



Telehealth and Children of Color with Special Health Care Needs: Lessons from the Pandemic

EXECUTIVE SUMMARY


The Children's
Partnership

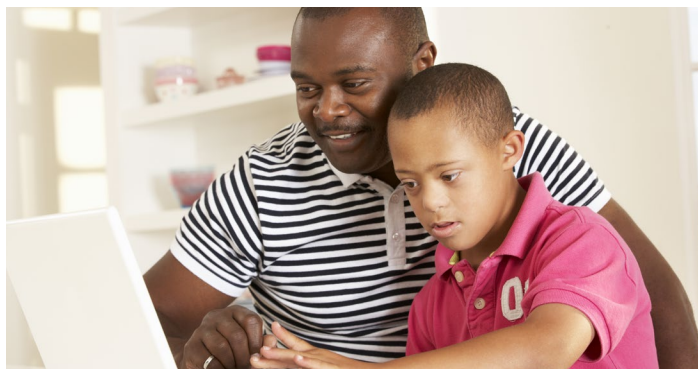
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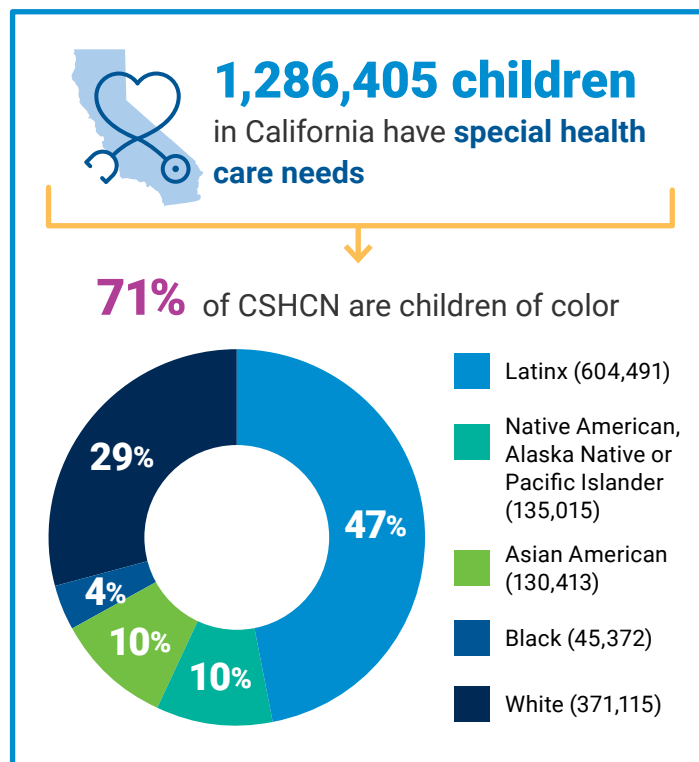


Introduction: Why we did this report

In California, two in three of the 1.3 million children with special health care needs (CSHCN) also identify as Latinx, Black, Asian American, Native American or multiracial. Yet, despite children of color making up a majority of CSHCN, research and recommendations that identify or address how multiple forms of discrimination (such as racism and ableism) compound challenges that impact well-being is limited.



Through our own research, The Children's Partnership (TCP) sought to center and learn directly from families of color with CSHCN about their unique lived experiences, their resilience, and the compounded challenges they face, in addition to uplifting their recommendations to policymakers in an effort to make our health care system more equitable. We focused on telehealth because of its potential to address some of the barriers children and families face in accessing health care. We sought to understand the role telehealth played in keeping children of color with special health care needs connected to care during the pandemic and provide policymakers with family-centered recommendations to make California's health care system and the use of telehealth more equitable.





Research Methods: Who we talked to

This project was intentionally designed to center the experiences, knowledge and recommendations of families of color who have children with a range of special health care needs in the development of a policy agenda.

We partnered with community-based organizations to recruit families of color in target regions whose children had special health care needs. We used several methods to center the lived experiences of these families. We coordinated and hosted 21 small-group, virtual listening sessions in English and Spanish. We created and guided families who participated in our listening sessions to complete an online bilingual survey. We also used strategies that sought to share power with families and make this research meaningful, inclusive and adaptive to their needs and circumstances, including by providing cash stipends, providing materials in English and Spanish, and working individually

with families to register and address any tech issues. TCP also reviewed each learning and recommendation with families and incorporated their feedback into this final report.

In total, TCP recruited 85 unique families of color to participate in this project from three different regions in California. Families self-identified themselves and their children as Latinx, Black, Native American or Asian American. Over half of the families were monolingual Spanish speakers. Children from almost all grades were represented, including pre-K. Children from these families have a range of unique health care needs that include physical, developmental, mental and complex health conditions. The learnings in this report reflect the voices and experiences of families of color with CSHCN captured through the listening sessions and online survey.





Learnings: What we learned from families



TCP reviewed and analyzed all the information families of color with CSHCN provided through the listening sessions and survey, highlighting themes and issues as overarching learnings. We intentionally describe the learnings with direct quotes from families, understanding that their voices are the most appropriate to tell the stories of their and their children's unique experiences. This research reaffirmed how resilient and hopeful families of color with CSHCN are despite the social and economic challenges they face, while at the same time highlighting the difficulty they continue to experience in navigating systems and accessing supports and services.



1. Telehealth helped keep children of color with special health care needs connected to health services during the pandemic. When schools and doctors' offices closed, telehealth helped keep children connected to care.



After the shutdowns, my child used telehealth for physical therapy, occupational therapy, and speech therapy and some specialty doctor visits with the gastroenterologist, endocrinologist and geneticist.

— MOTHER OF SON WITH DEVELOPMENTAL DISABILITIES



Using telehealth, my daughter received neurology and chronologist appointments, as well as speech therapy and counseling services over the phone. My daughter has telehealth appointments twice week. After she suffered a severe attack, she had more regular telehealth appointments with her neurologist.

— MOTHER OF DAUGHTER WITH EPILEPSY



2. Telehealth helped families address challenges children of color with special health care needs typically face when accessing care. Telehealth made it easier for families to access care by addressing issues like lack of transportation, long wait times for appointments, and lack of child care.



I don't drive, so I always had to find transportation to take my child to the doctor. With telehealth I didn't have to do that.

– MOTHER OF DAUGHTER WITH ADHD



I would recommend telehealth to other parents because it does save a lot of time especially when you have multiple children and they are not allowing you to bring siblings into appts so don't have to look for daycare for the other kid or stress out so just for comfort of it.

– MOTHER OF DAUGHTER WITH DOWN SYNDROME



I think services improved for the better. I feel like it was easier to be seen via telehealth, and the turnaround to be seen was much quicker than waiting for an office visit. The turnaround time for addressing concerns was much quicker [with telehealth].

– MOTHER OF SON WITH AUTISM



3. Families indicated a strong interest in the option of having telehealth appointments for their children while at the same time noting telehealth did not adequately address all special health care needs. Some children had a harder time using telehealth than others to address their special health care needs.



My son won't sit still. He tried sitting still for a computer and whacked the computer and they won't give him a new one. I think having a doctor come in to meet him in person is better. But [when the doctor] is talking about [my child's] progress and paperwork, we can use telehealth.

– MOTHER OF SON WITH AUTISM AND DEVELOPMENTAL DELAY



Using telehealth was a challenge – zoom it still very new to me – I don't believe telehealth can help with everything. How can a doctor diagnose her when they aren't there to see her? They can't do it over the phone. My greatest challenge was that being in front of a screen can cause my daughter issues – the light is a trigger for my daughter (with epilepsy) – so we had to limit her visit to 10 minutes or less and that was hard because sometimes the visit would last 30 minutes and they would have to take a break/stop it every 10 minutes.

– MOTHER OF DAUGHTER WITH EPILEPSY





4. Families continued to face long-standing systemic challenges that limited their ability to access care for their children using telehealth, including digital, educational, language and cultural barriers. Families faced a number of challenges they typically face in accessing care, whether in person or not, that made it harder for them to use telehealth to access health care and services for their children. Lack of access to providers, translation and interpretation services, and information/education remain barriers regardless of the ways children of color with special health care needs access care.



It was difficult because I wasn't taught how to use computers or technology. My kids helped me. But it was a challenge. My screen would freeze. My internet would drop because there were so many people using internet at the same time.

– MOTHER OF SON WITH SPEECH DELAY



I have to wait for a referral [to see my son's specialist] and that took a couple weeks. During the pandemic, [my son] never got the services he needed because of having to be referred out and it taking so long [to get the referral].

– MOTHER OF SON WITH ADHD



At first there were a lot of factors, we only have one computer. The school at first only allowed chromebooks and so sometimes I needed to use my phone and doing the exercises over the phone was difficult. After some time, the school offered chromebooks and then the internet started malfunctioning. We would need to cancel appointment and if we couldn't make it because of internet problems, they had to reschedule us. Yes, it was very difficult in the beginning.

– MOTHER OF DAUGHTER WITH SPEECH DELAY



The indigenous population has been growing exponentially [in Tulare County] and there are not enough services tailored to meet their needs.

– COMMUNITY STAKEHOLDER IN TULARE COUNTY



CCS [California Children's Services] has never provided [me] a report in Spanish in 25 years. [My child's] doctors will take notes with codes and it's sometimes difficult to understand the next steps. Every health or social services professional speaks a lot in code which is not easy for parents to understand.

– MOTHER OF THREE YOUNG CHILDREN WITH CEREBRAL PALSY



Getting interpretation is a barrier. Even when you get through, or [if it's in the] evening hours, it's difficult to connect with interpreters. It's important to have linguistic and culturally appropriate [staff with] ability to interpret.

– MOTHER OF DAUGHTER WITH SPEECH IMPAIRMENT



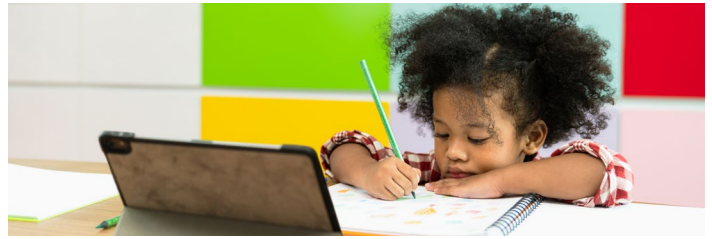


5. The pandemic caused instability, compounding and creating mental health issues and challenges for children of color with special health care needs and their families. CSCHN of color had to deal with many stressors during the pandemic that interrupted their daily routines while at the same time not having access to the supports they needed.



My daughter is depressed and losing motivation to move forward because of being inside for so long.

– MOTHER OF DAUGHTER WITH AUTISM



Recommendations: What should be done to support families

Acknowledging that those closest to the issues are also closest to the solutions, TCP also asked families their recommendations to address the challenges they faced as reflected in the learnings. Additionally, TCP engaged in policy research to support and expand upon their recommendations. The policy recommendations are directed to and can be implemented by all systems that serve children of color with special health care needs, including health and education systems.



1. Treat families as experts in their children’s care; provide them with a choice between telehealth or in-person services whenever possible. Systems must center the voices and recommendations of these families to better understand the challenges they face and how to serve them better.



I really liked that you took your time to ask us questions about what we need for our children, and it gives me hope knowing that you listen to our needs.

– MOTHER OF SON WITH ADHD



It would be great if we could have more time in telehealth appointments and more room for parents to ask questions during appointments.

– MOTHER OF DAUGHTER WITH DOWN SYNDROME



Policymakers should think about all types of cases – there are so many needs – that they don’t lose the focus for children who have more specific and special needs.

– MOTHER OF DAUGHTER WITH DYSLEXIA



2. Allow families to use multiple telehealth modalities to access health care. Families of color with CSHCN should be able to have a telehealth visit using the technology that is accessible and comfortable to them, including by phone, text or video.



3. Expand use and coverage of telehealth services in community spaces where children and families spend a lot of time. Address telehealth access issues by increasing the number of community sites where children can have a telehealth visit, including their schools, early learning and child care centers.

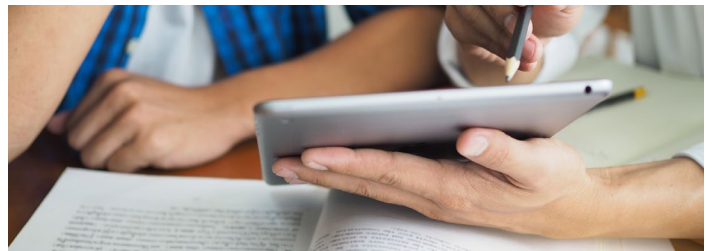


4. Engage in outreach and education on telehealth. Prepare families for telehealth appointments with information about when, where and how their children can get the services they need using telehealth as a component of care that is comprehensive and holistic.



You cannot give technology without training, otherwise it's useless to families.

— COMMUNITY STAKEHOLDER WHO SUPPORTS CHILDREN OF COLOR WITH SPECIAL HEALTH CARE NEEDS IN POMONA



5. Utilize community health workers and promotores (CHW/Ps) to help families navigate telehealth and ensure CHW/Ps can use telehealth to provide outreach, education, navigation and other services to children and their families. Integrate community members who reflect the experiences of families of color with children who have special health care needs, like peers, community health workers, and promotores, into the health care system to help families understand how to use and navigate telehealth, as well as provide services to families using telehealth.



Promotoras who also have children with special needs have been so helpful in supporting me and other families so that children with special needs get appointments with doctors and are able to access all of services and supports they need.

— MOTHER OF SON WITH DEVELOPMENTAL DELAY





6. Ensure services provided through telehealth are culturally and linguistically concordant, including by providing more time for bilingual appointments. Families should be able to easily find and access providers that mirror their identities and experiences and speak their language. Interpreters should be readily available to support families during telehealth visits. Materials provided before, during or after telehealth visits should be in a language the family understands.



There should be additional support for non-English speakers who utilize telehealth if they need translation, guiding them step by step and giving non-English speakers additional time in telehealth appointments.

– MOTHER OF DAUGHTER WITH SPECIAL HEALTH CARE NEED* IN TULARE



7. Increase access to mental health services using telehealth for children with special health care needs. Make it easier for children of color with special health care needs and their families to find and get mental health services.



Therapy is a necessity for parents of children with special needs. There are many parents that don't want to accept that their kids have disabilities. There are programs that help us recognize that our kids have needs and that they have rights.

– MOTHER OF A SON AND A DAUGHTER WITH AUTISM, AND A DAUGHTER WITH BIPOLAR DISORDER



Conclusion: Final thoughts

Children of color with special health care needs not only face challenges due to their health condition like other CSHCN, but they and their families must also deal with the economic, social and cultural challenges that all communities of color disproportionately face every day.

As telehealth continues to be used by our health care system as an alternative to in-person visits, policymakers, schools and providers need to continue to be flexible and make improvements based on direct feedback from families and CSHCN of color. Communities know best the solutions to the challenges they face. Through this project, the recommendations identified provide a better path forward for improvements to telehealth.

*This parent chose not to share the specific health care need of their child.



The Children's Partnership (TCP) is a California advocacy organization advancing child health equity through research, policy and community engagement.



www.childrenspartnership.org



The Children's Partnership envisions a California where all children—regardless of their race, ethnicity or place of birth—have the resources and opportunities they need to grow up healthy and thrive, and its mission is to advance this vision of child health equity through research, policy and community engagement.