HMA Lucile Packard Foundation *for* Children's Health

Recommendations for Continuing COVID-19 Policy Flexibilities Affecting Children and Youth with Special Health Care Needs

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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. Given what has been learned so far, we present recommendations about policy changes that should continue or cease after the PHE, as well as new actions for consideration to best support CYSHCN and their families and better prepare for future emergencies.

Summary of Findings

Policies that expanded the use of telehealth—the exchange of medical information from one site to another through electronic communication to improve a patient's health—have significantly impacted and been largely advantageous to CYSHCN and their families.

- Regulatory flexibilities included expanding Medicaid and/or Medicare reimbursement for telehealth provided and received:
    - In additional locations (including urban areas and in patients' and providers' homes)
    - For additional services (such as care coordination, well-child visits, pediatric behavioral therapy, [varies by state])
    - Through audio-only technologies
    - By additional types of providers (including physical, occupational, and speech therapists, and out-of-state providers, including subspecialists)
    - Through school-based telehealth (expanding Medicaid reimbursement to additional health services provided via telehealth)
- Payment parity with in-person visits enhanced the utilization of telehealth
- Relaxing enforcement of HIPAA privacy rules facilitated telehealth provision through additional (non-public-facing) technologies, such as video chats, Zoom, and Skype

However, these expansions in telehealth also highlighted disparities, 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 guidance 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 deserve further study.

A variety of other federal and state policy mechanisms were employed to soften the pandemic's negative impact on access to care. These included policies to:

- Increase federal funding to Medicaid and the Children's Health Insurance Program (CHIP), some of which flowed to providers to partially relieve financial strains of the pandemic and keep the doors open at critical providers
- Provide flexibility in consumer eligibility and enrollment and to curb increases in cost-sharing
- Relax provider enrollment, eligibility, and out-of-state licensure requirements for Medicare and Medicaid
- Broaden the scope of practice for certain members of the health care workforce
- Reduce administrative requirements for accessing specialty care and services
- Expand states' ability to pay family members for providing personal care and health-related services

Despite all of those welcome flexibilities, the cessation or reduction in both in-home and school-based therapies and services significantly undermined access to care for CYSHCN, especially those with medical complexities and in special education programs (i.e., those covered by the Individuals with Disability Education Act or Section 504 of the Rehabilitation Act).

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 caregivers and families**. The primary policy lever to address **mental health** issues has been the delivery of behavioral health services via telehealth. However, there has been a dearth of other policies or flexibilities focused on identifying and addressing the new stressors on CYSHCN and their caregivers.

Below we present recommendations to extend regulatory flexibilities beyond the PHE and additional actions to improve access and care for CYSHCN and better position children, families, and agencies for future emergencies. 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. We organize proposed actions by federal government (primarily Centers for Medicare & Medicaid Services [CMS]), state government, Medicaid managed care plans, the public health and maternal and child health community, and the general medical community. A full report describing policy mechanisms and flexibilities, interview results, and recommendations in more detail can be found here.

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I. Recommendations for CMS and Other Federal Government Actions

Telehealth

- 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 telehealth[1]
  - 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 ensuring *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.

Other Access-Related Areas

- 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 ensure *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.[2,3]
- 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.

Behavioral Health Care

- 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).

II. Recommendations for State Medicaid Agency and Other State Government Actions

Telehealth

- Medicaid telehealth flexibilities should be maintained, and telehealth should be considered another modality for providing services.
    - *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)
    - 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* to allow out-of-state telehealth providers (including specialists and subspecialists), which leverages resources across state lines
- State Medicaid agencies should think creatively about encouraging *and incentivizing virtual check-ins* (for example, global payments) and reducing the pressure to do everything in one visit.
- State Medicaid agencies should *identify and expand reimbursement for school-based physical and behavioral health services that are appropriate for telehealth delivery*, and provide guidance to school districts on requirements and billing.
- State Medicaid agencies and departments of education should consider *reimbursing telehealth by specialized practitioners or assistants supporting children with medical complexity in schools and childcare settings.*
- States should consider piloting the expansion of telehealth modalities to include *texting*, especially for young people who may not have privacy for telephone calls.

Other Access-Related Areas

Medicaid

- States should coordinate with the federal government and the private health care sector on efforts to thoroughly *evaluate the impact of the temporary policy flexibilities* on access, utilization, child/family experience, physical and mental health, and developmental outcomes of CYSHCN and other at-risk populations.
    - State Medicaid programs should assess the impact of suspending prior authorizations, *modify authorization requirements* accordingly beyond the PHE (while continuing to monitor quality and cost-effectiveness) for fee-for-service Medicaid, and encourage or require Medicaid managed care organizations to do the same.
    - Many of the Medicaid *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. States should consider continuing relaxation of Medicaid provider eligibility and enrollment requirements, revalidation, and personnel qualification requirements that address ongoing shortages if they do not sacrifice quality. However, documentation and medical record requirements and any provider qualification standards that resulted in compromised quality of care should cease.

- To further support critical *care coordination for CYSHCN* beyond the PHE, states should clarify that care coordination will be a covered benefit under EPSDT, secure and increase Medicaid reimbursement for care coordination services for CYSHCN, and consider covering care coordination by certain paraprofessionals and other service providers.
- Given that the pandemic highlighted disparities and unmet SDOH needs, Medicaid/CHIP *screening for SDOH, referrals, and interventions should become standard practice and incentivized*. Examples may include Medicaid managed care quality improvement requirements, pay-for-performance incentives, or as a requirement for state initiatives such as California's Advancing and Innovating Medi-Cal Enhanced Care Management or in lieu of services for children and youth with complex needs.
- To build the Medicaid home care workforce, states should increase Medicaid reimbursement rates for home health workers (home health nurses, for example, consistently earn less than hospital-based workers), and implement or continue the (temporary, varies by state) home- and community-based services (HCBS) waiver program retainer payments to home-based caregivers while a beneficiary is temporarily institutionalized or unable to receive services for a short time.
- Extending flexibilities, states should expand Medicaid *payment to family caregivers*, including legally responsible caregivers who provide personal care and health-related services to CYSHCN. States should develop communication channels to inform families of this benefit, design a user-friendly application process, and provide appropriate training and "guardrails" to help ensure quality and program integrity. (This may involve the use of waivers [e.g., HCBS or 1915(c)] to sidestep the legally responsible caregiver proscriptions.)
- The need for identifying providers that are clearly accountable for the well-being of CYSHCN is heightened during emergencies such as the pandemic. States should *test and support value-based, comprehensive service and reimbursement models for CYSHCN*, which are currently not well developed for pediatric care; such models might include accountable care organizations, health homes, outcomes/value-based payment, and shared-savings.

Additional State Government Access-Related Actions

- Given some practice closures and provider retirements during the pandemic, states should reassess the workforce (specialists, therapists, etc.) serving CYSHCN and identify gaps. One option for states to consider in addressing shortages is *extending expanded scope of practice* for non-physician clinicians beyond the PHE (for example, the ability to order durable medical equipment) while maintaining or establishing new clinical and training standards.
- States and localities should implement school re-openings with special attention to ensuring the *restart of quality, school-based therapeutic and other health services for CYSHCN*. Schools should be required to have plans in place to continue services in the event of another pandemic or other reasons for closing school-based health services.
- States should work with the federal government and the medical community to develop and fund creative solutions *addressing shortages in the home care workforce*, which were exacerbated during the pandemic. In addition to recommendations noted above (Medicaid), potential areas of exploration include building a pipeline through education programs for both professionals and paraprofessionals, including family caregivers; this may include developing Certified Nursing Assistant training programs for legally responsible caregivers (e.g., parent and spouse).

- Given reports of home care workers lacking personal protective equipment early during the PHE, the federal government and state governments need to develop emergency preparedness plans that *ensure the availability of basic materials* required to continue delivering home care services.

Behavioral Health Care

- Given the reported toll the pandemic has taken and may continue to take on the mental health of CYSHCN and their caregivers, states should target resources and incentives to encourage more *routinized behavioral health screenings and services* for CYSHCN enrolled in Medicaid. Behavioral health screenings and basic services may be best positioned as a primary care responsibility (rather than a behavioral health responsibility) given the variable nature of behavioral health carve-outs in many state Medicaid programs.
- Medicaid reimbursement for *new telehealth modalities for behavioral health services for CYSHCN*, such as audio-only visits, should extend beyond the pandemic.
- If permitted by CMS, state Medicaid programs should reimburse for *screening of caregivers of CYSHCN for mood disorders*, beyond the current reimbursement for maternal depression screening (i.e., perinatal mood and anxiety disorders).

III. Recommendations for Medicaid Managed Care Organizations

Telehealth

- Health plans should invest in providing *technical assistance and training* for clinicians as well as families who are not familiar or comfortable with telehealth, and ensure interpretation services during telehealth visits.
- Health plans should think creatively about incentivizing providers (for example, with global payments) to conduct *virtual check-ins* and reduce the pressure to do everything in one visit.

Other Access-Related Areas

- Health plans should *evaluate the impact of suspending prior authorizations* during the PHE by periodically conducting quality and cost-effectiveness assessments, and *modifying authorization requirements* accordingly.
- Given that the pandemic highlighted disparities and unmet social service and support needs, managed care organizations should target resources and incentives to encourage more *routinized screenings for SDOH, especially for CYSHCN*, and ensure that the care coordination process "closes the loop" to confirm that referred services are completed and to inform referring providers.

Behavioral Health Care

- Given the reported toll the pandemic has taken and may continue to take on the mental health of CYSHCN and their families, managed care organizations should target resources and incentives to encourage more *routinized behavioral health screenings and services for CYSHCN*, particularly during emergencies.
- Health plans should encourage *new telehealth modalities for behavioral health services*, such as audio-only visits, when appropriate or necessary.

IV. Recommendations for Public Health and Maternal and Child Health Programs

- 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 programs[4] 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

V. Recommendations for Actions by the Health Care Community (Health Systems, Medical Professional Associations, Providers, Accreditors, Medical Educators)

Telehealth

- 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.

Other Access-Related Areas

- 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 ensure that the care coordination process "closes the loop" to confirm that referred services are completed and to inform referring providers.

Behavioral Health Care

- 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] 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.

[2] 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.

[3] 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

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