



TESTIMONY TO NORTH DAKOTA SENATE APPROPRIATIONS COMMITTEE
HUMAN RESOURCES DIVISION

March 26, 2025

Dear Chairman Dever and Honorable Members of the Subcommittee:

I am submitting this testimony to provide context regarding the Medicaid Early and Periodic Screening, Diagnostic and Treatment (EPSDT) requirements and where concerns have arisen in North Dakota. Specifically, I recommend an amendment to the budget language to address issues with EPSDT, which I provide at the end of this statement. As it is currently applied, there are likely violations of Medicaid statute and regulation in the way that appropriated funds would be spent.

My name is Damon Terzaghi and I am the Senior Director of Medicaid Advocacy for the National Alliance for Care at Home, an organization that works to ensure that everyone has access to the highest quality, person-centered healthcare wherever they call home. I have 20 years of experience in Medicaid policy and programming, including with the Oregon state government, the Federal Centers for Medicare and Medicaid Services (CMS), and the National Association of State Medicaid Directors.

As some background, the EPSDT requirements are the backbone of supports for children in Medicaid, focusing on ensuring that Medicaid provides, “the right care to the right child at the right time in the right setting.”¹ Section 1905(r) of the Social Security Act creates EPSDT and requires that children receives all medically necessary services included in section 1905(a) of the Medicaid statute without limits on the amount of care provided. When defining “medically necessary,” this includes services, “when they have an ameliorative, maintenance purpose.”² Under EPSDT, though states may establish “soft” limits on services, there must always be a process to override/allow for exceptions those limits based upon the individualized needs of a child. In short, EPSDT requires that states provide children with the amount of care that is clinically and medically needed to correct or maintain a physical or mental condition.

Private Duty Nursing (PDN) is established by section 1905(a)(8) of the Social Security Act and is therefore a service that is included in the EPSDT mandate. CMS has defined these

¹ <https://www.medicaid.gov/medicaid/benefits/downloads/epsdt-coverage-guide.pdf>

² Ibid



services in regulations at 42 CFR §440.80 as, “nursing services for beneficiaries who require more individual and continuous care than is available from a visiting nurse or routinely provided by the nursing staff of the hospital or skilled nursing facility.” Further, §440.80(a) requires that the services be provided by either a registered nurse or a licensed practical nurse and §440.80(b) mandates that the services be delivered, “under the direction of the beneficiary’s physician.” As you can see, the services are very specialized and available only to individuals with significant conditions that require a substantial amount of skilled nursing care.

A number of lawsuits have challenged and defined the scope of EPSDT services over the years. For example, last year New Mexico was determined to be in violation of EPSDT requirements due to inadequate provision of PDN.³ Similarly, a district court found Florida in violation of both EPSDT and the Supreme Court’s Olmstead ruling due to lack of PDN access for children that resulted in inappropriate institutionalization.⁴ You can find a detailed summary of various EPSDT-related litigation over the years at:

<https://healthlaw.org/resource/epsdt-litigation-trends-and-annotated-docket/>

Lastly, the Supreme Court’s Olmstead decision provides important context for this discussion.⁵ In 1999, the Supreme Court found that unnecessary institutionalization of individuals with disabilities violates their civil rights under the Americans with Disabilities Act (ADA). As such, according to the Department of Justice, states and other public entities are required to, “provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.”⁶ Similar to EPSDT, there has been a significant amount of Olmstead-related litigation that has further defined the scope of state responsibilities to assure appropriate community integration for persons with disabilities of all ages.⁷

With this background, I want to address the current concerns in North Dakota. These challenges arise from the implementation of the InterQual® PDN Assessment in March of this year. The implementation of this tool has resulted in a significant reduction to the

³ M.G. v. Armijo, No. 23-2093, 2024 WL 5370776 (10th Cir. Sept. 17, 2024)

⁴ United States v. Florida, No. 12-cv-60460, 2023 WL 4372262 (S.D. Fla. July 14, 2023).

⁵ Olmstead v. L.C., 527 U.S. 581 (1999).

⁶ https://archive.ada.gov/olmstead/olmstead_about.htm

⁷ https://archive.ada.gov/olmstead/olmstead_cases_by_issue.htm

number of hours authorized for many children, overriding the recommendations of physicians, and creating significant concerns about the health and well-being of the kids. As examples:

- In one case, the physician's order for 16 hours of PDN per day was reduced to 10 hours per day on two days per week and 11 hours per day for the remaining five days. This reduction significantly compromises the family's ability to maintain the child's safety and complex care needs at home. The child has a rare and life-threatening genetic-metabolic disorder that requires constant monitoring to prevent metabolic crises triggered by even minor illness, stress, or dietary imbalances. The child is dependent on a G-tube for nutrition and must strictly follow a ketogenic diet. In addition to global developmental delays, this child has microcephaly and an elevated risk of seizures. The reduction in hours leaves dangerous care gaps that put health and safety at serious risk.
- In another case, a physician initially ordered 20 hours per day of PDN for the child, which was approved at only 12 hours per day and is now scheduled to be further reduced to just 9 hours per day. This reduction leaves a significant gap in coverage for a child with highly complex and life-threatening medical needs. This child has bilateral vocal cord paralysis and is tracheostomy-dependent, causing constant risk for airway obstruction, oxygen desaturation, and respiratory distress. The child also requires frequent suctioning, supplemental oxygen therapy, nebulized medications, and heated humidification to maintain a stable airway and prevent mucus plugging. In addition, this child is dependent on a gastrostomy tube for nutrition, hydration, and medication administration via a feeding pump. The proposed reductions in hours do not reflect the intensity of care required to manage this condition safely and could result in preventable hospitalizations or life-threatening complications. Continuation of the full 20 hours of in-home skilled nursing care is medically necessary to maintain stability and support the family in meeting care needs.

Overall, reviewing five pediatric patients, the new policy resulted in reductions totaling over 200 hours per week – more than 40 weekly or nearly 6 daily hours per child on average.

While the state contends that the InterQual® PDN tool provides the state with an accurate assessment of medically necessary services, it is unclear how and why the state's medical reviews consistently and significantly reduced the number of physician-ordered hours. Furthermore, the state's published policy on Medicaid PDN coverage says that services are, "limited to:

- Hours determined medically necessary;
- Hours requested by the ordering physician

- Hours that guardian(s) work and travel to work; or
- Hours that guardian(s) attend school and travel to school; or
- Additional hours for sleep may be allocated for up to 8 hours per 24-hour period when the member's condition and care plan requires intensive nursing interventions and monitoring [...]"

The policy also states that, "PDN hours are not 24 hours/7days a week and cannot be used for respite."⁸

This policy appears to assert that the hours are based on medical necessity or the time that a parent/guardian is absent from the home, which would be inappropriate based on both EPSDT requirements as well as the implicit expectation that parents provide care equivalent to PDN. As discussed earlier, the nature of PDN is highly specialized, clinical care and these types of supports cannot be provided by family members, guardians, or other non-clinical individuals. Further, it sets a limit on the number of daily and weekly hours.

Without appropriate amounts of care, these children are at serious risk of adverse events requiring hospitalization and/or long-term institutionalization. Placing children in institutional settings is an unnecessary and poor outcome, splitting up families, and reducing quality of life for everyone involved.

We are also concerned that the current policy will create significant challenges to finances for the North Dakota Human Resources division. Institutionalization and hospitalization are both considerably more expensive than care in the home and could greatly increase Medicaid expenditures. Furthermore, if the Medicaid budgetary projections include this erroneous authorization policy and it is overturned in the future, the increased hours would cause cost overruns from appropriated funds. Lastly, in the event that a lawsuit is brought challenging the PDN authorization policy (given recent precedent established in New Mexico and Florida), the state budget would be further strained by litigation-related expenses.

Since I was contacted for assistance with these concerns in 2024, I have communicated with my former colleagues at the Center for Medicaid and CHIP Services at CMS regarding the various EPSDT requirements to ensure that I am interpreting the statutory and regulatory requirements appropriately and in-line with current practice. As a result, I feel concerned about the current North Dakota policy's compliance with EPSDT and Olmstead

⁸ <https://www.hhs.nd.gov/sites/www/files/documents/Medicaid%20Policies/private-duty-nursing.pdf>



requirements. I therefore recommend that the Committee amend HB1012 and require ND Medicaid to:

1. Submit the revised PDN policy for independent review, ensuring compliance with CMS, EPSDT and Olmstead standards.
2. Engage stakeholders, including families, providers, and advocacy organizations, in the revision process.
3. Report findings and updates back to the Legislature, ensuring transparency and accountability.

I am not advocating for a specific change to the policy; however, I do believe that North Dakota Medicaid, this legislature, and your statewide stakeholders should collaboratively review the policy to ensure that:

- All statutory and regulatory requirements are met;
- Children's medical needs are fully addressed;
- Families are appropriately supported and maintained together in the community;
- and
- Unnecessary expenditures and cost overruns are avoided.

Thank you for the opportunity to submit this testimony. I am happy to answer any questions that you may have regarding these issues.