



OCTOBER 2019

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

Children with special healthcare needs are children 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.¹ 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.^{2,3} Federal Medicaid law recognizes the unique needs of children—including children with special healthcare needs—by requiring the provision 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).⁴ 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; if a service or device is medically necessary to correct or ameliorate a condition and could be covered under Medicaid, it must be provided to a Medicaid-enrolled child even if that service or device is not otherwise available to adults enrolled in the program.

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, including improper denials of care and shortage of pediatric specialists. These challenges contribute to uneven access to care and services across and within states.

This issue brief identifies a checklist of best practice strategies that states and state Medicaid agencies can implement—and some 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 issue brief was developed based on a review of the literature and 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; and a review of state regulations, provider manuals and training materials, and Medicaid managed care contracts across several states. The specific access issues vary across states and sometimes within states, and evolve depending on new policies and a changing healthcare landscape, but 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.

Checklist of Best Practice Access to Care Strategies for Children with Special Health Care Needs

- 1** Establish and maintain strong, consistent state leadership and a governance structure that is focused on children's needs by creating a pediatric-focused cabinet-level position or similarly high-level state position that promotes collaboration among child-serving agencies, such as those that oversee maternal and child health, child welfare, and education. Also important are robust pediatric representation on states' Medical Care Advisory Committees and strong leadership within the state Medicaid agency to oversee the Medicaid program for children; regularly engage and collaborate with families, providers and other stakeholders; and ensure the Medicaid guarantees for children are being implemented correctly.
- 2** Provide clear and consistent, easy-to-understand, and consumer-friendly information for families about what Medicaid offers to children 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.
- 3** Ensure pediatric care teams are well informed and trained on what Medicaid offers to children through a comprehensive and frequently updated provider manual focused on children and robust provider training that is required to be completed at regular intervals.
- 4** Establish a comprehensive definition of children with special healthcare needs that is focused on current and future health and functional status rather than specific underlying diagnoses, and establish strong processes for identifying children with special healthcare needs to promote early identification of health issues and expedite care coordination. In addition to using administrative/claims data and caregiver/provider referrals to identify children with special healthcare needs, states can encourage or require health plans or providers to conduct initial standardized health

(including mental health) screenings for new enrollees that consider adverse child experiences and social factors, such as hunger and homelessness, which affect children's health and well-being.

5

Ensure access to specialists and subspecialists through specific pediatric-focused network adequacy requirements in Medicaid managed care contracts, and institute corresponding corrective actions, fines, penalties and/or sanctions if those network adequacy requirements are not maintained. States can also use telehealth to ensure access to care, especially for children with special healthcare needs who live in rural areas far from pediatric specialist practices or in areas with a shortage of pediatric specialists.

6

Safeguard against utilization management controls that impede access to needed care by 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 inappropriately deny or delay the delivery of medically necessary services or create undue burden for the family. States can safeguard the process by requiring that any preliminary service denial for a child with special healthcare needs is reviewed and signed off by a healthcare provider with experience treating the particular condition before a denial can be finalized. A hotline or a Children's Ombudsman Office/Office of the Child Advocate can assist families in explaining the rules, navigating the system and, if necessary, appealing a denial or service limitation.

7

Require comprehensive and child-centered care management/care coordination for children with special healthcare needs by developing and regularly updating individualized care plans, relying on multidisciplinary care teams that meaningfully engage with families, and covering out-of-network services and providers as needed during times of transition. Pediatric care teams operating in a fee-for-service context can also be authorized and compensated to provide care management. Care provided either through managed care or in a fee-for-service context can be coordinated with other child-serving state agencies—such as Title V Maternal and Child Health Bureau programs, foster care agencies, early intervention services, and special education—to ensure treatment plans and services are coordinated for both physical and behavioral health and to avoid duplication of services.

8

Establish robust and ongoing state monitoring and oversight of access to services for children with special healthcare needs by collecting and analyzing a variety of data sets; reviewing appeal requests to monitor improper denials of services; utilizing secret shopper reviews to investigate potential access problems; and ensuring ongoing communication with families and providers to identify what is working, voice concerns, and offer recommendations for improvement.

As the source of critical health coverage for 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.

¹ Health Resources & Services Administration, Maternal & Child Health Topics, *Children with Special Health Care Needs* (March 2019), available at <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs> (last visited on May 28, 2019).

² *Id.*

³ Henry J. Kaiser Family Foundation, *Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending* (June 12, 2019), available at <https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/> (last visited on May 28, 2019).

⁴ Social Security Act § 1905(r)(5); 42 U.S.C. § 1396d.