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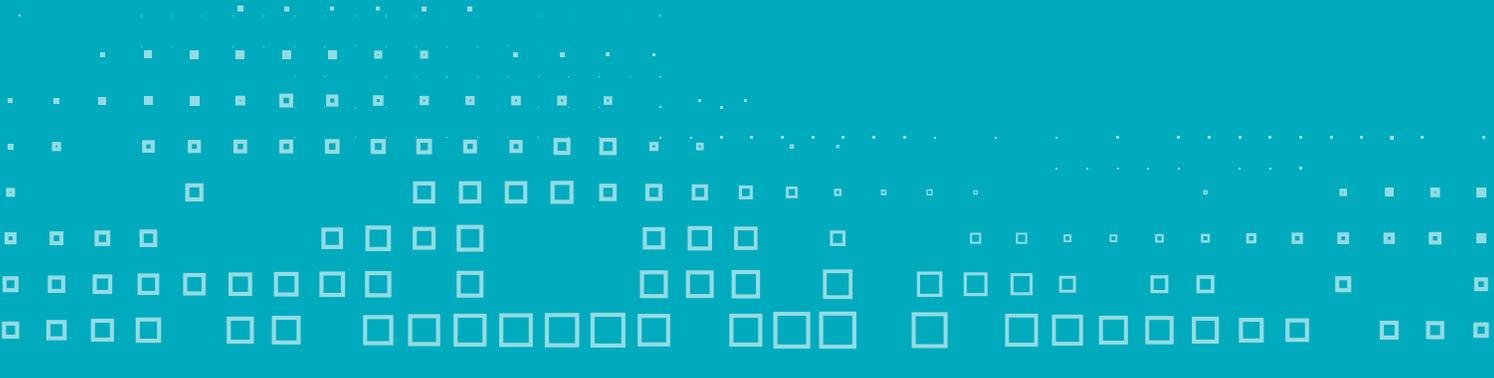
Keeping Medicaid's Promise: Strengthening Access to Services for Children with Special Healthcare Needs

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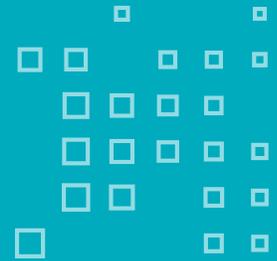


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Introduction

Nearly half of all children with special healthcare needs in the United States, including those with significant chronic and complex conditions, are insured through the Medicaid program. Medicaid promises children a comprehensive set of benefits that is designed to meet the needs of all children, including those with special healthcare needs, but implementation sometimes falls short. To support efforts by states, pediatric healthcare providers, families and children's advocates to ensure that children receive the care and treatment they need, this issue brief offers a checklist of best practices that can help states fulfill Medicaid's obligations to all the children it covers.

Federal Medicaid law recognizes the unique needs of children by requiring the delivery of comprehensive pediatric healthcare services to all Medicaid-enrolled children and youth under the age of 21 through provisions in the law known as Early and Periodic Screening, Diagnostic, and Treatment (EPSDT).¹ Coverage requirements for children under Medicaid are more robust than those that apply to Medicaid-enrolled adults. With a particular focus on prevention and early detection as well as a broad mandate related to treatment, the objective—and legal requirement—is for children to get the healthcare they need when they need it: the right child at the right time in the right setting.² The scope of services offered to children under Medicaid is important for all children's health, but particularly for children with special healthcare needs, whose needs are substantial.

Children with special healthcare needs are those who have, or are at increased risk of having, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that usually required by children generally.³ About 13.3 million children, or 18 percent of all children in the United States, have special healthcare needs.⁴ Medicaid plays an outsized role for this group of particularly vulnerable children, covering about half of all children in the United States with special healthcare needs.^{5,6} Children with special healthcare needs use both inpatient and outpatient medical services at much higher rates than the general pediatric population does, and their health-related social needs can be significant. Just under half of Medicaid/Children's Health Insurance Program (CHIP)-enrolled children with special healthcare needs live in families with incomes below the federal poverty level (FPL) (less than \$21,330 for a family of three as of 2019) while three-quarters of Medicaid/CHIP-enrolled children with special healthcare needs live in families with incomes below 200 percent of the FPL (less than \$42,660 for a family of three as of 2019).⁷

The EPSDT guarantee for all children enrolled in Medicaid has had a substantial positive impact on children with special healthcare needs, helping millions of children receive critically important care and services. At the same time, children with complex health needs and their families can also face challenges when seeking to access services. Not being able to receive services to which children are entitled can have a detrimental impact on their physical and behavioral health, and their opportunity to grow and develop to their full potential. Service delays and denials also create unnecessary challenges for their families.

This issue brief offers a comprehensive checklist of best practice strategies that state Medicaid agencies can implement—and many have already implemented—to improve access to services and healthcare for Medicaid-enrolled children with special healthcare needs and to sustain those improvements over time

through more effective monitoring, oversight, and collaboration with families and pediatric care teams. The checklist was developed based on a review of the literature, including the Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0⁸; an analysis of the federal requirements; interviews with family members of children with special healthcare needs, other national experts and state Medicaid agency leadership; an analysis of state data (see Tables 1 and 2 in Appendix 1); and a review of state regulations, State Plans, provider manuals and training materials, and Medicaid managed care contracts across several states.

There is no single solution to ensure that every child can access needed services. The specific access issues vary across states and sometimes within states, and evolve in each state depending on new policies and a changing healthcare landscape. However, taken together, this suite of recommended strategies can address the more common access barriers while creating the systems and accountability needed to ensure that children with special healthcare needs receive the care they need on an ongoing basis.

The Unique Needs of Children With Special Healthcare Needs

Children with special healthcare needs have a range of medical and behavioral needs, including those related to chronic asthma, autism, behavioral health and complex medical conditions. In addition to using inpatient and outpatient medical services much more frequently than the general pediatric population does, children with special healthcare needs often require other types of healthcare services and supports, such as habilitative services and home nursing services. Nineteen percent of families with a child with special healthcare needs reported at least one unmet need (e.g., preventive care, specialist care or prescription



drugs); this number increased to 44 percent when the child was medically complex.⁹ Additionally, either because of their families' low income or the financial strain that special healthcare needs can have on the entire family, children with special healthcare needs and their families often have significant social and economic needs related to housing, transportation and barriers to accessing social services.

Historically, states excluded children with special healthcare needs from enrollment in Medicaid managed care and instead delivered their services through a fee-for-service system. But in recent years, more states have enrolled individuals with complex needs, including children with special healthcare needs, into managed care to better coordinate care and control costs. As of June 2017, all 39 states with risk-based Medicaid managed care enroll at least some children with special healthcare needs in mainstream managed

care plans.¹⁰ Some states have also developed specialty Medicaid managed care plans targeted to a subset of high-needs children, such as children in foster care or children with disabilities. States must maintain EPSDT's guarantee of providing preventive care as well as all medically necessary services regardless of whether children with special healthcare needs are enrolled in Medicaid managed care or receive some or all of their services through a fee-for-service system.

Medicaid's Commitment to Children

More than 50 years ago, Congress established federal parameters in the Medicaid program to ensure access to a comprehensive set of services designed to meet a child's health and developmental needs. The Medicaid requirements for preventive care ("screenings"), the definition of medical necessity and the coverage requirements are unique to children.

- Early identification of health needs is promoted through the requirement of regularly scheduled comprehensive health and developmental screenings; appropriate vision and hearing testing, immunizations and laboratory tests; dental screenings; and diagnostic services.¹²
- Under EPSDT, every state must provide all "medically necessary services" that could be covered within the categories of mandatory and optional Medicaid services listed in Section 1905(a) of the Social Security Act, regardless of whether the services are identified in a state's Medicaid State Plan or available to adults enrolled in the program.¹³ This includes physical

Scope of EPSDT ¹¹	
E	arly: assessing and identifying problems early
P	eriodic: checking children's health at age-appropriate intervals
S	creening: providing physical, mental, developmental, dental, hearing, vision and other screening tests to detect potential problems
D	iagnostic: performing diagnostic tests to follow up when a health risk is identified
T	reatment: correcting, reducing or controlling health problems

and behavioral health services as well as long-term services and supports. States and Medicaid managed care organizations can require prior authorization for particular services to safeguard against unnecessary use of services, but prior authorization cannot result in a delay or denial of medically necessary services.¹⁴ Notably, for children, states and managed care organizations may not impose hard or fixed limits on specific services (e.g., no more than one wheelchair in five years). If the service or device is medically necessary, it must be provided. While all services—for adults as well as children—must be "medically necessary" for the particular individual in order for that service to be covered by Medicaid, Medicaid has a medical necessity standardⁱ that is unique to children.¹⁵ Unlike typical health coverage medical necessity definitions, the EPSDT pediatric medical necessity definition includes a focus on correcting or ameliorating conditions that can affect children's growth and development. And while states have some discretion

ⁱ Federal law defines EPSDT to include any treatment service found to be medically necessary to "correct or ameliorate defects and physical and mental illnesses and conditions."

within federal parameters to establish their own medical necessity definition for adults, EPSDT establishes a national pediatric standard of medical necessity that all states must follow to address children's unique physical and behavioral health needs.

- States must also offer services that promote access to healthcare, including scheduling assistance for appointments, necessary transportation to and from appointments, related travel expenses, and language assistance services for individuals with limited English proficiency.
- Many states also offer additional home- and community-based services (HCBS), such as respite care for family caregivers, environmental/home or vehicle modifications, and assistive technology and adaptive equipment, through 1915(c) HCBS waivers.

Challenges to Ensuring Access to Care for Children With Special Healthcare Needs

Despite their longevity, federal Medicaid law requirements for children are not well understood or consistently implemented across the country. This has a disproportionate impact on children with special healthcare needs and contributes to uneven access to care and services across states for Medicaid-enrolled children. While federal data to explain this variation across states is limited, interviews with parents, advocates, experts and program administrators identify important advances and agreement about the value of the Medicaid guarantees for children, but also numerous challenges across and sometimes within states. The following issues were most commonly noted:

- Lack of training on EPSDT for pediatric providers and managed care organizations.
- Limited or inaccessible consumer information and education on the services available to Medicaid-enrolled children.
- Improper application of service limits and exclusions as well as a nontransparent medical necessity determination process by managed care organizations, which lead to improper denials of care.
- Shortage of pediatric specialists generally, and lack of specific network adequacy requirements for pediatric specialists in some Medicaid managed care contracts.
- Limited state engagement with families and pediatric providers on systemic issues.
- Limited state monitoring and oversight aimed at preventing, tracking and remediating access challenges for Medicaid-enrolled children with special healthcare needs.

Checklist of Best Practice Strategies

Every state will inevitably face challenges administering a comprehensive health coverage program for children with diverse and complex healthcare and social needs in an ever-changing healthcare landscape. To address those challenges, the “basics” must be in place. For example, the state must have and broadly communicate the appropriate medical necessity definition along with clear contractual requirements with Medicaid managed care plans. But as essential as the “basics” are, they are not sufficient to ensure success. Overall, what emerges from a review of the innovations and best practices adopted by states is the importance of establishing accountability and systems for paying close attention to implementation and outcomes in collaboration with families and the pediatric healthcare community. Medicaid’s responsibility for the health and well-being of half of all children with special healthcare needs demands ongoing, high-level focus, partnership and problem solving. The following best practice strategies checklist was developed to assist state Medicaid agencies, families, advocates, providers and other interested stakeholders in identifying gaps in their states’ current practices and developing an action plan to promote continued improvement.

1 | Establish and maintain strong, consistent state leadership and a governance structure that is focused on children’s needs.

As the source of health coverage for nearly four out of 10 children in the United States, and half of all children with special healthcare needs, Medicaid is fundamental to children’s health and well-being.¹⁶ Yet, outside of state agencies that exclusively focus on children, children’s issues are often overlooked within state government, and children’s healthcare priorities are sometimes sidelined by other pressing issues within a Medicaid program and by adult enrollees or services that drive costs. High-level, consistent attention to the important role Medicaid plays for children is key. One best practice strategy is to create a cabinet-level position or a similarly high-level state position—for example, a dedicated advisor in the governor’s office—and a governance structure, such as a special children’s commission or cabinet, that promotes collaboration among child-serving agencies, such as those that oversee maternal and child health, child welfare, and education, and ensures that children’s healthcare issues, especially those for children with special healthcare needs, stay visible and get the attention that’s needed. Ideally this position or children’s cabinet would be created through legislation to ensure its continuity across administrations. Without an intentional effort to focus on children, especially children with special healthcare needs, states can inadvertently end up with programs and policies that are more tailored for adults and miss emerging issues until they become significant problems.

In addition to having a high-level position or entity within the executive branch that is focused on children, states can ensure there is strong, visible leadership within the state Medicaid agency that can work closely with the Medicaid director to oversee the Medicaid program for children; regularly engage and collaborate with families, providers and other stakeholders about EPSDT; and ensure the Medicaid guarantees for children are being implemented correctly. Another avenue for states to ensure strong state leadership that is focused on children’s needs is requiring robust pediatric representation on states’ Medical Care Advisory

Committees through appointing pediatricians and other child-focused health professions as well as parents of Medicaid-enrolled children, including children with special healthcare needs, and leaders of child-focused consumer groups. Federal law requires states to create Medical Care Advisory Committees to advise the Medicaid agency on health and medical care services; the committees must be given the opportunity to participate in policy development and program administration.¹⁷ Alternatively, a separate Medicaid Child Health Advisory Committee could be empaneled.



California Governor Gavin Newsom created the position of deputy secretary for early childhood development within the California Health and Human Services Agency in early 2019 to implement the governor's early childhood policy agenda, which includes expanded early childhood education and early intervention services.¹⁸ California also has a legislatively mandated Medicaid Child Health Advisory Panel.¹⁹



Maine Governor Janet Mills in early 2019 reconstituted the state's Children's Cabinet, which comprises the commissioners of the Departments of Health and Human Services, Education, Labor, Public Safety, and Corrections. The Children's Cabinet, which was originally created in 1996, meets approximately every six weeks and is focused on improving care and prevention for at-risk youth, especially those in child welfare, who are homeless or who are at risk of entering the juvenile justice system, as well as aligning the early care and early education system to best support children before they reach school age.²⁰ To support these efforts, Health and Human Services Commissioner Jeanne Lambrew created a new chief pediatrician position within the Department of Health and Human Services to help improve the physical, mental and social health of Maine's children and ensure they receive the full range of health and human services.²¹



Oregon Governor Kate Brown convened her Children's Cabinet, which comprises the governor's policy advisors who focus on issues regarding children, including education, healthcare, human services, housing, workforce and the opioid epidemic, to create a children's agenda in 2017 focused on reducing poverty and supporting family stability.²² The agenda includes specific strategies to ensure all children have healthcare coverage and parents have access to home visitation programs and other parenting supports.



Washington, D.C.'s associate director of the Division of Children's Health Services (DCHS) within the Department of Health Care Finance (DHCF) is responsible for ensuring what D.C.'s Medicaid program offers to children is being carried out in accordance with federal law. This includes, but is not limited to, overseeing EPSDT education and training, data and monitoring, managed care organization requirements, and coordination with other child-serving state agencies.²³

2

Provide clear, easy-to-understand and consumer-friendly information for families.

Families of children with special healthcare needs are involved day-to-day, often hour-by-hour, looking out for their children's well-being. Therefore, they need to have clear and consistent information about what their children are entitled to under Medicaid and how to address issues when they arise. The information needs to be communicated in multiple forms, at multiple times, and in accessible and culturally appropriate language from all the various child-serving state agencies as well as the Medicaid managed care plans. According to the Centers for Disease Control and Prevention, nine out of ten adults struggle to understand and use health information when it is unfamiliar, complex or jargon-filled.²⁴ A critical best practice strategy for helping families, especially those with children with special healthcare needs, understand the scope of what Medicaid offers to children is to develop consumer-facing and culturally appropriate materials that are easy to read, navigate and understand.



Federal law requires that states inform children and their families about the Medicaid services available to children within 60 days of an initial Medicaid eligibility determination, and then on an annual basis for families that have not utilized Medicaid services for their children.²⁵ As part of that communication, states must inform enrollees about the benefits of preventive healthcare; the services available under EPSDT and where and how to obtain those services, including treatment services; that services are free of charge if a child is under age 18 (and up to age 21 at the state's option); and that necessary transportation and appointment scheduling assistance are available upon request.²⁶ States are required to utilize a combination of oral and written communication using clear and nontechnical language.²⁷ Oral communication methods can include face-to-face and bidirectional communication by eligibility case workers, navigators and providers; public service announcements; and community awareness campaigns.²⁸ States must also ensure individuals who are blind or deaf, or who cannot read or understand the English language, are effectively informed.²⁹

To effectively inform children and their families about what Medicaid offers to children and how to get answers to questions or problem-solve when issues arise, state Medicaid agencies and health plans can work with families—for example, through a member advisory committee or other stakeholder group—to help design the following types of communications to ensure that families are able to understand what their children are entitled to and what processes are available to them if problems or gaps in care arise:

- Notices issued by the Medicaid agency regarding authorization or denial of benefits.
- Notices and welcome packet information issued by managed care organizations.
- A family-friendly homepage on state Medicaid agency website.
- A consumer hotline or an ombudsman to respond to questions.
- Social media.
- Text communication from Medicaid managed care coordinators.ⁱⁱ



New York outlines what Medicaid offers to children, which is called the Child/Teen Health Program, in its consumer eligibility notices.³⁰

Child/Teen Health Program by Medicaid

This is a Medicaid program for children from birth to age 21 called the Child/Teen Health Program (C/THP) which provides check-ups and follow-up care if problems are found. Children from birth to age 21 who have Medicaid can take advantage of this benefit.

How can I get help finding a health care provider for my child for regular checkups?

Children and young adults should see a doctor for regularly scheduled check-ups even if they are healthy. The C/THP recommends that children have 10 check-ups before the age of 3 and a check-up once a year after that. The C/THP helps establish a "medical home." A "medical home" is a situation in which each patient has an ongoing relationship with a physician who is responsible for the patient's health care needs and, when needed, arranges for care with other qualified physicians.

Depending on a child's age, the C/THP check-up includes:

- Health history
- Dental screening
- Complete physical exam
- Immunizations
- Asthma assessment, diagnosis and treatment
- Hearing and vision testing
- Blood tests (such as sickle cell anemia)
- Developmental/behavioral assessment
- Blood lead level lab test - Children who are 1 or 2 years old and children between 3 and 6 years old who have not had a blood lead level lab test will receive one.

Advice and answers to your health questions

There are no Medicaid co-pays for this benefit. The benefit also includes necessary services that might not normally be provided by the child's regular doctor or clinic. The medical provider will arrange for follow-up treatment for problems found during the check-up.

ⁱⁱ All outbound telephonic communications including text messages are potentially subject to the federal Telephone Consumer Protection Act regulations.



Michigan requires its Medicaid managed care plans to provide targeted outreach and education to children with special healthcare needs, including specific information on navigating the managed care health system and available member services for children with special healthcare needs. Plans must also establish and maintain educational content on the plan's website specifically directed to children with special healthcare needs. In addition, plans must provide children with special healthcare needs and their families with forums for discussion to provide input on the plan's policies and procedures that influence access to services.³¹



Washington, D.C., provides consumer-friendly information to families on what Medicaid offers to children through its HealthCheck brochure (see excerpt below).³² The brochure outlines when children should receive well-child visits and immunizations; what types of services children have access to; and phone numbers to call to schedule a dental checkup, get transportation to a child's medical appointment or voice a concern when a child may have a developmental delay. The brochure also clearly indicates that regular health and dental checkups are free for children.

HEALTHCHECK SERVICES

Free check-ups will include:

- Full physical exam
- Growth and development check
- Hearing and vision screenings
- Oral health assessments
- Appropriate shots
- Lab testing (including blood lead levels)
- Mental health and risk behavior check
- Health education for parents and youth
- Treatment or service referral

If medically necessary:

- Physical, Occupational, and Speech Therapy
- Vision services (including glasses)
- Dental follow-up treatment services (including braces)
- Behavioral health services
- Medication (including inhalers)
- Medical equipment & supplies (including nebulizers)

Check-ups

Regular check-ups with your PCP are needed so you can make sure your child is healthy. If you suspect a problem, call your PCP right away. Regular and non-regular check-ups are covered.

Check-ups are recommended at the ages below:

Infant/Toddler		Child/Teen
1 month	12 months	Once a year from ages 3 years through 20 years
2 months	15 months	
4 months	18 months	
6 months	24 months	
9 months	30 months	

If you have trouble getting services, contact your health plan's member services office or the DC Office of Health Care Ombudsman and Bill of Rights: **(877) 685-6391**

Continuity of Coverage Promotes Continuity of Care: Ensuring Children With Special Healthcare Needs Don't Lose Medicaid Coverage

Losing coverage can lead to healthcare crises for children with special healthcare needs. Current Medicaid eligibility regulations require more streamlined, data-driven renewal processes to ensure children and other Medicaid enrollees do not lose coverage due to paperwork renewal requirements. Recent reports of thousands of children losing coverage at or before renewal suggest that more may need to be done to ensure ongoing coverage of eligible children.³³ The uninsured rate for children increased in 2017 for the first time in nearly a decade—a statistic that demands focused attention to get back on track.³⁴

A federally available option that promotes continuity of coverage is for a state to adopt 12-month continuous coverage for all children in Medicaid, allowing a child's Medicaid enrollment to remain stable for 12 months, regardless of changes in family size or income, which can fluctuate from month to month. Research has shown that 12-month continuous eligibility for children reduces churn, or the rolling on and off coverage that disrupts continuity of care.³⁵ Thirty-two states have elected to provide 12-month continuous eligibility for all children in Medicaid or CHIP.³⁶

States can also ensure parents of children with special healthcare needs have health coverage by expanding Medicaid to all adults up to 138 percent of the FPL if the state has not already done so and ensure all eligible parents are enrolled in Medicaid. Research has shown that children are more likely to have health insurance if their parents are insured, and children with uninsured parents have a greater risk of being uninsured and are less likely to receive preventive care and other necessary healthcare services.^{37,38,39}

3

Ensure pediatric care teams are well informed and trained on what Medicaid offers to children.

Pediatric healthcare providers and other members of a child's care team, including care coordinators, practice managers, and the child care and education systems, must understand the full scope of the Medicaid guarantees for children, including the federal requirement that children are entitled to all medically necessary services under Medicaid without any caps or hard limits. States can do this by educating pediatric care teams about Medicaid's unique pediatric medical necessity standard and that services needed to correct and ameliorate health conditions must be covered if the service could be covered under the categories of mandatory and optional Medicaid services listed in Section 1905(a) of the Social Security Act, regardless of whether the services are identified in a state's Medicaid State Plan or available to adults enrolled in the program. Physicians and other members of the care team play a significant role in medical necessity determinations as they are typically responsible for providing information to state Medicaid agencies and/or managed care organizations to explain why a particular service is medically necessary for a child. Such communications are often needed for certain durable medical equipment, pharmaceuticals and treatment services for rare conditions. Providers, however, are not likely to submit the request or the information needed to support the request if they are unaware that the law requires the service be provided if medically necessary (using Medicaid's unique pediatric standard).

A comprehensive and regularly updated statewide provider manual on what Medicaid offers to children can detail the periodicity schedule and required screenings and screening tools; the medical necessity definition applicable to children and the allowable scope of services, especially treatment services which will often be more expansive for children than for adults; guidance on how to make referrals; and transportation, language interpretation and scheduling assistance. While most states have a provider manual or similar publication, the rules relating to children are not always prominent or clearly laid out; a separate guide for children can make these rules more accessible to providers. In addition to the provider manual, states can deliver robust provider trainings on what Medicaid offers to children and require providers to complete the trainings at regular intervals. The trainings can be offered directly by the state Medicaid agencies, through the Medicaid managed care plans, or in partnership with the state's Title V Maternal and Child Health Bureau (MCHB) program.



Washington, D.C.'s DCHS requires Medicaid managed care plans to ensure that every two years, providers complete training on what Medicaid offers to children. The training is accessible via an online portal, and DCHS also requires managed care organizations to pay for continuing education credits for providers to complete the training.⁴⁰

Utilizing Specialized Medicaid Managed Care Plans for Children With Special Healthcare Needs

States can enroll children with special healthcare needs into health plans that serve most Medicaid enrollees (known as a standard or mainstream managed care program) or in plans that are designed to serve the needs of specific populations. For example, Virginia enrolls children with medical complexity into its Commonwealth Coordinated Care (CCC) Plus specialized Medicaid managed care program.⁴¹ While specialized Medicaid managed care plans present an opportunity for states to focus on improving access to care for children with special healthcare needs, it is also important for states to ensure that children with special healthcare needs who may not qualify for the specialized Medicaid managed care programs are not overlooked by requiring robust contract provisions in the mainstream Medicaid managed care plan.

4

Establish a comprehensive definition of children with special healthcare needs and establish strong identification processes for better care coordination, monitoring and early identification of health issues.

An Inclusive Definition of Children With Special Healthcare Needs

In order to identify the broad array of children with special healthcare needs, a common and robust definition that focuses on current and future health and functional status rather than specific underlying diagnoses can be used by state Medicaid agencies and their partners in state government. Without a more robust definition of children with special healthcare needs, managed care organizations may tend to focus solely on children with medical complexity (high-cost, high-utilizers), but will miss some children, including children in foster care, who have special healthcare needs but haven't yet sought or received healthcare for those needs. By better identifying children with and at risk for developing special healthcare needs, a state and its contracted managed care plans can affirmatively take action to connect more of these children to needed diagnostic and treatment services, better coordinate care, and enhance its monitoring efforts. A common definition across state programs and initiatives will also help focus attention on this group of vulnerable children and promote collaboration across agencies and programs within a given state. A number of state Medicaid agencies have aligned their definition of children with special healthcare needs with the Title V MCHB definition: "Children with special health care needs are children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."⁴²

Stronger Identification Processes

Using a more comprehensive definition can help states identify children with special healthcare needs through administrative and claims data as well as through family, provider, community agency or caregiver referrals; this is particularly important for children who have yet to seek out healthcare services to address their special needs. States can also utilize a standardized physical and mental health screening tool, such as the Child & Adolescent Health Measurement Initiative (CAHMI) Children with Special Health Care Needs Screener, which is based on the MCHB definition of children with special healthcare needs, to identify new child enrollees who have special healthcare needs.⁴³ By more quickly identifying children with special healthcare needs, states, health plans and providers can better determine which children need a higher level of care coordination and support. Federal Medicaid managed care regulations require—at a minimum—that managed care organizations assess enrollees' needs within 90 days of beneficiary enrollment to determine what care coordination is needed, but states can require quicker turnaround of these assessments for children identified as having or likely to have special healthcare needs.

Encouraging strong identification processes is particularly important for children with mental health and substance use issues, which otherwise can go undetected by the healthcare system until a crisis arises. About 10 percent of U.S. children and adolescents have a serious emotional disturbance (SED), yet



approximately 80 percent of those children and adolescents with a SED do not receive needed services.^{44,45,46} In addition, about 80 percent of U.S. children and adolescents with mental health diagnoses have unmet mental health needs.⁴⁷ Similarly, 4 percent of adolescents ages 12 to 17 met criteria for a substance use disorder in 2017, yet 82.5 percent of those adolescents did not receive needed care.⁴⁸ Many children with special healthcare needs have conditions present at birth or shortly after

birth; but for others, conditions arise as they develop. While the healthcare system is a key locus for identifying children with special healthcare needs, early identification through schools, early childhood education, Title V MCHB entities, foster care agencies and foster care placements can be critical. This requires a high-level and coordinated focus on children with special healthcare needs across state government and child-serving agencies and programs.



Massachusetts requires its Medicaid managed care plans to complete an initial care needs screening to identify children with special healthcare needs as part of its care coordination assessment. The initial care needs screening assesses personal health history, self-perceived health status, cultural and linguistic needs, medical and diagnostic equipment needs, long-term services and supports needs, and behavioral health and substance use disorder needs. Managed care plans are required to ensure that children with identified long-term services and supports or special healthcare needs receive a person-centered, comprehensive assessment and documented care plan.⁴⁹



Virginia's Department of Medicaid Services requires both its mainstream Medicaid managed care program, Medallion 4.0, and its specialized Medicaid managed care program for adults and children with medical complexity, CCC Plus, to use a member health screening tool to assess enrollees' physical and behavioral health status and risk factors along with their social, economic and housing needs. Children with special healthcare needs identified as medically complex are enrolled in a CCC Plus plan, and children with special healthcare needs who do not meet the enrollment criteria for a CCC Plus plan are enrolled in a Medallion 4.0 plan.⁵⁰

Screening for Social Determinants of Health

In some cases, children's health can be compromised by personal and social factors affecting the child and family. These factors can interfere with both accessing and benefiting from medical care. States can gain key insight into children's healthcare needs through screenings for nonmedical needs that can impact health and health outcomes (often referred to as social determinants of health needs). The American Academy of Pediatrics updated its Bright Futures Guidelines and its Periodicity Schedule in 2017 to add to well-child visits a psychosocial/behavioral screening that assesses social determinants of health, including a child's and family's food security, housing stability, domestic violence, adverse childhood experiences, substance use, and other issues that may affect a child's and family's health.⁵¹



Minnesota requires its Medicaid providers to screen for social determinants of health, including housing stability, food security, home or community safety, and adverse childhood experiences, when obtaining a child's health history as part of a well-child visit.⁵² While there is no standardized social determinants of health screening tool, the electronic health record captures a number of social determinants of health components.



Oregon has developed a standardized method using system-level data to identify publicly insured children with health complexity, which is defined as the combination of medical and social complexity. Oregon's Medicaid agency, the Oregon Health Authority (OHA), is utilizing claims and administrative data as well as data-sharing agreements with other state agencies, such as the Department of Corrections and the Department of Human Services. The data are generating population-level reports showing results at both the state and county levels broken down by age, race and ethnicity.⁵³ OHA is also providing both population-level data reports to Oregon's managed care organizations (called Coordinating Care Organizations [CCOs]) that are specific to the population of children attributed to each CCO as well as child-level data files for each child attributed to the CCO. These findings are being used to engage community-level partners and facilitate discussion, develop better care coordination and case management models, and encourage culturally responsive approaches to care to address health disparities.⁵⁴

5

Ensure access to pediatric specialists and subspecialists.

Rigorous Network Adequacy Requirements

Issues relating to children's access to specialty services are not uncommon, although the issues relating to access vary across and sometimes even within states. Federal network adequacy requirements applicable to Medicaid managed care specify that states must ensure managed care organizations maintain and monitor provider networks sufficient to provide adequate access to all services covered under the Medicaid managed care contract for all enrollees.⁵⁵ Rules issued in 2016 direct states to establish network adequacy standards for time and distance for primary care, behavioral health, and specialist services for both adult and pediatric services, taking into account the numbers of providers accepting new Medicaid patients, language access, cultural competency, and physical access for Medicaid enrollees with physical or mental disabilities.⁵⁶ Under these federal rules, states must publish their standards on their state Medicaid managed care website, and the Centers for Medicare & Medicaid Services (CMS) can evaluate the reasonableness of state standards by comparing them with Medicare Advantage standards and those used in the state's commercial market. Regulations also require managed care organizations to pay for any "necessary services" that the provider network is unable to provide.⁵⁷

Revisions to the 2016 rules proposed in November 2018 drop the specific requirements around the time and distance standard, allowing states to use some type of quantitative standard (e.g., minimum provider-to-enrollee ratios, maximum wait times for an appointment).⁵⁸ The proposed rule also would no longer require states to establish network adequacy standards for pediatric specialists.⁵⁹ A final rule is expected in late 2019.

Regardless of how the Medicaid managed care rule is finalized, federal regulations are a floor and not a ceiling; states could require managed care organizations to have specific network adequacy requirements (and requirements for out-of-network access and payment as appropriate) for pediatric specialists and subspecialists, including academic medical centers and children's hospitals. States can institute corresponding corrective actions, fines, penalties and/or sanctions if those network adequacy requirements are not maintained. This is especially important for ensuring children with special healthcare needs are able to see pediatric specialists and subspecialists and receive needed personal care services without long travel times or delays.





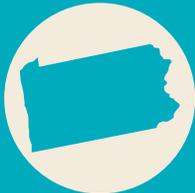
Delaware's Medicaid managed care plans must ensure that children with special healthcare needs have access to pediatric subspecialty care in a wide range of fields through participation agreements, single-case agreements and other provider arrangements for accessing out-of-network pediatric subspecialty providers. The managed care contract specifically distinguishes how pediatric specialty care (e.g., a pediatric cardiologist for children with congenital health defects) is significantly different from the need for adult specialists.⁶⁰



Maryland requires its Medicaid managed care plans to allow a child who was diagnosed with a special healthcare need following plan enrollment who requires specialty services to request approval to see an out-of-network provider to provide those services if the managed care plan does not have available an in-network specialist provider with the same level of expertise.⁶¹



New Jersey's Medicaid managed care contracts require that children with special healthcare needs have access to pediatric medical subspecialists, pediatric surgical specialists and pediatric specialty centers for the diagnosis and treatment of rare disorders (e.g., pediatric tertiary centers, craniofacial centers, hemophilia treatment centers, genetics centers and pediatric HIV centers).⁶²



Pennsylvania requires its regionally-based Medicaid managed care plans to contract with at least two pediatric specialists or pediatric subspecialists for children with special healthcare needs. If a plan does not have at least two pediatric specialists or pediatric subspecialists in its network, or if the child with special healthcare needs or the child's family is not satisfied with the in-network pediatric specialists or pediatric subspecialists in its network, the child with special healthcare needs can choose an out-of-network provider through a prior authorization process.⁶³



Washington, D.C., requires its Medicaid managed care plans to include pediatric specialists and subspecialists in their networks or face a fine of up to \$20,000 per specialist needed to meet the requirements for each day the managed care organization is not compliant. Washington, D.C.'s state Medicaid agency staff work collaboratively with the plans, using tools such as GeoAccess software, to ensure compliance with network adequacy requirements.⁶⁴

Telehealth

Access gaps can arise for many reasons, and under Medicaid rules, states can also use telehealth—the use of technology to provide and coordinate healthcare at a distance—to ensure access to care, especially for children with special healthcare needs. Obtaining timely and coordinated care can be challenging for children

with special healthcare needs, who require more specialized health-related services than are required by children generally. Telehealth can be used to address some of those challenges by making the types of specialized care and coordination needed by children with special healthcare needs more accessible. It can also be the only feasible access solution for children with special healthcare needs who live in rural areas far from large medical centers or pediatric specialist practices or in areas with a shortage of pediatric specialists, allowing families to stay in their communities while still getting the care they need. Federal law does not recognize telehealth as a distinct service; services delivered via telehealth are subject to the same Medicaid requirements that apply to the underlying service (e.g., a physician visit).⁶⁵

Telehealth also plays an important role when children with special healthcare needs have difficulties being transported to a provider's office or when families need help monitoring and managing their children's chronic conditions on a regular basis. In addition, telehealth can help facilitate coordination between providers, such as allowing a specialist in one location to provide a consultation to a pediatrician in another location or videoconferencing between a pediatrician, a social worker and the child's school to help improve the child's health and well-being.⁶⁶ While telehealth can be an important tool to improve access, it needs to be thoughtfully embedded in the care delivery system and should augment, and not substitute for, a robust in-person pediatric care team.



California's Tele-Audiology Program (CTP) utilizes telemedicine technologies to allow a pediatric audiologist to conduct a diagnostic evaluation for infants who do not pass their newborn hearing screening. The state's Hearing Coordination Centers refer families to a pediatric audiologist who uses videoconferencing and a laptop computer to run the audiology equipment remotely. Prior to the launch of the CTP, which is run by the University of California, Davis, many infants were lost to follow-up due to a regional shortage of trained pediatric audiologists.⁶⁷



New Jersey began the Pediatric Psychiatry Collaborative (PPC) in 2014 to build a statewide network of nine regional hospital-based programs that seek to properly screen and diagnose children with behavioral health needs and connect them to treatment locally. The PPC pays for pediatricians to receive training on how to better identify a behavioral or mental health concern or substance abuse problem and uses technology to connect the pediatricians to child psychiatrists who can advise them in real time about a diagnosis, medication management or a treatment plan. In early 2019, New Jersey received \$2.3 million from the federal Health Resources and Services Administration to expand its PPC by training 1,800 additional pediatricians on diagnosing and treating mental and behavioral health and substance abuse issues in children and adolescents. The new funding will also create an online referral database for providers.⁶⁸

Leveraging All Available Legal Authorities That Support Children With Special Healthcare Needs

In addition to the core federal Medicaid requirements related to children (see Appendix 3), a variety of federal authorities can be leveraged to increase funding and benefits and promote coordination of care for children with special healthcare needs.

- **Medicaid HCBS 1915(c) Waivers** allow states to provide additional HCBS services at home and in the community to children who meet the level of need that would meet the state's eligibility requirements for services in an institutional setting. Unlike most State Plan services, 1915(c) waivers give states the flexibility to target services to a specific population based on age and medical conditions, such as children with autism or a developmental disability. States can expand the group of children eligible for these services by disregarding parental income, and if they choose, states can cap enrollment under 1915(c) waivers.⁶⁹ All waiver programs must be cost neutral to the federal government, and as of 2013, all states used strategies such as enrollment limits or waiting lists in their 1915(c) waivers to control state costs.⁷⁰ As a result, waiting lists are common.⁷¹
- **Tax Equity and Responsibility Act or "Katie Beckett" option** (named after a child who was required to use a ventilator and lived in the hospital until age 3 because her parents' health insurance would not cover home care) allows states to disregard parental income and extend to those with higher incomes Medicaid coverage to children with significant disabilities. Children under this option must meet Supplemental Security Income (SSI) medical disability criteria and qualify for an institutional level of care according to the functional eligibility criteria set by the state. Some states cover "Katie Beckett" children as an optional State Plan group, while other states cover these children under a 1915(c) waiver.⁷²
- **Health Homes** are an optional Medicaid State Plan benefit established by the Affordable Care Act (ACA) to promote coordination of care for individuals with or at risk of multiple chronic conditions, such as diabetes, asthma, mental health conditions or substance abuse. Health home providers integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the "whole person." States that elect this option receive a 90 percent enhanced Federal Medicaid Assistance Percentage (FMAP) match for care coordination services during the first eight quarters that the health home program is in effect. While states cannot target this benefit by age, states can target children by focusing on particular provider groups (such as pediatricians) or chronic illness/disability (such as asthma).⁷³ In April 2019, Congress passed the Medicaid Services Investment and Accountability Act, which creates a new state option to establish hospital-coordinated health homes for children with medically complex conditions and provide states with two quarters of enhanced federal funding (set as a 15 percentage point increase over the state's regular matching rate, not to exceed 90 percent).⁷⁴ Under this option beginning in October 2022, medically complex children will select a designated provider or health home that will coordinate the child's care, including for emergency services and subspecialized pediatric services (including from out-of-state providers). The Department of Health and Human Services (HHS) will award planning grants to states for purposes of developing health homes for children with complex conditions, not to exceed \$5 million.
- **Title IV-E Families First Prevention Services Funding** is a new uncapped source of matched federal funding under Title IV-E of the Social Security Act (the section of the law that pertains to child welfare and foster care) for certain health/social services for children at risk of entering or re-entering foster care and

pregnant or parenting foster youth, as well as the parents and kin caregivers of such children/foster youth, regardless of income.ⁱⁱⁱ The services available under this new funding include mental health and substance abuse prevention and treatment services and in-home parent skill-based programs. States will be able to access the new funding beginning in Federal Fiscal Year (FFY) 2026 at its regular Medicaid FMAP rate; states will be able to receive funding at a 50 percent match rate beginning in FFY 2020 for administrative costs associated with implementing the new services. This new funding could overlap with Medicaid funding and/or could complement Medicaid funding, for example, by financing some services aimed at addressing social determinants of health that may not be covered by a state's Medicaid program.

- **Federal pediatric innovation grant funding** is another opportunity for states to improve access to care and outcomes for children with special healthcare needs. The Center for Medicare and Medicaid Innovation (CMMI) Integrated Care for Kids (InCK) model is the first CMMI initiative to specifically focus on child- and family-centered delivery and payment reforms. The seven-year model aims to integrate care across behavioral, physical, and other health-related social services and community-based child providers, while also sharing accountability for cost and outcomes.⁷⁵ CMMI plans to award grants of up to \$16 million each to up to eight states. The InCK model is an important first step toward testing more delivery and payment reform approaches for children with special healthcare needs.

6

Safeguard against utilization management controls that impede access to needed care.

Fixed or hard limits on the services available to children are not permitted under EPSDT. States, however, may impose a “soft” limit on the amount of a service a child can receive and require prior authorization for services above those limits. Services must, however, be provided if determined to be medically necessary, and prior authorization cannot delay the delivery of services. Despite federal law requirements, prior authorization processes can create challenges for children and families, particularly in the context of managed care when it is not always clear to families who is making the decision to deny care and the reasons for that decision. Children with special healthcare needs often have particular challenges when trying to access needed durable medical equipment.⁷⁶ To ensure access to needed care, states should be enforcing the federal requirement that managed care organizations follow a transparent, evidence-based process for making medical necessity determinations and ensure that utilization controls do not result in inappropriate denials or delays in the delivery of medically necessary services or create undue burden for the family. Given the way in which “soft” limits can turn into hard limits in practice, states can also safeguard the process by requiring through their Medicaid managed care contracts that any preliminary service denial for a Medicaid-enrolled child with special healthcare needs be reviewed and signed off by a healthcare provider with experience treating the particular condition before a denial can be finalized. If the service is ultimately denied, the law requires states—directly or through their contracted managed care plans—to communicate clearly in writing to the family and healthcare provider why the service was denied, based on transparent clinical judgment, and provide them with easy-to-understand information about how to appeal the decision.

ⁱⁱⁱ This new source of funding is provided by Section 50711 of the Social Security Act, which amends Section 471 of the Social Security Act, 42 U.S.C. § 671.

Finally, states can also establish a hotline or a Children's Ombudsman Office/Office of the Child Advocate that can assist families in explaining the rules and understanding the scope of services available to children, navigating the system and, if necessary, appealing a denial or service limitation. This can be in addition to the grievance process administered by managed care plans to be sure that the state itself is aware of and engaged in monitoring access-to-care issues for children with significant healthcare needs.



California utilizes its Medicaid managed care contracts to establish specific utilization management programs for children with special healthcare needs that ensure timely authorization of services from pediatric specialists, subspecialists, ancillary therapists and specialized therapists, and for specialized supplies.⁷⁷



Michigan requires its Medicaid managed care plans to utilize an appropriate pediatric subspecialist to review decisions to deny, suspend, terminate or limit pediatric subspecialist provider services for children with special healthcare needs.⁷⁸



Virginia's Medicaid managed care plan contracts explicitly state that medical necessity determinations must be made on a case-by-case basis, taking into account the particular needs of the child, including the child's long-term needs. The contracts require managed care organizations to consider all aspects of a child's needs, including nutritional, social and developmental as well as needs related to mental health and substance use disorders. If a family member or the treating physician requests a service for a child that does not meet the plan's general coverage criteria, a managed care plan physician with experience treating the child's condition or disease must conduct an individualized review of the request for that child, applying all EPSDT federal criteria to determine medical necessity. In addition, Virginia requires its Medicaid managed care plans to allow children with special healthcare needs whose treatment plan indicates the need for frequent utilization of a course of treatment to directly access specialists without prior authorization.⁷⁹



Washington, D.C., requires its Medicaid managed care plans to have a plan's chief medical officer personally review all denials of care for EPSDT physical health services and services for children with special healthcare needs. Similarly, the contract requires a managed care organization's chief psychiatric medical officer to review all denials of care for mental and behavioral health treatment services.⁸⁰ In addition, Washington, D.C.'s Office of Health Care Ombudsman and Bill of Rights has a children with special healthcare needs subcommittee on which the DCHS associate director sits in order to keep each office informed about coverage and access issues.⁸¹

7 | Require comprehensive and child-centered care management/care coordination for children with special healthcare needs.

Care Needs Assessment

Children with special healthcare needs have multiple needs that require support from a wide range of medical and nonmedical providers and also coordination among those various providers to ensure the needs of children with special healthcare needs are being met and that the right care is being delivered in the right place, at the right time and by the right person. Federal Medicaid managed care regulations require—at a minimum—that managed care organizations assess enrollees' needs within 90 days of beneficiary enrollment and coordinate care not only for services delivered by the plan but also services that enrollees may receive from other plans or through a fee-for-



service system. States have an opportunity to require quicker turnaround of these assessments for children identified as having or likely to have special healthcare needs (for example, because the child is in foster care). State Medicaid programs are federally required to ensure that managed care organizations develop service plans, connect enrollees to community and social support services, and provide access to specialists for enrollees who need long-term services and supports or have special healthcare needs. The service plans must be reviewed and revised upon reassessment of functional need at least once a year, when the enrollee's circumstances or needs change significantly, or at the request of the enrollee.⁸²

Some states require managed care organizations to use a health risk assessment tool to develop individualized care plans for children with special healthcare needs that include short- and long-term goals, service needs, available community resources to leverage, and the child's and family's preferences. States can also require that managed care organizations use the individualized care plans in their care coordination/case management efforts between and among providers. Health risk assessments should be redone regularly—for example, every six months—and the individualized care plans should then be updated accordingly. Finally, states can ensure managed care organizations rely on multidisciplinary teams that meaningfully engage the family in the delivery of care and include them as core partners in all planning and decision making.

Pediatric care teams operating in a fee-for-service context can also be authorized and compensated to provide care management, and the same needs assessment tools and individualized care plans discussed above can be utilized in a fee-for-service context for children with special healthcare needs.



Minnesota requires its Behavioral Health Home service providers to complete a needs assessment, an initial health wellness assessment and a health action plan for each Medicaid enrollee participating in the model, involving enrollee's family members through the process. These assessments are used to help identify enrollees' physical, behavioral and social needs, and the health action plans are updated at least once every six months or sooner if there are changes to an enrollee's needs or goals. The information is stored in a patient registry that providers use to inform population management strategies, identify and manage care gaps, and facilitate communication among care team members. The care team also uses this information to connect enrollees to community and social services that can help them overcome access or service barriers, increase self-sufficiency skills, and improve overall health. Team members follow up with patients and their family members to help ensure follow-through on referrals; when referrals are not completed, the team notes this in the enrollee's file. Providers are also required to offer to families, caregivers and other identified supports direct education and support related to chronic disease management and how to navigate complex systems of care.⁸³



Rhode Island's Patient Centered Medical Home (PCMH) – Kids, a multipayer primary care payment and delivery system reform initiative that is funded by the federal State Innovation Model Initiative and the state's Medicaid managed care plans, is transforming primary care for children across the state. The PCMH – Kids initiative developed a framework to identify high-risk children who would benefit from care coordination and allowed primary care practices to hire social workers as care coordinators to better meet the needs of children and their families. Today, PCMH – Kids represents almost the entire pediatric Medicaid population in Rhode Island.⁸⁴



Virginia requires its Medicaid managed care plans to use a health risk assessment tool to develop an enrollee's person-centered individualized care plan that encompasses enrollees' goals for their health outcomes as well as community resources the enrollee can leverage. As part of its care coordination efforts, Virginia requires its Medicaid managed care plans to develop programs or establish partnerships to address social determinants of health, including food security, housing stability, education, social cohesion and environmental needs. Health risk assessments are required to be redone regularly, and the individualized care plans are updated to reflect the needs determined by the reassessments.⁸⁵ Virginia also requires care coordination staffing ratios in both its mainstream and specialized Medicaid managed care programs. In its mainstream plan (Medallion 4.0), managed care plans are required to maintain a 1:350 ratio of care coordination staff to vulnerable subpopulation enrollees, which include children with special healthcare needs. In its specialized plan for medically complex enrollees (CCC Plus), care coordination staffing ratios are broken down by subpopulations, including, but not limited to, 1:75 for HCBS waiver populations, 1:200 for nursing facility populations and 1:150 for enrollees with a serious mental illness. Care coordination staff are required to assist children with special healthcare needs with scheduling appointments, providing referrals and identifying resources, as well as by contacting the family regularly and providing special transportation requirements as necessary.⁸⁶

Transitions of Care

For children with special healthcare needs, care coordination is particularly needed around times of transition, such as transitioning from the pediatric healthcare system to the adult healthcare system, and states can require managed care organizations or fee-for-service care management providers to offer enhanced care coordination during these times. Federal regulations require that states establish transition-of-care policies for enrollees moving from fee-for-service systems to managed care or from one managed care plan to another, where continued access to services and current providers is critical.⁸⁷ Given the unique needs of children with special healthcare needs, states have an opportunity to require Medicaid managed care plans to cover out-of-network services and providers who have an established relationship with a child with special healthcare needs for at least some period of time.



Texas requires its specialty Medicaid managed care plans to begin conducting ongoing transition planning when children turn 15 years old to prepare them for service and benefit changes that will occur when they turn 21 years old and transition to the adult healthcare system.⁸⁸



Virginia requires its specialty Medicaid managed care plans to have at least one dedicated care coordinator without a caseload to assist individuals with transitioning from institutional care to the community.⁸⁹



Washington State includes special provisions focused on transitions of care in its specialized Medicaid managed care contract that's tailored to meet the needs of children in foster care. To ensure continuity in care, Washington's integrated foster care contract allows children to continue receiving care from out-of-network providers with whom they have existing relationships during transitions in coverage. Children in foster care must be allowed to remain with their current out-of-network providers until the managed care plan conducts a care needs assessment and attempts to contract with the out-of-network providers, works with them as a nonparticipating provider or transitions the children to a network provider.⁹⁰

Coordinating With Other Child-Serving Agencies

Care coordination and complex care management programs provided through either managed care or fee-for-service systems can also coordinate and share data with other child-serving state agencies, such as Title V MCHB programs, foster care agencies, early intervention services and special education programs, to avoid duplication of services and ensure treatment plans and services for both physical and behavioral health are coordinated across the various entities serving children with special healthcare needs.^{iv}



New York requires its Medicaid managed care plans to have a process in place to coordinate with school districts, preschool services, child protective services, early intervention services and developmental disability service organizations in order to ensure appropriate service delivery.⁹¹

^{iv} There are legal restrictions with state Medicaid agencies receiving information from organizations outside the healthcare system. For example, schools must comply with the Family Educational Rights and Privacy Act (FERPA), which allows disclosure of children's information only under limited circumstances. The Medicaid agency may have to obtain a parent's consent before receiving the information from the school.



Washington, D.C.'s DCHS shares data with DC Public Schools and a major charter school, the Office of the State Superintendent of Education, DC Health, the Child and Family Services Agency, and the Department of Energy and Environment.⁹²

Class Action Lawsuits

Families and advocates have historically turned to class action lawsuits when states have fallen short on ensuring access to care for children with special healthcare needs. Class actions have resulted in major EPSDT reforms in a number of states around EPSDT consumer outreach and education, provider training, access to intensive HCBS, personal care services, and private-duty nursing services.

Some states and advocates, however, have resolved EPSDT-related issues short of resorting to class action lawsuits by actively engaging in discussions with managed care organizations, advocates, and children with special healthcare needs and their families. States can implement strategies to facilitate ongoing, open communication, such as standing calls with state advocacy organizations, which may help prevent issues from escalating, especially during delivery system reform and other major healthcare transformations.

8

Establish robust and ongoing state monitoring and oversight of access to healthcare services for children with special healthcare needs.

An overarching, essential component of an effective strategy to ensure the needs of children with special healthcare needs are met is ongoing state monitoring and oversight. Key to that effort is having regular communication with families and healthcare providers of children with special healthcare needs through advisory committees or other stakeholder forums to share information about what is working, identify where challenges are arising and collaborate on areas of improvement.



These efforts should be augmented with data. In addition to collecting and reporting the Children's Health Care Quality Measures for Medicaid and CHIP (known as the Child Core Set⁹³), states can collect and continually analyze other data sets, such as the National Survey of Children's Health (NSCH) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS), to get a complete picture of how Medicaid-enrolled children with special healthcare needs are faring in their state. States may also adopt quality measures specific to children with special healthcare needs and supplement CAHPS surveys with questions focused on these quality issues.

State-level claims and other utilization-based data are also important. States are required to submit annually to CMS through its "416" report the number of children that received an EPSDT screening service, the number of children referred for corrective treatment and the number of children receiving dental services.⁹⁴ While the CMS-416 report does not include all key indicators (such as whether the children referred for treatment received that treatment in a timely manner), the CMS-416 data can be utilized to drive improvements in care.

Since the CMS-416 data and other available national data sets do not fully capture children's access to treatment services, states can analyze utilization data for children with special healthcare needs across Medicaid managed care plans to detect any patterns of underutilization. States can review appeal requests to monitor improper denials of services and utilize secret shopper reviews to investigate potential problems with access to care for children with special healthcare needs. The hotline or ombudsman's office that might be established to answer questions and help families facing denials of services, as well as data showing the types of managed care grievances and state Medicaid appeals, can also be an important source of information on the kinds of issues that are arising for children with special healthcare needs. More timely and comprehensive data on utilization should be available in all states later in 2019 through the system for collecting and reporting data established by CMS, the Transformed Medicaid Statistical Information System (T-MSIS).⁹⁵



Minnesota publishes its CMS-416 reports on its state website and breaks down the data by county and tribe; race or ethnicity; fee-for-service and individual managed care organization; and foster care participation by county and tribe.⁹⁶



Virginia requires its Medicaid managed care plans to assess the quality and appropriateness of care as well as patient satisfaction through the CAHPS, including supplemental questions for children with chronic conditions. The state also requires its specialized Medicaid managed care plans in the CCC Plus program to develop at least two performance improvement plans, one clinical and one non-clinical, focused on medically complex populations—which may include children with special healthcare needs—that address acute and chronic conditions, behavioral health, care transitions, care coordination, and care management.⁹⁸



Washington, D.C., requires its Medicaid managed care plans to submit quarterly and annual 416 reports, which are used to monitor and track D.C.'s EPSDT performance. In addition to a monthly EPSDT working group with all managed care plans, DCHS meets with each managed care plan on a quarterly basis to go over all data reports and address any reporting, outreach or service delivery issues. The Division of Quality and Health Outcomes works closely with DCHS and requires its external quality review organization to conduct an audit of the 416 data submitted by the managed care organizations to ensure its accuracy.⁹⁹

Federal Data Are Limited but Can Help Efforts to Monitor Access to Care for Children With Special Healthcare Needs

Federal data that are available to provide state-specific insights on the healthcare experiences and quality of care for children with special health needs, and specifically the subgroup who are enrolled in Medicaid, are fairly limited but still can be part of states' overall monitoring efforts. Key sources include the NSCH, the Child Core Set and the T-MSIS.

The NSCH is designed to produce national- and state-level estimates for children ages 0–17, with approximately 1,400 respondents per state for the combined 2016–2017 data. States can assess state-level performance on a variety of measures regarding utilization, usual/coordinated care, and unmet needs and other difficulties. Through this data, it is possible to examine whether children with special healthcare needs in a state are significantly better or worse off than children with special healthcare needs nationwide, and whether children with special healthcare needs in a state are significantly better or worse off than children without special healthcare needs in that state. While the NSCH collects a rich set of information, small sample sizes for subgroups of children (e.g., children with special healthcare needs enrolled in Medicaid) make it difficult to detect whether results for a given state are significantly different than the national average. While this issue can be mitigated by pooling years of survey data, a recent survey redesign means that comparable data are currently available only for 2016 and 2017. With just two years of data, sample sizes are not large enough to report results separately for Medicaid-enrolled children with special healthcare needs, and even some measures for all children with special healthcare needs have wide margins of error that prevent determining with certainty whether differences from the national average are meaningful.

The Child Core Set data consist of state-reported quality-of-care measures for Medicaid and CHIP enrollees, which allow for an examination of each state's Medicaid/CHIP performance relative to the national median for selected measures. While the Child Core Set is not designed to provide separate estimates for children with special healthcare needs, some of the measures do focus on specific subpopulations of interest (e.g., children using behavioral healthcare). For Child Core Set measures, reporting remains voluntary until FFY 2024 and many states do not report all of the measures. In addition, states differ in the extent to which they report populations that reflect Medicaid and CHIP, Medicaid only, or (less frequently) CHIP only. States also vary in whether they use administrative (e.g., claims) data alone to populate certain measures, or whether they supplement this information with medical record reviews that can identify additional services provided or appropriate population exclusions for a given measure based on diagnoses or other criteria—potentially leading to different results than using administrative data alone. Improvements in Child Core Set measures reporting can add to the tools available for using data to answer key questions about how well children with special healthcare needs are faring.

While the currently available federal data have several shortcomings, work by CMS and the Agency for Healthcare Research and Quality includes an effort to provide new and improved benchmarks for measuring access to care. The agencies are jointly leading the Pediatric Quality Measurement Program to strengthen the Child Core Set and develop, strengthen and/or test new measures.¹⁰⁰ Some of these measures include measures specific to children with special healthcare needs, such as measures related to asthma, sickle cell treatment, attention deficit/hyperactivity disorder (ADHD), continuity of primary care for children with medical complexity and children with disabilities.¹⁰¹

In addition, CMS expects to make new and more granular T-MSIS data on Medicaid enrollees available in the near future; T-MSIS data are slated to be public later in 2019. States provide person- and claims-level data via T-MSIS, which can be aggregated in any number of ways to shed light on the care received by different subgroups, including children with special healthcare needs and specific subsets of children within that group. As noted by the Government Accountability Office, T-MSIS is intended to eventually provide states with the capability to analyze their program data and compare it with that of other states, potentially enhancing their ability to manage expenditures and identify concerns regarding access to care. CMS has indicated that it intends to access certain state data directly through T-MSIS to reduce the number of data requests that it makes to states (e.g., the CMS-416 data that states are currently required to submit for EPSDT purposes),¹⁰² and could also take the opportunity to work with states on ways to use T-MSIS for Child Core Set reporting and other quality measurement activities.

Conclusion

As the source of health coverage for about half of all children with special healthcare needs, state Medicaid programs have an extraordinary opportunity and responsibility to ensure the health and well-being of this vulnerable population. Federal law is strong and clear, but proper implementation at the state and local levels requires ongoing attention, engagement and collaboration among state policymakers and program administrators, families, pediatric providers and care teams, health plans, and the array of public and private agencies and organizations serving children. This can be a time of great opportunity for children with special healthcare needs, as an increasing number of states and collaborating partners are focusing their attention on care improvements and payment strategies that support and encourage those improvements. The best practice strategies described in this issue brief can help stakeholders identify gaps in current practices, develop effective action plans, and create sustainable systems for ensuring that Medicaid-enrolled children with special healthcare needs—no matter where they live or what their health and social needs may be—receive the right care at the right time in the right setting.

Appendix 1: Data Analysis

The tables included in this appendix are based on a cross-state data analysis of two key sources: the NSCH for 2016–2017, with a focus on children with special healthcare needs; and the Child Core Set for FFY 2017 from CMS, which reflects various Medicaid/CHIP enrollee populations. As expected, it is clear from this analysis that additional information is required for understanding performance across states; for example, the Child Core Set reporting remains voluntary until FFY 2024 and many measures are poorly populated. With regard to the NSCH, small sample sizes for children with special healthcare needs and other subgroups at the state level make it difficult to detect whether differences are statistically significant. While limitations exist with both data sources, the metrics selected for the tables below help inform the extent to which access and utilization gaps may exist for children with special healthcare needs.

Table 1 provides an analysis of seven state-reported quality-of-care metrics for Medicaid and CHIP enrollees at the state level from the 2017 Medicaid/CHIP Child Core Set data that are reported to CMS. The analysis examines a state's Medicaid/CHIP performance relative to the national median for selected measures. Data are color coded to identify whether the metric reported is above or below the national median.

Within related groups of measures (e.g., behavioral health), states tend to perform above or below the national median with relative consistency. In other words, if they do well or poorly on one of the measures in a group, they tend to do so for most or all of them. Screening for delays among children ages 0–3 shows substantial variation across states. Percentages for asthma medication management are relatively low across the board. Percentages for ADHD medication follow-up visits are also low.

Table 1: State Performance on Selected Child Core Set Measures of Quality in Medicaid and CHIP, FFY 2017

State	Percentage Screened for Risk of Developmental, Behavioral and Social Delays Using a Standardized Screening Tool: Ages 0–3	Percentage With Persistent Asthma Who Were Dispensed Appropriate Medication and Remained on Medication for at Least 75 Percent of Treatment Period: Ages 5–20	Percentage Newly Prescribed ADHD Medication With 1 Follow-up Visit During the 30-Day Initiation Phase: Ages 6–12	Percentage Newly Prescribed ADHD Medication With at Least 2 Follow-up Visits During the 10-Month Continuation and Maintenance Phase: Ages 6–12	Percentage on 2 or More Concurrent Antipsychotic Medications: Ages 1–17	Percentage of Hospitalizations for Mental Illness With a Follow-up Visit Within 7 Days of Discharge: Ages 6–20	Percentage of Hospitalizations for Mental Illness With a Follow-up Visit Within 30 Days of Discharge: Ages 6–20
Number reporting*	27	39	37	37	37	44	45
National median	39.8	27.3	50.0	61.5	2.7	47.8	69.2
Alabama	36.3	24.1	51.3	98.1	4.1	88.8	92.9
Alaska	3.7		60.0	64.8		11.7	29.7

State is below national median.

State is above national median.

State did not report.

* Depending on the state and measure, reflects Medicaid and CHIP, Medicaid only, or (in small number of cases) CHIP only.

Source: Manatt Health analysis of CMS, Child Core Set data for FFY 2017 as of February 2019.

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Number reporting*	27	39	37	37	37	44	45
National median	39.8	27.3	50.0	61.5	2.7	47.8	69.2
Arizona	23.6	26.2			1.1	63.3	78.6
Arkansas		23.3	61.6	68.9	0.9	44.9	68.3
California		28.9	43.5	55.2	3.6	67.5	79.8
Colorado	42.7	27.5	33.3	34.9	5.7	47.8	68.2
Connecticut	46.8	38.7	60.8	70.1	2.5	61.9	77.0
Delaware	47.4	28.2	43.2	55.4	1.1	60.3	67.5
District of Columbia		27.7	41.0	57.0	1.2	36.8	46.6
Florida	15.4	26.9	46.7	61.8	1.9	42.7	56.0
Georgia	52.1	26.5	44.8	59.2		47.7	65.9
Hawaii		20.5	55.3	65.4		38.6	58.2
Idaho							
Illinois	57.9	21.6	31.4	40.2		46.0	68.2
Indiana	13.4	39.4	50.8	61.5	0.6	65.5	81.7
Iowa	15.3	16.7	18.6	39.5	1.9	40.2	72.1
Kansas		31.8	52.1	61.4	4.8	64.4	78.7
Kentucky		36.7	60.4	71.0	2.0	38.0	59.3
Louisiana	17.8	20.2	48.3	62.2	1.8	40.2	61.5
Maine	29.6	38.3			1.5	65.0	82.7
Maryland		22.8					
Massachusetts	78.3	24.7	54.9	66.2	2.1	66.6	81.6
Michigan	27.3		42.5	55.0		57.0	75.9

State is below national median.

State is above national median.

State did not report.

* Depending on the state and measure, reflects Medicaid and CHIP, Medicaid only, or (in small number of cases) CHIP only.

Source: Manatt Health analysis of CMS, Child Core Set data for FFY 2017 as of February 2019.

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Number reporting*	27	39	37	37	37	44	45
National median	39.8	27.3	50.0	61.5	2.7	47.8	69.2
Minnesota	39.8	25.6				44.7	68.8
Mississippi		26.3	57.4	68.2	0.7	44.3	69.2
Missouri					4.0	39.1	60.4
Montana						49.5	71.4
Nebraska		31.0				29.5	63.3
Nevada		27.5			2.9	79.5	84.6
New Hampshire	25.5	35.3	49.7	55.4	3.4	67.7	84.2
New Jersey		26.6	31.7	36.8	2.9	33.0	43.2
New Mexico		24.0	50.3	62.2	3.5	41.1	63.8
New York		26.4	59.2	67.5	3.1	71.6	85.2
North Carolina	71.5	33.0	42.1	52.2	1.9	37.5	62.5
North Dakota							
Ohio		31.9	55.2	64.6	3.0	61.8	79.6
Oklahoma	16.4	37.4	62.7	61.2	4.0	25.5	49.4
Oregon	62.2		62.2	69.7		82.1	91.7
Pennsylvania	53.9	38.3	40.9	50.0	1.6	55.0	76.1
Rhode Island	60.5	29.5	50.0	63.3	3.3	68.9	81.6
South Carolina	15.6	24.3	53.7	63.5	0.9	41.9	63.6
South Dakota					3.9		
Tennessee		24.7	45.0	59.5	2.7	58.8	71.3
Texas	46.1	19.8	35.9	48.6	2.0	38.7	59.6

State is below national median.

State is above national median.

State did not report.

* Depending on the state and measure, reflects Medicaid and CHIP, Medicaid only, or (in small number of cases) CHIP only.

Source: Manatt Health analysis of CMS, Child Core Set data for FFY 2017 as of February 2019.

State	Percentage Screened for Risk of Developmental, Behavioral and Social Delays Using a Standardized Screening Tool: Ages 0–3	Percentage With Persistent Asthma Who Were Dispensed Appropriate Medication and Remained on Medication for at Least 75 Percent of Treatment Period: Ages 5–20	Percentage Newly Prescribed ADHD Medication With 1 Follow-up Visit During the 30-Day Initiation Phase: Ages 6–12	Percentage Newly Prescribed ADHD Medication With at Least 2 Follow-up Visits During the 10-Month Continuation and Maintenance Phase: Ages 6–12	Percentage on 2 or More Concurrent Antipsychotic Medications: Ages 1–17	Percentage of Hospitalizations for Mental Illness With a Follow-up Visit Within 7 Days of Discharge: Ages 6–20	Percentage of Hospitalizations for Mental Illness With a Follow-up Visit Within 30 Days of Discharge: Ages 6–20
Number reporting*	27	39	37	37	37	44	45
National median	39.8	27.3	50.0	61.5	2.7	47.8	69.2
Utah		27.3	29.8	28.0	7.4	63.6	75.4
Vermont	81.1	52.5	66.7	68.1	3.7	61.6	80.4
Virginia	35.4		50.3	64.5	3.2	44.8	66.8
Washington							
West Virginia	48.6	35.2	37.0	37.8	0.6	30.6	51.6
Wisconsin							71.6
Wyoming					4.4		

State is below national median.

State is above national median.

State did not report.

* Depending on the state and measure, reflects Medicaid and CHIP, Medicaid only, or (in small number of cases) CHIP only.

Source: Manatt Health analysis of CMS, Child Core Set data for FFY 2017 as of February 2019.

Table 2 contains an analysis of ten metrics regarding utilization, usual/coordinated care, and unmet needs and other difficulties reported at the state level from the 2016–2017 NSCH data set. For each measure, the assessment examined whether children with special healthcare needs in a state are significantly better or worse off than children with special healthcare needs nationwide, and whether children with special healthcare needs in a state are significantly better or worse off than children without special healthcare needs in that state. Data are color coded to identify whether the metric reported is above or below the national average. Metrics with small sample sizes are blinded, and metrics that may be unreliable because they exceed a predetermined confidence interval are underlined. Within states, children with special healthcare needs are significantly different from children without special healthcare needs on a variety of measures. For usual/coordinated care measures, there were fewer significant differences, but they tended to show children with special healthcare needs with lower performance than children without special healthcare needs.

Table 2: Selected Access Measures for Children With Special Healthcare Needs, 2016–2017 NSCH Data

State	Higher scores imply better access to care				Lower scores imply better access to care					
	Received services needed for transition to adult healthcare, ages 12–17 years	Had family who partnered in shared decision making for health, among those with 1+ visits	Received care in a medical home	Received effective care coordination, among those with need for 2+ visits	Needed specialist care but did not receive	Had problems obtaining specialist care, among those who needed or received it	Needed mental health care but did not receive, ages 3–17	Had problems obtaining mental health care, among those ages 3–17 who needed or received it	Had problems obtaining referrals, among those who needed them	Family sometimes or usually/always frustrated in efforts to get services
National	16.7%	83.0%	43.2%	61.8%	5.2%	32.4%	6.6%	50.1%	27.3%	35.3%
Alabama	<u>12.8%</u>	<u>78.4%</u>	40.0%	62.1%	<u>6.1%</u>	<u>24.6%</u>	6.1%	<u>53.0%</u>	<u>28.0%</u>	34.0%
Alaska	<u>22.7%</u>	91.0%	47.3%	63.7%	<u>3.5%</u>	<u>37.3%</u>	<u>6.3%</u>	<u>46.0%</u>	<u>31.5%</u>	40.5%
Arizona	<u>25.3%</u>	<u>72.6%</u>	36.5%	55.5%	<u>6.1%</u>	<u>31.9%</u>	<u>8.5%</u>	<u>45.3%</u>	<u>36.4%</u>	34.1%
Arkansas	<u>21.1%</u>	<u>80.0%</u>	42.2%	<u>53.4%</u>	<u>2.5%</u>	<u>42.5%</u>	<u>7.7%</u>	<u>51.0%</u>	<u>24.4%</u>	38.3%
California	<u>16.3%</u>	<u>83.0%</u>	42.2%	72.1%	<u>5.3%</u>	<u>35.9%</u>	<u>4.3%</u>	<u>56.8%</u>	<u>24.5%</u>	<u>37.0%</u>
Colorado	20.4%	81.3%	46.1%	61.9%	<u>4.2%</u>	<u>35.6%</u>	8.7%	<u>52.9%</u>	<u>38.7%</u>	34.8%
Connecticut	<u>14.0%</u>	85.9%	49.8%	56.3%	<u>3.2%</u>	<u>25.3%</u>	<u>4.1%</u>	<u>50.3%</u>	<u>26.3%</u>	33.5%

Notes: Percentages in table reflect values for children with special healthcare needs. Estimates underlined may be unreliable and should be interpreted with caution, as they have a 95% confidence interval that exceeds +/- 10 percentage points or 1.2 times the estimate.

- Significantly lower than national.
- Lower than national, but not significant.
- Higher than national, but not significant.
- Significantly higher than national.
- Suppressed due to small sample size.

Source: Manatt Health analysis of pooled 2016–2017 NSCH data.

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	Received services needed for transition to adult healthcare, ages 12–17 years	Had family who partnered in shared decision making for health, among those with 1+ visits	Received care in a medical home	Received effective care coordination, among those with need for 2+ visits	Needed specialist care but did not receive	Had problems obtaining specialist care, among those who needed or received it	Needed mental health care but did not receive, ages 3–17	Had problems obtaining mental health care, among those ages 3–17 who needed or received it	Had problems obtaining referrals, among those who needed them	Family sometimes or usually/always frustrated in efforts to get services
National	16.7%	83.0%	43.2%	61.8%	5.2%	32.4%	6.6%	50.1%	27.3%	35.3%
Delaware	16.8%	84.1%	51.7%	65.6%	<u>5.5%</u>	25.4%	6.4%	50.1%	22.3%	34.2%
District of Columbia	15.0%	88.3%	39.1%	65.4%	2.9%	25.2%	3.7%	34.9%	9.1%	<u>33.2%</u>
Florida	5.9%	<u>75.4%</u>	30.7%	55.0%	<u>7.0%</u>	<u>46.8%</u>	<u>8.7%</u>	66.6%	47.2%	49.5%
Georgia	14.0%	<u>75.1%</u>	45.4%	58.9%	<u>4.9%</u>	<u>27.2%</u>	11.6%	<u>54.2%</u>	<u>26.7%</u>	41.0%
Hawaii	21.8%	<u>78.7%</u>	44.7%	63.2%	<u>2.1%</u>	24.9%	4.5%	27.2%	24.9%	32.7%
Idaho	19.1%	86.0%	42.2%	65.5%	<u>2.8%</u>	<u>38.5%</u>	5.2%	<u>47.0%</u>	<u>19.8%</u>	35.3%
Illinois	20.9%	<u>74.5%</u>	43.3%	58.8%	<u>8.6%</u>	<u>31.4%</u>	5.3%	<u>39.6%</u>	<u>37.6%</u>	38.2%
Indiana	14.7%	88.4%	44.1%	60.5%	4.5%	27.5%	4.8%	41.8%	20.8%	32.0%
Iowa	23.0%	89.5%	51.8%	70.2%	1.7%	<u>33.4%</u>	2.6%	<u>46.2%</u>	20.3%	30.7%
Kansas	16.0%	88.5%	46.0%	65.5%	<u>8.9%</u>	31.4%	5.7%	<u>37.2%</u>	<u>25.7%</u>	29.8%
Kentucky	19.0%	87.9%	42.5%	68.5%	<u>2.8%</u>	31.3%	5.9%	<u>42.4%</u>	15.5%	26.2%
Louisiana	<u>16.8%</u>	88.7%	43.6%	67.5%	3.1%	31.2%	11.8%	<u>57.8%</u>	<u>27.2%</u>	32.6%
Maine	28.0%	88.2%	47.7%	63.1%	<u>6.3%</u>	<u>34.2%</u>	<u>7.3%</u>	<u>47.1%</u>	20.3%	36.2%
Maryland	16.2%	87.4%	53.4%	60.1%	<u>5.5%</u>	<u>32.0%</u>	5.0%	<u>49.9%</u>	<u>17.6%</u>	26.5%
Massachusetts	17.9%	87.9%	51.7%	60.7%	6.1%	33.2%	2.7%	41.1%	22.9%	39.9%

Notes: Percentages in table reflect values for children with special healthcare needs. Estimates underlined may be unreliable and should be interpreted with caution, as they have a 95% confidence interval that exceeds +/- 10 percentage points or 1.2 times the estimate.

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- Higher than national, but not significant.
- Significantly higher than national.
- Suppressed due to small sample size.

Source: Manatt Health analysis of pooled 2016–2017 NSCH data.

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National	16.7%	83.0%	43.2%	61.8%	5.2%	32.4%	6.6%	50.1%	27.3%	35.3%
Michigan	15.9%	88.9%	49.8%	65.7%	<u>7.3%</u>	24.5%	4.5%	46.4%	17.5%	31.4%
Minnesota	23.2%	89.4%	51.4%	<u>64.3%</u>	<u>6.2%</u>	<u>26.4%</u>	<u>4.8%</u>	<u>40.3%</u>	<u>22.2%</u>	39.7%
Mississippi	<u>25.0%</u>	<u>78.8%</u>	43.7%	66.9%	<u>4.8%</u>	<u>19.6%</u>	8.0%	46.6%	<u>15.7%</u>	30.7%
Missouri	<u>21.5%</u>	87.2%	48.5%	60.7%	<u>4.5%</u>	<u>28.5%</u>	<u>4.6%</u>	<u>46.3%</u>	13.7%	31.3%
Montana	22.7%	<u>82.9%</u>	39.8%	58.9%	<u>4.8%</u>	<u>26.5%</u>	1.5%	<u>37.3%</u>	<u>26.7%</u>	42.3%
Nebraska	<u>27.5%</u>	87.4%	57.0%	<u>67.5%</u>	<u>5.0%</u>	<u>33.1%</u>	<u>4.1%</u>	<u>37.1%</u>	<u>15.3%</u>	27.2%
Nevada	8.1%	<u>75.2%</u>	29.5%	<u>53.2%</u>	<u>5.3%</u>	36.6%	<u>8.6%</u>	<u>51.7%</u>	<u>43.4%</u>	<u>46.1%</u>
New Hampshire	19.5%	88.5%	50.8%	58.9%	<u>2.9%</u>	22.9%	2.4%	<u>44.1%</u>	13.4%	31.4%
New Jersey	<u>13.7%</u>	83.1%	35.2%	52.4%	<u>4.1%</u>	<u>35.3%</u>	<u>11.9%</u>	<u>64.2%</u>	<u>27.3%</u>	42.9%
New Mexico	22.1%	88.0%	42.0%	62.2%	4.3%	38.0%	3.3%	<u>56.9%</u>	<u>31.2%</u>	39.2%
New York	<u>13.7%</u>	82.4%	44.8%	67.6%	<u>5.3%</u>	<u>26.5%</u>	<u>3.6%</u>	<u>35.7%</u>	<u>19.1%</u>	25.7%
North Carolina	<u>22.4%</u>	<u>81.8%</u>	46.9%	64.6%	<u>2.5%</u>	<u>39.5%</u>	5.1%	<u>43.4%</u>	<u>23.0%</u>	32.3%
North Dakota	21.3%	84.3%	47.0%	67.2%	<u>2.9%</u>	<u>39.1%</u>	1.7%	<u>39.5%</u>	20.9%	29.7%
Ohio	13.6%	82.7%	45.1%	63.8%	<u>2.3%</u>	<u>26.9%</u>	<u>5.1%</u>	<u>45.1%</u>	<u>27.8%</u>	29.4%
Oklahoma	16.3%	83.5%	46.4%	67.2%	<u>5.3%</u>	<u>46.3%</u>	3.9%	32.9%	<u>27.4%</u>	30.5%
Oregon	16.5%	87.5%	38.5%	54.5%	<u>4.5%</u>	<u>39.3%</u>	5.2%	<u>54.8%</u>	50.4%	38.8%
Pennsylvania	15.7%	83.9%	45.8%	62.9%	<u>3.9%</u>	<u>33.3%</u>	2.5%	<u>51.9%</u>	<u>22.2%</u>	35.1%

Notes: Percentages in table reflect values for children with special healthcare needs. Estimates underlined may be unreliable and should be interpreted with caution, as they have a 95% confidence interval that exceeds +/- 10 percentage points or 1.2 times the estimate.

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National	16.7%	83.0%	43.2%	61.8%	5.2%	32.4%	6.6%	50.1%	27.3%	35.3%
Rhode Island	15.1%	<u>81.7%</u>	41.5%	59.6%	<u>2.2%</u>	<u>23.0%</u>	4.1%	<u>49.0%</u>	<u>28.3%</u>	31.4%
South Carolina	17.9%	94.4%	48.4%	67.7%	<u>7.3%</u>	<u>32.9%</u>	<u>10.3%</u>	<u>49.7%</u>	<u>26.5%</u>	31.2%
South Dakota	31.2%	<u>79.6%</u>	49.5%	70.6%	0.8%	<u>49.1%</u>	3.6%	<u>44.0%</u>	<u>21.0%</u>	28.8%
Tennessee	14.3%	89.7%	50.4%	70.0%	<u>6.0%</u>	<u>20.0%</u>	5.9%	<u>36.5%</u>	<u>16.6%</u>	23.8%
Texas	8.4%	<u>79.9%</u>	35.0%	<u>50.5%</u>	<u>7.8%</u>	<u>35.3%</u>	<u>12.6%</u>	<u>61.4%</u>	<u>29.8%</u>	<u>41.0%</u>
Utah	19.3%	91.0%	47.2%	59.3%	<u>2.7%</u>	<u>30.1%</u>	10.7%	<u>56.2%</u>	<u>28.9%</u>	38.7%
Vermont	20.4%	88.6%	47.5%	61.0%	<u>2.5%</u>	<u>33.5%</u>	2.9%	<u>55.3%</u>	<u>28.3%</u>	30.2%
Virginia	<u>28.1%</u>	92.0%	44.1%	60.8%	<u>3.7%</u>	<u>31.0%</u>	<u>7.5%</u>	<u>55.2%</u>	<u>20.7%</u>	30.3%
Washington	38.6%	<u>83.7%</u>	45.7%	64.8%	<u>2.9%</u>	<u>32.2%</u>	5.4%	<u>41.1%</u>	<u>30.6%</u>	37.1%
West Virginia	14.5%	84.7%	47.8%	59.0%	<u>7.8%</u>	30.4%	4.5%	<u>41.3%</u>	<u>36.9%</u>	31.1%
Wisconsin	19.1%	82.6%	40.9%	55.5%	<u>4.5%</u>	<u>34.3%</u>	<u>6.8%</u>	<u>50.2%</u>	17.9%	34.4%
Wyoming	16.4%	88.1%	43.7%	63.2%	<u>4.5%</u>	<u>28.7%</u>	<u>5.7%</u>	<u>32.6%</u>	<u>11.8%</u>	36.2%

Notes: Percentages in table reflect values for children with special healthcare needs. Estimates underlined may be unreliable and should be interpreted with caution, as they have a 95% confidence interval that exceeds +/- 10 percentage points or 1.2 times the estimate.

- Significantly lower than national.
- Lower than national, but not significant.
- Higher than national, but not significant.
- Significantly higher than national.

Suppressed due to small sample size.

Source: Manatt Health analysis of pooled 2016–2017 NSCH data.

Appendix 2: Methodology

1. Literature review and catalog of federal requirements. Manatt conducted a literature review to identify other research on EPSDT and access to care for children with special healthcare needs in order to leverage existing research and identify best practices. Manatt also reviewed federal statute, regulations and subregulatory guidance that set forth the federal parameters on EPSDT and how states need to ensure access to Medicaid services for children with special healthcare needs. See Appendix 3 for the Catalog of Federal Guidance on EPSDT.

2. National expert and family member interviews. Manatt interviewed eight national experts in EPSDT and access to care for children with special healthcare needs. Interviews were conducted by phone and ranged from 30 to 60 minutes, and interview guides were shared in advance. Manatt also interviewed family members of children with special healthcare needs from 13 states during a monthly Family Voices State Affiliate Organizations call.

National Expert and Family Member Interviewees

- **Margaret Comeau**, Senior Project Director, Boston University School of Social Work; Principal Investigator, Catalyst Center at Boston University
- **Family Voices** Affiliate Organizations from 13 states
- **Sara Rosenbaum**, Harold and Jane Hirsh Professor of Health Law and Policy and Founding Chair of the Department of Health Policy, Milken Institute School of Public Health, George Washington University
- **Elisabeth Wright Burak**, Senior Fellow, Georgetown Center for Children and Families
- **Tricia Brooks**, Senior Fellow, Georgetown Center for Children and Families; Associate Research Professor, Georgetown University McCourt School of Public Policy
- **Kelly Whitener**, Associate Professor, Georgetown University McCourt School of Public Policy's Center for Children and Families
- **Kay Johnson**, President, Johnson Group Consulting Inc.
- **Sarah Somers**, Managing Attorney, National Health Law Program and the Network for Public Health Law—Southeastern Region Office
- **Peggy McManus**, President, The National Alliance to Advance Adolescent Health

3. Data analysis. To shed light on the extent to which access to care differences exist across states, Manatt analyzed data from two sources: the NSCH for 2016–2017, with a focus on children with special healthcare needs, and the Child Core Set for FFY 2017 from CMS, which reflects various Medicaid/CHIP enrollee populations.

- The NSCH is designed to produce national- and state-level estimates for children ages 0–17, with approximately 1,400 respondents per state for the combined 2016–2017 data. Using the NSCH, Manatt assessed state-level performance on a variety of measures regarding utilization, usual/coordinated care, and unmet needs and other difficulties. For each measure, the assessment examined whether children with special healthcare needs in a state are significantly better or worse off than children with special healthcare needs nationwide, and whether children with special healthcare needs in a state are significantly better or worse off than children without special healthcare needs in that state.
- For the Child Core Set data, which consist of state-reported quality-of-care measures for Medicaid and CHIP enrollees, Manatt examined a state's Medicaid/CHIP performance relative to the national median for selected measures. While the Child Core Set is not designed to provide separate estimates for children with special healthcare needs, some of the measures do focus on specific subpopulations of interest (e.g., children using behavioral health care).
- Results were summarized in a series of state-level tables (see Appendix 1) designed to facilitate comparisons within and across states. Using findings from both sources, Manatt identified states where further inquiry into policies and practices might be warranted to inform the checklist of best-practice strategies for the issue brief.

4. State-specific review. Manatt selected eight states to do a “deep dive” review of their state regulations, State Plans, provider manuals and training, Medicaid managed care contracts, and any class action lawsuits around EPSDT or children with special healthcare needs. The states—Massachusetts, Minnesota, New Jersey, Tennessee, Texas, Virginia, Washington, D.C., and Washington State—were selected as “deep dive” states based on input gleaned from the literature review, national expert interviews and the data analysis. Manatt then conducted three interviews with state experts from Minnesota, Virginia and Washington, D.C., to learn more about their Medicaid policies and practices for ensuring access to care for children with special healthcare needs.

State Expert Interviewees

- **Marie Zimmerman**, Assistant Commissioner of Health Care and State Medicaid Director, Minnesota Department of Human Services
- **Samantha Mills**, Health Care Policy Director, Minnesota Department of Human Services
- **Pamela Weiner**, Managed Care Contracts and Compliance Manager, Minnesota Department of Human Services
- **Heather Peterman**, Care Delivery and Payment Reform Manager, Minnesota Department of Human Services
- **Tammy Whitlock**, Deputy Director of Complex Care and Services, Virginia Department of Medical Assistance Services
- **Adrienne Fegans**, Senior Program Administrator, Virginia Department of Medical Assistance Services
- **Colleen Sonosky**, Associate Director of DCHS, Washington, D.C., DHCF

Appendix 3: Catalog of Federal Guidance on Early and Periodic Screening, Diagnostic, and Treatment (EPSDT)

This table catalogs the federal statute, regulations, and subregulatory guidance with respect to EPSDT. A vast array of subregulatory guidance has been released since the introduction of EPSDT in 1967, subsequently improving access to care for children with special healthcare needs.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
Federal Statute	
Social Security Act § 1902(a)(43)	<ul style="list-style-type: none"> • States must adhere to administrative and reporting requirements: <ul style="list-style-type: none"> – Inform EPSDT-eligible enrollees of the availability and the importance of EPSDT services, including immunizations. – Arrange for screenings and corrective treatment (directly or through a referral) for any condition detected by a screening. – Report annually to CMS information related to the provision of EPSDT services: <ul style="list-style-type: none"> ▪ The number of children that received screenings. ▪ The number of children referred for corrective treatment. ▪ The number of children that received dental services/information. ▪ The state's achievement with respect to participation.
Social Security Act § 1905(a)(4)(B)	<ul style="list-style-type: none"> • Provides for coverage of EPSDT services for Medicaid eligible individuals under the age of 21.
Social Security Act § 1905(a)(16)	<ul style="list-style-type: none"> • The Cures Act amends the Medicaid benefit to require the provision of EPSDT services for children who are receiving inpatient psychiatric hospital services (effective January 1, 2019).
Social Security Act § 1905(a)(29)	<ul style="list-style-type: none"> • Provides for coverage of all medically necessary services, including “any other medical care, and any other type of remedial care recognized under state law, specified by the Secretary [of HHS].”
Social Security Act § 1905(r)	<ul style="list-style-type: none"> • The Omnibus Budget Reconciliation Act 89 amended sections 1902(a)(43) and 1905(a)(4)(B) and created Section 1905(r) of the Social Security Act, which defines EPSDT to include: <ul style="list-style-type: none"> – Screening Services. At periodic, age-appropriate intervals as determined by the state after consultation with recognized medical and dental organizations involved in child healthcare and at “such other intervals, as indicated as medically necessary, to determine the existence of a suspected illness or condition.” Screening services include: <ul style="list-style-type: none"> ▪ Comprehensive health and developmental history. ▪ Comprehensive unclothed physical exam. ▪ Appropriate immunizations based on the Advisory Committee on Immunization Practices (ACIP). ▪ Laboratory tests (including lead blood level assessment appropriate for age and risk factors). ▪ Health education (including anticipatory guidance). ▪ Vision testing. ▪ Dental screenings and referrals to a dentist. ▪ Hearing testing. – Diagnostic Tests. To follow up on identified risks.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
	<ul style="list-style-type: none"> - Treatment Services. Found to be medically necessary to “correct or ameliorate defects and physical and mental illnesses and conditions” discovered by screenings, regardless of whether or not the services are covered under the State Plan (states must cover all mandatory and optional Medicaid services). Treatment services include: <ul style="list-style-type: none"> ▪ Vision services, which at minimum must include treatment for defects in vision, including eyeglasses. ▪ Dental services, which at a minimum must include relief of pain and infections, restoration of teeth, and maintenance of dental health. ▪ Hearing services, which at a minimum must include treatment for defects in hearing, including hearing aids. • Each year, the Secretary of HHS shall set annual EPSDT participation goals for each state.
Federal Regulations	
42 CFR § 431.615	<ul style="list-style-type: none"> • Sets forth requirements for partnerships between state Medicaid agencies and Title V grantees, including for the provision of maternal and child health (MCH) services: <ul style="list-style-type: none"> - State Plans must describe what services the Title V grantees will provide to Medicaid enrollees as well as methods for early identification of individuals under age 21 in need of medical or remedial services. - State Plans must also describe the payment arrangement between the state and Title V grantees. If the Title V grantee requests reimbursement for services provided to Medicaid enrollees, the state Medicaid agency must reimburse the grantee or provider for the cost of the services. Federal financial participation is available for expenditures for Medicaid services provided by Title V grantees.
42 CFR § 441.50-441.62	<ul style="list-style-type: none"> • Describes the State Plan requirements for providing EPSDT to enrollees under age 21. <ul style="list-style-type: none"> - Required Activities. <ul style="list-style-type: none"> ▪ <u>Informing Eligible Enrollees About EPSDT.</u> Within 60 days of initial Medicaid eligibility determination and then on an annual basis for families that have not utilized EPSDT, states must inform eligible enrollees of the EPSDT program through a combination of written and oral communication methods using clear and nontechnical language. This includes informing enrollees about the benefits of preventive healthcare; the services available under the EPSDT program and where and how to obtain those services; that services are free of charge for children under age 18 (and up to age 21 at the state’s option); and that necessary transportation and appointment scheduling assistance are available upon request. States must effectively inform individuals who are blind or deaf, or who cannot read or understand the English language. ▪ <u>Screening.</u> States must provide regularly scheduled screenings for physical and mental health, growth, development, and nutritional status. Screenings must be provided in accordance with reasonable standards of medical and dental practice after consultation with recognized medical and dental organizations involved in child healthcare. At a minimum, the screenings must include, but are not limited to, comprehensive health and developmental history; comprehensive unclothed physical exam; appropriate vision, hearing and lab testing; and dental screening services furnished by direct referral to a dentist for children beginning at age 3. A state may request an exception from this age requirement up to age 5 for a two-year period and may request additional two-year exceptions by demonstrating to CMS that there is a shortage of dentists that prevents the state from meeting the age 3 requirement.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
	<ul style="list-style-type: none"> ▪ Diagnosis and Treatment. In addition to any diagnostic and treatment services included in the State Plan, the state must provide the following services if a need is indicated by a screening, even if the services are not included in the State Plan: <ul style="list-style-type: none"> » Diagnosis of and treatment for defects in vision and hearing, including eyeglasses and hearing aids. » Dental care, at as early an age as necessary, needed for relief of pain and infections, restoration of teeth, and maintenance of dental health. » Appropriate immunizations. ▪ Accountability. States must maintain records and program manuals, a description of their EPSDT screening benefit packages, and copies of rules and policies describing the methods used to inform eligible enrollees about EPSDT. ▪ Timeliness. Treatment services, if indicated as needed by a screening, must be initiated within six months. – Discretionary Services. States may provide any medical or remedial service that could be covered under Medicaid, regardless of whether the service is covered under the State Plan or provided in a lesser amount, duration or scope to other Medicaid enrollees. – Periodicity Schedule. States must implement a periodicity schedule for screening services that meets reasonable standards of medical and dental practices after consultation with recognized medical and dental organizations involved in child healthcare; the schedule must describe the services available during different stages of life, beginning with a neonatal exam, and provide for additional necessary screening services. – Requests for EPSDT Screening Services. Screenings must be provided to enrollees upon request, except in instances where the screening has already been provided. – Continuing Care Providers. Enrollees and providers may enter into a continuing care arrangement where the enrollee agrees to use one provider as his or her regular source of the EPSDT services for a stated period of time. Continuing care providers must provide all EPSDT services (except for dental services, which they must refer to a dentist or to the state if not directly provided), and transportation and scheduling assistance, which providers must also refer to the state if not directly provided. States must monitor providers' compliance with their continuing care agreements. – Utilization of Providers and Coordination With Related Programs. States must provide a variety of referrals for necessary treatment if treatment is not covered by the enrollee's managed care organization (MCO), including giving the family or enrollee the names, addresses and telephone numbers of a variety of individual and group providers who have expressed a willingness to furnish uncovered services at little or no expense to the family. States must also coordinate with Title V grantees and other related programs, such as Head Start and the Special Supplemental Food Program for Women, Infants, and Children (WIC). – Transportation and Scheduling Assistance. States must offer and provide necessary assistance with scheduling appointments and transportation.
Federal Subregulatory Guidance	
State Medicaid Director Letters	
<p>(October 1998) Key Approaches to the Use of Managed Care Systems for Persons With Special Health Care Needs</p>	<ul style="list-style-type: none"> • Provides optional guidance to states for designing and implementing Medicaid managed care (MMC) quality strategies for enrollees with special healthcare needs. • Recommends that states use the guidance when planning MMC programs for persons with special healthcare needs as part of 1115 and 1915(b) waivers, voluntary managed care programs, and State Plan option programs to: <ul style="list-style-type: none"> – Quantify the population needs. – Identify special characteristics relevant to the population's access and use of primary/specialty services.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
	<ul style="list-style-type: none"> – Tailor purchasing specifications and delivery systems contracts to create value-based systems of care. – Ensure adequate access to services and provider networks, while addressing this population's social and support needs.
(October 1999) Lead Screening: GOA Report and HHS Taskforce	<ul style="list-style-type: none"> • Clarifies the EPSDT lead screening policy: <ul style="list-style-type: none"> – Requires coverage of screenings for blood lead levels for all children enrolled in Medicaid at 12 and 24 months. – Requires coverage of screenings for blood lead levels for children over the age of 24 months, up to 72 months, without a previous record of a screening for blood lead level. – Requires coverage of any follow-up services, including diagnostic and treatment services determined to be medically necessary (i.e., case management services and one-time investigations to determine the source of lead poisoning). • Clarifies that CMS only reimburses for a health professional's time and activities during an on-site investigation of a child's home, but not for testing environmental substances such as water, paint or soil. • Encourages states that contract with MCOs to provide EPSDT services to Medicaid-eligible children to consider including specific language on lead screening requirements in MCO contracts.
(January 2000) Olmstead Decision	<ul style="list-style-type: none"> • Urges states to increase access to community-based services for individuals with disabilities in light of the ruling in the case <i>Olmstead v. L.C.</i>, in which the Supreme Court affirmed the right of individuals with disabilities to receive public benefits and services in the most integrated setting appropriate to their needs. • Encourages states to prevent and correct inappropriate institutionalization.
(December 2000) Foster Care Independence Program and Coverage for Individuals Transitioning from Foster Care	<ul style="list-style-type: none"> • States that the Foster Care Independence Act establishes an optional Medicaid eligibility group for foster care youth ages 18–21. • Reaffirms that when an EPSDT screening detects a physical or mental condition, the child is then eligible to receive medically necessary diagnostic, treatment and follow-up services, regardless of whether or not they are listed in the State Plan.
(January 2001) Tools to Improve State Health and Long-term Service Systems - Nursing Facility Transition Grants, Real Choice Systems Change Grants, Community-Based Attendant Services (Olmstead Update No. 5)	<ul style="list-style-type: none"> • Notifies states of federal guidance and a series of grants available to assist states in enabling individuals with disabilities to live in the most integrated setting appropriate for their needs.
(January 2001) Home and Community-Based Services Waivers Limits (Olmstead Update No. 4)	<ul style="list-style-type: none"> • Clarifies that states may utilize enrollment caps for their HCBS waivers. • Clarifies that states may use HCBS waivers to supplement services otherwise available to children under Medicaid, or to provide services to children who otherwise would not be eligible for Medicaid. • HCBS waivers do not, however, supplant a state's option to provide EPSDT services. Children enrolled in HCBS waivers must also be provided EPSDT screening and treatment services. • Clarifies that CMS considers any encounter with a healthcare professional practicing within the scope of his/her practice to be an interperiodic screening. When a periodic or interperiodic screening reveals the existence of a problem, EPSDT requires that Medicaid-eligible children receive all services necessary to diagnose, treat or ameliorate defects identified as long as the service is a covered Medicaid service (i.e., the service could be part of the basic Medicaid benefit if the state elected the broadest benefits permitted under federal law).

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
<p>(January 2001) Improving Children's Access to Dental Services State Compliance</p>	<ul style="list-style-type: none"> • Section 1902(a)(43) of the Social Security Act specifically requires State Plans to provide or arrange for dental services and to report to the Secretary of HHS on the number of children receiving dental services. • Explains how CMS will assess state compliance with children's access to dental services under Medicaid in the following areas: <ul style="list-style-type: none"> – Outreach and administrative case management for children. – Adequacy of Medicaid reimbursement rates. – Increasing provider participation. – Claims reporting and processing.
<p>(January 2001) Review Criteria for Children with Special Health Care Needs Mandatorily Enrolled in Managed Care</p>	<ul style="list-style-type: none"> • Section 1915(b)(1) of the Social Security Act requires that programs that waive freedom-of-choice of provider must not substantially impair access to services of adequate quality when medically necessary. • Includes federal review criteria to ensure that children with special healthcare needs who are mandatorily enrolled in MMC programs receive the services to which they are entitled. <ul style="list-style-type: none"> – Auto-assignment processes that assign children with special healthcare needs to an MCO must have a public process during the development and ongoing operation of the MMC program with relevant parties (e.g., advocates, providers, families, caregivers, consumer groups, state agencies, MCOs). – States must develop a definition of children with special healthcare needs, and at a minimum must include: <ul style="list-style-type: none"> ▪ Blind/disabled children and related populations (eligible for SSI under Title XVI). ▪ Eligible under Section 1902(e)(3) of the Social Security Act. ▪ In foster care or other out-of-home placement. ▪ Receiving foster care or adoption assistance. ▪ Receiving services through a family-centered, community-based coordinated care system that receives grant funds under Section 501(a)(1)(D) of Title V, as defined by the state in terms of either program participant or special healthcare needs. – States identify and/or require MCOs to identify children with special healthcare needs once they are enrolled in MMC. States indicate which entity is to determine whether a child has a special healthcare need and provide information on screening tools and linkages with other state agencies such as Child Protective Services and Title V. <ul style="list-style-type: none"> ▪ States perform outreach activities that are targeted specifically to reach children with special healthcare needs and their families, caregivers, providers and other interested parties. ▪ Auto-assignment processes assign children with special healthcare needs to an MCO that includes their current primary care provider (PCP) and/or specialists or to an MCO that is capable of providing a medical home. ▪ Children with special healthcare needs can disenroll into fee-for-service (FFS) or transfer enrollment into another MCO for good cause or without cause. – States ensure that the MCOs have sufficient provider and specialist capacity as well as capacity to provide case management to children with special healthcare needs. – States have specific performance measures for children with special healthcare needs and specific performance improvement projects (PIPs) that address issues for children with special healthcare needs. – States develop a payment methodology that accounts for children with special healthcare needs enrolled in capitated managed care. – Contracts with MCOs must specify what constitutes medical necessity for children with special healthcare needs.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
	<ul style="list-style-type: none"> - With respect to children with special healthcare needs, states are required to monitor/ensure: <ul style="list-style-type: none"> ▪ Access to services (including EPSDT), quality of care, coordination of care and enrollee satisfaction. ▪ Compliance with Americans with Disabilities Act (ADA) access requirements for enrollees with physical disabilities. ▪ MCO contracts must specify what constitutes medical necessity for children with special healthcare needs, and that definition must be available to families and advocates. ▪ Approvals/authorizations of services are done in a timely fashion. ▪ Service authorization policies are consistent with the medical necessity contract specifications and any practice guidelines adopted by the MCO that are relevant to children with special healthcare needs.
(January 2001) Coverage of Asthma and Asthma-Related Services	<ul style="list-style-type: none"> • Explains that certain state Medicaid prescription drug and medical equipment policies could pose barriers to appropriate asthma management and violate EPSDT service requirements; directs states to review Medicaid utilization controls and policies that could pose barriers. • Section 1905(r)(5) of the Social Security Act requires states to provide all medically necessary services regardless of whether the service is specified in the State Plan or has utilization limits generally. States cannot apply utilization limits to EPSDT services. • If a state requires prior authorization of asthma-related drugs, supplies or equipment under EPSDT, the state must ensure that these items are provided in a timely manner. • Important asthma-related supplies and equipment include inhalers, nebulizers, peak flow meters and spacers. Although expenditures for these items are covered under the home health benefit, the items can be provided by home health agencies, pharmacies, medical equipment suppliers or other providers. • Encourages states to implement disease management programs for asthma coordinated by pharmacists and other nonphysician practitioners. • Encourages states to establish procedures that allow pharmacies to be providers of asthma-related supplies and equipment under the Medicaid home health benefit.
(December 2004) Assuring Receipt of Influenza Shots for Children Eligible for Vaccines for Children (VFC) Program	<ul style="list-style-type: none"> • Clarifies that under EPSDT, Medicaid children under age 21 must be vaccinated based on the ACIP recommendations. • While children younger than age 19 are eligible for the VFC program, states also must cover influenza vaccinations for Medicaid children ages 19 and 20 in an ACIP high-priority group.
(May 2010) Community Living Initiative—Olmstead	<ul style="list-style-type: none"> • Announces a community living initiative to address barriers to community living for individuals with disabilities. • Reaffirms CMS' commitment to policies outlined in the Olmstead letters, and offers technical assistance and resources to promote the goals of the ADA.
(September 2010) Hospice Care for Children in Medicaid and CHIP	<ul style="list-style-type: none"> • Provides guidance to states on an ACA provision titled "<i>Concurrent Care for Children</i>," which requires states to make hospice services available to children eligible for Medicaid without forgoing any other service to which the child is entitled under Medicaid for the treatment of a terminal condition (e.g., pain and symptom management and family counseling). • EPSDT requires states to provide all medically necessary services, including hospice services, to children under age 21.
(January 2011) New Medicaid Tobacco Cessation Services	<ul style="list-style-type: none"> • Under EPSDT, states are required to provide medically necessary tobacco services (including counseling, pharmacotherapy and tobacco cessation drug therapy) for children under age 21. • EPSDT also includes anticipatory guidance and risk-reduction counseling for tobacco use during routine well-child visits.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
(November 2011) Tri-Agency Letter on Appropriate Use of Psychotropic Medications Among Children in Foster Care	<ul style="list-style-type: none"> Encourages states to use their Drug Utilization Review (DUR) programs to monitor dispensing of psychotropic medications to children in foster care at the point of service and to influence prescriber behavior.
(November 2012) Essential Health Benefits in the Medicaid Program	<ul style="list-style-type: none"> Through Alternative Benefit Plans (ABPs), states provide either “benchmark” or “benchmark-equivalent” coverage. Requires states to include EPSDT either as part of the benefit package or through a combination of the benefit package and additional services. Certain populations, such as people who are blind and disabled, are exempt from mandatory enrollment in an ABP, but states are permitted, however, to offer voluntary enrollment in an ABP to those exempt groups.
(July 2013) Tri-Agency Letter on Trauma-Informed Treatment	<ul style="list-style-type: none"> Recommends the integrated use of trauma-focused screening, functional assessments and evidence-based practices in child-serving settings to promote child well-being. Under EPSDT, children under age 21 are entitled to periodic screenings, including a comprehensive health and developmental history, which includes an assessment of both physical and mental health development. A child may require an interperiodic screening as a result of a change in living circumstances (e.g., foster care placement move), entry into the foster care systems and a change of behavioral health needs (e.g., school suspension or referral to residential psychiatric care). Screenings may trigger medically necessary diagnostic or treatment services, including services related to behavioral health.
(November 2018) Opportunities to Design Innovative Service Delivery Systems for Adults with a Serious Mental Illness or Children with a Serious Emotional Disturbance	<ul style="list-style-type: none"> Recommends incorporating an age-appropriate, evidence-based screening tool to identify mental health conditions and substance use disorder (SUD) early into EPSDT-required well-child visits. Clarifies that behavioral health counseling could be covered under the rehabilitative services benefit. Clarifies that states would not need to submit a State Plan Amendment (SPA) to add EPSDT coverage for screening and behavioral health services. States may, however, submit a SPA at their option to clarify services covered in the school setting. In other words, states interested in making school-based mental health screening and behavioral health counseling more widely available could do so under EPSDT. Notes that providing behavioral health screenings and mental health/SUD services in schools is an important component of identifying and engaging children with a SED; recommends that states ensure that their MCOs allow for reimbursement of school-based providers. Clarifies that Section 12005 of the 21st Century Cures Act requires Medicaid reimbursement for EPSDT services to individuals under age 21 receiving inpatient psychiatric services (effective January 1, 2019).
Center for Medicaid and CHIP Services Informational Bulletins (CIBs)	
(March 2012) Medicaid Lead Screening and External Quality Review Organization (EQRO) Protocols	<ul style="list-style-type: none"> Notifies states of the plan to align the Medicaid lead screening policy with the Centers for Disease Control and Prevention (CDC) recommendations, which encourage targeted screening in states that have sufficient data to demonstrate that universal screening is not the most effective method of identifying exposure to lead. Allows states to target their limited resources to children most in need of these services, rather than continuing to universally screen all Medicaid-eligible children ages 1 and 2.

Federal Parameters for States to Ensure Access to Medicaid Services for Children	
Citation	Summary
(August 2012) Resources Strengthening the Management of Psychotropic Medications for Vulnerable Populations	<ul style="list-style-type: none"> • Encourages states to utilize the framework provided by their DUR programs to ensure the appropriate use of psychotropic medications for children in foster care. • Encourages states to explore how their DUR programs can partner with prescribers of psychotropic medications to implement a plan for screening children in foster care for trauma.
(November 2012) Inpatient Psychiatric Services for Individuals under age 21	<ul style="list-style-type: none"> • Clarifies that states may structure coverage and payment for inpatient psychiatric hospital or facility services for individuals under age 21 to ensure that children receiving this benefit obtain all services necessary to meet their medical, psychological, social, behavioral and developmental needs. • CMS has historically prohibited states from claiming expenditures under the inpatient psychiatric facility benefit unless the expenditures were made to qualified providers of such services. This had the effect of denying coverage for other medically necessary Medicaid items and services, such as prescription drugs or practitioner services that were not included by the state as part of the rate paid to the facility for care but would be available under other benefit categories for individuals who do not reside in an Institution for Mental Diseases (IMD) such as EPSDT services. • Explains that several Departmental Appeals Board decisions have clarified that other covered services can be provided as part of the inpatient psychiatric facility benefit, even when payment was made to an individual practitioner or supplier other than the inpatient psychiatric facility itself, when services are furnished to a child residing in a facility, authorized under the child's Plan of Care, and provided under an arrangement with the facility. • Therefore, CMS is applying State Plan flexibility to allow states to directly reimburse individual practitioners or suppliers of arranged services the same fees as would otherwise be applicable when the services are provided to Medicaid enrollees under the State Plan outside the IMD.
(March 2013) Prevention and Early Identification of Mental Health and Substance Use Conditions	<ul style="list-style-type: none"> • Provides screening tools and trainings to help states provide mental health and SUD services under EPSDT. • Under EPSDT, eligible individuals must be provided periodic screenings (well-child exams), which include an assessment of physical and mental health development, including an age-appropriate mental health and substance use health screening. • If during a routine periodic screening a provider determines that there may be a need for further assessment, the individual should be provided additional diagnostic and/or treatment service. • EPSDT also ensures that children receive medically necessary physician screenings in order to detect a suspected illness or condition not present or discovered during the periodic exam. The screening may also trigger the need for a further assessment to diagnose or treat a mental health condition and/or SUD. • Recommends that states: <ul style="list-style-type: none"> – Leverage clinical guidelines to inform screening tools to identify children and adolescents with a mental health condition and/or SUD. – Assist providers in locating treatment and support resources for individuals with a mental health condition and/or SUD. – Collect and report on core measures from clinical quality reporting programs, which include measures related to screening and early intervention for children and youth with potential mental health conditions and SUD (e.g., screening for clinical depression and follow-up plan among individuals ages 12 and older; use of screening tools for potential delays in social and emotional development during the first three years of life; follow-up after hospitalization for mental illness among patients 6 years and older; child and adolescent major depressive disorder: suicide risk assessment; maternal depressions screening; and follow-up care for children prescribed ADHD medication).

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	<ul style="list-style-type: none"> • Includes examples of approaches to screening, follow-up treatment and quality improvement in various states: <ul style="list-style-type: none"> – Massachusetts: Provides universal behavioral health screenings of Medicaid members under age 21 through the Children’s Behavioral Health Initiative, a program that the state was required to implement as part of a legal judgment (Rosie D. v. Patrick). Primary care clinicians are required to use one of several approved screening tools during well-child visits. – North Carolina: The Assuring Better Child Health and Development program relied on the state’s 14 local community care networks to improve EPSDT screening efforts. Much of North Carolina’s success was due to improved communication, identifying standard screening tools and training providers. – Colorado: Developed a mental health toolkit for providers that included depression screening resources and tools; a specific Current Procedural Terminology code for depression screening in adolescents; and recommendations for making referrals to the state’s Behavioral Health Organizations and other community resources. – South Carolina: The state’s CMS Children’s Health Insurance Program Reauthorization Act of 2009 grant supports quality improvement work at pediatric practices. Efforts focus on pediatric care, health information technology, a physician-led quality improvement network, and the integration of mental health into the pediatric medical home model. Practices are provided with standardized mental health screening tools and coordination with mental health providers.
(April 2013) CMS Oral Health Initiative and Other Dental-Related Items	<ul style="list-style-type: none"> • CMS has invited states to develop Oral Health Action Plans to promote preventive dental services for children. • The American Dental Association’s Current Dental Terminology (CDT) provides two codes—D0190 screening of a patient and D0191 assessment of a patient—that do not require a dentist to render the services. • States must submit a SPA if they would like to cover or alter payment rates for these services.
(May 2013) Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions	<ul style="list-style-type: none"> • Assists states in designing a benefit that will meet the needs of children, youth and young adults with significant mental health conditions. Provides an overview of services that enable children—many of whom have traditionally been served in restrictive settings such as residential treatment centers, group homes and psychiatric hospitals—with complex mental health needs to live and participate in community settings. • Developing these services will help states comply with their obligations under the ADA and EPSDT, specifically with respect to mental health and SUD services. • Services include intensive care coordination; family and youth peer support services; intensive in-home services; respite services; mobile crisis response and short-term residential crisis stabilization services; and flex funds to purchase nonrecurring setup expenses (e.g., furniture, bedding or clothing for children; a one-time payment of utilities or rent; or academic coaching or memberships to local girls or boys clubs). Other HCBS services such as mentoring and supported employment for older youth may be provided through Section 1915(c) and Section 1915(i) authority. • To address trauma, states may provide training and coaching for clinicians in evidence-based practices such as Trauma-Focused Cognitive Behavioral Therapy and Parent-Child Interaction Therapy. • States may use the following authorities to cover mental health and SUD for children with significant mental health conditions: 1905(a); 1915(c); 1915(b); 1115 demonstrations; 1915(i); Section 2703 health homes; Money Follows the Person Rebalancing Demonstration; and Balancing Incentive Program. • States are encouraged to use the following reporting measures: follow-up after hospitalization for mental illness among patients 6 years and older; and child and adolescent major depressive disorder: suicide risk assessment.

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(November 2013) Update on Preventive Services Initiatives	<ul style="list-style-type: none"> • Defines preventive services in Section 1905(a)(13) of the Social Security Act as those that must be “recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under state law.” • Clarifies that preventive services may be provided, at the state’s option, by practitioners other than physicians or other licensed practitioners. • States that the U.S. Preventive Services Task Force recommends that clinicians screen adolescents and adults ages 15–65 at least once for human immunodeficiency virus (HIV) infection.
(July 2014) Clarification of Medicaid Coverage of Services to Children with Autism	<ul style="list-style-type: none"> • Clarifies that services addressing autism spectrum disorder (ASD) may be reimbursed through the following authorities: <ul style="list-style-type: none"> – 1905(a); 1915(i); 1915(c); and 1115 demonstrations. • Clarifies that all children must receive EPSDT screenings to detect health and development issues, including ASD, as early as possible. • Clarifies that under EPSDT, states must cover services that could otherwise be covered at the state’s option that are determined to be medically necessary to correct or ameliorate any physical or behavioral conditions, including those that address ASD. • States should inform families of the 1905(a) services available to meet their children’s needs, including services of other licensed practitioners; speech, occupational and physical therapies; physician services; private-duty nursing; personal care services (PCS); home health, medical equipment and supplies; rehabilitative services; and vision, hearing and dental services. • States may provide 1915(i) and 1915(c) services and supports for ASD children that are above and beyond services listed in Section 1905(a), such as respite care, supported employment habilitative supports and environment modifications. Services may also be provided to help with the transition into adulthood. • Extended State Plan services related to Section 1905(a) services are not available to children under age 21 through 1915(c) and 1915(i) authority, as EPSDT is expected to meet the individual’s needs.
(July 2014) Update on CMS Oral Health Initiative and Other Oral Health Related Items	<ul style="list-style-type: none"> • Clarifies that all dental services, regardless of whether they are performed by a dentist or by another type of dental professional (e.g., dental hygienist or a dental therapist working under the supervision of a dentist), and regardless of whether the services are provided in a dental office or in a school or community setting, meet the EPSDT dental requirement. However, oral health services (i.e., those performed by a dental professional not under the supervision of a dentist or by another type of medical professional) do not meet the EPSDT dental requirement. • Clarifies that states may allow dental professionals who are permitted by the terms of their license to practice without dental supervision to enroll as Medicaid providers and bill Medicaid directly for their services. • Encourages states to adopt CDT codes (i.e., D0190 (screening of a patient) and D0191 (assessment of a patient)) that can be used in schools and day care centers, expanding access to children. • Encourages states to reimburse medical providers for children’s oral health services including risk assessment, fluoride varnish and anticipatory guidance. Primary care clinicians are encouraged to apply fluoride varnish to the primary teeth of all infants and children starting at the age of primary tooth eruption. • To encourage better performance, states may incorporate dental measures in their MMC contracts, quality strategies and PIPs. • Flags three additional risk-based CDT billing codes: <ul style="list-style-type: none"> – D0601 (caries risk assessment and documentation with a finding of low risk). – D0602 (caries risk assessment and documentation with a finding of medium risk). – D0603 (caries risk assessment and documentation with a finding of high risk).

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<p>(January 2015) Coverage of Behavioral Health Services for Youth with Substance Use Disorders</p>	<ul style="list-style-type: none"> • Provides evidence from Substance Abuse and Mental Health Services Administration's technical expert panel, intended to assist states in designing a SUD benefit and complying with EPSDT requirements; these requirements entitle children under age 21 to any treatment or procedure they need (as determined through an EPSDT screen) that is covered within any of the categories of Medicaid-covered services listed in Section 1905(a) of the Social Security Act if necessary to correct or ameliorate a condition. • Findings suggest a continuum of treatment and recovery services and supports for youth with SUD. Components of the continuum include: <ul style="list-style-type: none"> – Identification. Children should be screened for SUD and mental health disorders. A psychosocial assessment instrument should be used for children with positive screens to inform the treatment or service plan. – Outpatient treatment for youth with SUD, including individual counseling/therapies; group counseling; family therapy; intensive outpatient treatment; and partial hospitalization. – Medication-Assisted Treatment (MAT). – Case management/targeted case management. – Continuing care (e.g., home- or community-based weekly meetings with a clinician to discuss goals and activities). – Recovery services and supports (e.g., peer-to-peer recovery coaching/mentoring, technological support services, parent/caregiver support). – Residential treatment. • SUD services may be provided through the following authorities: 1905(a), 1915(b), 1915(c), 1915(i), Section 2703 health homes and 1115 demonstrations.
<p>(October 2015) Coverage of Early Intervention Services for First Episode Psychosis</p>	<ul style="list-style-type: none"> • Provides assistance to states in designing a benefit package for youth and young adults experiencing first-episode psychosis. • Early intervention services for individuals experiencing first-episode psychosis (e.g., schizophrenia) include recovery-oriented psychotherapy, family psychoeducation and support, supported employment and education, pharmacotherapy and primary care coordination, and case management. • Clarifies that children under age 21 experiencing first episode psychosis are entitled to periodic screening services (e.g., well-child exams) as well as any mental health screenings and services that are necessary and coverable under Section 1905(a) of the Social Security Act, such as targeted case management and preventive, rehabilitative and other licensed practitioner services. • Measures that address behavioral health concerns include: <ul style="list-style-type: none"> – Follow-up After Hospitalization for Mental Illness. – Child and Adolescent Major Depressive Disorder: Suicide Risk Assessment Follow-up Care for Children Prescribed ADHD Medication. – Behavioral Health Risk Assessment (for Pregnant Women).

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(March 2016) Coverage of Maternal, Infant, and Early Childhood Home Visiting Services	<ul style="list-style-type: none"> • Highlights the importance of home visiting to promote child development and improve child health. • Home visiting services include standard screenings (e.g., infant/child developmental screening, behavioral screening/rescreening); case management; family support, counseling and parent/caretaker skills training (e.g., stress management, child discipline and limit setting, and anger management). • EPSDT entitles children under age 21 to any medically necessary service that fits within any category of Section 1905(a) of the Social Security Act. • Clarifies that EPSDT allows states to target services to children, including those provided in the home. • Medicaid benefit categories that include services that may be furnished as part of a home visiting program include case management; preventive, rehabilitative, therapy, home health and other licensed practitioner services; and health homes.
(May 2016) Maternal Depression Screening and Treatment: A Critical Role for Medicaid in the Care of Mothers and Children	<ul style="list-style-type: none"> • Clarifies that since the maternal depression screening is for the direct benefit of the child, states may allow such screenings to be claimed as a service—specifically a risk assessment—for the child as part of EPSDT during a well-child visit. • If a problem is detected as a result of the screening, states are required to cover medically necessary diagnostic and treatment services to address the child's needs. • Diagnostic and treatment services directed solely at the mother would be coverable under the Medicaid program only if the mother is Medicaid eligible. Mothers who are not Medicaid eligible may receive some benefit from diagnostic and treatment services directed at treating the health and well-being of the child (such as family therapy services) to reduce or treat the effects of the mother's condition on the child. Such diagnostic and treatment services must actively involve the child, be directly related to the needs of the child, and be delivered to the child and mother together, but can be claimed as a direct service for the child. Such services also must be coverable under one or more Section 1905(a) benefit categories such as rehabilitative services or other licensed practitioner services. • States should encourage the child's provider to refer mothers for other appropriate care, including diagnosis, therapy and/or medication. Mothers who are Medicaid eligible should be referred to their PCPs or other appropriate providers. Mothers who are ineligible for Medicaid, or lose their eligibility 60 days postpartum, can be referred to community resources that offer appropriate mental health services. • Recommends that states and MCOs promote maternal depression screening among providers through provider trainings, continuing medical education and posting on provider websites. • States that cover maternal depression screening must reflect that they do so in MMC contracts and can include performance standards to ensure that the screening is widely performed.
(June 2016) Medicaid Benefits Available for the Prevention, Detection and Response to the Zika Virus	<ul style="list-style-type: none"> • Clarifies that services related to the detection and treatment of Zika and microcephaly or other Zika-related disabilities is covered without limit for children under age 21 under EPSDT. • Diagnostic services used for the detection of Zika include CAT scans, magnetic resonance imaging, ultrasounds, blood tests, urine tests and genetic testing. • Treatment includes targeted care management services, physical therapy and related services, prescribed drugs, and long-term services and supports.

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<p>(November 2016) Coverage of Blood Lead Testing for Children Enrolled in Medicaid and the Children's Health Insurance Program</p>	<ul style="list-style-type: none"> • Reminds states of the importance of blood lead screening for children and the requirement that Medicaid-covered children receive blood lead screening tests at ages 12 months and 24 months. Children between 24 months and 72 months with no record of a previous blood lead screening test must also receive the screening. • Completion of a risk assessment questionnaire does not meet the Medicaid requirement. The Medicaid requirement is met only when the two blood lead screening tests are conducted. • Reminds states that under EPSDT, Medicaid covers any service described in Section 1905(a) of the Social Security Act that is medically necessary to correct or ameliorate defects in physical and mental illnesses or conditions identified by the screening services, whether or not such service is otherwise covered under the State Plan. • Clarifies that Medicaid reimburses for lead investigations conducted by credentialed health practitioners, as well as blood samples drawn in physicians' offices. • Encourages states to work closely with state health departments if they wish to target lead screenings to children most in need of these services. States must have sufficient data to demonstrate that universal screening is not the most effective method of identifying exposure to lead. • Provides a number of recommendations to states, including: <ul style="list-style-type: none"> – Reviewing Form CMS-416 data submission to understand the screening rate and determine areas for improvement of data submission. – Reviewing member and provider materials to ensure the lead screening policy is clear and consistent. – Collaborating with the state health department to reach children who have not received required screenings. – Partnering with providers as well as nontraditional providers such as WIC, Federally Qualified Health Centers and school-based health centers. – Requiring MCOs to partake in efforts through contract provisions, quality measures, PIPs and quality strategies. – Developing a Health Services Initiative to increase blood lead screening rates.
<p>(December 2016) Strengthening Program Integrity in Medicaid Personal Care Services</p>	<ul style="list-style-type: none"> • Promotes increased access to HCBS for Medicaid enrollees who have a disability. • Coverage of PCS, which enables enrollees to live with independence in their homes or in other community settings, is required of states under EPSDT when services are medically necessary for children under age 21. • PCS typically includes nonmedical services supporting activities of daily living (e.g., movement, bathing, dressing, toileting and personal hygiene) and instrumental activities of daily living (e.g., meal preparation, money management, shopping and telephone use). • PCS is generally available either as agency-directed or self-directed.
<p>(January 2017) The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) Benefit for Children and Youth in Managed Care</p>	<ul style="list-style-type: none"> • Recommends that MMC contracts be prescriptive enough to describe what EPSDT includes and what entity is responsible for delivering it to ensure that eligible individuals under age 21 have access to all EPSDT services. <ul style="list-style-type: none"> – Contracts between the state and MCO must identify, define and specify the amount, duration and scope of each EPSDT service that the plan is required to provide to enrollees. – States can have their MCOs provide the full range of EPSDT services, or states can carve out some EPSDT services and provide them through FFS or contracts with other MCOs. If an MCO is not required under its contract to provide all EPSDT services, the contract must clearly describe which services are included. Similarly, if an MCO is expected to provide all EPSDT services, it must be clearly stated and described in the contract.

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	<ul style="list-style-type: none"> – Any EPSDT services not provided by the plan remain the responsibility of the state. If a MMC contract excludes benefits over specified limits, the state retains responsibility for providing necessary services above those limits. • MMC contracts should specify the entity responsible for notifying enrollees of EPSDT. <ul style="list-style-type: none"> – If the MCO's contract includes coverage of services within EPSDT, the plan's enrollee handbook must include information about EPSDT, both information on services provided by the plan and EPSDT services delivered outside the plan and how to access them, if applicable. • States must report EPSDT data, by age and by basis of eligibility, on child health screening services, referrals for corrective treatment and dental services to HHS annually. Fulfilling this obligation requires participation from the contracted MCOs, and contracts should ensure that states have access to the plan data necessary to meet this requirement. • States have options as to how to incorporate EPSDT into their State Plans. <ul style="list-style-type: none"> – Many states add language to each service section of the plan specifying that limitations in the plan do not apply to EPSDT-eligible enrollees under age 21. Other states detail services available only to children in a separate EPSDT section of the State Plan. – To assure consistency and that the State Plan reflects the statutory requirements, CMS encourages states to consider including the following language in their state Medicaid plans: "All medically necessary 1905(a) services that correct or ameliorate physical and mental illnesses and conditions are covered for EPSDT-eligible enrollees from birth to age twenty-one, in accordance with 1905(r) of the Social Security Act."
(May 2018) Aligning Dental Payment Policies and Periodicity Schedules in the Medicaid and CHIP Programs	<ul style="list-style-type: none"> • Reminds states that coverage of dental services (i.e., dental care needed for relief of pain, infection, restoration of teeth, maintenance of dental health and medically necessary orthodontic services) is included as part of EPSDT. Oral health screening, risk assessment and referral to appropriate dental care are recommended parts of visits with PCPs. • Requires that states adopt a periodicity schedule for pediatric dental services, detailing the recommended intervals at which enrolled children should receive dental checkups. • States should ensure their fee schedules and payment policies align with their periodicity schedules. States should review their payment policies against their pediatric dental periodicity schedules and correct misalignments. (One example of a misalignment is when the periodicity schedule calls for biannual fluoride treatments and dental cleanings beginning at 6 months of age, but the fee schedule allows payment only beginning at age 1). • The periodicity schedule should be treated as a floor for coverage of dental services, not a ceiling. States should have a mechanism in place to cover medically necessary dental services that exceed the periodicity schedule. Individualized care plans for children may involve caries risk assessments, exams and preventive dental services at more frequent intervals. • While initial limits may be placed on coverage of a dental or oral health service, services must be covered if determined to be necessary to correct or ameliorate an individual child's condition. As such, dental care necessary to correct or ameliorate an individual child's condition must be covered (and reimbursed) even when these services fall outside of the standard scope and even when the frequency of services is greater than specified in the periodicity schedule or coverage policy. <ul style="list-style-type: none"> – For example, a child with a disability may need cleanings more frequently than twice each year. Or a child with a severe micrognathia (underdeveloped jaw) might require palatal expansion or mandibular advancement to promote the child's proper speech and nutrition. Even if these dental surgical procedures are not included in the state's Medicaid benefit, they must be covered if determined to be medically necessary. • States delivering dental services to children through MMC should ensure their contracted plans that use fee schedules are paying providers for all services in alignment with the state's Medicaid pediatric dental periodicity schedule.

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	<ul style="list-style-type: none"> To ensure that children can receive medically necessary dental care, states may need to implement a mechanism through which providers can obtain timely approval of, and payment for, additional or more frequent dental services beyond what is specified in the periodicity schedule or coverage policy.
(June 2018) Neonatal Abstinence Syndrome: A Critical Role for Medicaid in the Care of Infants	<ul style="list-style-type: none"> Provides recommendations for states developing approaches to Neonatal Abstinence Syndrome (NAS) treatment. <ul style="list-style-type: none"> Diagnosis: Asserts that assessment and screening tools are essential, along with hospitals/nurseries adopting standard protocols and training staff accordingly. Treatment: Highlights the importance of nonpharmacologic treatment (e.g., placing the infant in a dark and quiet environment, swaddling, rocking, breastfeeding when appropriate, providing high-calorie nutrition in frequent small feedings and rooming in with their mother) and case management. Reminds states of EPSDT, which must be provided by qualified providers and made available to children with a medical need for the services. Services for infants with NAS may include assessments, development of care plans, swaddling, feeding and specialized care of the infants. Services for Medicaid-eligible mothers of infants with NAS may include counseling and MAT for the treatment of SUD and other medically necessary services. Non-Medicaid-eligible mothers may receive services that are directed at treating and promoting the health of the child (e.g., counseling the mother in how to care for and interact with her infant with NAS). Other NAS treatment services may include targeted case management, evidence-based home visiting and continued assessment of the infant's development.
(June 2018) Requirements of Section 12005 of the 21st Century Cures Act	<ul style="list-style-type: none"> Notifies states of Section 12005(a) of the Cures Act, which amends the Medicaid benefit at Section 1905(a)(16) of the Social Security Act to require Medicaid reimbursement for EPSDT services for children under age 21 who are receiving inpatient psychiatric services (effective January 1, 2019). <ul style="list-style-type: none"> EPSDT services may be provided by a hospital or facility, under arrangement with a qualified nonfacility provider, and/or by a qualified provider in the community not affiliated with or under arrangement with the facility. Medicaid reimbursement is required for medically necessary services under Section 1905(a) of the Social Security Act, not just inpatient psychiatric services identified in the child's treatment plan and provided by the hospital or facility or under arrangement with the hospital or facility. CMS historically prohibited states from claiming expenditures under the inpatient psychiatric facility benefit unless the expenditures were made to qualified providers of such services. This had the effect of denying coverage for other medically necessary Medicaid items and services, such as prescription drugs or practitioner services that were not included by the state as part of the rate paid to the facility for care but would be available under other benefit categories for individuals who do not reside in an IMD, such as EPSDT. In 2012, CMS clarified that states were permitted to directly reimburse individual practitioners or suppliers of arranged services the same fees as would otherwise be applicable when the services are provided to Medicaid enrollees under the State Plan outside the IMD; however, when the Cures Act amended the Medicaid benefit at Section 1905(a)(16) of the Social Security Act, states became required to do so. This bulletin also clarifies that a Plan of Care is not necessary to authorize any other medically necessary services.
State Health Officer Letters	
(June 2009) Medicaid and CHIP Coverage of HIV Testing and Screening	<ul style="list-style-type: none"> The CDC recommends that opt-out HIV screening be a part of routine clinical care in all healthcare settings for all adults and adolescents ages 13–64. Under EPSDT, children under age 21 are covered for HIV screening and testing.

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Frequently Asked Questions (FAQs)	
(December 2013) Medicaid and CHIP FAQs: Funding for the New Adult Group, Coverage of Former Foster Care Children and CHIP Financing	<ul style="list-style-type: none"> • Clarifies that EPSDT is covered for children under age 21 in the former foster care eligibility group. • However, EPSDT is not covered for individuals ages 21–25 in the former foster care eligibility group.
(September 2014) Medicaid and CHIP FAQs: Services to Address Autism	<ul style="list-style-type: none"> • Clarifies that applied behavior analysis services are not required for children under age 21 with ASD. States are responsible for determining what services are medically necessary for eligible individuals, including for the treatment of ASD. • States may provide services to address ASD under certain benefit categories of Section 1905(a) of the Social Security Act, and they are encouraged to submit a SPA to articulate the ASD treatment services available.
Manuals	
CMS EPSDT Guide for States: Coverage in the Medicaid Benefit for Children and Adolescents	<ul style="list-style-type: none"> • Compiles the various EPSDT policy guidance issued by CMS dating up to June 2014; does not establish new EPSDT policy. • Overview of EPSDT. For children under age 21, EPSDT covers all medically necessary services that are included within the categories of mandatory and optional services listed in Section 1905(a) of the Social Security Act, regardless of whether such services are covered under a state's State Plan. The goal of EPSDT is to ensure that individual children get the healthcare they need when they need it—the right care to the right child at the right time in the right setting. • Informing Individuals. States are required to ensure that all eligible children (and their families) are informed of both the availability of screenings in a combination of written and oral methods and that a formal request for an EPSDT screening is not required. • Screenings. States are required to establish and maintain a periodicity schedule for screenings based on standards of medical and dental practice. <ul style="list-style-type: none"> – Medically necessary interperiodic screenings outside of the periodicity schedule are also required based on an indication of a medical need to diagnose an illness or condition that was not present at the regularly scheduled screening or to determine whether there has been a change in a previously diagnosed illness or condition that requires additional services. <ul style="list-style-type: none"> ▪ The determination of whether an interperiodic screening is medically necessary may be made by the child's physician or dentist, or by a health, developmental or educational professional who comes into contact with a child outside of the formal healthcare system, such as an individual working for the state's early intervention or special education programs, Head Start, or WIC. – A state may not limit the number of medically necessary screenings a child receives and may not require prior authorization for either periodic or interperiodic screenings. – Any qualified provider operating within the scope of his or her practice as defined by state law can provide a screening. The screening does not need to be conducted by a Medicaid provider in order to trigger EPSDT coverage for follow-up diagnostic services and medically necessary treatment. A screening provided before a child enrolls in Medicaid is sufficient to trigger EPSDT coverage after enrollment for follow-up diagnostic and treatment services. – States may develop a bundled payment rate to pay for the physical health screening components (see below), or pay for each physical health screening separately. States may encourage providers to perform all five components of the EPSDT screening (see below) but may not exclude providers who perform only partial screenings from being reimbursed for the parts they do provide.

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	<ul style="list-style-type: none"> - Covered screenings are medical, mental health, vision, hearing and dental. <ul style="list-style-type: none"> ▪ <u>Medical Screening.</u> A medical screen includes a comprehensive health and developmental history that assesses for both physical and mental health as well as for SUD; a comprehensive, unclothed physical examination; appropriate immunizations; laboratory testing (including blood lead screening); and health education and anticipatory guidance for both the child and caregiver. ▪ <u>Mental Health Screening.</u> ▪ <u>Vision and Hearing Screening.</u> ▪ <u>Dental Screening.</u> Professional guidelines recommend that physicians include an oral health screening and assessment as part of a well-child visit at specified ages, but this is separate from the required dental screening through a direct referral to a dentist beginning at age 3. • Diagnosis and Treatment. Children are entitled to any diagnostic and treatment service that fits within a category under Section 1905(a) of the Social Security Act, as long as it is necessary to “correct or ameliorate” conditions. Services that do not cure a condition may still be covered under EPSDT. - <u>Mental Health and Substance Use Services.</u> <ul style="list-style-type: none"> ▪ Rehabilitative Services: Community-based crisis services, such as mobile crisis teams and intensive outpatient services; individualized mental health and substance use treatment services, including in nontraditional settings such as a school, workplace or home; medication management; counseling and therapy, including to eliminate psychological barriers that would impede development of community living skills; and rehabilitative equipment, for instance daily living aids. ▪ HCBS Services (those that can be provided through EPSDT): Intensive care coordination (“wraparound”), intensive in-home services and mobile crisis response. ▪ Treatment Services for Victims of Trauma. - <u>PCS.</u> The determination of whether a child needs PCS must be based upon the child’s individual needs and the family’s resources. - <u>Oral Health and Dental Services.</u> <ul style="list-style-type: none"> ▪ Dental care needed for relief of pain, infection, restoration of teeth and maintenance of dental health. ▪ Emergency, preventive and therapeutic services for dental disease. ▪ Orthodontic services to prevent disease and promote oral health. Orthodontic services for cosmetic purposes are not covered. - <u>Vision and Hearing Services.</u> <ul style="list-style-type: none"> ▪ Diagnosis and treatment for defects in vision, including eyeglasses and eyeglasses replacements. ▪ Diagnosis and treatment for defects in hearing, including hearing aids and cochlear implants. - <u>Examples of Additional Services.</u> <ul style="list-style-type: none"> ▪ Examples include, but are not limited to, case management services, incontinence supplies, organ transplants, a specially adapted car seat that is needed by a child because of a medical problem or condition, and nutritional supplements. ▪ If a requested service or treatment is not listed by name in Medicaid’s list of services, it should still be provided if it is medically necessary and coverable under the list of services at Section 1905(a) of the Social Security Act. There may be cases in which the type of provider that is needed to deliver a service is not already participating in Medicaid, and the state could meet the EPSDT requirement by entering into a single-service agreement with the needed provider.

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	<ul style="list-style-type: none"> • Enabling Services. <ul style="list-style-type: none"> – <u>Transportation and Appointment Scheduling Assistance.</u> States are required to offer scheduling and transportation assistance to and from medical appointments. This includes the cost of an ambulance, taxi, bus or other carrier as well as reimbursement for mileage and medically necessary related travel expenses (e.g., meals and lodging). <ul style="list-style-type: none"> ▪ As with other services covered through EPSDT, states may cover the least-expensive means of transportation if it is actually available, accessible and appropriate. ▪ Some states address the transportation requirement by offering nonemergency transportation through brokers. – <u>Language Access and Culturally Appropriate Services.</u> States are required to take “reasonable steps” to ensure that individuals who have limited English proficiency have meaningful access to Medicaid services. States, MCOs and providers should all be culturally competent by recognizing and understanding the cultural beliefs and health practices of the families and children they serve. <ul style="list-style-type: none"> ▪ Although interpreters are not Medicaid qualified providers, their services may be reimbursed when billed by a qualified provider rendering a Medicaid covered service. ▪ States may raise reimbursement rates, as needed, to recognize the additional costs of the interpreter services. • Settings. <ul style="list-style-type: none"> – <u>Out of State.</u> States are required to pay for services provided out of state in certain instances such as when a necessary covered service is not available locally or if a Medicaid beneficiary is out of state at the time a need for medical services arise. – <u>Schools.</u> Medicaid covers services (e.g., screenings, physical therapy, occupational therapy, PCS, and services for children with speech, hearing and language disorders) provided in schools as long as they are listed in Section 1905(a) of the Social Security Act and the State Plan, or are available under EPSDT. Schools must agree to comply with Medicaid program requirements. – <u>Most Integrated Settings Appropriate.</u> States are required to cover services in the community for children with special healthcare needs pursuant to <i>Olmstead v. L.C.</i>, when the need for community services can be reasonably accommodated. • Permissible Limitations on Coverage of EPSDT Services. <ul style="list-style-type: none"> – <u>Individual Medical Necessity.</u> Services must be provided to a child only if necessary to correct or ameliorate a physical or mental condition (i.e., only if medically necessary). Medical necessity determinations must be made on a case-by-case basis, taking into account the particular needs of the child, including long-term needs and all aspects of a child’s needs, including nutrition, social development, and mental health and SUD. Flat limits or hard limits based on a monetary cap or budgetary constraints are not permitted. <ul style="list-style-type: none"> ▪ States may adopt a medical necessity definition that places tentative limits on services pending an individualized determination by the state, or that limits a treating provider’s discretion, as a utilization control, but additional services must be provided if determined to be medically necessary. ▪ Both the state and a child’s treating provider play a role in determining whether a service is medically necessary. If there is a disagreement between the two parties as to whether a service is medically necessary, the state is responsible for making a decision based on the evidence. That decision may be appealed by the child (or the child’s family) under the state’s Medicaid fair hearing procedures.

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Citation	Summary
	<ul style="list-style-type: none"> - <u>Prior Authorization</u>. Utilization controls are permitted to safeguard against unnecessary use of services; a state may establish tentative limits on the amount of a treatment service a child can receive and require prior authorization for coverage of medically necessary services above those limits. Prior authorization must be conducted on a case-by-case basis, cannot delay the delivery of services and may not be applied to screenings. Medical management techniques must comply with mental health parity. - <u>Experimental Treatments</u>. Treatments, services or items that are experimental or investigational may be covered at the state's discretion if the treatment or item would be effective to correct or ameliorate a child's condition. The state's determination of whether a service is experimental must be reasonable and should be based on the latest scientific information available. - <u>Cost-Effective Alternatives</u>. States cannot deny treatment based on cost, but may consider the relative cost-effectiveness of alternatives as part of the prior authorization process. States may cover the least-expensive service if it is equally effective and actually available, but the child's quality of life must also be considered. States are not required to make services available in every possible setting as long as the services are reasonably available through the settings where the service is actually offered. <ul style="list-style-type: none"> ▪ However, due to the Olmstead decision, even if an institutional setting is less costly than providing services in a home or community, the ADA's integration mandate may nevertheless require that the services be provided in the community. <p>• Services Available Under Other Federal Authorities.</p> <ul style="list-style-type: none"> - <u>HCBS</u>. HCBS waivers serve as a "wraparound" to EPSDT by providing services outside of Section 1905(a) of the Social Security Act (i.e., habilitative services, respite services or other services that prevent institutionalization). States may also offer services through other authorities: Section 1915(j) (self-directed personal assistance services), 1915(k) (home- and community-based attendant services and support) and Section 1945 (coordinated care in health homes for individuals with chronic conditions). - <u>ABP</u>. EPSDT services must be included in ABPs. - <u>Role of MCH Services</u>. States are required to collaborate with Title V MCH agencies and grantees to ensure better access to and receipt of the full range of screening, diagnostic and treatment services covered under EPSDT. CMS encourages state Medicaid agencies and their sister MCH agencies to enter into written agreements that allow for MCH agencies to provide outreach, screening, diagnostic or treatment services, health education and counseling, case management, and other assistance in achieving a comprehensive and effective child health benefit. MCH programs can also help Medicaid programs enlist providers who can help deliver a broad array of services, and inform potential and current Medicaid enrollees about EPSDT and refer them to necessary services. <p>• Access to Services.</p> <ul style="list-style-type: none"> - <u>Providers</u>. <ul style="list-style-type: none"> ▪ States are required to make available a variety of individual and group providers qualified and willing to provide services to children, and states must take advantage of all resources available to provide a broad base of providers who treat children. Therefore, states may need to recruit new providers to meet children's needs. ▪ Any qualified provider operating within the scope of his or her practice, as defined by state law, can provide a screening service. However, most states have received permission from CMS to provide some services to some children through managed care arrangements that restrict the freedom of choice of provider. ▪ While states have broad authority to set provider payment rates, payments to providers must be consistent with efficiency, economy and quality care, and be sufficient to enlist enough providers and services at least to the extent they are available to the general population in the geographic area.

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	<ul style="list-style-type: none"> ▪ Balance billing is prohibited, along with billing for missed appointments. – MMC. States have flexibility to determine how EPSDT is administered (i.e., through MMC or through FFS). <ul style="list-style-type: none"> ▪ MCOs' definition of medical necessity cannot be more restrictive than the state's definition. To ensure this, a state can include its definition of medical necessity in its MCO contracts. ▪ To provide for consistency across the delivery system and proper implementation of EPSDT, the state is responsible for educating its contracted MCOs about EPSDT requirements and verifying that managed care providers are informed about EPSDT requirements through trainings and provider manuals. ▪ States are also responsible for ensuring that MCOs inform all families (usually included in the member handbook) of the services available under EPSDT and how to access them, including which services the MCO will provide and how any EPSDT services not within the MCO contract can be accessed by enrollees. ▪ MCOs must demonstrate they have adequate provider capacity, 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. – States must monitor MCOs' compliance with EPSDT requirements. There are several monitoring methods MCOs can use: <ul style="list-style-type: none"> ▪ Tracking performance on specified performance measures and performance improvement projects. ▪ External quality review. ▪ Review of grievances and appeals related to children's services as well as monitoring complaints filed with the state's enrollee and provider hotlines. ▪ Data analysis of MCOs' encounter data to detect underutilization of services by children. ▪ Review CMS-416 data (which includes the number of children receiving screenings, dental and oral health services, and referrals for corrective treatment as well as EPSDT participation rates). – Timeliness. EPSDT services must be provided with reasonable promptness. <ul style="list-style-type: none"> ▪ A lack of providers does not automatically relieve a state of its obligation to ensure that services are provided in a timely manner. • Notice and Hearing Requirements. Children under age 21, like all other people enrolled in Medicaid, have the right to notice and an opportunity for a hearing. If a state or managed care entity takes an "action"—to deny, terminate, suspend or reduce a requested treatment or service—it must give the beneficiary written notice of the action and of their right to a hearing (a pre-termination hearing, in instances where services are reduced or terminated), including instructions on how to request a hearing.
<p>CMS State Medicaid Manual</p>	<ul style="list-style-type: none"> • Overview of EPSDT. EPSDT is a required service for categorically needy individuals under age 21, and optional for the medically needy population. However, if EPSDT is elected for the medically needy population, EPSDT must be covered for all individuals under age 21. EPSDT services must be sufficient in amount, duration or scope to reasonably achieve their purpose. States are required to report on and maintain policies, procedures and records related to EPSDT services. Confidentiality requirements apply to EPSDT. • Informing Individuals. <ul style="list-style-type: none"> – Within 60 days following eligibility determination, states are required to inform all Medicaid-eligible families—including foster parents and administrators of institutions, as well as newly eligible families (either determined eligible for the first time or determined eligible after a period of ineligibility if they have not used EPSDT services for at least one year)—about the EPSDT program and how to use the services. Families that experience churn in Medicaid do not have to be informed more than once in a 12-month period.

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	<ul style="list-style-type: none"> – States are required to inform Medicaid-eligible pregnant women about the availability of EPSDT services for children under age 21. A Medicaid-eligible woman's positive response to an offer of EPSDT services during her pregnancy constitutes a request for EPSDT services for the child at birth. • Screenings. Screenings must be provided at intervals (i.e., periodicity schedules) which meet reasonable standards of medical and dental practice. Screenings may be provided in a variety of settings such as state and local health departments, schools, and community health centers. Screenings are performed by, or under the supervision of, a certified Medicaid physician, dentist or other qualified provider. States must also provide interperiodic screenings when medically necessary to determine the existence of a suspected physical or mental illness or condition. The determination of whether an interperiodic screening is medically necessary may be made by the child's physician or dentist, or by a health, developmental or educational professional who comes into contact with a child outside of the formal healthcare system, such as an individual working for the state's early intervention or special education programs, Head Start, or WIC. <ul style="list-style-type: none"> – <u>Medical Screening.</u> <ul style="list-style-type: none"> ▪ Comprehensive health and developmental history to assess both physical and mental health development. ▪ Comprehensive unclothed physical exam. ▪ Appropriate immunizations recommended by ACIP. ▪ Appropriate laboratory tests, including blood lead level assessment appropriate to age and risk. Recommends that states require hematocrit or hemoglobin screening, urinalysis, tuberculosis skin testing, sexually transmitted infection screening, and cholesterol screening. ▪ Health education, including anticipatory guidance. To assist parents/guardians and children in understanding the child's development, the benefits of healthy behaviors and accident/disease prevention. – <u>Vision and Hearing Screening.</u> These screenings are subject to their own periodicity schedules. – <u>Dental Screening.</u> A dental screening includes a direct dental referral (which can be met in settings other than a dentist's office) for every child in accordance with the periodicity schedule. Dental paraprofessionals under direct supervision of a dentist may perform routine services when in compliance with state law. • Diagnosis and Treatment. States must provide any diagnostic or treatment service necessary to treat or ameliorate a defect, physical or mental illness, or a condition identified by a screen. Services must be provided regardless of whether the service is included in the State Plan. States are not required to provide any services or items the state determines to be unsafe, ineffective or experimental. <ul style="list-style-type: none"> – <u>Vision and Hearing Services.</u> Includes eyeglasses and hearing aids. – <u>Dental Services.</u> Includes preventive services (i.e., instruction in self-care oral hygiene procedures, teeth cleaning and application of dental sealants), therapeutic services (e.g., root canals and restoration of decayed teeth) and emergency services. – <u>Prenatal Care Services.</u> Provide pregnant women prenatal care, including nurse-midwife services. – <u>Case Management.</u> Critical to ensuring examinations, diagnosis, treatment and other functions are not conducted in a fragmented manner, and to notifying enrollees of the appropriate time to receive services. • Enabling Services. <ul style="list-style-type: none"> – <u>Transportation and Appointment Scheduling Assistance.</u> States must provide scheduling and transportation assistance (further defined to include related travel expenses) if requested and necessary. States must offer both transportation and scheduling assistance prior to each date of a child's periodic exam.

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	<ul style="list-style-type: none"> • Access to Services. <ul style="list-style-type: none"> – <u>Providers.</u> States cannot limit providers of EPSDT services to providers who are qualified to provide all diagnostic and treatment services. – <u>Coordination With Related Agencies and Programs.</u> States are required to coordinate EPSDT services with Title V MCH agencies and grantees as well as Head Start and WIC. Federal financial participation is available to cover the costs to public agencies of providing direct support to the Medicaid agency in administering the EPSDT program. The Title V MCH programs enter into written agreements with state Medicaid programs to provide EPSDT outreach, screening, diagnostic or treatment services, health education and counseling, and case management. Medicaid agencies reimburse Title V providers for delivering EPSDT services even if they are provided free of charge to low-income uninsured families. MCH programs can also help Medicaid programs enlist providers who can help deliver a broad array of services, and inform potential and current Medicaid enrollees about EPSDT and refer them to necessary services. – <u>Continuing Care.</u> As a best practice, EPSDT services should be part of a continuum of care where a child receives screening, diagnosis, treatment and any needed referrals for conditions identified during the screening from a single provider. Through a signed enrollment agreement, families agree to use one provider as the regular source of continuing care for a stated period of time. A continuing care provider performs the entire set of EPSDT functions but may refer enrollees to the state Medicaid agency for dental services, transportation and scheduling assistance. – <u>Timeliness.</u> Treatment services, if indicated as needed by a screening, must be initiated within six months.

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