



Q&A:

Medicaid Private Duty Nursing outside the Home

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- Q:** My client has a disability that requires twelve hours of private duty nursing a day. A nurse is necessary to continuously monitor her airway and assist her with ventilator care. She was recently told that she could only get Medicaid-funded private duty nursing while she was in her home. Because she works part time, the state wants to limit her hours to the times she is reasonably expected to be in her own home. Is such a limit permissible?
- A:** No, the state cannot restrict private duty nursing to inside the recipient's home. Private duty nursing is an optional Medicaid state service that provides medically necessary continuous nursing services. A state may opt to cover this service in a nursing facility, a hospital, the recipient's own home, or any combination thereof. When the state covers the service in a recipient's home, the state must also provide the service for the recipient's normal life activities outside of the home.

Discussion

Congress created the Medicaid program in 1965 by adding title XIX to the Social Security Act, 42 U.S.C. §§ 1396-1396w-5. The purpose of Medicaid is, in part, to "enable each state to furnish rehabilitation and other services to help . . . individuals attain or retain capability for independence or self-care...."¹ Within statutory limits, states may decide which services it will cover.² Specifically, the Medicaid Act mandates inclusion of eight enumerated services.³ A state may also opt to provide other services, such as prescription drugs, dental services, and prosthetic devices.⁴ Once a state elects

¹ 42 U.S.C. § 1396-1.

² See 42 U.S.C. §§ 1396a(a)(10), 1396d(a).

³ 42 U.S.C. §§ 1396a(a)(10), 1396d(a)(1)-(5), (17), (21), (28) (listing: inpatient hospital, outpatient hospital, laboratory and x-ray, nursing facility, physician, nurse-midwife, nurse-practitioner, and freestanding birth center services).

⁴ Id. §1396a(a)(10) and 1396d(a) (listing categories of optional medical assistance).

to provide a service, whether mandatory or optional, it becomes part of the state Medicaid plan, and the state “must comply with all federal statutory and regulatory mandates.”⁵ Furthermore, these optional services are mandatory for children under age 21 when needed to “correct or ameliorate” a condition.⁶

One of the optional services a state may choose to include is “private duty nursing.”⁷ The Medicaid Act does not define private duty nursing, nor is there any legislative history regarding the definition of private duty nursing.⁸ However, regulations explain that private duty nursing “means 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.”⁹ Services must be provided by a registered nurse or licensed practice nurse, under the supervision of the enrollee’s physician.¹⁰ Private duty nursing services are continuous skilled nursing assistance, beyond the services routinely provided by a periodic visiting nurse.¹¹

As of 2018, at least 25 states have opted to include private duty nursing services as a covered service in their state plan.¹² In addition, states may offer private duty nursing on

⁵ *Lankford v. Sherman*, 451 F.3d 496, 504 (8th Cir. 2006) (citation omitted); see also *Weaver v. Reagen*, 886 F. 2d 194, 197 (8th Cir. 1989), *Eder v. Beal*, 609 F. 2d 695, 701-02 (3d Cir. 1979).

⁶ 42 U.S.C. § 1396d(r); see also 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B).

⁷ 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(8). States are required to provide a similar, but more limited in scope, service called “home health services” for enrollees that are entitled to nursing facility states. 42 U.S.C. § 1396a(a)(10)(D). For those who are not entitled to nursing facility services, “home health care services” is an optional service. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(a)(7). See Jane Perkins, Nat’l Health Law Program, Q&A *The Medicaid Home Health Service Final Rule: Many Helpful Changes* (May 14, 2016), <https://healthlaw.org/resource/qa-the-medicaid-home-health-service-final-rule-many-helpful-changes/>

⁸ 42 U.S.C. 1396d(a)(8); see also *Detsel by Detsel v. Bowen*, 1988 WL 101020 (Sept. 23, 1986 N.D.N.Y.) (noting that there is no legislative history about the scope of private duty nursing); 52 Fed. Reg. 47934 (Dec. 17, 1987) (also noting that neither the statute nor the accompanying committee reports contains a definition of private duty nursing.).

⁹ 42 C.F.R. § 440.80. The current federal regulations on private duty nursing were adopted in 1987 and have not been substantively altered since. 52 Fed. Reg. 47934 (Dec. 17, 1987). In 1987, the scope of services was clarified to explain that private duty nursing does not need to be provided in all three settings, and that the state could limit the provision of the services to any one or more of the three cited locations. *Id.* at 47929. Any explanation as to why the regulation was originally drafted to reference these three settings is lost to history. See *Detsel by Detsel v. Sullivan*, 895 F.2d 58, 61 (2d Cir.1990) (“A substantially identical version of this definition appeared in the original Medicaid regulations, published in 1966 as the Handbook of Public Assistance Administration, Supplement D. Unfortunately, any documents that might shed light on the rationale for the definition were lost or destroyed in 1977, when the records of the newly-created Health Care Financing Administration (“HCFA”) were moved from Washington to Baltimore.”).

¹⁰ 42 C.F.R. § 440.80.

¹¹ *Id.*

¹² Kaiser Family Found., State Health Facts: Medicaid Benefits: Private Duty Nursing Services (2018), <https://www.kff.org/medicaid/state-indicator/private-duty-nursing->

a limited basis for some segments of the population via home and community based waivers.¹³ For children, the entitlement is broader. Pursuant to Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions, all states must cover private duty nursing services for eligible children under age 21 that are necessary to "correct and ameliorate" a physical or mental condition, even if such service is not included in the state plan.¹⁴

Restrictions on Providing Services During Hours Outside of the Home

In 1986, Melissa Detsel, a nine year-old New Yorker, requested that the state provide a private duty nurse while she attended elementary school. While the state did not dispute her need for private duty nursing, it denied her request, claiming that private duty nursing is only available in an enrollee's home, in a hospital, or in a nursing facility. New York refused to allow Detsel to use her hours in an elementary school. Detsel then challenged Health and Human Services (HHS') restriction of private duty nursing to the home, arguing that HHS' reading of the statute, and hence its regulation, was arbitrary and capricious. The district held it was reasonable for HHS to limit private duty nursing to the home because the "common understanding of private duty nursing care is one involving extraordinary medical care during periods of critical need."¹⁵

The Second Circuit reversed. The court found that Congress had not spoken directly to the issue, and therefore the court should defer to HHS' interpretation if reasonable. However, the court found the agency's interpretation unreasonable because: "the at-home limitation is based on obsolete medical assumptions, leads to a net increase in government spending, and is inconsistent with the only other analysis of the rule that the agency appears to have undertaken."¹⁶

After the Second Circuit's decision, the Centers for Medicare & Medicaid Services (CMS), the branch of HHS that administers Medicaid, clarified the policy. CMS stated that if an enrollee needs services *only* outside the home (or *only outside* the hospital or nursing facility), the enrollee is not entitled to private duty nursing. However, enrollees must be allowed to use their private duty nursing hours when normal life activities take them out of that setting:

[services/?currentTimeframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D#](#)

¹³ See, e.g. 42 U.S.C. 1396n(c)(4)B)(A waiver may "provide medical assistance to individuals (to the extent consistent with written plans of care, which are subject to the approval of the State) for case management services, homemaker/home health aide services and personal care services, adult day health services, habilitation services, respite care, and such other services requested by the State as the Secretary may approve . . .").

¹⁴ 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r)(5).

¹⁵ *Detsel by Detsel v. Bowen*, No. 87-CV-301, 1988 WL 101020, at *3 (N.D.N.Y. Sept. 23, 1988), *rev'd sub nom. Detsel by Detsel v. Sullivan*, 895 F.2d 58 (2d Cir. 1990).

¹⁶ *Detsel by Detsel v. Sullivan*, 895 F.2d at 66 (2d Cir. 1990).

[I]f a recipient wants to obtain private duty services to attend school or other activities outside of the home but does not need such services in the home, hospital or nursing facility, there is no basis for authorizing private duty nursing services. Rather, only those individuals who require and are authorized to receive private duty nursing services in the home, hospital or nursing facility setting may utilize their approved hours outside of those settings during those hours when normal life activities take the recipient outside of those settings. Any limitations a State chooses to impose on private duty nursing services, including maximum hour limits, are not affected by the policy change occasioned by the Detsetl case decision. Total time and payment allowed for such services is not expected to exceed that which would have been allowed strictly in a home setting.”¹⁷

If *Detsetl* took place today, plaintiffs might have been able to challenge the restriction as a violation of the Americans with Disabilities Act integration mandate. The “integration mandate” requires public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”¹⁸ As explained by the Seventh Circuit in a case challenging the reduction of waiver services:

The state designs, applies for, develops policies regarding, and executes its waiver programs. If those programs in practice allow persons with disabilities to leave their homes only 12 hours each week, cooping them up the rest of the time, or render them at serious risk of institutionalization, then those programs violate the integration mandate unless the state can show that changing them would require a fundamental alteration of its programs for the disabled.¹⁹

Other Limitations

Although states may not restrict private duty nursing to the hours an enrollee is at home, states may impose other limits. States are only required to provide services that are

¹⁷ CMS, STATE MEDICAID MANUAL § 4310.

¹⁸ 28 C.F.R. § 35.130.

¹⁹ *Steimel v. Wernert*, 823 F.3d 902, 918 (7th Cir. 2016); see also U.S. Dept. of Justice, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (“to comply with the ADA’s integration mandate, public entities must reasonably modify their policies, procedures or practices when necessary to avoid discrimination.”); CMS, *Dear State Medicaid Director, Olmstead Update No. 3*, attachment 3-g: (July 25, 2000) (*Prohibition of Homebound Requirement in Medicaid Home Health*) (“[E]nsuring that Medicaid is available to provide medically necessary home health services to persons in need of those services who are not homebound is an important part of our efforts to offer persons with disabilities services in the most integrated setting appropriate to their needs, in accordance with the Americans with Disabilities Act.”). Cf. *Vaughn v. Walthall*, No. 19-1244, 2020 WL 4500008, at *7 (7th Cir. Aug. 5, 2020) (reversing and remanding the district court’s grant of summary judgment to a plaintiff requesting that the state permit her to delegate nursing duties to training non-nurse staff as a reasonable accommodation necessary to remain in the community.).

“medically necessary.”²⁰ States can also impose appropriate utilization control procedures, such as prior authorization.²¹ However, the service must be sufficient in amount, duration and scope to achieve its purpose.²²

In addition, as noted above, all Medicaid recipients under the age of 21 are entitled to Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. EPSDT is a comprehensive benefits package that includes a broad array of diagnostic and treatment services, including all health care and treatment listed under the federal Medicaid statute that is necessary “to correct or ameliorate defects and physical and mental and conditions uncovered by [EPSDT] screening services” regardless of whether such services are covered under the state plan.²³

Thus, while states may place hard limits on the number of hours of services for adults, it cannot do so for children. For example, if a child needs twelve hours per day of private duty nursing to ameliorate his condition, then EPSDT should cover those services to the extent she needs them — even if the state places a quantitative limit on private duty nursing (e.g., six hours per day) or does not cover them at all for adults.²⁴ The federal Medicaid agency, the Centers for Medicare and Medicaid Services (CMS) has stated that medical necessity determinations should be individualized and based upon the recommendations of the child’s treating provider.²⁵

Conclusion & Recommendations

Many states provide private duty nursing. These services help individuals with disabilities maintain their health outside of a hospital or skilled nursing facility, and are an important support to enable access to the community. Despite the longstanding

²⁰ *Moore ex rel Moore*, 637 F.3d 1220, 1222-3 (11th Cir. 2011) (“even if a category of medical services or treatments is mandatory under the Medicaid Act, participating states must provide those medical services or treatments for Medicaid recipients only if they are ‘medically necessary.’”); 42 C.F.R. § 440.230(d) (state Medicaid agencies “may place appropriate limits on a service based on such criteria as medical necessity”).

²¹ 42 C.F.R. § 440.230.

²² See, e.g., 42 U.S.C. §§ 1396a(a)(10)(B), 1396a(a)(17); 42 C.F.R. § 440.230(b). For an in-depth discussion of the amount, duration and scope requirement, see Sarah Somers, Nat’l Health Law Prog. Medicaid’s Amount, Duration and Scope Requirements: Challenging Cuts to Services for Adults (April 2004), available from NHeLP.

²³ 42 U.S.C. § 1396d(r); see also 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B). States are not only required to pay for EPSDT services, but they must also “arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment. 42 U.S.C. § 1396a(a)(43); see also *O.B. v. Norwood*, 838 F.3d 837 (7th Cir. 2016) (holding that EPSDT requires a state to provide or ensure the provision of EPSDT services, not merely pay for them.).

²⁴ For in-depth explanation of the rules and policies for EPSDT coverage, see U.S. Dep’t of Health & Human Servs. Ctrs. for Medicare & Medicaid Servs., EPSDT-A GUIDE FOR STATES: COVERAGE IN THE MEDICAID BENEFIT FOR CHILDREN AND ADOLESCENTS (June 2014) (EPSDT Guide). https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.

²⁵ *Id* at 23.

requirement and clear guidance, state Medicaid agencies still periodically attempt to reduce enrollees' access to private duty nursing hours outside their home. Advocates should remain vigilant against such restrictions.

1. If a state tries to restrict private duty nursing to an enrollee's home, use the case law cited above and CMS' State Medical Manual to argue against such restrictions. If a state elects to provide private duty nursing to an enrollee in their home, it must permit the enrollee to use those hours during the recipient's normal life activities outside of the home.
2. Be aware that while not all states opt to provide private duty nursing to adults, all states must provide private duty nursing to children under 21 if the service is necessary to correct or ameliorate the child's condition. Advocates should challenge blanket quantitative limits on the provision of private duty nursing for children.
3. In addition to focusing on Medicaid law, consider whether the facts support an Americans with Disabilities Act (ADA) claim, particularly if restrictions on how the service is delivered is causing the client to be unable to access the community settings where people without disabilities pursue daily activities. See, e.g., *Steimel v. Wernert*, 823 F.3d 902 (7th Cir. 2016) (holding unjustified isolation is discrimination under the ADA).