# House Human Services Committee Informational Meeting
Room B31 Main Capitol
Harrisburg, PA 17120
June 09, 2026
9:30 AM

## Agenda

**Panel 1**

Meghann Luczkowski

Parent

Hannah Brown

Parent

**Panel 2**

Deanna Pack

Area Director of Clinical Services/Administrator, 365 Health Services, LLC.

Bill Sczepanski

Executive Vice President of Public Policy and Government Relations, Team Select Home Care

Michele Werner RNC, BSN

Regional Director of Regulatory and Government Affairs, Angels of Care Pediatric Home Health

**Panel 3**

Emily Katz, MPH

Executive Director, PA Medicaid Managed Care Organizations PAMCO

**And any other business that comes before the Committee**

**Adjournment**

## Attachments:

- House Human Services Committee Informational Meeting Agenda 6.9.26
- HHS Committee Testimony_Luczkowski
- Hannah Brown
- House Testimony June9th Deena
- Written Testimony for PA Legislature 6-9-26 Bill
- EPSDT Coverage Guide Final May 2026
- Family CNA Map
- Paid-Family-Caregiving-Advocacy-Action-Guide from AAP
- Testimony 20260609 AOC PA HB2164 Michele
- PAMCO House Human Services Complex Care Testimony 06.09.26 (final)

- Human Services Committee Official Meeting Notice 6.9.26

SEAL OF THE HOUSE OF REPRESENTATIVES OF PENNSYLVANIA

# House Human Services Committee Informational Meeting

Tuesday, June 9th, 2026
9:30AM
B31 Main Capitol
Harrisburg, PA 17120

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**1. Call to Order**

**2. Attendance**

**3.** Panel 1

**Meghann Luczkowski**, Parent

**Hannah Brown**, Parent

Panel 2

**Deanna Pack**, Area Director of Clinical Services/Administrator.

365 Health Services, LLC.

**Bill Sczepanski**, Executive Vice President of Public Policy and Government Relations

Team Select Home Care

**Michele Werner** RNC, BSN, Regional Director of Regulatory and Government Affairs

Angels of Care Pediatric Home Health

Panel 3

**Emily Katz**, MPH, Executive Director

PA Medicaid Managed Care Organizations PAMCO

## 4. Adjournment

PA House and Human Services Committee Hearing - June 9, 2026
Testimony from Meghann Luczkowski, Parent Advocate, (Philadelphia)

Good morning and thank you for having me here today. My name is Meghann Luczkowski. I am a former special educator from Philadelphia who has spent the last few years working in public health. What really brings me here today, though, is my favorite role — being Mom to Leo, George, and Miles.

Despite having an otherwise healthy pregnancy with our now 12-year-old twins George and Miles, my husband and I spent 5 weeks in the NICU managing different medical emergencies and interventions for both boys, who fought so hard every day. After those 5 weeks, baby George was strong enough to come home! Baby Miles was born with a rare genetic mutation not shared by his identical twin and was transferred to a specialty ICU in Delaware - an hour away from us and his twin. Miles lived his first 359 days in the hospital before he finally came home just 6 days shy of his and George's first birthday. And he did not travel back to PA lightly!

Miles came home with a tracheostomy (breathing tube), a ventilator (breathing machine), a gastronomy tube (feeding tube in the stomach), a feeding pump, an oxygen concentrator, a pulse oximeter, a suction machine, lots of o2 tanks, and all the tubes, wires, bags, catheters, syringes, and so on that come with having a medically complex condition. He did not move into the nursery with George. Miles had his own mini-ICU in the next bedroom over. It was all very different than planned, but we were overjoyed.

Instead of being stuck far away from us in a hospital or facility, Miles was now smiling in our living room with his portable ventilator next to him, 50 feet of oxygen tubing running down the stairs to reach him, playing with the toys we rigged on a little bar above his specialized seat, with George crawling over to see what his brother was up to. While we were still getting the whole parenting thing down, we felt confident having Miles home because we were well trained by the incredible doctors, nurses, RTs, PTs, OTs, and feeding specialists at Nemours on all Miles' needs. Equally importantly, we felt stable and supported because we had a team of wonderful home care nurses scheduled for all of Miles' authorized, medically necessary skilled nursing hours … until a couple months later when the staffing fell apart, and no number of nursing agencies could seem to put it back together. The bottom fell out from under us.

Remember I said I am a *former* special educator? Even though I managed to continue teaching through that whole year we were stretched across two babies in two different states, it soon became clear after weeks and months of unreliable nursing coverage for Miles that I could no longer be the reliable teacher my special education students required. The chronic missed nursing shifts didn't only take me out of my career in the high-need field of special education. My husband was also often missing work, unable to commit to special projects, negatively impacting his career as well. We were both fortunate to have FMLA available to us, but the truth is FMLA only protects your position – not your reputation.

My husband found a new job, more understanding of this situation where we do not control our own availability because we are at the mercy of a system that constantly fails to provide the medically necessary services authorized for Miles. I found flexible work projects to make ends meet while filling in the chronic workforce gaps of an inadequate system. I also made a mission of trying to improve this system that was not working the way it promised. I joined disability advocacy groups and served on DHS committees, learning more than I ever planned about PA's many related-but-disconnected Medicaid systems that provide home-and-community-based (HCBS) supports to vulnerable populations throughout their lifetime. My lived experience and deep knowledge of these systems led to my current job in a public health program helping families like mine with medically complex kids to navigate these systems in almost half the counties of PA.

There are currently several legislative efforts aimed at making sure families like mine can be compensated for the extremely important and skilled care they deliver day in and day out across Pennsylvania. I will be honest … I actually don't ever want to be Miles' paid caregiver. I've said a lot about how the home health system falls short but let me be clear that it is the several excellent home health nurses Miles HAS had over the years that have helped him grow and thrive at home, go to school, and, as a pre-teen, begin building independence in his community. The nurses are what give me and Len the chance to sleep regular hours, maintain relationships, work in our chosen fields, and be available to all three of our children as parents. We know what it looks during those periods when shift nursing is working the way it was intended. That's when we get to live like a (relatively) typical family – and addressing that issue must be the bigger goal.

Here's what I know, though, from my own experience and the experiences of the families I connect with across the state. Shift nursing is hardly being delivered the way it was intended, and it hasn't been for at least the 11 years my family has relied on it. What I know from my 6 years of service on the MAAC Consumer Subcommittee is that the Bureau of Managed Care Organizations data shows nearly 30% of authorized pediatric skilled nursing hours consistently go undelivered - with family members left to fill in those gaps. Not every family is as fortunate as Len and I have been with employment - so many are going with no income, no sleep, and no end in sight. Speaking with families and nursing agencies, I know that children with highest skilled care needs like trach-ventilator dependence are the hardest kids to staff and the families with the fewest natural supports that can step in to help. I personally have been part of several wonderful initiatives at the state level to address the needs of families with medically complex children, but in all these years not one of these well-meaning efforts has demonstrably improved the delivery of skilled nursing to kids in PA.

Thousands of amazing children like Miles across the state are authorized for medically necessary supports that never get delivered and our families are drowning. Until Pennsylvania is ready to rebuild a system of home health care designed around the needs of the most medically complex people, compensation for the extraordinary medical care families provide is the right thing to do. This system must stop banking off the backs of parents desperate to keep their children out of institutions. Any legislation for complex care compensation must include the children with high-acuity care like trach-dependence like HB1068 does or else we will have, once again, left the most vulnerable children and families behind. I thank you all for your time today and your thoughtful consideration on this issue.

Hannah Brown. Westmoreland County, Pennsylvania

Who I Am

- Mother and full-time caregiver to my 11-year-old son, Colton
- Colton has Spinal Muscular Atrophy (SMA) Type 1
- Trach dependent, ventilator dependent, feeding tube dependent
- Requires 24/7 skilled care and supervision

What Parents Like Me Do Every Day

- Airway management and suctioning
- Ventilator monitoring and troubleshooting
- Medication administration
- Feeding tube management
- Emergency response
- Coordination of medical care and therapies

Why Paid Parent Caregivers Matter

- Parents are already providing this skilled care
- We are not asking to be paid to be parents
- We are asking to be recognized for the skilled medical care we provide every day

Safety First

- Medically fragile children cannot simply be left with a babysitter or untrained caregiver
- Someone can be medically trained and still not know my child
- Parents recognize changes before they become emergencies
- Consistent caregivers improve safety and reduce risk
- High caregiver turnover can put medically fragile children at risk

The Financial Reality

- Many parents cannot maintain traditional employment due to their child's medical needs
- I am unable to work outside the home because Colton requires constant care
- My husband works nearly 80 hours per week to support our family
- Many families still struggle financially and fall through gaps in assistance programs

Why This Makes Sense for Pennsylvania

- Keeps medically fragile children safely at home
- Helps address nursing shortages
- Reduces hospitalizations and institutional care
- Saves taxpayer dollars
- Strengthens families while improving outcomes for children

My Message

At the end of the day, parents like me are already doing this work. We are providing skilled medical care, responding to emergencies, and keeping our children safe every hour of every day. We are saving the Commonwealth money while helping our children remain where they belong—at home with their families. Paid parent caregivers are not asking for special treatment. We are asking for recognition and support for the essential care we already provide.

Good morning Chairman, Chairwoman, and members of the committee.

My name is Deena Pack. I am a Registered Nurse and the Administrator and Director of Clinical Services for 365 Health Services, a licensed home health and home care agency providing pediatric private duty nursing and home care services throughout multiple regions of the Commonwealth.

Thank you for the opportunity to speak today about pediatric private duty nursing services in Pennsylvania and the realities facing medically fragile children and their families. I was asked to testify today as an expert in pediatric home health delivery in Pennsylvania, and I hope I can lend my knowledge to the committee in evaluating and understanding these services.

I am also here as a mother and consumer of Private Duty Nursing services. My son was diagnosed with an auto-inflammatory disorder when he was 3 years old. Until that time, I had never heard of home nursing for children. I began to live the experience of many parents in the commonwealth-how to ensure the safety of my medically fragile child while also maintaining a job and other responsibilities. How can I send him to preschool safely when his school doesn't have a dedicated staff member available to watch him and administer his medications? The answer is, Medicaid funded Private Duty Nursing.

For thousands of Pennsylvania families, these services are the difference between a child living safely at home with family or remaining unnecessarily in a hospital or institutional setting. These are medically fragile children with significant clinical needs. Many rely on ventilators, tracheostomies, oxygen support, feeding tubes, seizure management, mobility assistance, and continuous monitoring. They require highly skilled nursing care in order to safely remain in their homes or attend school.

Right now, Pennsylvania's pediatric home care system is under tremendous strain.

Across the Commonwealth, providers are struggling with a severe shortage of pediatric nurses. Agencies routinely receive approved nursing hours that cannot be fully staffed. Families are covering overnight shifts themselves. Parents are leaving the workforce. Some children remain hospitalized longer than medically necessary simply because home nursing coverage cannot be secured.

Importantly, this is not just a provider concern. It is a patient access issue. It is a workforce issue. And ultimately, it is a Medicaid cost issue as well.

A 2024 report commissioned by the Pennsylvania Homecare Association and prepared by The Menges Group found that Pennsylvania's Medicaid reimbursement rates for private duty nursing are lower than many neighboring and peer states, including New Jersey, Maryland, Delaware, and Ohio. The report further found that Pennsylvania ranks behind 30 other states nationally in average Medicaid PDN reimbursement rates.

That matters because healthcare providers are competing for the same nursing workforce. Hospitals, health systems, long-term care facilities, outpatient organizations, and home health agencies are all trying to recruit from the same limited pool of nurses. When reimbursement rates do not keep pace with labor realities, it becomes increasingly difficult to recruit and retain nurses in pediatric home care. When those nursing shifts go uncovered, the consequences are significant. Approximately 29% of approved nursing hours go unfilled due to lack of staff.

The Menges report estimated that improved reimbursement and workforce stabilization could permit approximately 71 additional Pennsylvania Medicaid patients per day to safely receive care at home instead of remaining hospitalized. That is an incredibly significant figure. These children do not belong in hospital beds, simply because staffing cannot be found.

From a financial perspective, the findings are equally important. Providing care for children at home, instead of facilities or hospitals, would save state Medicaid millions of dollars. Increasing reimbursement for Skilled Nursing Services and stabilizing the workforce, would almost completely pay for itself with reduction in facility and hospital costs. We should not think about pediatric home care solely as a cost center. In many cases, it is a cost-avoidance strategy. Providing for care at home medically fragile children to receive appropriate care in the lowest-cost and most family-centered setting possible.

Beyond the financial analysis, I also want to emphasize the human reality behind these numbers. Many families caring for medically fragile children operate in a constant state of exhaustion. Parents learn highly complex medical tasks because they have no other option. They administer medications, manage feeding tubes, monitor respiratory status, respond to equipment alarms, and provide around-the-clock care while also trying to maintain employment, care for siblings, and preserve some sense of normal family life.

These families are extraordinary. But they are also overwhelmed. The nurses providing this care are extraordinary as well but there are not enough of them to care for all the children in the Commonwealth who need specialized care.

There is some recent proposed legislation that could help address this crisis.

I believe it is important that any legislation have RN supervision requirements, competency standards, training requirements, and agency oversight. Those safeguards are critical and should remain central to any implementation discussions.

From an operational perspective, I believe these proposed bills have the potential to improve continuity of care, reduce unnecessary emergency room visits and hospitalizations, and help stabilize medically fragile children in the home environment.

I would, however, encourage careful attention to several areas as implementation is considered.

First, training and competency standards must remain robust and clinically appropriate. These children have complex needs, and agencies must retain responsibility for ensuring caregivers are adequately prepared and supervised.

Second, reimbursement structures must be sustainable. Agencies will be responsible for onboarding, education, competency validation, scheduling, supervision, compliance oversight, documentation review, and ongoing clinical management. Any long-term success of this program will depend on reimbursement models that realistically support those responsibilities.

Third, it is essential that these programs not inadvertently weaken the existing pediatric nursing workforce. Pennsylvania still desperately needs more pediatric nurses. We should continue investing in nurse recruitment, retention, and reimbursement while also supporting families through innovative solutions like this bill.

Finally, I strongly support provisions to protect these programs from waste, fraud and abuse. I would like to see strict measures implemented that require MCO's to respond more quickly to reports from agencies of improper utilization of these approved services.

As healthcare professionals, policymakers, and community leaders, I believe we all share that goal: to keep children safely at home with their families whenever possible. No legislation will completely solve the pediatric home care crisis overnight. But this committee can help take meaningful steps toward acknowledging the realities families are living with today and creating additional pathways to support medically fragile children safely and responsibly.

Thank you again for the opportunity to testify today, and I would be happy to answer any questions the committee may have.

# PUBLIC TESTIMONY

## Pennsylvania House Committee on Human Services

## Submitted: June 9, 2026

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## Testimony Presented by Bill Sczepanski
## for
## Team Select Home Care

Team Select
HOME CARE

# In Support of House Bill 2164

tshc.com

Thank you for the opportunity to testify in support of House Bill 2164/Senate Bill 1041, which would allow parents or family members to serve as paid Complex Care Assistants. We are especially grateful to Representative Kosierowski for sponsoring and championing this important legislation.

My name is Bill Sczepanski, and I serve as Executive Vice President of Public Policy and Government Relations for Team Select Home Care. Team Select provides Private Duty Nursing (PDN), Family Home Health Aide (FHHA), and Personal Care Services (PCS) from two offices, serving over 500 clients in Pennsylvania. We also serve clients from more than 50 locations across 15 additional states nationwide.

Every single day across the Commonwealth, families with medically fragile children face an agonizing crisis. They are trapped between the desperate medical needs of their children and a severe, systemic shortage of private duty nurses. HB 2164 offers a compassionate, common-sense, and structurally sound solution to this crisis. By establishing a program that allows family members to be certified as Complex Care Assistants, this bill acknowledges a fundamental truth: no one is more invested in the well-being of a medically fragile child than their own family. Once approved by the Legislature and the Governor, Pennsylvania would join nine other states (Colorado, Montana, Arizona, Oklahoma, North Carolina, Florida, Indiana, Massachusetts, and New Hampshire) and four other states in the process of implementing the program (Missouri, Illinois, New Jersey, and Maine).

I urge the legislature to pass and implement this vital legislation for three critical reasons:

### 1. It Addresses the Critical Nursing Shortage Safely and Professionally

Let me be entirely clear: this bill does not lower the bar for patient care. SB 1041 ensures strict accountability and safety by requiring family members to undergo the rigorous **75-hour training and competency evaluation standards** mandated for home health aides under federal law (42 C.F.R. §§ 483.151–483.154 and 484.80). These families would be allowed to provide skilled tasks of medication administration and/or tube feedings, which don’t allow families to provide these tasks as home health aides, which has been allowed in Pennsylvania since 2020 during the pandemic. These families already take on these tasks when nursing staff is unavailable, which, unfortunately, is very frequent in Pennsylvania.

Furthermore, these family members will not be acting in isolation. They will operate:

- Under the direct oversight and direction of a **Registered Nurse**.
- Through a licensed and certified **home health agency**.
- Subject to mandatory home visits by an **RN in accordance to CMS guidelines** to ensure the highest standards of care are maintained.

### 2. It Supplements - Not Replaces - Existing Care

A common misconception about this home-based care legislation is that it will scale back existing benefits. HB 2164 explicitly protects families by stating that Complex Care Assistant services are meant to **supplement, not replace, private duty nursing services**. For children under 21 who qualify for private duty nursing, this program steps into the dangerous gaps when a nurse calls out sick, a shift goes unfilled, or rural coverage is entirely unavailable. It builds a sturdier safety net around Pennsylvania's most vulnerable children. Additionally, under federal EPSDT requirements - recently reaffirmed in *United States v. State of Florida (Case No. 23-12231)* - states are expected to provide at least 90% of authorized in-home nursing services for children under 21. Pennsylvania is currently falling short of this standard (70%), and the Complex Care Assistant Program is a critical solution to help close that gap.

### 3. It Offers Economic Stability to Lifesaving Caregivers

Caring for a complex, medically fragile child is a full-time job that frequently forces parents to abandon their careers, driving families into financial ruin. HB 2164 corrects this injustice through several economic provisions:

- **Zero Cost to Families:** Home health agencies will absorb all upfront training and certification costs; family members will never be forced to repay these expenses.
- **Fair Reimbursement Rates:** The bill establishes a provider reimbursement rate of **at least $45 per hour**, ensuring agencies can adequately compensate these dedicated family caregivers.
- **Income Protection:** Crucially, the bill directs Medical Assistance to seek federal approval to **exclude income earned through this program from the family's countable income**. Parents will not be penalized or kicked off vital assistance programs simply for being paid to save their child's life.

### Conclusion

HB 2164 is a collaborative and bipartisan bill. It preserves parents’ and home health providers’ choice to participate, creates an advisory stakeholder workgroup to help Medicaid implement the program effectively, and requires Medicaid to submit a viability report to the Governor and General Assembly within three years of implementation.

But most importantly, it values human dignity. It allows a mother or a father to provide physician directed medical care, administering medications, administering enteral feedings, with the financial security and professional backing they rightfully deserve.

We are asking this committee to pass this bill as amended to allow families of these medically fragile children to have a choice on who can care for their medically fragile child.  I ask this committee to vote in favor of House Bill 2164 and send it to the House floor for swift passage.

Thank you, and I am happy to answer any questions you may have.

# Coverage Guide

# Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Guide for States:

## *Coverage in the Medicaid Benefit for Children*

**May 2026**

# Table of Contents

# Introduction

The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirements are a cornerstone of the Medicaid program and ensure robust health coverage for children. EPSDT provides a comprehensive array of prevention, diagnostic, and treatment services for Medicaid-enrolled infants, children, youth, and adolescents under 21 years of age (collectively referred to in this Guide as “children”), as specified in the Social Security Act (the Act).[1] The EPSDT requirements are more robust than the Medicaid requirements for adults and are designed to ensure that children receive early detection and care, so that health problems are either averted or diagnosed and treated as early as possible. The goal of EPSDT is to ensure that children get the health care they need when and where they need it—the right care to the right child at the right time in the right setting.

> The goal of EPSDT is to ensure that individual children get the health care they need when and where they need it—the right care to the right child at the right time in the right setting.

The states and the Centers for Medicare & Medicaid Services (CMS) share responsibility for implementing the EPSDT requirements. States have affirmative obligations to make sure that Medicaid-eligible children and their families are informed of what they are entitled to under EPSDT, have access to required screenings, and can obtain necessary diagnostic and treatment services to correct or ameliorate identified conditions in a timely way.[2] States have broad flexibility to determine how best to ensure that the EPSDT requirements are met. In general, states either administer EPSDT directly through fee-for-service (FFS) arrangements or contract with entities (e.g., managed care plans[3] [MCPs]) to administer some or all EPSDT benefits. Regardless of the approach taken, the states retain ultimate responsibility for ensuring that all EPSDT-eligible children in the state have access to the full EPSDT scope of coverage and services and that EPSDT requirements are met.

The Act establishes the scope of covered benefits for EPSDT-eligible children. States must ensure coverage of all medically necessary services that are included within the categories of mandatory and optional services listed in Section 1905(a) of the Act, regardless of whether such services are covered under the state plan for adults. This includes physician, nurse practitioner, and hospital services; physical, speech/language, and occupational therapies; home health services, including medical equipment, supplies, and appliances; treatment for mental health

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[1] SSA §1902(a) and 1905(r).

[2] CMS, State Medicaid Manual §§ 5010, 5121, 5310.

[3] In this document, “managed care plan” includes managed care organizations, prepaid inpatient health plans, and prepaid ambulatory health plans, as defined in 42 CFR § 438.2.

and substance use disorders (SUDs); treatment for vision, hearing, and dental diseases and disorders; and much more.

States need to arrange (directly or through delegations or contracts) for children to receive the physical health, mental health, vision, hearing, and oral health services they need to treat or ameliorate their health problems and conditions. Through the EPSDT requirements, children's health problems should be addressed *early,* before they become advanced and treatment is more difficult and costly. This broad coverage requirement results in a comprehensive, high-quality health benefit for EPSDT-eligible children under 21 years of age who are enrolled in Medicaid.

The Americans with Disabilities Act (ADA) and the *Olmstead* decision require states to ensure that services provided under EPSDT are delivered in the most integrated setting appropriate to a child's needs, such as in the child's home or elsewhere in the community, if doing so does not fundamentally alter the state's program.[4,5,6] Therefore, states should consider developing community-based treatment options wherever possible.

States report certain data about their delivery of EPSDT services to CMS annually[7] using the Form CMS-416 and the Core Set of Children's Health Care Quality Measures for Medicaid and the Children's Health Insurance Program (CHIP) (Child Core Set).[8] CMS and states use these data to monitor EPSDT performance.

Many states with a separate CHIP elect to cover a package of services that adhere to the Medicaid EPSDT requirements for beneficiaries who are enrolled in a separate CHIP.[9] In addition, states with Medicaid Alternative Benefit Plans (ABPs) must ensure that all EPSDT-eligible children who are enrolled in ABPs have access to services available under EPSDT requirements.[10,11]

Children are entitled to the full scope of EPSDT services regardless of delivery system. Thus, the vast majority of EPSDT-eligible children who are enrolled in managed care also are entitled to the full scope of EPSDT services. States should work closely with their MCPs to support proper implementation of EPSDT. Regardless of how significant the MCPs' role may be in administering EPSDT, the state retains ultimate responsibility for assuring compliance with the EPSDT requirements.

This Guide is intended to help states understand the scope of services that are covered under EPSDT so that they can realize EPSDT's goals and provide the best possible child health benefits through their Medicaid programs. In addition, the Guide can help build staff knowledge

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[4] 28 CFR § 35.130(d).
[5] CMS, Olmstead Update No. 4 (January 10, 2001).
[6] Department of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the ADA and Olmstead v. L.C. (June 22, 2011).
[7] SSA §1902(a)(43)(D) and 2108(e).
[8] CMS, State Medicaid Manual § 2700.4.
[9] Optional coverage of EPSDT services in separate CHIPs reflects all Medicaid EPSDT requirements, including coverage of all § 1905(a) services.
[10] U.S. Code. Title 42 § 1396u-7.
[11] 42 CFR § 440.345.

and expertise regarding EPSDT to help the state Medicaid agency implement EPSDT requirements across the program. This Guide does not establish new EPSDT policy but rather compiles into a single document various EPSDT policy guidance that CMS has issued over the years.

### Program Integrity:

States must comply with all applicable federal Medicaid statutes and regulations, including requirements governing provider screening and enrollment, payment methodologies, utilization controls, and program integrity. States are required to maintain effective systems and safeguards to prevent, detect, and address fraud, waste, and abuse (FWA) in the delivery of and payment for Medicaid services, including referrals to law enforcement when appropriate. States should also have robust internal controls and oversight mechanisms in place to identify and remediate vulnerabilities related to FWA and beneficiary access. Failure to meet program integrity obligations may result in compliance actions, including corrective action plans, withholdings, deferrals, disallowances, or other enforcement measures.

### Technical Assistance:

Technical assistance is available to help states determine how to implement state intentions under state plan or waiver authorities and remain consistent with EPSDT requirements. CMS encourages states to contact their CMS state lead or the EPSDT mailbox (EPSDT@cms.hhs.gov) when considering changes to benefits.

### This Guide outlines:

1. EPSDT’s requirements for informing families and children
2. EPSDT’s screening requirements, including interperiodic screening
3. The full scope of diagnostic and treatment services under EPSDT, including requirements governing dental, vision, and hearing services
4. Services available under other federal authorities
5. Strategies to ensure appropriate coverage, including ensuring medical necessity
6. Notice and Fair Hearing requirements
7. States’ responsibilities to ensure access to EPSDT services and providers
8. Assistance to states as they work with MCPs to provide the best child health benefit possible
9. Quality reporting mechanisms to measure EPSDT performance for states

# I. Informing

Federal law requires that states inform all eligible individuals of the availability of EPSDT services in a timely manner—in the case of families whose EPSDT-eligible children are enrolled in Medicaid but have not utilized EPSDT services—annually thereafter.[12,13] States employ a combination of written and oral methods to implement their informing process and ensure that EPSDT-eligible children and their families are aware of the comprehensive coverage available to them and how to access available benefits, and obtain necessary supports to facilitate getting the care they need.[14,15] To this end, states must inform EPSDT-eligible children and their families: 1) about the benefits of preventive care; 2) of the services available through EPSDT and how to obtain them; 3) that services are available without charge, except for premiums that may be charged for medically needy children; and 4) that transportation and appointment scheduling assistance are available upon request.[16] States must offer transportation and scheduling assistance "prior to the due date of a child's periodic examination," and once a request for support services has been made, states should assume that the request applies to any follow-up services as well.[17]

States must inform EPSDT-eligible beneficiaries and their families using clear and non-technical language. States also must provide information in a manner that is accessible to those who cannot read or understand English.[18,19] The ADA requires reasonable accommodations for an individual who may have difficulty receiving information about or accessing EPSDT because of a disability.[20] Therefore, states must provide the required EPSDT information in prevalent non-English languages, and that information must be available in alternative formats upon request and at no cost to the individual.[21]

In addition to informing EPSDT-eligible children and their families about the services available through EPSDT and how to obtain them, states also need to ensure that MCPs and other contractors, as well as participating health care providers, have the information about EPSDT that they need to ensure children receive all services to which they are entitled. This includes how children can obtain services when needed to correct or ameliorate a condition and how to use the grievance and appeal process. If states rely on MCPs to provide eligible children and their families with the required EPSDT information for beneficiaries, they should clearly delineate these responsibilities in the managed care contract, monitor and oversee the plans,

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[12] SSA § 1902(a)(43)(A).
[13] CMS, State Medicaid Manual §§ 5121.A, 5121.C.; 42 C.F.R. § 441.56(a)(4).
[14] SSA §1902(a)(43)(A).
[15] CMS, State Medicaid Manual §§ 5121.A, 5121.C.
[16] SSA § 1902(a)(43)(A) and 42 CFR § 441.56.
[17] CMS, State Medicaid Manual § 5150.
[18] 42 CFR § 441.56(a)(3).
[19] CMS, State Medicaid Manual § 5121.C.
[20] 42 CFR § 12131. Definitions.
[21] 42 CFR § 441.56(a)(3) and § 438.10.

and have mechanisms in place to hold plans accountable for fulfilling their contractual responsibilities.[22,23]

# II. Periodic and Interperiodic Screenings

EPSDT covers regular screening services (well-child visits) for infants, children, and adolescents that include medical, vision, hearing, and dental assessments. Well-child visits are designed to identify physical and mental health and developmental issues as early as possible. These visits are the foundation of EPSDT coverage and are a crucial entry point for providing preventive care as well as identifying matters that require follow-up. Well-child visits are intended to be comprehensive and include age-appropriate laboratory, developmental, and other screenings; referrals to diagnostic and specialty services; and referrals to establish ongoing dental, vision, and hearing care.

States have the responsibility to ensure that all EPSDT-eligible children and their families are informed of both the availability of screening services and that they are not required to make a formal request for an EPSDT screen.[24] States provide or arrange for screening services both at established intervals, typically referred to as "periodic screenings" or "well-child visits," and on an as-needed or "interperiodic" basis. An EPSDT well-child visit has five components:

1. Comprehensive health and developmental history that assesses both physical and mental health[25]
2. Comprehensive, unclothed physical examination
3. Appropriate immunizations, in accordance with the schedule for child and adolescent vaccines established by the Centers for Disease Control and Prevention's (CDC) Advisory Committee on Immunization Practices
4. Laboratory testing (including blood-lead screening appropriate for age and risk factors)[26]

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[22] 42 CFR § 438.210(a).

[23] 42 CFR § 438.10(c)(5).

[24] For minor beneficiaries, the involvement of parents, legal guardians, and other caregivers is often necessary to ensure access to benefits. We intend the term "family" to include all persons considered family members under applicable law.

[25] CMS has issued a number of bulletins to states offering guidance for coverage of behavioral health services for children and youth—e.g., State Health Official, "Best Practices for Adhering to Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) Requirement," SHO # 24-005, Leveraging Medicaid, CHIP, and Other Federal Programs in the Delivery of Behavioral Health Services for Children and Youth, and Informational Bulletin: Prevention and Early Identification of Mental Health and Substance Use Conditions.

[26] CMS issued guidance on June 22, 2012, to align blood-lead assessment for Medicaid children with CDC recommendations. After providing data that demonstrated that universal testing is not the most effective approach to identifying childhood exposure to lead, a state may request to implement a targeted lead screening plan rather than continue universal testing of all EPSDT-eligible children ages 1 and 2. Medicaid will also provide reimbursement for lead investigations in the home or primary residence of a child with an elevated blood lead level. See Informational Bulletin.

5. Health education and anticipatory guidance for both the child and the family[27,28]

Under the Act, states establish periodicity schedules for medical, vision, hearing, and dental screenings to set the frequency by which certain covered services should be provided to ensure that EPSDT-eligible children have access to screening services according to that schedule.[29] Although federal law does not prescribe the periodicity schedules, it does require states to establish the schedules based on current standards of pediatric medical, vision, hearing, and dental practice and to consult with recognized medical and dental organizations involved in child health care when developing the schedules.[30] Most states use Bright Futures, developed by the American Academy of Pediatrics (AAP), which includes screenings and assessments for physical, developmental, behavioral, and oral health, as well as vision and hearing. States should review all of their EPSDT periodicity schedules regularly to keep them up to date.[31,32]

States must adopt periodicity schedules for vision and hearing screening that meet reasonable standards of medical practice. For the vision and hearing screenings covered under EPSDT, most states adhere to professional guidelines that recommend these screenings be integrated into well-child visits.

Although professional guidelines (e.g. Bright Futures) recommend that screening professionals include an oral health assessment in the well-child visit at specified ages, states must also cover dental or oral health screening separately under EPSDT. Many states have adopted the American Academy of Pediatric Dentistry's (AAPD) recommended periodicity schedule for dental services for children and adolescents. Screenings for dental and oral health, which may be performed by dental professionals or by medical professionals according to state scope-of-practice rules, can take place in community or group settings, including schools, as well as in clinics or medical and dental offices. Such screenings can be helpful in identifying children with unmet dental care needs so they can be referred to a dental professional for treatment.

> States should review all their EPSDT periodicity schedules regularly to keep them up to date.

Under EPSDT, states are required to cover medically necessary interperiodic screening visits when an EPSDT-eligible child requires diagnosis or treatment of an illness or condition that was not present at the well-child visit or to determine if there has been a change that requires

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[27] SSA § 1905(r)(1)(B).

[28] CMS has clarified that states may cover maternal depression screening as part of a Medicaid well-child visit under EPSDT, as it is primarily for the benefit of the child. Any diagnostic or treatment services directed solely at the mother can be covered only if the mother is Medicaid-eligible. See Informational Bulletin.

[29] 42 CFR § 441.58.

[30] SSA § 1905(r).

[31] CMS, Vision and Hearing Services for Children and Adolescents.

[32] CMS, State Medicaid Manual § 5123.2.F.

additional services. Interperiodic screening visits may be requested by a beneficiary or their family or by a physician, dentist, or other qualified professional (e.g., a health, developmental, or educational professional) who comes into contact with a child outside of the formal health care system. This includes, for example, personnel working for state early intervention or special education programs, Head Start, and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). A state may not limit the number of medically necessary health care visits a child receives or require prior authorization for either periodic or interperiodic screenings.

Screening services need not be conducted by a Medicaid provider in order to trigger EPSDT coverage for follow-up diagnostic services and necessary treatment by a qualified Medicaid provider. Any provider operating within the scope of their practice, as defined by state law, may provide a screening service. For example, a school nurse may provide a vision screening to an EPSDT-eligible child, and that child would be entitled to further screening, diagnostic or treatment services regardless of whether the nurse is an enrolled Medicaid provider. Similarly, a screening service provided before a child enrolls in Medicaid is sufficient to trigger follow-up diagnostic and necessary treatment after enrollment. To receive the benefits of EPSDT, the family or child does not need to formally request an EPSDT screen. Rather, any visit or contact with a qualified medical professional is sufficient to satisfy EPSDT's screening requirement, and states should consider a child who is receiving services to be participating in EPSDT, whether the family or child requested screening services directly from the state or the health care provider.[33,34]

### Example of Screenings Beyond Those Required by the Periodicity Schedule

A child receives a regularly scheduled well-child visit at five years of age at which no problem is detected. Before their next annual checkup, the school nurse recommends to the child's parent that the child needs follow-up because a teacher suspects a vision problem. Even though the next scheduled well-child visit is not due until the age of six, the child would be entitled to receive a timely interperiodic screening to determine if there is a vision problem and to receive appropriate treatment as indicated.

The affirmative obligation to connect children with necessary treatment is a crucial component of EPSDT and makes the Medicaid benefits for children more robust than those for adults.[35] Screening services provide the crucial link to necessary covered treatment, as EPSDT requires states to "arrang[e] for … corrective treatment"—either directly or through referral to appropriate providers or licensed practitioners—for any illness or condition detected by a screening.[36]

# Establishing Payment for Screening Services

States with a FFS system establish their own fee schedules for screening services. Under the Health Insurance Portability and Accountability Act (HIPAA), CMS has adopted standardized code sets for diagnoses and procedures used in all transactions, and states should use

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[33] CMS, State Medicaid Manual § 5310.
[34] HCFA, Title XIX State Agency Letter No. 91-33; April 3, 1991.
[35] CMS, State Medicaid Manual § 5124.B.
[36] SSA § 1902(a)(43)(C).

compliant billing codes.[37] States may develop a bundled payment rate to pay for the medical screening components under one billing code or may recognize each component of the EPSDT screening separately. States may encourage providers to perform all five components of the EPSDT well-child visit but cannot exclude providers who perform only partial screenings from being paid for the parts they do provide.

# III. Treatment Services Available under EPSDT

EPSDT-eligible children should have access to a broad scope of treatment services to meet their individual needs. Section 1905(a) of the Act establishes the scope of benefits covered under EPSDT, including but not limited to, physician and hospital services; private-duty nursing; personal care services; home health and medical supplies, equipment, and appliances; rehabilitative services; and vision, hearing, and dental services. This section describes how states can ensure that a full range of treatment services are available to EPSDT-eligible children under section 1905(a) of the Act; this section also includes details on coverage of certain services, including oral health, vision and hearing, mental health, SUD, and personal care.

In addition to the treatment services authorized under Section 1905(a), EPSDT-eligible children may have access to services authorized under other Medicaid federal authorities that are not subject to EPSDT requirements (e.g., 1915(c) Home and Community-Based Services [HCBS] waiver services) and for which they are eligible. Although these other services may supplement an EPSDT-eligible child’s care, EPSDT is a legal entitlement, and medically necessary EPSDT-required services must be accessed under the Section 1905(a) authority prior to other Medicaid authorities. For more detailed information, please see the next section, “V. Services Available under Other Federal Medicaid Authorities.”

## A. Ensuring a Full Range of Treatment Services under EPSDT

States are required to cover under their state plan certain services described in section 1905(a) of the Act. States have the option to cover under their state plan all other section 1905(a) services. However, states are required to cover all section 1905(a) services “to correct or ameliorate defects and physical and mental illnesses and conditions” that EPSDT-eligible children may be experiencing regardless of whether or not the state has elected to cover the service under its state plan. If a section 1905(a) service, supply, or equipment is not listed as covered for adults in the state Medicaid plan, the state nonetheless must provide it to an EPSDT-eligible child if it is medically necessary. The broad range of such services includes, but is not limited to, case

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[37] CMS, Code Sets Overview.

management services (including targeted case management);[38] incontinence supplies; organ transplants and any related services; a specially adapted car seat that is needed by a child because of a medical problem or condition; and medical foods. Federal financial participation (FFP) is available at the state's Federal Medical Assistance Percentage (FMAP).

A state may need to take additional steps to ensure that EPSDT-eligible children have access to medically necessary care. For example, if an EPSDT-eligible child needs a medically necessary service that is not covered in the state Medicaid plan for adults, the state would need to develop a payment method for the service and may need to establish a single-service agreement with an in-state or an out-of-state provider who will accept Medicaid payment. Similarly, a state may need to enter into a single-service agreement with a provider if a certain provider type is not participating in Medicaid but is needed for an EPSDT-eligible child's medically necessary care. If an EPSDT-eligible child's physician or other provider uses medical terminology to prescribe a medical service or supply that does not mirror Medicaid terminology, the state must determine if the service or supply could be covered under Section 1905(a). If the service or supply could be covered under section 1905(a) of the Act, the state must ensure that the child has access to that service or supply if it is medically necessary to correct or ameliorate the child's condition.

In addition to services that can "correct" a condition, services that can "ameliorate" a condition (i.e., make a condition more tolerable) must be covered under EPSDT. Services that maintain or support health problems rather than cure or improve them can be ameliorative and are a crucial component of a comprehensive child-focused health benefit. In particular, children with disabilities may benefit from services that can prevent conditions from worsening, reduce pain, and avert the development of more costly illnesses and conditions. Less common maintenance services include medical supplies, equipment, and appliances (such as pressure-relieving cushions or bed rails). Ameliorative services are a crucial component of a comprehensive child-focused health benefit. If not available to a child under EPSDT, such services may also be covered under HCBS authorities in order to prevent or delay institutionalization. See Section IV. *Services Available to Children under Other Federal Authorities* of this Guide.

## B. Covering Oral Health, Vision and Hearing, Mental Health and SUD, and Personal Care Services

As noted above in Section IV.A of this Guide, *Ensuring a Full Range of Treatment Services under EPSDT*, the scope of services that must be covered under EPSDT provides eligible children with access to a wide range of services. This section goes into detail about certain services available under EPSDT, some of which are explicitly referenced in Section 1905(a) of the Act and some of which can be covered under various Section 1905(a) Medicaid service categories. The services discussed in this section, which include oral health and dental services, vision and hearing services, mental health and SUD services, and personal care

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[38] Care coordination is the organization of care across multiple providers and may focus on a specific service or condition and can be covered under the rehabilitative services option. See SSA § 1905(a)(19) and 42 CFR §§ 440.169 and 441.18.

services, are not an exclusive list of all services that must be covered under EPSDT when medically necessary.

## a. Oral Health and Dental Services

States must cover medically necessary dental services for EPSDT-eligible children, irrespective of whether the services are covered for adults. Section 1905(r)(1)(A) of the Act requires that states cover oral screenings and dental exams at the intervals identified in the state's selected dental periodicity schedule, which should be developed in consultation with recognized dental organizations involved in child health care.[39,40] Any services necessary to identify and treat an illness or condition identified during an oral screening or dental exam must be covered for EPSDT-eligible children.[41]

Although CMS does not define the specific dental treatment services that states must cover for EPSDT-eligible children, these services may not be limited to emergency situations and should include, at a minimum:[42]

- Dental care needed for relief of pain or infection, restoration of teeth, and maintenance of dental health (provided at as early an age as necessary);
- Emergency, preventive, and therapeutic services for dental disease that, if left untreated, may become acute dental problems or cause irreversible damage to the teeth or supporting structures;[43] and
- Orthodontic services for EPSDT-eligible children to the extent necessary to prevent disease, promote oral health, and restore oral structures to health and function.[44] Orthodontic services for cosmetic purposes are not covered.

Dental care that is deemed medically necessary for an individual child is covered even when the frequency is greater than specified in the periodicity schedule.[45,46] For example, for a child determined by a qualified provider to be at moderate or high risk for developing early childhood caries (i.e., tooth decay), a state may need to cover dental exams and preventive treatments more frequently than the twice-yearly periodicity schedule recommended by the AAPD. Risk assessment resources are available for providers, including an assessment tool from AAPD that includes a caries-risk assessment form, clinical guidelines, and treatment protocols.

Primary care medical providers can also offer evidence-based oral preventive care, such as fluoride varnish, risk assessment, and oral health education, and refer children to a dental professional for a complete checkup and any needed treatment. CMS has developed quality-

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[39] SSA § 1905(r)(3).
[40] CMS, State Medicaid Manual § 5110.
[41] CMS, State Medicaid Manual § 2700.4.
[42] CMS published an informational bulletin about CMS efforts working with states to improve access to oral health services for children enrolled in Medicaid and a toolkit for improving delivery of dental and oral health services.
[43] CMS, State Medicaid Manual § 5124.B.2.b.
[44] Ibid.
[45] CMS, State Medicaid Manual § 5110.
[46] CMCS, Informational Bulletin (May 4, 2018).

improvement resources related to improving the provision of oral health preventive services in primary care settings.[47]

Depending on the dental practice act in individual states, there is a wide range of dental professionals who can work under the supervision of a dentist to provide oral health services—e.g., dental hygienists, dental therapists, dental assistants, and community dental health coordinators. Dental supervision also can include a wide range of arrangements—e.g., direct, indirect, general, public health, and collaborative practice arrangements. Some state practice acts also permit specified dental professionals to work without dentist supervision in certain circumstances. Utilization of all provider types and arrangements permitted under a state's dental practice act can help ensure access to dental care as well as promote an integrated health care delivery system.

Given the limited supply of pediatric dental specialists, several states have worked to enhance the capacity of general dental practices to treat very young children, including offering enhanced payment rates for dentists who treat this population, reflecting the additional time required, after receiving state-approved training. In addition, the Center for Medicaid & CHIP Services' (CMCS) oral health strategy guide, Keep Kids Smiling: Promoting Oral Health Through the Medicaid Benefit for Children & Adolescents, provides additional information on oral health and EPSDT.

## b. Vision and Hearing Services

Vision and hearing services are a required component of EPSDT. Hearing impairments can lead to other problems, including interference with normal language development in young children, and can delay a child's social, emotional, and academic development. Vision problems can similarly lead to delays in learning and social development and can be evidence of serious, degenerative conditions.

To determine the existence of a suspected illness or condition, sections 1905(r)(2) and (4) of the Act require that vision and hearing services be provided at intervals that meet reasonable standards, as determined in consultation with medical experts, and at other intervals as medically necessary.

At a minimum, vision services must include screening, diagnostic services and treatment for defects in vision, including eyeglasses. Glasses to replace those that are lost, broken, or stolen also must be covered. Hearing services must include, at a minimum, screening, diagnosis and treatment for defects in hearing, including hearing aids, and states must establish a plan to exceed any limits in place for adults.[48]

In addition, if hearing and vision problems are detected through screening, medically necessary diagnostic and treatment services that fit into the categories listed under Section 1905(a) must be covered. This includes not only services provided by physicians, such as ophthalmologists, but also services from licensed professionals such as optometrists. In addition, any medically necessary

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[47] Learn more on the Oral Health Quality Improvement Resources page.
[48] SSA § 1905(r).

medical supplies, equipment, and appliances—which may include hearing aids, cochlear implants, and eyeglasses—must be covered by states.

## c. Mental Health and Substance Use Services

“Behavioral health” is not an identified, stand-alone service defined within the Act; however, treatment for mental health and substance use symptoms and conditions are available under several Section 1905(a) Medicaid service categories. States commonly use a variety of services to meet children’s identified needs, including but not limited to hospital, clinic, and physician services.[49] States may also make use of other categories, including rehabilitative services, preventive services, and other medical or remedial care provided by licensed practitioners, such as psychologists, to ensure that there is an array of services to treat EPSDT-eligible children’s behavioral health needs.[50,51] States may expand the range of existing providers of Medicaid-covered services by establishing qualifications for paraprofessional provider types, such as youth and family peer supports and other types of non-licensed providers.

Rehabilitative services, which must be restorative in nature, are often part of states’ coverage of mental health and SUD services, and include, “any medical or remedial services provided in a facility, a home, or other setting recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law, for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level.”[52] Rehabilitative services provided to children should reflect goals appropriate for the child’s developmental stage and level of cognition.

Some services offered in the community, including those that can be provided through Section 1905(a) of the Act, have proven to significantly enhance outcomes for children with serious emotional disturbances. Depending on the interventions that the individual child needs, services that can be covered under the rehabilitative services benefit include but are not limited to:

- Community-based crisis services, such as mobile crisis teams and crisis stabilization services
- Intensive community-based services such as intensive home-based therapy
- Individualized mental health and substance use treatment services provided in outpatient, community-based settings, such as a school, a workplace, or home, including medication management and therapies to eliminate psychological barriers that would impede development of community-living skills
- Peer support, including parent peers

With respect to the provision of any mental health and SUD services covered under the rehabilitative services benefit, including those noted above, CMS requires states to include service definitions and describe provider qualifications, as the rehabilitative services benefit

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[49] SSA § 1905(a).
[50] SSA § 1905(a) and 42 CFR § 440.130(d).
[51] CMCS, State Medicaid Director (November 13, 2018).
[52] SSA § 1905(a).

does not specify provider qualifications. As with any EPSDT service, states are not required to include coverage in the state plan, but states would need to include a payment method for each service it provides to EPSDT-eligible children.

CMS has issued detailed guidance encouraging states to include screening, assessments, and treatments focusing on children who have been victims of complex trauma. EPSDT can be a crucial tool in addressing the profound needs of this population, including children who are involved in the child welfare system.

## d. Personal Care Services

Medicaid state plan personal care services are optional services for adults, but they must be covered for EPSDT-eligible children when medically necessary to "correct or ameliorate" a condition in any setting in which normal life activities take place. Section 1905(a)(24) of the Act defines personal care services as services that are:

> *furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility …or institution for mental disease, that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State), otherwise authorized for the individual in accordance with a service plan approved by the State; (B) provided by an individual who is qualified to provide such services and is not a member of the individual's family; and (C) furnished in a home or other location.*[53]

Personal care services provide a range of assistance with performing activities of daily living, such as dressing, eating, bathing, transferring, and toileting, as well as instrumental activities of daily living, such as preparing meals and managing medications.[54] Personal care services cannot be provided in an inpatient setting or to a resident of a hospital, nursing facility, intermediate care facility or institution for mental disease.

The determination of whether a child needs personal care services must be based on the child's individual needs and in accordance with a treatment or service plan. Medicaid payments generally are not available for personal care services provided by the child's legally responsible relatives under the Medicaid state plan unless the state has exercised the option authorizing self-directed care.[55,56]

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[53] SSA § 1905(a) and 42 CFR § 440.167.

[54] CMS, State Medicaid Manual § 4480.

[55] 42 CFR § 440.167. States may apply for the state plan option that authorizes self-directed personal care and related services and, through that option, may allow beneficiaries to hire legally responsible relatives.

[56] SSA § 1915(j).

# IV. Services Available to Children under Other Federal Authorities

Children with disabilities or other complex health needs often have a combination of functional limitations, chronic health condition(s), ongoing use of medical technology, and high resource needs and use. These children usually require a robust set of Section 1905(a) services provided by primary care and pediatric subspecialists, as well as a variety of therapists. These children also may have behavioral health conditions or developmental or intellectual disabilities that add complexity to their clinical presentation. Case management, as previously described, is an essential tool for coordinating across a beneficiary's care team to ensure that these children, when eligible for EPSDT, receive the medically necessary services to which they are entitled.

EPSDT-eligible children may have access to other Medicaid services that are not subject to EPSDT requirements. When providing children with needed services, Medicaid services described under Section 1905(a) of the Act should always be used before providing services available under other federal authorities. Other services—such as respite authorized through a Section 1915(c) Home- and Community-Based Services waiver or Health Homes authorized through Section 1945 or 1945A of the Act—can supplement services authorized by Section 1905(a) but, unlike EPSDT services, they may be subject to caps on enrollment or dollar limits.

## A. Waiver and State Plan Home and Community-Based Services

Home and community-based services (HCBS) provide opportunities for Medicaid beneficiaries to receive services in their own homes or communities rather than long-term care in a nursing facility, intermediate-care facility, or hospital. States can implement HCBS programs to serve a variety of targeted groups, such as individuals (including children) with intellectual or developmental disabilities, physical disabilities, or mental health and/or substance use disorders. There are a few avenues states can take to provide HCBS that are not otherwise covered by Medicaid program in accordance with Section 1905(a) of the Act.

### a. Home and Community-Based Services Waivers

A state Medicaid program may offer services through HCBS waiver programs authorized under Section 1915(c) of the Act. Waiver programs provide coverage of services that are not otherwise covered by Medicaid (even for children under the EPSDT requirements) because they do not fit into one of the categories of coverable services listed in Section 1905(a) of the Act. Such HCBS includes respite services, supported employment, or other services approved by CMS that can help prevent institutionalization. These programs are sometimes called 1915(c) waivers after the section of the Social Security Act that authorizes them.[57] For each beneficiary enrolled in an HCBS waiver program, states must develop a written person-centered service plan that identifies the services that the beneficiary needs to function successfully and ensure their health and welfare.

Because HCBS waivers can provide services not otherwise covered under Section 1905(a) of the Act, they can be used to supplement the Section 1905(a) services available to children under EPSDT to provide a more comprehensive benefit package for children with special needs who would otherwise need the level of care provided in an institutional setting, thereby allowing children to remain in their homes or communities.[58] The HCBS waiver services supplement EPSDT services that are coverable under Section 1905(a). The child's needs must be met first with services available under Section 1905(a). A waiver may be employed to provide services that are needed to prevent institutionalization but that are not authorized under, or exceed what is considered medically necessary for purposes of, Section 1905(a).[59]

Further, children who have been determined eligible for Medicaid and are on a waiting list for an HCBS waiver program are entitled to EPSDT and to all medically necessary services that fit into the categories listed in Section 1905(a). States cannot deny Section 1905(a) services because a Medicaid enrolled child is on an HCBS waiver waiting list.[60] Conversely, although states may limit the amount, duration, and scope of HCBS waiver services provided to beneficiaries (including those under age 21) who are enrolled in a waiver, states may not limit the amount, duration or scope of Section 1905(a) services to EPSDT-eligible children under 21 years of age who are enrolled in an HCBS waiver program.[61,62]

Children who are enrolled in an HCBS waiver program are also entitled to all EPSDT services. If a child enrolled in Medicaid is on a waiting list for an HCBS waiver, they are entitled to EPSDT and to medically necessary services that fit into the categories listed in Section 1905(a).

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[57] 42 CFR § 440.167. States may apply for the state plan option that authorizes self-directed personal care and related services and, through that option, may allow beneficiaries to hire legally responsible relatives.
[58] SSA § 1915(j).
[59] Ibid.
[60] CMS, Olmstead Update No. 4 (January 10, 2001).
[61] SSA § 1905(d)(r)(5) and § 1915(c)(1).
[62] CMS, State Health Official (September 26, 2024).

### b. State Plan Home and Community-Based Services

States may choose to offer HCBS to children through several state plan authorities:1) Section 1915(i), which authorizes coverage of HCBS to individuals who meet certain financial eligibility criteria, needs-based criteria, and  any targeting criteria defined by the state[63]; 2) Section 1915(j), which authorizes self-direction of Section 1905(a) state plan personal assistance services and Section 1915(c) HCBS; and 3) Section 1915(k) home- and community-based attendant services and supports. Like services provided pursuant to a Section 1915(c) waiver, these Section 1915 authorities are not subject to EPSDT coverage provisions but can be used by states to supplement EPSDT services. States may also seek approval to offer services through Section 1115, which authorizes innovative programs that HHS finds consistent with the objectives of Medicaid and meet other statutory requirements, including the requirement that a Section 1115 demonstration be determined to be budget neutral as certified by the CMS Chief Actuary beginning January 1, 2027.

## B. Health Homes

The Affordable Care Act established a state plan option that allows states to design "health homes" to coordinate care for Medicaid beneficiaries with chronic conditions.[64] The Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment Act created an additional enhanced match for new health homes focused on SUD by amending Section 1945 of the Act.[65] The Medicaid Services Investment and Accountability Act created Section 1945A of the Act, establishing a new health home state plan option that provides an opportunity for states to cover care coordination for children with medically complex conditions.[66] Under these health home benefits, providers coordinate the full range of medical, behavioral health, and long-term services and supports that Medicaid beneficiaries with chronic health conditions need. In addition, health homes may be especially useful for children with medically complex conditions, as they cover care coordination services necessary to support family-centered systems of care.

States receive a 90 percent enhanced federal match for the first eight quarters of implementation under Section 1945 of the Act and an additional two quarters for new SUD-focused health home programs under Section 1945(c) of the Act. Under Section 1945A of the Act, states receive up to a 90 percent enhanced federal match for the first two quarters of implementation. Services can include comprehensive care management, care coordination, transitional care, parent and family support, use of health information technology to link services, and referrals to community and social support services.

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[63] CMS and SAMHSA. Joint Informational Bulletin. (May 7, 2013)
[64] SSA § 1945.
[65] SSA § 1945(c)(4).
[66] SSA § 1945A.

# C. Interagency Coordination

EPSDT-eligible children often receive services from other federal agencies. Federal rules require state Medicaid agencies to collaborate with their state's Title V[67] Maternal and Child Health (MCH) agencies and grantees to enhance health outcomes for children.[68] To meet this requirement, State Medicaid agencies need to have interagency agreements with their state's MCH program in order to improve access to EPSDT services.[69] Among other things, cooperating MCH agencies can provide outreach, screening, diagnostic or treatment services, health education and counseling, case management, and other assistance to provide comprehensive and effective child health services. MCH programs also can help Medicaid programs to enlist providers who can help deliver a broad array of services. In addition, they can inform potential and actual Medicaid beneficiaries about EPSDT and refer them to necessary services.[70] Ongoing collaboration with other child-focused programs may also contribute to an effective child health program. CMS encourages such collaborations, as these agencies are important partners in creating and delivering a high-quality, well-integrated child health benefit.

# D. Enabling Services

When requested, state Medicaid agencies are required to provide assistance with scheduling appointments and transportation to appointments for beneficiaries who need this assistance and to ensure that covered services are appropriately delivered to children.

## a. Transportation Services

Transportation is an essential part of making medically necessary health care available to children. To ensure that EPSDT-eligible beneficiaries can access needed preventive, diagnostic, and treatment services, states must offer appointment scheduling assistance and assure necessary emergency and non-emergency transportation to and from medical appointments.[71,72] This includes covering the costs of an ambulance, taxi, bus, or other carrier. It can also include reimbursing for mileage. States must use the least expensive mode of transportation that is appropriate to meet the individual's needs. For example, public transportation can be covered instead of a taxi if the public transportation is appropriate for a particular beneficiary and takes a reasonable amount of time.

In addition, "related travel expenses" are covered if necessary. For example, if the child needs to be accompanied to their medical services, the cost of transportation for the person accompanying the child is a related travel expense. This may include coverage for that person's transportation,

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[67] SSA § 509(a)(2).
[68] 42 CFR § 705(a)(5)(F), § 709(a)(2), § 441.61(c).
[69] 42 CFR § 431.615.
[70] CMS, State Medicaid Manual; § 5230.
[71] SSA § 1902(a)(4)(A) and 42 CFR §§ 440.170, 441.62.
[72] CMCS, Informational Bulletin (July 12, 2021).

including meals and lodging.[73,74] In other circumstances, states may cover transportation for a parent or caregiver if necessary for the direct benefit of the child; that is, in order to ensure the child's medically necessary services can be provided.[75]

States can offer assistance with transportation in a variety of methods. Some states offer non-emergency transportation through brokers and other types of administrative managers who coordinate transportation services. Transportation may also be included in managed care contracts. If a state chooses not to include transportation services in their managed care contracts, the state itself will need to administer the service. No matter the type of arrangement, it is important to remember that the state has ultimate responsibility for ensuring the provision of transportation services.

CMS has published a Medicaid Transportation Services Guide to provide states with a one-stop source of guidance on federal requirements and state flexibilities regarding the assurance of transportation.

## b. Interpretation and Translation

State Medicaid agencies and Medicaid MCPs, as recipients of federal funds, are required to take "reasonable steps" to ensure that individuals who have limited English proficiency have meaningful access to Medicaid services.[76] States should provide beneficiaries with notice of the availability of language-assistance services and auxiliary aids and services.[77] States must also ensure that directories of Medicaid-participating providers include the languages spoken by those providers.[78]

> Interpreters may not be paid separately, but their services may be included as part of an allowable Medicaid service when reimbursed when billed by a qualified provider rendering a Medicaid-covered service.

States are not required to—but may—pay providers for the cost of language services. States may consider the cost of language services to be included in the regular rate of payment for the

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[73] 42 CFR § 440.170(a).
[74] CMS, Medicaid Transportation Coverage Guide (2023).
[75] Ibid.
[76] 42 C.F.R. §§ 435.905, 436.901. State Medicaid agencies and MCPs also are subject to federal civil rights laws that have accessibility requirements. *See, e.g.*, Section 1557 of the Affordable Care Act (42 U.S.C. § 18116); Title VI of the Civil Rights Act of 1964 (42 U.S.C. §§ 2000d et seq.), Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 794), and the Americans with Disabilities Act (42 U.S.C. §§ 12101 et seq.).
[77] 45 CFR § 92.11.
[78] SSA § 1902(a)(83)(A)(ii).

underlying direct service. In those cases, Medicaid providers are obligated to provide language services to those with limited English proficiency and to bear the costs for doing so. Alternatively, states may allow providers to bill specifically for interpreter services. States have the option to make claims for the cost of interpretation services, either as medical-assistance-related expenditures or as administration.[79,80]

Interpreters are not Medicaid qualified providers and may not be paid separately. However, their services may be included as part of an allowable Medicaid service when billed by a qualified provider rendering a Medicaid- covered service. States have options in how they claim federal financial participation (FFP) for interpretation. States may claim standard 50 percent federal matching rate for translation and interpretation activities that are claimed as an administrative expense and may claim 75 percent federal matching for expenses related to the enrollment, retention, and use of services under Medicaid by children of families for whom English is not their primary language.[81] For example, a state may contract for a language telephone line to be used for enrollment as well as by providers when delivering care to beneficiaries as long as interpretation is not included and paid for as part of the payment rate for direct services.[82]

States can also raise payment rates to recognize additional service costs, including interpreter costs, but they must do so for services rendered by all providers in the class. CMS maintains claiming information on a webpage dedicated to Translation and Interpretation Services.

# V. Permissible Limitations on Coverage of EPSDT Services

States have many mechanisms to ensure that children get the right service at the right time, including setting parameters for medical necessity, requiring prior authorization for certain services, determining the relative cost-effectiveness of alternatives, and covering experimental treatments at their discretion.

## A. Individual Medical Necessity

Services within the Section 1905(a) scope of benefits must be provided to an EPSDT-eligible child only if they are necessary to “correct or ameliorate” the individual child’s physical or mental condition, i.e., only if “medically necessary.” States are permitted, but not required, to set parameters that apply to the determination of medical necessity in individual cases, but those parameters may not contradict or be more restrictive than the federal statutory EPSDT requirement to cover Section 1905(a) services needed to correct or ameliorate the child’s

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[79] CMS, State Medicaid Director (July 1, 2010).
[80] CMS, Informational Bulletin (April 26, 2011).
[81] SSA § 1903(a)(2)(E).
[82] CMS, State Medicaid Director (August 31, 2000).

condition. The determination of whether a service is medically necessary for an - EPSDT eligible child must be made on a case-by-case basis, taking into account the child's particular needs. The state—or the MCP as contracted by the state—must apply the "correct or ameliorate" standard and take into account the child's long-term needs, not just what is required to address the immediate situation. If the state or its contractors rely on software to streamline coverage decisions, the state should ensure that any software used in this process is consistent with EPSDT requirements.

Although most of the care and treatment that a child needs will fall within one or more Section 1905(a) categories, not all will. Services that are not listed in Section 1905(a) are not subject to EPSDT requirements. For example, home accessibility modifications and respite care do not fall into a section 1905(a) benefit category and are therefore excluded under EPSDT. A state may choose to cover these services under 1) a 1915(c) HCBS waiver; 2) a 1915(i) state plan HCBS benefit; or 3) other federal authorities authorizing coverage of HCBS.

Determination of whether a service is medically necessary for an EPSDT-eligible child must be made on a case-by-case basis, taking into account the child's particular needs.

As noted, EPSDT medical necessity decisions are individualized. Flat, fixed, hard, or arbitrary limits (e.g., budget or monetary caps, standard deviations from the norm, or hourly maximums) are not consistent with the EPSDT requirements and therefore may not be applied to the coverage of Section 1905(a) services for EPSDT-eligible children.[83,84,85,86] As a utilization control, states may adopt a definition of medical necessity that places "soft" limits on services, pending an individualized determination by the state, or that limits a treating provider's discretion. However, additional services beyond these limits must be provided if determined to be medically necessary to correct or ameliorate the individual child's condition.[87,88] For example, although a state may include in its state plan a limit on the number of physical therapy visits per year for individuals age 21 and older, such a hard limit could not be applied to EPSDT-eligible children. A state could impose a "soft" limit on the number of physical therapy visits, but if it were to be determined through review of an individual child's case that additional physical therapy services were medically necessary to correct or ameliorate the child's condition, those services would have to be covered.

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[83] Health Care Finance Administration, Regional Transmittal Notice (Sept. 18, 1990).
[84] Memorandum from Rozann Abato, Acting Director, HCFA, to Associate Regional Administrator (Sept. 5, 1990).
[85] Memorandum from Christine Nye, HCFA Medicaid Director, to Regional Administrator Region VIII (1991).
[86] CMS, Information on School-Based Services in Medicaid (August 18, 2022).
[87] 42 CFR §§ 440.230 and 438.210(a).
[88] CMS, State Health Official (September 26, 2024).

Although the treating health care provider is responsible for determining or recommending that a particular covered service is needed to correct or ameliorate the child's condition,[89] the state also has a role to play in determining whether a service is medically necessary. If there is a disagreement between the treating provider and the state's expert as to whether a service is medically necessary for a particular child, the state is responsible for making a coverage decision for the individual child based on the evidence and application of the EPSDT requirements. That decision may be appealed by the child (or the child's family) under the state's Medicaid fair hearing procedures, as described in "VI. Notice and Fair Hearing Requirements."

## B. Utilization Management Strategies

### Prior Authorization

States may impose utilization controls to safeguard against unnecessary use of services. For example, a state may establish limits on the amount of a treatment that will be covered for a child and require prior authorization for coverage of medically necessary services above those limits.[90] Prior authorization must be conducted on a case-by-case basis, evaluating each child's needs individually and under the EPSDT coverage standards. Importantly, prior authorization procedures and other utilization controls may not delay delivery of needed treatment services and must be consistent with what Congress described as the "preventive thrust" of EPSDT.[91,92] Therefore, prior authorization may not be required for any EPSDT screening services.

States need to ensure that their utilization control/prior authorization systems are programmed to apply the EPSDT requirements. Prior authorization decisions also need to be made and communicated to the requesting provider and Medicaid beneficiary promptly.[93] When the authorization request involves outpatient prescription drugs, the state must respond by telephone or other telecommunication device within 24 hours of a request and must provide for dispensing a 24-hour supply of the drug in emergency situations.[94] In addition, utilization management strategies used for mental health and SUDs must comply with the Mental Health Parity and Addiction Equity Act, including being no more restrictive than those strategies used for physical health conditions.

## C. Cost Effective Alternatives

A state may not deny medically necessary treatment to a child based on cost alone but may consider the relative cost-effectiveness of alternatives as part of the prior authorization process. A state need not make a service available in every possible setting as long that service is

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[89] SSA §§ 1905(a) and (r).
[90] SSA §§ 1905(a) and (r).
[91] H.R. Rep. No. 101-247 at 399, *reprinted in* U.S.C.C.A.N. 1906, 2125.
[92] CMS, State Health Official (September 26, 2024).
[93] For managed care, 42 CFR § 438.210(d).
[94] SSA § 1927.

available when a child needs it. Therefore, states may cover services in the most cost-effective mode as long as the less expensive service is equally effective and available.[95,96] The child's quality of life must also be considered.[97]

A state may not deny medically necessary treatment based on cost alone but may consider the relative cost-effectiveness of alternatives as part of the prior authorization process.

### D. Experimental Treatments

EPSDT does not require coverage of treatments, services, or items that are experimental or investigational. Such services and items may, however, be covered at the state's discretion if it is determined that the treatment or item could be effective in addressing the child's condition.[98] Neither the federal Medicaid statute nor the regulations define what constitutes an experimental treatment. Medicare guidance on whether a service is experimental or investigational is not determinative of the issue and may not be relevant to the pediatric population.[99] The state's determination of whether a service is experimental must be reasonable and should be based on the latest scientific information available.[100] In addition, for beneficiaries participating in a qualifying clinical trial, the routine patient costs that are otherwise covered under the state plan must be covered by the state agency.[101]

## VI. Notice and Fair Hearing Requirements

### A. State Notice and Fair Hearing Requirements

Children, as all beneficiaries, have fair hearing rights whenever the state denies a request for benefits or services (including a prior authorization request denied in whole or in part) and when a state takes action to terminate, suspend, or reduce covered benefits or services, including

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[95] CMS, Olmstead Update No. 4 (January 10, 2001).
[96] Letter from Rozann Abato, Acting Director, Medicaid Bureau, to State Medicaid Directors (May 26, 1993).
[97] Ibid.
[98] CMS, State Medicaid Manual §§ 4385.C.1, 5122.F.
[99] Ibid.
[100] Memorandum from S. Richardson to State Medicaid Directors (April 17, 1995).
[101] CMS, State Medicaid Director (April 13, 2022).

those for which there is a current approved prior authorization.[102,103] States must ensure that hearing officers who conduct fair hearings that involve EPSDT are knowledgeable about the state's EPSDT policies and procedures and the higher standard of coverage for EPSDT-eligible children than for adult Medicaid beneficiaries,[104] particularly the EPSDT requirement that states cover all Section 1905(a) services needed to "correct or ameliorate" a child's condition.[105]

States must provide children or their families written notice that includes information regarding the beneficiary's fair hearing rights, when services are being terminated, suspended, or reduced, including those for which a beneficiary has a current approved prior authorization, the notice generally needs to be sent at least 10 days before the effective date of the action ("advance notice").[106] Advance written notice of a denial or action must be: 1) written in plain language; 2) accessible to persons with limited English proficiency and individuals with disabilities; and 3) if provided in an electronic format, compliant with rules relating to electronic notices and information.[107]

Written denial and adverse action notices must contain:

- A statement of the decision or intended action, including the effective date of the action
- A clear statement of the specific reasons supporting the decision or intended action
- The specific regulations or changes in federal or state law supporting the decision or action
- An explanation of the individual's right to a fair hearing (including the right to request an expedited hearing), how to request a fair hearing, who can assist the individual at the hearing, circumstances under which benefits will be provided pending the outcome of the fair hearing, and the time frame in which the agency must take final administrative action on the fair hearing.[108]

Beneficiaries are entitled to a fair hearing before the state Medicaid agency.[109] Regardless of whether the hearing is held by the state Medicaid agency or another entity, the hearing must be conducted at a reasonable time, date, and place by an impartial official or other individual who was not directly involved in the initial decision or action.[110] Beneficiaries have the right to represent themselves or use legal counsel, a relative, a friend, or other spokesperson.[111] Before the hearing, beneficiaries or their representatives have the right to examine the case file and all documents that will be used at the hearing.[112] During the hearing, the beneficiaries have the right to: bring witnesses, establish facts, present their case without undue interference, question or refute the state's case, and ask questions of the state's witnesses (i.e., cross-examine).[113]

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[102] SSA § 1902(a)(3) and 42 CFR §§ 431 and 435.917.
[103] U.S. Supreme Court, Goldberg v. Kelly, 397 U.S. 254 (1970).
[104] CMS, State Health Official (September 26, 2024).
[105] 42 CFR § 431.240.
[106] 42 CFR §§ 431.211 and 431.213.
[107] 42 CFR §§ 435.917, 435.905(b), 435.918, and 431.206(e).
[108] 42 CFR §§ 431.206 and 431.210.
[109] SSA § 1902(a)(3) and 42 CFR § 431.205(b).
[110] Ibid.
[111] 42 CFR § 431.206(b)(3).
[112] 42 CFR § 431.242.
[113] Ibid.

The fair hearing process must be accessible to persons with limited English proficiency and individuals with disabilities.[114]

When a benefit or service is terminated, suspended, or reduced, if the beneficiary requests a hearing before the effective date of action, the beneficiary has the right to continued coverage of the contested benefit or service pending the outcome of the fair hearing.[115] This continued coverage may be referred to as “continued benefits,” “benefits pending,” or “aid paid pending.” If the beneficiary loses the fair hearing, the state may require them to repay the state for the cost of the contested services provided pending the outcome of the fair hearing.[116]

## B. Grievances and Appeals Through Managed Care

When benefits or services are provided through a managed care delivery system, MCPs must have a grievance and appeal system in place for enrollees.[117] MCPs must provide enrollees written notice explaining the action taken by an MCP when the decision is adverse to the enrollee (called an “adverse benefit determination”). This notice must include the reason for the determination and an enrollee’s right to appeal the MCP’s decision, how to access documents and information relevant to the determination, how to file an appeal and request a state fair hearing, how and when an appeal can be expedited, and the enrollee’s right to continued benefits in certain circumstances until the appeal is resolved.[118]

MCPs must resolve grievances and appeals in a timely manner.[119] “Timely” includes resolving appeals within a state-established timeframe that is no longer than 30 calendar days after the MCP receives the appeal for standard appeals and 72 hours after the MCP receives the appeal when the MCP determines or provider indicates that delay could seriously jeopardize the enrollee’s life, health, or ability to attain, maintain, or retain maximum function.[120] The state must require enrollees to exhaust the MCP’s appeal process before requesting a state fair hearing.[121] States may choose to provide an option for a no-cost independent external medical review.[122]

Like the state fair hearing process, the MCP grievance and appeal processes must be accessible to persons with limited English proficiency and individuals with disabilities.[123]

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[114] 42 CFR §§ 431.205, 435.917, and 435.905(b).
[115] 42 CFR § 431.230.
[116] Ibid.
[117] 42 CFR § 438.402.
[118] 42 CFR §§ 438.404(b) and 42 CFR § 438.420(c).
[119] 42 CFR § 438.408(b).
[120] 42 CFR §§ 438.408(b) and 438.410.
[121] 42 CFR § 438.402(c).
[122] Ibid.
[123] 42 CFR §§ 438.10 and 431.205(e).

# VII. Access to Services

EPSDT-required services, like all Medicaid services, must be provided with “reasonable promptness.”[124] States need to set standards for the timely provision of EPSDT services, consistent with medical and dental practice standards. States should have processes in place to ensure that services are initiated within a reasonable time.[125] What constitutes a reasonable time will depend on the nature of the service and the individual child’s needs. Because states have an affirmative obligation to arrange screening and corrective treatment, a lack of screening and/or treating providers does not relieve a state of its obligation to ensure that services are provided in a timely manner. For example, as noted above, it may be necessary to cover services provided out-of-state and, in the case of managed care, for MCPs to cover services rendered by providers outside the plan’s provider network when that network is unable to provide necessary services covered under the contract.[126]

> Because states have an affirmative obligation to arrange screening and corrective treatment, a lack of screening and/or treating providers does not relieve a state of its obligation to ensure that services are provided in a timely manner.

The providers available to treat a child’s condition may vary from state to state, depending on state scope of practice requirements (e.g., whether a state allows certain specialized provider types or midlevel providers). Section 1905(a)(6) permits states to cover “medical care, or any other type of remedial care recognized under State law, furnished by licensed practitioners within the scope of their practice as defined by State law.”[127] Therefore, a state may cover services performed by a class of providers (such as licensed dietitians) when the service is not specified in Section 1905(a), as long as the service is determined necessary to correct or ameliorate the child’s condition. Alternatively, a provider’s services can be covered as a component of a Section 1905(a) service. For example, in the case of a licensed social worker, the services could be provided through a federally qualified health center (FQHC) or a clinic, both of which are recognized providers under Section 1905(a). The process for covering a provider for a service not specified in Section 1905(a) varies depending on how the state intends to provide the service.

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[124] SSA § 1902(a)(8).
[125] 42 CFR §§ 441.56(e) and 438.68.
[126] 42 CFR § 438.206(b)(4).
[127] SSA § 1905(a)(6).

# A. Number and Range of Providers

Access to covered services is a critical component of delivering an appropriate health benefit to children. Accordingly, a number of Medicaid and EPSDT requirements are intended to ensure that children have access to an adequate number and range of pediatric providers. Medicaid EPSDT provisions require states to arrange for providing necessary corrective treatment to children, directly or through referrals to appropriate entities or individuals.[128] States should “make available a variety of individual and group providers qualified and willing to provide” services to children.[129] States also need to “take advantage of all resources available” to provide a “broad base” of providers who treat children.”[130] To this end, states publish and maintain online directories of providers who accept FFS payments, including by specialty and languages spoken, and ensure that Medicaid-participating MCPs publish similar directories.[131]

Some states may find it necessary to recruit qualified providers not currently enrolled in Medicaid to meet children’s needs.[132]

Under FFS, a child is entitled to receive Medicaid services from any provider qualified to provide the service and willing to furnish it. Although MCPs may restrict choice of providers in creating their networks, states must ensure that MCPs have adequate capacity to serve enrollees, including maintaining a sufficient number, mix, and geographic distribution of providers of services.[133]

An appropriate level of Medicaid payment can be critical to ensuring adequate access to providers.[134] Although the statute provides states with broad authority to set FFS provider payment rates, it requires that payments to providers be consistent with efficiency, economy, and quality care and be sufficient to enlist enough providers that care and services are available to Medicaid beneficiaries at least to the extent that they are available to the general population in the same geographic area.[135] For managed care, MCPs determine the payment rates that they pay providers that render covered services to their enrollees. These rates, which may differ from FFS rates, provide a tool for plans to be able to attract a robust network.

Federal regulations require that a Medicaid provider agree to accept, as payment in full, the Medicaid payment for a covered service or item.[136] This means that a provider *may not* bill a Medicaid beneficiary for the difference between the provider’s charge and the Medicaid payment (called “balance billing”). The payment in full requirement also prohibits Medicaid providers from billing beneficiaries for missed appointments. States may need to monitor compliance with this requirement.

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[128] SSA § 1902(a)(43)(C).
[129] 42 CFR § 441.61.
[130] CMS, State Medicaid Manual § 5220.
[131] SSA § 1902(a)(83) and 42 CFR § 438.10(h)(1).
[132] CMS, State Medicaid Manual § 5220.
[133] SSA § 1932(b)(5)(B), 42 CFR § 438.207(a), and U.S. Code 1396a(a)(23)(B).
[134] Health Care Finance Administration, State Medicaid Director (Jan 18, 2001).
[135] SSA § 1902(a)(30)(A) and 42 CFR § 447.204.
[136] 42 CFR § 447.15.

## B. Services Should be Delivered in a Range of Settings and Locations

EPSDT requires states to treat identified medical conditions and entitles eligible children to medically necessary Section 1905(a) services. Although EPSDT does not directly address settings and locations of services, CMS encourages states to deliver services within a range of settings to remove barriers to early care.

### a. Services Provided in Schools

Services provided in schools can play an important role in the health care of adolescents and children. Services may be provided by practitioners employed by the school district, by health clinics located in schools, or by community providers who are contracted to provide services in a school setting. Regardless of delivery model, medical, behavioral, and dental care can be efficiently and effectively delivered in schools, while avoiding a child's extended absence.

School health clinics and community clinicians can function as Medicaid providers who are providing services in a school setting. CMS has published a Comprehensive Guide to Medicaid Services and Administrative Claiming that details the implementation of "School-Based Services" in which providers employed by schools or local education agencies (LEAs) can appropriately submit claims for Medicaid-covered services. In addition, CMS, in collaboration with the US Office of Special Education and Rehabilitation Services, has established a technical assistance center to support state Medicaid agencies, LEAs, and school-based entities seeking to expand their capacity to provide school-based Medicaid services.[137] The intersection of federal education policy and Medicaid policy is complex, and CMS encourages states to take advantage of technical assistance opportunities when considering implementation of Medicaid services in schools.

> Services provided in schools can play an important role in the health care of adolescents and children.

### b. Telehealth

States have flexibility to cover and pay for Medicaid-covered services delivered via telehealth, including site- and service-specific coverage, school-based services, components of the well-child medical visit, in-home services for children with medically complex conditions, and mental health therapies. States should be aware that there may be limits on when services delivered

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[137] CMS, Medicaid & School-Based Services.

through telehealth can be counted in the Child Core Data Set and Form CMS-416 EPSDT reporting form. No federal approval is needed for state Medicaid programs to pay providers for telehealth-delivered services that are provided at the same rate that states pay for face-to-face services. A state plan amendment is needed to implement revisions to payment methods to account for telehealth costs.[138]

CMS has developed a Telehealth Toolkit to support states interested in expanding the use of telehealth to deliver Medicaid and CHIP services.

## c. Services Provided Out-of-State

States may need to rely on out-of-state services if medically necessary covered services are not available within the state in a timely way or when a Medicaid beneficiary is out-of-state at the time a need for medical services arises. States are required to pay for services provided in another state to the same extent as they would pay for services furnished in-state for in any of the following circumstances:

- The out-of-state services are required because of a medical emergency
- The beneficiary's health would be endangered if they were required to travel to their home state
- The state determines, on the basis of medical advice, that the needed services are more readily available in the other state
- It is the general practice of the locality to use the services of an out-of-state provider, e.g., in areas that border another state.[139]

Coordination among states will facilitate the provision of services when they are needed. Including out-of-state providers gives states the opportunity to expand the range and accessibility of Medicaid services that are available to their enrollees.[140] This can be particularly beneficial for children with disabilities or other complex health needs.[141]

## d. Most Integrated Setting Appropriate

Title II of the Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability in public programs, including Medicaid. In *Olmstead v. L.C.,* the U.S. Supreme Court held that unjustified institutionalization of Medicaid beneficiaries violates the ADA. Accordingly, states must cover services in the community, rather than in an institution, when the need for community services can be reasonably accommodated and providing services in the community will not fundamentally alter the state's Medicaid program.

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[138] CMS, Medicaid & CHIP Telehealth Toolkit (2024).
[139] SSA § 1902(a)(16) and 42 CFR § 431.52.
[140] CMS, Olmstead Update No. 3 (July 25, 2000).
[141] CMS, CMS Informational Bulletin (October 20, 2021).

Community-based care is considered a best practice for supporting children with disabilities or other complex medical needs.

CMS has long encouraged states to provide services in home and community settings, particularly for children, not only because of the *Olmstead* decision*,* but also because community-based care is considered a best practice for supporting children with disabilities and complex medical needs. In addition, it is generally more cost-effective.[142]

Medicaid provides states with many options for covering physical and mental health services in the community. For example, the EPSDT requirements include coverage of the following Section 1905(a) services when medically necessary to correct or ameliorate a child's condition: case management; personal care; private-duty nursing; medical equipment and supplies; and physical, occupational, and speech-language therapy. In addition, as discussed in section IV of this Guide, optional services provided through HCBS authorities can further advance the state's efforts to provide services in the community for children who qualify for those services.

# VIII. Managed Care

EPSDT-eligible children are entitled to the full scope of EPSDT services regardless of delivery system though which they receive services. The vast majority of children receiving Medicaid are enrolled in managed care. Properly implemented and monitored, managed care programs can support EPSDT's goal of ensuring that EPSDT-eligible children get the health care they need, when they need it, in the most appropriate setting.

States are responsible for ensuring the fulfillment of EPSDT requirements for all EPSDT-eligible children in the state, regardless of whether the state contracts with MCPs to deliver some or all services. To ensure accountability and that children get all needed services to which they are entitled, it is critical that the state's contracts with MCPs are drafted with sufficient precision so that MCPs' responsibilities are clearly delineated.[143]

If certain EPSDT-related responsibilities and/or services are excluded from the managed care contract, the contract should be explicit regarding those exclusions, and the state must ensure

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[142] More information on services in home and community settings can be found through documents such as: CMS Olmstead Update No. 2 (July 25, 2000); CMS Olmstead Update No. 3 (July 25, 2000); CMS Olmstead Update No. 5 (January 10, 2001); CMS State Medicaid Director (May 20, 2010); and CMS/SAMHSA Joint CMCS and SAMHSA Informational Bulletin (May 7, 2013).

[143] 42 CFR § 438.210(a).

that the excluded services are available to EPSDT-eligible children on a FFS basis or through another MCP. For example, the state may exclude dental services from the contract with a managed care organization, but the state must still ensure that children receive those services through either FFS or a specialized dental plan (e.g., a prepaid ambulatory health plan). Moreover, if a managed care contract excludes benefits above specified limits, the state must ensure provision of medically necessary services above those limits through another mechanism (e.g., on a FFS basis).[144]

Managed care plans may not use a definition of medically necessary services for children that is more restrictive than the state's definition.

Managed care plans may not use a definition of medically necessary services for children that is more restrictive than the state's definition,[145] which in turn cannot be more restrictive than the federal "correct or ameliorate" standard. One way to ensure this is for the state to include the EPSDT "correct or ameliorate" definition in the MCP's contract. States should ensure that MCPs' definitions of medically necessary services meet this requirement.

If MCPs are contractually responsible for informing beneficiaries about EPSDT and its benefits, states must ensure that MCPs inform all enrollees and their families of the services covered under EPSDT requirements and how to access them.[146] Information made available to enrollees, including the enrollee handbook, should clearly explain which EPSDT services the MCP is contracted to provide and how enrollees can access any EPSDT services that are not within the scope of the contract.[147]

Managed care plans are required to have adequate provider capacity to serve enrolled children in accordance with the terms delineated in their contract, including an appropriate range of pediatric and specialty services; access to primary and preventive care; and a sufficient number, mix, and geographic distribution of providers.[148] States must monitor their MCPs to ensure that they meet this requirement.

Monitoring MCPs' compliance with EPSDT requirements is essential; a strong oversight framework ensures that states meet both their responsibilities to children and federal reporting requirements. As outlined below, states use several mechanisms to oversee MCPs.

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[144] CMCS, Informational Bulletin (January 5, 2017).
[145] 42 CFR § 438.210(a)(5)(i).
[146] 42 CFR § 438.10(c)(5).
[147] 42 CFR §§ 438.210(g)(2) and 438.10(e)(2)(v).
[148] 42 CFR §§ 438.207 and 438.68.

States contracting with MCPs are statutorily required to draft, implement, and maintain a managed care quality strategy,[149] the goal of which is to provide a blueprint for states to assess and improve the quality of care provided to managed care enrollees.[150] Through this quality strategy, states identify measurable goals and objectives for continuous quality improvement and can monitor and evaluate MCPs' compliance with quality initiatives; their performance on specified performance measures; and their design, implementation, and results of performance improvement projects. States can leverage their quality strategy to focus some monitoring activities on performance measures or goals related to EPSDT, such as well-child visits and delivery of treatment.

States are also required to ensure that external quality reviews (EQRs) of MCPs are conducted by a qualified external quality review organization (EQRO).[151] In this way, states can determine whether MCPs are reporting accurate performance outcomes data and whether they are in compliance with state contract provisions. States can focus their EQRs on a range of EPSDT items, including informing, screening, and delivery of treatment. In addition, states may direct their EQROs to conduct optional EQR-related activities such as focus studies on a particular aspect of clinical or nonclinical services.[152]

The state's monitoring system must also address MCPs' grievance and appeal systems.[153] States can fulfill this responsibility by engaging in an ongoing direct review of grievances and appeals related to children's services, as well as monitoring complaints filed with the state's enrollee and provider hotlines (if the state operates such hotlines). States could also require MCPs to provide reports on these data and perform data analysis of MCPs' encounter data to detect underutilization of services by children.

# IX. State and Federal Quality Reporting and Monitoring of EPSDT

States are statutorily required to annually report the Core Set of Children's Health Care Quality Measures for Medicaid and CHIP (Child Core Set) to CMS. The Child Core Set is updated annually and includes measures related to access to primary and preventive care, behavioral health care, maternal and perinatal health, care of acute and chronic conditions, dental and oral health, and children's experience of care. In addition, states may use Child Core Set data to inform and drive quality improvement, for example by incorporating Core Set measures into their managed care Quality Strategy, leading to improved access to health care services for Medicaid and CHIP beneficiaries. Annual performance on Child Core Set measures is found on the Core Set Data Dashboard. In addition, all states, including those contracting with MCPs, are

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[149] SSA § 1932(c)(1).
[150] 42 CFR § 438.202340(a).
[151] SSA § 1932(c)(2) and 42 CFR § 438.350.
[152] 42 CFR § 438.358(c)(5).
[153] 42 CFR § 438.66(b)(2).

required by statute to complete and file Form CMS-416 each year, on which states report the number of children receiving health screening services, dental and oral health services, and referrals for corrective treatment The data reported on the CMS-416 informs CMS about the extent to which each state is meeting the EPSDT requirements with respect to these services.

# Conclusion

More comprehensive and less restrictive than the Medicaid benefit for adults, the EPSDT requirements are designed to ensure that children receive the medically necessary preventive services; early care; acute care; and ongoing, long-term treatment and services they need so that health problems are averted or diagnosed and treated as early as possible. For this reason, EPSDT requires coverage of age-appropriate medical, dental, vision, and hearing screening services at specified times, as well as when health problems arise or are suspected. In addition, EPSDT requires coverage for children not only of medically necessary treatment to correct or ameliorate identified conditions, but also of preventive and maintenance services.

The broad scope of EPSDT provides states with the tools necessary to offer a comprehensive, high-quality health benefit. To fully realize EPSDT's potential, however, families, Medicaid providers and managed care plans must be informed about EPSDT's requirements and states must consider how the intersection of various Medicaid policies can affect access to care for children. CMS is available to help states address these issues to ensure that EPSDT coverage meets the needs of children under 21 years of age who depend on Medicaid for their health care.

# Appendix: What You Need to Know about EPSDT

## EARLY: Assessing and identifying problems early

Children covered by Medicaid are more likely to be born with low birth weights; have poor health; have developmental delays or learning disorders; have behavioral health conditions; or have medical conditions (e.g., asthma) that require ongoing use of prescription drugs. Medicaid helps these infants, youth, and adolescents receive timely, quality health care.

EPSDT is a key part of Medicaid for children and adolescents. EPSDT emphasizes preventive and comprehensive care. Prevention can help ensure the early identification, diagnosis, and treatment of conditions before they become more complex and costly to treat. It is important that children and adolescents enrolled in Medicaid receive all recommended preventive services and treatment needed to promote healthy growth and development. States may contract out some EPSDT responsibilities, for example to managed care plans, but the state retains ultimate responsibility for ensuring compliance with the EPSDT requirements.

## PERIODIC: Checking children’s health at age-appropriate intervals

As they grow, infants, children, and adolescents should see their health care providers regularly. Each state develops its own periodicity schedule showing the well-child visits recommended at each age. In the vast majority of states, these are based on the American Academy of Pediatrics’ Bright Futures guidelines, Recommendations for Preventive Pediatric Health Care. Bright Futures helps doctors and families understand the types of care that infants, children, and adolescents should get and when they should get them. The goal of Bright Futures is to help health care providers offer prevention-based, family-focused, and developmentally-oriented care for all children and adolescents. Children and adolescents are also entitled to receive additional checkups when a condition or problem is suspected, regardless of whether such checkups are called for in accordance with the state’s periodicity schedule.

## SCREENING: Providing physical; mental; developmental; dental, hearing, and vision; and other screening tests to detect potential problems

All infants, children, and adolescents should receive regular well-child checkups of their physical and mental health, growth, development, and nutritional status. A well-child checkup includes:

- A comprehensive health and developmental history, including both physical and mental health development assessments
- Physical exam
- Age-appropriate immunizations

- Laboratory tests, including blood-lead level assessments at certain ages
- Health education, including anticipatory guidance.

In addition to medical screens, children need to receive periodic vision, hearing, and dental screening on an established periodicity schedule. Any encounter with a health care professional acting within their scope of practice qualifies as a screen for purposes of the child's obtaining treatment; a formal request for an EPSDT screen is not needed.

## DIAGNOSTIC: Performing diagnostic tests to follow up when a health risk is identified

When a well-child visit or other visit to a health care professional shows that a child or adolescent may have a health problem, follow-up diagnostic testing and evaluation must be provided under EPSDT. Diagnosis of mental health; SUD; vision, hearing, and dental problems is included along with other medical problems. Also included are any necessary referrals so that the child or adolescent can receive all needed treatment. A formal diagnosis is not a precondition for the child to receive treatment through EPSDT.

## TREATMENT: Correct, reduce, or control identified health problems

EPSDT covers health care, treatment, and other measures necessary to correct or ameliorate the child's or adolescent's physical or mental conditions found by a screening or a diagnostic procedure. "Ameliorate" means to improve or maintain the beneficiary's health in the best condition possible, compensate for a health problem, prevent it from worsening, or prevent the development of additional health problems. Even if the service will not cure the beneficiary's condition, it must be covered if the service is necessary to support, improve, or sustain the child's overall health. In general, states must ensure the provision of, and pay for, any treatment that falls within one of the services listed in the Social Security Act when it is considered "medically necessary" to "correct or ameliorate" the child's or adolescent's condition. This includes treatment for any vision and hearing problems, including eyeglasses and hearing aids. For children's oral health, coverage includes regular preventive dental care and treatment to relieve pain and infections, restore teeth, and maintain dental health. Some orthodontics are also covered.

# Resources

## CMS Resources

CMS, *State Medicaid Manual §§ 2700.4 and 5010-5360*

CMS, *Early and Periodic Screening Diagnostic and Treatment Resources*

CMS, State Medicaid Director, "Medicaid Payment for Services Provided without Charge (Free Care)" (December 15, 2014)

CMS, State Health Official Letter, "Access to Mental Health and Substance Use Disorder Services for Children and Pregnant Women in the Children's Health Insurance" Program (March 2, 2020)

CMS, State Medicaid Director, "Health Homes for Children with Medically Complex Conditions" (August 1, 2022)

CMS, State Health Official, "Opportunities in Medicaid and CHIP to Address Social Determinants of Health (SDOH)" (January 7, 2021)

CMS, State Medicaid Director, "Healthy Adult Opportunity" (January 30, 2020)

CMS, CMCS Informational Bulletin, "The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit for children and youth in managed care" (January 5, 2017)

CMS, CMCS Informational Bulletin, "Process for Amending Alternative Benefit Plans" (September 16, 2014)

CMS, CMCS Informational Bulletin, "Alternative Benefit Plan Conforming Changes" (January 28, 2016)

CMS, CMCS Informational Bulletin, "Information on School-Based Services in Medicaid: Policy Flexibilities and Guide on Coverage, Billing, Reimbursement, Documentation and School-Based Administrative Claiming" (May 18, 2023)

## Oral Health

CMS, *Keep Kids Smiling: Promoting Oral Health Through the Medicaid Benefit for Children and Adolescents* (September 2013)

CMS, *Improving Access to and Utilization of Oral Health Services for Children in Medicaid and CHIP Programs,* CMS Oral Health Strategy (April 11, 2011)

CMS, CMCS Informational Bulletin," CMS Oral Health Initiative and Other Dental Related Items" (April 18, 2013)

Medicaid/CHIP, *Improving Oral Health Care Delivery in Medicaid and CHIP: A Toolkit for States* (June 2014)

*CMS, Dental and Oral Health Services in Medicaid and CHIP* (February 2016)

CMS, "Issue Brief: Reducing Early Childhood Tooth Decay: Strategies for State Medicaid and CHIP Dental Program Managers" (May 2015)

CMS, CMCS Informational Bulletin, "Update on CMS Oral Health Initiative and Other Oral Health Related Items" (July 10, 2014)

CMS, CMCS Informational Bulletin, "Aligning Dental Payment Policies and Periodicity Schedules in the Medicaid and CHIP Programs" (May 4, 2014)

CMS, CMCS Informational Bulletin, "CMS Oral Health Initiative and Dental Technical Support Opportunity" (June 25, 2020)

## Mental Health

CMS, CMCS Informational Bulletin, "Prevention and Early Identification of Mental Health and Substance Use Conditions" (March 27, 2013)

CMS, Joint CMCS and SAMHSA Informational Bulletin, "Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions" (May 7, 2013)

CMCS, *Mental Health and Substance Use Disorder Action Plan* (July 2023)

CMS, State Medicaid Director, "New Service Delivery Opportunities for Individuals with a Substance Use Disorder" (July 27, 2015)

CMS, State Health Official Letter, "Medicaid Guidance on the Scope of and Payments for Qualifying Community-Based Mobile Crisis Intervention Services" (December 28, 2021)

CMS, CMCS Informational Bulletin, "Requirements of Section 12005 of the 21st Century Cures Act" (June 20, 2018)

CMS, Joint CMCS and SAMHSA Informational Bulletin, "Coverage of Behavioral Health Services for Youth with Substance Use Disorders" (January 26, 2015)

CMS, CMCS Informational Bulletin, "Clarification of Medicaid Coverage of Services to Children with Autism" (July 7, 2014)

CMS, Joint Informational Bulletin, "Coverage of Early Intervention Services for First Episode Psychosis" (October 16, 2015)

CMS, Joint Informational Bulletin, "Guidance to States and School Systems on Addressing Mental Health and Substance Use Issues in Schools" (July 1, 2019)

## Screening, Diagnostic, and Treatment Services

CMS, "Guide for States Interested in Transitioning to Targeted Blood Lead Screening for Medicaid-Eligible Children" (May 2012)

CMS, State Health Official Letter, "Mandatory Medicaid and Children's Health Insurance Program Coverage of Adult Vaccinations under the Inflation Reduction Act" (June 27, 2023)

CMS, State Health Official Letter, "Medicaid and CHIP Coverage of Stand-alone Vaccine Counseling" (May 12, 2022)

CMS, CMCS Informational Bulletin, "Maternal Depression Screening and Treatment: A Critical Role for Medicaid in the Care of Mothers and Children" (May 11, 2016)

CMS, CMCS Informational Bulletin, "Coverage of Blood Lead Testing for Children Enrolled in Medicaid and the Children's Health Insurance Program" (November 30, 2016)

CMS, CMCS Informational Bulletin, "Neonatal Abstinence Syndrome: A Critical Role for Medicaid in the Care of Infants" (June 11, 2018)

CMS, CMCS Informational Bulletin, "Medicaid Strategies for Non-Opioid Pharmacologic and Non-Pharmacologic Chronic Pain Management" (February 22, 2019)

## Accessibility

CMS, CMCS Informational Bulletin, "Recent Developments in Medicaid" (April 26, 2011)

CMS, State Medicaid Director, "Policy Guidance on Medicaid for Persons with Limited English Proficiency" (Aug. 31, 2000)

CMS, State Medicaid Director, "Olmstead Update No. 4," Att. 4-B EPSDT (Jan. 10, 2001)

CMS, *Medicaid School-Based Administrative Claiming Guide* (May 2003)

CMS, Joint Informational Bulletin, "Coverage of Maternal, Infant, and Early Childhood Home Visiting Services" (March 2, 2016)

## Transportation

CMS, State Medicaid Director, "Assurance of Transportation: A Medicaid Transportation Coverage Guide" (September 28, 2023)

## Other Federal Resources

Health Resources and Services Administration EPSDT website

## Other Resources

American Academy of Pediatrics, Bright Futures Recommendations for Pediatric Preventive Care (2024)

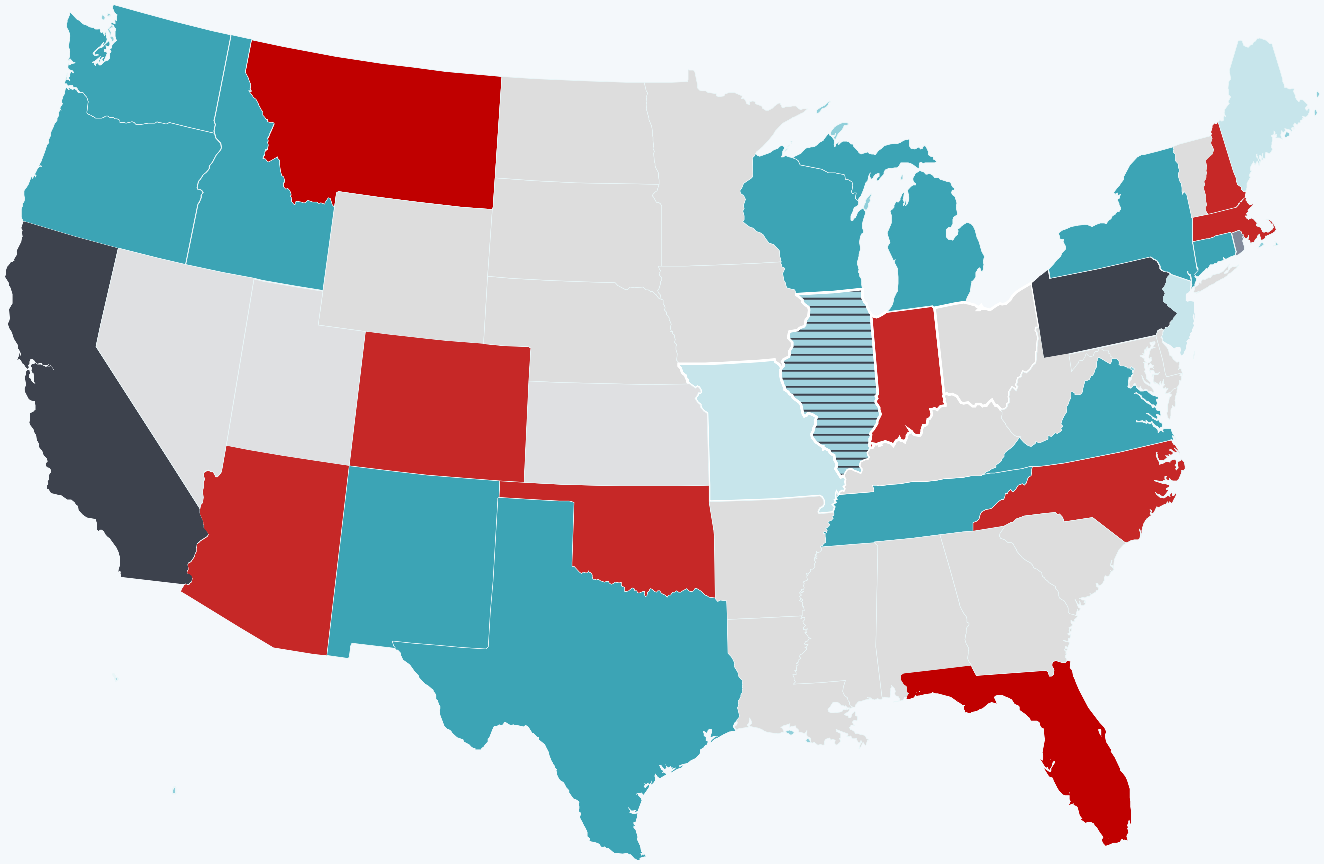
American Academy of Pediatric Dentistry, *Guideline on Periodicity of Examination, Preventive Dental Services, Anticipatory Guidance/Counseling, and Oral Treatment for Infants, Children, and Adolescents* (2022)

Association of Maternal and Child Health Programs, *Standards for Systems of Care for Children and Youth with Special Health Care Needs* (March 2014)

National Health Law Program, *Toward a Healthy Future: Medicaid EPSDT Services for Poor Children and Youth* (April 2003)

National Health Law Program, *Early and Periodic Screening, Diagnosis and Treatment – Annotated Federal Document* (May 2, 2014)

# Family CNA ***Map***



■ Implementation Underway to Bring Program to State

(IL, NJ, ME, MO)

■ Active Advocacy Underway

(NM, IL, NY, WI, CT, TX, WA, OR, MI, TN, ID)

■ **Family CNA Active Full Program**

(CO/AZ/NH/MA/IN/NC/FL/MT/OK)

■ **Family CNA Active – Limited Version of Program**

(CA/PA)

[ AS OF MARCH 2026]

# PAID FAMILY CAREGIVING

## STATE MEDICAID PATHWAYS FOR PAYMENT

## Advocacy Action Guide for AAP Chapters

### Overview

Children and youth with special health care needs (CYSHCN), including children with medical complexity (CMC), have high levels of health care utilization as well as unmet needs. Ongoing national shortages of home care services for such children, including private duty nursing, personal care, respite care, and therapists are drivers of such unmet needs. Without straightforward and consistent access to these essential services, CYSHCN are at increased risk for unnecessary hospitalization, institutionalization, and worsened health outcomes. Further, parents and caregivers often end up performing skilled tasks in the absence of home care services, which can increase stress, burnout, and financial hardship. One piece of the solution to the complex issue of home care workforce shortages and family burden is to enable parents and caregivers of CYSHCN to be paid for providing *personal care* and/or *home health* services. There are several potential pathways to paid family caregiving, involving a combination of assorted Medicaid *state plan authorities*, *waivers*, and changes to *state law and regulation*. This American Academy of Pediatrics (AAP) Advocacy Action Guide is intended as an introductory primer for AAP chapters on the need for and viability of these payment models, and considerations to address when advocating for coverage. Included in this resource are discussions of: *home health services vs personal care services; state plan benefits vs HCBS pathways; and state policy considerations*.

### Background

Over the last few decades, care for CYSHCN has been shifting from institutions to the home or a community-based setting, thanks in large part to policy changes such as the Katie Beckett/Tax Equality and Fiscal Responsibility Act (TEFRA), the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act, Home and Community-Based Services (HCBS) waivers, Section 504 of the Rehabilitation Act, and caselaw such as Olmstead v L.C.[1] Today, approximately half of all CYSHCN receive care at home from a family member.[2] This proportion increases when children have more than one special health care need, including CMC.[3] While medical literature demonstrates this shift to home and community-based care improves health outcomes, there is a growing number of CYSHCN reporting unmet home care needs.[4]

The most prominent barrier to accessing quality home care services is a shortage of workforce, a hurdle that can be even higher when considering home care services that specialize in pediatrics. Home care workforce shortages are driven by difficult hiring practices, variable training requirements, and most significantly, inadequate payment.[5] Research demonstrates that a lack of access to home care services drives increased risk of prolonged hospitalization and increased costs.[6] When these gaps exist, families are increasingly called upon to deliver specialized care for their children at home and at considerable personal cost. These issues can lead to family members forgoing employment to care for their children, which in turn can drive financial instability, unsafe workloads, and family stress.[7]

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Family caregivers of CYSHCN in the United States provide about 1.5 billion hours of health care to approximately 5.6 million children annually.[8] The cost of these services, if provided by a home health agency, would total anywhere between $11.6 and $35.7 billion annually.[9] Further, while CMC make up just 0.4% of children in the US, the number of hours their families spend caring for them at home is exponentially more than even other CYSHCN.[10] Unsurprisingly, the issues of stress, burnout, and financial instability are more common for parents of CMC, even compared to parents of children with other chronic conditions.[11]

However, research shows that when states enable parents and caregivers of CYSHCN to be paid for the extraordinary care they provide to their children, there can be numerous potential benefits to the parents, child, and state, including:

- Parents being able to maintain their "emotional and moral commitment" to care for their child;
- Stable access to high quality care, which drives continuity of care;
- Increased options and flexibility for parents of CYSHCN;
- Betterment of the child's health and wellbeing;
- Enhanced family financial stability; and
- Acquisition and development of skills that are transferable, including to elder care, which can help parents find employment and boost the provider network when their children age out to adult care.[12]

During the COVID-19 pandemic, states had the option to adopt temporary policies to pay family caregivers for providing personal care services.[13] But with the expiration of these temporary flexibilities, states wishing to continue or expand paid family caregiving will need to make changes to their Medicaid programs, which can entail additional, and often confusing, legislative or regulatory action. Most states already enable paid family caregiving for seniors and adults with disabilities through an array of HCBS options, though to date only a small number of states have done so for children.[14] However, in recent years, a handful of states have crafted innovative policies enabling parents of CYSHCN to be paid family caregivers, *either by obtaining skilled licensure types and performing services through a home health agency*, or through *HCBS pathways enabling self-directed services, which doesn't require licensure*.

AAP has created this Advocacy Action Guide to serve as an introductory primer for AAP chapters of the various pathways likely available in their states to unlock Medicaid payment for family caregiving of CYSHCN, including a discussion of the various policy considerations that should be taken into account when working with the state to advance these programs.

## State Pathways for Medicaid Payment to Family Caregivers

Broadly speaking, models for paid family caregiving can be categorized one of two ways: *models that require licensure and home health agency employment,*[i] *and models that do not*. CMS refers to these two options as the "agency service delivery model" and the "self-directed service delivery model."[15] There are several potential Medicaid pathways available to states to unlock these models, which can involve combination of Medicaid state plan authorities, waivers, and changes to state law and regulation. Within Medicaid, pathways can include the state plan home health benefit, HCBS waivers and state plan amendments, and 1115 waivers, all of which interplay with Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. In addition to identifying one or more Medicaid pathways, states will also likely need to analyze state law and regulations to either remove barriers or expressly authorize family caregivers to be paid. In particular, *home health services* are generally required to be provided by a home health agency and with the provider meeting some level of training, certification, or licensure, and are subject to rules about delegation, as determined by the state. Conversely, paid *personal care services* cannot normally be performed by a "legally responsible relative," unless through an HCBS pathway, which have their own policy and procedural safeguards states must meet.

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[i] *Note: There have been a small number of state models allow non-licensed individuals to provide services through a home health agency. Likewise, there have been a small number of states waivers allowing for self-direction of delegated skilled nursing tasks. However, these are largely exceptions to the rule.*

There are potential advantages and drawbacks to each pathway and service delivery model for the individual, the caregiver, and the state. As such, the model(s) and pathway(s) selected will likely be a state-by-state determination based on a number of policy considerations, which are discussed below.

*1905(a)(7) Home Health Services*

Home health, as defined in federal regulation, includes nursing and home health aide services through a home health agency, physical or occupational therapy, and the provision of medical supplies, all of which are 1905(a) services in and of themselves.[16] While these positions are able to perform skilled nursing tasks, they may also in the course of their duties provide services typically associated with personal care, as described below.[17] Home health is a mandatory state plan benefit when provided to an individual entitled to receive nursing facility services and for children is covered through EPSDT when medically necessary.[18] While there are no restrictions on a legally responsible relative's ability to be paid for providing home health services, these services generally have to be provided by a qualified provider through a home health agency, rather than be self-directed.[19] As such, states have enabled family caregivers to be paid for providing home health services if the family member (1) becomes employed by a home health agency, typically as some form of home health aide, and (2) meets state licensure and credentialing requirements – typically, LPN/RN, CNA, or newly-created parent caregiver licensure types (with a wide range of names, discussed below). Home health agencies need to meet federal Medicare standards, but states have flexibility to determine requirements for home health aides or these newly created licensure types, which can help lower barriers to entry for family caregivers.

**A Note on EPSDT**

ESPDT is the Medicaid program's mandatory benefit for children, designed to ensure that any enrolled child can receive the care they need, when they need it, in the setting they need it. Through EPSDT, eligible children under 21 can receive any Section 1905 service necessary to "correct or ameliorate" a condition, regardless of whether the service is covered under the state plan. As home health is a mandatory benefit and personal care is an optional benefit under Section 1905, both are covered for children via EPSDT when determined to be medically necessary. Conversely, HCBS falls under Section 1915; as such, those services do not fall within EPSDT, but rather "wrap around" EPSDT to create a comprehensive benefit for children with disabilities. Therefore, while states may have CYSHCN enrolled in a HCBS program, this does not limit children's entitlement to receive services through EPSDT as well.

Nevertheless, longstanding inconsistencies in state implementation of EPSDT have posed significant barriers to CYSHCN accessing the care they are entitled to. The policy pathways described within represent ways to work around barriers to family members providing these services – the need for home health services to be furnished by a qualified provider, and a prohibition on "legally responsible relative" providing paid personal care services.

For a robust discussion of EPSDT requirements, see the recent CMS guidance, SHO # 24-005.

*1905(a)(24) Personal Care Services via HCBS*

Personal care services include activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as cooking, cleaning, and shopping. Personal care is an optional state plan benefit; it nonetheless must be covered for children through EPSDT when determined to be medically necessary.[20] However, inconsistent application of EPSDT, compounded by provider shortages and the assumption parents are responsible for these tasks, can mean few eligible children actually receive this service. States set criteria for who can perform personal care services, including training requirements, supervision requirements, and whether personal care providers can operate independently or through an agency.[21] However, federal law prohibits "legally responsible relatives" from being paid for providing personal care services for minors under age 18, as the statue and regulations view these tasks as those a parent or guardian would otherwise be legally obligated to provide to a child.[22] Nevertheless, payment to a legally responsible relative for personal care services may be covered when included as part of a HCBS pathway, if the state demonstrates that performing these tasks for CYSHCN would be considered an "extraordinary" level of care.[23]

*HCBS*

HCBS is a patchwork of Medicaid waivers and state options that enable eligible individuals to receive institutional facility levels of care in their home or homelike setting in their community, rather than an institution. These programs enable coverage for services that are otherwise not available through Medicaid because they do not fit in a category listed in 1905(a), or can extend 1905(a) services beyond their normal amount, duration or scope.[24] As such, through HCBS pathways, states can enable a legally responsible relative to be paid for providing personal care services, either through becoming a qualified provider employed by a home health agency – similar to home health care state plan services – or through an option known as *participant-directed* or *self-directed care*, where the Medicaid enrollee essentially sets their own provider qualifications and "hires" their own provider.

While HCBS pathways can enable payment for personal care, there are hurdles the state must clear to overcome the federal limitation on paying legally responsible relatives for providing personal care.[ii] The state must establish that the care being provided is "extraordinary care" and develop a criteria for determining as much.[25] The state must also establish other safeguards, including: demonstrating the delivery of personal care by a legally responsible relative is in the child's best interest and will not hinder their ability to engage in meaningful community activities; implementation of appropriate oversight mechanisms to ensure the individual receives the services being paid for; and procedures to ensure payments are made for services rendered.[26]

There are several varying HCBS waivers and state plan pathways states can leverage to enable payment for family caregivers. States will need to asses the costs and benefits of pursuing paid family caregiving models through a waiver or its state plan, or even through multiple pathways, as discussed below.

**1915(c) Home and Community-Based Services waiver**

- The most common HCBS pathway, 1915(c) waivers enable states to tailor a wide array of services to specific populations as an alternative to institutionalization.
- States can elect to allow enrollees to self-direct services and/or have legally responsible relatives be employed by a Medicaid-enrolled home healthcare agency.
- If personal care services are provided by a legally responsible relative, must establish "extraordinary care" and the safeguards as described above.
- Individuals provided services under 1915(c) *must require* an institutional level of care.

**1915(i) Home and Community-Based State Plan Option**

- Enables states to provide HCBS services akin to 1915(c) to individuals who require *less than* an institutional level of care.
- Commonly used to limit service to a carefully constructed population
- If personal care is provided by a legally responsible relative, must establish "extraordinary care" and other safeguards

**1915(j) Self-Directed Personal Assistance Services State Plan Option**

- Enables participants to directly hire and self-direct personal care services and/or other 1915(c) HCBS services, including defining their own provider qualifications and managing their own personal care budget.
- States can elect to allow enrollees to hire a legally responsible relative, or other family member.

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[ii] See Elizabeth Edwards' excellent National Health Law Program (NHeLP) resource, *Paid Family Caregivers: State Options, Limitations, and Policy Considerations*, for a more detailed discussion of the procedural and technical requirements of an HCBS waiver for paid family caregiving. https://healthlaw.org/wp-content/uploads/2023/12/Paid-Family-Caregivers-NHeLP-2023.pdf

**1915(k) Community First Choice State Plan Option**

- ACA-created option that enables higher FMAP percentage for community-based attendant services and supports.
- States can elect to allow enrollees to set their own provider qualifications and self-direct services and/or have legally responsible relatives employed by a Medicaid-enrolled home health agency.
- Can't have waiting lists.

Nearly all states have active HCBS waivers, if not multiple. Research by KFF indicated that in FY2020 there were 267 HCBS waivers in place across 47 states + DC, with a large majority (255) of these waivers being 1915(c) waivers.[27] In 2022, KFF identified eighteen (18) 1915(c) waivers focusing exclusively on children who are medically fragile or technology dependent (other states may address children with medical fragility through other non-exclusive programs).[28] As of 2022, 32 states had HCBS waivers allowing legally responsible relatives to be paid for certain services; however, only 11 states had used a 1915(c) waiver to enable a legally responsible relative to be paid for personal care services (though this number is likely larger now).[29] Similarly, a 2023 survey of states by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) found that nearly all states allow payment for HCBS services delivered by a *non*-legally responsible relative, but only 12 at the time allowed payment to legally responsible relatives for personal care services, though most focus on parents of adults with disabilities who have guardianship.[30]

While the above HCBS pathways give states significant flexibility to craft programs that encompass payment for caregivers, there can also be limitations. Most notably, most HCBS options do not have a prohibition on enrollment caps or waitlists. As of 2020, the average wait time for HCBS waiver services for medically fragile or technology dependent children was 23 months (no data exists for children in waivers co-mingled with other populations).[31] That said, HCBS may be the most-favorable pathway for the state because the flexibility inherent in the program allows states to control costs by limiting the scope of services, number of recipients, and geographic area.

*1115 Waiver*

Section 1115 waivers are the most flexible waiver option for states to innovate. This option, which is not specific to HCBS services, gives states broad authority to test out new models of services and payments that advance the goals of the Medicaid program (within the constraints of budget neutrality). While HCBS services are usually delivered through a HCBS waiver, there are a handful of states (AZ, DE, HI, NJ, NY, RI, VT, WA) that deliver HCBS services through 1115 waivers, though not specifically for purposes of paid family caregiving.[32, 33] This is usually done to streamline eligibility processes and provide faster access to services.

## Policy Considerations

As indicated above, identification of a viable pathway for paid family caregiving for CYSHCN will be a state-by-state determination based on a number of factors, including the needs of the state's CYSCHN Medicaid population, fiscal and administrative costs to the state, the state's current utilization of HCBS pathways, and barriers located in state law and regulation. When assessing these pathways there are several policy considerations advocates and the state should take into account. Likewise, program evaluations such as those mentioned in the section below indicate a number of benefits that states can work to enhance, and some perceived drawbacks states can work to reduce.

**Employment through agency or direct payment** – When crafting a paid family caregiving policy, the state will need to weigh whether it will allow the Medicaid enrollee to self-direct their own care and hire a family member or guardian to provide personal care services, or whether family caregivers will need to be employed by a home health agency. As previously stated, home health services must be performed by a qualified provider through a home health agency. The provider types that typically perform home health aide services and their associated licensure, training, and certification requirements are prescribed by state law and nursing regulations, which may need to be amended to include parent caregivers. Self-direction options may reduce costs to the state, but can also be associated with increased administrative burden, including state oversight of the paid care giver and quality assurance processes.[34] Conversely, employment through a home health agency can enable the caregiver to be paid for providing low acuity tasks, which in turn can free up RNs to focus on higher acuity tasks and can boost the home health care workforce in the longer term, but may be associated with higher fiscal costs to the state.

**Delegation** – States may have nursing statutes or regulations that either enable or restrict delegation of skilled nursing tasks from a RN to a nursing assistant/aide. Assistants/aides are typically only permitted to provide low acuity tasks. While families of CMC may be highly familiar with complex care such as tracheostomy care and feeding tubes, in order to be paid for providing these home health services, it may be necessary to ensure delegation of these tasks is allowable under state law.

**Nomenclature** – State laws/regulations often have differing professional titles for the role that would be carried out by a family member providing paid home health services. Depending on the title, there could be associated certification and training requirements. For example, the term "Home Health Aide" is used in FL, IN, PN, and NJ, while the term "Complex Care Assistant" is used in MA and MT. Other states expressly indicate certification in the use of the titles "Certified Home Health Aide" (CA), "Certified Nursing Assistant" (CO), and "Certified Health Aide" (TX). Meanwhile, others expressly indicate licensure through the state nursing board, such as "Licensed Health Aide" (AZ) and "Licensed Nurse Aide" (NH). States will need to examine their own laws and regulations to determine which title will best fit within existing schemes.

**Training, credentialing, fees** – For states that require caregivers to go through training and hold a certificate or license, states should subsidize the cost of training to minimize barriers to entry and financial burden to family members participating in the program. If it is required that the caregiver be employed by a home healthcare agency, the state should work with the agencies operating in their jurisdiction to cover the cost of training for the parent caregivers they will be employing. For example, in Colorado, participants take a 4-week course through the hiring home healthcare agency, which is designed specifically for parents to become certified nursing assistants, including scheduling around family-friendly hours, with only fees to the parent for testing and licensure.[35] It may also be possible for states to exempt family caregivers from licensure requirements under a showing of competency or supervision by a registered nurse.[36] If such exemptions already exist in state law/regulations, policymakers should carefully weave a new paid family caregiving program into those definitions/exemptions.

**Optional vs mandatory participation** – When working with the state to craft paid family caregiver policies, advocates should ensure that the state makes explicit that participation in paid family caregiving by eligible individuals is entirely optional and not a mandate. For many families of CYSHCN, it is appropriate and desirable for family members to serve as paid family caregivers. However, not all families of CYSHCN prefer that caregiving arrangement, and policies allowing paid family caregiving should not supplant coverage of the same services through other means, as available. Just as receipt of private duty nursing should not be conditioned on family availability, parents of eligible CYSHCN similarly should not be compelled to go through the steps to become a paid family caregiver.[37]

**Who can provide** – State policymakers should be deliberate when defining which persons are eligible to be a paid family caregiver. As mentioned above, federal Medicaid law restricts "legally responsible relatives" from being paid for providing personal care services through the personal care state plan benefit, but no such prohibition exists for the home health state plan benefit. States may have a variety of terms already codified that could have legal implications vis-à-vis this federal restriction, including "legally responsible person," "legally liable relative," "legal guardian," "relative," and "legal representative."[38]

**Number of hours** – States may set limits on the number of hours in a week that a legally responsible relative can be paid for providing home care services, whether it be personal care or home health. Per NASDDDS, many states that allow for payment of a legally responsible relative limit the hours to 40 per week.[39] Others, such as North Carolina, use 40 hours as the base, but may allow up to 56 hours/week if there are extenuating circumstances.[40] Other states, such as Colorado, do not cap the number of hours that a parent can serve as a paid caregiver.[41]

**Preventing burnout** – Related to limits on hours, it is essential that when states craft these policies they consider options for respite care. A large percentage of parents of CMC want to care for their children at home, but the experience can be both exhausting and isolating.[42] Building care for the caregiver into the program can help protect against caregiver burnout, which in turn helps preserve quality of care and longevity of employment in the home health care workforce. Potential options for preventing caregiver burnout include prescribed respite hours, community-integration programs, support services, and ensuring that paid family caregiving services are appropriately supplemented with options delivered by non-relatives.[43]

**Appropriate payment and eligibility considerations** – One of the most frequently cited contributors to the home health care workforce shortage is the lack of adequate payment. Rates for personal care and home health services can vary widely by state, provider type, and service. Some states pay for home health services by visit, while others have an hourly rate. The average rate for a home health aide is around $36/hr, but can range from $15/hr to $60/hr.[44] Likewise, the average hourly rate for a provider of personal care services is about $22/hr, but can range from as low as $9/hr to $86/hr.[45] States should take care to craft their paid family caregiving program so as to support family stability and workforce development, but should also ensure that additional income from paid family caregiving does not impact the child's eligibility.[46] Likewise, states should take care to monitor the pass-through wages from agencies to families. To note, chapters should also monitor implementation of the HCBS provisions of CMS's recently released Access Rule, which could ultimately have the effect of increasing Medicaid payment for these services (See, AAP's Advocacy Action Guide on Access Rule and Managed Care Rule for a more robust discussion of these provisions).

**Implementation through multiple pathways** – Given the differences between HCBS pathways, or even within the same pathway, with respect to eligibility requirements, the ability to target specific populations, set different service limits, or enable participant self-direction, states may want to consider implementing paid family caregiving across multiple authorities. Likewise, in practice, there can be significant overlap between personal care tasks and home health tasks, with home health tasks often encompassing personal care tasks. Leveraging multiple state plan and waiver authorities can help enable "a comprehensive set of options that allow CYSHCN with varying needs and conditions to receive services from paid family caregivers."[47]

## Conclusion

Creating paid family caregiving programs for CYSHCN can be complicated given the various state plan and waiver pathways, state law and regulation barriers, and various policy considerations. However, as can be seen above, there is a great need to create better support for the family members who are already doing this work at great personal cost, and there are likely available pathways in each state for enabling some form of payment for either personal care or home health services. Enabling paid family caregiving is but one piece of the puzzle for ensuring adequate access to care and strong provider networks, but for those caregivers who desire to provide the services for their child, states should aid them in that choice. Furthermore, while paid family caregiving is one piece of the solution to improve the home care workforce shortage and ensure CYSHCN and CMC continue to receive supports in the community, states must also work to address the overarching barriers of difficult hiring practices, variable training requirements, and inadequate payment. AAP stands ready to assist chapters wishing to explore these policies in their home states. Contact AAP State Advocacy at stgov@aap.org for consultation and technical assistance.

## Addendum: Examples of Recently Passed State Legislation*⁺

*This following list does not purport to be exhaustive of the number of active paid family caregiving programs or those in development, but rather is illustrative of the type of legislation that has recently advanced in state legislatures. It likewise does not include programs established exclusively through a waiver or state plan amendment. A recent presentation by the Lucile Packard Foundation, in collaboration with Team Select (a home health agency), indicated that **as of March 2023 programs were operating in CA (limited), AZ (full), CO (full), IN (limited), PA (limited), MA (partial), and New Hampshire (full)**. (see, Paid Family Caregiving for Children with Medical Complexity and Disabilities - Lucile Packard Foundation for Children's Health (lpfch.org))

⁺At the time of publication, there is active legislation pending in Illinois, Oklahoma, and Rhode Island. Likewise, in recent years legislation has been introduced, but not advanced, in New Mexico, Washington, Texas and Connecticut.

| State | Year Passed | Bill Number(s) | Title Used | Summary |
|---|---|---|---|---|
| Arizona | 2021 | HB 2521 | License Health Aide | • Creates position of "licensed health aide" – parent or guardian of a member of the Arizona long term care system currently receiving service. Licensed only to provide services to that eligible member. Same scope of practice as a "licensed nursing assistant," but may also provide medication administration, tracheostomy care, enteral care and therapy, and other tasks approved by the Board of Nursing. Services must be ordered by physician.<br>• Add's licensed health aide services to definition of HCBS<br>• Licensed Health Aide must submit application to Board of Nursing, including: proof the licensed health aide is a parent/guardian/family member of an individual <21 years of age eligible to receive continuous skilled nursing or skilled nursing respite care services; completion of basic curriculum and certificate from a training program prescribed the Board that must include medication administration, tracheostomy care, enteral care and therapy, and any other tasks required by the Board; completion of competency exam approved by Board.<br>• License fee: $50<br>• Director shall request CMS approval no later than 60 days after promulgation of rules to implement; |
| Montana | 2023 | HB 449 | Pediatric Complex Care Assistant | • Creates position of "Pediatric complex care assistant"<br>• Must complete a training curriculum to be created by the Department and pass a hands-on examination. Training must include medication administration, airway clearance therapies, tracheostomy care, enteral care and therapy for persons <21.<br>• Can only provide care to person < 21 for whom the assistant is a parent, guardian, other family member, or kinship care or foster care provider.<br>• Services must be ordered by physician and consistent with plan of care<br>• Duties limited to: Duties considered by the department equivalent to those of a certified nursing assistant; medication administration; tracheostomy care and enteral care and therapy; airway clearance therapies; other services as allowed by the department by rule<br>• Department shall adopt rules to implement |
| Florida | 2023 | SB 452 | Home Health Aide for Medically Fragile Children | • Creates the Home Health Aide for Medically Fragile Children Program (HHAMFC), allowing a family caregiver to be paid by Medicaid, through employment with a home health agency, for care provided to a relative < 21 with an underlying physical, mental, or cognitive impairment, eligible to receive skilled care or respite care services through Medicaid |

|  |  |  |  |  |
|---|---|---|---|---|
|  |  |  |  | • Reimbursement rate: $25/hr, up to 8 hours/day<br>• Directs the Department to file any state plan amendments or waivers necessary to implement<br>• Authorizes HHAMFC to perform tasks delegated by a registered nurse, such as medication administration, tasks associated with activities of daily living, maintaining mobility, nutrition and hydration, and safety and cleanliness.<br>• Requires services provided by HHAMFC to result in a reduction in the number of private duty nursing service hours provided to an eligible recipient.<br>• Prohibits services provided by a HHAMFC from duplicating private duty nursing services provided to an eligible recipient<br>• Requires AHCA, in consultation with the Board of Nursing, to approve a training program<br>• Establishes civil liability protection for a home health agency<br>• Requires AHCA to conduct annual assessment of program and report the findings to Governor and Legislature |
| New Jersey | 2023 | S 1307 | Homemaker -home health aide | • Directs the State Medicaid agency to establish a program in which family members of Medicaid enrollees can seek certification through the Board of Nursing to become a "homemaker-home health aide" and provide certified nursing assistant services through a home health agency.<br>• Enrollee must be <21 and entitled to receive private duty nursing services through Medicaid<br>• Requires family member to complete any training and certification required by state or federal law and requires the employing home health agency to cover all costs of training and certification<br>• Tasks delegated to homemaker-home health aides shall be consistent with those consistent to ones allowed by the Board of Nursing to be delegated to certified nursing assistants<br>• Reimbursement rate: no less than $30/hr<br>• Provides Department and Board of Nursing with rulemaking authority<br>• Requires Department to issue report to the governor and legislature 3 years after implementation on the viability of the program |
| Maine | 2023 | HP 163 | Home health aide | • Directs Maine Dept of HHS to file a state plan amendment by 7/1/24 enabling qualifying parents of children and youth with in-home personal care needs eligible for MaineCare program to be reimbursed for providing home health aide services under the Medicaid home health benefit<br>• Department to promulgate rules to establish and implement the program |

## Additional Recommended Resources

- National Health Law Program – Paid Family Caregivers: State Options, Limitation, and Policy Considerations (2023)
- National Association of State Directors of Developmental Disability Services – Caring Families: Paying Family Caregivers Topic Brief (2023)
- Lucile Packard Foundation – Medicaid Paid Family Caregiving for Children (2023)
- National Academy for State Health Policy – State Approaches to Reimbursing Family Caregivers of Children and Youth with Special Health Care Needs Through Medicaid (2021)

# Endnotes

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[13] During the pandemic there were 14 states used 1135 waivers to allow personal care services to be provided by a legally responsible relative (AK, GA, IA, MD, MN, MT, ND, NH, NJ, NM, OK, OR, PA, VT). Likewise there were 39 states that used an Appendix K amendment to an existing 1915(c) waiver to temporarily permit payment for services rendered by family caregivers, including legally responsible relatives (AK, AL, AZ, CA, CO, CT, DC, DE, FL, GA, HI, ID, IL, IN, KS, LA, MD, ME, MN, MO, MS, MT, NC, ND, NH, NJ, NM, NV, OH, OK, PA, RI, SC, SD, UT, VA, VT, WI, WV). KFF. (2021). *Medicaid Emergency Authority Tracker: Approved State Actions to Address COVID-19*. KFF. https://www.kff.org/coronavirus-covid-19/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/

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[20] 42 CFR 440.167

[21] CMS, Preventing Medicaid Improper Payment for Personal Care Services.

[22] *"[P]ersonal care services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the [individuals with intellectual disabilities], or institution for mental disease that are (A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, (B) provided by an individual who is qualified to provide such service and* ***who is not a member of the individual's family****, and (C) furnished in a home or other location."* Social Security Act § 1905(a)(24)

[23] CMS, All-State Medicaid and CHIP Call, June 6, 2023.

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[25] Centers for Medicare and Medicaid Services. (2019). Application for a §1915(c) Home and Community-Based Services Waiver: Instructions, Technical Guide, and Review Criteria. https://wms-mmdl.cms.gov/WMS/help/35/Instructions_TechnicalGuide_V3.6.pdf

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[27] O'Malley Watts, M., Musumeci, M., Ahmula, M. (2022). *State Policy Choices About Medicad Home and Community-Based Services Amid the Pandemic*. KFF. https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-appendix/#table1

[28] States with 1915(c) waivers for medically fragile or technology dependent children: AK, CA, CO, CT, FL, IL, KS, MD, MN, NM, NY, NC, ND, OK, OR, SC, TX, UT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[29] Per KFF, as of 2022 there were 32 states that allowed legally responsible relatives to be paid providers for HCBS waiver services: AL, AK, AR, CO, DE, FL, HI, ID, IL, IN, KS, KY, ME, MD, MN, MO, MT, NH, NM, NC, ND, OH, OK, PA, SD, TN, UT, VT, VA, WV, WI, and WY. However, there were only 11 states that allowed legally responsible relatives to be paid providers for personal care state plan services: AK, AR, CA, ID, IN, IA, MN, MT, NJ, OR, and VT. O'Malley Watts, Musumeci, Ahmula, M, *State Policy Choices*.

[30] Of the 27 states that responded to the NASDDDS survey, the following states indicated that they allow payment of a legally responsible relative for the provision of personal care services: CT, CO, DC, GA, IA, LA, MD, MN, NM, OH, PA, WV. National Association of State Directors of Developmental Disability Services. (2023). *NASDDS Topic Brief: Caring Families: Paying Family Caregivers Topic Brief*. National Association of State Directors of Developmental Disability Services. https://www.nasddds.org/wp-content/uploads/2023/07/Caring-Families_final-0713.2023tss.pdf

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[32] Guth, M., Musumeci, M. (2021). *State Options to Expand Medicaid HCBS: Examples and Evaluations of Section 1115 Waivers*. KFF. https://www.kff.org/medicaid/issue-brief/state-options-to-expand-medicaid-hcbs-examples-evaluations-of-section-1115-waivers/

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[43] Edwards, *Paid Family Caregivers*.

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ANGELS OF CARE
PEDIATRIC HOME HEALTH

Committee on Human Services
June 9, 2026

Thank you, Chair Williams and Committee members, for the opportunity to provide testimony today in support of HB2164. My name is Michele Werner, and I serve as Regional Director of Regulatory and Government Affairs for Angels of Care (AOC) Pediatric Home Health. Angels of Care provides pediatric private duty nursing and aide services across the Commonwealth.

Before joining AOC in my current role, I served as Vice President of Operations for five years. Earlier in my career, I held nearly every role within a home care agency, including nurse, case manager, biller, and owner of my own company before selling it to AOC. Over the past 30 years, I have been involved in many grassroots projects and roll outs of new concepts. I have both witnessed and been a part of the evolution of home health care in Pennsylvania. HB2164 is the next step in that evolution. It is a necessary measure to address workforce shortages, reduce missed shifts, and provide the stability that patients and families need and deserve.

This bill will allow more families to participate in the Complex Care Assistant program by including medication administration and enteral feeds. Providers are already equipped to educate family caregivers and provide oversight to maintain regulatory compliance. What providers lack is the staffing needed to fully meet patients' prescribed plans of care.

Family caregivers are already delivering essential care to their loved ones every day. This legislation would allow providers to formally train them, supervise their work, and compensate them for a portion of the care they are already providing when staffing shortages prevent us from delivering all the services patients are entitled to.

Let's take the next step together and support HB2164. I am happy to answer any questions the committee may have.

Thank you for your time and consideration.

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**Pennsylvania House Human Services Committee**
**Informational Hearing on Complex Care Assistant Programs**

Testimony provided by Emily Katz, Executive Director of PAMCO

Tuesday, June 9, 2026

Majority Chairman Williams, Minority Chairman Heffley, and Members of the Committee:

Thank you for the opportunity to provide testimony on complex care assistant programs and services provided to medically fragile children in Pennsylvania's Medicaid program. Families caring for medically complex children face significant and ongoing challenges. Pennsylvania's policies should support those families while also ensuring that services are delivered consistently, appropriately, and in a manner that preserves access for those with the greatest clinical need.

Pennsylvania Medicaid Managed Care Organizations (PAMCO) represents the seven Physical HealthChoices Managed Care Organizations (MCOs) across the Commonwealth who contract with the Department of Human Services to deliver the Physical HealthChoices program.

In recent years, utilization and costs associated with pediatric shift care services in the HealthChoices program have increased substantially, all while membership in HealthChoices has decreased by over 700,000 members. Across PAMCO MCOs, these services have grown by approximately 410% between 2023 and 2025. This growth has coincided with several programmatic changes, including increased care provided by legally responsible relatives, the absence of standardized assessment tools, inconsistent use of Activities of Daily Living (ADL) criteria, and a lack of clearly defined medical necessity guidelines.

As a result, similarly situated children may receive significantly different authorization outcomes depending on how need is assessed and documented. Without a consistent statewide framework, determinations regarding hours of care and services can vary, creating both equity concerns and program integrity risks.

PAMCO believes these and complex caregiver programs under consideration can be strengthened through the implementation of clearer parameters and standardized criteria. Establishing a uniform assessment framework, including standardized, age-appropriate ADL criteria, would help ensure that service determinations are based on consistent clinical standards. In addition, implementing medical necessity review processes, such as a standard threshold for approved service hours that triggers additional documentation would support appropriate utilization while maintaining access to additional services when clinically indicated.

Other states have implemented similar utilization controls related to legally responsible relative services, including New Jersey, Texas, Colorado, California, Minnesota, and Washington. These efforts demonstrate that states can adopt parameters that promote appropriate use while continuing to support medically complex children and their families.

At the federal level, the Centers for Medicare & Medicaid Services (CMS) has recently taken steps to address program integrity concerns in home-based care by implementing temporary moratoria on certain home health providers in Medicare, citing concerns about high-risk categories associated with fraudulent activity. All state Medicaid programs, including Pennsylvania, are being asked to swiftly revalidate all home care providers. This underscores the importance of proactively addressing these recommendations for pediatric home care programs.

Given the current trajectory of utilization and the absence of standardized oversight mechanisms, further expansion of complex care assistant programs should be considered carefully. Until consistent assessment tools, ADL criteria, and medical necessity guidelines are established, programs should be limited to those currently in place.

Importantly, these recommendations are consistent with Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirements. EPSDT ensures that medically necessary services are available to eligible children; however, it does not preclude the use of standardized clinical review processes to determine appropriate levels of care. The goal is not to impose arbitrary limitations, but to ensure that services are clinically appropriate, consistently applied, and accessible to children with the most significant needs.

No medically fragile child should be denied medically necessary care. Strengthening assessment and review processes would help ensure that limited workforce capacity and program resources are directed to children with the highest levels of need.

PAMCO MCOs already maintain the clinical infrastructure, care management capabilities, and appeals processes necessary to administer these services effectively. Increased collaboration between PAMCO MCOs and the Department of Human Services presents an opportunity to establish consistent utilization parameters that promote medical necessity, fiscal responsibility, and program integrity.

We respectfully urge the Committee to support the Department of Human Services in adopting standardized assessment tools, consistent ADL criteria, and clear medical necessity guidelines as complex care assistant programs are considered.

Thank you for your time and consideration.

DAN WILLIAMS, MEMBER
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House of Representatives
COMMONWEALTH OF PENNSYLVANIA
HARRISBURG

COMMITTEES

HUMAN SERVICES, CHAIR

CAUCUSES

PENNSYLVANIA BLACK LEGISLATIVE CAUCUS
PENNSYLVANIA BLACK MATERNAL HEALTH CAUCUS
SOUTHEAST DELEGATION

# MEMORANDUM

**TO:** Members of the House Human Services Committee
**FROM:** Representative Dan Williams, Majority Chair, House Human Services Committee
**DATE:** June 4th, 2026
**RE:** House Human Services Committee Informational Meeting

The House Human Services Committee will hold an Informational Meeting on Tuesday, June 9th, at 9:30 AM in room B31 Main Capitol. The topic is Complex Care Assistant Programs.

Please contact Amanda Stockton (Astockton@pahouse.net) with any questions. If you are unable to attend this meeting, please submit a Leave Request Form to the appropriate Chair's office prior to the start of the meeting. Thank you.

DW/as