



State Strategies for Defining Medical Necessity for Children and Youth with Special Health Care Needs

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This brief captures key themes that emerged during a May 2015 teleconference of state EPSDT benefit coordinators and CHIP directors convened by the National Academy for State Health Policy (NASHP) with the support of the U.S. Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA)'s Alliance for Innovation on Maternal and Child Health (AIM).

Introduction

Medicaid programs nationwide are mandated to use the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit to improve the health of low-income children with special physical, emotional, and developmental health care needs. This benefit supports children and youth with special health care needs (CYSHCN) by ensuring they receive individualized health care when they need it—provided those services are deemed medically necessary for the individual beneficiary.¹ Determining the medical necessity of services under EPSDT can prove challenging for states.

The EPSDT benefit and the challenges surrounding its implementation are nothing new for states. In a recent survey and conference call, state EPSDT coordinators and CHIP directors shared their experiences navigating the definition of medical necessity for CYSHCN. The brief takes a fresh look at the current issues affecting the state EPSDT and CHIP officials who implement medical necessity policy, and looks ahead to new and emerging issues that may affect state EPSDT policy in years to come.

Key challenges faced by states in determining medical necessity under EPSDT:

- **Setting the Parameters for Medical Necessity**
- **Using Evidence to Define Medical Necessity**
- **Managing Medical Necessity and Managed Care**

Determining Medical Necessity

According to the Centers for Medicare and Medicaid Services (CMS), EPSDT is designed to “assure that individual children get the health care they need when they need it – the right care to the right child at the right time in the right setting.”² The federal statute requires the EPSDT benefit to cover “necessary health care, diagnostic services, treatment, and other measures...to correct or ameliorate defects along with physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the State plan.”³ This includes treatment for conditions discovered outside of an EPSDT screening visit. The “correct or ameliorate” standard also requires EPSDT to cover services beyond those considered medically necessary for

adult medicaid beneficiaries.⁴ The statute does not define “medical necessity” but rather describes a broad standard for coverage without providing a prescriptive formula for ascertaining necessity (see box on left).

Setting the Parameters for Medical Necessity

States can choose to establish parameters to guide their medical necessity decisions as long as those parameters are not more restrictive than the federal statute. States are crafting definitions, contracts, and internal processes to help apply medical necessity criteria consistently, and ensure children receive the individualized health care services they need, when they need them, in the most appropriate setting.

“While there is no federal definition of preventive medical necessity, federal amount, duration and scope rules require that coverage limits must be sufficient to ensure that the purpose of a benefit can be reasonably achieved. Since the purpose of EPSDT is to prevent the onset or worsening of disability and illness in children, the standard of coverage is necessarily broad.” – Federal EPSDT Coverage Policy: An Analysis of State Medicaid Plans and State Managed Care Contracts*

*Sara Rosenbaum & Colleen Sonosky, Federal EPSDT Coverage Policy: An Analysis of State Medicaid Plans and State Medicaid Managed Care Contracts (2002). Prepared for the Health Care Financing Administration (now CMS).

State Medicaid programs—and Medicaid managed care organizations (MCOs) that provide the benefits in some states—must determine on a case-by-case basis the medical necessity of treatments or services for the individual beneficiary. As states strive to ensure individual children receive the services that are medically necessary for them, states, as stewards of public funds, must also guard against covering services that may be available and considered helpful by providers and families, but are not medically necessary. If a service that is not specified in the state plan is requested for a child, states need a process to determine whether the service fits under one of the federally defined categories specified in Section 1905(a) of the Social Security Act—such as hospital, home health, and private duty nursing services—and if so, the process for determining medical necessity for the individual beneficiary.⁵ States that do not establish their own parameters for medical necessity default to the federal statutory requirements.⁶ States need to design an approach that works for them and helps balance the needs of children with finite funding limits.

While states need to take an approach that works for them, one health law expert shares some advice for states establishing their own parameters to guide their medical necessity decisions:

- Draw from the terms used in the federal statute. While there is no detailed federal standard of medical necessity, the term “early” modifies all the components of EPSDT services: screening, diagnosis, and treatment. When interpreting medical necessity challenges, courts have historically placed great emphasis on the terms “early” and “ameliorate.”
- Emphasize the clinical judgment of the health care professionals treating the individual child.⁷

Table 1. States Setting Their Own Guidelines

State	Medical Necessity Parameters
California	“A service is ‘medically necessary’ or a ‘medical necessity’ when it is reasonable and necessary to protect life, to prevent significant illness or significant disability, or to alleviate severe pain.” ⁸
Colorado	The state has an EPSDT-specific medical necessity definition that, among other provisions, requires a service to be “an equally effective treatment among other less conservative or more costly treatment options,” in order to be considered medically necessary. ⁹
Illinois	“Necessary medical care” under EPSDT is that which is “generally recognized as standard medical care required because of disease, disability, infirmity or impairment.” ¹⁰
Washington	The state Administrative Code defines as medically necessary those services which are “reasonably calculated to prevent, diagnose, correct, cure, alleviate or prevent worsening of conditions in the client that endanger life, or cause suffering or pain, or result in an illness or infirmity, or threaten to cause or aggravate a handicap, or cause physical deformity or malfunction.” ¹¹
Wyoming	State Rules and Regulations define a medically necessary service as one “that is required to diagnose, treat, cure or prevent illness, injury or disease which has been diagnosed or is reasonably suspected, to relieve pain or to improve and preserve health and be essential to life. The services must be: <ul style="list-style-type: none"> o Consistent with the diagnosis and treatment of the recipient’s condition o Recognized as the prevailing standard or current practice among the provider’s peer group o Required to meet the medical needs of the recipient and undertaken for reasons other than the convenience of the recipient and the provider; and o Provided in the most efficient manner and/or setting consistent with appropriate care required by the recipient’s condition.¹²

Medical Necessity and the Law

Setting parameters for determining what can be deemed medically necessary has, in some states, led to legal challenges by those who feel that the state parameters are more restrictive than the federal statute.¹³ These legal challenges — or the risk of legal challenges — may in some states impact the medical standard definition.

For instance, the **Tennessee** EPSDT program’s medical necessity standard was the subject of a lengthy legal challenge.¹⁴ However, Tennessee code now stipulates that the convenience of families or providers will not be considered in medical necessity determinations, and that medically necessary services must be the least costly options that are adequate for the patient.¹⁵

Some states have faced legal challenges over coverage of services for autism. Following such a challenge, one state went on to create a robust applied behavioral analysis (ABA) program with great success. Another state reported that it worked collaboratively with an advocacy group to develop a mutually agreeable set of medical necessity parameters, which may have helped forestall potential legal challenges. One state noted that sometimes the threat of litigation, or litigation in other states, is sufficient to prompt a state to cover certain services.

Correct and Ameliorate

An additional challenge for determining medical necessity arises from the federal statutory requirement to cover those services considered medically necessary “to correct or ameliorate” conditions.¹⁶ Services that “ameliorate” are generally those that make a condition more tolerable or improve or maintain a child’s overall health, even if they will not cure the child’s condition.¹⁷

Georgia and North Carolina both define “ameliorate” to mean “to improve or maintain” a child’s health “in the best condition possible, compensate for a health problem, prevent it from worsening, [or] prevent the development of additional health problems.”¹⁸

One national expert in health law and policy expects the definition of “ameliorate” in relation to children’s growth and development to remain an evolving issue for states implementing the EPSDT benefit in years to come. Under EPSDT, the concept of improving a condition is considered in the context of children’s growth and development, so coverage limits that might apply to adults—such as limits on services that avert the deterioration of function—would be different for children.¹⁹ States will continue to face this nuanced issue in coming years.

Out-of-State Treatment

Determining the medical necessity of services or procedures often involves deciding when out-of-state treatment is necessary. In some instances, out-of-state treatment may be routinely determined to be medically necessary, such as when a child lives near a state border, or requires emergency services while out-of-state. States must also approve out-of-state care if a medically necessary service is determined to not be available in the state. States use various strategies to help determine when and where out-of-state treatments are provided.

- Some states rely on large or teaching hospitals to determine whether specific services, such as transplants, are

available in the state. If a service is not available in-state, the hospitals make the recommendation for the best out-of-state facilities.

- In some states, MCOs have established contracts with out-of-state facilities to perform medically necessary transplant services.

Using Evidence to Define Medical Necessity

State EPSDT and CHIP programs strive to use research evidence, when available, to help determine whether services and diagnostic testing are medically necessary for children.²⁰ Finding the strong evidence to support the determination of medical necessity can be challenging for states. Some states cited multiple treatments and other services they believed were in need of further research. These treatments and services are listed in the box on the next page.

Several states expressed reluctance to provide diagnostic testing for conditions that, if identified, may not have evidence-informed treatment or services available to correct or ameliorate them. For example, as genetic testing in children becomes more commonplace to diagnose developmental and other conditions,²¹ some states struggle to determine whether or how certain testing would help determine the course of a child’s health care.

“When possible, adopt a clearly defined evidence based standard for service coverage. If you wish to cover a service that is not evidence based, then clearly define the criteria for coverage and the expected outcomes of the service.”— State Official

States draw on a number of resources to help determine whether the evidence supports the necessity of particular services. For example, some states use evidence vendors to review and compile the most recent evidence on the effectiveness of certain services, and grade them according to a rating system. States can draw on the evidence vendor’s report to make their own

determination about the medical necessity of that service for a particular child.

Some states use the recommendations of and receive support from professional organizations such as the American Academy of Pediatrics²² and the National Association of Medicaid Directors. Finally, states also look at norms for coverage in the private sector and examine whether commercial payers generally cover a treatment for children, and, if so, under what circumstances.

Even when evidence shows certain services to be effective for a particular condition, states may still struggle to determine their medical necessity for individual children. For instance, determining whether dental services, including surgery, are necessary or merely cosmetic can be challenging for states.



Some states use the American Academy of Pediatrics' policy statement for guidance in determining medical necessity.

*The pediatric definition of medical necessity should be as follows: health care interventions that are evidence based, evidence informed, or based on consensus advisory opinion and that are recommended by recognized health care professionals, such as the AAP, to promote optimal growth and development in a child and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.**

* American Academy of Pediatrics, "Essential Contractual Language for Medical Necessity in Children." Pediatrics, Vol. 132, No. 2, August 1, 2013. Available at <http://pediatrics.aappublications.org/content/132/2/398.full>

Research and Medical Necessity - EPSDT coordinators and CHIP directors provided examples of services and treatments in need of additional research on their effectiveness in order to support states' work in determining medical necessity:

- Adaptive equipment, such as standers and car seats
- Assistive devices
- Autism services such as applied behavior analysis (ABA)
- Behavioral health services
- Continuous glucose monitoring
- Donated human breast milk, or other services to promote breastfeeding
- Educational programs, such as vision therapy and early intervention for developmental delays or disabilities
- Habilitative and rehabilitative services
- Hormonal suppression therapy
- Medical foods and supplements
- Oral surgeries, such as implants to treat cleft palate
- Orthodontia
- Personal care services
- Psychological testing
- Therapeutic horseback riding

Managing Medical Necessity and Managed Care

While managing medical necessity in managed care is not a new challenge for states, as managed care grows in Medicaid and CHIP,²³ states will need to continue to develop strategies to engage MCOs in making appropriate medical necessity determinations and address the variations in medical necessity determinations across MCOs.

When states use MCOs in their Medicaid and CHIP programs, they retain the responsibility for ensuring that the services under EPSDT are available to eligible children. MCOs must make medical necessity determinations according to the guidelines set by the state, or, in states that have not established their own guidelines, according to the parameters set by federal statute. To ensure MCOs meet medical necessity standards, some states provide MCOs with policy guidance on how to apply EPSDT medical necessity guidelines, including instructions for making determinations on a case-by-case basis.

Some states also leverage the managed care contracting process to ensure that the state's expectations for medical necessity determinations are clear from the outset. At least two states included clauses in their Medicaid MCO contracts requiring the MCOs to use the state's definition of medical necessity when determining the coverage of services under EPSDT. States often have more than one MCO serving the EPSDT population, and embedding the same medical necessity definition in all the MCO contracts can help ensure consistency. In fact, a 2014 American Academy of Pediatrics study found that having a consistent standard of medical necessity across MCOs would also benefit providers and support them to "apply the standard more uniformly."²⁴

Managed care enrollees are entitled to an appeals process through their plan, and states can use the MCOs' appeals processes to ensure that medically necessary services are provided to eligible children.²⁵ Under one state's appeals

process, the contested service is automatically granted--unless it is medically contraindicated--in the event that the MCO does not respond to the appeal within the established timeframe. Another state—which has six MCOs using six different sets of rules for medical necessity—established a two-step re-determination process that enabled the beneficiary or family to appeal a decision and potentially override a denial. The state plans to use the information obtained through this process to improve the system overall.

"If the hospital says 'The child needs a service,' then the MCO also says, 'Ok, the child needs the service,' and they will take care of it. So we don't have a big fight with the MCOs regarding payment for EPSDT services that may be out of state."
 – State Official

Looking Ahead

The need to ensure the delivery of "the right care to the right child at the right time in the right setting" while adhering to a state's definition of medical necessity will remain a priority and at times a challenge for EPSDT coordinators, CHIP directors and others impacting an individual child's care.²⁶ Though states have put in place various strategies to address many of the issues related to defining medical necessity, policymakers still may need to address questions such as:

- Is there a need to align EPSDT requirements with other federal programs serving children, such as Head Start?
- Would states and children benefit from state and federal policymakers aligning EPSDT medical necessity standards consistently nationwide?
- Would detailed federal guidance identifying treatments and services that may generally be considered medically necessary help states consistently apply medical necessity standards and stave off legal challenges?

- Would such detailed federal guidance limit states' ability to determine medical necessity on a case-by-case basis for each beneficiary, or undermine states' efforts to meet the specific needs of its population?
- What kind of research agenda would support state officials in making evidence-based determinations of medical necessity for CYSHCN?

While states have been confronting medical necessity challenges for years, a national expert points to a few current pediatric-specific issues that state Medicaid agencies will continue to confront related to the EPSDT benefit:²⁷

- Managing and overseeing “soft” limits in a manner that is not too burdensome for state Medicaid programs, yet ensures that children receive the appropriate services may remain a challenge for states.²⁸ “Hard” limits—for example, on the number of covered therapist visits—are not permissible under EPSDT. “Soft” limits are permitted, and allow for adjustments in the quantity of services for individual children.
- Developing treatment guidelines that conform to the unique needs of pediatric care rather than adult care—for example, in the use of medicines—will remain an important issue for state EPSDT benefit programs going forward.

As new screening and treatment services are developed for children and youth with special health care needs, states—particularly state EPSDT and CHIP officials—can benefit from sharing lessons learned to safeguard the health of CYSHCN and ensure fair and consistent medical necessity determinations. State challenges with interpreting the medical necessity of preventive services under EPSDT may also provide valuable lessons for state Medicaid programs leveraging Affordable Care Act support for preventive services and vaccines.²⁹ By sharing lessons learned about the ongoing challenges of determining medical necessity, state officials can support one another in their efforts to ensure that the EPSDT program provides children with the right care at the right time in the right setting.

Endnotes:

1. EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSTD_Coverage_Guide.pdf. See also: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>
2. EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-and-Periodic-Screening-Diagnostic-and-Treatment.html>
3. See section 1905 (r)(5) of the Social Security Act: http://www.ssa.gov/OP_Home/ssact/title19/1905.htm
4. According to Medicaid.gov, “States establish and administer their own Medicaid programs and determine the type, amount, duration, and scope of services within broad federal guidelines. States are required to cover certain “mandatory benefits,” and can choose to provide other “optional benefits” through the Medicaid program.” <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/benefits/medicaid-benefits.html>.
5. See section 1905 (a) of the Social Security Act: http://www.ssa.gov/OP_Home/ssact/title19/1905.htm
6. See the “Medical Necessity” section of NASHP’s EPSDT Toolkit to see which states set their own parameters and which default to the federal statutory requirements: <http://www.nashp.org/medical-necessity/>
7. Sara Rosenbaum, personal communication, September 18, 2015.
8. California Code, Section 14059.5: http://leginfo.ca.gov/faces/codes_displaySection.xhtml?lawCode=WIC§ionNum=14059.5.
9. 10 CCR 2505-10 8.280.1: <http://www.sos.state.co.us/CCR/GenerateRulePdf.do?ruleVersionId=6239&fileName=10%20CCR%202505-10%208.200>
10. Illinois Administrative Code, Section 140.2: <http://www.ilga.gov/commission/jcar/admincode/089/089001400A00020R.html>

11. Washington Administrative Code, Section 182-500-0070 <http://apps.leg.wa.gov/wac/default.aspx?cite=182-500-0070>
12. Wyoming Rules and Regulations, Chapter 6: <http://soswy.state.wy.us/Rules/RULES/1526.pdf>
13. <http://scholarship.law.edu/cgi/viewcontent.cgi?article=1027&context=jchlp>. See also the July 2008 CHCS resource paper “EPSDT at 40,” which states that “A sizable body of federal case law, nearly all of it decided in favor of children, underscores the problems that can arise when states attempt to apply across-the-board treatment limitations, exclusions based on an allegation of the ‘experimental’ status of a proposed treatment, or other form of flat exclusion of certain types of health interventions that fall within the range of professional standards of care.” http://www.chcs.org/media/EPSDT_at_40.pdf
14. <http://kff.org/medicaid/issue-brief/tennessees-new-medically-necessary-standard-uncovering-the/>; <http://scholarship.law.edu/cgi/viewcontent.cgi?article=1027&context=jchlp>
15. Tennessee Code 71-5-144: https://www.lawserver.com/law/state/tennessee/tn-code/tennessee_code_71-5-144; see also <http://www.comptroller.tn.gov/repository/SA/pa14034b.pdf>
16. See section 1905 (r)(5) of the Social Security Act: http://www.ssa.gov/OP_Home/ssact/title19/1905.htm
17. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf.
18. Georgia Code, Section 49-4-169.1: <http://www.lexisnexis.com/hottopics/gacode/> ; North Carolina EPSDT policy: <http://www2.ncdhhs.gov/dma/epsdt/epsdtpolicyinstructions.pdf>
19. Sara Rosenbaum, personal communication, September 1, 2015.
20. Even before determining the evidence base for services, states must first determine whether the service fits under one of the federally defined categories specified in Section 1905(a) of the Social Security Act, which defines the term “medical assistance.” The categories of services include physical therapy, private duty nursing, hospital, home health, clinic, personal care, and dental services. The complete list is available here: http://www.ssa.gov/OP_Home/ssact/title19/1905.htm
21. <http://www.genome.gov/27527629>; <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2869000/>
22. AAP, Essential Contractual Language for Medical Necessity in Children, 2013. <http://pediatrics.aappublications.org/content/132/2/398.full.pdf>
23. Jee, J. “Medicaid Managed Care for Children and Youth with Special Health Care Needs,” NASHP: February 2014. Available at: <http://www.nashp.org/medicaid-managed-care-children-and-youth-special-health-care-needs/>
24. Markus, A.R., and K. D. West. “Defining and determining medical necessity in Medicaid managed care.” *Pediatrics*. 2014 Sep; 134(3): 516-22.
25. See Medicaid.gov: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf, p. 34. See also 42 CFR 438.402: <https://www.law.cornell.edu/cfr/text/42/438.402>
26. EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Downloads/EPSDT_Coverage_Guide.pdf.
27. Sara Rosenbaum, personal communication, September 1, 2015.
28. See also EPSDT – A Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents:.
29. See February 1, 2013 Dear State Medicaid Director letter: <http://www.medicaid.gov/Federal-Policy-Guidance/downloads/SMD-13-002.pdf>.

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