



Q&A: EPSDT Coverage of Private Duty Nursing, May Hours Be Reduced Based On Natural Supports?

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- Q:** My client is a child with profound physical and developmental disabilities. Her provider says she needs 18 hours of private duty nursing per day. The Medicaid Managed Care Organization (MCO) responsible for her care will only authorize 8 hours per day on the grounds that her parents should provide the remaining hours as “natural supports.” Is this permissible?
- A:** State Medicaid agencies and MCOs regularly make this argument about coverage of private duty nursing or personal care for children. There are strong arguments that parents cannot be required to provide medically necessary nursing services and personal care services when paid supports are in fact necessary.

Background

Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) provisions entitle eligible children under age 21 to all Medicaid services, including private duty nursing and personal care services, that are necessary to “correct and ameliorate” a physical or mental condition.² 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.³

Children with medical needs may be authorized for private duty nursing or personal care

¹ This Q&A is based in part on research by Elizabeth Edwards and Jen Lav.

² 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(B), 1396d(a)(3), 1396d(a)(8), 1396d(r)(5). Add definition of services.

³ 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 at 23 (June 2014) (EPSDT Guide).

services; those with profound disabilities may need many hours of nursing care per day. However, state Medicaid agencies or managed care plans may authorize fewer hours than recommended by their doctors, on the basis that their parents should be expected to provide the remaining hours. The agency and plan's expectations may not be sufficiently individualized or be actually based on medical necessity. Such a judgment may not reflect the reality of the family's situation, particularly if the parents work or have other children. Moreover, the tasks required to meet a child's needs may require the expertise and professional judgment of a licensed caregiver.

Many advocates have faced this problem and overcome it through advocacy or litigation. Below are examples of cases in which advocates have prevailed.

State of Georgia

Courts have struck down individual determinations requiring significant parental provision of services because they were not based on medical necessity. In the most notable, *Hunter v. Medows*, the court held that the Medicaid agency's reductions of the number of hours of private duty nursing violated Medicaid's EPSDT requirements.⁴ Plaintiffs Marketric Hunter and R.E. had been receiving significant numbers of hours of private duty nursing services to address their intense medical needs for extended periods of time. Neither of their conditions had improved, but the agency reduced the authorizations for services. The reduction was based on Georgia Medicaid's policy providing that parents of children receiving nursing should be trained to provide the services themselves and the children gradually weaned off nursing.⁵

Treating providers for each child testified that the decision to reduce services was not based on medical necessity because their parents were not able to actually provide the amount of services expected. Marketric's adoptive mother was 73 and had great difficulty performing suctioning on him for fear of harming him.⁶ R.E.'s mother worked full time and had two other children. She also had some training but did not feel confident of her ability to perform the tasks. Moreover, her provider testified that, even if she were a skilled nurse, she could not be expected to provide nursing for 15 hours per day.⁷ The court, therefore, struck down the authorizations as arbitrary and capricious, violating the Medicaid Act, including EPSDT requirements. Moreover, the court held that the reductions in services violated the integration mandate of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, because it placed the children at risk of institutionalization.⁸

Washington State

Washington state courts invalidated a regulation that did not allow individualized

⁴ No. 1:08-CV-2930-TWT, 2013 WL 5429430 (Sept. 27, 2013).

⁵ *Id.* at *1-9.

⁶ *Id.* at *6-7, *13.

⁷ *Id.* at *2-4, *12.

⁸ *Id.* at *13.

determinations of medical necessity for children who needed personal care services (PCS), because it presumed that parents would provide a specified amount of natural supports. Samantha A. was a 15 year old with severe medical and behavioral problems. She filed a challenge to Washington Medicaid's determination of the number of hours of personal care services (PCS) that she needed and the policy governing authorization of PCS for children.⁹

To determine the number of hours of PCS covered, Washington Medicaid applied a formula that scored individuals based on factors such as ability to perform ADLs and mental status. Next, an assessor would consider selected individual factors to determine a base amount of hours covered. The base amount was then reduced based on the level of informal supports available from family or other sources.¹⁰ In 2005, however, the agency adopted a regulation requiring automatic, standardized reductions to the base hours if the recipient was a child. It mandated that the child's needs were deemed to be met by natural supports 75% of the time if the child lives with legally responsible parents, step-parents, or adoptive parents. The rationale underlying this policy was that children under a certain age were deemed to have certain developmental needs that should be met by parents; for example, a two year old's need for a diaper change was due to developmental needs and not a disability. However, the regulation did not provide for consideration of individual evidence from a provider or allow challenges on the basis that the child's needs are actually unmet after the reductions. A parent could request an exception to the rule (ETR), but this process does not allow for a hearing nor consideration of evidence of individual needs.¹¹

Before the regulation became effective, Samantha's assessment called for 90 hours per week of PCS. After it was effective, this amount was automatically reduced to 39 hours. Samantha's mother contested the determination with an ETR. When it was denied, she appealed to the superior court, which held that the regulation violated Medicaid's comparability and EPSDT requirements. The agency appealed to the court of appeals, which granted Samantha's motion to transfer to the Washington Supreme Court.¹²

In a majority opinion signed by five justices, the Washington Supreme Court affirmed the decision that the regulation violated Medicaid's comparability provision. This provision requires that services made available to a beneficiary be the same in amount, duration, and scope as those made available to other beneficiaries.¹³ Because the regulation provided for automatic reduction of the number of hours covered for children without regard to individual needs, the court held that it violated the comparability requirement. Moreover, while the court acknowledged that utilization controls are permissible, this rule was not actually a utilization control tool because it was not aimed

⁹ *Samantha A. v. Dep't of Soc. Servs. and Health Servs.*, 171 Wash. 2d 623 (2011).

¹⁰ 171 Wash. 2d at 626-27. For an in-depth discussion of using standardized assessment tools in Medicaid, see Jane Perkins, *Q&A: Using Assessment Tools to Decide Medicaid Coverage: Case Developments* (May 27, 2016).

¹¹ 171 Wash. at 627-8.

¹² *Id.* at 628.

¹³ *Id.* at 630, citing 42 U.S.C. § 1396a(a)(10)(B).

at unnecessary coverage of services. Such a determination requires a finding of what hours are actually needed by the recipient, which did not occur here.¹⁴ Lastly, following state precedent, the court held that agency presumptions could not be used to avoid an individualized determination of need.¹⁵ Thus, the court struck down the regulation and the assessment without reaching the EPSDT issue.¹⁶

Four justices dissented, holding that the limit was appropriate because Medicaid's comparability provision does not require a state to "pay for 100% of a client's assessed personal care needs with Medicaid dollars."¹⁷ It did not address the EPSDT claim.¹⁸

Guidance from the Federal Government

CMS has provided some guidance to help states determine when parents should be expected to provide personal care services for their children. In its recent EPSDT implementation guide, CMS states that "the determination of whether a child needs personal care services should be based on the child's individual needs and a consideration of family resources that are *actually and not hypothetically available*."¹⁹

Conclusion and Recommendations

It is a fundamental principle of EPSDT that Medicaid agencies should base determinations of how many hours of nursing or personal care services should be covered on an individualized assessment. Therefore, if the agency (or a Managed Care Organization (MCO) makes a determination that parents should provide care, it should be based on evidence that the parents are actually available – not working or caring for other children – and will in fact be able to perform the necessary tasks. Moreover, if parents are expected to provide nursing services, they must actually be trained for and capable of performing those tasks.

When advocates have clients who are denied coverage for services on the grounds that the parents should be providing services, they should focus on the above principles. Moreover, they should help the family and provider prepare a comprehensive recommendation for services that explains not just the child's medical need for the nursing, but explains why the parent is not available to provide more services.

¹⁴ *Id.* at 632-33.

¹⁵ *Id.* at 633, citing *Jenkins v. Dep't of Soc. Servs.*, 160 Wash. 2d 287 (2007).

¹⁶ *Id.* at 637.

¹⁷ *Id.* at 639.

¹⁸ *Id.*

¹⁹ EPSDT Guide at 13 (emphasis added).