

Q&A: COVID-19 Telehealth Policies Affecting CYSHCN: What to Keep, Modify, or Discard?

Below are responses to questions the panel was unable to answer during the webinar.

Respondents

- **Sharon Silow-Carroll, MSW, MBA**, Principal, Health Management Associates
- **Cara Coleman, JD, MPH**, Director of Public Policy and Advocacy, Family Voices
- **Alison Curfman, MD, MBA**, Clinical Director of the Pediatric Operations, Mercy Clinic

Q&A

Family-Centered Telehealth Care

Do you have distinct ways to include families with the process of deciding what is needed for this to work?

Cara: At the individual level, using shared decision-making to decide what is needed is the best way. The CARES Telehealth Act funded materials created by Family Voices, specifically the preparing for a telehealth visit, offers a way for a family to make notes on what they are thinking/ needing to bring to discussion with their providers: [Family-Centered Telehealth Resources](#).

This American Academy of Pediatrics publication also lays out a pathway to shared decision-making that can easily be utilized for individual level telehealth planning: [Shared Decision-Making and Children with Disabilities: Pathways to Consensus](#).

At the systems level, partnering with youth, families, and family-led organizations provides ample ways to include lived experience in the design and decision-making around what is needed for the future of telehealth. These materials by the National Partnership for Women and Families, and funded in part by the Patient-Centered Outcomes Research Institute, outline priorities and ways to engage patients and families in designing e-health: [Digital Health](#).

If you seek actionable guidance and planning for how to include families in systems-level efforts, consider using this tool from Family Voices: [Family Engagement in Systems Toolkit](#).

What about the real concerns for our undocumented or marginalized families living in freedom and concerned with "big brother" taking them away and making families depressed while accessing telehealth and education? What about cultural responsiveness of providers and policymakers?

Cara: Many families have continued to express concerns over the use of telehealth with regard to their privacy and confidentiality. Although telehealth has been in use for a while now, such concerns should not be dismissed or diminished. Instead, the principles of family-centered care and cultural competence should be present in every individual-level interaction with children and youth with special health care needs and families to ensure that there are meaningful and authentic conversations about concerns and needs. As we continue to advocate for the use of telehealth as an option to become permanent, we must also continue to advocate for equitable

access to technology and broadband for all Americans. Additionally, we must work together to ensure that the practice of family-centered care, specifically dignity, respect, and cultural competence, are part of telehealth. Consider this definition: [Family-Centered Telehealth](#) and in Spanish [Tele-salud Centrada en la Familia](#).

Telehealth has also changed adult care. Because the adult population is the larger group with the power of the vote and the dollar, policy changes to adult health care often are made more easily than those affecting pediatric care. Can children with special health care needs (CSHCN) somehow find a way to leverage that power?

Cara: Very often advocacy and policy efforts for CSHCN and disabilities is included in and/ or done in conjunction with similar efforts for adults with disabilities. The current administration is very focused on promoting and investing in new opportunities for people with disabilities, which includes our children. Leveraging the power of the adult voice requires recognizing shared experiences and needs, and sometimes in health care we are quick to point out that children are not little adults. While that is very true, there is power in connecting with the needs for accommodations, accessibility, and person-centered care shared by children, youth, and adults with disabilities. The bridge between childhood and adulthood is transition; something that starts in pediatrics and connects the voices of our children to their future as adults. Transition does not receive the attention of early childhood, and maybe this offers opportunity for unity in the future. Lots of voices are uniting around providing access and accommodations across the entire life course of those with disabilities, their families, and allies.

Does telehealth have the potential to increase coordination of services that a child receives through their health care coverage and through their IEP or 504 plan? The funding streams are obviously different but the actual service needs can overlap greatly and, ideally, should be complementary but, from what I know, true coordination of health care and special education needs rarely occur.

Cara: Potential = HUGE! Telehealth has largely untapped potential to truly advance coordination of health care and IEP/504 plan services, both as siloes in their own sector and across sectors. And as you note, the funding sources are different but definitely can be worked out. A key aspect of moving such cross-sector coordination forward is collaboration between Medicaid, the Department of Education, and other relevant governmental agencies, as well as provider and family-led organizations. We need policy that ensures telehealth remains an option in health care and education. In health care, we need billing codes that cover participation of a provider in an IEP/504 meeting. Precedent for such cross-sector collaboration, policy and billing already exists when a school bills Medicaid for the provision of physical therapy, for example. Notably, during the pandemic, there are great examples of additional cross-sector collaboration between education and Medicaid fostered by telehealth from which lessons and other innovations can be drawn. Feel free to learn more in a report from the National Academy for State Health Policy: [State Strategies to Support the Health Needs of Children with Special Needs in Schools During COVID-19](#).

Telehealth Pediatric Patient Care

I agree with having guidelines on the length of patient visits – whether video or on the phone – as the determinant for the cost of the visit. Who will decide what the right amount of time is?

Alison: I do not know who will determine the most appropriate length of time for a telehealth visit. Unfortunately, this is still a concept modeled after the fee-for-service model of care. Once we reach true value-based contracting in pediatrics, the answer to this question becomes simple – the right amount of time is the amount of time that the patient needs to get their problem solved. In the current system, pediatricians struggle to be compensated for all the care they provide, particularly in primary care pediatrics. These will need to be ongoing conversations with pediatricians and payers. For the short term, I anticipate that pediatricians will bill their visit codes via telehealth based off the same complexity E/M codes that are used for in-person visits, with similar length of visits for each.

It would seem to be an opportunity to develop procedures to connect interpreters for limited English proficient parents using telehealth services. Were there any best practices or models to coordinate the use of interpreter services (via telephone or video medical interpreting) with telehealth services?

Alison: Unfortunately, we did not have interpretation services in our pilot program at Mercy, but it is an essential point that we have emphasized in the upcoming American Academy of Pediatrics policy statement on telehealth, which will be released in September. In our program, we were able to have an interpreter for three-way phone calls, but since we didn't have services to support our messaging and video visits, we were limited in our ability to enroll non-English speaking families. There are challenges with both written and verbal interpretation and translation needs, as evidenced by the fact that many patient portals do not support a wide variety of language needs. This is an issue that will need to be addressed.

Do we have any assessment tools as yet to help determine which individual children/families could use/benefit from telehealth, and from which modality of telehealth, and which kids/families need to retain in-person attention?

Alison: All kids need in-person care at times. Pediatrics as a whole is going through the growing pains of determining best practices for telehealth, which is a challenge since it is such a new tool. However, we use the guideline that quality of care should never be sacrificed for the care modality. For instance, if we require visualization of a tympanic membrane (eardrum) to diagnose ear infection in an in-person visit, then telehealth visits must be held to the same standard. The child either needs to have technology in the home to visualize the eardrum or they need to be seen in person if they are going to be treated for an ear infection. The same goes for all other conditions. However, as technology continues to develop to support additional needs at home, we will have to adapt what we believe is feasible to do virtually. For instance, a well-child visit (currently) needs to be done in person. Children need to have their growth and development assessed and receive vaccinations. However, SOME components of the well-child visit, such as discussions about sleep and nutrition, may someday take a different form such as a remote interview. We do not have best practices defined yet, but we do align around the concept that telehealth or virtual care needs to be held to the same level of quality as in-person care.

Future of Telehealth

Does the report evaluate the impact of telehealth vs in-person physical, occupational, speech, and ABA therapies? A lot of families of my caseload report a poor outcome of therapies, indeed some families cancelled telehealth therapies.

Sharon: Interviewees reported a mix of experiences with therapies provided via telehealth. For example, telehealth is challenging if the child, caregiver, and therapist haven't had the opportunity for in-person practice or training of the parents to reinforce specific interventions. Our report calls for comprehensive clinical evaluations of outcomes from the various therapies provided via telehealth. This research should inform development of pediatric clinical guidelines that identify the appropriate use of telehealth for specific therapies and conditions among children and youth with special health care needs (CYSHCN). Still, each child and family situation is different – therefore the family should always be part of the decision whether to use telehealth.

There are also barriers to successful telehealth that can be mitigated. Practitioners reported telehealth “no shows” because some caregivers don't know what to expect and have anxiety about the quality of care or about their technical skills to access the virtual visit. Therefore, we need funding for equipment, broadband, outreach, and trainings (e.g., through national and local family/peer support groups) for families of CYSHCN on accessing telehealth services. Also, some physical, occupational, and speech therapists may not yet be comfortable with telehealth, potentially affecting quality of care. So, we need training for therapists to provide high quality services via virtual modalities, to support and encourage families with their role, and to recognize when in-person visits are the better choice.

What is needed to ensure that increasing use of/reliance on telehealth doesn't adversely affect access to needed in-person care?

Sharon: As noted above, pediatric clinical guidelines should be developed to identify when telehealth is appropriate versus *when in-person care is needed for specific services, ages, and conditions among children and youth with special health care needs* (as well as for other patient populations). Screening tools are already being developed to help determine when telehealth would or would not be a good option, and these should consider the child and family readiness to use telehealth as well as clinical indications. Legislation expanding telehealth should include monitoring, evaluation, and patient/family protections. For example, Massachusetts' telehealth legislation enacted in 2021 (2020 Mass. Acts Ch. 260), charges the Massachusetts Health Policy Commission with preparing annual reports analyzing the use of telehealth services and the effect of telehealth on patients' access to health care, and ensures patients the right to decline telehealth services and receive in-person services instead.

I have heard that for Medicaid, states don't need to submit a state plan amendment (SPA) to set telehealth policies as long as reimbursement is the same as other modalities, is that correct? If so, it seems very easy for state Medicaid programs to keep telehealth policies because there is no paperwork they need to submit to the Centers for Medicare & Medicaid Services (CMS).

Sharon: It is correct that “States are not required to submit a (separate) SPA for coverage or reimbursement of telemedicine services, if they decide to reimburse for telemedicine services the same way/amount that they pay for face-to-face services/visits/consultations.” (Medicaid brief (CMS 17a), can be found [here](#).) CMS developed a [toolkit](#) to assist states, and a

[supplement to the toolkit](#) to help states as they implement telehealth policies and consider extending flexibilities after the public health emergency.

One area where states are struggling with extending payment parity (same reimbursement as for in-person service) is for audio-only services. If states want to use/allow audio-only but reimburse it differently, there will be a need for a SPA.

These are all terrific recommendations! Is there any indication that any states are taking these recommendations? Do you have a sense of how states will be approaching telehealth as the public health emergency ends and if they are generally supportive of keeping the telehealth flexibilities in place?

Sharon: Many states want to continue at least some flexibilities extended during the public health emergency, while also considering budgetary pressures and Medicaid program integrity (protecting against fraud and abuse). For telehealth, there appears to be a trend toward making certain telehealth policies permanent after the pandemic, though this will continue to vary by state. New Hampshire was one of the first states to transition its temporary telehealth coverage policy to permanent in 2020, shifting from a state that covered relatively few virtual care services prior to the pandemic to a state on the leading edge. In May and July 2021, Arizona and Colorado, respectively, implemented permanent virtual care coverage and payment policies that enable patients to receive care via telehealth at home, from out-of-state clinicians, and for mental health services. The Arizona law also requires payment parity for virtual care services relative to in-person services. Massachusetts enacted a telehealth bill in 2021 that expands the definition of telehealth (includes audio-only), reduces certain barriers to telehealth services, and expands certain coverage requirements and rate parity requirements.

Anyone interested in supporting the report's recommendations should share them with their legislators and program administrators at the local, state, and federal levels, and with their professional associations, colleagues, and peers.