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Providing Equitable Medical Care for Children at Home: Federal Law and State Policy

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I. Executive Summary

While federal laws guide pediatric home health care policy, provision of home health care services occurs through states' policies and programs. State governments have endeavored to build systems that fulfill their legal obligations, yet nation-wide access to pediatric home health care remains elusive, and many children with disabilities risk unnecessary and lengthy institutional placement in hospitals and nursing facilities.

This issue brief provides background on the federal laws governing access to pediatric home health care and outlines results from a ten-state review examining how state regulations and policies establish and implement access. The review identified inconsistencies with the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of the Medicaid Act and federal anti-discrimination laws that create and maintain inequities in access to pediatric home health care. Such inconsistencies within state Medicaid pediatric home health care regulations and policies include:

- Infringement on medical necessity determinations due to the assumption of family availability
- Narrowed definitions of medical necessity
- Absence of standardized processes for medical necessity determinations and allocations
- Limitations in state policy on service hour allocations and payment
- Lack of care standardization within states
- Scarcity of transparency and monitoring

Recommendations for how states can meet their legal obligations to provide accessible and high-quality medical care at home for children include:

- Updating legal standards for EPSDT
- Developing policy statements and clinical guidance on pediatric home health care
- Requiring all home health care access information to be publicly available and readily accessible
- Enacting minimum standards of data and quality monitoring

Importantly, all efforts encapsulated in the recommendations and the reimagining of pediatric home health care must be done in partnership with youth and families.

II. Introduction

In 2012, Medicaid enabled six-year-old Justice Hope Coleman to return home to live, grow, and play with her three siblings and school friends in her Virginia neighborhood after four months in the hospital following a catastrophic bowel obstruction.[1] But for the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of the federal Medicaid Act, Justice would have likely remained institutionalized indefinitely. Policy is personal, affects everyone, and articulates who we are as a society—particularly in-home health care, where policy meets daily life for children, and their families. While federal laws guide pediatric home health care policy, provision of home health care services occurs through states' policies and programs. Although state governments have endeavored to build systems to fulfill their legal obligations, many children with disabilities across the country risk unnecessary and lengthy institutional placement in hospitals and nursing facilities because access to pediatric home health care remains elusive.[2,3]

Policy is personal, affects everyone, and articulates who we are as a society—particularly in-home health care, where policy meets daily life for children, and their families.

This Issue Brief provides background on the federal laws governing pediatric home health care, specifically private duty nursing (PDN) and personal care services (PCS), by highlighting specific challenges across states' existing pediatric home health care policies. Furthermore, it offers recommendations for how states can work to meet their legal obligations to provide truly accessible and high-quality medical care at home for children. The review occurred from 2021 to 2023 and examined state Medicaid policy governing eligibility for and access to pediatric home health care in one state from each of the ten Health Resources and Services Administration (HRSA) regions: California, Colorado, Iowa, Illinois, Massachusetts, New York, Oregon, Pennsylvania, Tennessee, and Texas. The authors were assisted in their review by family leaders from the Maternal and Child Health Bureau (MCHB) family-to-family health information centers (F2Fs).

The findings reflect wide variations in policies and a need for reforms to ensure that children receive their legally entitled medical services.

III. Background

Federal Medicaid Law Requires States to Provide Pediatric Home Health Care

Enacted in 1967, the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) provisions of the Medicaid Act entitle children under 21 to a comprehensive range of services, including home health care services.[4] Medicaid provides a comprehensive home health benefit for children that includes part-time or intermittent nursing services, home health aide services, medical supplies and equipment, and, at states' option, physical, occupational, and speech therapy. EPSDT obligates states to cover all mandatory and optional services under Medicaid— whether or not such services are covered for adults— when those services are determined to be medically necessary by a child's provider.[5,6] The Act also requires the Medicaid agency to "arrang[e] for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment" that the child needs.[7] The active, obligatory, non-discretionary duty of states to effectuate the treatment aspect of EPSDT is clear in the Act and its legislative history.[8] As such, if a health care provider determines that a child needs PDN or PCS at home, EPSDT requires coverage even if the state otherwise places a quantitative limit on nursing or personal care hours, or does not cover these services at all for adults. Accordingly, courts have found that EPSDT obligates states to provide in-home nursing, and in so doing also enforces the state's active obligation to "arrange for" such services with reasonable promptness.[9] All children enrolled in state Medicaid programs, including those enrolled through home and community-based service waiver programs (HCBS), are entitled to EPSDT. Waiver programs offer services beyond the medical assistance of the Medicaid Act, such as habilitative or respite services, and thus "wrap around" the EPSDT benefit.

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The Integration Mandate

Managing the "T"- or treatment- aspect of EPSDT to access pediatric home health care for children with disabilities has been fraught with challenges since its inception. In 1990, Congress enacted the Americans with Disabilities Act (ADA) to prohibit discrimination against individuals with disabilities, including by public entities, recognizing that "historically, society has tended to isolate and segregate individuals with disabilities" and that "forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."[10,11] Federal regulations implementing the ADA require public entities to "administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[12,13] In 1999, the Supreme Court's *Olmstead* decision affirmed that institutionalization is a form of discrimination prohibited by the ADA in cases when health care could be provided in the community.

IV. Key Findings

Our review found extensive inconsistencies with state regulations and policies.

A. Family Availability Rather Than Medical Necessity

The medical necessity standard put forth in the Medicaid Act does not allow for determinations of eligibility and assessment of medically necessary services for a child to presume a family is available or trained and able.[14]

Unfortunately, the review found that over half of the reviewed states (6 of 10) had Medicaid regulations that infringed on medical necessity determinations in both eligibility for and assessment of the number of pediatric nursing and personal care hours, by presuming some aspect of "family availability" in both their eligibility criteria and allocation of hour processes (IA, PA, OR, TN, MA, and IL) (**Table 1**).[15] These states explicitly included language indicating that pediatric nursing care and/or personal care would not be approved for "maintenance care," "convenience," "child care" or "not replace the parent or guardian as primary caregiver," suggesting a presumption that parents are routinely available, able, and willing to provide medical care for their child despite the EPSDT mandate. For example, Pennsylvania Managed Care Organization (MCO) Aetna has a policy for private duty nursing and home health care services that puts the burden on parents to prove their *unavailability*, explicitly stating that the "parent or caregiver is considered able and available" absent "supporting documentation" establishing their daily schedule or a medical certification regarding their inability to provide care.[16] This policy creates a harmful barrier for the family that is disconnected from the question of whether a child has a medical need for in-home medical care. In addition, it adds paperwork burdens that require documentation of personal and intimate information that arguably invades the family's privacy.[17]

Such state polices also infringe on the medical necessity standard of federal Medicaid law. Family availability policies sidestep a state's legal obligation and formally shift responsibility to provide medically necessary care to a family. Furthermore, these policies favor working families who can more easily establish their unavailability, penalize families where one or more parents are not in the workforce (possibly caused by lack of nursing care or prolonged hospitalizations), and limit family members' ability to conduct basic functions like sleep or care for other children in order to provide essential medical care that is supposed to be provided by the state.[18] It is important to note that at the time of review, Colorado was the only state that had an established program with a pathway for families of children under the age of 18 to become certified as nursing aides who have the ability to be paid for the skilled care they provide for their child.[19] While some states, such as Pennsylvania, created temporary paid family caregiving programs in response to the federal Public Health Emergency (PHE), some are revoking this option with the end of the PHE. Other states including Arizona, Massachusetts, Illinois, and Montana recognize that the medical need of a child for home health care and the state's obligation to meet it remain and are taking additional regulatory and legislative steps to make these programs permanent.

Only 1 of the 10 reviewed states had language cautioning against assuming parental availability. Texas rewrote its policies after a court ruled that the state's Medicaid policies requiring caregivers to provide a portion of their child's medically necessary nursing services "deprive these children of their entitlement to all medically necessary nursing services, in violation of the Medicaid Act, and are, therefore, invalid."[20] The state's PDN manual now indicates that "because Texas Medicaid is obligated to provide all medically necessary PDN services, a parent or guardian is not obligated to provide PDN services even if the parent or guardian has received the appropriate training. Medically necessary PDN services will not be denied to clients based on the parent or guardian's ability to provide the PDN services."[21]

Table 1: State PDN Policies Regarding Family Availability

State	Policy Language	Citations
California	No language regarding family availability found. California applies the EPSDT "correct or ameliorate" standard for PDN services.	California Department of Health Care Services, Private Duty Nursing Frequently Asked Questions, 10 (Aug. 2019), available at: https://www.dhcs.ca.gov/services/Documents/PDN.FAQ.20190731.pdf
Colorado	"A pediatric client may be approved for up to 24 hours per day of PDN services if the client meets the … medical necessity criteria." "medical case management" will be provided "with the goal of resolving the problem that precipitated the need for extended PDN care of more than 16 hours." "Twenty-four hour care may be approved for pediatric clients during periods when the family caregiver is unavailable due to illness, injury or absence periodically for up to 21 days in a calendar year."	10 Colo. Code Regs. § 2505-10-8.540.2.
Iowa	"Prior authorization approvals shall not be granted for treatment plans that exceed 16 hours of home health agency services per day." "The Private Duty Nursing/Personal Cares (PDN/PC) program is part of the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program that provides in home private duty nursing and personal cares services by Medicare-certified home health agencies. . . . A maximum of 16 hours, based on medical need, may be prior authorized per day." "PDN/PC does not include medical needs that can be met by a family member, significant other, friend, neighbor, community or other unpaid resources."	Iowa Admin. Code § 441-78.28(10)(b)(3); Id. § 441-78.9(10) Iowa Dept of Human Services, "Private Duty Nursing/Personal Cares Program," https://hhs.iowa.gov/programs/welcome-iowa-medicaid/iowa-medicaid-programs/personal-cares
Illinois	"When determining the hours of care necessary to maintain the participant at home, consideration shall be given to the availability of other services, including direct care provided by nonpaid caregivers, such as, but not limited to, the participant's family or legal representative, that can reasonably be expected to meet the medical needs of the participant."	89 Ill. Admin. Code § 120.530
Massachusetts	"When a family member or other caregiver is providing services, including nursing services, that adequately meet the member's needs, it is not medically necessary for the home health agency to provide such services."	130 Code Mass. Regs. § 403.409(D); see also id. §414.409(H)
New York	"The intention of PDN services is to support – not replace – the skilled care provided to a member by parents, family, and other responsible caregivers. Commitment by the family and community are necessary to meet the member's needs and to ensure the member can remain safely at home." "Backup caregivers will need to be identified for use when a nurse is not available. Family and other caregivers should routinely provide hands on care to maintain their general care skills, and assure they are competent in providing backup care when the nurse is unavailable." Each backup caregiver must submit a training statement confirming that they are "fully trained in all skilled tasks, and willing to care for the member." Furthermore, as part of the initial request for PDN services and every 12 months, the state requires information regarding "psychosocial and home information," which includes information regarding "persons living in the home environment, including ages of minors, member's school schedule, including pick up and drop off transportation times. Names and ages of all backup caregivers and their college schedules (on college letterhead) and work schedules (with work hours and days of the week, including travel time, on company letterhead, signed/dated by the employer)."	Private Duty Nursing Policy Manual, eMedNY New York State Medicaid Provider Policy https://www.emedny.org/ProviderManuals/Nursing-Services/PDFS/Private_Duty_Nursing_Policy.pdf

State	Policy Language	Citations
Oregon	"Private duty nursing is considered supportive to the care provided to a client by the client's family, foster parents, and delegated caregivers, as applicable. . . Increases or decreases in the level of care and number of hours or visits authorized shall be based on a change in . . . the family, foster parents, or delegated caregiver's ability to provide care."	Or. Admin. R. 410-132-0020
Pennsylvania	"A request may not be denied . . . [b]ecause a parent or caregiver is present in the home unless the PH-MCO has adequate documentation that substantiates the parent or caregiver is actually able and available to provide the child's care during the time hours are requested."	Laurie Rock, Dir. Penn. Bureau of Managed Care Operations, "Managed Care Operations Memorandum, General Operations, MCOPS Memo # 07/2016-008," available at https://pdf4pro.com/amp/cdn/managed-care-operations-memorandum-general-2aad.pdf
Tennessee	Private duty nursing services will only be authorized when there are competent family members or caregivers as indicated below: 1. Private duty nursing services include services to teach and train the recipient and the recipient's family or other caregivers how to manage the treatment regimen. Having a caregiver willing to learn the tasks necessary to provide a safe environment and quality in home care is essential to assuring the recipient is properly attended to when a nurse or other paid caregiver is not present, including those times when the recipient chooses to attend community activities to which these rules do not specifically permit the private duty nurse or other paid caregiver to accompany the patient. 2. To ensure the health, safety, and welfare of the individual, in order to receive private duty nursing services, the recipient must have family or caregivers who: (i) Have a demonstrated understanding, ability, and commitment in the care of the individual related to ventilator management, support of other life-sustaining technology, medication administration and feeding, or in the case of children, other medically necessary skilled nursing functions, as applicable; and (ii) Are trained and willing to meet the recipient's nursing needs during the hours when paid nursing care is not provided, and to provide backup in the event of an emergency; and (iii) Are willing and available as needed to meet the recipient's non-nursing support needs. (iv) In the case of children under the age of 18, the parent or guardian will be expected to fill this role.	Tenn. Comp. R. & Regs. 1200-13-13-.04
Texas	"Because Texas Medicaid is obligated to provide all medically necessary PDN services, a parent or guardian is not obligated to provide PDN services even if the parent or guardian has received the appropriate training. Medically necessary PDN services will not be denied to clients based on the parent or guardian's ability to provide the necessary PDN services."	Texas Medicaid Provider Procedural Manual May 2024 4.1.2 https://www.tmhp.com/sites/default/files/microsites/provider-manuals/tmppm/html/index.html#t=TMPPM%2F2_10_HH_Nursing_and_PDN_Srvs%2F2_10_HH_Nursing_and_PDN_Srvs.htm%23998975&rhtocid=_21; see also 1 Tex. Admin. Code § 363.309(g) https://www.law.cornell.edu/regulations/texas/1-Tex-Admin-Code-SS-363-309

B. Narrowing the Definition of Medical Necessity

The U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services (CMS) provides clear guidance to state Medicaid agencies on the goal of EPSDT: "[t]he goal of EPSDT is to assure that individual children get the health care they need when they need it—the right care to the right child at the right time in the right setting."[22]

CMS also offers guidance as to a definition of medical necessity for EPSDT, but it is up to each state to develop their own. In 6 out of 10 reviewed states (CO, IA, IL, MA, NY, and PA), the definition of medical necessity that is used by the state to make determinations for pediatric home health care services was not readily available through a basic internet search. The absence of clear guidance regarding how a state follows CMS guidance and determines whether a child needs in-home nursing or other home health services creates barriers to families and prescribing providers who do not know what information the state requires to approve or allocate hours. Moreover, when a state's definition was located, some included additional language that improperly narrowed the EPSDT standard that services must be covered if they are "necessary to correct or ameliorate."[23]

For instance, the Tennessee Medicaid program limits PDN eligibility to children who are "dependent upon technology-based medical equipment requiring constant nursing supervision, visual assessment, and monitoring of both equipment and child."[24,25] While the language goes on to state that determinations of medical necessity be made on an individualized basis, families in Tennessee indicate that in practice this language excludes children from PDN unless they have medical technology dependence. The F2F in Tennessee further reported that in practice, this barrier disproportionately affects low-income and rural families because of lack of knowledge about the goals of EPSDT.

C. Lack of Standardized Processes for Medical Necessity Determinations and Allocation

CMS, the American Academy of Pediatrics, and courts have agreed that medical necessity determinations should be made based on concepts of reasonableness and necessity.[26] Federal Medicaid regulations require that all coverage standards be designed to "reasonably achieve" the purpose of the benefit.[27]

Express Limits on Hour Allocations

The review also included evaluating how policies guided hour allocation assessment, which is the process by which a child's medical and disability-related needs are reviewed and the state determines the number of hours of service that will be paid for. The review revealed a variety of limitations in state policies in the number of hours that can be assessed, which prevents "reasonable achievement" of PDN and personal care services.[27] Only one state, Texas, expressly stated in their Medicaid regulations that a cap on the number of hours of care assessed is prohibited.[28] One state, Iowa, has regulations explicitly capping the number of home health agency services a child may receive, regardless of medical necessity, at 16 hours per day.[29]

Lack of Standardization Within State

Those children who receive pediatric home health care services through managed care organizations retain the right to receive medically necessary services through the EPSDT benefit.[30]

Children access home health care through fee-for-service, MCOs or both. In six states, determinations of eligibility for PDN care (CA, IA, NY, PA, TN and TX) were made by an MCO. Only three of six states created some sort of guidance for MCOs as to eligibility criteria and processes for nursing care (CA, PA and TX).[31] In eight states (CA, CO, IA, IL, MA, NY, PA, and TN) personal care eligibility determinations were made by an MCO. Only three of the eight states (NY, PA and TN) provided guidance for MCOs determining eligibility for personal care. In states with multiple MCOs, a lack of guidance creates inconsistency in eligibility and access within each state, as MCOs are left to develop their own policies — let alone between different states. Effectively, this ensures that two children with the same level of medical needs receive different access depending on the MCO in which they are enrolled. Family leaders in each state with MCOs indicated that inconsistencies abound and that families report lack of access to eligibility and assessment information from MCOs. Only two states (MA and IL) had a specific entity (separate from the MCO) contracted to provide streamlined processing of most home health care for children with disabilities.[32]

Only three of ten states had a pediatric-specific standardized assessment tool publicly available (CO, IL, and OR) (**Table 2**).[33] While Iowa does have standardized tools for assessment, they are not pediatric-specific. Current standardized eligibility assessment tools have several challenges, including how they are developed and how to monitor and ensure fair application, without evidence of validation in children and clear inter-rater reliability. Further, Illinois halted use of a standardized tool by a third-party contractor as part of a class action settlement, after families showed that unfair application of the tool by MCOs stripped their child of previously approved nursing hours, dramatically decreasing nursing hour approval.[34] The settlement required that the state discontinue using third party contractors for assessments, provide clear notice of changes, and communicate with medical professionals in assessments of medical necessity.

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Table 2: Publicly Available Assessment Tools for PDN and Personal Care Services

State	Assessment Tool Identified
California	n/a
Colorado	**PDN:** PDN Acuity Tool, https://hcpf.colorado.gov/sites/hcpf/files/PDN%20Acuity%20Tool.pdf **Personal Care Services:** Personal Care Assessment Tool, https://hcpf.colorado.gov/sites/hcpf/files/Personal%20Care%20Assessment%20Tool%20%28PCAT%29.pdf **CAN and Intermittent RN-LPN Services:** Health First Colorado Pediatric Home Assessment Tool CNA Services and RN-LPN Services, https://hcpf.colorado.gov/sites/hcpf/files/Pediatric%20Assessment%20Tool%20-%20rev%20March%202022%20final.pdf
Iowa	**PDN and PCS:** Iowa references three tools in its Home Health Provider Manual: "the Medical Needs Acuity Scoring Tool (MNAST)," the "Functional Needs Acuity Scoring Tool (FNAST)," and the "Social Needs Acuity Scoring Tool (SNAST)." Home Health Services Provider Manual, page 32, https://dhs.iowa.gov/sites/default/files/Hhserv.pdf?101120211749 We were unable to locate publicly available copies of those tools.
Illinois	**PDN:** Illinois uses a Level of Care tool for the MFTD Waiver (http://mftdwaiver.org/files/documents/ccmn_level_care_mftdwaiver.pdf) and offers a manual for guidance as to how to score the tool http://mftdwaiver.org/files/documents/ccmn_mftd_loc.pdf
Massachusetts	n/a
New York	n/a
Oregon	**PDN:** PDN Acuity Grid https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/oe0591.pdf **Psychosocial Grid:** https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/oe0590.pdf Scoring rubric is established in regulations at Or. Admin. R., 410-132-0080(d)
Pennsylvania	n/a
Tennessee	n/a
Texas	n/a

D. Lack of Transparency and Monitoring

The Medicaid Act requires states to effectively inform all Medicaid-eligible persons in the state who are under age 21, of the availability of EPSDT.[35]

The review found that pediatric nursing along with personal care eligibility criteria and assessment processes were not always clear or made publicly available. Family leaders from the F2Fs in each state verified that this lack of transparency is experienced regularly by families. F2Fs also noted that when information is shared, it is often not in plain language or in languages other than English. This calls into question whether states are meeting their obligation to effectively inform Medicaid-eligible children of the services available and how to access them.

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>
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Likewise, information on program-wide implementation is not readily available and information on how states monitor access and quality metrics was lacking. The Massachusetts and Illinois legislatures do require some reporting on various aspects of access and quality to inform how they create home health care policy.[36] California and Illinois also require some quality monitoring because of court settlements over violations of EPSDT for failure to arrange for in-home nursing.[37] Notably, neither the federal EPSDT regulations nor CMS EPSDT guidance provide uniform or consistent requirement or parameters as to reporting pediatric home health care, thereby creating little ability to monitor and evaluate whether most states are meeting their obligations to children requiring home health care.

> Federal EPSDT regulations nor CMS EPSDT guidance provide uniform or consistent requirement or parameters as to reporting pediatric home health care.

V. Recommendations

The following recommendations represent ways to make advances in the pediatric home health care policy landscape:

Legal Standards

CMS initiate a notice of proposed rulemaking process to remedy the significant gap that exists between the provisions of EPSDT in the Medicaid Act and implementation at the state level. Given that the last update of EPSDT occurred in 1989 in the Omnibus Reconciliation Act, it is time to update alignment with health equity needs and, at a minimum, provide additional, updated, and clear legal standards for medical necessity determinations to prevent further erosion of access to this right for all children. Changes to Medicaid access and managed care represent the most significant strides forward for home and community-based services (HCBS) in over a decade.[38] However, since most children access home health care through EPSDT, this barely scratches the surface on ensuring quality and access for children. With the final rule as a model, updates to EPSDT must also reflect the vastly decentralized and unmonitored landscape of managed care.

Medical Necessity

Clinical societies should undertake development of policy statements and clinical guidelines that inform their membership as well as federal and state officials about the intricacies of what a child's condition dictates are needed to ameliorate their condition(s), in relation to pediatric home health care. More detailed and clearer guidance could help correct some of the policies that inappropriately limited eligibility and hour allocation.

Transparent and Accessible Information

All information regarding how to access home health care must be publicly available and accessible, including the tools and standards used to allocate hours of PDN or PCS. Standards of communication should meet a spectrum of needs. For example, families must have access to linguistically appropriate information that is understandable (plain language), accessible to individuals with vision impairment or other disabilities impacting comprehension, and available in languages other than English. Clinicians must also have clear information regarding what the assessment process entails, so they can fulfill their role of providing the relevant and comprehensive documentation, which accurately reflects a child's medical needs. Let us learn from the unwinding of Medicaid continuous coverage, when over two-thirds of recipients did not know redeterminations had begun.[39]

Quality and Access Monitoring

Minimum standards of required data to monitor the access to and quality of pediatric home health care must be established and deemed required reporting under a new EPSDT rule. As a baseline, all states should track and require each MCO to track how many hours of pediatric nursing and personal care were assessed versus how many were received. Additionally, metrics for quality of care received in the home should also be created, as unsafe or poor-quality care negates access. The Medicaid Access final rule focus only on HCBS standards of quality, but CMS should further promote standardization by also requiring measurement of quality for children receiving nursing and personal care through EPSDT.[38]

Partnership

All efforts to reimagine home health care, fulfill existing obligations, and eliminate inequitable policies, must be in meaningful and authentic partnership with youth and families who bring the lived knowledge of how policies are implemented and can be effectively changed. Care in the home affects families across the life course. The state examples in this issue brief provide ideas and strategies to develop effective home health policies. Only in partnership with families will equitable and full access to care be achieved, no matter where a child calls home.

References

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3. See Sobotka SA, Lynch E, Quinn MT, Awadalla SS, Agrawal RK, Peek ME. Unmet Respite Needs of Children With Medical Technology Dependence. Clin Pediatr (Phila). 2019 Oct;58(11-12):1175-1186. doi: 10.1177/0009922819870251. PMID: 31502488; Maynard R, Christensen E, Cady R, et al. Home Health Care Availability and Discharge Delays in Children With Medical Complexity. Pediatrics. Dec 3 2018;doi:10.1542/peds.2018-1951
4. Social Security Act, 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r).
5. See 42 U.S.C. § 1396d(r)(5); 42 U.S.C. § 1396d(a) (listing services).
6. CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents 1 (2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.
7. 42 U.S.C. § 1396a(a)(43)(C).
8. S.D. ex rel. Dickson v. Hood, 391 F.3d 581, 592 (5th Cir. 2004) (concluding that "the legislative history demonstrates Congress intended the health care and treatment available under the EPSDT program to be made more accessible and effective by: removing the Secretary's express authority to define the means and the standards for its operation; placing the goal, means and standards in the statute itself; and by imposing an obligatory, not discretionary, duty on states to effectuate this aspect of the EPSDT program 'whether or not such services are covered under the State plan.'") (quoting 42 U.S.C. § 1396d(r)(5)).
9. See e.g., O.B. v. Norwood, 838 F.3d 837, 840 (7th Cir. 2016); I.N. v. Kent, No. C 18-03099 WHA, 2019 WL 1516785 (N.D. Cal. Apr. 7, 2019); A.H.R. v. Wash. State Health Care Auth., No. C15- 5701JLR, 2016 WL 98513 (W.D. Wash. Jan. 7, 2016); See also M.H., v. Berry, No. 1:15-CV-1427-TWT, 2021 WL 1192938, *4-5 (N.D. Ga. Mar. 29, 2021) (quoting CMS Guide to find, "The goal of EPSDT is to assure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting."); C.R. by & through Reed v. Noggle, 559 F. Supp. 3d 1323, 1336-37 (N.D. Ga. 2021) (deferring to CMS Guide's explanation of "correct or ameliorate"); A.A., by & through P.A. v. Phillips, 339 F.R.D. 232, 237 (M.D. La. 2021) (citing CMS Guide to find that "all services and interventions recommended by a physician or other licensed practitioner of the healing arts to correct or ameliorate a diagnosed condition . . . necessarily includes recommended IHCBS").
10. Americans with Disabilities Act, 42 U.S.C. § 12132.
11. Americans with Disabilities Act, 42 U.S.C. § 12101(a)(2).
12. 28 C.F.R. § 35.130(d).
13. 28 C.F.R. § 41.51.
14. See 42 U.S.C. § 1396d(r)(5); See e.g., M.H. v. Berry, No. 1:15-CV-1427, 2021 WL 1192938 (N.D. Ga. Mar. 29, 2021) (finding that PDN must be provided by a nurse and enjoining the State's "teach and wean" policy, which reduced nursing hours by shifting more of the burden onto caregivers without adequate consideration of caregivers' capacity to provide the care); A.R. by and through Root v. Sec. Fla. Agency for Health Care Admin., 769 Fed. App'x 718 (11th Cir. 2019) (finding EPSDT and ADA challenges to Florida's provision of PDN services to medically fragile children moot after Florida changed policies through formal rulemaking to: (1) stop applying a convenience standard (that denied PDN services as merely for the convenience of the caretaker if the child's parents were available to provide nursing services to the child); Hunter v. Meadows, 4 No. 1:08–CV–2930–TWT, 2013 WL 5429430 (N.D. Ga. Sept. 27, 2013) (holding that reduction of PDN hours violated Medicaid's EPSDT requirements where 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); see also CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents 13 (2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf ("the determination of whether a child needs personal care services must be based upon the child's individual needs and a consideration of family resources that are actually—not hypothetically—available.").
15. See Iowa Dept of Human Services, "Private Duty Nursing/Personal Cares Program," https://hhs.iowa.gov/programs/welcome-iowa-medicaid/iowa-medicaid-programs/personal-cares, last visited Feb. 14, 2024 (noting that the state will not authorize hours for "medical needs that can be met by a family member, significant other, friend, neighbor, community or other unpaid resources."); Laurie Rock, Dir. Penn. Bureau of Managed Care Operations, "Managed Care Operations Memorandum, General Operations, MCOPS Memo # 07/2016-008," available at https://pdf4pro.com/amp/cdn/managed-care-operations-memorandum-general-2aad.pdf

(permitting MCOs to deny requests for PDN hours if the MCO has "adequate documentation that substantiates the parent or caregiver is actually able and available to provide the child's care during the time hours are requested."); Or. Admin. R. 410-132-0020 ("Increases or decreases in the level of care and number of hours or visits authorized shall be based on a change in . . . the family, foster parents, or delegated caregiver's ability to provide care."); Tenn. Comp. R. & Regs. 1200-13-13-.04 (requiring parents, family, or other caregivers to be "trained and willing to meet the recipient's nursing needs during the hours when paid nursing care is not provided"); 130 Code Mass. Regs. § 403.409(D)("When a family member or other caregiver is providing services, including nursing services, that adequately meet the member's needs, it is not medically necessary for the home health agency to provide such services."); Id. § 414.409(H) ("When a family member or other caregiver is providing services that adequately meet the member's needs, it is not medically necessary for the independent nurse to provide such services."); 89 Ill. Admin. Code § 120.530 (" … (4) When determining the hours of care necessary to maintain the participant at home, consideration shall be given to the availability of other services, including direct care provided by nonpaid caregivers, such as, but not limited to, the participant's family or legal representative, that can reasonably be expected to meet the medical needs of the participant.).

16. Aetna Better Health of Pennsylvania, Clinical Guidelines: Private Duty Skilled Nursing & Home Health Aide Services, available at https://www.aetna.com/cpb/medical/data/100_199/0136.html#dummyLink2
17. Fratantoni K, Raisanen JC, Boss RD, Miller J, Detwiler K, Huff SM, Neubauer K, Donohue PK. The Pediatric Home Health Care Process: Perspectives of Prescribers, Providers, and Recipients. Pediatrics. 2019 Sep;144(3):e20190897. doi: 10.1542/peds.2019-0897. PMID: 31467245.
18. See Meltzer LJ, Boroughs DS, Downes JJ. The Relationship Between Home Nursing Coverage, Sleep, and Daytime Functioning in Parents of Ventilator-Assisted Children. Journal of Pediatric Nursing. 2010;25(4):250-257. doi:10.1016/j.pedn.2009.01.007; Baumgardner, D. J. and Burtea, E. D. Quality-of-life in technology-dependent children receiving home care, and their families - A qualitative study. Wisconsin Medical Journal, 97, 8 (1998), 51-55; Margolan, H., Fraser, J. and Lenton, S. Parental experience of services when their child requires long-term ventilation. Implications for commissioning and providing services. Child: Care, Health & Development, 30, 3 (2004), 257-264.
19. Parents as their child's Certified Nursing Aide (CNA) | Department of Public Health & Environment (colorado.gov) Accessed February 14, 2024. See also Foster C, Kwon S, Blakely C, Carter K, Sobotka SA, Goodman DM, Agrawal R, Brittan M. Paying Family Medical Caregivers for Children's Home Healthcare in Colorado: A Working Medicaid Model. J Pediatr. 2023 Feb 10:S0022-3476(23)00106-3. doi: 10.1016/j.jpeds.2022.12.043. Epub ahead of print. PMID: 36775189.
20. Alberto N. v. Hawkins, No. 6:99-cv-459, 2007 WL 8429756, *13 (E.D. Tex. June 8, 2007) ("Nothing in the Medicaid Act or its implementing regulations allows states to avoid their obligation to provide medically necessary services to EPSDT beneficiaries based upon non-medical criteria, such as the ability of the primary caregiver to provide medical services themselves, or medical criteria that does not track the Medicaid Act's 'correct and ameliorate' standard.").
21. Texas Medicaid Provider Procedure Manual, Section 4.1.2, https://www.tmhp.com/sites/default/files/microsites/provider-manuals/tmppm/html/TMPPM/2_HH_Nursing_and_PDN_Srvs/2_HH_Nursing_and_PDN_Srvs.htm. Accessed January 5, 2023. See also 1 Tex. Admin. Code § 363.309(g).
22. CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents 1 (2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf
23. 42 U.S.C. § 1396d(r)(5).
24. Tenn. Comp. R. & Regs. § 1200-13-13-.01 et seq; See also OHA Regulations, 410-132-0080(1)(b)-(c), https://www.law.cornell.edu/regulations/tennessee/Tenn-Comp-R--Regs-1200-13-13-.04 ("Private duty nursing is considered supportive to the care provided to a client by the client's family, foster parents, and delegated caregivers, as applicable. Nursing services shall be medically appropriate. Medically appropriate for private duty nursing shift care is determined by qualifying for services based on the Private Duty Nursing Acuity Grid (DMAP 591). Increases or decreases in the level of care and number of hours or visits authorized shall be based on a change in the client's condition, program limitations, and the family, foster parents, or delegated caregiver's ability to provide care.").
25. Tenn. Comp. R. & Regs. § 1200-13-13-.01(103)(d).
26. Angelo P. Giardino, Mark L. Hudak, Beena G. Sood, Stephen A. Pearlman, THE COMMITTEE ON CHILD HEALTH FINANCING; Considerations in the Determination of Medical Necessity in Children: Application to Contractual Language. Pediatrics August 2022; 150 (3): e2022058882. 10.1542/peds.2022-058882
27. 42 C.F.R. §440.230(b).
28. "Texas Medicaid is not allowed to place a cap or limit on medically necessary services, including PDN." https://www.txhealthsteps.com/static/courses/pdn/sections/section-1-1.html. See also 1 Tex. Admin. Code § 363.309(i) ("The amount of medically necessary PDN services available to recipients will not be capped.").

29. See Iowa Admin. Code § 441-78.28(10)(b)(3); Id. § 441-78.9(10); Iowa Dep't of Human Services, "Private Duty Nursing/Personal Cares Program," https://hhs.iowa.gov/programs/welcome-iowa-medicaid/iowa-medicaid-programs/personal-cares (last visited Feb. 14, 2024).

30. CMS, EPSDT - A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents, 29 (2014), https://www.medicaid.gov/medicaid/benefits/downloads/epsdt_coverage_guide.pdf.

31. See California Department of Health Care Services, All-Plan Letter 20-012, "Private Duty Nursing Case Management Responsibilities For Medi-Cal Eligible Members Under The Age Of 21," https://www.dhcs.ca.gov/services/Documents/APL-20-012.pdf (describing case-management requirements that MCOs have for PDN services); Pennsylvania Managed Care Operations Memorandum General Operations MCOPS Memo # 07/2022-004, available at https://www.dhs.pa.gov/HealthChoices/HC-Services/Documents/Managed%20Care%20Operations%20Memos/MCS-07-2022-004.pdf (referencing several bulletins describing prior authorization requirements for MCOs, including Managed Care Operations Memorandum, General Operations, MCOPS Memo # 07/2016-008 and MA Bulletin NUMBER 05-16-04, 24-16-18, 25- 16-03, 31-16-21 (PA Medicaid has issued several bulletins how MCO should assess and allocate hours); 1 Tex. Admin. Code §§ 363.305(b)(6), 363.309, 363.311 (directing how medical necessity determinations will be made establishing prior authorization requirements that are described in the provider manual and requiring all PDN providers to comply with the PDN Manual).

32. See UIC, DSCC, "Home Care Nursing Information for Families," https://dscc.uic.edu/home-care-nursing-information-for-families/ (HFS delegates responsibility for care coordination and monitoring utilization of in-home shift nursing to the University of Illinois at Chicago Division of Specialized Care for Children); Continuous Skilled Nursing Biennial Report, January 2020, https://www.chiamass.gov/assets/docs/r/pubs/2020/continuous-skilled-nursing-care-report.pdf (page 7 of the PDF) (MassHealth designates the prior authorization process to the University of Massachusetts Medical School Commonwealth Medicine Community Case Management (CCM) Program.)

33. See Colorado Pediatric Home Assessment Tool Pediatric Home Assessment Tool (colorado.gov) and Personal Care Assessment Tool (PCAT)_1.pdf (colorado.gov); Oregon PDN Acuity Grid, https://sharedsystems.dhsoha.state.or.us/DHSForms/Served/oe0591.pdf.

34. Erin Butler, "Illinois Kids Deserve Care: Big Win for In-Home Nursing Services," (Feb. 21, 2019) https://legalcouncil.org/in-home-nursing-settlement-illinois/. Accessed Feb. 14, 2024.

35. 42 U.S.C. § 1369a(a)(43)(A).

36. See Illinois Department of HealthCare and Family Services, Report of Medicaid Services for Persons who are Medically Fragile, Technology Dependent: Presented Pursuant to Public Act 095-0622 (2022), https://www.ilga.gov/reports/ReportsSubmitted/3050RSGAEmail5862RSGAAttachFINAL%20MFTD%20Biannual%20Report%202022.pdf; Mass. General Laws, Chapter 12C, Section 24 https://malegislature.gov/Laws/GeneralLaws/PartI/TitleII/Chapter12C/Section24 (The Massachusetts Legislature passed a law requiring MassHealth and the Center for Health Information and Analysis to prepare a biennial report on the provision of continuous skilled nursing care).

37. See I.N. v. Kent, No. 3:18-cv-3099, N.D. Cal, Settlement agreement, available at https://www.disabilityrightsca.org/system/files/file-attachments/IN_Settlement_Agreement.pdf; O.B. v. Eagleson, No. 15-cv-10463, N.D. Ill. Settlement Notice, available at https://legalcouncil.org/settlement-ob-2019/?fbclid=IwAR2_Hy6kX1TOMSNBcuqBrHzdUbTDyEE7oh3H_fzVKio6v8_rZD_Su1s7OSQhttp://.

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