Disability Rights Michigan

September 16, 2025

Aimee Khaled
Michigan Department of Health & Human Services
KhaledA@michigan.gov

RE: Comments on Proposed Private Duty Nursing Policy (2538-PDN)

On behalf of Disability Rights Michigan ("DRM") and numerous PDN recipients,[1] we write to bring a number of serious problems with the proposed PDN policy to MDHHS's attention.

As MDHHS is aware, DRM was instrumental in bringing about the removal of the 16-hour per day PDN cap and mandatory 8-hour caregiver requirement. While we are hopeful that these changes will benefit PDN recipients, it is extremely disappointing that MDHHS failed to take this opportunity to comprehensively address its deeply flawed PDN policy. In creating this proposed policy, MDHHS ignored previous feedback from advocates, declined to engage directly with recipients, and failed to confer with the nursing agencies that will implement the policy. The result is a policy that potentially resolves some issues, ignores other issues, and creates new issues.

Forcing Family Caregivers to Provide PDN

While the proposed policy facially complies with federal EPSDT requirements by removing the caps and caregiver service mandate, it strongly suggests that, in practice, MDHHS will continue to limit recipients' PDN authorizations by requiring caregivers to provide skilled nursing services. Facial compliance with EPSDT requirements is insufficient. MDHHS must also ensure that it complies with those requirements *in practice*, by authorizing all medically necessary services to PDN recipients without regard to caregivers' ability or capacity to provide PDN.

The policy's assertion that "nursing care beyond the skills or capacity of the caregiver(s) must be documented in the PA request" turns the medical necessity inquiry on its head. ***The starting point must be the nursing care required by the recipient,*** not a family caregiver's ability or availability to provide nursing care. The presumption should *never* be that family caregivers have the ability or availability to provide skilled nursing services. Precisely the opposite: under Michigan's nursing delegation regulations, unlicensed individuals should *never* provide skilled nursing services absent an express delegation and retention of responsibility by a licensed nurse.

[1] DRM sent outreach letters to PDN recipients across the state seeking input on the proposed policy. Certain feedback is included here.

See Mich. Admin. Code R. 338.10104. The PDN policy should instead provide that medical necessity must be documented in the PA request, and it should expressly say that a beneficiary's natural supports should never be required to provide PDN services.

The proposed policy presumes that "family caregivers are trained by hospital staff to provide care prior to the beneficiary discharging to home," and it once again requires "their availability and skills [to be] taken into account." Many family caregivers simply cannot be adequately trained to provide private duty nursing level of care, because the care is complex and requires the regular exercise of skilled nursing judgment. Many caregivers who are "trained" prior to discharge only receive emergency backup training: while they can (probably) keep their child alive if a nurse calls off, the training is not intended to prepare untrained and unlicensed family caregivers to regularly provide skilled nursing care. The presumption should never be that parents with no medical background will return home from the hospital and immediately begin providing hours of daily nursing assessments and interventions to extremely medically complex infants.

The "availability of caregivers living in the home" section (which appears to have been copied wholesale (minus the caps) from the prior policy) should be removed. Its inclusion strongly suggests that the starting point (or at least a significant consideration) for MDHHS's eligibility determinations will continue to be a recipient's caregiver(s)'s presence in the home. As set forth above, the starting point must be the recipient's medical needs; the ability or capacity of family caregivers to provide skilled nursing services should never be presumed.

The initial hospital discharge "checklist" requirement likewise suggests that caregivers are obligated to provide skilled nursing care. It could also be used to expressly force, or implicitly pressure, parents into assuming some of their children's care. Unless both parents and hospitals are assured that children will be able to receive sufficient PDN to live safely at home even when parents choose not to attest that they have been "trained," parents will face Hobson's choice.[2] If parents sign off on the checklist, MDHHS could use it to justify authorizing fewer PDN hours (because the "trained" parents can supposedly provide the remaining hours), causing the child to receive insufficient PDN. But if parents do not sign off on the checklist and MDHHS has authorized insufficient PDN at home, the hospital could refuse to discharge for safety reasons.[3]

---

[2] A recent situation in Florida, where parents were given advice of rights and consent forms to sign in order for their children to remain in pediatric skilled nursing facilities, is analogous. Parents were led to believe that their options were either 1) to keep their children in the facilities, where they could receive around-the-clock nursing care, or 2) to take them home and become responsible for their nursing care. The court found that parents who would have chosen to care for their children at home with Medicaid-funded PDN signed the informed consent forms to keep their children in facilities because they were not informed of their children's right under federal law to receive medically necessary 24/7 PDN at home. *United States v. Fla.*, 682 F. Supp. 3d 1172, 1235-36 (S.D. Fla. 2023).

[3] Some parents and advocates fear that hospitals or nursing agencies will feel mandated to contact CPS if a parent cannot be deemed sufficiently trained on one or more tasks in the checklist. It would be tragic and appalling if MDHHS's refusal to authorize medically necessary 24/7 PDN resulted in CPS calls about potential medical neglect by the *parent.*

As MDHHS is aware, Michigan has no pediatric nursing homes. Keeping children hospitalized is far more expensive than paying for medically necessary PDN, and it violates children's right to receive services in the least restrictive/most integrated setting.

The "skills review and training" provision,[4] in addition to presuming that family caregivers can and should provide skilled nursing services, could also be read as an attempt to sneakily delegate care from nursing agency nurses to family caregivers pursuant to the nursing licensing delegation regulations—something that nurses and their employers certainly will take (and, as their feedback attests, already have taken) serious issue with. No nurse or nursing agency will assume responsibility and liability for nursing care provided by unlicensed family caregivers who have been sleeping in 3-hour shifts for the last two years and have a toddler demanding attention in the next room.[5] Currently, nursing agencies are not responsible for—and most do not track—caregiver training. Creating new responsibilities and liabilities for nursing agencies, which already struggle to hire staff at below-market Medicaid rates, could exacerbate the staffing crisis that MDHHS blames for its PDN shortcomings.

The skills checklist should instead be used to guide nursing agencies' charting practices (*i.e.* in terms of how frequently to chart which tasks), and to help doctors write detailed medical necessity letters. In no event should it be used to limit the amount of medically necessary PDN a child can receive by forcing care onto family caregivers, or to assign additional responsibilities and liabilities to nursing agencies.

Respite

When it announced its intention to reform its PDN policies, one of MDHHS's stated goals was to "expand[] access to respite care." The proposed policy does exactly the opposite, categorically *prohibiting* respite just because a recipient receives PDN.

This is legally problematic. Some PDN recipients are also eligible for services under the state plan[6] or waivers like the Habilitation Supports Waiver, and those recipients are entitled to receive medically necessary services, including respite, with reasonable promptness. MDHHS cannot strip those individuals of their right to receive respite just because they receive PDN.[7]

It is also terrible policy. Caregivers of medically complex children are *especially* likely to need respite. Parents of children who receive PDN often report having to put their lives on hold and foregoing academic or career gains to care for their medically complex children—often in addition to caring for other children or working. Family caregivers are constantly on call because they are the only option for backup care if a nurse misses a shift. Unlike their nurses, parents cannot call out. Parents with less than 24/7 PDN frequently sleep in shifts, with each parent getting 3-4 hours of sleep per night. These parents routinely skip their own doctor appointments,

[4] The checklist has not yet been posted to MDHHS's website.
[5] A real situation as described by the parent of a child currently receiving PDN. Both parents work.
[6] Including certain recipients entitled to respite under the *D.D. v. MDHHS* settlement.
[7] Some CMHs currently authorize nursing respite.

and they see grocery shopping, taking their kids to the park, or spending time with family as rare luxuries. Without respite, parents are at high risk of illness and burnout.

Concurrent Direct Care Services

The policy's categorical bar on concurrent direct care services is doubly problematic because, unlike respite, many direct care services *must* be provided pursuant to the federal EPSDT mandate. Numerous PDN recipients could be entitled to receive a service like CLS, for example, and there are situations where CLS could be provided at the same time as PDN in an entirely non-duplicative manner. For example, a teenager could need CLS to learn social skills and practice social integration at a bowling alley but also require a nurse to be present for assessments and interventions. A toddler could need CLS to implement PT or OT plans to learn how to walk, drink from a straw, or chew, but also need a nurse to titrate oxygen during frequent seizures. The services function differently, require different skill sets, and achieve different goals. Instead of a blanket ban on concurrent direct care services, the policy should simply provide that "duplicative" concurrent services are prohibited. MDHHS should permit PDN and non-duplicative direct care services to be authorized concurrently when medically necessary and necessary to implement a recipient's individual plan of service.[8]

PDN in Schools

The proposed policy continues to prohibit PDN from replacing a "Local School District or Intermediate School District's responsibility for services" which includes time at school or on school transportation. While schools must provide all necessary services under IDEA, Medicaid is the payor of first resort for a service like PDN when a child is in school. 34 C.F.R. §§

[8] It should not be assumed that nurses could provide a service like CLS during whatever downtime they might have. Nurses' downtime is severely limited: children typically get PDN because they are fragile and could experience a medical episode requiring nursing intervention at any time, and PDN nurses constantly assess their patients. PDN nurses also chart exhaustively, since every single assessment and intervention should be charted to prevent MDHHS from reducing an authorization for lack of nursing activity. PDN nurses additionally mix medicines, dilute formula, and prepare medical supplies.

Even if time permitted, Medicaid-funded PDN nurses are already paid below-market rates and would likely be opposed to substantially adding to their job responsibilities. Employer agencies would also likely take issue with their staff performing non-nursing tasks. And a service like CLS could be provided, at best, only unpredictably, whenever charting, medicine mixing, and assessing allowed.

Finally, most types of community involvement—a core aspect of CLS services—cannot be provided by a private duty nurse without a concurrent direct care service. At least one nursing agency has an explicit policy prohibiting nurses from taking their patients out alone without a second caregiver (*e.g.* a CLS worker), because nurses cannot provide nursing services while driving.

300.154(b), 300.34(c)(13). Under Michigan's school funding structure, however, Medicaid reimburses schools only a fraction of the cost necessary to provide many services. This means that, even if a nurse spends 100% of her time providing 1:1 nursing to a Medicaid-eligible student pursuant to IDEA, the school will pay for most of the care with non-Medicaid funding.

In practice, therefore, schools will rarely or never be able to provide 1:1 nursing using their own staff or contracted staff.[9] If students cannot receive fully-Medicaid-funded PDN in school and on school transportation, but also cannot receive 1:1 nursing from the school due to school funding limitations, students will either be unsafe at school or be medically forced into homebound schooling. This risk is far from hypothetical: of the PDN recipients who have contacted DRM, at least two must currently participate in "homebound" preschool because their school district cannot transport them safely. This contravenes recipients' right to receive services in the most integrated setting under *Olmstead* and IDEA. *See* 20 U.S.C. § 1412(a)(5).

The policy should allow for fully-Medicaid-funded PDN to be used in schools when schools are unable to provide the service. We propose a carve out from the school-based services Medicaid reimbursement methodology for in-school 1:1 nursing for Medicaid PDN recipients, so that schools can properly leverage Medicaid funds to pay for 1:1 nurses.

Hours Determinations

The proposed policy does not address hours determinations, which is problematic because MDHHS has a long history of focusing only on interventions and ignoring assessments when it authorizes hours. Both assessments and interventions are skilled nursing tasks, and assessment needs should be considered when determining whether a nurse must be present. PDN is medically necessary during a given hour if skilled nursing assessments ***or*** interventions are required to prevent the beneficiary's condition from worsening, prevent development of additional health problems, or improve the beneficiary's condition.

The authorization should be informed by the beneficiary's medical condition; the type and frequency of needed nursing assessments, judgments, and interventions; and the potential impact of nursing assessments and/or interventions to prevent adverse health outcomes.

Eligibility Criteria

The proposed policy does not address PDN eligibility criteria, which depart from federal EPSDT guidelines by imposing requirements that are more restrictive than the federal definition of PDN and the medical necessity criteria necessary to receive it.

Consistent with the federal definition, MDHHS defines PDN as "nursing services for beneficiaries who require more individual and continuous care, in contrast to part-time or intermittent care, than is available under the home health benefit." Michigan MPM, PDN Chapter, p 1. If an individual meets this standard, s/he should be entitled to PDN.

[9] Many school districts do not currently offer even non-nurse attendants on school transportation.

MDHHS, however, requires individuals wishing to receive PDN to:

- Require continuous skilled nursing care on a daily basis, ***and either***
- Have frequent episodes of medical instability within the past three to six months, ***or***
- Be dependent daily on technology-based medical equipment to sustain life.

MPM PDN Ch. pp 11-13.

These additional criteria exclude certain individuals who meet the federal medical necessity criteria for the service. For example, a child with a severe seizure disorder who needs rescue medications and intermittent supplemental oxygen so urgently that waiting for a 911 response would result in dangerous hypoxia, but who does not use a ventilator or require consistent titration of oxygen flow, would meet PDN medical necessity criteria (by requiring continuous skilled nursing assessments and swift medication/supplemental oxygen administration), but would be denied under the current criteria and practices. It is antithetical to the preventative nature of EPSDT to require hospitalizations or avoidable tracheostomies before authorizing services. Additionally, the three "Intensity of Care categories" should be removed, and the section should be rewritten to provide that eligibility determinations will always be made on a case-by-case basis.

Below is our proposed replacement language, which was previously provided to MDHHS:

"The determination of whether PDN is medically necessary for an individual child must be made on a case-by-case basis, taking into account the particular needs of the child. The child's long-term needs should be considered, as should all aspects of the child's individual situation. The EPSDT definition of medical necessity (*see* EPSDT Chapter, p 1) controls. PDN should be provided when a beneficiary requires more individual and continuous care, in contrast to part-time or intermittent care, than is available under the home health benefit. This care includes both necessary assessments and hands-on interventions."

"Transitional" Benefit and "Weaning"

The proposed policy does not remove current policy language identifying PDN as a "transitional benefit." Many PDN recipients' conditions are lifelong and not expected to improve; for those recipients, PDN is necessary to *maintain* their condition. Under EPSDT requirements, states must cover "medically necessary services that sustain or support" a recipient, and services must be covered when they prevent a condition from worsening or prevent the development of additional health problems.[10] "Maintaining" an individual's health falls squarely under the federal EPSDT medical necessity definition.

Beneficiaries should never be "weaned" from PDN simply because their condition is stable, and the policy should expressly say that stabilization is *not* necessarily a reason to decrease or

[10] EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents. CMS (2014).

discontinue PDN. In some cases, stabilization results from, and can only be maintained by, the provision of PDN services.

Likewise, the language in the current policy identifying PDN as a transitional benefit for the purpose of transitioning nursing responsibility to family caregivers must be removed. If a beneficiary needs fewer PDN hours because his/her condition has improved, then the PDN authorization should be decreased. There may be situations where family members are willing and able to provide certain aspects of care, but this cannot be a policy objective.

We propose the following language:

"Stabilization of a beneficiary's condition is not necessarily a reason to decrease or discontinue PDN. In fact, stabilization of the beneficiary is a goal of EPSDT services. PDN services should be authorized in an amount, scope, and duration sufficient to stabilize, maintain, and, if possible, improve the beneficiary's health condition. PDN should only be reduced when nursing assessments and/or interventions are no longer necessary during certain hours of the day to prevent the beneficiary's condition from worsening, prevent the development of additional health problems, or improve the beneficiary's condition."

Caring for More Than One Patient

The presumption should be that 1:1 nursing will be authorized if requested, medically necessary, and justified by the circumstances. The "weaning" language should also be removed.

Sincerely,

Disability Rights Michigan