

February 3, 2025



Dear Beneficiary, Parent, and/or Guardian,

Disability Rights Michigan ("DRM") is investigating restrictions that Michigan's Medicaid Agency (the Michigan Department of Health & Human Services, or MDHHS) imposes on Medicaid-funded Private Duty Nursing ("PDN") services for individuals under the age of 21.

Why am I getting this letter?

Pursuant to DRM's investigative mandate and records access authority, we requested that MDHHS provide the names and contact information of all individuals (and/or their parents or guardians) under the age of 21 who currently receive PDN in Michigan, and you were on the list that MDHHS provided.

Federal law gives DRM the authority and obligation to investigate incidents of abuse and neglect of individuals with disabilities, if there is probable cause to believe that such an incident has occurred. Under Michigan's Mental Health Code, the failure to provide medically necessary Medicaid services (including PDN) is neglect.

We are investigating to determine 1) to what extent MDHHS's restrictions on PDN negatively impact beneficiaries, and 2) whether we can and should advocate to lift those restrictions.

What is Disability Rights Michigan?

Disability Rights Michigan is part of the federally mandated national protection and advocacy network and has been designated by the governor of Michigan as Michigan's protection and advocacy system. Disability Rights Michigan advocates for the rights of individuals with disabilities through information and referral, direct advocacy, policy advocacy, and systemic litigation. Among other things, we help individuals with disabilities receive or maintain medically necessary Medicaid services and supports. We do not charge for our services. You can read about our advocacy areas and our litigation on our website: http://www.drmich.org.

Confidentiality

Federal regulations require us to keep our records confidential. This includes all information relating to clients and individuals who have received information or participated in consultations; the names of individuals who have received services, supports or other assistance, or who provided information to Disability Rights Michigan; and the identity of individuals who have reported to us incidents of abuse or neglect. Your name, contact information, and all other information provided to DRM will be kept strictly confidential.

Our PDN Investigation

Medicaid services provided to individuals under the age of 21 must be provided to the full extent that they are "medically necessary." In Michigan, however, without regard to individual medical necessity, the maximum number of hours that any PDN recipient under the age of 21 can receive is capped by a state policy requiring "natural supports" to provide at least 8 hours per day of unpaid care. The only exceptions are narrow and time limited. Recipients under 18 are prohibited from receiving any other medically necessary Medicaid services during those 8 hours, and parents/guardians are even prohibited from using non-Medicaid sources to obtain services during those hours. The result is that recipients are often authorized for fewer hours than they need, and untrained caregivers are often forced into the role of providing significant numbers of medically necessary service hours.

We are also investigating 1) Michigan's highly restrictive PDN eligibility criteria, and 2) MDHHS's policy/practice of "weaning" recipients off of PDN.

How can we help?

If you or your child has been impacted by restrictions on Medicaid-funded PDN services, we invite you to contact us by email at PDNInvestigation@drmich.org. If you send us an email, we will schedule a phone call. If you do not have access to email, please call us at (517) 487-1755. We will try to respond to your email quickly, but please understand that our availability will vary over the coming months.

Sincerely,

Anastassia Kolosova Staff Attorney