

**Private Duty Nursing Workforce Capacity Study:  
Agency Representatives:  
Interview Results**

Authors:

Mary Culnane, MSN, MS  
Sue Giancola, PhD

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

[cresp.udel.edu](http://cresp.udel.edu)  
Twitter: @udcresp

## **CRESP Leadership Team**

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

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# Private Duty Nursing Workforce Capacity Study: Agency Representative Interview Results

## EXECUTIVE SUMMARY

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

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

- Agency representatives report a critical shortage of nurses to care for CMC. In addition, agency providers compete for the same pool of nurses.
- Agency representatives believe the number of CMC has increased in the past five years and predict that if they were able to staff and take care of the children who qualify for care but who are not currently covered, their case load would increase significantly.
- Agency representatives attribute the PDN nursing shortage to individuals choosing careers other than nursing; nurses choosing to work in competitive work settings other than home care; and nurses perceiving working as a PDN in the home as a liability.
- According to agency representatives, nurses who choose PDN work with CMC do so because they want a flexible schedule; a slower paced job; and to work with children.
- Given the current reimbursement climate, agencies tend to recruit LPNs rather than RNs, even though agencies recognize that some children would benefit from having the skill set of an RN.
- Agency representatives report delays in hiring due to the lengthy process of getting fingerprints processed at the state level.

- Direct and indirect compensation varies across agencies. Workforce stability is affected as nurses leave the field for more competitive benefits or switch agencies based on wages and incentives.
- Low wages, poor benefits, and unpredictable pay have repercussions for PDN health and well-being, family caregiver satisfaction, and workforce stability.
- Gaps in care result when there isn't a good fit between PDNs and the family.
- Lack of home nursing coverage negatively impacts family caregivers and also creates anxiety for agency personnel who are working to fill open shifts.
- Agencies differ with respect to the types of training they offer, including orientation and preceptorship experiences.
- Agency representatives believe private duty nursing care for CMC is underfunded thus making it difficult to cover costs to recruit, train, prepare, incentivize, and pay PDNs. In some cases, agency costs are barely covered.
- Agency representatives observe the demand for in home care from all sectors of the population is increasing given the changing demographics in the state. They are anxious to work on innovative, creative solutions to meet the demand, particularly for PDNs who work with CMC.

See the full report (T21-026) for a list of recommendations based on these findings.

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# **PRIVATE DUTY NURSING WORKFORCE CAPACITY STUDY: AGENCY REPRESENTATIVE 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 interviews conducted with nursing agency representatives 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 for family caregivers and PDNs were made available in Spanish, Creole, and English. Survey instruments and interview protocols may be requested from CRESPI.

## 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 ( $\chi^2$ ) 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: AGENCY REPRESENTATIVE INTERVIEWS**

### **AGENCY REPRESENTATIVE INTERVIEW INSTRUMENTS**

The agency representative interviews were designed to collect data about the PDN workforce and characterize demand for services from the perspective of the agency providers who recruit, employ, train, schedule, and manage PDNs who care for CMC. The semi-structured interview protocol explored the following topics from the agency representative perspective:

- Factors that impact the supply of PDNs;
- Factors that impact gaps in care; and
- The agency's role in ensuring PDNs have the necessary clinical and cultural competence to care for CMC in the home.

### **IDENTIFYING THE AGENCY REPRESENTATIVE SAMPLE**

All agencies in Delaware who employ PDNs and provide hourly shift services for CMC in the home were eligible to participate in the study. 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 identified, DMMA met with leads from 13 agency locations during several study outreach calls. During the calls, DMMA and CRESP provided information about the study, and sought collaboration and cooperation from the agencies.

Agencies were asked to identify an agency representative(s) willing to participate in an in-depth interview with the CRESP research staff. Representatives from all 13 agency locations were eligible. While operational structure varied across agencies, research staff offered guidance that the ideal person at their agency for the in-depth interview was likely an operations/clinical director that not only understood business operations but also had a strong overall knowledge about the front-line factors associated with managing, coordinating, and scheduling nursing care for CMC in the home.

### **INTERVIEW RESPONSES**

Following the DMMA:Agency calls, CRESP coordinated recruitment, scheduling, and data collection efforts with agency contacts. All 13 agency locations were invited to participate in the in-depth interview and were asked to identify a representative from their organization to participate. CRESP followed up with all agencies via telephone calls and/or emails to encourage participation in the study, as well as clarify any expectations or answer any questions. Eight agency representatives, representing six unique agencies who provide PDNs for CMC care in the home, participated in the interviews. All interviews were completed during May and June 2021.

## FINDINGS A: FACTORS THAT INFLUENCE THE SUPPLY OF PDNS

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

**Assertion 1. Agency representatives report a critical shortage of nurses to care for CMC. In addition, agency providers compete for the same pool of nurses.**

Agency representatives report the pool of nurses to choose from to serve as PDNs for CMC has dwindled. Not only is it harder to find nurses, there is competition across agencies for the same pool of nurse(s).

*"It's harder and harder to get nurses to want to do it. It's a different type of nurse that's coming out these days. It's just a different level. It's harder for us to find these nurses, because when I first started there was four PDN agencies in Delaware that were doing pediatrics. Now, there's probably 12 or 13 and we're all fishing for the same nurses, and so it's hard. I think every agency is really struggling with that, but for us it's definitely been really challenging to staff these new, higher-acuity cases because the staffing's just not there."*

*"Home care agencies have increased probably by threefold at least, so that's a smaller pool of nurses, and there's just less people getting into nursing."*

*"This has been...this has been the worst nursing shortage I have seen in years."*

**Assertion 2. Agency representatives link the nursing shortage to the large increase in the number of referrals, perhaps due to an increase in the number of CMC needing homecare.**

*"I don't know, from my perspective there's just more kids that have medical complexities now than there was even five years ago. I don't know if my perception's off, but that's what it seems like from looking at just the volume of referrals that we're getting."*

*"The amount of referrals that we get has increased exponentially. We were talking about a few here and there; to I have a whole list...it's just an ever-going list of kids that are ... A lot of infants, a lot of kids under 18 months that have trachs and have vents and need nurses, but there's just not the nursing available."*

**Assertion 3. Agency representatives attribute the PDN nursing shortage to individuals choosing careers other than nursing; nurses choosing to work in competitive work settings other than home care; and nurses' perception of working as a PDN in the home as a liability.**

Agency representatives shared that they think nurses do not choose to enter the PDN workforce due to a variety of reasons, including low wages and the perception that PDN positions are a liability.

Agency representatives attribute the challenges to finding nurses to multiple factors including:

- ✓ There are less individuals choosing nursing as a profession;

- ✓ For those who do choose nursing as a profession, there are multiple settings where one can work and most have more competitive wages and benefits than PDN work;
- ✓ Nurses have a perception that working in the home is a liability; and
- ✓ Of those who enter the PDN workforce, nurses trained and/or willing to work with CMC who have tracheostomy and/or use ventilators has decreased. Nurses who do work with higher acuity clients, want to be compensated for taking care of the higher acuity cases.

The following exemplars capture these reflections:

*"There are many children at A.I. du Pont Children's Hospital that can't come home because there's no coverage for them, and I know this for a fact."*

*"[Nurses] have a lot more choices, so when you have a lot more choices, you can kind of pick and choose what you want to do."*

*"We had nurses that have been with us for 20 years...but some retired after a while and we're not really able to replenish the pool of trach/vent nurses with the same efficiency that we did in the past."*

*"I would say our base nurse we're looking for is probably the type of nurse that works at a nursing home. Nurses that work at hospitals are paid probably 20% to 30%, to 35% more than we can pay them...some people want to make as much money as they possibly can, which is fine, and those people are probably working at hospitals...Nurses [without] big financial burdens...can work in home care."*

*"More things can happen when you're working with kids that have higher acuity, and I think that that scares a lot of nurses so they feel like they're putting themselves at risk as far as something happening, and being held liable for some kind of sentinel event, or possibly having their license suspended or revoked."*

At the same time, the demand is high. The number of referrals has increased, as has the number of cases without coverage.

**Assertion 4. Agency representatives predict that if they were able to staff and take care of the children who qualify for care but who are not currently covered, their number of cases would increase significantly.**

*"I think every agency is having the same problem we're having; from what I understand. We see the referrals go around...and a lot are the same kids, the same names that you see circling around. Some have partial coverage...some have virtually no coverage, so it's hard...everyone says there's a nursing shortage, and there definitely is a nursing shortage...looking at all of the referrals that are out there, if we had the staffing to take them...our census would be at least 40% or 50% more. There's just so many...there's so many kids out there that have needs and that have opens, but there's just not the nurses to cover them."*

In addition, agency representatives note that, for higher acuity cases, referring hospitals often prefer at least two agencies by assigned to the case prior to discharge. This policy may be necessary for safe transition to the home, but can also make it difficult to arrange care for CMC.

*“Now sometimes when we're given the referral, we're told that agency 1 may be able to do the days, Monday through Friday, and they're looking for us to do the weekends and the nights...we first check to see if we have the proper staffing. If we have the nurses that are available for the skill level, be it trach, vent, or intravenous skills. So, we look to see if we have the capacity to be able to handle that case.”*

*“[AI] wants you to have two agencies because it'll help you with coverage. If you have a call out with one agency, you can hopefully rely on the other agency to cover it which could be factual...the problem is this agency only wants to staff Monday through Friday days and then the other agency [is stuck with] staffing the weekends and nights which is where the high premiums come from and it's hard to get nurses to work that.”*

## RESULTS AREA 2: RECRUITMENT CHALLENGES

**Assertion 5. According to agency representatives, nurses who choose to work with CMC, do so because they want a flexible schedule; a slower paced job; and to work with children.**

Recruitment methods vary by agency, including but not limited to: job fairs at schools; traditional services such as Career Builder or Indeed; social media; and television ads. Some agencies also use bonus incentives. For others, word of mouth appears to be the most successful mode to recruit nurses. Some agencies accept new graduate nurses; of those who accept new graduate nurses, several agencies have special long term training programs for novice nurses.

Agencies take recruitment seriously and may have a half of a staff member's time or more dedicated solely to recruiting new nurses.

Agency representatives said the nurses who apply for PDN positions want flexible hours, will request to work full-time, part-time, or PRN shifts depending on their circumstance, and prefer the slower pace of a 1:1 care setting compared to hospital or facility settings.

*“A lot of the nurses like the flexibility. So when we present it, [we say] you pick and choose your days that you want to work.”*

*“I think it maybe, and I don't like to really say it, but it's a convenience for them and for their own family that they have a job that's easier for them.”*

*“So they're looking to strike that rapport and just have that one-on-one interaction with that one patient and not be pulled in 10 million directions with maybe a caseload of 15 or 28 patients.”*

*"It is somebody who really desires to provide a one-on-one level of care to either a child or an adult receiving those services. They have a real love for that and engagement. Even in home health where you can look at certified home health and you go from patient to patient to patient within a day, and you have those individual interactions, it's just not the same. You really are there like almost a member of the family and you're providing very specialized care."*

PDNs who work with CMC are clearly interested in working with children, as opposed to adults.

*"I would say one, that they like working in pediatric fields because [most] nurses will tell you, I don't want to do kids, I just want to do adults. That's number one, they actually like working with pediatric children with disabilities."*

Although nurses may apply for PDN positions, sometimes their employment history does not match the agency needs. For example, agencies prefer nurses who are interested in committing to full-time or part-time work. Some PDNs who are only interested in PRN work are not well suited to work with the CMC population, given the training requirements and care needs. Also, some agencies are often looking to cover specific shifts, such as night shifts.

*"We're really struggling with night nurses. What I've realized, we have a lot more people looking for days. And we've gotten a decent amount of day cases, which is good, but night nurses are few and far between. People looking for full-time nights is even harder."*

*"Parents want consistency. They don't want somebody for one or two shifts a month, and then every other day or something, a random day during the week once or twice a month. They want one nurse to do stuff. Kids like routines. Parents like the routines as well, so it's not really helpful having this large influx of nurses that are not super-committal to things, and don't really keep their end of the bargain."*

Some agency representatives note many nurses don't choose to work as a PDN as their full-time career, but rather have other jobs. Even though agencies spend time investing in training all PDNs, working with the agency to cover cases is not their top priority.

*"Most of the nurses that we get have other jobs. We're not their top priority, which is unfortunate because we kind of really need to be their top priority as far as their main jobs."*

*"If they [PDNs] invest in us, and if we [agency] invest in them, they're able to cover more of our hours. But like I said, there's a dozen agencies in Delaware so a lot of people work for multiple agencies. They want to keep their hands in multiple pots, which is understandable. A lot of the nurses work at nursing homes and facilities, things like that, but we're just not getting the kind of nurse that we need."*

**Assertion 6. Given the current reimbursement climate, agencies tend to recruit LPNs rather than RNs, even though agencies recognize that some children would benefit from having the skill set of an RN.**

Agencies often focus on recruiting LPNs, rather than RNs, although some agency representatives believe high acuity cases should be covered by RNs. However, RNs are more difficult to recruit given the low reimbursement limits.

*"It seems like some nurses just do not want to do trach and vent. They don't want to learn that skill. "*

*"You don't have the nurses that want to [work with high acuity], because we're not really able to pay them much more than a basic case for that, a basic, like a regular G-tube kid."*

*"We are targeting LPNs with the current reimbursement climate...we are taking care of trach and vent patients...and our RN:LPN ratio is much more heavy on the LPN side than it is on the RN...and you really need more RN, to take care of [high acuity patients] rather than LPNs...but reimbursement is so low, you have to provide care with LPN's."*

**Assertion 7. Direct and indirect compensation varies across agencies. Workforce stability is affected as nurses leave the field for more competitive benefits or switch agencies based on wages and incentives.**

Aside from base hourly wage, other direct compensation components including overtime pay, holiday pay, or pay by case may be offered by agencies depending on the circumstance. The following quotes provide a few examples of monetary incentives offered by agencies.

*"If you offer them sometimes a little bit more for picking up a shift last minute or if you're able to be a little bit flexible. If it's a vent-trach case, if you're able to offer them a little bit more, that's helpful. If we're able to offer them multiple shifts instead of just one, sometimes that helps, too. Doesn't always work out that way. But if you're able to say, 'Hey, I got these two shifts for these two days. Are you willing to pick them up? I'll bump you up a little bit,' or, 'It's going to be a little bit more consistent,' I feel like that helps."*

*"If it's a case [we had] for two, three years...and this client knows me and I know them...if I can get somebody in there and pay them a little bit more to keep the case I will."*

*"You can negotiate their rates if it's a case that's been out there for 100 years and you need somebody to really fill it we can always increase or decrease their rate."*

Indirect compensation such as health benefits, disability insurance, pensions plans, paid leave, and scholarship programs vary across agencies. Some offer benefits, and some do not.

*"We have health benefits, medical, dental, and vision for people who meet those requirements. We do have a 401(k) program for the people who meet those qualifications. We do not have vacation and sick pay, per se. Our employees do start to, if they work a specific number of hours, and I honestly do not know exactly how many hours it is, they do start to qualify for some PTO."*

*"We have a full-time benefited program, so that is what we offer full-time nurses that are interested in benefits. They have to commit to a certain amount of hours...and they get increased PTO. So when they accrue PTO, they accrue it at a higher level so they end up getting more PTO. They get benefits at a discount rate, so their benefits are cheaper, so that's one program."*

Agency representatives recognize that if some nurses need benefits, they may choose settings other than home care. Nurses who need benefits may be challenged to find the right agency, and the right combination of affordable benefits.

*"[If they have to] carry medical insurance and medical insurance is, I can't say this for sure but my thought is it's cheaper at the hospital...if they [could] make more money [as a PDN], they could pay their medical insurance and they wouldn't have to pick the hospital versus home care."*

**Assertion 8. Agency representatives report delays in hiring due to the lengthy process of getting fingerprints processed at the state level.**

When asked if there were policies that interfere with agency recruitment or operations, more than one agency representative mentioned the lengthy process of getting fingerprints due to limited office hours and a long wait for the results. In addition, the detailed and comprehensive onboarding process at an agency can be a hindrance.

*"The state is really holding us hostage on fingerprints and when nurses can go get fingerprinted to get them on board and then make sure that they're not a criminal. So right now I think they can only do walk-ins on Mondays and Fridays or else they have to have scheduled appointment to go get fingerprinted. It's a long time and then for the turnaround process to get the results. We can't work them until we know that they're cleared."*

**RESULTS AREA 3: RETENTION CHALLENGES**

**Assertion 9. Low wages, poor benefits, and unpredictable pay have repercussions for PDNs health and well-being, family caregiver satisfaction, and workforce stability.**

Agency representatives identified several reasons PDNs leave the field including: low wages; poor benefits; unpredictable pay; and lack of career advancement opportunities. Agency Representatives explained how each of these factors have repercussions for retention.

First, PDNs work long hours to make ends meet, leading to fatigue, exhaustion, and burn out. As a result, PDNs may leave the field or take a break from working as a PDN.

*"I have had cases where nurses are working [too much]...and they burnout...it's their own fault for picking up too much or agreeing to too much...they are tired of the constant stress that they put themselves under."*

*"Some of these nurses will work a lot of shifts. May come in and be a casual, and then one week they might work 30 hours and the next week they could work 60 hours. So sometimes they need health benefits or other benefits like retirement and things like that. The funding does not support that."*

*"They leave because they're working every day...every day, I'm telling you...after a year or two they're exhausted."*

*"They just need a break for a while, and sometimes some of them will come back after two months."*

Second, PDNs leave the field to seek a wage and benefit package that allows them to support their families.

*"They may leave us for better benefits...it could be just the life circumstance that they have going on...they may be a single mom and need more money, more coverage, more benefits that we can't offer them."*

*"[In our agency] some positions are benefited and some are not. So if you don't have enough benefited positions, they will seek out another position or transition to one within the organization that has that."*

Last, although families prefer consistent nurses, PDNs are unwilling to make a commitment to one family or agency given the potential for unexpected changes to the schedule.

*"You'll find that [PDNs] they work for another agency and they're doing cases at another agency too because if their child gets sick at one agency, at least they have some money to fall back on because in home care... you can lose your case at any time. All a parent has to do is say, 'I don't want that person anymore,'...so they try to stay on more than one case even if they stay with your agency...they only want two days on one case, two days on another case because if the child or the parent gets rid of them, they always have some sort of money to fall back on."*

Some agencies note that nurses may not leave the field but simply switch agencies based on wages and incentives.

*"You have to pay them well. Money, they might hop around to every agency and whatever agency is paying them the best, that's the agency they want to stay with."*

In order to retain nurses, agencies provide several incentives and career advancement opportunities, such as clinical ladders for both LPNs and RNs. To advance, nurses need to demonstrate advanced skills. In some cases, nurses can advance to become preceptors.

It is important to note that not all nurses spread themselves across agencies and cases. Some PDNs stay with one case, especially those who work long term.

*"I feel like the people who work the long term and stay on the same case ... we have had nurses on cases for years...it's their choice because they enjoy staying there, and it creates that comfortability with the family."*

Finally, some nurses leave the PDN field to further their education.

## **FINDINGS B: FACTORS THAT CONTRIBUTE TO GAPS IN CARE**

As noted in the prior section, agencies report they are recruiting, advertising, offering sign on bonuses, and giving incentives to those currently employed. However, open shifts and gaps in care continue.

*"We are recruiting, we are paying bonuses, we're advertising, we are offering different kinds of incentives, we're offering our current nurses incentives if they pick up more hours."*

**Assertion 10. Gaps in care challenge agencies in a variety of ways, particularly if it's a case that is hard to fill. In these situations, the agency and MCO need to communicate closely and work together to find coverage.**

## RESULTS AREA 4: DEALING WITH OPEN SHIFTS AND CANCELLATIONS

Gaps in care occur for a variety of reasons and challenge agency representative to meet demands. First, monthly assignment calendars for clients often include shifts that are open with no assignments. Agencies report this may be due to lack of available nurses to meet shift hours requested and/or due to cases that are difficult to fill. For cases that are difficult to fill, some agencies will have conversations with the insurance company about expanding requests to other agencies.

*“For hard-to-fill cases...we let [the insurance company] know what we've done and where we are so that they may need to have a conversation with the client...that we have exhausted all measures...[We need to hear from them if] they would like us to contact another agency to get involved to share the case...so we're going to need some help in getting that case filled. It's not going to happen overnight.”*

*“[To get shifts covered], we're transparent [with the family caregivers], it's like, 'Well, we can continue to cover the day shifts, but we're going to need help with the night shifts. Do you give us permission to reach out to another agency? Do you want to reach out to the agency, or do you prefer that we do that for you? So that we can work together with another agency to get them fully staffed.'”*

Second, although nurses typically commit to a schedule, gaps in care occur when a nurse assigned to a client takes a lengthy vacation, or cancels at the last minute. Nurses may cancel due to sickness, emergencies, or issues such as lack of babysitters for their own family. While many PDNs maintain their schedule, some agency representatives become frustrated with those that are unreliable.

*“There are some clients that may have perfect coverage, and then their nurse goes to Africa...we both know ahead of time, but it's not always good...it's not always easy to fill those shifts while that nurse is out of the country...and usually they're out of the country at least six to eight weeks.”*

*“Nurses pretty much are consistent and they're professional, so they commit to a schedule, a set schedule and they keep to it. So they pick up days and they commit to those days and the expectation is that they'll be there.”*

Nurses that are professional and reliable are juxtaposed against those that are not.

*“It's a reliability thing with a lot of nurses, and a level of professionalism that's definitely dropped off. It's very noticeable, and it's just a different feel. A lot of nurses say that, too. A lot of nurses that have been with us for a long time, or are more experienced, or have a different work ethic, will say that it's just a different type of nurse now.”*

Agencies are left to find replacements. If it is clear a replacement will not be found, agencies report they try to communicate with the family (and insurance company) as soon as possible.

*"Let's say it's an 11:00 to 7:00 shift and at noon that day, we get a call-out. So what we do is, first we inform the family. We let them know, and we let them know that we're going to work on it. So we reach out to all the other nurses on the case to see...if they're available. Sometimes we fill it fast, quick. Other times it might take all day. Sometimes it doesn't cover it at all. So we look to see, based on nurses that are already on the case, if they can cover. If not we may ask them, 'Do you want another nurse that hasn't been oriented on the case?'"*

*"Our first option is to always ask a nurse who's been there before. It's not the end-all-be-all. We can offer other nurses to the families. A lot of them will say no if it's someone who hasn't been there before just based on comfortability."*

## RESULTS AREA 5: FINDING THE RIGHT FIT

Finding the right fit for the client can be a challenge and lead to gaps in care until a family and PDN "click."

**Assertion 11. Gaps in care result when there isn't a good fit between PDNs and the family.**

At times, family caregivers will decide the PDN is not a good fit for the child. Agency representatives note family caregivers decide whether or not a PDN is a good fit based on multiple factors, including: skill sets; the way the PDN dressed or what they eat; the age of the PDN; difficulty communicating with the PDN (accents); or personalities. When informed the family feels they are not a good fit for the care of their child, the nurse will leave the case, and often go to another agency.

*"The biggest challenge that the agency has is keeping [PDNs] in the home...if a client starts complaining and you tell a nurse, because we have to tell a nurse, if the client is telling us that the nurse is doing something wrong and if the nurse is telling us something that's going on with the client and we should rectify all of it so that everybody is okay with working together... it's a lot of challenges into providing services, finding the right nurse is a challenge."*

*"Sometimes that happens because personalities are personalities. And you can have all the knowledge that you need, but you just don't kind of click, and that's all it is. And in home care, you need to click...and sometimes, even [after you are on] a case [something changes] and [the family or nurse] think 'they just rubbed me the wrong way' or something...it happens. It really happens. It's nobody's fault and it's better to leave that case and let's put somebody else in there than to stay there and just get anxious. We're not there to cause a problem. We are there to help."*

Agency representatives also note nurses may feel the situation is not a good fit. Usually, it has nothing to do with the client. Rather, it may be the hours requested; perceived neighborhood safety; driving distance; home environment such as cleanliness, the presence of animals, guns, or drugs; and, demands and expectations from the family that are outside of their nursing scope of practice. Also, Agency Representatives report nurses do not want to be in homes with high familial stress.

*“Some families have stressors whether that’s financial, whether that’s marital, whatever it might be and they end up taking out a lot of stressors on our nurses or our nurses get put in the middle of divorces or what have you and then our nurses don’t want to go because they don’t want to have to deal with that.”*

If the PDN’s decides to leave the home for reasons related to the client themselves, Agency Representatives report it is often associated with the client’s weight and the physical demands necessary to care for the child. Although some families resist getting a lift in the home due to the space it takes up, agency representatives do recommend that lifts be installed in the home when needed for client and nurse safety.

While agencies believe that it is important for PDNs to feel comfortable in the home in which they are working, agency representatives recognize that some family caregivers disagree. They said that some family caregivers believe the business model is broken, and nurses should be assigned to work on a case, based upon need and not preference.

*“[One family caregiver said] that essentially, we should be able to tell our nurses where to work and where to go, and they should do it. Well, it doesn’t work like that in home care. We can’t do that. We’re not a hospital. We can’t say, ‘Patient so-and-so, you’re seeing these five patients today.’ It’s not like that. They have to be comfortable being in someone’s home.”*

## RESULTS AREA 6: SHORTAGE OF PDNS TO CARE FOR HIGH ACUITY CASES

Some nurses do not want to care for children who use ventilators. Agency representatives note more nurses seem to be comfortable with children with less acute medical problems.

*“It’s very difficult to staff children with trachs and vents. I don’t know if it’s a fear...and I tell them, ‘Don’t be afraid of the machine.’...you [just] need to know how to troubleshoot, and as long as you know how to troubleshoot it’s going to be okay.”*

*“From their perspective, it’s a lot more work. It’s more risk for them, if something happens. There’s more of a chance that something could happen, so it’s just really hard to motivate nurses to want to do that. We can’t really... You know, a dollar more an hour is not really going to be efficient. It’s not really going to be impactful.”*

## RESULTS AREA 7: LACK OF RESPECT LEADS TO GAPS IN CARE

Gaps in care occur when there is a lack of respect particularly around care delivery. Agency representatives note how important it is that PDNs be respectful of the home space in order for PDN placements to work.

*“The private duty nurse really has to have great respect that this is not a facility or an environment, it is someone’s home. Oftentimes we are in overnight shifts where family members are present, but asleep. So being able to be quiet and respectful to kind of maintaining that environment so that they’re able to sleep while we provide the care is critical. Just being respectful of people’s space. And just the way they manage their home is really a critical piece to the success in that relationship.”*

At the same time, family caregivers need to be respectful of PDNs. Some homes are not “psychologically safe” for the PDNs

*“Some homes are not psychologically safe for the PDNs...[for example], you can’t bring things up, that you could have a conversation even, or say, ‘I noticed that the patient responded to this really well. And so maybe I want to turn him maybe about every half hour because his breathing was better when we moved him around in the bed more frequently.’ And say the family caregiver is not in line with that and is offended by that and doesn’t want it done, that caregiver could then yell at that person for having a suggestion, ‘and I just want things done my way.’ So just being able to bring up a suggestion or an idea to maybe enhance the care would not be well received. And so you don’t feel safe that you could bring it up.”*

*“There is a high level of attention to PDN care delivery by the family caregiver...it can create a stressful work environment for the nurse that is there. And the ability to kind of manage those behaviors, develop trust, can be challenging. And so if that relationship is not going well in those high stress homes, they [family caregivers] will sometimes not ask to have that particular nurse back, or the nurse may also ask not to go back there because of how they’re made to feel while providing care. So it can be stressful on either end.”*

*“I just would like to mention that, and I think it’s important for the MCOs, the case managers, to be transparent with the families, let them understand or see it from a different perspective that this is somebody else’s valuable human being coming into your home. So they’re not just a nurse, a title, they’re a human being, so just treat them humanely.”*

#### RESULTS AREA 8: BOTH FAMILY CAREGIVERS AND AGENCIES EXPERIENCE ANXIETY AND STRESS ABOUT GAPS IN CARE

**Assertion 12. Lack of home nursing coverage negatively impacts family caregivers and also causes anxiety for agency personnel who are working to fill open shifts.**

Agencies recognize family caregivers depend on having coverage and understand the stress, frustration, and anger when there are gaps in care. Agencies also experience anxiety and frustration when they can’t fill in the gaps; further, agencies shared that they try to provide transparent communication about the scheduling process as well as scheduling changes. Regardless, sometimes agencies get formal complaints.

*“Just meeting the needs of their child is stress enough, and I think all agencies are trying to do their very best in coverage.”*

*“It’s very anxiety-provoking when you have a client who you know is going to give you a lot of crap, for lack of a better term, for it. But we try our best. At the end of the day, we try. As long as we did everything we could to cover the shifts, then at the end of the day we have to be satisfied with our efforts.”*

*“Whenever we do the initial intake, we always make it known and we’re transparent that there has to be a backup person [i.e. the family caregiver]. When there is a cancellation...usually it’s a lot of anger and [the families] are frustrated because they’re planning their day-to-day activities around the nurses being there, so it’s a lot of anger.”*

*“What I will hear is that especially when it comes to staffing, ‘Well, I didn't know that that shift was open. I was expecting the nurse to come.’ Then you'll hear from the scheduler, ‘I told them, they just forgot.’ We encourage them to communicate a couple different ways, maybe call them, but also email them, because parents like to have that information...I know the parents have a lot on their plate, so it could be on both ends...I always tell the schedulers, ‘When it comes up to the weekends, make sure that all your openings, that your parents are aware that they're not getting service...’ They should be aware all the time. They get a written schedule, but if there's any updates to that schedule, there should be clear communication.”*

*“It's heartbreaking especially when, and it happens all the time, and then the clients they take it up with their managers and then it comes to [the head of our office] because then it becomes a formal complaint that we're not stocking shifts and we have to explain again to the families that we don't have enough nurses and this is what it is and this is what we're doing.”*

*“Sometimes family caregivers use [their advocacy] in a threatening [way] to get what they need – ‘If I don't get what I want, or my case doesn't...I'm going to call the governor.’ Everything is, ‘I'm going to call someone, and that's how I get what I want or I need.’ So it's kind of what works for them, if you will, to alleviate that stress.”*

## **FINDINGS C: CLINICAL AND CULTURAL COMPETENCE**

### **RESULTS AREA 9: CULTURAL COMPETENCE**

In general, agencies report there are not many issues with respect to cultural competency. PDNs are trained to be sensitive to cultural differences. However, from time to time concerns do come up. For example, some families don't want specific food products in the home, such as meat or dairy, while other families are not comfortable with nurses who have accents. On the other hand, some nurses are not comfortable with multi-family households.

*“Some families have different cultures where they don't want meat in the home or they don't want dairy in the home or whatever it might be. We want our nurses to understand that and accept it if that's what they choose to do.”*

*“We haven't had too many...I know one in particular it took us a while to find the right fit for a nurse...there were about...12, 15 people living in the house all together...it took a little bit more time to find the right nurse where none of that bothered her and they were able to care for the patient without worrying about mom's right next to me or the family's right here.”*

Nurses are trained that “you can't judge a book by its cover.”

*“We touch on it in...[for example], we talk about that you could go into a family's home that is in a really “nice” development but the family might have altercations in the home because of the stress levels...we have talk about how you might go somewhere where you might see roaches or bedbugs or mice or what have you and so we can't judge a book by its cover and that we have to work through these things that we encounter.”*

When language differences make it difficult to communicate, some agencies have access to interpretive services and appreciate the role interpretive staff play.

#### RESULTS AREA 10: CLINICAL COMPETENCE

**Assertion 13. Agencies differ with respect to the types of training they offer, including orientation and preceptorship experiences. Some report offering multiple trainings; others expect nurses to be trained at the time they are hired.**

Agencies are responsible for ensuring nurses meet the clinical care requirements for each case. Yet every agency is different with respect to training protocols and assessments. Some agencies share they have a strong emphasis on training; others note they expect nurses to come to them trained.

Across many agencies, there appears to be a competency assessment for PDNs; however, it is not clear if the assessment is standardized. For agencies that have a competency assessment, the appraisal may include a skills review in the classroom, simulation lab, and/or in-home observation.

*“All PDNs get an orientation and there are specific skills that they have to be signed off on as a part of that. They both have classroom orientation, and we do have a lab in our education department that does support a skill sign off and all of the education that is needed for that. The education would both go over the assessment requirements, skills that would be performed, and the electronic health record documentation requirements. After they have received the classroom portion of that, they also do have to be aligned with a preceptor in the field and signed off on the care. Usually they're signed off in the case that they're going to be aligned with.”*

*“We have to make sure the PDN has the appropriate skills per what the patient needs or the client needs. And if they don't, we have to make sure that they gain those skills whether that is through competencies in the lab and/or training in the field.”*

The training timeline and content varies depending on the nurse's need.

*“We used to have a set timeline. We removed the set timeline only because some people learn faster than others. We do it based off of how well they do showing that they know the skill. So if it's a vent-trach person, if they're really good at their skill and they learn it very quickly, they may only shadow three or four shifts, and then they're ready to work on their own with a little bit of extra supervisory visits. And some take longer and it may be two weeks' worth of shadowing before they're comfortable enough to work on their own.”*

Some agencies assure all of their nursing staff that they will prepare and train them prior to taking a case.

*“I'll tell them... 'Don't worry about it. I'm not just going to throw you out there. I'll give you some courses and then I'm going to see how you do with the doll, then I'll send you out with a preceptor, and when you're comfortable you let me know.' [That is for] their sake because you want to keep them.”*

Once trained and working in the field, some agencies provide backup contacts if further training or consultation is needed on the job.

*“We always have an on-call manager. So if there is a clinical issue...say the nurse is working a night shift and she has a question about the feeding pump and what's going on with it, then the clinical manager will talk her through doing a check-in and how to check it and what to do to troubleshoot.”*

Some agencies believe training investments are not only important for care delivery, but also for professional development and job satisfaction of the nurse.

*“Ultimately whether they were going to stay with us or not, we still want them to be fulfilled and want to support them in any way we can personally and professionally. Because we know, even if they're not going to be with us in three years, let's say that they want to become a nurse practitioner or something. We still [think] when they're motivated and they want to learn, and they know that we're invested in them, I think that we're more likely to have them satisfied. They're more likely to do a better job. They're more likely to commit to us within a time frame that they're going to be with us. So ultimately, that's like a mutually beneficial relationship.”*

Depending on their experience, nurses may be assigned to take a case without agency specific training if it is clear they have the experience necessary to handle the case. Other agencies, in lieu of in-depth training programs, may require PDNs to have at least one year of experience before they come to home health. Agency representatives note clients may appear to be stable in the home environment, however, *“they can change on a dime”*.

Identifying nurses on staff who can serve as preceptors and trainers is a challenge given the shortage of nurses.

*“It doesn't really work in peds to have a bunch of PRN nurses, who are looking to just fill in here and there. Because you've got to train them, and if you have an open on a case, you have an open because you don't have a nurse for it. But if we have this new PRN nurse that needs to get trained, how are we going to train them if there's not even a nurse to train them on that night anyway?”*

More formal training, such as nurse residency programs designed to help new graduates develop clinical skills, are recommended by the National Boards of Nursing. However, residency programs are not available for nurses who elect to work in the private duty nursing sector. It is unlikely they will be developed and offered unless reimbursement for such programs become available.

*“Nurse residency programs are for brand new graduate nurses whether that be LPNs or RNs for home care...you get intensive SIMLab training on different scenarios with different skills...you go out to the home with multiple preceptors on various levels and you learn how to provide skills in home care independently, you learn the critical thinking that's needed for home care since you're out there all by yourself, you learn how to talk to*

*doctors and get orders when you need to and that's for the first total year...it's very structured and you have a mentor and an educator that is available... it takes money to support those types of programs, and the funding and reimbursement for private duty is so low that there isn't any margin to do those types of programs to support that."*

## RESULTS AREA 11: CHALLENGES TO DELIVER QUALITY CARE

In the affiliated study with PDNs, concerns were raised about care communication challenges. Agency representatives echoed similar communication concerns that impact the agency's ability to supervise the delivery of safe, quality care. Care communication is difficult both within and across systems.

First, CMCs are often cared for by more than one agency and medical care plans are not shared across agencies.

*"Every single private duty nursing case that we have currently is shared with other private duty nursing agencies, because none of us can staff any one case for the needs of what is actually authorized. That creates safety and hand-off issues because none of us are on the same [care communication platform] ...because of HIPAA, right? You're not sharing your medical record with them and they're not sharing their medical record with us."*

*"If a physician is providing orders, now he's got to talk to three different agencies providing care to one patient. And so it makes it very challenging."*

Care communication is important and interferes with clinical assessments, particularly if the child is in a declining condition.

*"If you have a patient who's in a declining condition [and there isn't a shared communication platform] ...you can't see what the prior assessments were to know, 'Okay, this person was breathing a certain way or they had an elevated temperature' and what were their vital signs and that kind of thing. And now I walk into a home and I didn't get a good handoff and I can't look back. I'm kind of starting from scratch...I mean, that's pretty scary to not have that information. And to me that's critical, I really think if they have to be deliberate in anything, they really need to think about the vent cases that are out there. Because somebody receiving ventilator services, is trached and vented, really should not have more than one agency in home."*

Agency representatives wondered if using the Delaware Health Information Network (DHIN) would be a possible solution. They recognized it would be a "big lift" to have agencies across the state uploading information into the DHIN, but felt a shared electronic record that could be accessed by the health care provider would be useful.

*"There has to be a way for a better sharing of information and handoff of information that is electronic in nature. You know, do we get into Delaware Health Information Network? Does everybody launch into DHIN? Can we see it through there? Are there certain sign-offs where certain information can be shared electronically? That's a big lift. How would we do that? But it would be necessary."*

## FINDINGS D: BUSINESS OPERATIONS COSTS

**Assertion 14. Agency representatives believe private duty nursing care for CMC is underfunded thus making it difficult to cover costs to recruit, train, prepare, incentivize, and pay PDNs. In some cases, agency costs are barely covered.**

Agency representatives reported there is limited funding to support private duty nursing for CMC. Agencies are not reimbursed enough to offer competitive wages, affordable benefits, and address other in house costs such as training, shift incentives, overtime pay, or mileage reimbursement. In addition, the COVID-19 pandemic has impacted business operations costs.

*“The biggest challenge for home health agencies in the State of Delaware right now for private duty nursing services is the lack of funding to support it. And that's been a bone of contention that's been discussed through these advocacy groups...and that's also gone back through our government affairs and things like that.”*

*“Medicaid is the primary funding for private duty nursing services, and they don't frequently have adjustments to the rates that they're paying for the cost of the care...and oftentimes for agencies the costs of the care either just covers it, or it is a cost to the agency to provide it because it is so underfunded...as a result the wages for the nurses are much lower compared to the market for nursing. And so it's extremely difficult to get anyone interested in applying for a position in private duty nursing. Oftentimes those positions are not benefited.”*

*“If we are paying them what they deserve to be paid, and then overtime, and then incentives on top of that, and then mileage to travel over an hour or whatever it might be...we are coming down to making negative money and then that impacts the agency financially too.”*

*“Trach and vent training is expensive...it's an expensive training even if I teach them...they still have to go out there and learn and nobody gives us any money for training. We don't get anything for training, this is really just our time.”*

*“We don't ask the payer to pay that training so we're paying the seasoned nurse their regular rate, we're paying the trainee their regular rate, and then sometimes we're paying an overtime on top of that and sometimes incentives because we need that trainer to actually train.”*

*“You have only so much money from the insurance company, and there are times when I don't think we make a dollar off a case...to cover a shift.”*

*“We're not reimbursed enough in order to pay the nurses more in order to make them full-time...which is why there's a nursing shortage and because nurses are like, ‘Well, why would I do this job? I'm not going to get a lot of PTO. I'm going to make less money.’”*

*“We are trying to pay our nurses a little bit more. We're trying to give small raises. [At the same time], everything else has increased for us. A case of N95 masks is \$700, so we're taking all this cost but we're not able to pay our nurses more...meanwhile, everybody else is getting paid more...so that gap between what a nurse was before is now shrinking...more entry-level positions are getting closer to what we were paying a nurse. So it's going to be harder and harder to retain nurses and hire new nurses.”*

## SUMMARY STATEMENT

Agency representatives remain concerned about the standard of care children receive when there are gaps in care. Without nurses available to cover authorized hours, the health and well-being of the child suffers. Agency representatives are also sensitive to the burden on parents and the impact gaps in care have on both work and family demands.

### RESULTS AREA 12: ADVOCATING FOR REIMBURSEMENT INCREASES

Agency representatives would like to see wages for PDNs increased to match a wage similar to what a hospital nurse is paid. In turn, they believe the pool of PDNs would increase, cases with open shifts would be covered, and most importantly, children would have access to safe, quality care. Agency representatives believe that wages need to compete not only with hospitals, but also with the wages of unskilled fields, especially as those wages begin to climb.

Some agency representatives have advocated for their PDNs and clients by testifying at legislative sessions and committees when invited. Many are willing to continue advocacy work.

*"I'm very hopeful and optimistic that we will get an increase in reimbursement for all of home healthcare agencies in Delaware so our nurses can get paid the correct rate increase. And that way I think if they can get paid similar to what a hospital nurse gets paid, they would be willing to work for us more hours and if they work for us more hours we could fill more of our open shifts. And if we fill more of our open shifts, we'd have better client satisfaction and we would make sure that our clients are a lot safer."*

*"Base pay [for a PDN] should be minimally...it would have to be between \$35 and \$40 an hour base...for a full-time nurse."*

*"Minimum wage at some point is going to go to \$15, so unless we get an increase, why are you going to go to school for nursing when you can make \$20 an hour, and not have all the same challenges that a nurse has. You can go to UPS and make \$20 an hour or something, and then there's just other options for people...as the costs of everything goes up, we're not keeping up with that. We're not keeping up with that curve. We're kind of staying flat, with tiny increases. But we have lots of nurses that are maxed out...we have nurses that are making the same that they made 15 years ago, and that's sad."*

*"I'm very passionate about getting increases in reimbursement. I'm very passionate about nurses making more money in the field...I am a strong advocate. I have lots of experience talking to legislators and senators and speaking at the Joint Finance Committee...and if there is anything else that I can be part of or need to be part of to get this needle moving in the right direction, I'd be happy to explore that."*

### RESULTS AREA 13: CONSIDER THE BIG PICTURE

**Assertion 15. Agency representatives observe the demand for in home care from all sectors of the population is increasing given the changing demographics in the state. They are anxious to work on innovative, creative solutions to meet the demand, particularly for PDNs who work with CMC.**

In the bigger picture, agency representatives observe the demand for home care and long term care in facilities will likely increase given the changing demographics in the state. The problem needs creative, innovative discussions across all stakeholders.

*“It’s a broad issue, so it’s not just about our ability to pay nurses, but I think that limits the amount of people that are interested in even becoming nurses...I think that’s a big problem, especially in Delaware. There’s just not as many people becoming nurses anymore.”*

*“Delaware is growing...that’s why you have all these agencies come in, because people are moving to Delaware...people are retiring and moving to Delaware...so you’re going to have more nursing homes in the next decade...more assisted living facilities, more rehab facilities, things like that. That’s going to take away from this already-shrinking nursing pool... we have to be creative...we have to work together, all agencies and the state, to think about ways to get more nurses on board and be able to compensate nurses, because nurses are going to get paid more at nursing homes. They can get paid more at hospitals.”*

*“We have to be able to compensate nurses better, and somehow increase the pool of individuals that are getting into nursing.”*

One agency representative believes some parents are advocating that pediatric patients receiving long term care should be able to convert their PDN hours to certified nursing assistant hours if they so desire and wonders if that should be explored to lessen the hardship experienced by parents providing care to their children.

## **CONCLUSIONS AND RECOMMENDATIONS**

Interview data gathered from agency representatives provide evidence that there is a shortage of nurses, leading to gaps in PDN services for CMC. Based on the feedback from agency representatives who participated in the interviews, the research team provides the following summary of the findings and recommendations. These recommendations emerged from the study data and should be discussed in the context of work that has been completed, or is ongoing/planned by DMMA, CMCAC, the SHHN Workgroup, or other stakeholder entities in the state.

### **FINDINGS**

- ⇒ Agency representatives report a critical shortage of nurses to care for CMC. In addition, agency providers compete for the same pool of nurses.
- ⇒ Agency representatives strongly believe the number of CMC needing care has increased over the last five years as evidenced by the increase in number of referrals and the observation that some children, particularly infants, have prolonged hospitalizations and can’t be placed in the home due to lack of PDN coverage.

- ⇒ Agency representatives believe nurses are taught that one should mitigate practice risks. Given the independent nature of home care practice, nurses who do not work in the field, perceive private duty nursing positions as a liability, creating yet another scenario that makes recruiting difficult.
- ⇒ Agency representatives predict that if they were able to staff and take care of the children who qualify for care but who are not currently covered, their census would increase significantly.
- ⇒ According to agency representatives, nurses who choose PDN work with CMC do so because they want a flexible schedule; a slower paced job; and to work with children.
- ⇒ Given the current reimbursement climate, some agencies tend to focus on recruiting LPNs rather than RNs, even though some children would benefit from having the skill set of a RN.
- ⇒ Agency representatives report delays in hiring due to the lengthy process of getting fingerprints processed at the state level. In addition, the detailed and comprehensive onboarding process at an agency can be a hindrance.
- ⇒ Agency representatives note that low wages, poor benefits, and unpredictable pay have repercussions for PDNs health and well-being, family caregiver satisfaction, and workforce stability.
- ⇒ Direct and indirect compensation varies across agencies. Workforce stability is affected as nurses leave the field for more competitive benefits or switch agencies based on wages and incentives.
- ⇒ Gaps in care challenge agencies in a variety of ways, particularly if there is a case for which shifts are difficult to fill. In these situations, some agencies work with the MCO to find coverage.
- ⇒ Gaps in care result when there isn't a good fit between PDNs and the family. Agency representatives note family caregivers may decide the PDN is not a good fit based on multiple factors, including skill sets; the way the PDN dresses or the foods they eat; difficulty communicating with the PDN due to accents; or personality differences. Once the PDN is informed by the agency that it is not a good fit, the nurse will leave the case, and often go to another agency.
- ⇒ Agencies differ with respect to the types of training they offer, including orientation and preceptorship experiences. Some report offering multiple trainings; others expect nurses to be trained at the time they are hired.
- ⇒ Agency representatives report lack of home nursing coverage causes anxiety for agency personnel who are working to fill open shifts.

- ⇒ Agency representatives believe private duty nursing care for CMC is underfunded, making it difficult to cover costs to recruit, train, prepare, incentivize, and pay PDNs reasonable wages. In some cases, agency costs are barely covered.
- ⇒ Agency representatives observe the demand for in home care from all sectors of the population is increasing, given the changing demographics in the state. Most agency representatives believe innovative, creative solutions are needed to meet the demand, particularly for PDNs who work with CMC.

### RECOMMENDATIONS

- ⇒ The results of this study (and other PDN Workforce Capacity studies) identified multifaceted factors that impact the ability to offer PDN services for CMC in Delaware at both macro and micro levels. We suggest the following be considered as next steps:
  - Create a task force to review the findings and recommendations across all studies.
  - Identify action items by responsible parties with an accompanying implementation schedule.
- ⇒ We also recommend the following:
  - Share best practices across the state of how agencies operate to create a work environment and culture that supports and maintains the PDN workforce in the CMC care landscape. Consider investigating practices from other states.
  - Facilitate discussions at the macro level, addressing solutions to gaps in care for CMC; consider the creation of a focused policy, research, and payment reform agenda.
  - Seek inclusiveness across all stakeholders, including health care providers, payers, regulators, and policy makers in the identification and testing of models addressing supply and demand issues.
  - Triangulate study findings with quantitative data from agency and MCO reporting systems documenting PDN coverage; analyses from the reporting database can be used to clearly identify, articulate, and advocate for improvements across the system.
- ⇒ Policy makers and payers are key players that were not part of the PDN Workforce Capacity study. Interviews with these stakeholders, and possibly others, may yield further insights into workforce capacity issues.

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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 Representatives: Interview Results* (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: COVID-19 - Impact on PDN Services & Use of Telehealth* (Publication T21-028). Newark, DE: Center for Research in Education and Social Policy.