



Continuing COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health Care Needs: *Recommendations for Federal Government Actions*

By **Sharon Silow-Carroll and Helen DuPlessis**
[Health Management Associates](#)

Policy and regulatory changes enacted during the COVID-19 public health emergency (PHE) have significantly impacted children and youth with special health care needs (CYSHCN), their families, and their health care providers.

In an effort to ameliorate the negative consequences of the pandemic on access to and utilization of health care services, the federal government and state governments created temporary flexibilities through a variety of legislative, regulatory, and administrative mechanisms. With support from the Lucile Packard Foundation for Children's Health, Health Management Associates conducted a comprehensive review of these policy changes and identified those with particular implications for CYSHCN. We discussed these flexibilities and their impact on CYSHCN with frontline clinicians, legal and family advocates for CYSHCN, researchers, program leaders, and other public and private stakeholders.

The study's findings, which can be found at lpfch.org/COVID-19-HMA-Report include the following:

- Policies that expanded reimbursement for telehealth¹ have significantly affected and been largely advantageous to CYSHCN and their families. These included flexibility in services provided via telehealth, patient and practitioner location, technologies used, and types of providers.
- Expansions in telehealth also highlighted disparities, however, as many low-income and rural families face language barriers or lack broadband access, technologies required for telehealth, safe locations from which to conduct visits in private, or training on how to request or use telehealth. Further, states, health systems, and providers did not consistently adopt the flexibilities and make telehealth opportunities universally available, suggesting additional access challenges and inequities that warrant further study.
- To soften the pandemic's negative consequences on access to care, the federal government and state governments also relaxed provider enrollment, eligibility, and out-of-state licensure requirements for Medicare and Medicaid; broadened the scope of practice for certain health care workers; reduced administrative requirements for accessing specialty care and services; and expanded the ability of states to pay family caregivers for providing personal care to CYSHCN.
- The sudden and long-term school closures, isolation, cessation of many in-person clinical visits and home care visits (both home health and personal care/direct services), lack of child care and respite care, rampant unemployment, and social determinants of health (SDOH) that have been created or exacerbated by the pandemic have put tremendous strains on CYSHCN and their families. While use of telehealth for behavioral health services increased significantly during the PHE, there has been a dearth of policies or flexibilities focused on identifying and addressing the stressors on CYSHCN and their caregivers – many of which will continue beyond the PHE.

Given what has been learned so far, Health Management Associates developed recommendations about temporary policy changes that should continue or cease after the PHE, as well as new actions for consideration to best serve CYSHCN and their families and better prepare for future emergencies. ***This policy brief presents recommendations for the Centers for Medicare & Medicaid Services (CMS) and other federal government actions.*** As more data become available, further assessment of how policy changes have affected quality, costs, and experiences of CYSHCN will provide additional guidance to policymakers.

Recommendations for Retaining and Advancing Telehealth Policies

- Telehealth should be considered another routine modality for providing appropriate services; CMS should extend flexibilities including:
 - *Payment parity* with in-person visits, noting that telehealth visits are not shorter and can be longer (and demand the same if not more documentation); parity rules should apply in all states
 - Reimbursement for *audio-only* telephone access (especially for behavioral health visits)
 - Reimbursement and support to *pediatric providers providing behavioral health services* via telehealth²
 - Coverage of *therapies as appropriate and care coordination* via telehealth
 - *Flexibility in and reimbursement for “originating” and “distant” sites* to include patient’s and practitioner’s home, without geographic or rural/urban restrictions
 - *Easing of out-of-state licensing restrictions* for telehealth providers, which leverages resources across state lines
- Additional federal funding must be targeted to reduce disparities in access to telehealth, including grants for *telehealth equipment and training* for families, providers, and schools; *extending broadband coverage* to ensure equitable access across all communities, especially in low-income and rural areas; and assuring *interpretation services* are available during telehealth visits.
- Additional consideration and *continued flexibility of some aspects of HIPAA/privacy rules* are needed to accommodate and encourage telehealth through non-public-facing virtual platforms under certain circumstances.
- CMS should consider encouraging states to *pilot expanding telehealth modalities* for Medicaid beneficiaries to include texting, especially for young people who may not have privacy for telephone calls.

Recommendations for Other Access-Related Policies

- The federal government should fund and coordinate with states and the private health care sector on efforts to thoroughly *evaluate and document the impact of the temporary policy flexibilities* implemented during the PHE on access, utilization, child/family experience, physical and mental health, and developmental outcomes of CYSHCN and other at-risk populations.
- The Centers for Disease Control and Prevention should prioritize establishing guidelines for reopening schools, with special attention to assure *the restart of quality school-based health services for CYSHCN*, for future public health crises.
- Many of the *enrollment and eligibility flexibilities* affecting both consumers and providers should be retained beyond the PHE. For example, the benefits of continuous eligibility argue for changing this program feature from a state option to a mandatory feature, at least for children and pregnant women. CMS should examine the impact of temporarily loosening provider eligibility and enrollment

rules in Medicaid and Medicare, and consider extending those that address ongoing shortages if they did not sacrifice quality.

- To further *support critical care coordination for CYSHCN* beyond the PHE, CMS should clarify that Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) will cover care coordination (beyond explicitly delineated “case management”), define care coordination, and develop standards for CYSHCN, potentially using proposed standards as a guide.^{3,4}
- CMS should continue the state Medicaid waiver *flexibility to pay family caregivers*, and expand options more generally through state plans, to include the opportunity to reimburse legally responsible caregivers who provide personal care and appropriate health-related services to CYSHCN.
- The federal government should work with states and the medical community to develop and fund creative solutions *addressing shortages in the home care workforce*, which were exacerbated during the pandemic. Potential areas of exploration include building a pipeline through education programs for both professional and paraprofessionals; increasing Medicare reimbursement rates for home care workers (home health nurses, for example, consistently earn less than hospital-based workers); and developing Certified Nursing Assistant training programs for family members including legally responsible caregivers (e.g., spouse and parent).
- Given reports of home care workers lacking personal protective equipment early during the PHE, federal and state governments need to develop emergency preparedness plans that ensure the availability of *basic materials required to continue delivering home care services* while considering the unique needs of CYSHCN.
- CMS should continue beyond the PHE the *enhanced Medicaid federal medical assistance percentage* support to states, tied to certain coverage protections such as maintaining eligibility requirements. This would promote both stability for the Medicaid and CHIP programs and access to services for families.
- The need for identifying providers that are clearly accountable for the well-being of CYSHCN is heightened during emergencies such as the pandemic. CMS should *test and support value-based, comprehensive service and reimbursement models for CYSHCN*, which are currently not well developed for pediatric care; such models include accountable care organizations, health homes, outcomes/value-based payment, and shared-savings.

Recommendations to Support Behavioral Health Care for CYSHCN and Caregivers

- As noted above, CMS should continue reimbursement and support to pediatric providers providing behavioral health services via telehealth.
- Given the severe toll of the pandemic on caregivers, CMS should allow state Medicaid programs to *reimburse pediatric and other providers for screening of caregivers of CYSHCN for mood disorders*, beyond the current reimbursement for maternal depression screening (i.e., perinatal mood and anxiety disorders).

About Health Management Associates

[Health Management Associates \(HMA\)](#) is an independent, national research and consulting firm specializing in publicly funded health care and human services policy, programs, financing, and evaluation. We partner with government, public and private providers, health systems, health plans, community-based organizations, institutional investors, foundations, and associations to improve health care and social services. Drawing knowledge from the frontlines of health care delivery and reform, we work with our clients to explore innovative solutions to complex challenges. HMA has 22 offices and more than 200 multidisciplinary consultants coast to coast. Learn more at healthmanagement.com/.

About the Authors

Sharon Silow-Carroll, MSW, MBA, Principal, has more than 30 years of experience in health care policy research and analysis, focusing on innovative initiatives to enhance health care system quality, access, value, and coverage. Her areas of interest include maternal and reproductive health, children and youth with special health care needs, long-term care, and Medicaid managed care.

Helen DuPlessis, MD, MPH, Principal, is an accomplished pediatrician and physician executive with extensive leadership experience and comprehensive knowledge about public sector health programs. She has expertise in program and policy development, practice transformation, public health, maternal and child health (MCH) policy, community systems development, performance improvement, and managed care.

About the Foundation

The Lucile Packard Foundation for Children's Health unlocks philanthropy to transform health for all children and families - in our community and our world. Support for this work was provided by the Foundation's Program for Children with Special Health Care Needs. We invest in creating a more efficient system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. The views presented here are those of the authors and do not reflect those of the Foundation or its staff. Learn more at lpfch.org/CSHCN.

Endnotes and Citations

¹ Telehealth or telemedicine refer to the exchange of medical information from one site to another through electronic communication to improve a patient's health.

² The Consolidated Appropriations Act, 2021, expands Medicare telehealth services to allow beneficiaries to receive mental health services via telehealth (in the patient's home or other originating site) if the beneficiary has been seen in person at least once by the qualifying practitioner during the prior six months.

³ The federal EPSDT statutes and regulations make reference to case management and not care coordination. While those two terms and others such as care management are often used interchangeably, case management is generally understood to relate to medical care and services (e.g., assessment, planning, facilitating, coordinating, and monitoring of services required to meet medical needs with an eye toward safety, quality of care and cost effectiveness [Case Management Society of America]). Among more than 40 definitions of care coordination, one adapted from the American Academy of Pediatrics and included in a recommended set of national care coordination guidelines for CYSHCN is: a collection of patient- and family-centered, assessment-driven, team-based activities designed to meet the needs of children and youth; care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes, and efficient delivery of health-related services and resources within and across systems. In the past 15 years, increasing focus on care coordination in programs for the adult population (e.g., section 2709 Home Health Programs, Whole Person Care Programs) have highlighted the importance of coordinating not only medical services, but also assessing for and managing a host of health-related needs, including SDOH, that influence health outcomes.

⁴ National Care Coordination Standards for Children and Youth with Special Health Care Needs, National Academy for State Health Policy, October 2020. <https://www.nashp.org/wp-content/uploads/2020/10/care-coordination-report-v5.pdf>