Supporting Children and Youth with Special Health Care Needs During COVID-19

Produced by Manatt Health with the American Academy of Pediatrics, Family Voices, and the Georgetown Center for Children and Families

December 15, 2020, 1:00 – 2:00 PM ET

A grantee of the Robert Wood Johnson Foundation
About State Health and Value Strategies

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Questions? Email Heather Howard at heatherh@Princeton.edu.
Acknowledgments

Today’s webinar draws on research produced by Manatt Health, the American Academy of Pediatrics, Family Voices, and the Georgetown Center for Children and Families. Funding for this work was provided by the Robert Wood Johnson Foundation and the Lucile Packard Foundation for Children’s Health. The views expressed during this webinar do not necessarily reflect the views of the Foundations.
Housekeeping Details

All participant lines are muted. If at any time you would like to submit a question, please use the Q&A box at the bottom right of your screen.

After the webinar, the slides and a recording will be available at www.shvs.org.
COVID-19 Resources for States

State Health and Value Strategies has created an accessible one-stop source of COVID-19 information for states at www.shvs.org/covid19/. The webpage is designed to support states seeking to make coverage and essential services available to all of their residents, especially high-risk and vulnerable people, during the COVID-19 pandemic.
About Manatt Health

Manatt Health, a division of Manatt, Phelps & Phillips, LLP, is an integrated legal and consulting practice with over 160 professionals in nine locations across the country. Manatt Health supports states, providers, and insurers with understanding and navigating the complex and rapidly evolving health care policy and regulatory landscape. Manatt Health brings deep subject matter expertise to its clients, helping them expand coverage, increase access, and create new ways of organizing, paying for, and delivering care. For more information, visit www.manatt.com/ManattHealth.aspx
About Family Voices

Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that promotes partnership with families—including those of cultural, linguistic and geographic diversity—in order to improve health care services and policies for children.
Webinar Overview

- Medicaid’s Commitment to Children and Youth with Special Health Care Needs (CYSHCN) During the COVID-19 Pandemic
- How States Have Responded (So Far)
- Supporting CYSHCN During (and Beyond) the COVID-19 Pandemic
  - Promote Continuous Home Health and Other Home- and Community-Based Services (HCBS) for CYSHCN
  - Ensure Access to Medically Necessary Medicaid-Covered School-Based Services
  - Leverage Medicaid Managed Care Organizations (MCOs) in Supporting CYSHCN During COVID-19
- Discussion
Medicaid’s Commitment to Children and Youth with Special Health Care Needs During the COVID-19 Pandemic
Children and youth with special health care needs (CYSHCN) 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.

### Characteristics

CYSHCN tend to:
- Use medical services much more frequently than the general pediatric population.
- Require various types of health care services and supports such as habilitative services and home nursing services.
- Face significant social and economic needs.
- Receive medically necessary services through Early Intervention under Part C of IDEA, or in schools through an Individualized Education Plan (IEP) or Section 504 Plan.

### By the Numbers

- **19% of all children in the U.S. have special health care needs.**
- **47% of children with special health care needs in the U.S. are covered by Medicaid.**
- **36% of CYSHCN in the U.S. require health care provided at home and/or health care coordinated on a weekly basis (compared to 6% of non-CYSHCN).**

Sources:
- Henry J. Kaiser Family Foundation (KFF), Medicaid’s Role for CSHCN Look at Eligibility, Services, and Spending, June 2019.
- Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), Children with Special Health Care Needs, NSCH Data Brief, July 2020.
**Medicaid’s Commitment to Children**

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

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<th>Early and Periodic Screenings</th>
<th>Diagnostic Services</th>
<th>Treatment Services</th>
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<td>Regularly scheduled comprehensive health and developmental screenings</td>
<td>Medically necessary diagnostic services when a risk is identified, including follow-up testing, evaluation, and referrals</td>
<td>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)</td>
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<tr>
<td>Comprehensive unclothed physical exams</td>
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<td>Appropriate vision and hearing tests, immunizations, and laboratory tests</td>
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<td>Dental screenings and referrals</td>
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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 CYSHCN.

**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 Medicaid. This includes physical and behavioral health services and long-term services and supports.

- States and Medicaid 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. **States and MCOs may not impose hard or fixed limits on specific services for children or youth.**

Insights from Cara Coleman, Program Manager, Family Voices
The Impact of COVID-19 on CYSHCN

- Disruptions to health care, education, and community life, which may result in delayed development, reduced learning, and mental health challenges.

- School closures/remote learning has resulted in loss of access to health-related school-based services.
  - As of May 2020, only 1 in 5 parents whose children are in special education reported that they were receiving all the services their children needed during the pandemic.

- COVID-19 has exacerbated home health workforce shortages, leaving many CYSHCN without access to home health care services (e.g., Personal Care Assistant, Private Duty Nursing, respite care).

- Families of CYSHCN face a difficult choice between forgoing needed services or allowing home health providers into their homes and increasing risk of COVID-19 exposure as home health providers often work across multiple settings.

The Impact of COVID on CYSHCN and Their Families Could Be Long-Lasting

Potential Long-Term Negative Impacts

- Reduced in-person appointments due to risk of COVID-19 exposure has forced practices to permanently close. Some CYSHCN — particularly those in rural areas — will have fewer provider options, which will impact access to needed services.

- The risk of caregiver burnout increases the longer the pandemic lasts, putting strain on families’ health and security.
  - Caregiver burnout has been associated with higher rates of depression and anxiety.
  - Families are taking on more caregiving responsibilities, often suddenly and in addition to schooling responsibilities.
  - Formal and informal support networks may be inaccessible due to social distancing requirements. Isolation, which many families of CYSHCN experienced pre-COVID-19, is a significant factor in caregiver burnout.

- The full developmental impacts of the pandemic, particularly on young children with special health care needs, will not be known for many years.

How States Have Responded (So Far)
Guiding Principles When Developing Effective Short- and Long-Term Strategies

- There is no “pandemic exception” to Medicaid’s obligation to provide children and youth access to needed care.

- The law requires state Medicaid programs to address the needs of CYSHCN who are Medicaid eligible through their state plan and who are Medicaid eligible through a 1915(c) waiver.

- Strategies described here should not be deployed exclusively. States may wish to use numerous strategies to provide families with multiple options for meeting their needs and the needs of their children.

- All hands on deck: Cross agency collaboration among state and local agencies serving CYSHCN and their families is essential.

- States that establish a bi-directional feedback loop with families and family-led organizations will better monitor the on-the-ground impact of COVID-19 on access to Medicaid services for CYSHCN.
Medicaid Strategies to Support CYSHCN and Their Families During the Pandemic

States received temporary flexibilities through various federal authorities — State Plan Amendments (SPAs) and waivers — to help ensure access to Medicaid coverage and services.

Examples of Approved Temporary Federal Flexibilities

- Removed typical barriers to services and equipment:
  - Modified prior authorization requirements
  - Allowed pharmacy pre-fills
  - Modified eligibility requirements to streamline enrollment
  - Expanded 1915(c) waiver services, scope, or coverage through Appendix Ks

- Expanded the provider pool:
  - Allowed family caregivers to provide waiver and personal care services
  - Increased provider payments
  - Provided retainer payments to some 1915(c) waiver providers
  - Modified required provider types and qualifications

Continuous Coverage

Federal Medicaid continuous coverage requirements under the Family First Coronavirus Response Act require states maintain coverage for all Medicaid enrollees (as a condition of enhanced Federal Medical Assistance Percentage [FMAP]), mitigating loss of coverage and churn that normally occurs mid-year or during the renewal process.

Sources: Manatt analysis of states’ Medicaid Disaster Relief SPAs, 1915(c) Waiver Appendix Ks, and 1135 waivers.
States Have Significantly Expanded Access to Telehealth During the Pandemic

Key Pandemic-Related Changes to Medicaid Telehealth Policy

| Coverage and Reimbursement | • Video Visits – Almost all states now allow some services to be delivered via video visits, with many reimbursing for any “medically necessary and clinically appropriate services” delivered via video visits at parity with in-person visits.  
| | • Audio only (telephone) visits – All states issued guidance covering some form of audio-only visits in lieu of video or in-person visits.  
| Sites of Care | • Eligible sites of care – Almost all states are allowing patients to receive telehealth care from their homes (or wherever they may be located) and providers to deliver telehealth care from their homes, outside of their typical clinical settings.  
| Services for CYSHCN | • Well-Child Services – Several states have allowed well-child visit services that do not require physical touch to be available via video visit for children over 24 months of age.  
| | • Specialized Therapies – Many states enabled the delivery of some physical, occupational, and speech therapy services via video visits.  
| | • Early Intervention Services – Some states have enabled a limited set of services that can be delivered in a clinically appropriate manner (e.g., case management, patient/family training) to be delivered via video.  
| | • Children’s Behavioral Health – Almost all states have enabled a broad set of behavioral health services (that can be delivered in a clinically appropriate manner via telehealth), such as applied behavioral analysis (ABA) and research-based autism spectrum disorder services, to be delivered via video or audio-only visit.  

Without Telehealth, Some CYSHCN Would Be Unable to Access the Services They and Their Families Rely on

Impact of Expanded Telehealth on CYSHCN and Their Families

- Expanding telehealth maximized access to care and reduced the risk of disease exposure during the pandemic and will continue to be an essential service modality for CYSHCN.
- In addition to maximizing access to services, expanded telehealth has provided other benefits for CYSHCN and their families, such as:
  - Families who have typically experienced challenges travelling for regular check-ins with specialists can more easily access services.
  - Providers can observe a child’s home environment and how families are implementing services or therapies at home. Providers can then offer corrective guidance on implementing therapies and services, as well as modifying the home environment.
  - Families can more easily meet with multiple providers at the same time to virtually participate in care coordination discussions and conduct care planning activities.

Telehealth May Not Be a Solution for Every Child

- Some CYSHCN are unable to benefit from telehealth due to a lack of technology or reliable and sufficient internet connection.
- Telehealth is not an effective or appropriate modality for some CYSHCN, including children under three and some children with developmental disabilities.

Sources: [Urban Institute, Urgent Action Needed to Address Children’s Unmet Health Care Needs During the Pandemic, Oct. 2020.](https://www.urban.org/publication/urgent-action-needed-address-childrens-unmet-health-care-needs-during-pandemic)
Supporting CYSHCN During (and Beyond) the COVID-19 Pandemic
Priority Actions for Supporting CYSHCN

The following slides are a guide for identifying gaps and developing an action plan to promote continued improvement. Working closely with families is essential to successful implementation of these strategies.

- Ensure Continuous Access to Home Health and other HCBS for CYSHCN
- Promote Continuous Access to Medically Necessary School-Based Services
- Leverage Medicaid MCOs in Supporting CYSHCN
Ensure Continuous Access to Home Health and Other HCBS for CYSHCN
Address Workforce Shortages and Stabilize Provider Pool

Example Strategies

- **Increase Payments.** Increase payment rates and provide “retainer” payments to certain providers (SPA or 1915(c)/Appendix K for waiver providers)

- **Expand Eligible Provider Pool.**
  - Temporarily allow graduate registered nurses (RNs) or graduate licensed practical nurses (LPNs) to provide private duty nursing (PDN) before receiving their license (1135 Waiver)
    - After the PHE has expired, states may issue a temporary, provisional license (e.g., 60 days) to graduate RNs or LPNs so they could provide PDN until permanent licensure is granted (state policy)
  - Temporarily allow non-state licensed providers to provide services across state borders for the duration of the public health emergency (PHE) (1135 Waiver)
    - After the PHE expires, states may issue a temporary, provisional license (e.g., 60 days) to providers while they apply for permanent licensure through an expedited process (state policy)

- **Respond to Unique COVID-19 Circumstances.** Require MCOs to pay home health service providers for their time in quarantine so providers are not disincentivized to work in homes with COVID-19-positive individuals or individuals at high risk of contracting COVID-19 (MCO Contract)

Sources: Honsberger et al. State Approaches to Providing Home Health Services to Children with Medical Complexity Enrolled in Medicaid, National Academy for State Health Policy (NASHP), July 2020.
### Example Strategies

**Expand family caregiving.** Reimburse parents/guardians—at a rate that supports a living wage—for providing home-based personal care services to dependent minor children *(1915(c) HCBS waiver, Medicaid HCBS state plan option)*

- Though states may allow payment to parents/guardians for personal care services, states have historically limited payment to parents/guardians of children over age 18.
- States more commonly allow payment to family (or other close relation) providers who are not a parent/guardian.

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Ohio pays family caregivers, including parents/guardians of minor children to provide waiver services under its Home Care waiver. Eligible services include personal care aide services, waiver nursing, home modification services, and supplemental transportation services.

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Sources: [Wolff et al., Family Caregivers as Paid Personal Care Attendants in Medicaid, Johns Hopkins Bloomberg School of Public Health, Oct 2016](#); [OH Home Care 1915(c) wavier (0337.R04.00)](#).
Additional Strategies for Ensuring Access to Home Health

Example Strategies

- **Save a Spot.** Remove requirement that waiver participants use a waiver service at a minimum frequency in order to maintain waiver eligibility so that they can resume services when they feel safe to do so (1915(c)/Appendix K)

- **Fund and Ensure Access to Technology.** Allow waiver participants to purchase (up to a certain threshold) assistive technology (e.g., computer, tablet, or other device) to access telehealth services if a participant does not already have access to this technology (1915(c)/Appendix K)

- **Ensure PPE.** Authorize additional funding for PPE (for providers and families) and allow service limitations to be exceeded for medical supplies, equipment and appliances (1915(c)/Appendix K)

- **Access to COVID Testing.** Ensure COVID-19 testing is easily accessible for home health providers (state policy)

Sources: Urban Institute, Urgent Action Needed to Address Children’s Unmet Health Care Needs During the Pandemic, Oct. 2020; State Health and Value Strategies (SHVS), Strategies for Supporting and Strengthening Medicaid Information, May 2020.
Promote Continuous Access to Medically Necessary School-Based Services
States and Schools Remain Obligated to Provide Health Services to CYSHCN During COVID-19

CYSHCN are entitled under federal law to the medically necessary services they have traditionally received in school settings, including when schools operate on virtual or hybrid schedules due to the pandemic.

Federal Requirements for School-Based Services

- **Federal Medicaid law (EPSDT)** requires states to provide Medicaid-enrolled children with all medically necessary services to correct or ameliorate a condition, even when schools are closed due to COVID-19.

- **Federal education law (Individuals with Disabilities Education Act [IDEA])** requires public schools to provide children with disabilities a free and appropriate education in the least restrictive environment through special education and related services and supports (including Medicaid-covered services included in an IEP). Schools must continue to provide IEP services to CYSHCN during COVID-19.

Examples of Medically Necessary IEP Services for CYSHCN

- Nursing services
- Speech, physical, and occupational therapy
- Applied Behavior Analysis (ABA)
- Audiology services
- Personal care services
- Behavioral health services

“No matter what primary instructional delivery approach is chosen, state and local education agencies and IEP teams remain responsible for ensuring that a free appropriate public education is provided to all children with disabilities.” -- US Department of Education Office of Special Education and Rehabilitative Services, September 28, 2020

Multiple state agencies and providers are responsible for ensuring the health and well-being of CYSHCN. Navigating this complexity is a challenge for families, particularly in states without a “system of care” approach.

**Example Strategies**

**Release joint guidance from state education and Medicaid agencies reinforcing Medicaid and school districts’ obligation to provide EPSDT services**
- If services are not provided through schools due to the pandemic, Medicaid and school districts have a joint obligation to ensure medically-necessary services are provided and may do so through community providers (as opposed to school district employees).
- Medicaid agencies can provide information to families and family-led organizations reminding them that CYSHCN remain eligible for medically-necessary Medicaid-covered services that they typically receive in school and that states remain responsible for delivering those services.

**Establish a cross-agency workgroup** to coordinate the delivery of school-based services during remote or hybrid learning.
- Include representatives from Medicaid, education, child welfare, providers, health plans, and children’s advocates including family-led organizations.
- The workgroup should monitor and track on-the-ground issues and establish a feedback loop to address those issues.

Sources: [HRSA, Children with Special Health Care Needs: NSCH Data Brief, July 2020.](https://www.hrsa.gov)
Strategies for Ensuring Access to School-Based Services During Remote Learning (Cont.)

Example Strategies

- Work with families and state and local education agencies to prioritize in-person instruction and/or delivery of specialized therapies for CYSHCN.
- **Utilize shared decision making** among families, providers and educators when deciding between in-person, virtual, or hybrid learning.
- Target funding to **address the digital divide** that limits access to telehealth services for some children.
- **Ensure the appropriate level of PPE** is provided to schools.
- **Build on the collaborative relationship between providers and schools** — which has been strengthened during the pandemic—for managing the care of CYSHCN.

Florida used CARES Act funding to make $2 million available to rural counties with low rates of internet connectivity and limited access to providers to increase access to telehealth to provide mental health services for school-age children.

Leverage Medicaid MCOs in Supporting CYSHCN
Leveraging Managed Care Contracts to Support CYSHCN During and Beyond COVID-19

States are increasingly using MMC to deliver services to CYSHCN. 38 states include CYSHCN in risk-based MMC, and 11 states operate specialized, risk-based MMC plans for CYSHCN.

Key Contract Provisions

- **Network Adequacy.** Establish specific network adequacy requirements for pediatric specialists and subspecialists, and institute corrective actions, fines, penalties and/or sanctions if those requirements are not maintained.

- **Utilization Controls.** Ensure MCOs follow a transparent, evidence-based process for making medical necessity determinations and require preliminary service denials from an MCO to be reviewed by a health care provider with experience treating the particular condition before finalizing a denial.

- **Care Management/Care Coordination.**
  - Use a health risk assessment tool to develop individualized care plans for CYSHCN that include short and long-term goals, service needs, available community resources to leverage, and the child’s and family’s preferences; and require MCOs to use the individualized care plans in their care coordination efforts between providers.
  - Coordinate and share data with other child-serving state agencies (e.g., special education and early intervention programs) to ensure plans and services are coordinated for both physical and behavioral health.

- **Monitoring.** Require MCOs to assess the quality and appropriateness of care as well as patient experience; and develop performance improvement plans focused on CYSHCN.
Utilizing Medicaid Managed Care (MMC) Funds to Support CYSHCN

Many MMC plans have surplus funds due to the steep drop in health care visits. States can encourage or direct MCOs to use those funds to support CYSHCN and their providers.

Strategies for Reinvesting MMC Funds

- **State Directed Payments.** MCOs can increase payment rates to providers to preserve access in light of declined utilization and/or make retainer payments to providers for HCBS covered under the managed care contract. States may also direct MCOs to implement these strategies.

- **PPE.** MCOs can provide N95 masks and other PPE equipment to network providers, including home health providers, and donate PPE to local communities.

- **Broadband and Device Access.** MCOs can use their funds to pay for its members’ broadband and needed devices to be able to access virtual care.

- **Social Determinants of Health (SDOH).** MCOs can contract with or provide payments to family-led and community based organizations, primary care practices and community health centers and local nonprofits to address SDOH needs, including food and housing security.

**Virginia** directed MCOs to increase reimbursement for many primary care services by 29% between March and June 2020. Virginia estimates the directed payments will increase rates for primary care services by $30 million.

States Can Take Steps to Protect CYSHCN and Their Families During and After COVID-19

Medicaid, as the source of health coverage for about half of all CYSHCN, has a responsibility to help CYSHCN and their families respond to the challenges of this pandemic. The strategies discussed today will help states meet these obligations.

- Federal requirements are clear, but proper implementation of Medicaid’s guarantees requires providing families with multiple options to meet their service needs during and after COVID-19.

- States can also consider putting tools in place to help families resolve issues in a timely manner.

- To support CYSHCN, states can emphasize ongoing attention and collaboration among program administrators, families, providers and care teams, health plans, and the array of public and private agencies and organizations serving children.
Discussion

The slides and a recording of the webinar will be available at www.shvs.org after the webinar.
Thank You

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