

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

What to Keep, Modify, or Discard?

PREPARED FOR
LUCILE PACKARD FOUNDATION
FOR CHILDREN'S HEALTH

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About the Foundation

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Summary

Policy and regulatory changes enacted during the COVID-19 pandemic 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 policy flexibilities through a variety of legislative, regulatory, and administrative mechanisms. With support from the LPFCH, HMA 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.

This report identifies key flexibilities enacted during the COVID-19 public health emergency (PHE) and the mechanisms that enabled them. It summarizes stakeholders' perspectives about the impact of the pandemic and policy flexibilities on CYSHCN and their families and providers. Given what has been learned so far, we present recommendations for continuing or ceasing temporary policy changes after the PHE, as well as new policies and actions to best support CYSHCN and their families and better prepare for future emergencies.

Key Findings

The pandemic, risks associated with in-person medical visits, and near-universal school closures have disproportionately affected CYSHCN who rely on frequent medical appointments and school-based habilitative and rehabilitative services (e.g., physical, occupational, speech, language, and nutritional therapies; applied behavioral analysis) and socialization opportunities. It may take years before we understand how the interruption in services has affected the long-term development and outcomes for children with medical complexity. Stakeholders are reporting many short-term, negative effects of the pandemic as well as positive consequences of temporary policy changes on CYSHCN. In addition to reducing barriers to accessing needed services, federal COVID-19 relief bills have provided much-needed grants, loans, and payments to Medicaid (and Medicare) programs, providers, and lower-income families, including pediatric specialists and families of CYSHCN.

Telehealth

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 had a significant and largely positive impact on CYSHCN and their families.

- Regulatory flexibilities expanded 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, and pediatric behavioral therapy, often varying 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 Medicaid-covered health services)
- Payment parity with in-person visits enhanced utilization of telehealth
- Relaxing enforcement of some aspects of the HIPAA privacy rules facilitated telehealth provision through additional (non-public-facing) technologies, such as video chats, Zoom, and Skype

Stakeholders emphasized how greater use of telehealth had significant advantages, particularly for CYSHCN and their caregivers, including:

- Less need to transport the child, their equipment, and in many cases, siblings, to appointments
- Lower potential for exposure of already-high-risk children to COVID-19 and other infections
- Greater access to distant, specialized services for CYSHCN, particularly for families in rural areas or those requiring services across state lines
- Potential to reduce disparities and address workforce shortages (especially pediatric specialists and subspecialists)

However, the shift to telehealth has 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 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 deserve additional study.

Access to Care

Besides extending telehealth, other federal and state policy flexibilities employed to soften the pandemic's negative impact on access to care also benefited CYSHCN and their families, including:

- States maintaining Medicaid eligibility and enrollment as a condition for receiving higher federal matching rates, which reduced family concerns about losing coverage or benefits, in addition to shoring up strained programs for Medicaid and the Children's Health Insurance Program (CHIP)
- Relaxing provider enrollment, eligibility, and out-of-state licensure requirements for Medicare and Medicaid, helping to maintain or expand access to specialists
- Loosening scope of practice for certain members of the health care workforce, somewhat alleviating workforce shortages of the specialists and therapists upon whom CYSHCN frequently rely
- Easing of prior authorization rules and extending authorizations, reducing the administrative burden of caregivers and providers of CYSHCN with frequent or ongoing needs
- Expanding states' ability to pay family members for providing personal care and other health-related services

Mental Health

The pandemic's impact on the mental health of both CYSHCN and their caregivers has been underreported and largely overlooked. 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 childcare and respite care, rampant unemployment, and exacerbation of social determinants of health (SDOH) have put tremendous strains on CYSHCN and their families. Caregivers of CYSHCN have struggled to serve as parents, teachers, therapists, and wage earners. Behavioral health care via telehealth has been the primary policy lever to address mental health issues. However, there has been a dearth of other policies or flexibilities focused on identifying and addressing the new stressors on CYSHCN and their caregivers.

Recommendations

Based on this study's findings, the following are recommendations for adopting or continuing specific temporary policies and practices, and additional considerations to improve the care and experience of CYSHCN and their caregivers beyond the PHE. Most of these recommendations refer to maintaining or extending flexibilities enabled by the Centers for Medicare & Medicaid Services (CMS) and states for the Medicaid program, which covers a disproportionate number of CYSHCN.¹ Some recommendations target other governmental entities such as public health and Title V programs, Medicaid managed care plans, health systems, and pediatric practitioners and professional associations.² Certain flexibilities are being adopted or considered for extension at the state or federal levels.

Recommendations for Telehealth

- Telehealth should be considered another routine modality for providing appropriate services; CMS and state Medicaid programs should extend flexibilities including:
 - **Payment parity** with in-person visits
 - Reimbursement for **audio-only** telephone access (especially for behavioral health visits), FaceTime, and other technology options including asynchronous³ contact
 - Coverage for physical, occupational, speech, and other **therapies provided by appropriate therapists** via telehealth
 - Extended coverage for **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 providing 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.⁴

- Similarly, **health systems and Medicaid managed care plans should provide technical assistance and training** for clinicians and families who are unfamiliar or uncomfortable with telehealth, and ensure interpretation services are available during telehealth visits.
- Additional consideration and **flexibility of some aspects of HIPAA/privacy rules** are needed to accommodate and encourage telehealth through non-public-facing virtual platforms under certain circumstances.
- State Medicaid programs should be creative about **encouraging and incentivizing telehealth** beyond the end of the PHE, including:
 - Exploring/expanding payment methods that encourage virtual check-ins and reduce pressure to “do everything” in one visit
 - Piloting expanded telehealth modalities for Medicaid beneficiaries such as texting, especially for young people who may not have privacy for telephone calls
 - Identifying and expanding reimbursement for school-based physical and behavioral health services that are appropriate for telehealth delivery, and providing guidance to school districts on Medicaid requirements and billing
 - Considering reimbursement for telehealth by specialized practitioners or assistants supporting children with medical complexity in schools and childcare settings
- Health Resources and Services Administration’s (HRSA’s) Maternal and Child Health Bureau (MCHB), state and local public health agencies, and Title V programs should promote telehealth services for CYSHCN through:
 - **Outreach and trainings for families of CYSHCN** on how to access telehealth services, especially **through national and local family/peer support** organizations
 - Collection and dissemination of best practices for **implementing or expanding telehealth in school-based health centers and settings**⁵
- 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 professional associations, researchers/analysts, and accreditation organizations should:
 - Evaluate expanded telehealth utilization during the PHE and other evidence to **develop clinical guidelines** that identify appropriate (and conversely, inappropriate) use of telehealth for specific services and conditions among CYSHCN.
 - Explore 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. Similarly, guidelines should ensure that well-child care and related preventive services that require in-person visits, such as immunizations, are not deferred for too long during a PHE.

- Document how 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 for new physicians in conducting telehealth visits. In light of the disparities and inequities highlighted by the pandemic, training should include a focus on the importance of cultural concordance, where possible, and **cultural competence** and humility.

Recommendations Related to Other Access-Related Flexibilities

- The federal government should fund and coordinate with states and the private health care sector to thoroughly **evaluate and document the impact of the temporary policy flexibilities** on access, utilization, child/caregiver experience, physical and behavioral health, and developmental outcomes of CYSHCN and other at-risk populations. For example, 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.

Medicaid Stability and Coverage Protection

- Beyond the PHE, CMS should continue the **enhanced Medicaid federal medical assistance percentage (FMAP)** support to states, **tied to certain coverage protections**; 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. This would promote both stability of Medicaid and CHIP programs and access to services for families.

Strengthening Workforce

- 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 these shortages is extending **expanded scope of practice for non-physician clinicians** beyond the PHE (for example, the ability of nurse practitioners to order durable medical equipment) while maintaining or establishing new clinical and training standards.
- To further expand access to specialists important to CYSHCN, many **enrollment and eligibility flexibilities** affecting Medicaid and Medicare-participating providers should be retained beyond the PHE. In addition, 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.)
- The federal government should work with states and the medical community to develop and fund creative solutions to **address 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, including Certified Nursing Assistant training programs for legally responsible caregivers (e.g., parent and spouse); increasing Medicare and Medicaid reimbursement rates for home care workers (home health nurses, for example, consistently earn less than hospital-based workers); implementing or continuing home- and community-based services (HCBS) waiver program retainer payments to home-based workers while

a beneficiary is temporarily institutionalized or unable to receive services for a short time (even if unrelated to COVID-19).

- 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 availability of basic materials** required to continue delivering home care services while considering the unique needs of CYSHCN.
- 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 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 ensure quality and program integrity. (This may involve using waivers [e.g., HCBS or 1915(c)] to sidestep the legally responsible caregiver proscriptions.)

Care Coordination, SDOH

- To further support critical care coordination for CYSHCN beyond the PHE, CMS should clarify that Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) covers care coordination (beyond more explicitly delineated case management), define care coordination, and develop standards for CYSHCN, potentially using proposed standards as a guide.⁶ States should **secure and increase Medicaid reimbursement for care coordination services for CYSHCN** and consider covering care coordination by certain paraprofessionals and other service providers. States can also promote care coordination through managed care quality improvement requirements, pay-for-performance incentives, and enhanced care management initiatives.
- Given that the pandemic highlighted disparities and unmet SDOH needs, states, managed care plans, health systems, provider associations, and practices should **establish tools, protocols, and incentives to promote routine screenings for SDOH, especially for CYSHCN**. This must be supported by a care coordination process that “closes the loop” to confirm that referred services (both SDOH supports and health services) are completed and referring providers are informed.

Creative Value-Based Models for Pediatric Care

- The need to identify providers that are clearly accountable for the well-being of CYSHCN is heightened during emergencies such as the pandemic. CMS and 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 include accountable care organizations, health homes, outcomes/value-based payment, and shared-savings.

Prioritizing School-Based Health Services

- The Centers for Disease Control and Prevention should prioritize establishing guidelines for reopening schools, and 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 health services in the event of another pandemic or other reasons for closing school-based health services. This could occur in conjunction with states continuing or expanding Medicaid reimbursement for school-based health services provided through telehealth (described above).

Public Health and Title V

- State and local public health agencies, MCH, and Title V programs should:
 - **Include family members and advocates of CYSHCN in emergency preparedness** planning to inform contingency planning at the individual and system level and ensure the needs of CYSHCN will be met in the next emergency
 - 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

Recommendations on Behavioral Health Care for CYSHCN and their Caregivers

- As noted above, Medicaid and Medicare should keep and expand the ability to provide behavioral health services via telehealth.⁷ Medicaid **reimbursement for new telehealth modalities for behavioral health services** for CYSHCN, such as **audio-only visits**, should extend beyond the pandemic. Medicaid managed care plans should encourage the use of these new modalities when appropriate or necessary.
- Given the severe toll the pandemic has taken and may continue to take on the mental health of CYSHCN, states and Medicaid managed care plans should encourage and incentivize more **routine behavioral health screenings and services**. However, access to behavioral services for certain CYSHCN is limited by physical barriers, time constraints in typical behavioral health practice settings, and other factors (particularly, but not exclusively during a pandemic). These factors argue for broader access to behavioral health screening and services 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.
- In addition, CMS should allow state Medicaid programs to **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).

Efforts to improve our future readiness for pandemics must include an understanding of the broader socioeconomic ramifications of pandemics and other emergencies on high-risk groups. We need to learn from new policies implemented on national, state, or health system levels, as well as by examining differences in policies and experiences across states. Assessing the risks, costs, and benefits of the flexibilities during the COVID-19 PHE will equip policymakers and practitioners with evidence-based data to further inform decisions about policies to modify, continue, or expand further.

I. Background

The COVID-19 pandemic created particular challenges for CYSHCN and their families. This diverse group of individuals has chronic conditions, medical complexities, and/or behavioral or emotional conditions. The MCHB describes CYSHCN as requiring health and related services of a type or amount beyond that required by children generally.⁸ As a result, this population has been especially vulnerable to disruptions in access to health care and health-related services caused by the COVID-19 pandemic. They face heightened risks of becoming infected and greater consequences from the disease and the pandemic-related social distancing and isolation.

Federal and state legislation and numerous other policy mechanisms have established flexibilities and funding to help consumers, providers, and health systems deal with the pandemic and its consequences. Many of these actions focused on expanding the use of telehealth, given the risks of in-person visits during a highly contagious and dangerous disease outbreak. Other actions were intended to maintain eligibility and enrollment in health coverage, address new health care workforce shortages, and support health care practices facing a sudden loss of patient visits and revenue.

With support from the LPFCH, HMA examined how COVID-19 and the responses by the federal government and state governments, health systems, and providers have influenced health care for CYSHCN. The objective of this analysis was to identify the challenges and opportunities these changes created in health care delivery, financing, and policy. We sought to answer the following questions:

- What are the major mechanisms and components of new federal and state grant programs, waivers, and rule changes that have implications for access to and quality of care for CYSHCN?
- How are health care systems and providers modifying their practices in ways that may impact CYSHCN, positively or negatively?
- What are the significant consequences of the pandemic and new policy flexibilities on the workforce serving CYSHCN, families, and caregivers?
- Are there certain policy or care delivery changes made during the crisis that hold promise for improving care for CYSHCN that should be continued or expanded beyond the crisis period, or alternatively, should be modified or curtailed?
- What lessons can be learned from caring for children and CYSHCN during the pandemic that can be used to transform health care systems, especially government-funded systems such as Medicaid and CHIP, to be more efficient, responsive, equitable, and effective in the future?

Methodology

For this analysis, HMA conducted policy tracking, key stakeholder interviews, data synthesis, and developed recommendations. The research team reviewed state and federal policy through an environmental scan using numerous sources (outlined in Appendix A). We tracked COVID-19-related policies including relevant federal legislation, state Medicaid waivers and State Plan Amendments (SPAs), and CMS rule changes. We also conducted an environmental scan, including analyses and updates on federal and state-level executive orders, policy directives, licensing changes, and delivery system changes related to the pandemic. We focused on policies with potential consequences for access to services for CYSHCN. We did not track policies and provisions primarily related to vaccinations, school closures, or income supports, which are beyond the scope of this study.

From August 2020 through February 2021, the research team conducted semi-structured interviews or consulted with 22 individuals affiliated with more than 15 organizations (names and affiliations are listed in Appendix B). The interviews sought stakeholders' perspectives on the impact of policy changes on CYSHCN. We collaborated with the LPFCH to select individuals representing: 1) a range of clinical, policy, and advocacy roles; and 2) varied local, state, and national perspectives including state and federal agencies administering or funding children's programs. The clinicians interviewed included physicians serving CYSHCN and children with medically complex conditions in hospitals, specialty clinics, and primary care settings around the country. Based on our initial scan of policy flexibilities and care delivery changes with potential impact on CYSHCN, we developed a master interview guide (presented in Appendix C) that we tailored to each interviewee based on their areas of responsibility and experience.

The research team synthesized the policy review, stakeholder interview findings, and additional relevant information available during the course of the study. Based on this analysis, we developed and presented recommendations for continuing or expanding select "temporary" policies, delivery system changes, and funding beyond the PHE. These recommendations are intended to improve health care access and outcomes for CYSHCN, their families, and the providers and systems serving them.

II. Key Vehicles for Health Care Policy and Delivery Changes under COVID-19

Federal Legislation, Executive Orders, and Rule Changes

Establishment of PHE: On January 31, 2020, then-Secretary of the US Department of Health & Human Services (HHS) Alex M. Azar II declared that a public emergency exists nationwide (as of January 27, 2020) as a result of COVID-19. The PHE declaration activated emergency authorities under the Public Health Service Act, and its timeline is linked to regulatory flexibilities and mandates, funding sources, and emergency measures, described below.

The PHE lasts until the HHS secretary declares that the PHE no longer exists or upon the expiration of a 90-day period beginning on the date the HHS secretary declared a PHE exists, whichever occurs first.⁹ Secretary Azar later declared renewing the PHE four times as a result of continued consequences of COVID-19, on April 21, 2020, July 23, 2020, October 2, 2020, and January 7, 2021.¹⁰ On January 22, 2021, HHS under the new Biden administration sent a letter to governors indicating that it anticipates the PHE will last through the end of calendar year 2021, with enhanced Medicaid match—FMAP—through that period.

Federal Legislation: Table 1 presents the six major stimulus and relief acts passed by Congress through March 2021 to address the economic and health issues related to the COVID-19 pandemic. We highlight select provisions with potential relevance to CYSHCN, including increased funding for state Medicaid programs (tied to beneficiary protections), health care providers and infrastructure, broadband expansion and telehealth, and expansion of HHS/CMS authority to approve policy flexibilities and rule changes.

Table 1. Federal Stimulus Legislation Responding to the Economic Impacts of the COVID-19 Pandemic

Title, Date Enacted	Select Health Care-Related Provisions
Coronavirus Preparedness and Response Supplemental Appropriations Act March 6, 2020	Funded public health/emergency response, vaccine development. Removed restrictions on Medicare providers to allow reimbursement of telehealth services regardless of whether the beneficiary is in a rural community .
Families First Coronavirus Response Act (FFCRA) March 18, 2020	Section 6008 provides a temporary 6.2 percentage point increase to qualifying state and territory's Medicaid match (FMAP) and indirectly increases the federal CHIP match . Eligibility for increased FMAP requires states to provide continuous enrollment through the end of the month in which the PHE ends; not implement more restrictive eligibility standards or higher premiums than those already in place as of January 1, 2020; and provide coverage without cost-sharing for COVID-19-related testing and treatment services. The increase is retroactive to January 1, 2020, and will last through the last day of the quarter in which the PHE ends.
Coronavirus Aid, Relief, and Economic Security (CARES) Act March 27, 2020	Establishes the Paycheck Protection Program for small businesses, allocates \$100 billion into the Public Health and Social Service Emergency Fund for grants to health care providers; provides \$200 million to the COVID-19 Telehealth Program administered by the Federal Communications Commission (FCC); and expands HHS/CMS authority to use Section 1135 waivers for flexibilities and rule changes .

Title, Date Enacted	Select Health Care-Related Provisions
Paycheck Protection and Health Care Enhancement Act April 24, 2020	Provides authority to HHS to distribute hospital and provider grants under the Public Health and Social Services Emergency Fund, allocating \$75 billion to support the need for COVID-19-related expenses and lost revenue. The act provides \$25 billion for COVID-19-related testing, including \$825 million for community health centers and rural health clinics .
Consolidated Appropriations Act, 2021¹¹ December 21, 2020	Allots nearly \$900 billion in relief funding to address the COVID-19 pandemic and \$1.4 trillion in spending to fund the government for FY2021. Provisions include \$22 billion for health-related expenses incurred by state, local, Tribal, and territorial governments; ¹² \$7 billion for broadband expansion; an additional \$250 million in funds to develop the FCC's COVID-19 Telehealth Program administered by the FCC; Medicare-funded telehealth services expansion to cover mental health services made permanent (patient home may be originating site, but requires initial in-person visit¹³); \$3 billion to the provider relief fund; 3.75 percent one-time, one-year increase in Medicare's fee schedule for services rendered by physicians and other professionals; and a moratorium on introducing a new Medicare physician fee schedule complexity code that will result in higher payment rates for physicians in 2021. ¹⁴
American Rescue Plan Act of 2021 March 11, 2021	Allocates \$140 million for information technology, telehealth infrastructure, and the Indian Health Service electronic health records system; \$80 million for pediatric mental health access; an increase in the FMAP by 10 percent to supplement current HCBS expenditures; Emergency Rural Development Grants for Rural Health Care can be used to increase telehealth capabilities, including underlying health care information systems; and additional funding to providers, including community health centers, rural providers, and for local behavioral health needs

Executive Orders: Presidential executive orders are directives to federal agencies related to how legislation should be enforced and to dealing with emergencies. President Trump issued numerous executive orders during the pandemic. In August 2020, President Trump issued the [Improving Rural Health and Telehealth Access](#) (Executive Order 13941 of August 3, 2020) related to extending telehealth flexibilities established during the pandemic.¹⁵ This order tasked HHS to test new payment mechanisms/flexibilities from Medicare rules for rural health providers; develop and implement a strategy to improve physical and communications health care infrastructure available to rural Americans; and report on initiatives that increase rural access to providers, drive health outcomes, reduce maternal mortality and morbidity, and improve mental health in rural communities.

This executive order also called for HHS to review and propose a regulation to extend temporary flexibilities beyond the PHE related to additional telehealth services and other flexibilities for Medicare providers in rural areas. However, the impact of this order is limited, as extending certain temporarily waived telehealth restrictions requires Congressional action.¹⁶ CMS did use its rule change process to extend Medicare telehealth-related payment flexibilities, described below. President Biden has signed numerous executive orders since his inauguration on January 20, 2021, including a directive to federal agencies to re-examine rules and policies that may limit access to care, such as demonstrations and waivers under Medicaid and the Affordable Care Act that make it difficult to enroll and reduce coverage or undermine Medicaid programs.

CMS Rule Changes: CMS issued four COVID-19 Interim Final Rules with Comment Periods during 2020. These implemented directives of the CARES Act; created temporary revisions to Medicare and Medicaid regulations including flexibilities in scope of practice, medical education, and telehealth coverage; established Medicare payments for new COVID-19 treatments; and included numerous provisions to support vaccinations for Medicare and Medicaid beneficiaries.

On December 1, 2020, CMS issued the [CY2021 Medicare Physician Fee Schedule Final Rule](#) that updated earlier policy changes under the physician fee schedule, making some Medicare telehealth flexibilities permanent, extending others for the remainder of the year in which the PHE ends, and ending coverage post-PHE for more than 50 telehealth services that the agency had covered during the PHE. Final rule provisions went into effect on or after January 1, 2021.^{17,18,19} While Medicare primarily covers individuals age 65 and older, certain provisions may be relevant to some CYSHCN, and Medicare changes often influence Medicaid policies in the future, potentially affecting more CYSHCN and their families. Table 2 summarizes select provisions of the Final Rule.²⁰ Notably, CMS did not propose to extend recognizing audio-only telehealth or using the patient's home as a telehealth originating site, as it would require Congressional action to waive these statutory requirements.

Table 2. CY2021 Medicare Physician Fee Schedule Final Rule

	Select Telehealth-Related Payment Provisions that may Affect CYSHCN
Extended Telehealth Services and Communication Technology-Based Services	<ul style="list-style-type: none"> Finalized Medicare reimbursement for telehealth assessment and care planning services for individuals with cognitive impairment, psychological and neuropsychological testing, and "home visits" for established patients
	<ul style="list-style-type: none"> Finalized the addition of new services to the Medicare telehealth list on a permanent basis, including home visits for established patients and group psychotherapy. Telehealth services finalized on a temporary basis (through the calendar year in which the PHE ends) include physical and occupational therapy services (all levels), inpatient neonatal and pediatric critical care, and continuing neonatal intensive care services
	<ul style="list-style-type: none"> As audio-only communication is not a permissible Medicare telehealth service by statute, CMS created a new code under the heading Communication Technology-Based Services for audio-only telephone services, including a new Healthcare Common Procedure Coding System G-code for 11–20 minutes of medical discussion to determine the need for an in-person visit
Expanded Scope of Practice to Non-Physicians	<ul style="list-style-type: none"> Clarified that licensed clinical social workers, clinical psychologists, physical therapists, occupational therapists, and speech-language pathologists can furnish Communication Technology-Based Services, such as brief online assessment and management services ("e-visits"), virtual check-ins, and remote physiologic monitoring services
	<ul style="list-style-type: none"> Made permanent the ability of non-physicians—nurse practitioners, clinical nurse specialists, physician assistants, certified nurse-midwives, and nurse anesthetists—to supervise the performance of diagnostic tests (subject to state laws and scope of practice) beyond the COVID-19 PHE
	<ul style="list-style-type: none"> Granted physical therapists and occupational therapists the discretion to delegate the performance of maintaining therapy services, as clinically appropriate, to a physical therapist assistant or an occupational therapy assistant, beyond the PHE

Return to Established Relationship for Remote Patient/Physiologic Monitoring

- Clarified that following the PHE for the COVID-19 pandemic, CMS **will again require that an established patient-physician relationship exist for remote physiologic monitoring** services to be furnished and that consent to receive these services can be acquired at the time they are furnished

(Sources: Centers for Medicare & Medicaid. (2020, December 1). *Final policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2021*. <https://www.cms.gov/newsroom/fact-sheets/final-policy-payment-and-quality-provisions-changes-medicare-physician-fee-schedule-calendar-year-1> and 85 Fed. Reg. 248 (December 28, 2020) (to be codified at 42 C.F.R. Parts 400, 410, 414, 415, 423, 424, and 425) <https://www.govinfo.gov/content/pkg/FR-2020-12-28/pdf/2020-26815.pdf>

Waiver Authorities and Other Regulatory Mechanisms for Temporary Changes

The following federal waiver authorities and mechanisms enable states to request or automatically receive flexibilities in their Medicaid and CHIP programs (and Medicare where noted) to mitigate the consequences of the COVID-19 pandemic. Each contains provisions that may affect CYSHCN, their caregivers, and their providers. Table 3 presents the end dates and number of states with approvals for each mechanism.

Emergency Section 1135 Waivers: With declaration of both a national emergency and PHE, HHS can use Section 1135 authority to waive or modify certain Medicare, Medicaid, and CHIP requirements to ensure that sufficient health care items and services are available to meet the needs of beneficiaries. CMS issued blanket Section 1135 waivers for many provisions (primarily but not exclusively related to Medicare) that were automatically enacted (summarized in Table 4).²¹ In addition, states have requested and received [approval for Medicaid flexibilities](#), based on a checklist [template provided by CMS](#), including easing provider licensing requirements, waiving of prior authorization requirements, facilitating provider enrollment to Medicaid programs such as waiving licensure in the state if they have equivalent licensing in another state, and suspending two-week supervision by a registered nurse for home health agencies (described further in Section IV.A. Access-Related Policy Changes and New Flexibilities).^{22,23} All 50 states plus the District of Columbia received Emergency Section 1135 waivers.

Medicaid Disaster Relief SPAs: CMS provided a [template](#) for states to request [approval for amendments](#) related to the COVID-19 PHE, resulting in temporary changes to their Medicaid and CHIP state plans that address access and coverage issues.^{24,25,26,27} States may request flexibility in:

- Eligibility, expanding coverage to additional populations or income levels
- Enrollment, such as presumptive eligibility determinations, continuous eligibility up to 12 months for children, or simplified applications
- Premiums and cost-sharing, suspending deductibles and copayments for certain eligibility groups or income levels that previously faced cost-sharing
- Benefits, adding optional benefits or adjustments to benefits such as new ways to utilize telehealth, and expanding quantity limits and prior authorizations for medications
- Payments, increasing rates for specified services such as telehealth or telehealth ancillary costs
- Post-eligibility treatment of income, increasing the personal needs allowance for institutionalized individuals
- Other modifications the state may request

Through January 2021, 47 states, the District of Columbia, and four territories applied and received CMS approval for Medicaid disaster relief SPAs.²⁸ Among these, 28 were approved to temporarily expand telehealth benefits and 31 were approved to increase payment rates to providers.

CHIP Disaster Relief SPAs: States have the opportunity to [submit CHIP SPAs to CMS](#) to allow for temporary adjustments to their CHIP programs during the COVID-19 PHE.²⁹ The provisions are primarily intended to ease requirements related to enrollment and redetermination policies (e.g., extending application and renewal deadlines, maintaining enrollment, providing continuous eligibility, providing presumptive eligibility) and cost-sharing requirements (e.g., waiving premiums, co-payments) during the PHE. Through January 2021, 35 states had applied and received approvals for flexibilities through CHIP disaster relief SPAs. This includes California's emergency SPA approved in 2018, which indicated the state could notify CMS if they intended to invoke the approved flexibilities in future emergency situations.³⁰

Section 1915(c) Waiver Appendix K: All 50 states and the District of Columbia have been approved by CMS to modify Medicaid HCBS waiver programs (authorized under Section 1915(c) of the Social Security Act) during emergencies through an Emergency Preparedness Response Appendix K amendment.³¹ This mechanism allows for flexibilities in eligibility criteria and other standards. [Appendix K can be used to](#) add to the number of participants allowed in the program, lift budget and service limitations, add services, expand telehealth, change provider qualifications, pay caregivers for personal attendant services, extend timelines for level of care determinations and service plans, raise provider rates, and make other changes intended to improve access to and maintenance of community-based services for people with disabilities.³² (Appendix K approvals can also apply to HCBS provision through 1115 waivers.³³)

California HCBS waiver Appendix K flexibilities

California received CMS approval for Emergency Preparedness Response Appendix K amendments to four 1915(c) HCBS waivers for which children are eligible (Home and Community-based Waiver Alternatives; Home and Community-based Waiver for Californians with Developmental Disabilities; Self-Determination Waivers for Californians with Developmental Disabilities; and HIV/AIDS Waiver). The following newly permitted temporary flexibilities (approved through six months after the end of the PHE) may apply to more than one of these waivers:³⁴

- Payments for services by family caregivers and legally responsible individuals
- Retainer payments for services related to habilitation, behavioral intervention, personal care, and activities of daily living for periods up to 30 days (supports home and residential workers if the client is temporarily in quarantine or absent, or workers are otherwise unable to provide the services for reasons related to COVID-19)
- Allowing change of location and modification of provider qualifications for private duty nursing and home care workers
- Allowing telephonic or video conferencing for care coordination/level of care evaluations, service plan development/monitoring, home environment assessments, and home visits/service provision as an alternative to face-to-face interaction
- Expanded settings where services may be provided, including a participant's home or in a community setting
- Coverage of assistive technologies

COVID-19 PHE Demonstration Section 1115 Waivers: CMS developed a new temporary [Medicaid Section 1115 demonstration opportunity and application template](#) as a mechanism for states to modify their existing 1115 demonstrations to help address the COVID-19 PHE.^{35,36} States may request temporary modifications to eligibility, benefits, cost-sharing, long-term services and supports provisions, and expenditure authority. Budget neutrality requirements (part of Section 1115 waivers) are waived. Through mid-February 2021, six states had received approvals for new COVID-specific 1115 waivers, and five states were approved amendments. North Carolina's waiver, for example, allows the state to make retainer payments to certain habilitation and personal care providers to maintain capacity during the emergency and modifies eligibility criteria (including permitting self-attestation) for long-term services and supports, among other provisions.³⁷

Table 3. Federal COVID-Related Authorities, Timelines, and Number of States with Approvals

Federal authority to address COVID-19	Effective end dates ³⁸	Number of states with approvals as of February 9, 2021
Section 1135 waiver	Termination of the COVID-19 PHE	50 states, District of Columbia, and 3 territories
Disaster-Relief Medicaid or CHIP SPAs	Termination of PHE or shorter timeframe selected by the state in the SPA	Medicaid: 47 states, District of Columbia, and 4 territories CHIP: 35 states
Appendix K of Section 1915(c) HCBS waivers (or re: HCBS provision through 1115 demonstration)	Typically effective for one year after date of approval, or until 6 months after end of PHE; specified in approval document and updates	50 states and District of Columbia
COVID-19 PHE Demonstration Section 1115 waivers	Will expire no later than 60 days after the end of the PHE	New waivers: 6 states Amendments: 5 states (Appendix Ks through 1115 demonstrations are counted in the row above)

Additional State-Level Policy Levers

In addition to applying to CMS for Medicaid emergency authorities (including Section 1135 waivers, Section 1915(c) Appendix K strategies, and Disaster Relief SPAs), states can take many actions to alleviate the impact of the COVID-19 pandemic that do not require CMS approval. States have made modifications to address the pandemic through governors' executive orders, emergency policy directives and guidance, state legislative and administrative actions, state Medicaid regulatory and rule changes, and modifications in workforce licensing requirements. These state-level flexibilities are often tied to the state's emergency schedule (declared through a governor's executive order), rather than to the federal PHE.

State and Federal Funding

The federal COVID-19 relief bills described above have provided much-needed grants, loans, and payments to Medicaid programs, providers, and lower-income families, including pediatric specialists and families of CYSHCN. Federal legislation and waiver flexibilities also authorize funding for programs to expand telehealth access and infrastructure and create new payment mechanisms. Most of these funding provisions are temporary, intended to bring relief during the PHE and the resulting economic crisis. Following we highlight examples that may affect CYSHCN.

A temporary increase in the Medicaid FMAP and flexibilities in payment structures are helping to shore up Medicaid provider networks and HCBS waiver programs. The FFCRA's 6.2 percentage point increase in federal matching rates to states' Medicaid and CHIP programs are enabling economically strapped states to continue reimbursing Medicaid and CHIP providers. The American Rescue Plan Act of 2021 increases the FMAP for Medicaid HCBS by 10 percentage points from April 1, 2021, through March 31, 2022—helping states support the HCBS provider workforce and maintain or expand benefits and the number of individuals receiving HCBS.

Through Appendix K waivers, some states were approved payment structure flexibilities for HCBS providers. For example, states could provide retainer payments to home-based caregivers or providers of habilitation and behavioral intervention while a beneficiary is temporarily in quarantine or institutionalized, or unable to receive services due to COVID-19.

The FCC COVID-19 Telehealth Program, administered by the FCC, supports eligible health care providers responding to the COVID-19 pandemic by fully funding their telecommunications services, information services, and devices necessary to provide critical connected care services. The program approved 539 funding applications in 47 states plus Washington, DC, and Guam for a total of \$200 million provided by the CARES Act.^{39,40} The Consolidated Appropriations Act, 2021, allocated an additional \$250 million for this program.

The California Telehealth Network, in Sacramento, California, was awarded \$1 million through the COVID-19 Telehealth Program for laptop computers, smartphones, mobile hotspots, a videoconferencing software license, and remote monitoring devices to offer member hospitals telehealth technical assistance, customized emergency workflows for virtual treatment of patients, network devices and network design support, virtual visit software, and the ability to expand telehealth training and support for rural and medically underserved clinics and hospitals in California.⁴¹

FCC Three-year Connected Care Pilot program provides up to \$100 million from the Universal Service Fund for selected pilot projects to cover 85 percent of the eligible costs of broadband connectivity, network equipment, and information services necessary to provide connected care services. Eligible applicants will include nonprofit and public eligible health care providers, with an emphasis on supporting these services for low-income Americans and veterans.⁴²

HRSA grant program for 14 HRSA-funded Telehealth Resource Centers provides customized telehealth technical assistance on telehealth to help rural and underserved areas combat COVID-19, while also acting as a clearinghouse for telehealth research, program design, and implementation.⁴³

USDA Distance Learning and Telemedicine Grant program provides CARES Act funds to state and local governments, tribes, and private organizations to help rural communities acquire technology/equipment, broadband facilities, computer hardware and software, and technical assistance and training to connect medical and educational professionals with their counterparts in other communities.⁴⁴

The **American Rescue Plan Act of 2021** includes \$500 million in Emergency Rural Development Grants that can be used to increase telehealth capabilities, including underlying health care information systems, among other purposes; \$140 million for information technology, telehealth infrastructure, and the Indian Health Service electronic health records system; \$50 million in grant funds for community behavioral health (including telehealth, among other services).

Under the CARES Act, **HRSA's MCHB** was awarded a modest \$15 million in total additional funding to the Bureau's four technical assistance centers. Each award supports a key area in MCH: pediatric care, maternal health care,⁴⁵ state public health systems, and family engagement for children with special health care needs. These investments were intended to provide telehealth care for adolescents and young adults; *expand telehealth services for children with special health care needs through trainings for families and national family organizations on accessing telehealth (\$1 million to Family Voices, Inc.)*⁴⁶, including for routine care and services they are not accustomed to accessing virtually; and help community-based pediatric practices develop telehealth capacity, particularly in rural and underserved areas.

The Title V MCH Services Block Grant program offers ways states could adapt grant funds to support COVID-19 programs. The program permits states to redirect these funds to support responding to an evolving issue, such as COVID-19. MCHB guidance indicated that potential state responses may include:⁴⁷

- Offering the support or leadership of Title V epidemiologists, in partnership with other state staff, to an outbreak investigation
- Providing support in educating the MCH population about COVID-19 through partnerships with other state agencies, medical providers, and health care organizations
- Working closely with state and local emergency preparedness staff to ensure that the needs of the MCH population are represented
- Funding infrastructure that supports the response to COVID-19 (e.g., public health nurses who are routinely supported through the Title V program may be able to be mobilized, using Title V funds or separate emergency funding, to support a call center or deliver health services)
- Partnering with parent networks and health care providers to provide accurate and reliable information to all families
- Engaging community leaders, including faith-based leaders, to educate community members about strategies for preventing illness

III. Expanded Telehealth

According to all interviewees, the most significant health system change affecting CYSHCN and their families has been the immediate transformation of much health service delivery to telehealth. CMS describes [telehealth and telemedicine](#) as the exchange of medical information from one site to another through electronic communication to improve a patient's health⁴⁸ (we use "telehealth" for simplicity). It may include audio/video and audio-only technologies, use of the patient portal, interprofessional e-consults, and remote patient monitoring.⁴⁹ Telehealth may be synchronous (two-way interactive, real-time interaction between a patient and a care provider at a distant site) or asynchronous or "store-and-forward" transmission of medical information and images.

Pre-COVID, telehealth was viewed as holding "particular promise in facilitating the management and coordination of care for medically complex children and those with chronic conditions, such as asthma, chronic lung disease, autism, diabetes, and behavioral health conditions."⁵⁰ Telehealth had already been increasing as a service modality, particularly in geographically isolated areas (Medicare limited telehealth reimbursement primarily to rural areas) and in behavioral health, but increased exponentially after the pandemic began. With less than one percent of pediatric visits provided through telehealth pre-pandemic, CMS reported preliminary data showing delivery of services via telehealth to children increased by more than 2,500 percent from February to April 2020, with utilization higher in urban areas than in rural areas and more than half of pediatric telehealth visits for behavioral health and developmental disorder diagnoses.⁵¹ In-person visits began to rebound in April as providers modified their practices to safely accommodate them; however, in October 2020, in-person visits for younger children (including primary and preventive health services and immunizations) remained substantially below the pre-pandemic baseline.⁵²

A. Telehealth Policy and New Flexibilities

States have broad ability to cover telehealth through Medicaid. CMS released a State Medicaid and CHIP Telehealth Toolkit to help Medicaid agencies identify state-level policy considerations to facilitate widespread adoption of telehealth services. CMS emphasized that states have broad ability to cover telehealth through Medicaid, and that federal approval is not needed for state Medicaid programs to reimburse for telehealth services in the same manner or at the same rate paid for face-to-face services, visits, or consultations. Any revisions to payment methodology to account for telehealth costs would require an SPA, facilitated through Medicaid and CHIP Disaster Relief SPAs (described in Section II). CMS also "encouraged" states to amend their Medicaid managed care contracts to ensure the same telehealth flexibilities authorized under their state plan, waiver, or demonstration are included in their contracts,⁵³ though it is not clear to what degree states have done so. States' telehealth-related laws and regulations continue to vary and evolve.⁵⁴

To further promote telehealth during the pandemic, federal and state policies temporarily waived restrictions and expanded types of services, locations, and providers eligible for Medicare and Medicaid reimbursement. Federal policies have enabled the expansion of Medicare services via telehealth, while state Medicaid agencies have used waiver authorities, executive orders, and guidance to promote greater use of telehealth services for Medicaid and CHIP beneficiaries. For example, by December 3, 2020, all 50 state and Washington, DC, Medicaid agencies had issued guidance to allow for

a form of audio-only telehealth services.⁵⁵ Notably, the telehealth flexibilities do not address communication or resource gaps between health care technologies and technology used by the education, child welfare, or juvenile justice systems.

Table 4 summarizes temporary telehealth flexibilities not targeted to pediatric care specifically but that affect CYSHCN, and the federal or state mechanisms that made them possible. Policies that authorize funding and resources to increase telehealth access and infrastructure are discussed further below in Section VI.

Table 4. Select Temporary Telehealth Flexibilities During the COVID-19 PHE

Telehealth Provisions and Related Programs/Populations	Policy Mechanism(s)
<i>Medicare:</i> Extends telehealth beyond rural locations, waiving the requirement that the patient is located in a rural location or in a provider shortage area at the time of the visit	Coronavirus Preparedness and Response Supplemental Appropriations Act
<i>Medicare and Medicaid:</i> Broadens HHS/CMS waiver authority, allowing CMS to temporarily remove requirements to expand Medicare and Medicaid telehealth coverage Directs the HHS secretary to clarify guidance and conduct outreach to encourage the use of telecommunication systems for home health services, including remote patient monitoring, during the PHE <i>Medicare:</i> Allows telehealth services to be provided to eligible telehealth individuals at federally qualified health centers (FQHCs) and rural health clinics	CARES Act
<i>Medicare:</i> Extends telehealth coverage to all Medicare beneficiaries, not just those treated by a provider within a three-year period prior to emergency telehealth	FFCRA
<i>Infrastructure:</i> Funding/grants that can be used for telehealth infrastructure, rural telehealth expansion, technology supporting students with disabilities, and telecommunications between schools and students	American Rescue Plan Act of 2021
<i>Medicare:</i> <ul style="list-style-type: none"> Expands eligible practitioners that can furnish distant site telehealth services to include those eligible to bill Medicare for their professional services (but were previously ineligible to bill for telehealth), including physical therapists, occupational therapists, speech language pathologists, and others Allows physicians to supervise their clinical staff using virtual technologies Broadens audio-only telephone visits to include evaluation and management services, including advance care planning, tobacco and smoking cessation counseling, behavioral health counseling, and patient education services⁵⁶ Allows clinicians to provide virtual check-ins and remote patient monitoring to new and established patients (with acute and chronic conditions), and to provide remote patient monitoring for patients with only one disease <i>Hospitals and Critical Access Hospitals:</i> <ul style="list-style-type: none"> Waives requirements to make it easier for telehealth to be furnished through an agreement with an off-site hospital, promoting access to specialty care 	“Blanket” 1135 Waivers (not requiring state requests) ⁵⁷

Telehealth Provisions and Related Programs/Populations	Policy Mechanism(s)
<p><i>Medicaid:</i></p> <ul style="list-style-type: none"> Clinic services may be provided via telehealth when neither the patient nor practitioner is physically on-site at the clinic (including services provided in clinic practitioner's home) Allow out-of-state providers with equivalent licensing in another state to provide care to Medicaid beneficiaries via telehealth⁵⁸ 	1135 Waivers (requires state request and CMS approval)
<p><i>Medicaid and CHIP (varies by state):</i></p> <ul style="list-style-type: none"> Expand telehealth services eligible for reimbursement (e.g., for targeted case management services – Minnesota) Add payment methodologies for telehealth (e.g., including rates based on face-to-face fee schedule – Kentucky) 	Disaster Relief SPAs
<p><i>Medicaid HCBS Waiver program (varies by state):</i></p> <ul style="list-style-type: none"> Allow providers of speech therapy, physical therapy, and occupational therapy to utilize video conferencing/telehealth Permit virtual eligibility assessments, service planning meetings/case management, personal care services that require only verbal cueing, in-home habilitation, or monthly monitoring Temporarily modify processes for level of care evaluations, re-evaluations, and medication management Example: North Carolina's Traumatic Brain Injury and Innovations HCBS waivers have waived face-to-face requirements for monthly and quarterly care coordinator/beneficiary meetings⁵⁹ 	Appendix K (HCBS) ⁶⁰ Section 1915(c) Waiver
<p><i>Medicaid and CHIP (varies by state) – Examples:</i></p> <ul style="list-style-type: none"> Extend telehealth in Medicaid to additional care providers and services, such as speech therapy, physical therapy, and occupational therapy,⁶¹ behavioral health providers, and practitioners with out-of-state licenses Reimbursing for audio-only telehealth for evaluation, management, behavioral health, and educational services (adding new coverage codes or allowing providers to bill existing codes for services delivered via telephone) Extend reimbursement to providers for telehealth services in the same manner or at the same rate (parity) that states pay for face-to-face services Expand allowable originating site (where the patient is located) and distant site (where the practitioner is located) to include homes, FQHCs, rural clinics (and schools in California) (Note: FQHCs are common care entry sites for low-income children) Allow telehealth consultations for hospitalized patients with specialists at other locations (Note: In instances where non-pediatric facilities can have easier access to pediatric specialists via telehealth, this flexibility would be a significant benefit to CYSHCN) Expand the allowable platforms for delivering telehealth Relax the requirement that telehealth visits must only be conducted with previously established patients Waive face-to-face requirements for monthly and quarterly care coordinator/beneficiary meeting Expand Medicaid reimbursement for school-based telehealth services 	State mechanisms (executive orders, guidance, Medicaid regulations and rule changes, etc.)

Child-focused telehealth flexibilities typically involved state guidance and expanded Medicaid reimbursement for well-child visits delivered via telehealth, and for remote care delivery for early childhood intervention services.⁶² As of December 3, 2020, 19 states and Washington, DC, had issued telehealth guidance for well-child care and EPSDT visits, in accordance with American Academy of Pediatrics recommendations that children continue to receive EPSDT services during the pandemic.⁶³ Sixteen states have issued guidance to providers to allow for telehealth or remote care delivery for early childhood intervention services.⁶⁴ Following are some examples.

- Maine, North Carolina, and Rhode Island are allowing **telehealth well-child visits** delivered via fee-for-service and/or through Medicaid health plans and require follow-up in-person visits as soon as possible.
- Kentucky **requires the in-person follow-up visit** after pediatric well-child visits to occur within six months of the end of the declared emergency.
- Colorado added **pediatric behavioral therapy services** to its list of eligible services to be delivered via telehealth.⁶⁵
- North Carolina Medicaid **expanded telehealth codes and guidance to services delivered through local education and children's developmental service agencies**, and for dietary evaluation and counseling, medical lactation, research-based behavioral health treatment for autism spectrum disorder, and diabetes self-management education.⁶⁶
- Illinois implemented **Early Intervention Teletherapy**, and its Early Intervention Program instituted live Video Visits during the state emergency period.⁶⁷

The majority of states expanded Medicaid reimbursement for school-based telehealth services during the PHE. Prior to the pandemic, 24 states had policies that explicitly permitted schools to be reimbursed by Medicaid for telehealth services. Audiology and speech-language therapy were the most commonly covered telehealth services. During the pandemic, CMS issued guidance clarifying that schools can receive Medicaid reimbursement for telehealth services except where limited by the Medicaid state plan. Thirty-one states expanded reimbursement for school-based telehealth during the PHE, most often for behavioral health services, followed by occupational and physical therapy. At least four states have made their changes permanent or plan to do so.⁶⁸

Relaxation of certain aspects of HIPAA privacy rules are intended to facilitate telehealth during the PHE. HHS' Office for Civil Rights announced it will [not impose penalties](#) against covered health care providers for noncompliance with HIPAA Rules⁶⁹ requirements in connection with the good faith provision of telehealth during the COVID-19 PHE. As a result, covered health care providers may use popular applications that allow for video chats, including Apple FaceTime, Facebook Messenger video chat, Google Hangouts video, Zoom, or Skype, bringing telehealth to families that might not otherwise have access.⁷⁰ To reduce risks, the Office for Civil Rights has provided bulletins, notifications of enforcement discretion, guidance, and resources that help explain how patient health information may be used and disclosed, and issued guidance on telehealth and HIPAA during the COVID-19 PHE.^{71,72} Providers would continue to bill for their services using existing codes regardless of the platform.

Consent, privacy laws, and HIPAA requirements may have a unique impact on children and adolescents. CMS's State Medicaid and CHIP Telehealth Toolkit includes a section on pediatrics, which notes that states must consider consent laws, regulations, procedures, and policies for pediatric populations when developing telehealth coverage policy for children. For example, state consent laws that establish the age of consent may vary by type of service. Depending on each state's requirements, there may be a need for parent/guardian involvement at some point during the course of telehealth treatment.⁷³

Similarly, privacy laws have a unique impact on the pediatric population, and some of these laws are beyond the authority of Medicaid and CHIP. Medicaid programs may need to consult with the Department of Education regarding school-based services and requirements for school records and related issues in the [Family Educational Rights and Privacy Act](#) or the [Individuals with Disabilities Education Act](#).

B. Impact of Telehealth Flexibilities

1. Impact of Telehealth Flexibilities on CYSHCN and their Families

All of the stakeholders interviewed described direct experience with the sudden decline of in-person visits at the start of the pandemic, and with new flexibilities and reimbursement designed to increase the use of telehealth. They unanimously concluded that telehealth has been beneficial and has expanded access to care for a large portion of CYSHCN and their families, but there are disparities in access to the necessary technology, training, supports, and broadband coverage.

Stakeholders emphasized that telehealth overcomes transportation and logistical barriers that are particularly challenging for low-income families of CYSHCN, offering opportunities to reduce pervasive inequities. Telehealth mitigates challenges related to:

- Transporting wheelchair, respiratory, and other cumbersome equipment used by children with medical complexities
- Accessing vehicles or paying for transportation
- Needing to bring the child's siblings to appointments
- Traveling long distances, especially for families in rural and provider shortage areas
- Taking time off from family member/caregiver's work, given the significant time commitment for each in-person appointment

Telehealth also improves time efficiency, as caregivers can often make same-day appointments and do not have to sit in waiting rooms for long periods before seeing a practitioner.

Telehealth expands access to services and professionals (including specialists) in a low-risk setting.

Interviewees pointed out that telehealth is particularly conducive to behavioral health visits, and for therapies whereby the patient already had a relationship with the therapist who can then view, provide instructions, and support families via telehealth. Practitioners noticed there were more appointments with specialists available during the early months of the pandemic and that telehealth facilitates access to out-of-state specialists and expertise. Interviewees relayed examples of complex care visits now being

conducted via telehealth, eliminating the need for a family to travel for a procedure only offered out of state. A few interviewees noted that telehealth via audio-only telephone is particularly helpful for families without broadband or computers. Other important benefits include:

- Reduced isolation, especially for CYSHCN who have difficulty leaving homes
- Increased touchpoints and opportunities to communicate with providers, especially for follow-up care
- Lower overall infection risk and less family concern about communicable disease exposure of in-person visits (particularly critical for many CYSHCN)

However, nearly all interviewees pointed out that telehealth is not adaptable to certain services.

Interviewees stressed that the pandemic has disrupted “hands-on” therapies and services that are more beneficial in person, such as developmental or neurological assessments, and initiation of therapy services where the child is first meeting the therapist. Telehealth is challenging if the child, caregiver, and therapist have not had the opportunity for in-person practice or training of the parents to reinforce specific interventions. Immunizations cannot be conducted via telehealth and must wait until the next in-person visit.

The pandemic has exacerbated disparities for low-income families with technology and language barriers. Nearly all interviewees described the greatest challenges to telehealth as lack of technologies and systemic infrastructure issues that affect broadband access in certain geographies. Low-income families of CYSHCN are less likely to have computers or stable internet access and often struggle to pay for minutes on their mobile telephones, which often serve as the default technology needed for telehealth visits. 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 additional study. Most interviewees also noted that language barriers and lack of interpretation services among some clinics and providers make telehealth inaccessible to non-English speaking families. One interviewee reported that several high-risk clinics in her region lack interpretation services for telehealth, despite federal requirements.

“Unless we [start to] provide basic investment in connectivity while wealthier people have tech access, disparities are going to get worse.”

– DR. RISHI AGRAWAL

Stakeholders reported that many caregivers of CYSHCN have concerns or lack confidence about telehealth, which may lessen the benefits and decrease the successful completion of telehealth visits.

With little to no funding for training caregivers on using telehealth, some caregivers fear they will not conduct therapy exercises with their child correctly, struggle with new platforms, and worry that face-to-face visits will not resume. Ancillary care providers often do not have the resources or time to provide pre-visit instructions and prep materials for virtual visits. Practitioners reported telehealth “no shows” because some caregivers do not know what to expect and have anxiety about the quality of care. Some families are reportedly uncomfortable with providers being able to see their home, embarrassed about

their home conditions or viewing telehealth as an invasion of their privacy. Other families have inadequate home space to ensure privacy, particularly for mental health virtual visits.

2. Impact of Telehealth Flexibilities on CYSHCN Providers and Health Systems

Using temporary flexibilities and federal funding, providers and health systems rapidly shifted to telehealth for patients, including CYSHCN. Many interviewees were surprised that both public and private payers were willing to reimburse for telehealth, and how quickly health systems responded. Mercy Health System (based in St. Louis, Missouri) deployed and trained thousands of providers to conduct telehealth, representing a “huge paradigm shift,” according to a Mercy clinician. A large California FQHC that serves a major portion of the region’s children with complex needs reported transitioning to 70 percent telephonic visits during the earlier period of the PHE, after securing federal grants to obtain telehealth equipment.

Interviewees universally agreed that payment parity between telehealth and in-person visits was essential to the ramp up. By late April 2020, 38 states plus Washington, DC, provided payment parity in Medicaid for telehealth services,⁷⁴ and by September, 17 states had enacted laws requiring parity from private insurers.⁷⁵

California Medicaid (Medi-Cal) had enacted a number of telehealth reimbursement expansions prior to the pandemic, including payment parity for services via live video, select store-and-forward services (dermatology, ophthalmology, and some tele-dentistry), certain California Children's Services' (CCS) covered therapy services, and behavioral health services. After the PHE began in early 2020, telehealth location and provider limitations on FQHCs and other community health centers were lifted, and reimbursement was instituted for audio-only telephone services.⁷⁶

“If there is not payment parity at PPS rates for audio/telephone visits, which are crucial for our patients, many community health centers will face serious financial issues and may need to cut staff and services to the most vulnerable in our communities.”

– DR. ELISA NICHOLAS

“In one month, [our health system] did our five-year plan moving the system forward in telehealth.”

– DR. ALISON CURFMAN

Effective telehealth required major adaptations; providers with prior telehealth capabilities were most successful at scaling up. Providers learned that delivering virtual care effectively required adapting workflows, documentation and consent procedures, staff roles, assessment and supervision approaches, as well as mastering complex billing and variable reimbursement across states. Multiple stakeholders reported that successful expansion or pivoting to telehealth depended largely on the health system’s or practice’s telehealth infrastructure that was already in place and their ability to leverage existing resources.

Stakeholders cited aspects of telehealth that improved providers’ ability to serve CYSHCN. Telehealth offered providers the opportunity to be more patient-centric, “meeting the patient where they are.” Physicians and therapists can learn how children are faring in their natural, home environment; they can

see and provide direct feedback on how a parent applies care at home. Some providers found they were better able to conduct care coordination online and by telephone. And practitioners reported that fewer office personnel are needed to conduct telehealth visits.

Despite the benefits of telehealth, some providers and health systems are shifting back to in-person visits (with strategies to reduce risk of contagion) as a result of perceived limitations to telehealth, financial pressures, and the inability to adapt to telehealth. Practitioners

voiced challenges to telehealth, including the inability to see signs of potential problems in patients without “hands-on” examinations and lack of sufficient remote monitoring devices (such as blood pressure or glucose monitors, or apps whereby parents send health information to their child’s care team).⁷⁷ Though not prevalent, a couple of interviewees relayed concerns about some older physicians choosing to retire rather than adapt to unfamiliar telehealth platforms. Other interviewees described staff being redeployed to support telehealth without sufficient training, raising concerns about quality of care.

A few interviewees emphasized the high expense of building telehealth infrastructure and the difficulty and delays in obtaining federal funding. One clinician reported challenges in fully adapting the California Children’s Services Medical Therapy Program,⁷⁸ which is located in designated public schools, to telehealth due to reimbursement challenges and hurdles getting necessary equipment.

Providers described pressure to shift back to in-person visits from administrators at hospitals and health systems that experienced significant declines in revenues from ancillary services and facility fees. Some cited administrators’ concerns about financial strains when the PHE ends if telehealth services are no longer reimbursed or are paid at lower rates.

A physician leading a pediatric telehealth program in a large hospital system prior to the pandemic reported that the program’s comprehensive care coordination and virtual support services for children with medical complexities reduced emergency room and inpatient utilization, improving care and saving hundreds of thousands of dollars in Medicaid spending. However, because those savings were not shared with the hospital, it shut down the program when the COVID pandemic severely strained hospital finances. The interviewee reported that after the program’s closure, they are seeing an increase in emergency room use and negative health outcomes.

“Some providers get a better sense of at-home life...they can see it via telehealth.”

– MEG COMEAU

C. Recommendations for Telehealth Policies: Keep, Modify, or Discard

“Telehealth shouldn’t be thought of as a separate and distinct method of care delivery. It should simply be considered another useful tool providing appropriate care to appropriate patients, in appropriate settings.”

– BROOKE YAEGER MCSWAIN

Telehealth flexibilities should be maintained, and telehealth should be considered another modality for providing services. In fact, CMS has extended Medicare reimbursement for select telehealth services and circumstances beyond the PHE. The Consolidated Appropriations Act made certain behavioral health telehealth coverage permanent in Medicare, and the Biden Administration is reviewing telehealth flexibilities as well. A few states are cautiously proposing to extend telehealth flexibilities in their Medicaid programs, particularly related to behavioral health services. For example, Maine’s Medicaid adopted rule 2020-136 makes some “emergency” telehealth provisions, including expanding telehealth to pharmacy services permanent, and expands coverage for communications between health care providers via a virtual platform.⁷⁹ The California governor’s proposed 2021–2022 budget calls for expanding and making permanent certain telehealth flexibilities authorized during COVID-19 for Medi-Cal providers, adding remote patient monitoring as a new covered telehealth modality.⁸⁰

Key stakeholders expressed the telehealth flexibilities most critical for maintaining or expanding health care access for CYSHCN, and that CMS and state Medicaid programs should extend beyond the PHE, include:

- **Parity in payment** 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), FaceTime, and other technology options including asynchronous contact**
- **Coverage of therapies** by appropriate therapists via telehealth, and care coordination via telehealth
- **Flexibility in “originating” and “distant” sites** to include a 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

“We’ve learned that prior telehealth restrictions were not necessary.”

– MEG COMEAU

While easing of enforcement of privacy restrictions was essential to increase access to telehealth and client information sharing, it also creates risks to privacy if not done carefully. Legal experts suspect that enforcement of HIPAA/privacy rules will return after the PHE, but additional consideration and **flexibility of some aspects of HIPAA/privacy rules** are needed to accommodate and encourage telehealth through non-public-facing virtual platforms under certain circumstances.

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, especially in low-income and rural areas; and interpretation services during telehealth visits. These funds could be distributed through family support organizations, school systems

“We all need stronger telehealth infrastructure, not just for public health emergencies but for every day.”

– MEG COMEAU

and educational agencies, and Medicaid programs. The Consolidated Appropriations Act for FY2021 includes funding for broadband expansion and telehealth programs. The American Rescue Plan Act of 2021 includes over \$120 billion in grants and subgrants, some of which could be used to purchase technology supporting low-income students and students with disabilities. The new grant programs should be monitored to ensure they target low-income families and rural areas to address gaps in access to telehealth.

Similarly, Medicaid managed care plans and health systems should provide technical assistance and training for clinicians and families who are unfamiliar or uncomfortable with telehealth, and ensure interpretation services are available during telehealth visits. Medical centers that provide resident training should be required to include telehealth instruction. In light of the disparities and inequities highlighted by the pandemic, training should include a focus on the importance of cultural concordance, where possible, and cultural competence and humility.

State Medicaid programs should be creative about encouraging and incentivizing telehealth. For example, states should explore and expand payment methods that encourage virtual check-ins and reduce pressure to “do everything” in one visit. They should pilot expanded telehealth modalities for Medicaid beneficiaries such as texting, especially for young people who may not have privacy for telephone calls. States should also consider reimbursing telehealth by specialized practitioners or assistants supporting children with medical complexity in schools and childcare settings.

States could 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 Medicaid requirements and billing. Similarly, states can identify services that are not appropriate for telehealth delivery for CYSHCN, and provide guidance to school-based providers about prioritizing those services for in-person delivery when possible.

HRSA’s MCHB, state and local public health agencies, and Title V programs should support outreach, training, and dissemination of best practices in telehealth. These public health entities could promote telehealth services for CYSHCN through outreach and trainings for families of CYSHCN on how to access telehealth services, especially through national and local family/peer support organizations. They could also play an important role in collecting and disseminating best practices for implementing or expanding telehealth in school-based health centers and settings.

Pediatric clinical guidelines should be developed to identify the appropriate use of telehealth services for specific conditions among CYSHCN, based on evaluations of expanded telehealth utilization during the PHE and ongoing monitoring. 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. The experience with flexibilities during the pandemic could help determine what kinds of visits for CYSHCN are appropriate or inappropriate for telehealth, the desired frequency of telehealth versus in-person visits, and criteria for converting a telehealth visit into an in-person visit. Many interviewees stressed that families need choices and must be part of the decision about telehealth versus in-person visits. Related recommendations for pediatric providers and health systems include:

- Clinicians and policymakers must **be creative**; some pediatric services we traditionally consider as only face-to-face could be adapted for telehealth and monitored for quality. 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.
- Exploration is needed on **how well-child visits through telehealth can be reimbursed and monitored for quality**. 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. Similarly, guidelines should ensure well-childcare and related preventive services that require in-person visits such as immunizations are not deferred for too long during a PHE.
- 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.

“Telephonic/ telehealth visits are an essential addition to ways we can safely care for our patients. They are not a replacement of face-to-face visits but an important and necessary alternative visit that takes equal time and attention of the provider.”

– DR. ELISA NICHOLAS

IV. Other Policies and Factors Affecting Access to Services for CYSHCN

A variety of other federal and state policy mechanisms were employed to soften the pandemic's negative impact on access to care. In some instances, the federal government's actions were directly targeted to assist consumers through flexibility in consumer enrollment and eligibility and in curbing increases in cost-sharing. Other policies addressed provider licensure, enrollment and eligibility, the scope of practice for certain members of the health care workforce, and provider reimbursement. Still, others reduced administrative requirements for accessing specialty care and services, the effects of which were readily appreciated by both providers and consumers. In addition, the MCHB gave states flexibility in the Title V block grant renewal schedule and provided guidance for using the funds to meet challenges related to the pandemic.

Despite all of those welcome flexibilities, the obstacles to effectively meet safety requirements to allow the broad reopening of schools for in-person instruction and school-based therapies and health services is perhaps the most significant factor undermining access to care for CYSHCN, especially those in special education programs covered by the Individuals with Disability Education Act or Section 504 of the Rehabilitation Act.⁸¹

A. Access-Related Policy Changes and New Flexibilities

The federal government and state governments enacted numerous access-related policy changes not related to telehealth. Section B below discusses the impact of these policies as well as school closures on access to needed services for CYSHCN and the shifting of those responsibilities onto family caregivers.

The federal government incorporated Maintenance of Effort (MOE) and related consumer protections to prevent loss of coverage or benefits during most of the pandemic. States that accepted the 6.2 percent increase in the federal Medicaid match provided in the FFCRA retroactive to January 1, 2020, must meet MOE requirements. This helps ensure that CYSHCN will not lose Medicaid coverage during the pandemic, will not be subjected to changes in benefits or services for which they are eligible, and will not be subjected to new or unanticipated costs for Medicaid coverage or benefits. Continuous eligibility as part of the MOE is a requirement through the end of the last month of the PHE for pediatric populations. The following is a summary of the MOE requirements that affect CYSHCN:

- States may not restrict eligibility, raise premiums, or terminate coverage mid-month
- States must place limits on or impose no cost-sharing for telehealth required due to the COVID emergency
- States must retain EPSDT coverage for children aging out of EPSDT (when they reach age 21) when medically necessary, through the end of the month in which the PHE for COVID-19 ends
- States must provide COVID-19 testing and treatment without cost-sharing

CMS allowed states to relax some Medicaid provider eligibility and enrollment requirements to help promote access to providers. In an effort to ensure the oversight and quality of the provider network serving Medicaid and CHIP beneficiaries and to guard against fraud in these programs, states impose fairly stringent and sometimes administratively onerous, if not complex, eligibility and enrollment requirements on providers in these programs. Primarily through 1135 waiver flexibilities, CMS allowed

states to relax enrollment and personnel qualifications to expand the number of qualified providers. Following are examples:

- Easing provider licensing rules by temporarily waiving requirements that out-of-state practitioners be licensed in the state where they are providing services (so long as they are licensed in another state and not otherwise barred from practice). In addition to the 1135 waivers, some governors issued temporary waivers of licensure for out-of-state telehealth providers and practice standards during the state emergency. Some legal experts posit, however, that “it is not intuitive that states will take a permissive approach to licensure when the need for health care providers subsides.”⁸²
- Temporarily suspending certain provider enrollment and revalidation requirements
- Allowing physicians to practice at hospitals after privileges expire, or before full review/approval, and easing of minimum personnel qualifications, documentation, and medical record requirements
- Waiving critical access hospital minimum personnel qualifications for clinical nurse specialists, nurse practitioners, and physician assistants
- Waiving medical record requirements and documentation requirements by other personnel (e.g., respiratory therapists)

Workforce capacity expansions were addressed through flexibilities related to the scope of practice of the existing health care workforce (especially for FQHCs and rural health clinics [RHCs]) and the inclusion of new members in the workforce. Access to skilled health care workers was and continues to be a fundamental concern for CYSHCN and their families who often rely on one or more teams of specialists, primary care providers, and health-related therapists (e.g., physical therapists, occupational therapists, respiratory therapists). Access to those workers may be needed in a variety of locations, including local outpatient settings (e.g., clinics or private offices), medical centers or inpatient settings, schools, and even in the home depending on the needs and least restrictive environment. Federal and state scope of practice flexibilities were intended to minimize the adverse effects of the pandemic on the availability of the professional health care workforce. Where allowed by state law, non-physician practitioners are no longer required to communicate clinical findings of the face-to-face encounter to the ordering physician. Certified nurse assistants in California may provide private duty nursing services. (Typically, private duty nursing must be provided by a registered nurse, licensed vocational nurse, or certified home health aide.)

Examples of workforce flexibilities granted to FQHCs and RHCs include:

- CMS modified the requirement that nurse practitioners be supervised by and seek consultation from physicians in RHCs and FQHCs (to the extent permitted by state law)
- Waiver of the requirement that nurse practitioners, physician assistants, and certified nurse midwives furnish services at least 50 percent of the time an FQHC or RHC operates
- In areas determined to have a shortage of home health agencies, FQHCs and RHCs would be able to provide home nursing visits to beneficiaries within their service plan areas without additional approval/determination from CMS

Flexibilities are permitting payment for certain services rendered by family caregivers, intending to alleviate gaps in the home care workforce during the PHE. Using the 1915(c) Appendix K waiver authority and 1115 waivers, states may request the ability to pay for services rendered by family caregivers or legally responsible individuals (i.e., parents and spouses) if this strategy is not already included in their existing waivers.⁸³ For example, Alaska’s approved 1915(c) Appendix K waiver includes provisions that allow providers to hire family caregivers as direct service workers when regular staffing for services approved in a support plan cannot be ensured. The services include respite care, supportive living services, and in-home supports.

One clinic physician reported that prior to the pandemic, California’s In-Home Support Services had a provision for paying hourly rates (up to a limit)⁸⁴ to paraprofessional caregivers (including family caregivers) who provide hands-on care to eligible Medi-Cal beneficiaries meeting certain criteria. Other states’ HCBS waiver programs may allow similar “self-direction” of services in which family caregivers are compensated by Medicaid as paid personal care attendants.

Flexibilities in procedural requirements that facilitated access to services for CYSHCN included relaxed prior authorization rules for specialty services and equipment, relaxed durable medical equipment prescribing, and numerous strategies to increase access to long-term services and supports. Many of these provisions are included in CMS’s checklist of various Medicaid and CHIP flexibilities that states may request through 1135 waivers. The long-term services and supports (LTSS) flexibilities may be requested through the 1135 waiver application or through the 1915(c) Appendix K template (created specifically for COVID-19) for states’ HCBS programs. Specific flexibilities include:

- Suspension of Medicaid (fee-for-service) prior authorization requirements and extension of pre-existing authorizations
- Numerous flexibilities (enumerated in this report and Appendix D) to facilitate LTSS including HCBS, like providing services in settings that have not been determined to meet the HCBS criteria, reimbursing for remote patient assessments (instead of face-to-face), easing financial eligibility requirements for consumers, and allowing remote patient monitoring during the emergency
- Authorize non-physician licensed practitioners, including nurse practitioners, clinical nurse specialists, and physician assistants, to order durable medical equipment

B. Impact of Pandemic and Access-Related Policy Changes

1. Impact of Pandemic and Access Policy Flexibilities on CYSHCN and Families

MOE requirements tied to the enhanced federal Medicaid match to states provided protections that benefit CYSHCN. The requirements that states maintain Medicaid eligibility, enrollment, and benefits offered considerable relief to families of CYSHCN from concerns about whether their children will retain their Medicaid coverage and whether new charges would be levied for needed services. Although many states had adopted continuous Medicaid or CHIP eligibility (i.e., retention of enrollment for up to a year once eligibility determination has been verified) before the pandemic, others still require regular redetermination of eligibility.⁸⁵ Disruptions in the mail and other communication services during the pandemic would likely have resulted in many families being unable to respond to the solicitations for new or updated documentation that is often required for redetermination of eligibility, resulting in

potential discontinuation or lapses in coverage. Similarly, the ability to extend the generally richer EPSDT benefit package to CYSHCN who may otherwise have aged out during the pandemic relieves parent concerns about losing services during a stressful time.

The closure of schools during the pandemic ended or disrupted special education, in-school therapies, and supplemental programming, likely resulting in regression. While the debate around reopening schools has garnered significant attention, there has been less focus on how critical school-related services are for CYSHCN. Families and providers of CYSHCN are keenly aware of the importance of the therapies and special programming in the overall care plan for CYSHCN. Many interviewees underscored the impact of losing access to in-school physical and occupational therapy, communication/speech therapy, as well as educational and socialization opportunities for CYSHCN. Despite many states expanding reimbursement during the pandemic for school-based health services delivered via telehealth, interviewees reported seeing or anticipate backsliding among CYSHCN in health, educational, and social-emotional development. Interviewees pointed out that COVID highlighted how fragile daily care planning is for children with medical complexity, and how easily that plan can unravel when schools close. Family caregivers try to fill the care gaps while losing school time as an opportunity for respite, increasing the overall stress and anxiety among caregivers (discussed further below).

California CCS Medical Therapy Program: Re-opening of Medical Therapy Units

In California, the CCS Medical Therapy Program provides children who have disabling conditions (primarily from neuromuscular and musculoskeletal disorders) with assessments and physical therapy, occupational therapy, and medical therapy conferencing at Medical Therapy Units (MTUs) in designated public schools (CCS describes an MTU as a hospital outpatient therapy clinic that has been relocated to a public school). With school closings due to the pandemic, these services essentially ended, according to interviewees. However, state Department of Health Care Services guidance (updated 9/17/20) allowed for the re-opening of MTUs in closed schools to provide physical therapy and occupational therapy services that cannot be delivered effectively through telehealth. Although not all MTUs had re-opened at the time of this writing, CCS representatives expressed that with the MTUs re-openings in at least one school per county, this created some options for CYSHCN to get needed therapy.

Despite temporary coverage and payment flexibilities around physical, occupational, and speech therapy through telehealth, interviewees noted that many CYSHCN are not getting the assessments, therapy, and habilitation they need. Some interviewees voiced concern about the impact of these gaps on development, especially for younger children. Others noted that the telehealth model is incongruous with some therapies, adding stress on parents and providers.

One physician emphasized the need for greater innovation to enhance the potential of virtual therapeutic services for children. Interviewees also noted the advantage of temporary flexibility allowing therapists to order durable medical equipment.

Home care visits severely declined during the pandemic, leaving CYSHCN and their caregivers without important care and respite. Interviewees described the decline of home care visits resulting from fears of infection by both the families and the home care workers. This was exacerbated by the reality that home care staff had inconsistent access to or lacked personal protective equipment. Many home care providers—whether licensed professional staff, certified or paraprofessional staff—were redeployed to other settings (this was particularly true of registered nurses and licensed vocational/practical nurses) or severely or completely curtailed their hours in order to care for their own children now at home due to school or childcare closures. Several interviewees pointed out that while registered nurses conduct initial intake assessments and periodic reassessments, the vast majority of home care workers are low wage staff whose wages are crucial to the household income, setting up conflicts between the health and financial well-being of themselves and their families. Some interviewees expressed concern that these workforce shortages would jeopardize the quality as well as quantity of essential home care.

Flexibilities to pay family caregivers were viewed as important but were apparently not widely utilized and faced numerous barriers. Medicaid payment for family caregivers who provide personal care services and limited health-related services for children with medical complexity was permitted in some states prior to the PHE, and approved for others states as a temporary flexibility during the pandemic. However, interviewees suspected that states do not “advertise” this flexibility and caregivers are largely unaware of it (in states where there is the option), although family-led organizations have been sharing this information within their networks. Others pointed out that the application process for family caregivers is burdensome and not worthwhile for a temporary flexibility, and that family members fear losing unemployment insurance if they receive payments as caregivers. Historically, states have been cautious about extending payments to family caregivers without stringent rules to avoid potential misuse of the benefit or to avoid Medicaid serving as an income support program rather than a health coverage program.

“Drug store flu shots don’t work for children with medical complexity.”

– MEG COMEAU

Despite policies that increased telehealth access and utilization, interviewees described general avoidance and deferral of primary and routine preventive care, posing particular risks for CYSHCN. During the pandemic, families understandably deferred routine health care services and addressed only the care necessary to manage the chronic or complex medical conditions of their CYSHCN.⁸⁶ For example, interviewees reported seeing the rate of flu shots and other immunizations plummet among CYSHCN, whose families were concerned about their child’s higher risk of serious complications if they were exposed to and contracted COVID-19 during transport to the primary care provider’s office. Moreover, caregivers are unable to transport children with severe complexities to alternative sites for flu shots such as drug stores. Gaps in immunization and routine developmental and other preventive screenings threaten to further amplify disparities in health over the long term in a population that is already vulnerable.

Lifting prior authorization requirements have reportedly improved access to specialty care. Several interviewees found the temporary suspension of service authorization requirements and extensions of existing authorizations in fee-for-service Medicaid through Section 1135 waivers to be “enormously helpful” for ensuring continuity and timely access to care, especially for CYSHCN who require multiple, ongoing services. Benefits of these flexibilities accrue to the patient and family, as well as to the provider who is less encumbered by the administrative burden of compiling the supportive data and information needed to submit an effective prior authorization request. One interviewee noted, however, that despite these flexibilities, some providers are still insisting on requesting and applying for prior authorization to avoid any risk of payment denials.

For some CYSHCN, the pandemic has exacerbated health, socioeconomic, and racial and ethnic disparities; care coordination to identify and address interrelated health needs and SDOH continues to be lacking. Caregivers have always struggled to meet the multiple and varied needs of CYSHCN, and the pandemic has generated a new set of obstacles, according to stakeholders interviewed. High unemployment is creating food and housing insecurities, as well as difficulty obtaining and paying for the therapeutics and durable medical equipment needed by many CYSHCN.

Access to care coordination⁸⁷ (intended to address multiple, interrelated needs) and universal screening

“Families of CYSHCN lived with inequities and challenges with getting what their child needed to begin with, and now we see that on a population level.”

– MEG COMEAU

to identify SDOH have always been lacking. Though a few interviewees reported seeing some care coordination through telehealth, they noted that care coordination continues to be an unreimbursed service without a universally accepted definition. Screening for SDOH is inconsistent and may not even be perceived as the care coordinator’s responsibility. Care coordinators tend to have heavy caseloads and struggle with limited resources in their own programs as well as in the broader health and community-based networks they may tap into to address SDOH.

Program staff under the California MCH Services Block Grant (Title V of the Social Security Act) report that their nurses have traditionally engaged proactively in outreach and limited care coordination for CYSHCN, but because many nurses have been redeployed to address immediate public health needs related to the pandemic, even that limited care coordination has not been always available.

2. Impact of Pandemic and Policy Flexibilities on Providers and Health Systems

Interviewees acknowledged that relaxing provider eligibility and enrollment criteria generally had a positive influence on access to health care services. During the COVID-19 crisis, health care providers look favorably on policies that reduce administrative burdens, including relief from enrollment revalidation or out-of-state licensure requirements. Interviewees from smaller states where the care for CYSHCN often relies on access to regional specialty care centers across state lines considered these flexibilities vital to ensuring access to high-quality care for CYSHCN. A provider from a densely populated state noted the potential for these flexibilities to enable unqualified providers to deliver care to CYSHCN, but that concern was not shared by most of our interviewees.

Interviewees noted practice-based consequences of avoidance or deferral of primary and routine preventive care. Interviewees reported that deferring routine preventive and primary care services during the pandemic has threatened the financial stability of provider practices and clinics, including those who serve CYSHCN. A CMS analysis pointed to sharp declines in visits and services for children enrolled in Medicaid and CHIP, including a 22 percent decline in immunizations received by beneficiaries under two years old between March and May 2020, a 44 percent decline in screening services such as development screenings to diagnose cognitive delays or autism, and a 69 percent decline in dental services compared to the same timeframe in 2019.⁸⁸

In addition to a reduction in patient volume and associated revenue, providers faced the sluggishness of payers and quality measurement, accreditation, and oversight bodies in making accommodations for the shift to telehealth. For a long period during the pandemic, payers would not pay for a well-child visit unless the encounter was face-to-face. Quality metrics (often tied to performance goals and financial incentives) were slow to accommodate the shift as well.⁸⁹ A large California FQHC reported having to close two school-based clinics that could not be sustained with the decline in visit volumes; another clinic transitioned to well-child care exclusively for children under five years old whose parents were more comfortable bringing them in for these visits.

The pandemic has resulted in significant financial strain on children's hospitals and many providers serving children with medical complexity. With a significant downturn in utilization of specialty inpatient and outpatient services, a representative of children's hospitals reported that these hospitals are facing an "existential" financial threat of billions of dollars in losses during the pandemic. Even when families desire a face-to-face visit, not all specialty care centers are able to make responsive workflow and other accommodations. A physician interviewee reported that while some well-established, hospital-based programs for children with medical complexity are continuing as usual (particularly those that had telehealth infrastructure in place prior to the pandemic), most CYSHCN are not receiving care from these facilities and are experiencing reduced access to needed services.

State Title V programs' activities and their ability to address the needs of CYSHCN through COVID-19 response planning varies across states. According to key stakeholders, the flexibility in the Title V block grant renewal schedule was helpful to some states. They noted, however, that some state Title V programs were not included in the public health response planning, making it difficult to ensure the needs of CYSHCN were incorporated. In California, the Title V program (CCS) collaborates with state public health and other health services programs on general COVID-19 guidance.

C. Recommendations for Access-Related Policies: Keep, Modify, or Discard

Evaluation

The federal government should fund and coordinate with states and the private health care sector to thoroughly evaluate and document the impact of the temporary policy flexibilities. Assessment is needed to understand the short- and long-term consequences of the policy changes on access, utilization, patient experience, physical and mental health, and developmental outcomes of CYSHCN and other at-risk populations. The findings will inform continuation, modification, or ending flexibilities during the PHE.

For example, state Medicaid programs and health plans should evaluate the impact of suspending prior authorizations and modify authorization requirements beyond the PHE. States and health plans should examine changes in utilization and health outcomes while prior authorization requirements are relaxed. Interviewees suspect that Medicaid health plans or programs (in the case of fee-for-service) can scale back prior authorization requirements for many services without significant risk of over-utilization, while the benefits include avoiding care delays and reducing the burden on providers and caregivers.⁹⁰

Medicaid Stability and Coverage Protection

CMS should continue beyond the PHE the enhanced Medicaid FMAP support to states, tied to certain coverage protections. Most of the flexibilities in beneficiary enrollment and eligibility (such as continuous eligibility and cost-sharing restrictions for telehealth and COVID testing and treatment), resulted from CMS MOE requirements imposed on states accepting the increased FMAP. Some, such as continuous eligibility (i.e., 12 months of continuous coverage), are optional program features states can elect to include in their Medicaid/CHIP programs. According to the Kaiser Family Foundation, as of January 2020, 23 state Medicaid programs and 25 CHIP programs provide continuous eligibility for children even if the family experiences a change in income or family size during the year. 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. Continuous eligibility prevents coverage disruptions that may occur in families with volatile incomes and living circumstances, reduces administrative costs from the unnecessary reprocessing of applications, improves access and utilization of health services by children, reduces emergency room utilization, and increases the likelihood of better health outcomes for children.

Strengthening Workforce

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, while maintaining or establishing new clinical and training standards. Certain flexibilities that may threaten quality should not become permanent, while expanded scope of practice that helps address workforce shortages—for example, the ability of certain therapists to order durable medical equipment—should be extended, with caution. Conversely, requirements for provider eligibility (re)validation, hospital privileges, minimal personnel requirements (for critical access hospitals) and

medical record documentation all serve the legitimate purpose of ensuring standards, quality, and assessment of current skills/proficiency and should not be relaxed as a matter of permanent policy.

The relaxation of requirements for non-physician practitioners (for example, to present findings of a face-to-face patient encounter to a physician) is already evolving, as California recently became the 23rd state to offer full and independent practice authority to nurse practitioners (AB-890 takes effect in January 2023). One interviewee stressed the need to maintain clinical and training standards for advanced practitioners at FQHCs even as their expanded scope of practice can address workforce shortages.

CMS and states should examine the impact of temporarily relaxing provider enrollment, revalidation, and personnel qualification requirements affecting Medicaid, and consider extending those 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.

Compromise is needed to facilitate the navigation of state medical licensure requirements. Many smaller states without pediatric specialty care infrastructure rely on out-of-state pediatric specialists and medical and specialty care centers. Yet, medical licensing boards and related state laws and statutes vary from state to state, can be quite complex, and often become a barrier to critical specialty care access. State medical licensure boards should consider the FCVS model to facilitate cross-state licensure in key vulnerable regions if not nationwide. The FCVS is based on a uniform process for states to access primary source verification of certain physician credentials.

The federal government should work with states and the medical community to develop and fund creative solutions to 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, including developing Certified Nursing Assistant training programs for legally responsible caregivers (e.g., parent and spouse); increasing Medicare and Medicaid reimbursement rates for home health workers (home health nurses, for example, consistently earn less than hospital-based workers); and continuing HCBS waiver program retainer payments to home-based caregivers while a beneficiary is temporarily institutionalized or unable to receive services for a short time (even if unrelated to COVID-19).

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 while considering the unique needs of CYSHCN.

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 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 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.)

Care Coordination, SDOH

“CYSHCN need so much more than a doctor visit. We need to pay for care coordination and additional services and therapies to keep them healthy and out of the hospital.”

– DR. ALISON CURFMAN

To further support critical care coordination for CYSHCN beyond the PHE, CMS and states should clarify that EPSDT covers care coordination (beyond the explicitly delineated “case management”), define care coordination, and develop standards for CYSHCN, potentially using proposed standards as a guide.⁹¹ The lack of comprehensive care coordination for CYSHCN and ambiguity around its definition predate the PHE. Consequently, federal and state governments accountable for government sponsored programs including EPSDT should define and codify care coordination as a recognized and reimbursable benefit. States should secure and increase Medicaid reimbursement for care coordination services for

CYSHCN and consider covering care coordination by certain paraprofessionals and other service providers. States can also promote care coordination through managed care quality improvement requirements, pay-for-performance incentives, and enhanced care management initiatives.

Given that the pandemic highlighted disparities and unmet SDOH needs, Medicaid/CHIP screening for SDOH, referrals, and interventions should become standard practice and incentivized. States, managed care plans, health systems, provider associations, and practices should establish tools, protocols, and incentives to promote routine screenings for SDOH, especially for CYSHCN. This must be supported by a care coordination process that “closes the loop” to confirm that referred services (both SDOH supports and health services) are completed and referring providers are informed.

Creative Value-Based Models for Pediatric Care

CMS, states, and health systems should test and support value-based, comprehensive service and reimbursement models for CYSHCN that might better protect them in the next pandemic. The need for identifying providers that are clearly accountable for the well-being of CYSHCN is heightened during emergencies such as the pandemic. Unpublished, new research described by a physician interviewee on health improvements and cost savings from care coordination and other supports for children with medical complexities suggests the need for shared-savings models, which are currently not well developed for pediatric care. Another physician interviewee called for the pediatric community to take a long-term view “rather than focusing on how to bring patients back to the office next month.” This involves building a “diversified portfolio” with virtual and in-person encounters and reimbursement systems that support it. They call for exploring and testing accountable care organizations and health homes for CYSHCN (currently used primarily for adults with multiple chronic conditions),⁹² with a care coordinator embedded in large practices and payments for ancillary visits and navigation support.

Prioritizing School-Based Health Services

Special attention is needed to ensure the restart of quality school-based therapeutic and other health services for CYSHCN during a PHE. The Centers for Disease Control and Prevention should prioritize establishing guidelines for reopening schools, and states and localities should prepare the teachers, staff, and environment to support the habilitative, rehabilitative, and behavioral health services that CYSHCN receive in the school setting. Schools should be required to have plans in place to continue care in the event of another pandemic or other reasons for closing school-based health services. This could occur in conjunction with states continuing or expanding Medicaid reimbursement for school-based health services provided through telehealth (described above).

Public Health and Title V

State and local public health agencies and MCH/Title V programs should:

- **Include family members and advocates of CYSHCN in emergency preparedness planning** to inform contingency planning at the individual and system levels; Title V programs should strengthen their role in bringing the needs of CYSHCN to state planning
- 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. Mental Health for CYSHCN and Caregivers

The sudden and long-term school closures, isolation, cessation of many in-person clinical visits and home care visits, and rampant unemployment resulting from the pandemic has put tremendous strains on CYSHCN and their families. Expanded behavioral health via telehealth has been the primary policy lever to address mental health issues.

A. Few (Non-Telehealth) Behavioral Health-Related Policy Changes and New Flexibilities

Federal and state policies temporarily extended coverage and reimbursement of behavioral health services via telehealth in Medicare and Medicaid (described in Section III). Telehealth was more likely to be used for behavioral rather than for physical conditions during the pandemic, with approximately 54 percent of patients with a prior behavioral health condition using telehealth (30 percent by video) between mid-March and early May 2020.⁹³ Recent federal legislation (Consolidated Appropriations Act, 2021) and a growing list of state legislation and executive orders are making permanent certain waived restrictions around telehealth behavioral health services under Medicare and Medicaid, respectively.⁹⁴

It is not clear how much this increase reflected a shift from in-person behavioral health services versus utilization of telehealth to address new, pandemic-related mental health needs. There has been a dearth of other policies or flexibilities focused on identifying and addressing the new stressors on CYSHCN and their caregivers related to respite and childcare needs, isolation, unemployment, and SDOH that have been created or exacerbated by the pandemic.

B. Heightened Mental Health Needs

1. Impact of Pandemic on Behavioral Health of CYSHCN and their Caregivers

Social isolation is exacerbating behavioral health needs. Interviewees reported that fewer interactions and a lower sense of connection between primary care providers and families resulted in many people in need of behavioral health services falling through the cracks. With schools closed, CYSHCN are no longer getting the social interactions at school and with personal care attendants, and the “downstream” impact is not yet known. One advocate and researcher pointed out that this isolation means fewer eyes looking at potential risk factors for neglect and abuse. Another pointed out that children in foster care, who often have special health care needs, are even more vulnerable and more likely to experience physical and behavioral health challenges compared to children in the general population.

“The behavioral health impact [of the pandemic] on complex kids has been astronomical.”

– MARK WIETecha

An interviewee representing children’s hospitals reported seeing an uptick in prescribed antidepressants, and another physician reported an increase in suicides. A legal expert interviewed raised privacy concerns about behavioral health visits through telehealth.⁹⁵ Another interviewee noted that during home-based telehealth sessions, some youth feel more comfortable talking by telephone than in person, but youth in unstable or violent homes may have less ability to be candid during telehealth sessions if in crowded living conditions.

Stress on CYSHCN families to act as “24/7” caregivers is underreported. According to nearly all interviewees, parents of CYSHCN are under incredible stress from caregiving (as home visits from nurses, therapists, and personal care attendants were curtailed), homeschooling, and in some cases trying to work inside or outside of the home as well. These caregivers have little opportunity for respite, while their burdens have steadily increased. The pandemic also underscored the need for family crisis plans if the primary caregiver becomes ill.

“Home care nursing cannot come in, leading to caregiver exhaustion, decline in mental health, then that can lead to error.”

– MEG COMEAU

One interviewee reported that many parents brought CYSHCN who had been living in group homes or residential facilities home early during the pandemic because of concerns about coronavirus exposures and the inability to visit facilities during closures. These families reportedly faced challenges obtaining needed equipment and supplies, in addition to taking on round-the-clock caregiving.

The medical community recognizes that caregiver stress is an issue, but few providers have the bandwidth to assess and

address it. Family Voices, a national grassroots network organization of families and friends of CYSHCN, has expanded its role facilitating critical peer-to-peer support through a federal grant, but many caregiver needs go unmet.

2. Mental Health-Related Impact on Providers

Pediatricians have taken up mental health visits via telehealth, but extensive unmet needs remain.

A physician at a large children’s hospital reported that pediatricians have embraced the opportunity to conduct behavioral health visits (particularly treating anxiety and depression in teens) through telehealth. This interviewee viewed the potential shift of a large segment of mental health treatment to general practitioners as a positive and necessary reaction to the rapid growth in demand, assuming these practitioners are equipped to provide high-quality behavioral health care. Other interviewees pointed out the advantage of addressing mental health and providing crisis intervention virtually in the patient’s naturalistic home setting. A clinic physician reported that no-show rates for behavioral health visits were “down to zero” and suggested that telephonic visits make it easier for individuals to discuss sensitive topics.

C. Recommendations for Behavioral Health Care Policies: Keep, Modify, or Discard

As noted in a previous section, **Medicaid and Medicare should retain and expand the ability to provide behavioral health services via telehealth.** Medicaid reimbursement for new telehealth modalities for behavioral health services for CYSHCN, such as audio-only visits, should extend beyond the pandemic. Medicaid managed care plans should encourage the use of these new modalities when appropriate or necessary. Additional consideration and flexibility are needed to protect privacy while also expanding access to needed behavioral health services.

Pediatricians should receive greater support and training in behavioral health services to address needs of CYSHCN. Access to behavioral services for certain CYSHCN is limited by physical barriers, time constraints in typical behavioral health practice settings, and other factors (particularly, but not exclusively during a pandemic). These factors argue for broader access to behavioral health screening and services 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. States, health systems, and managed care organizations should target resources and incentives to establish and encourage more routinized behavioral health screenings and services for CYSHCN. This can be supported by supervision guidelines from national professional organizations and modification of measurement specifications by accrediting organizations.

“The risks are increasing, and more attention needs to be paid to these families [of CYSHCN].”

– KIM LEWIS

Greater attention and funding are needed to identify and address the behavioral health needs of caregivers of CYSHCN. CMS should allow state Medicaid programs to reimburse for screening of caregivers for mood disorders, beyond the current reimbursement for maternal depression screening (perinatal mood and anxiety disorders) at well-child visits. Screening caregivers could identify high levels and sources of stress and should be coupled with informing families about available respite services and childcare support.

Conclusion

The COVID-19 crisis has created challenges but also opportunities for CYSHCN and their families. States and the federal government have used legislation, waivers, executive orders, guidance, and rule/regulatory changes to temporarily waive restrictions and expand Medicare and Medicaid reimbursement for certain services in order to facilitate access to health care services while minimizing in-person visits. We have an opportunity to assess the impact of these flexibilities and to inform policy decisions affecting health care after the COVID-19 PHE ends.

The pandemic created and exacerbated distinct challenges for CYSHCN, underscoring the importance of examining the policy changes through the lens of these children, their families, and their health care providers. CYSHCN and their caregivers are especially vulnerable to disruptions in access to health care and health-related services, as well as to school closures, reductions in the home-visiting workforce, high unemployment, and the need for social distancing. According to a range of leaders and stakeholders interviewed for this study, many policy flexibilities implemented—particularly those that expanded the availability of telehealth—have been beneficial for CYSHCN and their families and should be continued beyond the PHE, with additional efforts to reduce the inequities in access to telehealth. Other policy flexibilities, including those related to easing rules or extending service authorizations, and expanded scope of practice for non-physicians, have also been helpful for CYSHCN, many of whom have extensive service needs and often receive care from therapists and ancillary providers.

This report also presented policy recommendations, based on stakeholders' experiences during the pandemic, to improve health care delivery and access (including addressing disparities in access to telehealth), identify and address the physical, behavioral, and SDOH needs of CYSHCN and their families, and incentivize clinicians, health plans, and health systems to provide comprehensive care to CYSHCN effectively and efficiently.

Finally, the pandemic presents the opportunity—and necessity—to more thoroughly evaluate the impact of the temporary policy flexibilities on the physical and mental health of CYSHCN, and developmental outcomes, as well as to understand the full range of positive and negative consequences on CYSHCN, their families, and their providers. We can learn from flexibilities implemented on a national level, as well as by assessing the varied policies and experiences across states. This additional information should inform future policy decisions to transform health care systems, especially government-funded systems such as Medicaid and CHIP, to be more efficient, responsive, equitable, and effective in serving CYSHCN.

Appendix A. Policy/Environmental Scan Sources

Sources included, but were not limited to:
American Academy of Pediatrics Council on Children with Disabilities/COVID-19 Staff and Leadership Group
Association of Maternal & Child Health Programs
American Academy of Pediatrics
Bill and Melinda Gates Foundation
Centers for Disease Control and Prevention Foundation
Center for Health Care Strategies
Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity
Complex Care Special Interest Group listserv
David and Lucile Packard Foundation
Federal guidance on telehealth/virtual health innovation
Federal regulation and grant programs
Georgetown Center on Children and Families
Grantmakers in Health
US Department of Health & Human Services – Administration for Children & Families
Health Resources and Services Administration – Maternal and Child Health Bureau
Kaiser Family Foundation
Manatt: 50-state telehealth and LTSS tracking briefs and summaries
mHealthInsight, mHealthIntelligence
National Academy for State Health Policy
National Conference for State Legislatures
National Governors Association
National Health Law Program
Robert Wood Johnson Foundation
Stanford School of Medicine Department of Pediatrics
State Medicaid waivers and State Plan Amendments

Appendix B. Key Stakeholders Interviewed or Consulted

Name	Affiliation/Organization
Jill Abramson, MD	Associate Medical Director, California Children's Services
Rishi Agrawal, MD	Attending Physician, Hospital-Based Medicine, Lurie Children's Hospital of Chicago; Associate Professor of Pediatrics, Northwestern University Feinberg School of Medicine; Co-Chair, Academic Pediatric Association – Special Interest Group on Complex Care in Clinical Pediatrics
Richard Antonelli, MD, MS	Medical Director of Integrated Care, Department of Accountable Care and Clinical Integration; Medical Director, National Center for Care Coordination Technical Assistance; Medical Director, National Care Coordination Academy Boston Children's Hospital
Treeby Williamson Brown, MA	Chief, Integrated Services Branch Division of Services for Children with Special Health Needs; Health Resources and Services Administration – Maternal and Child Health Bureau
Paige Bussanich, MS	Senior Program Manager for Children and Youth with Special Health Care Needs, Association of Maternal and Child Health Programs
Cara Coleman, JD	Program Manager, Family Voices
Meg Comeau, MHA	Senior Project Director, Center for Innovation in Social Work and Health, Boston University School of Social Work; Principal Investigator for the Collaborative Improvement and Innovation Network to Advance Care for Children with Medical Complexity and The Catalyst Center: National Center for Improving Coverage and Financing of Care for Children and Youth with Special Health Care Needs
Abbi Courselle, JD	Senior Attorney, National Health Law Program
Alison Curfman, MD	Clinical Director, Pediatric Operations – Mercy Clinic; Pediatric Emergency Medicine Physician, Mercy Clinic St. Louis
Alicia Emanuel, JD	Senior Attorney, National Health Law Program
Janis Guerney, JD	Director of Public Policy, Family Voices
Maria Jocson, MD	Medical Officer, California Children's Services
Ben Kaufman, MSW	Associate Director, Workforce Development and Capacity Building, Association of Maternal & Child Health Programs
Dennis Z Kuo, MD, MHS	Division Chief of General Pediatrics at UBMD Pediatrics and the University at Buffalo; Medical Director of Primary Care Services at the John R. Oishei Children's Hospital; Associate Professor, University at Buffalo

Carlos Lerner, MD	Pediatrics Specialist, UCLA Mattel Children's Hospital, Department of Pediatrics
Kim Lewis, JD	Managing Attorney, National Health Law Program
Marie Y Mann, MD, MPH, FAAP	Senior Medical Advisor, Division of Services for Children with Special Health Needs Maternal and Child Health Bureau
Brooke Yeager McSwain, MS, RRT	Health Policy Lead, SPROUT/NCATS NIH Award HIMSS Foundation Policy Fellow
Elisa Nicholas, MD, MSPH	Pediatrician, Chief Executive Officer, The Children's Clinic "Serving Children & Their Families" dba TCC Family Health (a federally qualified health center in Long Beach, CA)
Patricia Notario, MD	General Pediatrics & Pediatric Complex Care, Billings Clinic
Nora Wells, MS	Executive Director, Family Voices
Mark Wietecha, MS, MBA	President and Chief Executive Officer, Children's Hospital Association (national)

Appendix C. Master Interview Guide

Note: Each interview guide was tailored prior to the interviewee, to reflect both the type of key stakeholder (e.g., clinical associations and practitioners, children and disability advocates, state and federal officials), and the specific individual's role.

Interviewee(s) and positions:

Name of organization:

Name of interviewer:

Date of interview:

Welcome and Introductory Points: (5 min)

- Thank you for contributing your time and expertise to this important project.
- Brief introductions – (Health Management Associates [HMA] and Lucile Packard Foundation for Children's Health [LPFCH] staff on call)
- As we shared [in our email], LPFCH contracted with HMA to examine COVID-19-related "temporary" federal and state policy changes and regulatory flexibilities that are affecting care delivery for children and youth with special health care needs (CYSHCN), their families, and providers.
- We're talking with a range of experts and key stakeholders – including clinical associations and practitioners, child and disability advocates, and public officials -- to get their perspectives on the most impactful policy changes, the resulting changes in care delivery for CYSHCN, and both positive and negative consequence for this population.
- Feel free to ask us to skip questions if you don't have a response to share.
- This work will inform recommendations about continuing certain policy or care delivery changes after the Emergency that hold promise for improving care for CYSHCN – for example by increasing access to specialists or therapists at home; and conversely, about policies or practices that should be curtailed—for example, if certain flexibilities are lowering standards and quality of care for CYSHCN. We'll be happy to share the report with you.

Housekeeping for Interview: (2 min)

- We'll be taking notes, but do you mind if we record our conversation just for notetaking purposes? (If ok, record)

Interview Questions: (50 min)

1. First, could you tell us briefly if, and how, your [clinical, administrative, policy, advocacy] work related to CYSHCN has changed as a result of the pandemic?
2. Through our analyses to date, we've identified several categories of policy changes and flexibilities we think may have significant consequences for care delivery for CYSHCN, their families and providers, and we will share those with you later on our call. But we would like to hear from you first about what is most salient in your mind. Thinking broadly, what would you say is the most

significant change in health care policy, delivery, and systems related to COVID-19 that is affecting or has the potential to affect CYSHCN? (open-ended)

- a. Has this had a positive or a negative impact on CYSHCN?
 - b. What gives you that impression – e.g., direct experience with children/families, anecdotal, statistics/other evidence?
3. We all know that **telehealth** has expanded greatly during the pandemic. New flexibilities in telehealth include: greater options for telehealth “originating” and “distant” sites; expanded telehealth services and practitioners like physical therapy, occupational therapy, speech pathology, behavioral health, and care coordination; more technology platforms and modalities, like telephones and audio-only calls; limits on telehealth copays; increased reimbursement or payment parity with in-person visits; and relaxed privacy and security rules to facilitate telehealth.
 - a. How have you seen these flexibilities play out for CYSHCN?
 - b. Which among these flexibilities have helped CYSHCN, their families, and their providers?
 - c. Which of these policies have had unintended or negative consequences?
 - d. Are there any specific examples of hospitals, clinics, or practices that have been particularly successful or innovative in using telehealth with CYSHCN during the pandemic?
 - e. What additional thoughts do you have about telehealth expansion and CYSHCN?
4. Besides telehealth, have you seen ways that **primary, specialty, or subspecialty** care providers have changed the way they serve CYSHCN? Describe.
5. Have you seen changes in how providers are addressing the **mental health needs** of CYSHCN? Describe.
 - a. Have you seen new ways of addressing **caregiver burden and stress**? Describe.
6. Thinking more broadly about **delivery system changes** in response to the pandemic,
 - a. How are **hospital systems**, [for providers: accountable care organizations and independent practice associations] making modifications that may affect CYSHCN?
 - b. Have you seen any significant changes in how local or state **Public Health** Departments are responding in ways that may impact CYSHCN? Describe.
 - c. Have you seen changes in **care coordination or chronic care management**—including screening, assessment, care plans, referrals—that are affecting CYSHCN and their families? Describe.

- d. Has the pandemic led to changes in assessing or addressing social determinants of health? Describe.
 - e. Have you seen changes in the provision of physical, occupational, speech, or respiratory **therapy** and other services commonly needed by children with medical complexity?
 - f. In what additional ways have providers and systems made modifications during the pandemic?
7. What are the effects of the pandemic and the related policy changes on **network adequacy and the health care workforce** that serves CYSHCN?
8. *[For state or fed Medicaid respondents, if applicable]:* Have you seen any significant changes in how **Medicaid** programs—either fee-for-service or managed care organizations—are serving CYSHCN? Describe.
- a. To what extent are states amending their managed care organization contracts to incorporate telehealth flexibilities?
9. I'm going to read a list of temporary flexibilities that we've identified. For each, do you think the impact—positive or negative—on the care or outcomes of CYSHCN is: Very significant, Somewhat significant, or Not significant? [For "Very significant" responses, ask: In what ways?]:
- a. Suspending Medicaid (fee-for-service) prior authorization requirements or extending previous authorizations for ongoing services
 - b. Easing provider licensing and staffing requirements, out-of-state restrictions, documentation, and medical record requirements
 - c. Expanding the role of licensed non-physicians (nurse practitioners, certified nurse specialists, physician assistants) including the ability to order durable medical equipment
 - d. Facilitating access to long-term services and supports for home- and community-based services waiver recipients
 - e. Allowing rural health clinics and federally qualified health centers to expand service locations and expand the role of nurse practitioners at clinics
 - f. Permitting payment for services rendered by family caregivers and additional payments to foster caregivers
 - g. Higher federal matching contribution to states for Medicaid and CHIP services
 - h. Other special temporary funding for health care practices and institutions
10. Has availability of CARES Act and other new hospital and provider grants affected access to primary care providers?

11. Have you seen ways that new policies and practices are either reducing or exacerbating disparities in care for certain sociodemographic groups of CYSHCN? Describe.
12. Thinking about all we've discussed, are there certain policy or care delivery changes made during the crisis that hold promise for improving care for CYSHCN that **should be continued beyond the crisis period**? Why?
13. Alternatively, are there policy or care delivery changes have had or might have unintended negative consequences for CYSHCN that **should not continue after the public health emergency**? Why?
14. [ADD ANY QUESTIONS SPECIFIC TO INTERVIEWEE'S ROLE/PERSPECTIVE]
15. What lessons can be learned from caring for children and CYSHCN during the pandemic that can be used to transform health care systems, especially government-funded systems such as Medicaid and CHIP, to be more efficient, responsive, equitable, and effective in the future?

Closing: (3 min)

16. Before we end, is there anything we haven't covered about the impact of COVID-19-related policies and changes on CYSHCN that you'd like to share with us?
 17. May we cite you as a contributor to this research project in the final report?
- Review any follow-up items if interviewee offered to send materials or contacts
 - Request to check back if we need to clarify or confirm information in the final report
 - Thank you for offering your time and perspective

Endnotes and Citations

¹ Approximately four in 10 children covered under Medicaid and CHIP have a special health care need that requires health services (Musumeci, M., & Chidambaram, P. [2019, June 12]). *Medicaid's role for children with special health care needs: A look at eligibility, services, and spending*. Kaiser Family Foundation.

<https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-with-special-health-care-needs-a-look-at-eligibility-services-and-spending/>

² Although an analysis of the budget implications of these recommendations was beyond the scope of this report, implementing some recommendations would require additional or reallocated federal or state funding.

³ Asynchronous and “store and forward” refer to the transmission of a patient's medical information from an originating site to a health care provider at a distant site.

⁴ The Consolidated Appropriations Act, 2021, (H.R. 133) passed and signed in December 2020, includes funding to reduce barriers for providers and patients to effective telehealth services.

⁵ See, for example, States Expand Medicaid Reimbursement of School-Based Telehealth Services, National Academy for State Health Policy, May 2021. <https://www.nashp.org/wp-content/uploads/2021/05/telehealth-report.pdf>

⁶ 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>

⁷ 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.

⁸ Taft, K., & Bussanich, P. (n.d.). *Children & youth with special health care needs*. Association of Maternal & Child Health Programs. <http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx>

⁹ Centers for Medicare & Medicaid Services. (n.d.). *Public health emergency declaration questions and answers*. <https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertEmergPrep/Downloads/PHE-Questions-and-Answers.pdf>

¹⁰ Office of the Assistant Secretary for Preparedness and Response. (2021, January 12). *Public health emergency declarations*. <https://www.phe.gov/emergency/news/healthactions/phe/Pages/default.aspx>

¹¹ Consolidated Appropriations Act, 2021, H.R. 133. (2021). <https://www.congress.gov/116/bills/hr133/BILLS-116hr133enr.pdf>

¹² Pelosi, N., & Schumer, C. (2020, December 20). *Pelosi, Schumer joint statement on coronavirus relief & omnibus agreement*. Office of the Speaker of the House. <https://www.speaker.gov/newsroom/122020>

¹³ HIMSS. (2021, January 25). *Consolidated appropriations act, 2021, for healthcare and health IT*. <https://www.himss.org/news/consolidated-appropriations-act-2021-healthcare-and-health-it>

¹⁴ Other health-related provisions in the Consolidated Appropriations Act include: provides \$8.75 billion to the CDC to support federal, state, local, territorial, and tribal public health agencies to distribute, administer, monitor, and track coronavirus vaccination and \$25.4 billion to the Public Health and Social Services Emergency Fund to support COVID-19 testing and contact tracing; mitigates the budget neutrality conversion factor reduction for Medicare physicians, reversing payment cuts as stipulated in the Medicare Physician Fee Schedule Final Rule; establishes the No Surprises Act to protect patients from surprise medical billing; and extends funding for some Medicare and Medicaid health programs that were set to expire.

¹⁵ Exec. Order No. 13941, 3 C.F.R. 47881-47883 (2020). <https://www.federalregister.gov/documents/2020/08/06/2020-17364/improving-rural-health-and-telehealth-access>

¹⁶ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>

- ¹⁷ Centers for Medicare & Medicaid Services. (2020, August 3). *Proposed policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2021*. <https://www.cms.gov/newsroom/fact-sheets/proposed-policy-payment-and-quality-provisions-changes-medicare-physician-fee-schedule-calendar-year-4>
- ¹⁸ Centers for Medicare & Medicaid Services. (2020, December 1). *Final policy, payment, and quality provisions changes to the Medicare physician fee schedule for calendar year 2021*. <https://www.cms.gov/newsroom/fact-sheets/final-policy-payment-and-quality-provisions-changes-medicare-physician-fee-schedule-calendar-year-1>
- ¹⁹ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>
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- ²¹ Centers for Medicare & Medicaid Services. (2020, December 1). *COVID-19 emergency declaration blanket waivers for health care providers*. <https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf>
- ²² Centers for Medicare & Medicaid Services. (2021). *Federal disaster resources*. Medicaid.gov. <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/federal-disaster-resources/index.html>
- ²³ Centers for Medicare & Medicaid Services. (n.d.). *Section 1135 waiver flexibilities*. Medicaid.gov. <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/section-1135-waiver-flexibilities/index.html>
- ²⁴ Centers for Medicare & Medicaid Services. (n.d.). *Section 7 General provisions: 7.4 Medicaid disaster relief for the COVID-19 national emergency*. Medicaid.gov.
- ²⁵ Centers for Medicare & Medicaid Services. (n.d.). *State plan flexibilities*. Medicaid.gov. <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/state-plan-flexibilities/index.html>
- ²⁶ Centers for Medicare & Medicaid Services. (n.d.). *Medicaid state plan amendments*. Medicaid.gov. <https://www.medicaid.gov/medicaid/medicaid-state-plan-amendments/index.html>
- ²⁷ States can also receive CMS approvals for making changes through traditional Medicaid and CHIP SPAs and can implement changes under existing authority that do not require SPA approval.
- ²⁸ All states except Indiana, Tennessee, and New York received approval for Medicaid disaster relief SPAs.
- ²⁹ Centers for Medicare & Medicaid Services. (n.d.). *CHIP state program information*. Medicaid.gov. <https://www.medicaid.gov/chip/state-program-information/index.html>
- ³⁰ Approved by CMS April 11, 2018 with a retroactive effective date of October 1, 2017, the CHIP SPA (CA-17-0043) provides temporary policy adjustments (continued coverage when premiums have not been paid, waiving or extending premium due date, extend time to complete renewal process) for children in families impacted by disaster events. By notifying CMS, California could implement the policy adjustments in future disasters. (California SPA Ca-17-0043 Approval Letter and Final Approved State Plan, April 11, 2018. <https://www.medicaid.gov/sites/default/files/CHIP/Downloads/CA/CA-CHIPSPA-17-0043.pdf>)
- ³¹ Centers for Medicare & Medicaid Services. *Emergency preparedness and response for Home and Community Based (HCBS) 1915(c) waivers*. Medicaid.gov. <https://www.medicaid.gov/resources-for-states/disaster-response-toolkit/home-community-based-services-public-health-emergencies/emergency-preparedness-and-response-for-home-and-community-based-hcbs-1915c-waivers/index.html>
- ³² Edwards, E. (2020, March 30). *COVID-19 changes to HCBS using Appendix K: Approval trends*. National Health Law Program. <https://healthlaw.org/wp-content/uploads/2020/03/Trends-in-Appendix-K-Approvals-3-30-20-final.pdf>
- ³³ *Medicaid emergency authority tracker: Approved state actions to address COVID-19*. (2021, February 8). Kaiser Family Foundation. <https://www.kff.org/medicaid/issue-brief/medicaid-emergency-authority-tracker-approved-state-actions-to-address-covid-19/>

- ³⁴ California 1915(c) Home and Community-Based Services waivers for which children are eligible and that were approved Emergency Preparedness Response Appendix K amendments include: Home and Community Based Alternatives Waiver (<https://www.dhcs.ca.gov/Documents/COVID-19/CA-0139-Appendix-K-4-2-2020.pdf> and <https://www.dhcs.ca.gov/Documents/COVID-19/CA-0139-Appendix-K-8-10-2020.pdf>); HIV/AIDS (<https://www.dhcs.ca.gov/Documents/COVID-19/CA-0183-Appendix-K-4-2-2020.pdf>); HCBS Waiver for Californians with Developmental Disabilities (<https://www.dhcs.ca.gov/Documents/COVID-19/CA-0336-Appendix-K-4-2-2020.pdf> and <https://www.dhcs.ca.gov/Documents/COVID-19/CA-0336-Appendix-K-Amendment-9.14.2020.pdf>); Self-Determination Waivers for Californians with Developmental Disabilities (<https://www.dhcs.ca.gov/Documents/COVID-19/CA-Combined-Appendix-K-8-10-2020.pdf>)
- ³⁵ Centers for Medicare & Medicaid Services. (n.d.). *State waivers list*. <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>
- ³⁶ Centers for Medicare & Medicaid Services. (2020, March 22). *COVID-19 public health emergency section 1115(a) opportunity for states*.
- ³⁷ Centers for Medicare & Medicaid Services. (2020, June 25). *COVID 1115 demonstration approval documents template*. <https://www.medicaid.gov/medicaid/section-1115-demonstrations/downloads/nc-covid19-public-health-emerg-demo-ca.pdf>
- ³⁸ Perkins, J., & Somers, S. (2020, May). *Medicaid in transitions—Monitoring COVID-related changes in coverage*. National Health Law Program. <https://healthlaw.org/wp-content/uploads/2020/05/IB-Medicaid-transitions-COVID-formatted.pdf>
- ³⁹ Federal Communications Commission. (2021, February 9). *COVID-19 telehealth program*. <https://www.fcc.gov/covid-19-telehealth-program>
- ⁴⁰ Federal Communications Commission. (2020, July 8). *FCC approves final set of COVID-19 telehealth program applications*. <https://docs.fcc.gov/public/attachments/DOC-365417A1.pdf>
- ⁴¹ Federal Communications Commission. (2020, July 8). *FCC approves final set of COVID-19 telehealth program applications*. <https://docs.fcc.gov/public/attachments/DOC-365417A1.pdf>
- ⁴² Federal Communications Commission. (2020, September 3). *FCC provides information and guidance for Connected Care pilot program*. <https://docs.fcc.gov/public/attachments/DOC-366664A1.pdf>
- ⁴³ US Department of Health & Human Services. (2020, April 22). *HHS awards nearly \$165 million to combat the COVID-19 pandemic in rural communities*. <https://www.hhs.gov/about/news/2020/04/22/hhs-awards-nearly-165-million-to-combat-covid19-pandemic-in-rural-communities.html>
- ⁴⁴ US Department of Agriculture. (n.d.). *Distance learning & telemedicine grants*. <https://www.rd.usda.gov/programs-services/distance-learning-telemedicine-grants>
- ⁴⁵ Support access to services and supports via telehealth such as virtual doula care, remote pregnancy monitoring, and other evidence-based practices for delivering trauma-informed perinatal and behavioral health care.
- ⁴⁶ Recipients are American Academy of Pediatrics, Association of Maternal and Child Health Programs – Public Health Systems, Family Voices, Inc. – Family Engagement for Children with Special Health Care Needs, and University of North Carolina-Chapel Hill – Maternal Health Care (US Department of Health & Human Services. (2020, April 30). *HHS awards \$20 million to combat COVID-19 pandemic through telehealth*. <https://www.hhs.gov/about/news/2020/04/30/hhs-awards-20-million-to-combat-covid19-pandemic-through-telehealth.html>)
- ⁴⁷ Health Resources & Services Administration Maternal & Child Health. (2020, July 27). *Coronavirus disease (COVID-19) Maternal and Child Health Bureau frequently asked questions*. <https://mchb.hrsa.gov/coronavirus-frequently-asked-questions>
- ⁴⁸ Centers for Medicare & Medicaid Services. (2020, May 17). *Medicare telemedicine health care provider fact sheet*. <https://www.cms.gov/newsroom/fact-sheets/medicare-telemedicine-health-care-provider-fact-sheet>
- ⁴⁹ Remote patient monitoring (RPM), sometimes used interchangeably with remote physiologic monitoring, generally refers to the use of digital technologies to collect health data from an individual in one location and electronically transmit that information securely to a health care provider in a different location for assessment and recommendation.

⁵⁰ American Telemedicine Association. (2017, April). *Operating procedures for pediatric telehealth*.

https://www.aap.org/en-us/Documents/ATA_Pediatric_Telehealth.pdf

⁵¹ Augenstein, J., & Marks, J.D. (2020, September 1). *Ensuring children's access to care using telehealth in Medicaid during COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/manatt-on-health-medicaid-edition/ensuring-childrens-access-to-care-using-telehealth>

⁵² Mehrotra, A., Chernew, M., Linetsky, D., Hatch, H., Cutler, D., & Schneider, E.C. (2020, October 15). *The impact of the COVID-19 pandemic on outpatient care: Visits return to prepandemic levels, but not for all providers and patients*. The Commonwealth Fund. <https://www.commonwealthfund.org/publications/2020/oct/impact-covid-19-pandemic-outpatient-care-visits-return-prepandemic-levels>

⁵³ Centers for Medicare & Medicaid Services. (n.d.). *State Medicaid & CHIP telehealth toolkit. Policy considerations for states expanding use of telehealth*. <https://www.medicaid.gov/medicaid/benefits/downloads/medicaid-chip-telehealth-toolkit.pdf>

⁵⁴ The Public Health Institute's Center for Connected Health Policy created a Telehealth Policy Finder tool that tracks telehealth-related laws and regulations at the federal level and in all 50 states and the District of Columbia. The tool can be found at: <https://www.cchpca.org/all-telehealth-policies/>. In addition, Manatt updates federal and state telehealth changes in response to COVID-19; its May 2021 update can be found at: <https://www.manatt.com/insights/newsletters/covid-19-update/update-tracking-telehealth-changes-state-by-state>.

⁵⁵ Augenstein, J., Marks, J.D., Peng, A., & Fong, M. (2020, December 10). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19- December 2020*. <https://www.jdsupra.com/legalnews/executive-summary-tracking-telehealth-77278/>

⁵⁶ Magoon, V. (2020, May 1). *Two welcome changes for audio-only telephone visits*. https://www.aafp.org/journals/fpm/blogs/inpractice/entry/telephone_visits.html

⁵⁷ Centers for Medicare & Medicaid Services. (2020, December 1). *COVID-19 emergency declaration blanket waivers for health care providers*. <https://www.cms.gov/files/document/summary-covid-19-emergency-declaration-waivers.pdf>

⁵⁸ Guth, M., & Hinton, E. (2020, June 22). *State efforts to expand Medicaid coverage & access to telehealth in response to COVID-19*. Kaiser Family Foundation. <https://www.kff.org/coronavirus-covid-19/issue-brief/state-efforts-to-expand-medicaid-coverage-access-to-telehealth-in-response-to-covid-19/>

⁵⁹ Centers for Medicare & Medicaid Services. (n.d.). *Application for a 1915(c) HCBS waiver. Appendix K: Emergency preparedness and response*. <https://www.medicaid.gov/state-resource-center/downloads/nc-0423-3-appendix-k-appvl.pdf>

⁶⁰ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>

⁶¹ Guth, M., & Hinton, E. (2020, June 22). *State efforts to expand Medicaid coverage & access to telehealth in response to COVID-19*. Kaiser Family Foundation. <https://www.kff.org/coronavirus-covid-19/issue-brief/state-efforts-to-expand-medicaid-coverage-access-to-telehealth-in-response-to-covid-19/>

⁶² Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>

⁶³ American Academy of Pediatrics. (2021, January 6). *Guidance on providing pediatric well-care during COVID-19*. <https://services.aap.org/en/pages/2019-novel-coronavirus-covid-19-infections/clinical-guidance/guidance-on-providing-pediatric-well-care-during-covid-19/>

⁶⁴ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>

- ⁶⁵ American Academy of Pediatrics. (2021, January 15). *State notices on telehealth policy in response to COVID-19*. <https://downloads.aap.org/DOCCSA/State-Telehealth-Notices.pdf>
- ⁶⁶ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>
- ⁶⁷ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>
- ⁶⁸ States Expand Medicaid Reimbursement of School-Based Telehealth Services. (2021, May). National Academy for State Health Policy. <https://www.nashp.org/wp-content/uploads/2021/05/telehealth-report.pdf>
- ⁶⁹ The HIPAA Privacy, Security, and Breach Notification Rules (HIPAA Rules) refer to regulations issued under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), as amended by the Health Information Technology for Economic and Clinical Health (HITECH) Act, to protect the privacy and security of protected health information. (US Department of Health & Human Services, <https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/notification-enforcement-discretion-telehealth/index.html>)
- ⁷⁰ Office for Civil Rights. (2021, January 20). *Notification of enforcement discretion for telehealth remote communications during the COVID-19 nationwide public health emergency*. US Department of Health & Human Services. <https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/notification-enforcement-discretion-telehealth/index.html>
- ⁷¹ Office for Civil Rights. (2021, January 19). *HIPAA and COVID-19*. US Department of Health & Human Services. <https://www.hhs.gov/hipaa/for-professionals/special-topics/hipaa-covid19/index.html>
- ⁷² Office for Civil Rights. (n.d.). *FAQs on telehealth and HIPAA during the COVID-19 nationwide public health emergency*. US Department of Health & Human Services. <https://www.hhs.gov/sites/default/files/telehealth-faqs-508.pdf>
- ⁷³ Centers for Medicare & Medicaid Services. (n.d.). *State Medicaid & CHIP telehealth toolkit. Policy considerations for states expanding use of telehealth*. <https://www.medicaid.gov/medicaid/benefits/downloads/medicaid-chip-telehealth-toolkit.pdf>
- ⁷⁴ Manatt reported that as of 4/29/20, 38 states plus the District of Columbia provided payment parity in Medicaid for telehealth services (Augenstein, J., Peng, A., Marks, J.D., & Fong, M. [2021, February 11]. *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>).
- ⁷⁵ Kaiser Family Foundation reported that 17 states have enacted laws requiring private insurers to use provider reimbursement parity between telehealth and in-person services (Kaiser Family Foundation. [2021, February 12]. *State COVID-19 data and policy actions*. <https://www.kff.org/coronavirus-covid-19/issue-brief/state-data-and-policy-actions-to-address-coronavirus/>)
- ⁷⁶ The Center for Connected Health Policy. (2019). *State telehealth laws and reimbursement policies*. https://www.cchpca.org/sites/default/files/2019-05/cchp_report_MASTER_spring_2019_FINAL.pdf
- ⁷⁷ Remote patient monitoring devices include non-invasive technologies that measure or detect common physiological measures and wirelessly transmit patient information to a health care provider or other monitoring entity.
- ⁷⁸ In California, the Medical Therapy Program is a special program within California Children's Services (CCS) and located in designated public schools that provides comprehensive assessments, physical therapy, occupational therapy, and medical therapy conference services for children who have disabling conditions, generally due to neurological or musculoskeletal disorders.
- ⁷⁹ Office of MainCare Services. *MainCare Benefits Manual: Ch. I Section 4, Telehealth Services*. Maine Department of Health and Human Services (DHHS). <https://s3.amazonaws.com/fn-document-service/file-by->

[sha384/e3905a2f7549c10c9738bde8578c55d72f0c14394ea0859d0aeeacd13e86f35be7246b54f7a7550af3546440fa2082d6](https://www.dhcs.ca.gov/Documents/Budget_Highlights/DHCS-FY-2021-22-Governors-Budget-Highlights.pdf)

⁸⁰ California Department of Health Care Services. (2021, January 8). *FY 2021-22 Budget Highlights*.

https://www.dhcs.ca.gov/Documents/Budget_Highlights/DHCS-FY-2021-22-Governors-Budget-Highlights.pdf

⁸¹ The IDEA covers all school-aged children who fall within one or more specific categories of qualifying conditions (i.e., autism, specific learning disabilities, speech or language impairments, emotional disturbance, traumatic brain injury, visual impairment, hearing impairment, and other health impairments) and requires that a child's disability adversely affects her/his educational performance. Section 504 of the Rehabilitation Act requires that reasonable accommodations be made for and cover individuals who meet the definition of qualified "handicapped" person (e.g., a child who has or has had a physical or mental impairment that substantially limits a major life activity, such as walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks, or who is regarded as handicapped by others).

⁸² Faget, K. (2020, September 1). *Telehealth today and in a post-COVID-19 world*. Foley & Lardner LLP.

<https://www.foley.com/en/insights/publications/2020/09/telehealth-today-and-in-a-post-covid19-world>

⁸³ Legally responsible caregivers are generally prohibited by CMS from being reimbursed as caregivers for family members. However, states have used other pathways to get exceptions (e.g., HCBS, 1115, 1915(c) waivers).

⁸⁴ Payment limits are based on the monthly IHSS hours authorized for the client, the requirement for those hours to be spread evenly over the month, adjustments for overtime and the county hourly provider wage rate.

⁸⁵ Centers for Medicare & Medicaid Services. *Continuous eligibility for Medicaid and CHIP coverage*. Medicaid.gov.

<https://www.medicare.gov/medicaid/enrollment-strategies/continuous-eligibility-medicare-and-chip-coverage/index.html>

⁸⁶ Depending on the organization of health service delivery, CYSHCN may or may not receive their routine preventive and primary care services from the same care delivery team that addresses their specialty care needs.

⁸⁷ Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity that addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes. (Definition adapted from: American Academy of Pediatrics Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. "Patient- and Family-Centered Care Coordination: A Framework for Integrating Care for Children and Youth Across Multiple Systems." *Pediatrics* 133, no. 5 (2014): e1451–1460. <https://pediatrics.aappublications.org/content/133/5/e1451>

⁸⁸ Centers for Medicare & Medicaid Services. (2020, September 23). *Fact sheet: Service utilization among Medicaid and CHIP beneficiaries age 18 and under during COVID-19*. <https://www.cms.gov/newsroom/fact-sheets/fact-sheet-service-use-among-medicare-chip-beneficiaries-age-18-and-under-during-covid-19>

⁸⁹ For example, the National Committee for Quality Assurance (NCQA) did not make changes to the technical specifications for their quality measures to accommodate the COVID-driven pivot away from face-to-face visits until July 2020, and even then the modifications covered only 40 of the 71 measures that are part of the Healthcare Effectiveness Data and Information Set. (National Committee for Quality Assurance. *Coronavirus and NCQA*. [2020, December 18]).

<https://www.ncqa.org/covid/#:~:text=NCQA%20has%20updated%20telehealth%20guidance,Medicaid%20Services%20and%20other%20stakeholders>

⁹⁰ Federally funded, state-administered programs that continue to provide services under a fee-for-service arrangement may still have treatment authorization or other prior authorization requests. These were the target of the 1135 prior authorization waivers.

⁹¹ 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. (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>). 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. (

⁹² The Medicaid health home option enables states to provide integrated and coordinated care for beneficiaries with chronic physical, mental, or behavioral conditions. Coordinated care management integrates physical and behavioral services and links patients with nonclinical services and social supports. (US Department of Health & Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Report To Congress on the Medicaid Health Home State Plan Option*, May 2018. <https://www.medicaid.gov/state-resource-center/medicaid-state-technical-assistance/health-home-information-resource-center/downloads/medicaidhomehealthstateplanoptionrtc.pdf>

⁹³ Fischer, S.H., Usher-Pines, L., Roth, E., & Breslau, J. “The transition to telehealth during the first months of the COVID-19 pandemic: Evidence from a national sample of patients.” *Journal of General Internal Medicine* 36, no. 3 (March 2021): 849–51. <https://link.springer.com/article/10.1007/s11606-020-06358-0>

⁹⁴ Augenstein, J., Peng, A., Marks, J.D., & Fong, M. (2021, February 11). *Executive summary: Tracking telehealth changes state-by-state in response to COVID-19*. Manatt Health. <https://www.manatt.com/insights/newsletters/covid-19-update/executive-summary-tracking-telehealth-changes-stat>

⁹⁵ Early during the pandemic, the Office for Civil Rights at the Department of Health & Human Services announced it will exercise its enforcement discretion and will not impose penalties for noncompliance with the regulatory requirements under the HIPAA Rules against covered health care providers in connection with the good faith provision of telehealth during the COVID-19 nationwide PHE. (Office for Civil Rights. [2021, January 20]. *Notification of enforcement discretion for telehealth remote communications during the COVID-19 nationwide public health emergency*. US Department of Health & Human Services. <https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/notification-enforcement-discretion-telehealth/index.html>)