility, but other nurses don't...they [depend] on having a certain amount of money every week."

"They're working full time and they're not just working 32 hours, 40 hours. Some pick up extra shifts, but they have to pay all this money to have benefits. Honestly, I wouldn't do it. If I needed benefits, I wouldn't be doing this job."

"I'm at a stage in my life...I don't have a mortgage, my bills are very low, so for me, I could weather those up and downs. But for a younger person... [with] a mortgage...car payment...childcare, everything...that is literally paycheck-to-paycheck where they had to have that 30 hours or else they were going to go past due on something, it's stress."

RESULTS AREA 4: COMPETITIVE FLEXIBLE WORK SCHEDULES OFFERED IN OTHER WORK SETTINGS

Nurses repeatedly emphasized the importance of having a flexible work schedule. Of all factors that motivate nurses to work as a PDN, nurses repeatedly said that having a flexible work schedule was an important reason to work as a PDN. Over three-quarters of survey respondents (77.9%; 106/136) strongly agreed the flexibility to work various shifts was important to them. See Table 16 for details.

Table 16. Number and percent of respondents who agree flexible schedules are important

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
The flexibility to work various shifts and times is important to me (n=136)	5	3	22	106
	3.7%	2.2%	16.2%	77.9%

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

PDNs reported having a flexible work schedule is a “big draw” for a nurse interested in PDN work. Flexible, personalized schedules allow nurses to juggle home and family responsibilities, attend school, and take time off when they desire. In turn, agencies work with the PDN’s specific scheduling and client characteristic requests.

“I worked at a hospital where I had to do shift work and weekends and it was quite taxing when you have children.”

“I was in school, so the ability to change my schedule around based on my academic workload was very important.”

“You really can pick your hours. You can pick how many days you want to work...if I wanted to take two weeks off, I could take two weeks off. If I wanted to switch to working nights, I’m sure I could work nights. There’s just so many opportunities.”

“They [agency] know my specifications...for example, I only work day shift...and only take care of kids under xx pounds.”

Some nurses prioritize having a flexible, personalized work schedule over securing desirable benefits, noting that having a “great schedule” is more important than having competitive benefits as captured by the following exemplars:

“A lot of the agencies don’t offer benefits. You don’t get paid time off. A lot of them don’t really offer insurance, which ... You have to take good with the bad. You get a great schedule but you have crappy benefits. It depends on what you want and what you need.”

“The schedule is so much better. The pay isn’t as great, but the schedule is a lot better.”

Assertion 7. Having the flexibility to select shifts and cases is important to PDNs; for some nurses, flexibility was more important than wages and benefits.

While flexibility appears to be one of the key reasons PDNs elect to work in the field, PDNs believe other work settings now offer the flexible schedules and benefits thus competing with the private duty nursing arena.

“The younger nurses are being more attracted to facilities with the big sign on bonuses and the coffee shop perks downstairs...”

RESULTS AREA 5: CHARACTERISTICS OF NURSES WHO CHOOSE TO WORK IN THE HOME

Assertion 8. Many nurses choose to care for CMC because they want to work in pediatrics, enjoy the autonomy of the setting, or prefer 1:1 care with clients; these are some of the same reasons their colleagues elect to leave the field.

In addition to flexible work schedules, reasons why some respondents said they chose to work as a PDN include because they specialize in working with children, are challenged by the care needs, and view themselves as an advocate for children. Some PDNs reported having pediatric

experience, whether it be in an acute care setting (e.g., hospitals), or pediatric primary care outpatient settings prior to joining the PDN workforce. A few reported having experience in medical daycares and/or facilities for CMC.

Another reason PDNs shared about why they chose to join the field is because they enjoy the autonomy of working in the home. Compared to other settings, there is “*no one micromanaging their day*”, “*no difficult co-workers to deal with*”, no “*gossip*” among co-workers, etc. PDNs value the independence they have in how and when they manage their time and provide care.

“The autonomy, I’m in the home, I’m with these children sometimes with a parent that is in the home, in and out, sometimes totally by ourselves... It’s just me and this child, and so I have a lot of leeway in how I perform my duties. We of course have the medical care plan that we have to abide by, but there’s an awful lot of free time that we can use to nurture and play with the children in ways that will just either help their mobility or help their learning ability...”

“If things start to go wrong especially like respiratory wise, you have to know how they go into action. And you don’t have a team where you can call in somebody from down the hall to help you out. You have to be comfortable on your own.”

PDNs also choose to work with CMC for the 1:1 experience. PDNs note that in a hospital setting one may only take care of a child for a couple of shifts and never see them again. In addition, you are pressed for time. Working with CMC in the home allows one to get to know the child and embrace a care delivery model that addresses the medical, emotional, and physical needs of the child. PDNs appreciate the opportunity to observe progress in development, as well identify clinical changes in the child.

“When you [are] working in a home, it typically is a long-term relationship. You get to know the families; you get to know the child. It’s not like you work in a hospital where you may have a child for a day and you never see them again. When you work in the home, it’s a professional relationship but it’s also an ongoing relationship where you get to know your kid, not just medically but emotionally, physically.”

“It’s different, but at the same time, it’s still challenging and can be just as rewarding, if not more so because you do become a part of the family...and I do feel like I enjoy that aspect of it.”

“So when small things change with [the child], I notice right away because it’s not [typical]...whereas I feel like working in the hospitals, you’re kind of a revolving door and you don’t get that bond. That feeling where you actually know the child and you pick up right away when something’s different.”

“[I get to celebrate] milestones...that most people don’t even think about. They don’t get excited when [a child] finally rolls over for the first time in their life. Most people are like, ‘Yeah, so?’ I’m like, ‘that was their first. Oh my gosh, it’s so exciting.’”

However, respondents also pointed out that the very reasons they elect to join the PDN workforce are often the same reasons their colleagues elect to leave the field, or do not consider a PDN career, thus limiting the supply of PDNs. They shared that some nurses don't feel comfortable working alone and/or without a team.

"You don't have your team working with you. You know what I mean? You don't have your nurses you're with every day."

"I wouldn't just recommend anybody. I do feel that it's a different type of clientele than working in a group setting or a facility just for the simple fact that not everybody is cut out to be able to work alone."

On the other hand, some nurses may want a consistently, faster paced setting:

"There [are] some nurses that they're more like the adrenaline junkies, it is may not be the best place for them. I think it's very individualized...and not everybody is suited for home care."

At the same time, other nurses may not feel comfortable juggling the many roles a PDN must be capable of serving:

"When I started doing the neb treatments and the ventilator...[The nurse was like]...'Oh no, no, we can't do that. We're nurses.'...I'm like, 'Yeah.' [The nurse was like] 'Respiratory therapy has to do that.'...'No, this is home healthcare. Trust me, we do this all the time.'...'Oh, I'm not going to do that'...and [they are] out the door."

RESULTS AREA 6: CONCERNS ABOUT LOSING CLINICAL SKILL SETS

PDNs note that working with CMCs, particularly those that require high acuity care, allows one to use, maintain, and improve technical and clinical problem-solving skills. PDNs observe that, compared to other settings, it is a necessity to have a strong skill set given that you don't have a team to call on if something goes wrong.

"You're there by yourself. You have the care of this child, if they crash, if they have respiratory failure or anything, you're on your own. You're doing CPR, you're bagging, you're doing...you don't have a team to call. You're going to call 911 but you're on your own. If something's going wrong, you're the one sitting there troubleshooting. You may be calling the doctor; you may be doing other things but pretty much you have to have a good skill set to be a home care nurse. For the most part, if you're not a good technician, you're not going to be able to stay in home care."

"In the emergency room you just kind of stabilize, they go upstairs and that's where they get the ICU or the medical needs that they need. At home, you're doing that type of care. You have this mini-ICU that you're taking care of this critical patient in."

PDNs need to feel confident providing advice and support to caregivers and calling other providers if need be, e.g., to propose a change in the care plan.

“If I’ve been talking to mom and she says, ‘I don’t think he should have this one treatment,’ like a nebulizer treatment or something that causes the patient’s heart rate to race, ‘because the doctor says he needs this, but I don’t like it because it makes his heart rate goes so high.’ I’ll call the doctor and say, ‘Listen, this is what she [Mom] is saying. This is why. There’s got to be something else we can do.’ I’ll do that. I have no problem calling the doctor’s offices to discuss things like that.”

“If I think the child needs something different in terms of a wheelchair or braces for his feet, I’ll call the physical therapist, anything, if I think the child needs more...Or say there’s been three or four nights in a row where her mom has had no nursing at all, then I’ll call our agency and say, ‘She really needs help. You need to get somebody here.’”

On the other hand, some PDNs agree that working as a PDN could mean you lose skills and believe some nurses don’t consider PDN careers and/or leave the PDN field for this reason. Some PDNs recognize this as a possibility and only want to work with high acuity cases in order to maintain their hi-tech skill set:

“I wasn’t doing anything. I literally just sat there and watched her...I wasn’t using any of my skills. I could have done that and stayed with that but I would have lost everything that I had. All the skill that I had.”

“With lower cases [lesser acuity], you are losing some of your ability...doing vent trach...I feel like I’m gaining skills rather than losing.”

Nurses recognize that maintaining strong clinical skills is important so they can provide quality care to their clients.

“I’d say 85% of the time...it’s just to get basic care. But 15% of the time, it may be you need to do something life-saving for this patient and it’s just you and the patient. You are everything. So you have to be ready for that and that’s a lot of responsibility.”

“So especially with the really medically needy kids, with really medically complex kids, you need a good nurse in there. There are some kids who get nursing who have a G-tube and maybe that’s all they have and they’re not high tech but the high-tech kids they need a really skilled nurse.”

RESULTS AREA 7: WORKLOAD DEMANDS

Nearly all PDNs (132/137; 96.4%) somewhat or strongly agree their workload is manageable. See Table 17 for details.

Table 17. Respondents’ agreement with manageable work load

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
My workload is manageable (n=137)	3	2	29	103
	2.2%	1.5%	21.2%	75.2%

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

At the same time, many nurses report the work is at least sometimes physically (105/136; 77.2%) or mentally (89/136; 65.4%) exhausting. See Table 18 for details. Some acknowledged the emotional demands can be taxing but have learned how to prevent burning out; others reported they leave cases because of the physical, mental, or emotional demands.

“You have to be autonomous. You have to be able to work by yourself and you have to be able to give up that...When you work in a hospital, you have coworkers, you get to talk to all day long. Not all day long but you can bounce things off of you. You have to be able to not have that social aspect of work.”

“[Sometimes] I feel stressed...I worry...it affects me physically...I feel sick to my stomach and nauseous.”

“[When my shift is cancelled], it's hard, but sometimes I like having a little bit of time off too, especially with times that you're picking up. Sometimes you're picking up more shifts...so have that little bit of downtime is good at times.”

“I feel I have to have a good break so I can be rested physically and mentally to provide the care needed.”

“[It's a difficult case] I've had times, [where I need to] take a break, and stepped away for like a month or two [from the case].

“Working in private duty is rewarding and fulfilling, but many nurses do not stay because the pay does not match the amount of work put in. As a PDN, you are by yourself and do not have any extra hands as you would in a facility which leads to quicker burn out. Most families are with not home or not always willing to help with a client's care.”

“You learn...how to deal with a difficult patients and families, then how to cope with yourself and not to burn out yourself, but still you can do it without totally getting upset from all this extra stuff.”

Table 18. Respondents' perception of physical and mental exhaustion in caring for CMC

	Never	Rarely	Sometimes	Most of the time	Always
Caring for a child with medically complex needs is physically exhausting (n=136)	8 5.9%	23 16.9%	83 61.0%	18 13.2%	4 2.9%
Caring for a child with medically complex needs is mentally exhausting (n=136)	10 7.4%	37 27.2%	66 48.5%	17 12.5%	6 4.4%

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

Assertion 9. Over three-quarters of respondents agreed they plan to continue to work with CMC.

Regardless of working environment, most respondents somewhat or strongly agreed (117/137; 85.4%) they planned to continue to work with CMC for at least the next three years or more. See Table 19 for details.

Table 19. Number and percent of respondents who plan to continue to work with CMC

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I plan to work with CMC for at least three or more years (n=137)	10	10	39	78
	7.3%	7.3%	28.5%	56.9%

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

Nurses elaborated on reasons why they intend to remain as a PDN working with CMC. Some nurses said they have established bonds with the children and once involved are hesitant to leave. Longevity with a case is important to them.

“You fall in love with the kids first off that you work with and the atmosphere in the family, if the family makes you feel welcome or makes you at least feel valued that you're coming in, that you feel safe when you're in the home.”

“I know we're not supposed to, but of course, we get attached a little bit to the children. And it's hard to leave home, especially if you've been with them for a while. And the families sometimes you just really click really, really well.”

“And I really like sticking with a child for a long time to see their progression. And it's so nice to see them grow and improve medically, and it's just awesome to be a part of that and get to see it.”

“Just being a part of that and seeing these kids just becoming the most that they can be, to achieve their greatest potential, is for me just really special. Some have less potential than others do, and that's a different situation, but you still got to love them and give them that attention and support...I'm only part-time...I'm trying to just branch out a little bit but I can't let it go. I love it.”

RESULTS AREA 8: CAREER ADVANCEMENT AND WORK CULTURE

Respondents shared that some PDNs leave the field to seek other opportunities because there is little room for career advancement in the PDN field. When asked about career advancement opportunities, over one-third of respondents somewhat or strongly disagreed that PDN positions offer career advancement opportunities (52/138; 37.7%). See Table 20 for details.

Table 20. Respondent’s agreement with career advancement opportunities

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I have career advancement opportunities in my job (n=138)	20	32	49	37
	14.5%	23.2%	35.5%	26.8%

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

Nearly all respondents somewhat or strongly agree that they receive feedback on their job performance from the agency (123/138; 89.1%) and receive adequate employee recognition (107/138; 77.5%). See Table 21 for details.

Table 21. Respondents’ agreement with agency personnel practices

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I receive feedback on my job performance from the agency (n=138)	7	8	36	87
	5.1%	5.8%	26.1%	63.0%
I receive adequate employee recognition (n=138)	13	18	50	57
	9.4%	13.0%	36.2%	41.3%

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

FINDINGS B: FACTORS THAT CONTRIBUTE TO GAPS IN CARE

The findings presented in this section capture PDNs perspectives on how various factors contribute to gaps in coverage.

RESULTS AREA 9: INADEQUATE TRAINING

Some agencies, but not all, provide PDNs with an orientation and preceptorship when they first start on a case. If this is an option, preceptorships/trainings with the current nurse can last from a few hours to several days as captured by the following exemplars.

“If I’m not comfortable with something, at least I could say, ‘Could I have another day out there with that so I can see that again?’ That’s why I like to do the preceptorships and not doing just a meet and greet because if I don’t feel comfortable I can go back and say, ‘Let me have another week out with this person before I take a shift.’”

“If they have regular nurses already, you might go in and kind of just do a partial shift with them...just to kind of see where everything was...so I wasn’t like fish out of water, just to see where all her stuff is and that type of thing...or if it’s very complex...they gave us days of training...maybe a week of training with another nurse.”

Once on the job, some agencies offer trainings to PDNs on new equipment and/or refresher trainings. For some, competencies are assessed annually. These sessions allow PDNs opportunities to refresh their skills. Some trainings are completed remotely viewing videos, using virtual platforms, or face-to-face in training labs.

Assertion 10. Nurses value orientations, preceptorships, ad hoc trainings, and competency reviews. However, they observe some colleagues are undertrained; those that are undertrained may leave a case, creating a void in coverage.

PDNs believe they are adequately trained and if not will ask for additional training. However, families may request they leave a case. In addition, some PDNs find themselves in situations where other PDNs assigned to the case appear to be undertrained.

“Unrealistic family expectations have increased and they don't care there is State nursing regulations/ standards. The nursing agency I work for backs up their nurses, that usually ends with family requesting nurse be removed off case. Also nurses request removal off case due to this...especially in regards to safety [of the child].”

“It doesn't happen a lot, but...there's been a handful of times where I'm just like... they either need more training or I don't know, maybe a discussion because, I can't go to sleep [with that sort of care].”

“Once they get hired, they need to support their nurses, they need to make sure they have all the training, that they have everything they need to be successful in the home. You can't throw somebody in a home and ask them to do something they've never done before and say, 'Okay, you're just on the job training by yourself.’”

RESULTS AREA 10: CHALLENGES IN PROVIDING COVERAGE

Sometimes there are gaps in care when shifts are never filled and/or a PDN cancels. From the PDNs perspective, schedulers working for agencies appear to be juggling schedules and frequently contacting nurses to request adjustments to the schedule to meet demands. Most interviewees shared that they provide their availability two to three weeks in advance to their agency provider. Requests for time off may be related to planned vacation, a doctor's appointment, and other personal reasons. However, even with planned time off, unplanned events can still occur. For instance, PDNs may need to cancel shifts unexpectedly if they are too ill to work or have a family emergency.

Some PDNs said scheduling can be unexpected and that nurses are sometimes asked to cover shifts when there is a cancellation without previous knowledge of the case.

“Well in all honesty, in most cases it's just a crapshoot...some of the families are very educated and very proactive...will actually request what they call a meet and greet...but those are few and far between, most of the time it's just, okay, Case A has a need, we have a nurse, plug said nurse into this case. If it works, great. If not, we'll try again.”

“And they might switch some nurses around to make sure that everybody's covered or they might say, 'Hey, do you mind going and seeing somebody that you haven't seen for two years?’”

“We typically give them a month in advance and if I do have to cancel for something that comes up, I typically try to give at least two weeks' notice.”

“I've been with the agency long enough and they trust me...it has happened that I've gone out to a new case without ever doing a meet and greet or just basically gotten a quick rundown from the clinical manager what the client's needs are... that's very rare. It's only if there's like an emergency need to have somebody come out there.”

Communication directly with families is discouraged, albeit, sometimes families and PDNs communicate about the schedule.

“In my case in my agency, I contact via on-call. We have 24-hour on-call. I call the on-call person and then they contact the family. My agency discourages direct communication with the family. In that kind of situation, it’s supposed to be done through the agency itself.”

“[Communication with families about schedules] is strongly discouraged because it does cross a barrier or a line that’s drawn between nurses and caregivers. But [sometimes] I feel that it is almost necessary to have some type of direct communication with caregivers.”

RESULTS AREA 11: PDNS MAY ELECT NOT TO ACCEPT AN ASSIGNMENT

When asked to cover an open shift, approximately 40% of nurses reported they sometimes/most of the time elect not to take an assignment, even if they were available to work. See Table 22 for details.

Table 22. Number and percent of respondents deciding not to take an assignment

	Never	Rarely	Sometimes	Most of the time	Always
How often do you decide not to take an assignment even though you were available to work (n=142)	18	63	55	6	0
	12.7%	44.4%	38.7%	4.2%	0.0%

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

Assertion 11. PDNs are selective in the assignments they take, thus contributing to gaps in care. The most common variables they consider include: location, travel time, home environment, shift timing, and clinical characteristics of the child that might affect their ability to care for the child (e.g., weight; acuity).

Survey and interview data revealed that several variables enter into a PDNs decision to accept an assignment. Of all reasons listed in Table 23, travel time, followed by the home environment, safety of the neighborhood, and parking were mentioned most frequently. A few nurses specify that client characteristics, such as the weight of the child, are also important considerations, as they may impact a nurse’s ability to physically care for the child.

Twenty percent of nurses may refuse an assignment based on previous knowledge of the home situation and/or client. Clinical expertise rarely factors into whether they take an assignment or not.

Table 23. Respondents’ reasons for not taking an assignment or covering a case

	Never	Rarely	Sometimes	Most of the time	Always
	27	28	52	14	3

The travel time to get to the home is too great (n=124)	21.8%	22.6%	41.9%	11.3%	2.4%
The home environment (not the case) makes me uncomfortable (n=123)	24	37	47	13	2
	19.5%	30.1%	38.2%	10.6%	1.6%
The neighborhood is not safe (n=124)	38	27	47	11	1
	30.6%	21.8%	37.9%	8.9%	0.8%
There is no place to park (n=124)	50	35	30	8	1
	40.3%	28.2%	24.2%	6.5%	0.8%
I worked with the same CMC in the past and the work was too much (n=123)	54	45	20	3	1
	43.9%	36.6%	16.3%	2.4%	0.8%
I am familiar with the case and the home lacks the necessary equipment for me to do my job effectively (n=124)	58	38	20	3	5
	46.8%	30.6%	16.1%	2.4%	4.0%
I did not feel I had the clinical skills to take the case (n=125)	85	28	10	2	0
	68.0%	22.4%	8.0%	1.6%	0.0%
Other reasons for not taking an assignment (n=78)	29	11	21	13	4
	37.2%	14.1%	26.9%	16.7%	5.1%

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

FINDINGS C: CLINICAL AND CULTURAL COMPETENCE

In addition to identifying factors that may explain PDN supply and gaps in care, survey and interview questions evaluated ways the current workforce is clinically and culturally competent. Findings are presented below. The first section explores cultural competence; the second section explores clinical competence; and the last section explores challenges PDNs experience in delivering quality care.

CULTURAL COMPETENCE

Assertion 12. PDNs said caring for a child in their home requires one to be sensitive to working in the personal spaces of the family; interacting with the whole family; and respecting and accepting diverse lifestyle and cultural norms.

Some PDNs noted there are several unique aspects to home care. For example, working in the home is different than working in a hospital setting. Caring for a CMC in their home means working in someone's personal space, interacting with the whole family, and being cognizant and accepting of lifestyle choices and cultural norms. In addition, there may be nuances about the expectations of how the family wants the nurse to care for the child.

"You're going into somebody else's personal space. So you have to be cognizant that you're not in a hospital. You're in their home and it has to be treated as such."

"When you walk in somebody else's house, you don't deal with only the patient, you deal with the whole family, and all of the siblings, and all these different cultures, and all different expectations from each family."

"I follow my orders, but I'm also not going to do something if a family's uncomfortable with it or ... Whereas in the hospital, you kind of have a little bit more leniency on what you're doing. Yes, it's still their child, but you're in a hospital whereas at home and in their home particularly, you need to be very cognizant that you need to take into account what they want for their child."

PDNs acknowledged that language may create challenges; however, interpreters and family members are often available, if need be. Nurses note that if they follow the plan of care and demonstrate competencies, families are comfortable even though communication may be a problem.

"I do work with some families that are not English speaking...so that can definitely be a challenge...the care still has to happen so hopefully you can use an interpreter if you need to and if not then you try your best to work and follow the plan of care. Again, a lot of families once they see that you can take care of the child, somehow the language isn't as important as you being able to take care of the kid."

"When they go to Al duPont for their medical procedures and all that. And many times we would get the doctor's notes or the appointment notes. Mom would come back and give them to us, but they would be in [another language]. So we have to call and say, 'Can you please send it in English?'"

"I've gone into some homes and they've just immediately said, 'Nope, we don't want [you] here,' turned me away at the door...you don't get offended because it is their home, and if they don't feel like you're going to fit in their home, they don't think you're going to respect their culture or their lifestyle, then that's their right."

Sometimes nurses will leave a case, or not accept an assignment, if they think the requested activities go beyond the necessary clinical care and/or if they feel that once on a case, the family asks the nurse to manage household activities that were not related to the care of the child, or if the nurses feel the parents are negligent.

"Some of the cases, they just broke your heart and you just couldn't deal with it anymore...[for example], when you had parents that were negligent. How long can you take care of this knowing that you can't make a difference? You've done what you can, but if you walk away that's another person that's walked away and abandoned them. Those are the ones that are really hard and nurses do walk away from."

CLINICAL COMPETENCE

In general, respondents believe they are clinically competent. As noted previously in the report, the majority of respondents rated themselves as experienced or highly experienced in caring for CMC. See Table 7 for details. Over two-thirds of respondents (95/137; 69.3%) strongly agreed they receive the necessary information about the case from their agency; the majority also

strongly agreed they receive appropriate training from their agency (100/138; 72.5%) and are adequately trained care for the CMC cases they are assigned to (118/137; 86.1%). See Table 24 for details.

Table 24. Respondents’ agreement with adequacy of training provided by the agency provider

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I am given access to information that adequately prepares me for my case (n=137)	8	8	26	95
	5.8%	5.8%	19.0%	69.3%
I receive the training I need from my agency to be successful at my job n=138)	7	4	27	100
	5.1%	2.9%	19.6%	72.5%
I am adequately trained to care for the CMC cases I am assigned to (n=137)	3	0	16	118
	2.2%	0.0%	11.7%	86.1%

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

CONCERNS REGARDING QUALITY OF CARE

Assertion 13. Nurses report barriers to delivering quality care including: insurance policies; clinical practice policies, lack of adequate supplies; challenges by family caregivers about the PDNs approach to care delivery practices; and care communication between PDNs and across agencies.

While most PDNs expressed compassion and a deep caring for their clients, some PDNs recognize that not all of their PDN colleagues deliver quality care. PDNs describe some of their colleagues as “lazy”, “not having a work ethic”, and/or “not interested in [meeting] the basic needs”.

“The [CMC] cannot express that they need the care, that doesn't mean they don't know. They still know that they're uncomfortable...you check it out...if there were some blankets wrinkled up...make them a little bit more comfortable...it seems like to me, those are the very, very basic nursing...but well, you just cannot expect from these nurses.”

PDNs attribute the lack of trained colleagues to agency practices and policies as captured in the following exemplars:

“There is a competition for nurses across agencies...some [agencies] are considered more professional as far as like accountability and quality of care delivered.”

“Just that all agencies are not the same...there's not scrutiny of the agencies. I've worked for some pretty bad agencies, there's definitely a huge difference between agencies.”

“I’ve worked for agencies who have never laid eyes on me and still sent me a check. Family hired me, and I never even talked to the agency. They didn’t know if I existed. I just sent them my license number and nursing notes and a check would come. But never an interview with me, I don’t even know if they background checked me. There’s some pretty bad agencies.”

CHALLENGES TO DELIVERING QUALITY CARE

While PDNs feel clinically competent, the following section captures information that affect their ability to deliver quality of care. First, PDNs do not always have adequate supplies to perform job duties, nor do families have durable medical equipment necessary for care. While over 90% of PDNs reported that they did have adequate supplies and the homes they work in had the necessary durable medical equipment, slightly over 5% of respondents disagreed that they had the resources necessary to perform their job. See Table 25 for details.

Table 25. Respondents’ agreement with adequate supplies and equipment to provide quality care

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I have adequate supplies to perform all my job duties (n=137)	2	7	37	91
	1.5%	5.1%	27.0%	66.4%
The homes I work in have the necessary durable medical equipment to care for the child (i.e., equipment designed for long-term use) (n=136)	2	6	31	97
	1.5%	4.4%	22.8%	71.3%

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

Second PDNs feel insurance policies interfere with quality of care delivered. For example, PDNs perceive care is jeopardized when children are required to be switched to tier 1 or 2 medication, rather than continuing on the tier 3 medication they have been stable on for years.

“That’s something that really, I don’t want to say that I try to advocate for, but it just doesn’t make sense to me. If somebody has been on a certain medication for so many years, why do they have to try the tier one, tier two medications to get back up to the tier three medication that’s been working for them now they have to jeopardize their entire care and their entire life to try these medicines that you say they have to try before they can go back to what they’re used to. Things like that.”

Third, PDNs question why they are not allowed to accept verbal orders from a nurse practitioner over the phone when the same nurse practitioner sees the child during a face-to-face visit.

“We are not allowed to accept orders from a nurse practitioner or a PA... my requirement is I have to have an MD or DO to sign off on this...for us it was kind of frustrating because if these nurse practitioners were able to conduct the visit and give a prescription and everything else, why could we not accept a verbal order? That's something I would like to see changed eventually.”

Fourth, PDNs observe that the same opportunities for care are not provided in the home compared to facilities.

“I guess I just feel that the same opportunities for care are not always provided to home health cases versus facilities. They might not always have the availability for a medication.”

A fifth challenge is working with family caregivers. Over two-thirds of PDNs note that it is at least sometimes challenging to work with families (96/136; 70.6%), albeit, it is rarely due to families asking the PDN to do things unrelated to their job. See Table 26 for details.

Table 26. Respondents’ agreement with challenges in working with families of CMC

	Never	Rarely	Sometimes	Most of the time	Always
It is challenging to deal with family members (n=136)	11	29	82	9	5
	8.1%	21.3%	60.3%	6.6%	3.7%
I am asked by the family to do things that are unrelated to my job (n=136)	44	41	43	6	2
	32.4%	30.1%	31.6%	4.4%	1.5%

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

When asked to elaborate on challenges with families, PDNs note that mostly they are challenged by family members about care delivery practices. In response, PDNs often share their clinical knowledge, contact their clinical manager for back up in necessary, or compromise with the family if changes in a routine does not impact the safety of the child or change the care plan.

“Challenges are sometimes families want to do things a certain way. They do care a different way that maybe is not the most appropriate or most grounded in science for nursing to do. So some of them can be complex about how care is done. Parents may want you to do things or not do things that are not consistent with the plan of care.”

“I also rely on my clinical managers to back me up if I bring up an issue, and I have gone over reteaching with a caregiver and they still... It's just not clicking with them, or they're doing whatever they want to do.”

“I'll explain the reason I do it the way I do it. And if they don't agree with that, then I'll say, 'What can I do? How would you like me to do it?'... Because it's their child. They know their child best. I'm a guest in their home. I am working there, but it's also still their home and their child.”

CARE COORDINATION COMMUNICATION

Quality of care sometimes suffers due to communication challenges within the same agency and across agencies. Nurses suggest that communication can improve with better documentation, one central care plan, and access to up to date care notes from primary care providers, ED visits, etc., as well as better systems for ordering supplies and medications. The following exemplars capture care coordination communication issues:

"When there's more than one agency [involved], the communication is not really good between individual nurses."

"[Communication] just in the same agency...there's a [shift] break between one nurse and another nurse and unless there's really good communication, things happen that fall through the cracks. I think that's the biggest issue that I have with care for the most part, is the communication, documentation especially like I said in between nurses and in between agencies."

"Each agency has their own plan of care. There's not one central plan of care...they should look similar but sometimes they're not exact because sometimes, for example, one agency may have a medication as a PRN medication, another agency may have it as an ongoing medication...one agency has the dosage change and the other agency doesn't have, somehow that didn't get communicated. There's feedings change, the amounts of feeding, the rates of feedings, things like that."

"For example, if you work with [agency name]...they get a complete medical history, background, everything. Even the CNAs and health aids in the home, they can see doctor visit summaries and everything with the software that they have...with my agency, I can't. It's possible, but then the reason I was always given is it was kind of a need to know. They felt that we had the information that we needed, that we didn't need to know everything else, we didn't need to know the whole backstories. It's frustrating."

"I've been on some cases where there are two different agencies and then others when it's just the one agency. And either way it's consistency and communication. We have a little tablet that you're supposed to write things down in. I always write down if I place the order or call it in prescriptions, but not everyone does. So it's just something that should be more consistent. I actually found it was more communication between two different agencies than now that I just have one agency on the case."

Even though written communication in notebooks and electronic communication can help to share information, nurses would like to see more communication.

"We also have in the homes, what we call a communication book, which is just a tablet, a spiral. And we can summarize the shift that we just completed and write pretty much anything, 'Can you follow up on this?' Can you keep a closer eye on this?"

"A lot of us share phone numbers with each other, so we can talk to each other...but there's not a whole lot of communication between nurses...I wish there was more...I would like to have more communication."

PDNs do not always receive consistent information when they have a question, even from personnel working in the same agency.

“There have been specific times when I have tried to contact the office to narrow down a specific policy or procedure...and I don't get an answer...and I call the next person in line, don't get an answer...call the next person in line, they answer, 'I don't know, I have to look it up.' In the meantime, the first person gets back to me and says, 'Oh, well this is the case.' Then person two gets back to me the next day and it's totally different from what person A said.”

SUGGESTED SOLUTIONS FROM THE PDN PERSPECTIVE

Admittedly, PDNs said that convincing nurses to join the PDN field in light of low pay, lack of benefits, unpredictable take home pay, may be a “hard sell” until these issues are resolved. At the same time, they offered the following suggestions.

SUGGESTIONS FOR AGENCIES, INSURANCE COMPANIES, & DMMA

PDNs offered several suggestions that address supply issues as well as gaps in care.

OFFER COMPETITIVE MONETARY COMPENSATION

- ✓ PDNs believe a “decent” and “competitive pay scale” would incentivize nurses to work as private duty nurses. Suggestions included offering:
 - Pay scales comparable to what nurses would earn in other settings.
 - Differential pay based on client acuity, shifts, weekends, and holidays.

“I think there should be a different pay scale...[for the person who] is picking up all the extra shifts...I think they should be rewarded differently.”

- ✓ PDNs believe if the low wages and poor benefits were addressed, more nurses may be willing to join the PDN workforce and stay on once hired.

“Agencies are really eliminating a large sector of nurses that would be very good in this job just by the benefits.”

SUGGESTIONS FOR AGENCIES

IMPLEMENT INNOVATIVE RECRUITMENT AND RETENTION PROGRAMS

- ✓ PDNs appreciate some of the recruitment and retention programs initiated by the agencies. Such innovations may help with recruitment and retention, even if there are differing opinions about the programs.

“Right now my agency is giving \$5,000 sign-on bonuses to new nurses...I think we would get \$3,000, they would get \$2,000...I get \$3,000 after they work 40 hours...but I don't think [the agency] needs to put the money towards the nurses that are actually here because I could leave and get more money I think working somewhere else.”

"They have a program where they issue us this dollar amount and then we can shop with it. So a lot of times they will, if we pick up a shift out of appreciation, they'll award us those dollars."

- ✓ Creating a career ladder may improve PDN retention.

"The agencies that hire these nurses to be able to pay them an equal wage and give them benefits that are equivalent and give them a reason to encourage their nurses to go get BSNs and MSNs and give them a career ladder within home care. So those are the things that I think would improve that shortage."

"Basically with home care nursing, there's not a lot of places to go up and out especially if you want to continue to do hands on nursing. So if you want to do administrative work, then you can kind of move up...but if you really just want to do hands on nursing, there's not a lot of places to advance and in general, they don't encourage you to advance your career, to get advanced degrees. There's no incentive for that."

- ✓ Consider alternative work assignments to alleviate the problem of reduced take home pay when shifts are cancelled. Ideas include having nurses whose shift(s) was canceled to work in the office, pickup supplies, or assist the agency in other ways.

RECRUIT NEW GRADUATES TO WORK AS PDNS (AND PROVIDE TRAINING)

- ✓ PDNs had mixed message about recruiting new graduates to work as PDNs. Most PDNs felt new graduates need an acute care experience before working as a PDN in the home caring for CMC. PDNs rationalized that new graduates need to first build their confidence and skills before working alone in the home. This is particularly true so new graduates can respond appropriately to clinical emergencies, as well as knowing when and how to reach out to physicians and specialists to advocate for the client. Many comments circled back to the fact that PDNs have multiple roles and new graduates may not be able to juggle all of those roles and responsibilities.

"I would not say a brand new nurse should do home care nursing. They need the experience and have people at their back that are right there to learn. I would say you need to do at least a few years in the hospital."

- ✓ Some joined the PDN workforce as a new graduate themselves and would encourage others to do the same with some caveats. All referred to training provided by the agency as a necessity. In some cases, the training lasted for one month. Those who did join, felt the training was sufficient and prepared them for the job. Some felt new graduates should start with "low-tech" cases.

"I started [as a new graduate]...I was provided [training] which I was very thankful for...and I found that it completely prepared me for the job setting that I'm in today."

“I would recommend new nurses to do home health care, especially if they have any kind of medical background and they understand what is going on in the home setting versus other settings.”

“A new graduate could come on and do low-tech cases and I think they would be fine...and of course, the agencies are going to provide whatever training they need...when you first get hired that you'd have to go through and demonstrate your skills, go through any extra training for skills that you don't have. So it is a process.”

COLLABORATE WITH NURSING SCHOOLS TO INTRODUCE STUDENTS TO PRIVATE DUTY NURSING

- ✓ Regardless of the debate about new graduates and whether or not they need experience prior to entering the field, PDNs do believe schools should begin to rotate nurses through the CMC home care setting.

“If we could get private duty nursing to be a rotation in some of the nursing schools to kind of expose the nurses...because a lot of nurses probably don't even know about it.”

“As long as you get the education and the training, there's no reason that we couldn't bring in new grads and at least start them on some of those other cases, which would free up the nurses that maybe have been with private duty that now have some experience or have the background to work with the more complex patients.”

PDNS SUGGESTED THAT AGENCIES ENSURE NURSES ARE APPROPRIATELY TRAINED

- ✓ PDNs value training and believe all agencies should ensure nurses have access to appropriate training. One suggestion was to have a group of preceptors available to train PDNs.

“Have a handful of actually vetted, qualified preceptors to orient the new hires or new to the cases.”

SUGGESTIONS FOR DMMA (AND FAMILIES)

WORK WITH PARENTS TO FIND THE RIGHT PDN FOR THEIR CHILD.

- ✓ Consider creating a formal assessment of what parents want for their child to assist in matching nurses to families.

“Ask parents what do you expect out of a nurse? Have a nurse's list of what they're comfortable with, because some nurses are scared of technology, they don't want to deal with these ventilators. Some nurses are fine with the technology but they're not so good with kids that can speak their own mind and where they're going to have to have some discipline issues or anything like that. It's good to know what the nurse's comfort level is and what the parents' expectations are, because we have some parents that their only expectation is there's a warm body there. That's it. Throw a warm body in that room with that kid, they're fine.”

PROVIDE FAMILY NAVIGATION SUPPORT

- ✓ Consider assigning navigators to assist family caregivers.

"I don't know what [caregivers] need - I don't know if it's more social workers to help kind of with the intricacies of trying to change suppliers...or how many different nursing agencies you have to go through to get the coverage you need...just the stress and the time on the phone trying to get things worked out by the families is immense and there's got to be some way to make it better."

CONCLUSIONS AND RECOMMENDATIONS

Survey and interview data gathered from the PDN population provides evidence that there are gaps in PDN services resulting in shortages in nursing care for CMC. Findings and recommendations are organized into four sections. The first section focuses on findings and recommendations related to factors that influence the supply of PDNs. The second section focuses on findings that influence gaps in care from the PDN perspective. The third section focuses on findings that address what was learned about PDNs cultural and clinical competencies. The last section reviews next steps regarding further research and evaluation that are important to consider in order to more thoroughly understand the PDN shortage, gaps in care for CMC, and clinical and cultural competencies. 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.

FACTORS THAT INFLUENCE THE SUPPLY OF PDNS

FINDINGS

- ⇒ PDN respondents were affiliated with 6 of 13 Delaware agency locations that participated in the DMMA:Agency outreach calls. Respondents were mostly female; equally divided among RNs and LPNs; and over ninety percent described themselves as experienced or highly experienced in caring for CMC.
- ⇒ PDNs identified low pay, limited benefits, and unpredictable take home pay as disincentives in motivating nurses to join the private duty nursing workforce, take on full-time positions, and stay employed as a PDN.
- ⇒ PDNs join the workforce because they need or want the flexibility in scheduling provided by a career as a PDN. In many cases, the flexibility in scheduling is the most important reason they elect to work as a PDN, irrespective of low pay and costly benefits.
- ⇒ Other major factors influencing a nurse's choice to become a PDN caring for CMC in the home include, they:
 - ✓ enjoy working with children;
 - ✓ thrive when working autonomously;
 - ✓ enjoy working 1:1 with CMC and establishing a bond with the child and family;

- ✓ have opportunities to use high tech nursing skills (note: some nurses, however, leave the field due to fear of losing those skills);
- ✓ can work as a PDN while also being employed in other jobs;
- ✓ are LPNs and have limited job opportunities in other nursing settings; and/or
- ✓ are not concerned about subpar PDN wages or benefits because they have benefits through a spouse/partner or another job.

⇒ PDNs pointed out that the same reasons they are attracted to work as a PDN are the very reasons other nurses are not interested in working as a PDN, or elect to leave the field. Of all the reasons listed above, PDNs repeatedly shared that the flexibility in scheduling is a key reason nurses join the PDN workforce. However, PDNs noted that some hospitals and other settings now offer competitive flexible scheduling and benefits.

RECOMMENDATIONS

⇒ *Address low pay, limited benefits, and unpredictable take home pay*

- ✓ If factors such as low pay, limited benefits, and unpredictable take home pay were addressed, it is possible gaps in care could be reduced. Currently these are disincentives for nurses to join the PDN work force, and for PDNs currently employed to stay on, and/or to work full-time. Further, not addressing these factors may restrict the pool of nurses who can be employed as a PDN.

⇒ *Support agency providers, MCOs, and other stakeholders to address solutions*

- ✓ As federal funds become available to states for Medicaid home and community-based services, continue to work with stakeholders to identify priorities.
- ✓ Factors that impact care coverage, as identified by PDNs in this study, often circle back to agency providers and MCOs. Brainstorm across stakeholders regarding agency providers' recruitment policies, including increasing interactions with academic and tech training as well as education programs; easing restrictions on wage increases; and perhaps reevaluating hours and types of PDN coverage authorized on a case-by-case basis.

⇒ *Develop recruitment and retention innovations that focus on factors that motivate nurses to join the PDN workforce*

- ✓ Use the findings about why PDNs elect to work with CMC in the home to guide, design, and implement training, recruiting, and retention program innovations. Brainstorm about how these findings can be used by leadership in government, agencies, professional organizations, and schools to design such innovations.

- ✓ With respect to recruitment efforts, reaching out to LPNs may be helpful given that LPNs are more likely to agree their pay scale is about right for the work they do compared to RNs.
- ⇒ *Review PDNs suggestions to incentivize nurses to join the PDN workforce*
- ✓ PDNs provided a number of suggestions to address the limited supply of PDNs in the workforce. Review, consider, discuss, and prioritize suggestions. See section, “Suggested Solutions from the PDN Perspective.”
- ⇒ *Disseminate information about the value of PDNs and the care and service they provide.*
- ✓ Capitalizing on the role PDNs play and the contributions they make may be helpful in recruiting and retaining nurses.

FACTORS THAT IMPACT GAPS IN CARE

FINDINGS

- ⇒ PDNs make decisions about what cases to accept based on a number of variables including: location, travel time, home environment, shift timing, and clinical characteristics of the child that might affect their ability to care for the child (e.g., weight; acuity).
- ⇒ PDNs have worked on cases where they didn’t feel nursing care was justified and other cases where it was and families were not getting authorized for the hours they need.

RECOMMENDATIONS

- ⇒ *Create favorable conditions so more nurses take on assignments*
- ✓ Before accepting an assignment, PDNs consider location, travel time, home environment, shift timing, and clinical characteristics of the child that might affect their ability to properly care for the child (e.g., weight; acuity). Brainstorming how to address issues that influence PDNs taking an assignment and how to best support PDN concerns regarding issues that may improve coverage, including but not limited to:
 - Offering mileage reimbursement; and
 - Identifying, advocating, and connecting families to various social services, particularly those that focus on improving living conditions for families with CMC (e.g., housing cleanliness).

CLINICAL AND CULTURAL COMPETENCIES

FINDINGS

- ⇒ Respondents believe they are clinically competent and rated themselves as experienced or highly experienced in caring for CMC.

- ⇒ Prior to joining a case, two-thirds of respondents strongly agreed they receive the necessary information about the case from their agency; the majority also strongly agreed they receive appropriate training from their agency, albeit, they describe situations where colleagues are undertrained for the respective assignment. PDNs attribute the lack of trained colleagues to agency practices and policies.
- ⇒ Appropriate training, orientation, and preceptorship allow nurses to build trust with the families. When orientation and preceptorship procedures are not followed, some nurses end up leaving the case creating another void in coverage.
- ⇒ PDNs report quality of care is impacted by insurance policies; competition across agencies; care coordination communication; lack of training; and lack of adequate supplies and equipment to provide quality care.
- ⇒ PDNs identified several challenges to delivering quality care including, but not limited to, family caregivers who ask they not follow the care plan and/or challenge their clinical expertise and judgement.
- ⇒ Nurses note that if they follow the plan of care and demonstrate competencies, families whose primary language is not English are often satisfied even though communication may be a challenge.
- ⇒ Nemours often sends the clinical visit summary home in the primary language of the caregiver. While useful for the families, PDNs cannot read the clinical visit summary.
- ⇒ PDNs observed that working in a CMC's home means working in the family's personal space, interacting with the whole family, and being cognizant and accepting of lifestyle choices and cultural norms.

RECOMMENDATIONS

⇒ *Address factors that impact the delivery of quality care*

- ✓ Consider required preceptorships, training, and competency reviews for all PDNs across all agencies. Include training(s) that focuses not only clinical skills and nursing practice but also on communication and interpersonal skills and the social-cultural nuances of working in the home. Consider opening training opportunities across agencies.
- ✓ Ensure all homes have the necessary equipment required to lift and move the child. For example, begin by evaluating whether the recommended maximum lift for health care workers set by the National Institute for Occupational Safety and Health (NIOSH) is appropriate for the CMC population.

- ✓ Address situations where PDNs don't have the necessary information about the case from their agency prior to arriving at the home.
- ✓ Address situations where English speaking PDNs do not have clinical care information in English; for example, when follow-up care information is sent home with the families from Nemours in a language other than English.

FURTHER RESEARCH AND EVALUATION

RECOMMENDATIONS

⇒ *Conduct further research using quantitative data from the DMMA, MCOs, and agency providers*

- ✓ Examine quantitative data from DMMA, MCOs and agency providers, will allow greater insights into PDN gaps in care in the following areas:
 - Severity and longevity of gaps in care, including how many hours are authorized, covered, and missed, as well as trends over time (e.g., by month, year, season);
 - Trends in PDN supply juxtaposed against demand data;
 - Differences in geographic locations in order to better understand service location needs; and
 - How gaps in care differ by case acuity.

By using quantitative data, DMMA can pinpoint specific factors associated with the PDN workforce capacity for this population as well as develop and align programmatic and policy solutions.

⇒ *Review the literature*

- ✓ Review the academic and gray literature to identify evaluations and studies that address similar challenges regarding gaps in care and PDN nursing shortages. It is possible other states are facing some of the same challenges and may have identified innovative solutions that Delaware might adopt or adapt. These may include innovative strategies and program models such as policy initiatives, model innovations, and collaborations across government, insurance, agency providers, schools, and professional organizations.

⇒ *Track why PDNs leave the field*

- ✓ Systematically conducting exit interviews with PDNs who leave the field may provide valuable information and/or corroborate and clarify findings from this study. Such information may contribute useful information for increasing the retention of PDNs for CMC.

⇒ *Triangulate findings with other study populations from the Private Duty Nursing Workforce Capacity Study*

- ✓ PDNs provided insights into factors that contribute to nursing shortages and care gaps. Salient findings and themes identified should be triangulated with findings from the agency, family caregiver, and non-PDN workforce study populations. Understanding how perspectives are similar as well as how they differ between groups is important given that a “shortage” and gaps in care may be interpreted differently by different stakeholders.

⇒ *Collect data from MCOs and DMMA*

- ✓ Consider collecting data relevant to the study questions from insurance company representatives and DMMA policy makers. Both are important stakeholders that were not part of the sampling strategy for this study.

STUDY LIMITATIONS

This study has several limitations. First, participants were reached through a two-stage sampling method. That is, agencies were contacted and asked to send the survey to their roster of PDNs. With this method, we did not have direct control over sending surveys to potential respondents, nor were we able to directly follow-up with reminder emails. While the survey theoretically should have reached nearly all PDNs in Delaware, it is possible that some PDNs did not receive the survey and thus did not have the opportunity to respond. Thus, the resulting sample is likely not representative or truly random given this survey distribution method.

Second, PDN interviews were only conducted with PDNs who participated in the survey and provided their contact information at the end of the survey. Data reflects those nurses affiliated with 6 of 13 agency locations.

Third, a limitation of this study is that count data from DMMA, MCOs, and agency providers were not available. Accurate count data are critical for truly understanding the scope and severity of PDN workforce capacity shortages, as well as for determining whether gaps in services are associated with certain types of care or skills. Without count data, including the

- 1) number of hours authorized;
- 2) number of hours scheduled, charged, and missed; and
- 3) number of PDNs available;

as well as other details about PDN employment status and family PDN service data, gaps in care cannot be thoroughly understood. It is recommended that findings from this study be combined with an analysis of quantitative count data from DMMA, MCOs, and agency providers in order to develop strategies to remediate service gaps.

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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.

APPENDIX B. PDNS' PERSPECTIVES ON THE EFFECTS OF GAPS IN CARE ON CHILDREN AND THEIR FAMILIES

Assertion 14. PDNs empathize with family caregivers who struggle with gaps in coverage.

Nurses are sensitive to the needs and struggles of family caregivers when there are gaps in coverage. They see families struggle with maintaining their employment, finances, and family structure, as well as the continued exhaustion and stress as they try to juggle the many aspects of caring for their child and families.

"It's very difficult, because there's just not enough staff in home care, and you feel terrible as a nurse even calling out, because you know that the family cannot go to work."

"With nursing [gaps in coverage], part of them, it's like, well maybe [the family caregiver] should just quit their job. They'll be poor. And then they're going to need help from the government [if the caregiver can't work]...but the caregiver is like, 'What am I supposed to do? I don't have the coverage that I need. I can't work and stay up all night. We just can't.'"

"The [family caregivers] are exhausted. It's a lot of work [to care for their child] because it's appointments...it's PT coming in the home, OT coming in the home. [Family caregivers] got nurses coming into your home... every time you have to [take the child] to AI, it's a huge process."

"It's also important to realize that when nursing isn't available, the effects that it has on the family. Families having to take off work, families having to be sleep deprived, it puts a lot of stress on the families. It puts them oftentimes in economic issues."

"[I'm concerned for] their marriage...sick children can cause quite a deal of stress on a marriage."

"The families are in such a state of always panic. What if somebody calls out? Or what am I going to do if somebody gets sick? The stress on the families, I just don't think they get enough help."

PDNs note that some families use multiple agencies in order to get enough support for their child or pay out of pocket for services:

"I have a number of families that have two and three different agencies just trying to staff every night. I don't know of a single case that has gone a whole month without having a hole, meaning they didn't have a nurse for either a night shift or a day shift. It's tough."

Without adequate care and coverage, nurses point out there are economic costs for society and health care costs for CMC associated with gaps in care.

"It's a higher cost to us publicly because [the children] end up in the hospital and Medicaid is paying for those hospital stays...so taxpayers' money is getting wasted because there's this unavailability of nursing and home care."

“Chances are when I get there again, since [the caregiver] is the only one's been taking care of the child and the child might end up sick just because [the caregiver] is exhausted...they also have other kids and a family, and a home. It's just frustrating and they know it. [They] feel bad. But you just can't do everything.”

Challenges in recruiting nurses to cover family service needs

Comments often circle back to factors that impact recruiting nurses such as the unpredictable nature of the work and pay.

“Family after family after family will tell you they're desperate to get sleep, and there's just not enough nurses willing to take the risk of not getting a 40-hour week or not getting their hours or taking less than they can make if they're working at a hospital or another setting.”

“Families [are] losing income when we cannot staff them, they don't have a nurse for the day they have to call out of work, so we're not the only ones being impacted by this whole payout issue.”

“[Parent advocates are] petitioning...for better reimbursement...I just feel for these families, it's tough. They have a hard time and to not have the nursing that they need makes it much more difficult.”

APPENDIX C. PDNS’ PERSPECTIVES ON JOB SATISFACTION AND REWARDS IN CARING FOR CMC

Providing care to a CMC provides a sense of fulfillment

Nurses find working with CMC fulfilling. The majority of nurses note they have a sense of pride in their work (125/138; 90.6%), believe they make a difference in the lives of the children they care for (127/137; 92.7%), and also believe their skills are valued by the families (111/136; 81.6%). See Table 27 for details.

Table 27. Respondents’ agreement regarding job rewards in providing care to CMC

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I have a sense of pride in my work (n=138)	4	0	9	125
	2.9%	0.0%	6.5%	90.6%
I make a difference in the lives of the children I care for (n=137)	4	0	6	127
	2.9%	0.0%	4.4%	92.7%
My skills are valued by the families of the children I care for (n=136)	4	2	19	111
	2.9%	1.5%	14.0%	81.6%

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

Multiple exemplars from the interviews support these survey findings. Nurses often reported that working as a PDN is rewarding. At the end of the shift, one feels they have made a contribution in caring for a CMC, which one nurse described as a “*sacred responsibility.*”

“After you take care of the patient, end of the day, you feel pretty good like you’ve done something that is worth it.”

“Families and children depend on us to not only keep their child home where they deserve to be but most of my cases I take to school. The family and the kids can rely on me to care for any medical issues that may arise while their child attends school in a public school setting. The CMC get the socialization, therapies and education they deserve and are entitled to while the parents know they will be kept safe during the day.”

“Home care is sacred responsibility.”