

Continuing COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health Care Needs: Recommendations for Public Health and Maternal and Child Health Programs

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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 public health and maternal and child health (MCH) programs.*** 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 and program administrators.

Recommendations

- Additional funding is needed for the Health Resources and Services Administration's (HRSA's) Maternal and Child Health Bureau (MCHB) to support expanding telehealth services for CYSHCN through *trainings for families* on how to access telehealth services, especially for services families are not accustomed to accessing virtually. MCHB could increase funding to national family/peer support organizations that have direct communications with many families of CYSHCN to conduct outreach and trainings.
- State and local public health agencies and maternal and child health programs² should *include family members and advocates and incorporate the needs of CYSHCN in emergency preparedness planning*. Legal advocates and family advocates should inform contingency planning at the individual and system level to ensure the needs of CYSHCN will be met in the next emergency.
- Reflecting guidance by HRSA's Maternal and Child Health Division during the COVID-19 pandemic, state and local Title V programs should:
 - Work closely with state and local emergency preparedness staff to *develop contingencies at the health system level* and ensure that the needs of the maternal and child health population are represented
 - Partner with other state agencies, family networks, and health care providers to develop *communication channels* that provide timely, accurate, and reliable information to all families of CYSHCN, offer guidance about accessing needed services during a PHE, and respond to questions and incorporate feedback from families
 - Explore developing *registries of technology-dependent children and youth* that make action plans and advance directives available to EMT staff and other first responders
 - Ensure that *individual crisis plans for families of children with medical complexities* are completed and updated annually (or as needed during a PHE)
 - Provide *care coordination support* where applicable

About Health Management Associates

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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.

² Funded by the Maternal and Child Health (MCH) Services Block Grant (Title V of the Social Security Act).