



Covering Pediatric Screenings Through Medicaid: Key Decision-Making Factors

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ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

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KEY TAKEAWAYS

- The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Medicaid benefit plays a crucial role in children’s health and well-being by requiring broad coverage of medically necessary preventive screenings for all Medicaid-eligible children and adolescents under 21.
- State Medicaid agencies make decisions on a periodicity schedule for pediatric screenings based on national guidelines, however, overall decision-making processes for screening coverage and implementation within and beyond EPSDT are often unclear to stakeholders and vary by state.
- Factors that influence state-level decisions to cover screenings through Medicaid include (1) EPSDT requirements; (2) existing expert guidance; (3) clinical benefits and potential harms; (4) alignment with state priorities and capacities; (5) fiscal impact; (6) access to testing, interventions, and treatment services; and (7) stakeholder input.
- States can facilitate opportunities for Medicaid stakeholders to help inform pediatric screening coverage decisions and ultimately improve child health and well-being by: (1) strengthening the clinical evidence base around child health screenings; (2) ensuring screenings are implemented equitably; and (3) leveraging partnerships to improve education and guidance on implementing screening-related best practices.

Introduction

Upstream prevention and early identification of diseases or conditions are powerful strategies to support children in reaching their optimal health and ensuring they can thrive as they grow. This is crucial for children from families with low-incomes that often face numerous health-related social needs and systemic barriers to health care access and utilization. Medicaid and the Children’s Health Insurance Program (CHIP) provide coverage to more than 35 million and 7 million children, respectively, in the United States.^{1,2} This includes almost half of all children with special health care needs, members of historically marginalized communities, and children younger in age than those covered by private insurance.³ Medicaid and CHIP also cover nearly 60 percent of Black and Latino children and are thus critical partners in efforts to promote health equity.⁴

Through the federally-mandated Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, Medicaid plays a crucial role in maintaining children’s health and well-being by covering medically necessary preventive screenings for all Medicaid-eligible children and adolescents under 21. However, overall decision-making processes for pediatric screening coverage and implementation within and beyond EPSDT are often unclear to stakeholders and vary by state.

This report can help child health stakeholders — including policymakers, health care providers, advocates, researchers, health plans, philanthropic organizations, community-based organizations, and family and community leaders — better understand opportunities and challenges associated with obtaining Medicaid approval of coverage for pediatric screenings. The report explores seven key factors that influence state-level decisions to cover screenings through Medicaid based on a literature review and key informant interviews with Medicaid program staff, health care providers, national advisory organizations, and researchers. It also offers recommendations for how states can facilitate opportunities for Medicaid stakeholders to help inform pediatric screening coverage decisions and ultimately improve child health and well-being by: (1) strengthening the clinical evidence base around child health screenings; (2) ensuring screenings are implemented equitably; and (3) leveraging partnerships to improve education and guidance on implementing screening-related best practices. While this report explores what it takes to obtain Medicaid coverage for pediatric screenings, many of the lessons are applicable to coverage for adult screenings as well.

Factors Influencing Medicaid Decision Making Around Screening

State Medicaid programs are federally required to cover children through age 18 in families with income up to at least 133 percent of the federal poverty level, although most states cover children in families with higher income levels.⁵ Medicaid agencies are also required to cover a set of mandatory services for children, including health-related screenings under the EPSDT benefit.⁶ Within federal requirements, state policymakers can set differing Medicaid eligibility levels, benefit coverage, and provider reimbursements, and can also use an array of waivers to operate Medicaid programs with further flexibilities to federal requirements.⁷ Most beneficiaries receive services through managed care organizations that are subject to state benefit requirements and have additional leeway to provide services beyond the scope of what is required (e.g., value-added services).⁸ All of these flexibilities result in substantial variation among states in Medicaid eligibility, covered benefits, and provider payment.⁹ Given this variability, stakeholders focused on child well-being must not only understand Medicaid at the federal level but also at the individual state level.

Medicaid agencies weigh a variety of factors and seek input from many sources when considering coverage of a new pediatric screening. Screening-coverage decisions impact what is included in newborn screening panels for a multitude of genetic conditions, as well as screenings at various ages related to physical, mental, developmental, dental, hearing, vision, and other health or health-related social needs (such as food and housing insecurity) to enable early detection and treatment or provide needed supports.¹⁰ While strategies vary by

state, Medicaid programs consider similar questions when deciding to cover pediatric screenings, including:

- **What is required under the EPSDT benefit?**
- **What expert guidance exists on recommended screening to add to existing coverage?**
- **What are the clinical benefits or potential harm of a proposed screening?**
- **Does adding a screening align with a state’s Medicaid priorities and capacities?**
- **What are the fiscal impacts of covering a screening?**
- **Is there adequate access to testing, interventions, or treatments?**
- **What input are stakeholders providing on screening coverage and how?**

This section walks through each of these questions to explore how Medicaid policymakers approach decisions related to covering screenings for children and adolescents — within and beyond the EPSDT benefit. Note that CHIP is authorized differently than Medicaid and the EPSDT benefit is not required to be provided in CHIP standalone programs.^{11,12}

What is required under the EPSDT benefit?

EPSDT is a required benefit for children and adolescents under age 21 who are covered by Medicaid.¹³ The EPSDT benefit is broad in nature and aims to identify and address health issues early in life to prevent more serious and costly health problems later. It covers comprehensive screening, diagnostic, and treatment services — including physical, behavioral, dental, hearing, and vision health services. Children and adolescents who receive EPSDT-required screenings have fewer hospitalizations, improved school performance, and overall better health outcomes compared to children who do not receive these screenings.¹⁴

EPSDT-required screenings are conducted on a regular basis, including at birth, periodically throughout childhood as part of regular well-child visits, and at times of increased risk. Screenings must be offered at intervals within a recommended periodicity schedule as part of well-child visits through age 21. Many states use the periodicity schedule and guidelines provided by Bright Futures, a program led by the American Academy of Pediatrics (AAP) and supported by the Maternal and Child Health Bureau, among others.¹⁵ Beyond the periodicity schedule, providers are required to conduct all appropriate and medically necessary EPSDT screenings to children and adolescents covered under Medicaid, regardless of whether or not the services are specifically requested by the child or their caregiver or covered by a Medicaid health plan.¹⁶

Under EPSDT, “medical necessity” screenings are not federally defined, but instead refer to a broad standard for coverage. While state definitions vary, medically necessary services are generally defined as those that promote better health by preventing, reducing the impact of,

or treating a condition.¹⁷ Additionally, medically necessary services are evaluated on a case-by-case basis.¹⁸ For example, a child experiencing hearing loss would be covered for diagnostic services (i.e., hearing screening) to determine needed medical equipment (e.g., hearing aids, cochlear implant) and services to monitor and treat their condition.¹⁹ Of note, beyond recommended screenings and services by national medical organizations, such as the AAP, states may use their own discretion to cover experimental or investigational services based on an individual child or adolescent's needs and available scientific evidence on services' effectiveness to address the individual's condition.²⁰

Overall, the EPSDT benefit is a critical component of Medicaid that helps ensure that children and adolescents have access to high-quality health care services. States determine their own decision-making processes to include specific screenings under the EPSDT periodicity schedule or to cover additional screenings to augment that benefit (detailed below). State Medicaid agencies can administer the benefit through fee-for-service or provide oversight to contracted private entities like managed care organizations to administer the benefit.

What expert guidance exists on recommended screenings to add to existing coverage?

Evidence-based guidance to recommend, incentivize, or require coverage of new screenings by Medicaid agencies can come at the federal or state government levels or from national independent advisory entities.

At the federal and national levels, the Centers for Medicare & Medicaid Services (CMS) releases Informational Bulletins (for example, CMS issued a bulletin after the water crisis in Flint, Michigan, detailing requirements for blood lead screening in young children enrolled in Medicaid) or State Medicaid Director letters to share changes to a program policy or operation, or communicate policies in a new regulation.^{21, 22} States also rely on the U.S. Department of Health and Human Services' (HHS) Recommended Uniform Screening Panel (RUSP) to inform decisions on newborn screening programs.²³ There are also independent advisory bodies at the national level that evaluate clinical and scientific evidence and provide guidance on the need for and appropriateness of screenings per age groups. These expert advisory panels include the U.S. Preventive Services Task Force (USPSTF) and the AAP's Bright Futures.

Federal- and National-Level Screening Recommendations

U.S. Department of Health and Human Services' Recommended

Uniform Screening Panel: RUSP guidelines include a comprehensive list of newborn screenings that the Secretary of HHS recommends all newborns receive to reduce infant mortality and morbidity. Screenings for selected conditions are included based on potential net benefit, capacity of states to implement a screening, and the existence and availability of effective treatment.²⁴ Any person or organization can nominate a condition they would like the RUSP to consider for screening recommendation.²⁵ Although the RUSP recommends states screen for all included conditions, Medicaid agencies and public health programs at the state level make decisions regarding added newborn screenings.²⁶ It can take, on average, five to six years for a state to add a screening to its newborn panel.²⁷ As of July 2022, 10 states passed RUSP alignment legislation to ensure that their state programs have streamlined processes for including newly added screenings recommended by RUSP.²⁸



U.S. Preventive Services Task Force: The USPSTF is an independent volunteer panel of experts in prevention and evidence-based medicine that assesses the scientific evidence and makes recommendations on preventive services, including screenings.²⁹ Any person or organization can nominate a service or screening for recommendation or request the update of an existing one.³⁰ When evaluating recommendations, USPSTF follows a rigorous and transparent process to assess the benefits and harms of specific preventive services and their effectiveness.³¹ In evaluating recommendations related to child health, USPSTF considers several important issues, including: (1) the service's ability to keep children on the most advantageous developmental trajectory; (2) family and caregiver influence on child health decisions; and (3) the strength of clinical evidence.³² USPSTF assigns letter grades to its recommendations, ranging from "A" (strongly recommended) to "D" (not recommended), along with an "I" grade (insufficient evidence). Medicaid is required to cover USPSTF-recommended services that receive a grade of "A" or "B."³³

American Academy of Pediatrics' Bright Futures: Bright Futures is a comprehensive set of guidelines and recommendations developed by AAP for pediatric preventive care. It provides guidance on the types and periodicity of health care services that infants, children, and adolescents should receive to best promote their health and well-being. Collection and testing of newborn blood for universal newborn screening, according to the RUSP, as well as follow-up services, are included under Bright Futures' recommended periodicity schedule.³⁴ A 2018 analysis identified 37 states as using Bright Futures for their EPSDT pediatric preventive care screening recommendations, with an additional eight states' periodicity schedules being comparable to Bright Futures.³⁵

At the state level, legislatures can create advisory bodies to make recommendations on screening tests to cover screenings beyond what is federally required. Maryland, for example, recently passed a legislative bill creating a rare-disease advisory council to address the needs of patients with rare diseases and recommend improvements to the state’s Newborn Screening Program.³⁶ States can also change which screening tests are covered by Medicaid through administrative rulemaking instead of legislation.³⁷ Other state agencies can be involved as well. For example, in Louisiana, the state’s department of health determines the list of genetic or other congenital conditions that can be tested, with the list reviewed regularly by the state health officer and departmental genetic disease advisory experts.³⁸

For information on what vehicles states provide the public to nominate a screening for inclusion as a Medicaid-covered benefit, see the section, ***What input are stakeholders providing on screening coverage and how?***

What are the clinical benefits or potential harm of a proposed screening?

When considering the addition of a new pediatric screening, state Medicaid agencies often start with recommendations from the national advisory bodies mentioned earlier and supplement their decision with additional review of clinical and scientific evidence (including clinical trials) to determine the positive and potentially negative impacts of a screening test on children’s health outcomes.

While the process varies by state, decision makers have evaluation processes to determine whether a screening test should be covered by their Medicaid program. Many states, Massachusetts for example, use coverage committees that work across agencies to evaluate whether new tests, treatments, and other services recommended by stakeholders should be covered. Interviews with Medicaid staff involved in these processes highlighted criteria that targeted whether proposed services: (1) are sensitive and specific in identifying the conditions they are designed to detect, with minimal false positives and negatives;^{*} (2) effectively detect the early signs of a disease or prevents it; (3) are age and population appropriate; (4) have the potential to prevent future health complications and benefit the trajectory and management of a condition or illness, or improve outcomes through early diagnosis; (5) do not pose any significant risks or adverse effects on a child’s physical health or development; (6) do not lead

^{*} “Sensitivity” refers to a test’s ability to accurately identify individuals with a disease as positive, while specificity refers to the ability of the test to correctly designate those without the disease as negative. J. Schreffler and M.R. Huecker. *Diagnostic Testing Accuracy: Sensitivity, Specificity, Predictive Values and Likelihood Ratios*. StatPearls, March 2023. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK557491/>. The terms “positive predictive value” (the probability that those with positive test results have the tested condition) and “negative predictive value” (the probability that those with negative test results reliably do not have the tested condition) are also commonly used.

to unintentional significant psychological or mental health consequences for the child or their caregiver; (7) help address the health-related social needs and family-specified concerns of children and their families; and (8) are not unnecessarily duplicative of other covered services, among other considerations.

While state Medicaid programs might be more likely to cover screenings where a positive result leads to a direct treatment or cure, some screenings for conditions with no cure, like cystic fibrosis, can still be covered when early detection and intervention may lead to improved health outcomes and quality of life. Medicaid programs, however, sometimes grapple with these decisions to approve effective screenings. For examples, some screenings for diseases or conditions with no cure or effective treatments can cause psychological harm to children and caregivers when results are inconclusive, the onset of symptoms can be delayed, the development of the disease is not certain, or there is insufficient treatment guidance or counseling to deal with a difficult or uncertain diagnosis.³⁹ Under these circumstances, states can rely on varied stakeholders to provide input and recommendations to understand how the screening may positively impact the experience and/or outcomes for individuals who receive it. Stakeholders can also engage in this work by participating in or supporting clinical research, or by becoming advocates for screenings, screening counseling, or educational outreach.

The Need for a Preponderance of Clinical Evidence in Pediatrics

Although clinical trials are often the gold standard of evidence to inform clinical practice, as well as Medicaid coverage decisions, additional research might be considered to make the case for a pediatric screening depending on study design and rigor (e.g., sample size, recruitment, outcome measures, confounding factors).⁴⁰ There are many challenges in clinical pediatric research since initiating and conducting trials in pediatric populations is more difficult than in adults due to multifaceted ethical barriers, overall low burden of disease, market incentives that favor adult-focused research, and lack of pediatric state and federal funding.^{41, 42, 43} Even when trials are conducted, results are not always publicly available, despite the requirement that trials be prospectively registered on ClinicalTrials.gov and results of FDA-regulated or NIH-funded interventional trials be made available within 12 months of primary study completion.⁴⁴



Does adding a screening align with a state's Medicaid priorities and capacities?

When considering whether to cover new pediatric screening, state Medicaid agencies have to balance state and federal legal requirements, budget constraints, provider workforce and lab testing capacities, stakeholder input, and other state-specific needs. States also have unique public health considerations, demographics, and a prevalence of certain conditions and health disparities that lead to different priorities based on local needs. Screening prioritization by Medicaid agencies typically involves careful analysis, data-driven decision making, and a collaborative approach to identify services and interventions that will have the most significant impact on improving health outcomes for individuals enrolled in Medicaid, including children. State leadership input can include the governor's office or state legislators who may task a state Medicaid agency to prioritize investment in specific screening strategies during their tenure.

What are the fiscal impacts of covering a screening?

State Medicaid programs continuously grapple with maintaining a manageable budget that enables them to run their programs in a fiscally responsible manner while providing services in the best interest of beneficiaries. Since almost all states are subject to balanced budget requirements in each budget cycle, and Medicaid is the second largest category in many state budgets, agencies often face enhanced scrutiny from legislators to ensure funds are being used appropriately.^{45,46}

When states consider a new service, including screenings, they look to the potential cost and benefit of coverage and implementation. They often develop a fiscal impact statement to estimate how the proposed policy change will impact revenue and expenditures for the program.⁴⁷ Services that can demonstrably lead to both short- and long-term returns on investment are more likely to be approved by decision makers. By comparing the costs of preventive interventions with the benefits of those interventions, cost-benefit analyses allow states to better determine what kinds of investments have the greatest potential to positively impact children and adolescents in a fiscally responsible manner.

The decision-making process also includes the setting of provider reimbursement rates and covering the services under fee-for-service or value-based payment options. Setting adequate reimbursement rates and opting for value-based payments can help incentivize improvements in screening rates and prioritize prevention and other services that can lead to better health outcomes across the life span.⁴⁸

Medicaid Benefit Flexibilities: Actions States Can Take to Add a Screening

States operate their Medicaid programs within federal standards, but flexibilities allow states to design their programs to meet state-specific priorities. Federal standards outline minimum Medicaid benefits, including screenings, for children through EPSDT. Beyond EPSDT, states can cover additional services for children through **Medicaid waivers**



and/or **managed care organizations** (see below). After deciding under which federal authority or administrative vehicle to provide a screening, states may need to get legislative approval, ask for public comments, and get formal approval from CMS. This lengthy policymaking process means that changes in Medicaid benefits can take years to be put in place.⁴⁹

- **Medicaid Waivers:** Waiver authorities allow Medicaid programs to gain programmatic flexibility to federal requirements, which involves the federal government “waiving” specific rules to allow for expanded services and/or eligibility to better serve specific populations.⁵⁰ For example, Louisiana’s Children’s Choice Waiver is designed to support medical care, caregiving, home modifications, and additional services for children with developmental disabilities.⁵¹ It includes specialty services such as aquatic therapy, sensory integration, specialized medical equipment, and environmental accessibility adaptations that would otherwise be assessed on a case-by-case basis through EPSDT.⁵²
- **Managed Care Organizations:** States with Medicaid managed care programs have additional leeway to provide services beyond the scope of what is federally required through managed care organizations.⁵³ These health plans may offer value-added services that go beyond the standard benefit package to improve quality and health outcomes, and/or reduce costs.⁵⁴ Examples of value-added services can include but are not limited to: (1) assessing home environment for environmental concerns (e.g., lead, mold); (2) gift card incentives for families completing specific well-child screenings; and (3) access to disease and lifestyle management programs.⁵⁵ Managed care organizations may also cover “in-lieu-of” services, which are cost-effective, medically appropriate substitutes for existing approved services.⁵⁶ This may involve coverage of an approved service (e.g., nutrition counseling) in an alternative setting (e.g., fitness center) or by a non-traditional provider (e.g., personal trainer).⁵⁷

Is there adequate access to testing, interventions, or treatment?

Medicaid programs interested in covering new screenings need to ensure that their beneficiaries can access testing services, as well as any follow-up interventions and treatments. Access to care relies on an adequate network of providers who are trained to assess the need for and the delivery of the screenings and services in a timely manner. Specialized training may be needed to ensure that providers have the skills to evaluate a child's progress, identify areas of concern, and make informed decisions regarding referrals for further evaluation or intervention. Additional access considerations may include the availability and geographic distribution of pediatricians, screening specialists, and laboratory testing sites, as well as follow-up intervention and treatment services for children.

Anticipatory guidance also needs to be developed and disseminated to inform families on available screenings. State AAP chapters, like Ohio's AAP Chapter through their Lead-Free initiative, can help disseminate information and training on recommended screenings.⁵⁸ Tools like well-child visit planners, including the one from the Child & Adolescent Health Measurement Initiative, are useful for families in advance of health care provider appointments to get information on developmental milestones and important screenings, and to help families get their questions answered and their needs met as part of a continuous cycle of engagement with providers.⁵⁹

Another consideration is the ability of providers to incorporate newly added screenings during well-child visits. Pediatricians deliver an array of services during these visits, but they are often challenged to appropriately manage their time and resources to fulfill the delivery of all medically necessary services.⁶⁰ Even when a service is recommended or required through EPSDT, it does not guarantee that a child will receive it — approximately half of all Medicaid beneficiaries under age 21 do not receive recommended EPSDT screenings and services.⁶¹

What input are stakeholders providing and how?

By soliciting input from a diverse range of stakeholders — including beneficiaries and providers who may be affected by a decision to add a screening, as well as clinical experts — state Medicaid programs can ensure that they make informed decisions about whether to cover and how to implement a new service.

State Medicaid agencies and managed care organizations often use advisory committees as a mechanism to solicit input on what types of services may benefit Medicaid beneficiaries. Currently, every state is required to operate a singular Medicaid Care Advisory Committee (MCAC) that convenes various Medicaid stakeholders, including beneficiaries, to provide feedback and input to the state.⁶² A recently proposed CMS regulation would require states to

form beneficiary advisory groups, comprised of individuals with lived experience in Medicaid, that will be tasked to provide feedback to the state Medicaid agency and participate in the state’s Medicaid Advisory Committee (or MAC, currently known as MCAC).⁶³ In addition to beneficiary advisory group members, MACs would include representation from other interested stakeholders, such as community-based organizations, providers, managed care organizations, and other state agencies.⁶⁴ CMS’ prioritization of input from a diverse set of stakeholders offers the potential to positively influence Medicaid decision making, including for pediatric screenings.

Providers and provider groups, including state AAP chapters, are key stakeholders that are engaged on these issues. Additionally, some state Medicaid agencies have developed collaboration mechanisms for connecting directly with providers through regularly scheduled pediatric Medicaid-provider meetings where practitioners and Medicaid staff collaborate to understand challenges providers face when caring for Medicaid members. For example, Colorado’s Children’s Services Steering Committee, the state’s EPSDT advisory group, which includes providers, state partners (e.g., public health), and parents, offers an additional avenue for stakeholders seeking to improve child health and well-being to advise Medicaid on issues related to children’s services.⁶⁵ The group can bring coverage options for the Medicaid agency’s consideration. Parents and caregivers are key stakeholders that can also engage policymakers through other committees focused on special pediatric populations, such as Colorado’s Children’s Disabilities Advisory Committee, which makes recommendations to the state’s Medicaid agency on issues impacting children and youth with disabilities, including access to preventive and screening services.⁶⁶

Community Stakeholders Can Look to Influence Policymaking

In Ohio, the Lead Safe Cleveland Coalition is a public-private partnership with 200 members that focuses on advancing holistic, sustainable, and preventive solutions to lead poisoning in Cleveland. Strategies include lead exposure prevention, screening, treatment, intervention, as well as education and outreach. The Coalition seeks to propose legislative recommendations and to advocate for more resources at the state and federal levels, including that children who are at high-risk, or live in at-risk communities, receive yearly lead screenings. Children covered by Medicaid in Ohio are at higher risk of lead exposure, and while Ohio law requires blood lead test at one and two years of age for this population, only half of children meeting the criteria get tested.



Stakeholders — including patient advocates, providers, and other interested parties — often engage state legislators directly to request the addition of benefits, but state Medicaid programs may set up additional avenues for stakeholders to nominate new benefits for consideration, although the mechanism to do this is often unclear to the public and varies by state.

Stakeholders can contact state Medicaid officials to learn about specific input or nomination processes in their state. For example, Texas solicits this information via a public nomination form (*summarized in the table below*) available online. The form requests information on: (1) the policy request; (2) procedure, treatment, or device information; (3) effectiveness; (4) safety; (5) cost; and (6) coverage.⁶⁷

State Medicaid decision makers look to the totality and strength of evidence before making a recommendation for new preventive care screenings and services. In the absence of studies and recommendations that answer experts’ questions regarding the validity and reliability of results for their members, Medicaid decision makers may be unable to move forward with including a screening as a covered service, regardless of stakeholder input.

Medicaid Coverage Nomination Form Example: Texas Health and Human Services⁶⁸

CATEGORY	SUMMARY OF REQUESTED INFORMATION
Policy Request	<ul style="list-style-type: none"> • Policy request or concern
Procedure, Treatment, or Device Information	<ul style="list-style-type: none"> • Brief description • Current alternatives • Patient populations • Desired and/or expected outcome(s) • Settings in which to be used • Types of providers to deliver • Reimburse if remotely delivered?
Effectiveness	<ul style="list-style-type: none"> • Potential effectiveness for the indicated condition • Comparison to alternatives • Potential to improve the health of the Medicaid population
Safety	<ul style="list-style-type: none"> • Potential harm(s) or other safety concern(s) • Likelihood and severity of potential harm(s) • Potential harm(s) compared with alternative for indicated condition
Cost	<ul style="list-style-type: none"> • Cost • Cost compared to alternatives for indicated condition • Examples of cost savings, increases, offsets, or avoidances
Coverage	<ul style="list-style-type: none"> • Private insurers that currently reimburse (if known) • CMS or local coverage determinations and date issued • Food and Drug Administration approved?

Opportunities to Positively Impact the Decision-Making Process

There are opportunities for stakeholders — including policymakers, providers, advocates, researchers, health plans, philanthropic organizations, community-based organizations, and family and community leaders — to positively impact decision-making processes around pediatric screening, especially around: (1) strengthening the clinical evidence base; (2) implementing screenings in an equitable manner; and (3) leveraging partnerships to increase screening education and access.

Build Upon Existing Clinical Evidence

Medicaid beneficiaries are underrepresented in clinical trials but efforts to develop new screenings for pediatric conditions can be challenged by limited participation of children for many pediatric chronic conditions, such as type 1 diabetes.^{69,70} To increase participation, Medicaid and commercial payers can cover routine clinical trial participation costs, including fees associated with physician visits, hospital stays, diagnostic tests, and other standard clinical services. Yet, in 2020, only 16 state Medicaid programs mandated coverage for participation costs in clinical trials.⁷¹ Recently, in 2022, the Clinical Trial Act expanded this right to Medicaid beneficiaries.⁷² In light of the Clinical Trial Act, researchers are well positioned to improve the rate of participation in clinical trials for children covered by Medicaid.

Federal guidance requires Medicaid to cover clinical trial participation costs, but each state is left to develop their own expectations and standards. Stakeholders could benefit from understanding their state's policies in this area, providing feedback (e.g., through advisory committees, town halls, surveys, online forms), and further identifying opportunities for partnering with Medicaid agencies and Medicaid managed care organizations to encourage clinical trial participation through a variety of mechanisms, including: (1) leveraging Medicaid's nonemergency medical transportation benefit for facilitating transportation to and from study sites; (2) investing in care coordination and navigation programs to assist children in gaining entry to trials; and (3) establishing standardized data collection and reporting to monitor the level of participation by Medicaid beneficiaries, particularly for Black, Latino, Indigenous, and other people of color enrolled in Medicaid.⁷³ When studies are completed, ensuring that trial results are shared through peer-reviewed and open-access publications, data depositories, and registries can help support evidence-based decision making. When new evidence is available, stakeholders can uplift findings to experts who can issue recommendations at the state and federal level (e.g., USPSTF, RUSP, state-specific nomination processes).

Implement Screenings Equitably to Decrease Health Disparities

Child health stakeholders can work with Medicaid agencies to develop quality improvement initiatives that focus on increasing screening rates and improving the overall quality of care provided under EPSDT for marginalized populations. Medicaid managed care organizations, for example, can support access to screenings by removing potential access barriers that may impact specific populations, including children living in rural areas who are more likely to live further away from a primary care site compared to those living in urban areas.⁷⁴ To decrease disparities in care access and screening rates in underserved areas, Medicaid programs — in partnership with managed care organizations and community-based partners, among other partners — can maximize access to non-traditional and integrative settings for screenings through telehealth or school-based services.⁷⁵ Medicaid providers can also be incentivized to practice in underserved rural or high-poverty communities through financial supports and enhanced payment models.⁷⁶

Stakeholders can additionally encourage the uptake of evidence-based models to ensure children receive support aligned with their needs in a more equitable manner. For instance, ZERO TO THREE's HealthySteps program offers a structured model for providers to better support the development of young children and has been shown to improve outcomes in areas where there are persistent inequities for communities of color and those with lower incomes.⁷⁷ HealthySteps helps primary care practices to operationalize Bright Futures guidelines through the use of a team-based care model that focuses on supporting providers' ability to promote healthy development as well as offer timely screening and referrals.⁷⁸ Children who receive HealthySteps are eight times more likely to receive a developmental assessment and have significantly higher rates of developmental and other nonmedical referrals.^{79,80,81}

Leverage Partnerships to Improve Screening Education, Access, and Effective Implementation

Stakeholders can also partner with state Medicaid agencies to advance screening efforts and to ensure newly added screenings are smoothly implemented through several levers, including: (1) guidance on advocacy and policy development; (2) demonstration of peer-reviewed evidence-based research; (3) development of comprehensive screening guidelines; (4) needs assessments to understand barriers to implementing screenings; (5) plan-do-study-act cycles to optimize clinic workflows when incorporating new screenings; (6) funding for adequate screening education and awareness, including anticipatory guidance; (7) provider education and training; and (8) community engagement efforts. For example, provider organizations, including state AAP chapters, the American Academy of Family Physicians, and

nurse associations can partner with Medicaid agencies to offer education and training programs to health care providers. This can help ensure that providers are aware of the importance of new and existing screenings under EPSDT and have the skills to implement them effectively and do referrals as needed.

Using Learning Collaboratives to Focus on Increasing Screening Rates

The Idaho AAP Chapter set up learning collaboratives with Idaho’s Medicaid program to identify strategies to implement Bright Futures Guidelines more effectively. One learning collaborative targeted increasing pediatric asthma screening in partnership with eight Medicaid-enrolled pediatric practices.⁸² Through this effort, the percentage of asthma patients with asthma severity that was newly identified and classified increased from 48 to 80 percent and the number of patients with an asthma action plan to treat asthma increased from 18 to 57 percent.⁸³ The chapter continued similar work through a second collaborative for adolescent depression screening. There were significant improvements in screening usage, with the percentage of providers using an evidence-based tool for adolescent depression screening increasing from two to 50 percent, while the use of a screening tool for substance abuse increased from 18 to 58 percent.^{84,85}



Managed care organizations can encourage the use of EPSDT and well-child visit services by reimbursing for value-added services. Value-added services are additional services outside of the Medicaid benefit package that seek to improve quality and health outcomes, and/or reduce costs by decreasing the need for more expensive care.⁸⁶ For example, West Virginia’s UniCare offers incentives to patients and their families for engaging in good health care practices, including: \$25 for completion of six well-baby visits by 15 months; \$25 for completion of lead screening for members ages zero to two years of age; and \$24 for the completion of yearly wellness exams for members ages three to 21.⁸⁷

Stakeholders can also collaborate with Medicaid agencies to engage communities and raise awareness about the importance of services, including screenings, under EPSDT. This can involve organizing community events, distributing educational materials, and partnering with community-based organizations to reach underserved populations. Additionally, managed care organizations can use cost-effective, medically appropriate in-lieu-of services to cover approved screenings in alternative settings and/or by non-traditional provider-types to increase patient access and utilization.⁸⁸

Partnering with Stakeholders to Create Toolkits and Trainings that Improve Screening Education

California’s Department of Health Care Services (DHCS) recently partnered with providers, health plans, advocates, and Medicaid-enrolled children and families, to launch the Medi-Cal (California’s Medicaid program) outreach and education toolkit.^{89, 90} The effort aims to improve member understanding of how Medi-Cal covers children and its role in EPSDT, and to increase coordination of EPSDT services with child-serving stakeholders — including managed care plans, providers, state agencies, local government entities, and community advocates.⁹¹ The toolkit includes child- and teen-focused brochures that describe EPSDT and covered services, how to access services, and the importance of preventive care. Managed care organizations are required to publish these materials online and mail them to new members upon enrollment, as well as to existing members.⁹² DHCS sought consumer feedback in creating the brochures to develop clear messages and identify any language barriers, image concerns, or other issues.⁹³ DHCS also developed standardized trainings for EPSDT providers that Medi-Cal managed care organizations are required to conduct bi-annually beginning in 2024.⁹⁴



Conclusion

States have to follow some federal requirements but have a lot of state-level flexibility when determining which services to cover through their Medicaid programs to help ensure that children have access to high-quality preventive health care screenings and services. Medicaid stakeholders — including policymakers, health care providers, advocates, researchers, health plans, philanthropic organizations, community-based organizations, and family and community leaders — can offer invaluable input to help state Medicaid agencies determine which screenings to cover for children. While the process to adopt new pediatric screenings varies by state, there are many factors that Medicaid programs may look to as a part of the decision-making process. In tandem, there are clear opportunities for stakeholders to be part of the process.

By demystifying this decision-making process, this report aims to facilitate opportunities for Medicaid stakeholders to help inform Medicaid pediatric screening decisions. By working together, stakeholders and Medicaid leaders can identify opportunities to not only enhance access and utilization of pediatric screenings, but also to improve access to treatments, therapies, and supports that can promote greater health and well-being for children.

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