

## **Trillium Member Advisory Committee Brief (003): Private Duty Nursing and the Gap in Care**

It is important to understand who we are talking about when we talk about the population that requires Private Duty Nursing (PDN). Meet Liam, a fictional Medicaid beneficiary whose story illustrates the challenges faced by members and families who depend on PDN services. Liam\* is a 9-year-old, medically fragile boy who requires continuous, complex care due to severe cerebral palsy and chronic respiratory failure. Liam has seizures and is tracheostomy-dependent and relies on a ventilator 24 hours a day to breathe.

For Liam and his family, PDN isn't a convenience; it's a lifeline. His care is too complex and risky for his parents to manage alone, especially at night. A PDN nurse may be needed for extended hours to perform medically necessary treatment such as skilled tasks: monitoring ventilator settings, administer required nebulizer treatments at least 2 times a day, performing frequent deep suctioning of his trachea to prevent mucus plugs, administering medications via his G-tube as needed based upon nursing assessments, and assessing the member every shift for changing ventilator requirements or insufficient respiratory functioning. Liam is at risk for requiring ventilator support if these assessments by a nurse are not performed every shift.

Liam's care team, through Tailored Care Management, secured 16 hours of nursing care every day. This authorization means an RN or LPN is supposed to be in their home from 10 PM to 6 AM to care for Liam's complex needs, giving his parents, Sarah and Mark, a vital chance to sleep, recharge, and be the best possible caregivers and parents during the day.

### **The Member's Need:**

- **Complex Continuous Care:** Sarah and Mark are physically and emotionally exhausted. They have been trained to manage Liam's G-tube feedings and routine care, but they lack the professional training to manage a critical ventilator malfunction, code situation or more severe situation that may arise based on Liam's chronic conditions. They have another child who also needs their attention.
- **Quality and Safety Assurance:** The presence of a PDN nurse provides them with medically safe skilled nursing care and decreases the risk of an error in care.

### **The Challenge:**

Despite the authorization for 16 hours of PDN daily, Liam's family consistently has four to five nights a week where the shift goes unfilled—it is an "Authorized but Not Provided Hour." The home health agency simply cannot find a nurse to reliably work each shift. The wages they can offer, constrained by the state's Medicaid reimbursement rates, are not competitive or adequate enough to pull nurses away from hospitals.

So, the family's reality is this: The data shows Liam is approved for 112 hours of weekly nursing care,

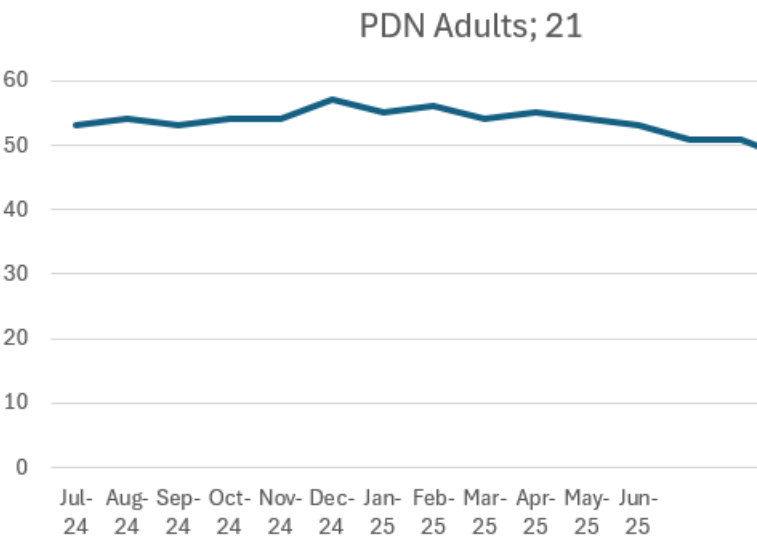
*\* Liam and his family's names and conditions are changed to protect his health information.*

but only 70 are provided. The 42 unprovided hours leave Liam vulnerable to unexpected medical emergencies and jeopardize his ability to maintain a reasonable level of health. .

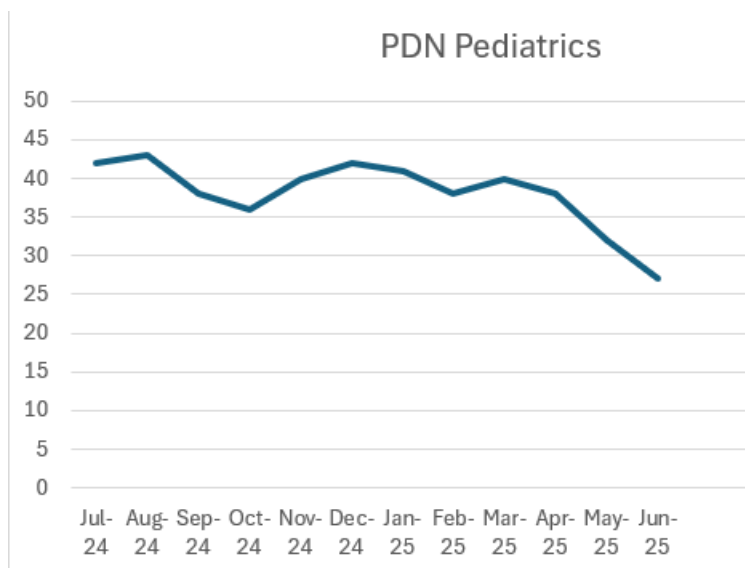
Liam’s story highlights the fundamental challenge facing the entire Private Duty Nursing sector, including being reflected in the data Trillium analyzed for adults: The gap between the authorized, medically necessary care and the provided care is caused by the PDN workforce shortage, and its consequence is borne directly by medically fragile individuals and their exhausted families.

**Trillium’s Data Story:**

Over the last 15 months, PDN has moved to managed care and each new and concurrent request for PDN is now reviewed against the state’s published Clinical Coverage Policy for the service. This review is a standard process for managed care health plans in order to determine whether PDN is a medically necessary service, and in what amount. Trillium data shows that during the first year of Tailored Plan operations from July 1, 2024 to July 1, 2025, adults and children receiving medically necessary PDN has stayed relatively steady in our plan.



- Adults (21+): The number of adults receiving PDN stays in the low to mid 50s.



**Children:** The number of children receiving PDN ranges from 42 to 27 from July 2024 to June 2025.

It is important to note that there are many reasons for a change in the number of members served in any service. These reasons range from a claims lag for providers not billing when reports are run on dates of services, plan eligibility changes, Medicaid eligibility changes, services are no longer meeting medical necessity, members receive alternate services or unfortunately, sometimes our members pass away who are medically fragile. A deeper dive into the individual member data is necessary to fully determine the reason for the changes in the data and we are committed to transparency in understanding and explaining reductions in services.

For this committee, the core message is members are being consistently reviewed using state-approved Clinical Coverage Policies and all denials have followed the defined appeals processes. We also know that workforce shortages in our catchment impact a provider's capacity to maintain full and consistent staffing for medically necessary and authorized PDN services for our members. In rural communities' providers can have difficulties hiring and retaining trained nurses for PDN and other nursing services.

### The PDN Landscape:

Trillium sits within a broader North Carolina and national context:

- North Carolina:
  - The NC Health Talent Alliance's 2025 analysis of annual workforce data for key health occupations in the state indicates 1 in 3 LPN positions and 1 in 8 positions statewide are vacant.
  - The state is investing in home- and community-based services and in direct-care workforce initiatives, signaling that PDN access and staffing are a known problem statewide, not just in one plan.
  - NC Medicaid recognizes PDN as essential high-intensity home-based nursing and allows significant weekly hours when medically necessary.

- National managed care plans:
  - Across the country, states and managed care plans report serious workforce shortages in home care, including PDN, and note that medically complex children are particularly hard for staff to manage, exacerbating the talent deficit.
  - Plans often must raise rates or add incentives to keep PDN providers available; gaps between authorized and delivered PDN hours for children are a common concern that requires focus.

### **3. Trillium's Commitment**

Trillium is committed to supporting member health and wellbeing, while also meeting its legal and contractual obligations. Trillium is a NCQA-accredited health plan and has demonstrated compliance with quality standards with regard to the determination of medical necessity for the review and authorization of services, including PDN. Trillium also complies with state network adequacy standards for PDN. In recognition of the challenges faced by members and families, and children in particular, who are in need of skilled nursing services, Trillium is committed to continuing to examine the data and root causes that lead to Authorized but Not Provided Hours.

**January to March 2026** – validate data trends, understand root causes and define fixes.

- Trillium reports back to the committee on the main reasons members have difficulties accessing authorized PDN services (e.g. staffing shortages, provider agency practices not accepting referrals, agency closures, family choice, etc.).

### **4. Next Steps for the Member Advisory Committee**

To support Trillium's commitment, the committee recommends:

- Asking Trillium to adopt a regular cadence of reporting and scheduled presentations at quarterly committee meetings. Updates will focus on provider workforce shortages, data trends and difficulties or barriers to receiving medically necessary authorized PDN services.
- Request that the committee appoint at least one PDN-focused family advisor to co-review each PDN update before it is presented to the full committee for the purpose of adding lived experience perspective.