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 telehealth 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 health care community serving CYSHCN, including health systems, medical professional associations, providers, accreditors, and medical educators. As more data become available, further assessment of how policy changes have affected quality, costs, and experiences of CYSHCN will provide additional guidance to health care decision makers.

Recommendations for Retaining and Advancing Telehealth Policies

- Pediatric providers should not rush to reduce or curtail access to telehealth for CYSHCN as reopening continues. They must recognize that access concerns will exist post-pandemic and telehealth should be a part of everyday practice as much as possible to address the challenges.

  - Pediatric clinical guidelines should be developed to identify the appropriate use of telehealth for specific services and conditions among CYSHCN, based on evaluations of expanded telehealth utilization during the PHE and ongoing monitoring.
    - In some instances, a hybrid approach for CYSHCN could involve wrap-around skilled nursing or other supports in the home, in conjunction with a telehealth video chat with a clinician.
    - Exploration is needed on how well-child visits through telehealth can be reimbursed and monitored for quality. For example, this would require reimbursement approval from CMS, modification of measurement specifications by accrediting organizations (e.g., National Committee for Quality Assurance), and supervision guidelines from national professional organizations to address and allow modest flexibility in the frequency of in-person examinations.
    - Telehealth should be used to enhance interdisciplinary team-based care, which is especially important for CYSHCN and can reduce the communication and coordination burden on caregivers.
    - Medical centers that provide resident training should be required to include comprehensive instruction in conducting telehealth visits. In light of the disparities and inequities highlighted by the pandemic, this training should include a focus on the importance of cultural concordance, where possible, and cultural competence and humility.
    - Guidelines are also needed to ensure that well-child care and related preventive services (particularly services that require an in-person visit such as immunizations) are not deferred for too long during a PHE.

- Health system funding should be used to provide technical assistance and training for clinicians as well as families who are not familiar or comfortable with telehealth, and for interpretation services during telehealth visits.

Recommendations for Other Access-Related Policies

- Health care systems and researchers should coordinate with federal and state entities to thoroughly evaluate the impact of the temporary policy flexibilities on the physical and mental health and developmental outcomes of CYSHCN and other at-risk populations.

- State medical licensure boards should consider the federation of credentials verification services (FCVS) as a model that could be adapted to facilitate cross-state licensure (in key vulnerable regions if not nationwide). (Note: The FCVS is based on a uniform process for states to access primary source verification of certain physician credentials.)
• Given that the pandemic highlighted disparities and unmet SDOH needs, health systems, provider associations, and practices should establish more routinized screenings for SDOH, especially for CYSHCN, and assure that the care coordination process “closes the loop” to confirm that referred services are completed and to inform referring providers.2

Recommendations to Support Behavioral Health Care for CYSHCN and Caregivers

• Access to behavioral services for certain CYSHCN is limited by physical access, time constraints in typical behavioral health practice settings, and other factors, particularly, but not exclusively, during a pandemic. This argues for broader access to behavioral health screening and services for CYSHCN through their regular sources of care (i.e., their primary care provider and special care center staff). Pediatricians should receive behavioral health training from medical school through continuing education, and specialist support and consultation.
• Health systems should target resources to establish and encourage more routinized behavioral health screenings and services for caregivers as well as CYSHCN.
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.

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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.