

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

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manatt

- **Introduction**
- **Overview of Children with Special Healthcare Needs, Medicaid's Commitment to Children, and Current Access Challenges**
- **Best Practice Strategies to Improve Access to Care for Children with Special Healthcare Needs**
- **Moving Forward**
- **Questions**

Introduction

The Robert Wood Johnson Foundation and the Lucile Packard Foundation for Children’s Health funded a new resource that identifies policies and practices that states can implement and sustain over time to promote better outcomes for children with special healthcare needs.



Issue Brief Key Topics Include:



A review of the complex and diverse challenges children with special healthcare needs face



An overview of Medicaid’s commitment to children



A checklist of eight best practice strategies and tools to improve access



Real-world examples of innovative initiatives states are executing

Methodology



**Literature review
and catalog of
federal
requirements**



**Interviews with
national experts
and family
members of
CSHCN**



Data analysis



**State-specific
review and state
expert interviews**

Acknowledgements

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Overview

Who Are Children with Special Healthcare Needs?

Children with special healthcare needs have, or are at increased risk of having, a chronic physical, developmental, behavioral or emotional condition and require health and related services of a type or amount beyond that usually required by children generally.

Characteristics

Children with special healthcare needs tend to:

- Use medical services much more frequently than the general pediatric population.
- Require various types of healthcare services and supports such as habilitative services and home nursing services.
- Face significant social and economic needs.
- Be enrolled in risk-based Medicaid managed care (MMC).

By the Numbers



18% of all children in the U.S. have special healthcare needs (13.3 million children).



50% of children with special healthcare needs in the U.S. are covered by Medicaid.



19% of families with children with special healthcare needs have at least one unmet need (e.g., preventive care, specialist care).

Medicaid's Commitment to Children

Federal law requires the delivery of comprehensive pediatric healthcare services to all enrolled children and youth under 21 through provisions in the law known as Early and Periodic Screening, Diagnostic, and Treatment (EPSDT).



Early and Periodic Screenings

- Regularly scheduled comprehensive health and developmental screenings
- Comprehensive unclothed physical exams
- Appropriate vision and hearing tests, immunizations, and laboratory tests
- Dental screenings and referrals
- Health education

Diagnostic Services

- Medically necessary diagnostic services when a risk is identified, including follow-up testing, evaluation, and referrals

Treatment Services

- Timely treatment services as determined by child health screenings (which includes treatment services medically necessary to correct or ameliorate defects and address physical and behavioral health conditions)

The Importance of EPSDT for Children with Special Needs

While the scope of services offered to children under Medicaid is important for children's health broadly, the comprehensive array of preventive, diagnostic, and treatment services are particularly important for children with unique medical needs.

EPSDT Treatment Parameters



- If a service or device is **medically necessary to correct or ameliorate a condition** and **could be covered under Medicaid**, it must be provided even if that service or device is not identified in the Medicaid State Plan or otherwise available to adults enrolled in the program. This includes physical and behavioral health services as well as long-term services and supports.
- States and Medicaid managed care organizations (MCOs) can require prior authorization to safeguard against unnecessary use of some services, but prior authorization cannot result in a delay or denial of medically necessary services. Notably, **for children, states and MCOs may not impose hard or fixed limits on specific services.**

EPSDT has been a lifesaver for children, but implementation gaps can lead to uneven access to care and services across and sometimes within states.

- **Providers who don't understand Medicaid's guarantee for kids**, which impacts the provision of critical services and treatment.
- **Limited or inaccessible consumer information**, leaving children and their families without knowledge about what services their children are entitled to under Medicaid.
- **Improper denials of care**, leading to delays in children receiving necessary services.
- **Shortage of pediatric specialists and limited provider networks** causing long travel or wait times for care.

Best Practice Strategies to Improve Access to Care for Children with Special Healthcare Needs

Checklist of Best Practice Strategies

These best practice strategies emerged as key to identifying gaps and developing an action plan to promote continued improvement.



Strong, Consistent State Leadership and a Governance Structure Focused on Children's Needs



Access to Pediatric Specialists and Subspecialists



Clear, Easy-to-Understand, and Consumer-Friendly Information for Families



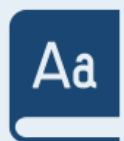
Safeguarding Against Utilization Management Controls that Impede Access to Needed Care



Pediatric Care Teams That are Well Informed and Trained on What Medicaid Offers to Children



Comprehensive and Child-Centered Care Management/Care Coordination for CSHCN



Comprehensive CSHCN Definition and Strong Identification Processes for Care Coordination/Monitoring



Robust and Ongoing State Monitoring and Oversight of Access to Healthcare Services for CSHCN

Best Practice Strategy 1: Strong, Consistent State Leadership and a Governance Structure Focused on Children's Needs

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Implementation Strategies

- Create a cabinet-level or similarly high-level state position and a governance structure that promotes collaboration among child-serving agencies and prioritizes children's issues.
- Ensure leadership position within the Medicaid agency that works closely with the Medicaid director to oversee Medicaid for children and regularly engages with families, providers, and other stakeholders.
- Ensure there is active state-level engagement with family members of children with special healthcare needs, including requiring robust pediatric representation on states' Medical Care Advisory Committees through appointing parents, child-focused health professionals, and advocates.



Maine

In early 2019, Governor Janet Mills reconstituted the state's Children's Cabinet, which:

- Meets approximately every six weeks; and
- Focuses on improving care and prevention for at-risk youth as well as early care and early education system.

Maine also created a new Chief Pediatrician position devoted to improving children's physical, mental, and social health.

Best Practice Spotlight: Active Family Engagement

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Through her extensive work with the Colorado Department of Health Care Policy and Financing (HCPF), Christy Blakely knows firsthand the importance of having a parent or family member actively engaged at the state-level to ensure a focus on children's needs.

Stakeholder and Advocacy Experience

- 1 Parent of child with special healthcare needs
- 2 Parent Advocate, The Safety Net Project
President, Medical Services Board and
Chair of the Children's Disability
Advisory Committee at the Colorado
HCPF
- 3 Contractor for HCPF working with the
EPSDT Coordinator on "Creative
Solutions" Children With Special
Healthcare Needs project



The Blakely Family

Best Practice Strategy 2: Clear, Easy-to-Understand, and Consumer-Friendly Information for Families



Implementation Strategies

- Provide consistent information through accessible consumer-facing and culturally-appropriate materials.
- Work with families to design:
 - **Clear notices** regarding authorization or denial of benefits;
 - **Notices and welcome packet information** issued by MCOs;
 - A **family-friendly homepage** on state Medicaid website;
 - A **consumer hotline** or an **ombudsman** to respond to questions;
 - **Social media communication**; and
 - **Text communication** from MMC coordinators.



Michigan

Requires its MCOs to:

- Provide targeted outreach to children with special healthcare needs, including specific information on navigating the managed care health system and member services.
- Maintain educational content on the plan's website directed to children with special healthcare needs.
- Provide families with forums for discussion to provide input on the plan's policies/procedures that influence access to services.

Best Practice Strategy 3: Pediatric Care Teams That are Well Informed and Trained on What Medicaid Offers to Children

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Implementation Strategies

- Regularly train pediatric care teams on Medicaid's pediatric medical necessity standard.
- Develop comprehensive (and regularly updated) provider manuals that detail:
 - The periodicity schedule and required screenings/screening tools;
 - The medical necessity definition applicable and the allowable scope of services;
 - Guidance on how to make referrals; and
 - Transportation, language interpretation, and scheduling assistance.



Washington, D.C.

- MCOs must ensure that every two years providers complete training on what Medicaid offers to children.
- The training is accessible via an online portal, and MCOs are required to pay for continuing education credits for providers to complete the training.

Best Practice Strategy 4: Comprehensive CSHCN Definition and Strong Identification Processes for Care Coordination/Monitoring

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Implementation Strategies

- Establish a definition of children with special healthcare needs that focuses on current and future health/functional status rather than specific underlying diagnoses.
- Strong Identification Processes:
 - Use administrative and claims data and family/provider/community agency/caregiver referrals;
 - Use a standardized screening tool to more quickly determine whether children with special healthcare needs need a higher level of care coordination and support; and
 - Establish other routes for identification (e.g., through schools, Title V Maternal and Child Health Bureau entities, foster care agencies).
- Screen for nonmedical needs that impact health.



Massachusetts

- MCOs must complete an initial care needs screening to identify children with special healthcare needs as part of the care coordination assessment.
- The screening assesses cultural and linguistic needs, long-term services and supports needs, and behavioral health and substance use disorder needs.
- Children with identified long-term services and supports or special healthcare needs receive a person-centered comprehensive assessment and documented care plan.

Best Practice Strategy 5: Access to Pediatric Specialists and Subspecialists



Implementation Strategies

- Rigorous Network Adequacy Requirements that include:
 - Specific network adequacy requirements for pediatric specialists and subspecialists, (including academic medical centers and children’s hospitals); and
 - Corrective actions, fines, penalties, and/or sanctions if those requirements are not maintained.
- Utilize telehealth to make care more accessible and to facilitate coordination between providers, (e.g., allow a specialist to provide a consult to a pediatrician in separate locations).



Pennsylvania

- Regionally-based MCOs must contract with at least two pediatric specialists or subspecialists for children with special healthcare needs.
- If a plan does not meet these requirements, or if the child with special healthcare needs or the child’s family is not satisfied with the in-network pediatric specialists/sub-specialists, the child can choose an out-of-network provider through a prior authorization process.

Best Practice Strategy 6: Safeguarding Against Utilization Management Controls that Impede Access to Needed Care



Implementation Strategies

- Ensure MCOs follow a transparent, evidence-based process for making medical necessity determinations; ensure utilization controls do not inappropriately deny or delay the delivery of medically necessary services.
- Require preliminary service denials from an MCO to be reviewed by a healthcare provider with experience treating the particular condition before finalizing a denial.
- Establish a hotline or a Children’s Ombudsman Office/Office of the Child Advocate to assist families in explaining the rules, understanding the scope of services, navigating the system, and appealing a denial or service limitation.



Washington, D.C.

- MCOs are required to have a plan’s chief medical officer review all denials of care for EPSDT physical health services and services for children with special healthcare needs.
- The MCO chief psychiatric medical officer must review all denials of care for mental and behavioral health treatment services.

Best Practice Strategy 7: Comprehensive and Child-Centered Care Management/Care Coordination for CSHCN



Implementation Strategies

- 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.
- Require MCOs to use the individualized care plans in their care coordination efforts between providers.
- Rely on multi-disciplinary teams that engage the family in the delivery of care and include them as core partners in all planning and decision making.



Virginia

- MCOs must use a health risk assessment tool to develop an enrollee's person-centered individualized care plan that encompasses enrollee goals for meeting health outcomes. Health risk assessments are redone regularly.
- Specific care coordination staffing ratios are required to ensure care coordination staff are able to schedule appointments, provide referrals, identify resources, and contact the family regularly.

Best Practice Strategy 7: Comprehensive and Child-Centered Care Management/Care Coordination for CSHCN (Cont'd)



Implementation Strategies

- Require MCOs (or fee-for-service (FFS) care management providers) to offer enhanced care coordination during times of transition, including a requirement to cover out-of-network services and providers who have an established relationship with children with special healthcare needs for at least some period of time.
- Coordinate and share data with other child-serving state agencies (e.g., early intervention services, schools) to ensure plans and services are coordinated for both physical and behavioral health and to avoid duplication of services.



Washington

- Has a specialized MMC contract tailored to meet the needs of children in foster care.
- Allows children to continue receiving care from out-of-network providers with whom they have existing relationships during transitions in coverage.
- Requires continuity until the MCO conducts a needs assessment and attempts to contract with the out-of-network providers or transitions the child to a network provider.

Best Practice Spotlight: Virginia's MCO Requirements

In addition to requiring the MCOs to use the health risk assessment tool to develop individualized care plans and maintain care coordination staffing ratios, Virginia promotes access to care for children with special healthcare needs through its Commonwealth Coordinated Care (CCC) Plus contract in the following ways:



Specialized MMC Program

- Enrolls children with medical complexity into its CCC Plus specialized MMC program.
- The specialized program presents an opportunity for Virginia to focus on improving access to care for children with special healthcare needs.

Quality Improvement Strategies

- Requires MCOs in the CCC Plus program to develop at least two performance improvement plans (one clinical and one nonclinical) focused on medically complex populations that address acute and chronic conditions, behavioral health, care transitions, care coordination, and care management.

Medical Necessity Determinations

- If a family member or the treating physician requests a service for a child that does not meet the plan's general coverage criteria, an MCO 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.

Best Practice Strategy 8: Robust and Ongoing State Monitoring and Oversight of Access to Healthcare Services for CSHCN

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Implementation Strategies

- Establish regular communication with families and providers of children with special healthcare needs through advisory committees or other stakeholder forums to share information, identify challenges, and collaborate on areas of improvement.
- Analyze a variety of data sets to determine how children with special healthcare needs are faring and use that data to drive improvements in care.
- Analyze state-level claims and other utilization-based data to detect any patterns of underutilization.
- Review appeal requests to monitor improper denials of services.
- Utilize secret shopper reviews to investigate access problems.



Minnesota

- Publishes its Centers for Medicare & Medicaid Services (CMS)-416 reports on its state website and breaks down the data by county and tribe, race or ethnicity; FFS and individual MCO; and foster care participation by county and tribe.

States are required to submit annually to CMS “416” reports on the number of children that received an EPSDT screening service/dental services and that were referred for corrective treatment. CMS expects to make new Transformed Medicaid Statistical Information System (T-MSIS) data available in November 2019, which may provide additional insights, particularly on the utilization of services.

Moving Forward

Best Practices Lead to Positive Results

State Medicaid programs have an extraordinary opportunity and responsibility to ensure the health and well-being of children with special healthcare needs. Some states, including Colorado, are undertaking innovative approaches in this area.



Problem

Children/youth in Colorado with Intellectual/Developmental Disabilities (I/DD) and co-occurring mental illnesses face challenges accessing needed services due to:

- The I/DD and mental health systems operating in silos.
- A shortage of providers, beds, trained case managers, and supports in the mental health system.



Solution

- Colorado established “Creative Solutions” to coordinate regular conference calls for this vulnerable population bringing together family members, providers, case managers, school personnel, and Regional Accountable Entities staff, among others.
- The goal of the calls is to share information and support families by coordinating and identifying gaps in services and supports.



Impact

- From August 2018 to March 2019, Creative Solutions convened 206 calls for 26 children.
- Efforts led to improved access to mental health services, which reduced ED visits and prevented children/youth from cycling from home to hospital treatment or into the juvenile justice system.

Questions

Appendix

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