



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

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Executive Summary

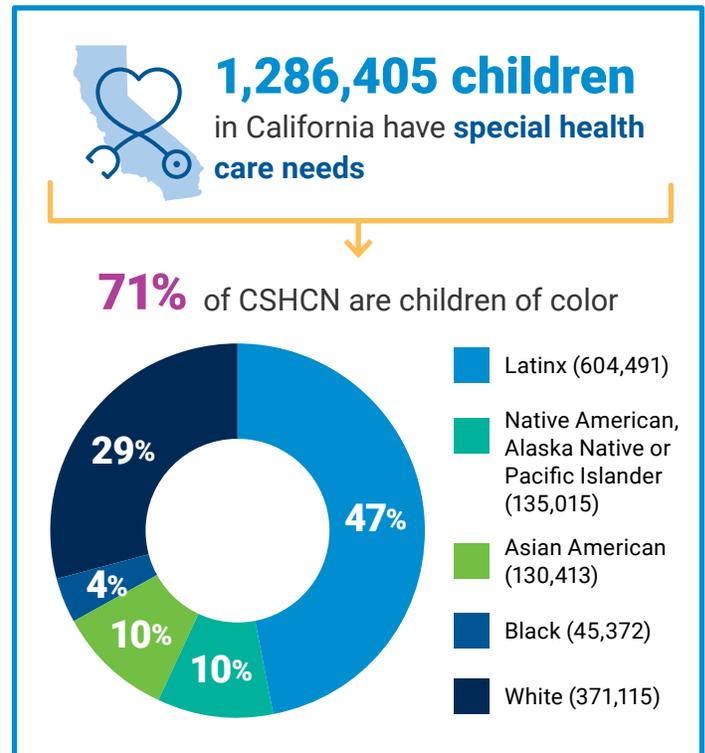


Introduction: Why we did this report

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.

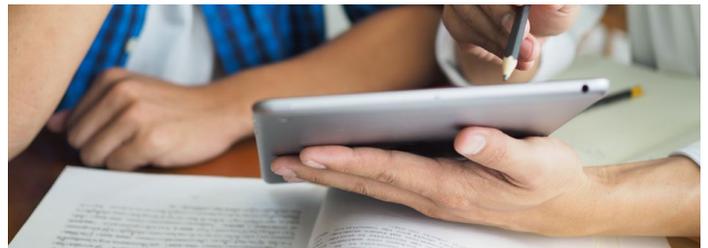


4. Engage in outreach and education on telehealth. Prepare families for telehealth appointments with information about when, where and how their children can get the services they need using telehealth as a component of care that is comprehensive and holistic.



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.

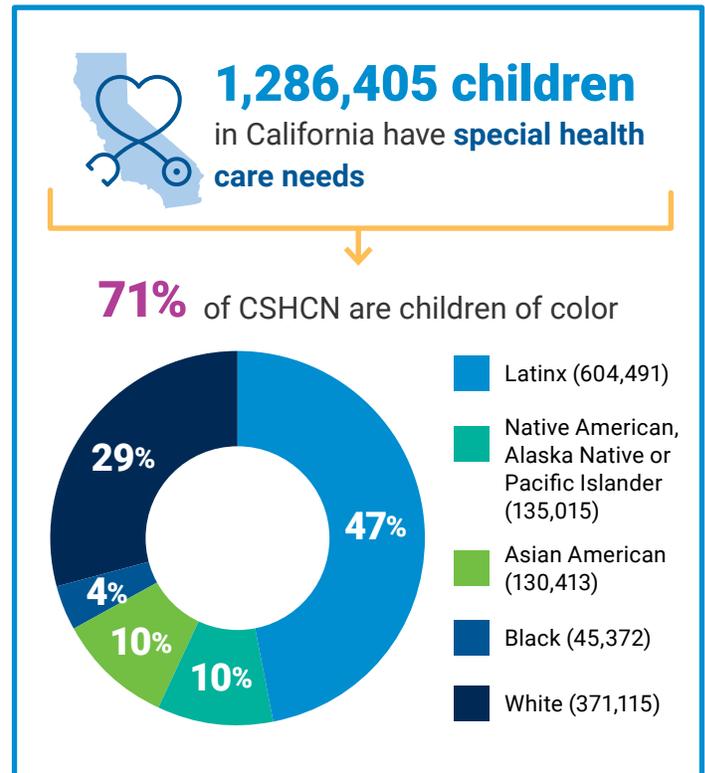
Introduction

There are approximately **1,286,405 children in California** who have special health care needs, **71% (915,291)** of whom also identify as children of color: **Latinx (604,491)**; **Native American, Alaska Native or Pacific Islander (135,015)**; **Black (45,372)**; **Asian American (130,413)**.¹ Before the pandemic, children with special health care needs (CSHCN) and their families experienced elevated caregiving difficulties, financial strains, and heightened vulnerability to mental health and behavioral problems.² The continued disproportionate impact of the COVID-19 pandemic on communities of color has put CSHCN of color and their families at even higher risk of facing distress and difficulties because of increased caregiving burden due to illness, death and school shutdowns; elevated financial strains due to employment losses; and reduced accessibility or complete loss of health care services.

Despite the unique experiences and hardships they face, CSHCN of color and their families are resilient, resourceful and motivated to succeed. Through this report, The Children's Partnership (TCP) centers the experiences of CSHCN of color and their families in policy advocacy in order to create systemic changes that will respond to their unique needs, ultimately leading to a more equitable health system for all children.

“What makes me smiles is my motivation for continuing to help my son with special needs and learning how to help him better and with all of my love.

— MOTHER OF SON WITH AUTISM



“Seeing my son makes me happiest. It’s difficult taking care of a special needs child but I love seeing his happy face when he enjoys music and uses his electric jeep. Seeing him smile and seeing him healthy makes me happy.

— MOTHER OF SON WITH DEVELOPMENTAL DISABILITIES





INTERSECTIONALITY: RACISM AND ABLEISM



As part of TCP's [core beliefs](#) that guide our advocacy, we approach our work through an intersectional lens that acknowledges how multiple identities intersect and create compounded and unique challenges and oppression for marginalized communities.

Intersectionality is a framework for understanding the unique challenges and experiences created by the confluence of multiple marginalized identities. Developed by legal scholar Kimberlé Crenshaw, intersectionality arose to address the unique and compounded experiences of discrimination that Black women face at the intersection of race and gender.

Intersectionality is a promising framework for research, policy and advocacy related to children of color with special health care needs, who experience systems and society through the lens of multiple identities that have been marginalized, including race and ability. As [explained](#) by Isabella Kres-Nash:

"Racism and ableism are often thought of as parallel systems of oppression that work separately to perpetuate social hierarchy. Not only does this way of looking at the world ignore the experiences of people of color with disabilities, but it also fails to examine how race is pathologized in order to create racism. Meaning that society treats people of color in specific ways to create barriers, and these poor conditions create disability. The concept of disability has been used to justify discrimination against other groups by attributing disability to them."

TCP has championed and helped with the adoption of telehealth as a critical tool for improving access to care and health outcomes for children in the state. Telehealth, historically used to increase access to care, has proven particularly valuable during the pandemic to children with special health care needs who may have challenges in accessing care, see multiple specialty providers, and need to limit exposure to the virus because they are immunocompromised.³ However, though telehealth remains a key way to increase access to health and mental health services, there are still barriers in making telehealth easily accessible for children and families of color.

In 2021, TCP began holding virtual convenings and listening sessions to create a telehealth policy agenda rooted in and responsive to the challenges CSHCN of color and their families were facing during the COVID-19 pandemic, their experiences using telehealth to access care, and their recommendations for policymakers to better support the health and well-being of their children. **This report provides a synthesis of our engagement with 85 unique families of color who have children with special health care needs and live in communities across California, highlighting key learnings that reflect their experiences and voices as well as policy recommendations to better leverage telehealth to support their health and well-being.**

Background



DEFINITION: CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The federal Maternal and Child Health Bureau defines children with special health care needs as “[children] who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁴ For example, CSHCN may experience one or more of the following:

- ▶ Asthma, epilepsy (physical condition)
- ▶ Autism, Down syndrome (developmental condition)
- ▶ Anxiety, depression, ADHD (behavioral/emotional condition)



Children of color with special health care needs in California

California is home to the most diverse population of children in the country, and diversity is also apparent in the population of children of color with special health care needs.

Children of color and children in immigrant families make up over a majority of children with special health care needs.

Children of color make up over a majority (71%) of the 1.3 million children under 18 with special health care needs in our state:⁵

- ▶ 47% (604,491) are Latinx
- ▶ 4% (45,372) are Black
- ▶ 10% (130,413) are Asian American
- ▶ 10% (135,015) are Native American, Alaska Native or Pacific Islander



1 in 3 (33%) of CSHCN in California live in immigrant families where at least one parent was born outside of the United States.⁶



Slightly over 1 in 10 (12%) of CSCHN in California live in homes where English is not the primary spoken language.⁷



Nearly 1 in 5 (17.4%) of California CSHCN have Medi-Cal, California’s public health insurance program.⁸



CALIFORNIA'S CHILDREN WITH SPECIAL HEALTH CARE NEEDS FACE DISPROPORTIONATE CHALLENGES TO THEIR HEALTH AND WELL-BEING.

Children with special health care needs in California face disproportionate social and economic challenges:



Nearly 1 in 10 (9%) CSHCN in California sometimes or often experience food insecurity compared to 3.6% of children without special health care needs.⁹



Over 1 in 3 (36%) have faced two or more adverse experiences in their childhood compared to 12.6% of children without special health care needs.¹⁰

Children with special health care needs in California also face unique systemic issues in accessing health and other services:



Nearly 1 in 4 (24%) have one or more oral health problems compared to 14.6% of children without special health care needs.¹¹



43% do not have health care coverage that is adequate to meet their needs.¹⁵



Nearly half (46%) faced difficulty in accessing the mental health treatment or counseling they needed.¹²



Over half (61%) do not receive coordinated, ongoing, comprehensive care within a medical home.¹⁶



Nearly half (40% or 355,334) do not receive effective care coordination.¹³



50th state

California ranks last in the nation in the percentage of children with special health care needs whose families experience shared decision-making with health care providers.¹⁷



Nearly 1 in 3 (31%) have difficulty getting needed referrals.¹⁴

The data in this section is inclusive of all children with special health care needs and highlights the disparities they face across the board. However, it is important to note that because in California children of color make up 71% of this population, the data is primarily reflective of their experiences. Still, an accurate picture of the health of children of color with special health care needs in California is impossible without publicly accessible, accurate and detailed data that is disaggregated by racial and ethnic subgroups. Without this data, health inequities that exist within racial and ethnic populations of children with special health care needs will be understudied and overlooked.



Children of color with special needs face disparate experiences when it comes to accessing and receiving the health services they need.

Though many parents of children with special health care needs — regardless of race — struggle to receive prompt diagnoses and access to adequate therapy and support services,¹⁸ the struggle for California’s families of color is more acute. **Children of color with special health care needs face multiple intersecting challenges in their interactions with the health care systems, and society more broadly, as they embody multiple communities that have been historically marginalized in our society — both as people of color and individuals with a special health care need.**

In a 2020 report, Public Counsel found that, **for decades, families of color and non-English-speaking families received fewer services than white families through California’s regional centers (agencies that provide and coordinate services for children with developmental disabilities).**¹⁹ For example, the report found that Latinx children received only 69% of spending on services that white children received.²⁰ It also highlighted that although regional center spending on Black children has improved in recent years, it remains 11% less than the amount spent on white children.²¹ In addition, it found that Asian American

children received 16% less funding than white children in 2018-19.²²

A 2016 study that assessed the medical home presence for California’s CSHCN by immigrant family type and evaluated which medical home components were associated with disparities found similar access and equity issues. The study found that **only 28% of foreign-born CSHCNs and 37% of CSHCNs with a foreign-born parent have a medical home in California, compared to 49% among CSHCNs with U.S.-born parents.**²³ It also found that **only 37% of foreign-born CSHCNs have care coordination, compared to 56% of CSHCNs with U.S.-born parents.**²⁴

Other studies point to inequities in diagnosis rates for conditions like autism spectrum disorder (ASD). **Researchers and clinicians have acknowledged the persistent disparities in the prevalence of Black and Latinx children, who continue to receive delayed or alternative diagnoses.**²⁵ A study in the journal *Pediatrics* found that **Black children are diagnosed with autism on average more than three years after their parents express concerns about their development,** which is generally several months later than their white peers.²⁶ As a result, authors said the delays could mean Black children are diagnosed too late for early interventions and could contribute to high rates of intellectual disability, where disparities between Black and white children are especially prominent.²⁷

Latinx children in the U.S. face the worst disparities when it comes to diagnosis rates and are less likely to be diagnosed compared to all children, including white children, according to a 2020 report from the Centers for Disease Control and Prevention.²⁸ Additionally, because of social and cultural privilege associated with speaking English in the United States, **children from Latinx households with limited English proficiency experience more barriers to accessing ASD-related services compared with children from English-proficient families.**²⁹



Impact of COVID-19 pandemic on children of color with special health care needs and their families

Although all children were significantly impacted by the COVID-19 pandemic, children of color with special health care needs – who already faced numerous barriers to having regular access to health care, mental health care, and support services – suffered exponentially under the impact of the pandemic.

Heightened risk of COVID-19 illness and death

Children of color with special health care needs are at the greatest risk for negative outcomes from COVID-19 among children, including severe disease, hospitalization and death.³⁰ A report from the CDC analyzing data on COVID-19 illness and death impacting children and youth across the United States found that among the children and youth who had passed away from COVID-19,



78% were Latinx, Native American or Black, and 75% had at least one underlying health condition, with the most common being asthma, obesity, neurologic and developmental conditions, and cardiovascular conditions.³¹ Children of color with special health care needs also have



an increased risk of severe COVID-19 illness and multisystem inflammatory syndrome in children (MIS-C), compared with white children and youth.³²



Significant mental health challenges

The mental health of children of color with special health care needs and their families has been detrimentally impacted by the pandemic. School closures, job loss, isolation, cessation or disruption of in-person clinical visits and home care visits, lack of child care, and economic instability have put tremendous strains on CSHCN and their families, impacting their mental health.³³ School closures not only led to social isolation and challenges with virtual learning, but they also significantly reduced access to health and social services and care that children of color were only able to receive at school. For example, more than half of the children who use mental health services receive at least some services in school settings, with 35% receiving services exclusively in schools.³⁴



Children of color with special health care needs also consistently faced the overall threat of the virus and the collective and individual grief over loved ones who died from COVID-19, a disproportionate percentage of whom were from communities of color. Children of color are more likely to have lost a parent or caregiver to COVID-19. A recent study found that of the 140,000 children under the age of 18 in the United States who became an orphan due to losing a caregiver during the pandemic, 65% are children of color.³⁵ Specifically, compared to the number of white children who lost a parent or caregiver, Native American children were 4.5 times more likely, Black children were 2.4 times more likely, and Latinx children were nearly 2 times (1.8) more likely to have lost a parent or caregiver.³⁶



Rise of telehealth during COVID-19

Prior to the pandemic, access to telehealth services was extremely limited, despite the promise of telehealth reducing access to care barriers in California.³⁷ Payment for live video and asynchronous telehealth services by health insurance, including Medi-Cal, was restricted.³⁸ Other forms of telehealth, including use of audio-only services, e-consults, and remote patient monitoring, were completely excluded. Previous statewide policy in the form of regulations also limited the location at which patients could receive telehealth services, excluding them from being able to receive care in their own homes.³⁹

With the onset of the COVID-19 pandemic, health care access for non-emergency services came to an abrupt stop with shelter-at-home orders that required families to stay at home and providers to stop in-person visits. Telehealth services became a critical link to continue providing and receiving health care services, especially for CSHCN.⁴⁰

In response to the pandemic and a commitment to supporting access to health care, federal and state telehealth policies were quickly expanded so that telehealth became the primary way to deliver acute, chronic, primary and specialty care.⁴¹ As a result of the COVID-19 public health emergency (PHE), California implemented broad telehealth flexibilities through waivers and disaster relief state plan amendments.⁴² Medi-Cal significantly revised prior policies and



65%
of children who became an orphan during the pandemic due to losing a parent or caregiver are children of color

Compared to the number of white children who lost a parent or caregiver:

Native American children were **4.5x more likely**, Black children were **2.4x more likely**, and Latinx children were **nearly 2x (1.8) more likely to have lost a parent or caregiver.**³⁶

practices for telehealth.⁴³ All telehealth policies issued by the Department of Health Care Services (DHCS) pertaining to Medi-Cal services were also applicable to the California Children’s Services (CCS) Program, which primarily serves children with special health care needs.⁴⁴ Specifically, providers were reimbursed for telehealth services provided through telephone at the same rate as services provided in person; audio-only telehealth visits were reimbursed at the same rate as video telehealth visits; location restrictions were lifted so patients could communicate with their providers from their home; and Federally Qualified Health

Centers, who serve predominantly low-income community members, were permitted to provide telehealth services through whatever modality was most accessible and convenient to the patient.⁴⁵

These flexible policies helped enable California’s health care delivery systems to meet the health care needs of CSHCNs.⁴⁶ Telehealth lessened the need for families and caregivers of CSHCNs to transport their children and equipment to appointments, enabled lower potential for exposure of already high-risk children to COVID-19 and other infections, and offered greater access to distant, specialized services for CSHCN.⁴⁷



TELEHEALTH 101

Telehealth refers the use of technology to provide and coordinate health care at a distance. Examples of telehealth:



Cell phone or electronic device to send health information to a doctor or speak with the provider by telephone, video conference, or e-mail.



Online patient system to send messages to a doctor, view test results, and request prescription refills.



Email, text, or telephone for important health updates or reminders.

Telehealth has long been seen as a potential solution to address health disparities caused by geography and a lack of providers, especially specialists. Health care providers have also used telehealth to enlist the assistance of language interpreters from third-party services to better communicate with individuals with limited English proficiency.

PRIOR TCP TELEHEALTH RESEARCH

As part of our work to create a more equitable health system, for the last 10 years, TCP has championed and helped with the adoption of telehealth as a critical tool for improving access to care and health outcomes for children in the state.

[Realizing the Promise of Telehealth for Children with Special Health Care Needs](#)

[School-Based Telehealth: An Innovative Approach to Meet the Health Care Needs of CA Children](#)

[Roadmap for Action: Advancing the Adoption of Telehealth in Child Care Centers and Schools to Promote Children’s Health and Well-Being](#)



CALIFORNIA TELEHEALTH POLICY BEYOND THE COVID-19 PANDEMIC

In 2021, the California Legislature passed and Governor Newsom signed legislation (AB 133) which maintains the COVID-19 telehealth flexibilities through December 31, 2022. The bill also required the state to consult with an advisory group of stakeholders to provide recommendations for establishing telehealth policies post-PHE. The Telehealth Advisory Group was quickly created and met regularly to address long-term changes to California's telehealth policies using equity and access as guiding principles. Using the recommendations from the stakeholder workgroup, DHCS released its proposed post-COVID, permanent telehealth policies which maintained the existing flexibilities in location, payment and modality, as well as expanded use of telehealth for additional Medi-Cal covered benefits and services when clinically appropriate.⁴⁸

In July 2022, Governor Newsom signed the California budget and related trailer bills, including the health budget trailer bill [SB 184](#). SB 184, among other things, implements the DHCS proposal regarding permanent Medi-Cal telehealth policies, including continued coverage of and payment parity for synchronous video, audio-only, and asynchronous telehealth modalities. It also ensures that providers using video or audio-only services also offer those services via in-person, face-to-face contact, or arrange for in-person care. Furthermore, DHCS must develop a telehealth research and evaluation plan by January 2023 that examines access and other issues using an equity framework that includes stratification by available geographic and demographic factors to understand inequities and disparities in care. These factors include, but are not limited to, race, ethnicity, primary language, age and gender.



Methods



Community-centered approach



In its work to promote equity and anti-racist values by creating avenues for people directly impacted by policy advocacy to contribute their experiences and knowledge, **The Children's Partnership launched this project to better understand the experiences of children of color with special health care needs and their families during pandemic shutdowns, including their struggles and their ability to use telehealth to continue accessing health care and services.** This project included qualitative and quantitative components that were 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. The components included partnering with community-based organizations to recruit families of color in target regions whose children had special health care needs and coordinating and hosting bilingual virtual convenings that included in-language virtual

listening sessions, as well as creating and helping families complete an online bilingual survey.

TCP also used strategies that sought to share power with families and make this research meaningful, inclusive and adaptive to their needs and circumstances. In an effort to address structural issues that may impede families' participation and value families' time and expertise, families were provided with stipends. Family participants were also called individually to strengthen trust, answer questions around how to join the virtual sessions, and address Zoom and technology issues. Family-focused telehealth resources in English and Spanish were also provided ahead of each convening. **TCP also reviewed each learning and recommendation with families and incorporated their feedback into this final report.**



Participants

TCP recruited families of color with children with special health care needs and other stakeholders who work directly with them. Stakeholders included families, health and mental health providers, community health clinics, county health and mental health agencies and public health departments, parent leaders from local student and family advocacy organizations, wellness centers, community health workers and promotores, schools, regional centers, churches, and family resource centers. Recruitment focused on three regions: Los Angeles County (Pomona), Tulare County and San Bernardino County. For more details, see *Appendix A – Regional Data*.

TCP partnered with community-based organizations and agencies in each region of focus to recruit families, focusing on organizations who serve mostly communities of color. Many of them led by people of color with lived experiences themselves, these community-based organizations included [East Los Angeles Family Resource Center](#), [Parents’ Place Family Resource Center](#), [Padres Con Poder](#), [Vision y Compromiso](#), [Gente Organizada](#), [Uncommon Good](#), St. Lourdes Church - Special Needs Children Support Group, [Lugonia Family Resource Center](#), [Franklin Family Resource Center](#), [Mentone Family Resource Center](#), and [Early Start Family Resource Network](#).

In total, TCP recruited 85 unique families to participate in this project. Once selected, the parents self-reported the health care needs of their children, which included physical, developmental, mental, and complex health conditions, specifically attention deficit hyperactivity disorder, oppositional defiant disorder, asthma, autism, Down syndrome, speech delays, epilepsy, STXP1, 1P36 deletion syndrome, depression, anxiety, compulsive disorder, cerebral palsy, diabetes, developmental delays, and dyslexia. Parents who participated in

this project, its listening sessions and reviewing the draft report, emphasized the importance of including their child’s special health care need in the quotes included across this report.

TYPES OF STAKEHOLDERS



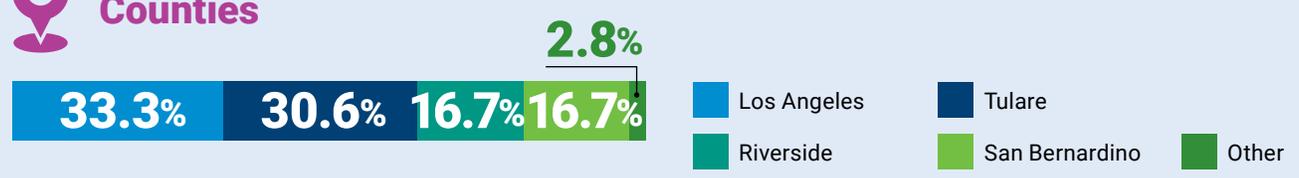
 Families	 Health and Mental Health Providers	 Community Health Clinics
 County Health and Mental Health Agencies and Public Health Depts	 Parent Leaders from Local Student & Family Advocacy Orgs	 Wellness Centers
 Community Health Workers & Promotores	 Schools	 Regional Centers
 Churches	 Family Resource Centers	



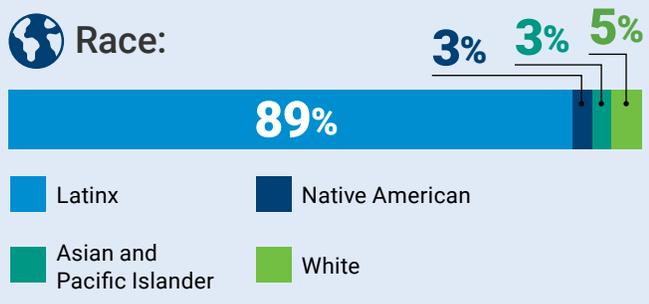


WHO ARE THE FAMILIES AND CHILDREN OF COLOR WITH SPECIAL HEALTH CARE NEEDS WHO PARTICIPATED IN THIS PROJECT?

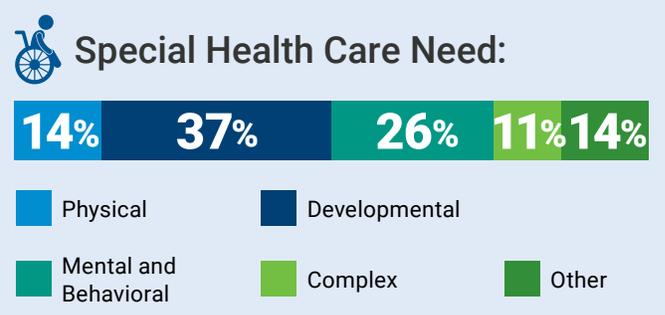
Counties



Families



Children



Language:



Age Range:

10 months – 34 years old

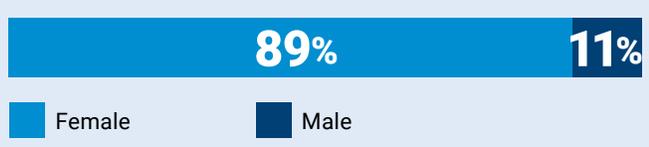
Age Range:

24 – 60

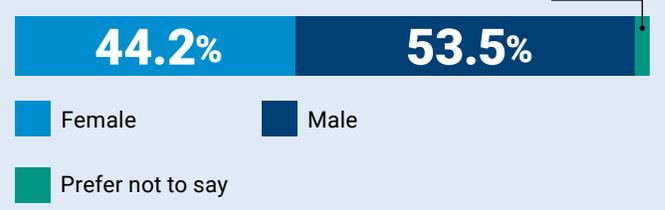
Grades:

Pre-K, K, 3rd, 4th, 6th, 7th, 8th, 9th, 11th, 12th, Adult School

Gender:



Gender:

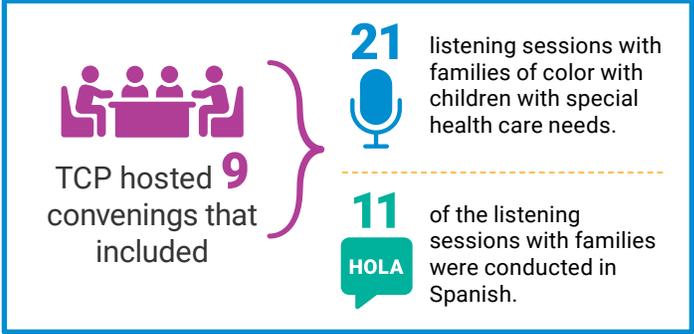


Source: Responses to Survey Questions at Appendix C.



Convenings, listening sessions, survey

During the spring, fall and winter of 2021, TCP hosted a total of nine convenings that included 21 listening sessions with families of color with children with special health care needs. About half of all the listening sessions with families (11) were conducted in Spanish. Listening session topics focused on the most urgent health and mental health needs of these children in each region, barriers in accessing health and mental health services that address those needs, the impact of the pandemic on children’s access to services and the rapid shift to telehealth, obstacles faced using telehealth to access care during the pandemic, whether telehealth adequately addressed a child’s special health care needs, and recommendations for policymakers to improve the use of telehealth and better support children of color with special health care needs.



Thirty-five families also completed an online survey, provided in both English and Spanish, to obtain additional details about families’ demographic information and their children’s experience with telehealth. The survey was conducted together with parents at the beginning of the second round of listening sessions and included questions that asked about family and child racial and ethnic background; accessing telehealth in general and during the pandemic; the modality used to access telehealth; technological, cultural and language barriers experienced; satisfaction with telehealth; preference for telehealth over in-person services; and other questions. For more details, see *Appendix C – Survey Questions*.



Limitations

This research is not meant to be representative of our state’s overall population of children of color with special health care needs and their families. Families of color who identify as Black, Latinx, Native American, Asian American, Native Hawaiian or Pacific Islander all have unique experiences interacting with the health care system. Furthermore, we intentionally took a community-centered approach to this research and the development of a policy agenda that may not conform to traditional research methods. Nonetheless, the learnings from participating families are valuable contributions from those most directly impacted to inform advocacy around policy changes to better meet the needs of children of color with special health care needs – a population that has historically not been centered in research or policy advocacy.



Learnings

The learnings from the listening sessions provide unique insights into the challenges faced by families of children of color with special health care needs and their experiences using telehealth during pandemic shutdowns.



1. Telehealth helped keep children of color with special health care needs connected to health services during the pandemic.



2. Telehealth addressed some challenges children of color with special health care needs typically face when accessing care, including lack of transportation, long wait times for appointments, and lack of child care.



3. Families indicated a strong interest in the option of having telehealth appointments for their children while at the same time noting that telehealth did not adequately address all special health care needs.



4. Families continued to face unique systemic challenges that limited their ability to access care for their children using telehealth, including digital, educational, language and cultural barriers.



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.



1. Telehealth helped keep children of color with special health care needs connected to health care and services during the pandemic.

Parents reported that the pandemic abruptly ended their child's existing access to providers, leading to a loss of health care services.

Families talked about how the shutdowns and rapid shift to telehealth led to their children losing access to services, some for significant amounts of time that were never recuperated. Compounding the loss of access, some health care providers were able to quickly use telehealth to continue seeing children with special health care needs while others provided in-person appointments only.

When the pandemic began, my daughter's physical and speech therapies were cancelled.

— MOTHER WITH DAUGHTER WITH DEVELOPMENTAL DELAY

Before the pandemic, my daughter had a 1:1 assistant in school for 6 hours each day and 5 days each week. When the schools shut down, no assistant was made available to help my daughter. All that work done by the assistant went to the parent who did all of the therapies at home. It is so unjust because even though her Individual Education Plan (IEP) required 1:1 aid, that was never given to her during the pandemic. And her telehealth appointment was only 30 minutes.

— MOTHER OF DAUGHTER WITH CEREBRAL PALSY AND AUTISM



[My daughter] lost access to some, not all of her providers during the pandemic. Her primary care doctor quickly jumped on telehealth and held our first telehealth visit in March, right when the shutdowns happened. She lost her services from her endocrinologist and therapist because they didn't have telehealth available, and it was difficult and frustrating. I'm extremely afraid of COVID, and I didn't want to take my child in, so we lost access to those doctors.

— MOTHER OF DAUGHTER WITH A GROWTH DISORDER

Some providers won't do telehealth because they wanted the appointment to be in person. But there are so many requirements for an in-person visit that inhibited me from having certain visits. I didn't want to take my child to an in-person visit, and they didn't want us there either. We lost access to those doctors and are still trying to get her back into seeing them. It was difficult and frustrating. I'm extremely afraid of COVID.

— COMMUNITY ORGANIZER IN POMONA AND PARENT OF TWO CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Some children of color with special health care needs were able to access a range of specialty providers using telehealth during the pandemic.

Parents from across all three regions reported that their children had telehealth visits with specialty providers such as a gastroenterologist, endocrinologist, neurologist and geneticist. Telehealth was also used for counseling and speech therapy as well as physical and occupational therapy. One parent reported having telehealth visits twice a week with various specialists for her daughter who has epilepsy.

“*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 MULTIPLE 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 a week. After she suffered a severe attack, she had more regular telehealth appointments with her neurologist.*”

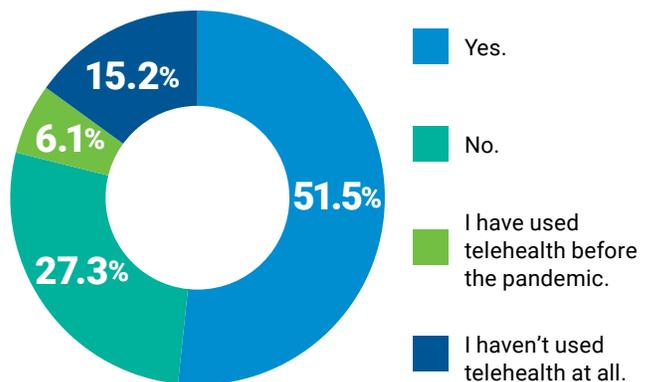
— MOTHER OF DAUGHTER WITH EPILEPSY



FIRST-TIME TELEHEALTH USERS

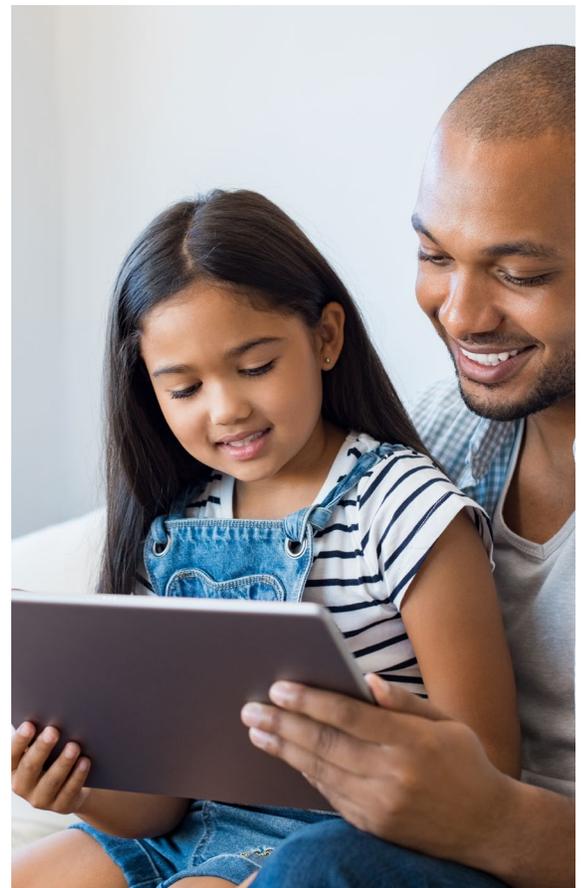
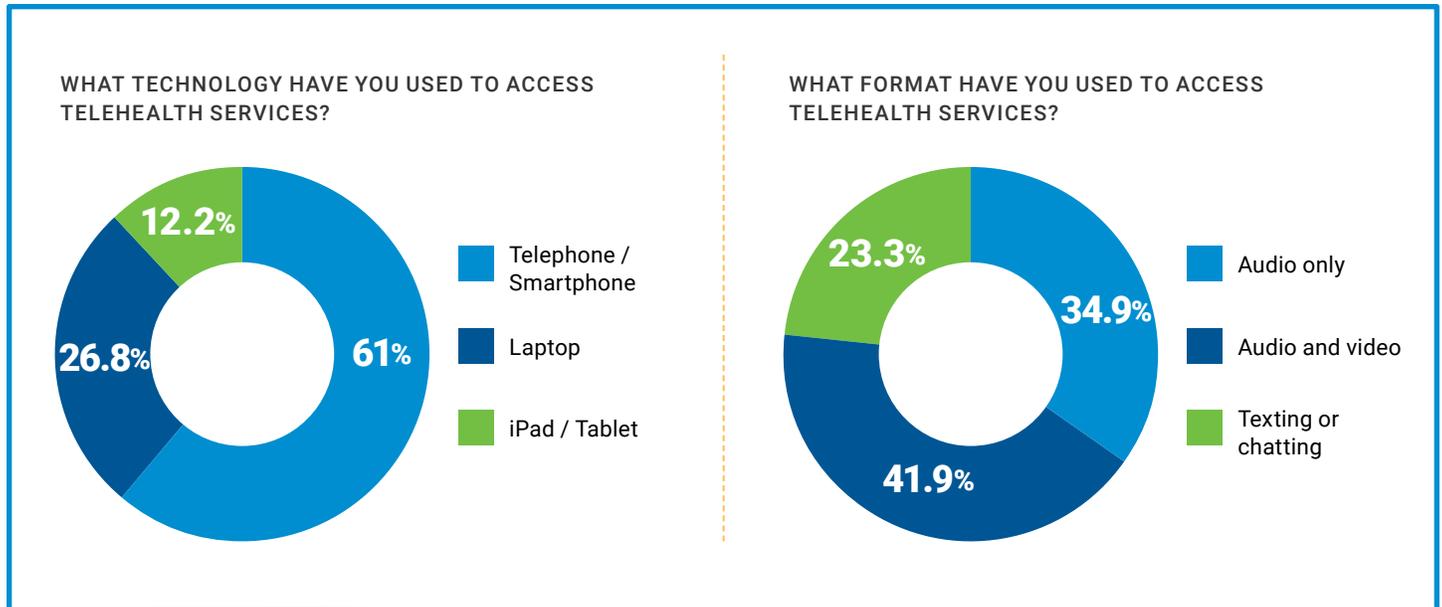
With the pandemic shutdowns, many children of color with special health care needs and their families found themselves using telehealth to access care and services for the first time. Over half (51.5%) of the families who participated in our listening sessions reported that they used telehealth for the first time during the pandemic.

DID YOU FIRST USE TELEHEALTH TO ACCESS SERVICES FOR YOUR CHILD DURING THE PANDEMIC BEGINNING IN MARCH 2020?



Families used multiple telehealth modalities to access care and services for their children.

Most families (61%) used their phone to connect to their child's provider offering telehealth. Less than one-third of families (27%) used laptops for telehealth appointments. In terms of format, 23% of families used texting or chatting for telehealth appointments, 35% used audio-only services, and 42% used audio and video services.





2. Telehealth addressed some challenges children of color with special health care needs typically face when accessing care, including lack of transportation, long wait times for appointments, and lack of child care.



Barriers related to transportation were greatly eased, saving families time and stress.

Parents reported that not having to travel was a huge benefit of telehealth, with some describing challenges including not knowing how to drive or not having reliable transportation and relying on complicated and exhausting public transportation routes to travel very long distances. Telehealth was also useful for those children who experienced anxiety when they traveled, found it challenging to interact with other people, or felt more comfortable and safer in a home environment.



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



My child is also sensitive to light and sound and experiences so it's difficult for him when we [physically travel to his] appointments. We can't use my car so we take the bus [for his visits]. In the bus he bangs his head.

— MOTHER OF SON WITH AUTISM

Appointments for their child were more easily scheduled and timelier.

Parents appreciated that telehealth often addressed long wait times for appointments and enabled their child to see their providers and access care and services much more quickly.

“

I think services improved for the better, I feel like it was easier to be seen via telehealth, 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

“

The biggest benefit for myself was being able to access services remotely, not having to be in the same city as the provider to get answers, being able to be seen quicker and have remote access and not having to be at home.

– MOTHER OF SON WITH AUTISM

Telehealth was helpful in addressing a child's acute needs.

Parents expressed that telehealth was especially helpful with small health issues.

“

If it is something physical, I would like to take him in person, but if it's just to get something small, like a runny nose, we would prefer to do it remotely.

– MOTHER OF SON WITH AUTISM



Telehealth was more accommodating to a family's specific needs around child care.

Prior to the pandemic, families noted experiencing difficulty because of policies that do not allow families to bring in siblings when their children have appointments because they would always have to find child care. Telehealth eliminated the need for child care; families with multiple children appreciated the flexibility that telehealth offered because siblings could continue to be in the home during appointments.



“

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



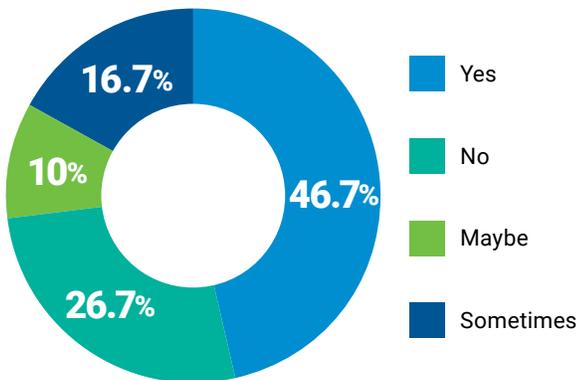
3. Families indicated a strong interest in the option of having telehealth appointments for their children while at the same time noting that telehealth did not adequately address all special health care needs.

Families shared that telehealth should be an option for all children, but it is not a substitute for in-person services.

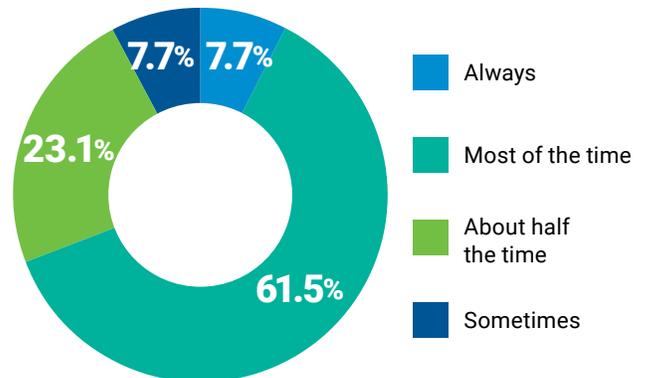
Results from our survey indicated that many families often prefer telehealth over in-person health appointments, particularly for discussing a child's progress or other scenarios that do not require interaction with the child. Over 1 in 2 (47%) parents affirmatively replied that were situations where they preferred in-person health appointments and wanted to have that choice. Of these parents, 61.5% preferred telehealth over in-person health appointments most of the time.

However, during our listening sessions, many families also indicated having a number of challenges utilizing telehealth to adequately assess and address all of their child's special health care needs described in more detail in the subsections below.

ARE THERE TIMES WHEN YOU PREFER TELEHEALTH INSTEAD OF IN-PERSON HEALTH APPOINTMENTS?



IF YES TO THE LAST QUESTION, HOW OFTEN DO YOU PREFER TELEHEALTH OVER IN-PERSON HEALTH APPOINTMENTS?



Children and families who do not do well when communication and interaction is limited to audio or video struggled with telehealth.

“

Telehealth is not the same as in person. Doctors tend to pay more attention to my child in person. For me, I communicate better in person about what's going on with my child.

– MOTHER OF DAUGHTER WITH AUTISM

“

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

“

My daughter is a bit shy/introverted and in her case she prefers in person meetings. She was going to see a psychologist regularly and she didn't want to attend anymore because they changed it to using computer and my daughter preferred to speak to her psych in person. My daughter is very shy so we are trying to figure out what is going on with her.

– MOTHER OF DAUGHTER WHOSE NEEDS ARE BEING ASSESSED

“

With telehealth, it was really challenging for doctors to understand her (my daughter) and she's four years old and want to ask her questions and her speech isn't that great its more like people who live with her can only understand her and so it was a lot of guessing on their side asking her stuff.

– MOTHER OF DAUGHTER WITH DOWN SYNDROME

“

Since my son is non-verbal, it was hard for him to communicate over a screen. Nobody ever really tried to accommodate that.

– MOTHER OF SON WITH NON-VERBAL AUTISM

“

I had an experience with my daughter who had an appointment to see a psychologist and she did not feel comfortable because it was not private virtually and did not feel the same like it would have in person. I feel like the doctor does not pay attention over the phone. It is uncomfortable and one does not feel confident to share anything.

– MOTHER WITH DAUGHTER WHOSE NEEDS ARE BEING ASSESSED

“

I guess my one-year-old is just moving around, so it's difficult to do it online. It may be easier to see her pediatrician in person. I am pretty sure she has a little bit of ADHD.

– MOTHER OF DAUGHTER WITH DEVELOPMENTAL DELAY AND CHRONIC EYE INFECTIONS

“

In person is better for my son receiving behavioral health services. When my son was doing BH services we had a gentleman come to the house to help. Being in person with some of his therapy needs were a lot better than doing them over telehealth. It was a lot better for therapy in-person kids with ADHD it's hard for them to keep focus. The BH coach was in person, and he came to the house. We did do some sessions via telehealth it was hard to get himself into it.

– MOTHER OF SON WITH ODD, ADHD-SPECIFIC LEARNING DISABILITY

“

Telehealth was very difficult for my daughter because she had trouble w/ attention. Zoom, text, phone, in my case with my daughter - none of that worked for me. My daughter's need required in person support - my daughter fell behind with telehealth. With my daughter, telehealth doesn't work. She needs more in person visits.

– MOTHER OF DAUGHTER WITH DYSLEXIA

Some children of color with special needs have health conditions that do not respond well to the use of technology to access care.

Families noted how children respond differently to technology as a result of their condition. For children with certain conditions, telehealth could cause confusion, delayed progress, or harm. For example, one mother spoke about the difficulty she faces utilizing telehealth for a child with epilepsy whose episodes are triggered by too much light. Another mother spoke about how her child with speech development issues struggled with telehealth, noting that the doctor could not clearly see her daughter's mouth movements to determine whether she was accurately using her muscles and that her daughter similarly could not understand her doctor.



“

The therapies that my child needs, they need to work with her mouth, the movements, the pronunciations and through a computer it's difficult for them to determine whether she's accurately using her muscles and its difficult for her to understand what [the providers] saying using telehealth.

— MOTHER OF DAUGHTER WITH A SPEECH AND LANGUAGE DELAY

“

Using telehealth was a challenge - zoom is 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.

The ability to use telehealth during the pandemic has not been equitable across families. More than a third of parents (38%) believed telehealth was either “somewhat difficult” or “extremely difficult” to use. Families faced a number of challenges they typically face in accessing care, whether in person or not, that also made it harder for them to use telehealth to access health care and services for their children. Digital inequities; lack of access to providers, translation and interpretation services; and information/education remain barriers.

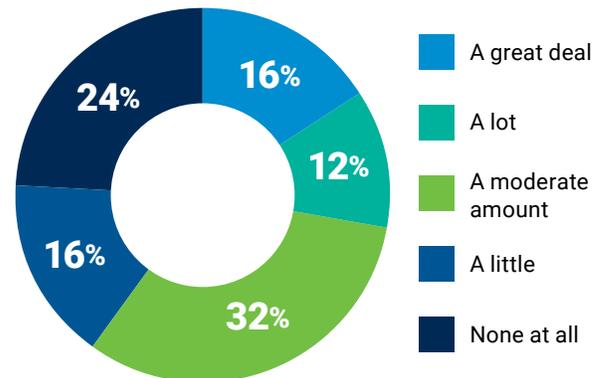
The digital divide faced by families of children with special health care needs greatly limited the benefit of telehealth.

More than half (60%) of parents experienced some technological barrier to using telehealth.



6 out of 10 families
experienced some sort of
technological barrier to telehealth

HAVE YOU OR YOUR CHILD EXPERIENCED ANY
TECHNOLOGICAL BARRIERS IN YOUR TELEHEALTH
EXPERIENCES?



Parents lacked the technology and digital infrastructure that telehealth requires. Many families mentioned not having access to broadband or Wi-Fi.

I live in a zone where the wifi fails a lot and the school has given us internet devices that are not that great. I do not have another source of internet because the companies tell me that they are not available in my location.

– MOTHER FROM TULARE WHOSE DAUGHTER’S NEEDS ARE BEING ASSESSED

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 had so many internet challenges; my internet would freeze a lot.

– MOTHER FROM POMONA

Not all families have internet at home. We’ve struggled with migrant communities going to Starbucks or sitting outside to get internet - even if telehealth, wouldn’t necessarily be able to access at home in a private setting.

– TULARE STAKEHOLDER WHO WORKS WITH FAMILIES OF COLOR WITH CHILDREN WHO HAVE SPECIAL HEALTH CARE NEEDS

Families also lacked the hardware necessary to successfully access care for their children using telehealth or had to share one device among many family members.

At first there were a lot of factors, we only have one computer. The school at first only allowed chrome books and so sometimes I needed to use my phone and doing the exercises over the phone was difficult. Through time, the school offered chrome books 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 and yes, it was very difficult in the beginning.

– MOTHER OF DAUGHTER WITH SPEECH DELAY



Insufficient information, education and tools were provided to families around accessing health care services using telehealth.

Telehealth relies on having access to the necessary technology and the ability to use it well. However, a number of parents received no explanation or instruction on the structure and logistics of a telehealth visit. They did not know what to expect before, during or after a telehealth visit and thus could not adequately prepare their children to be comfortable using technology to access care.

I wasn't explained how to use telehealth or if I had the right devices and apps to use telehealth. My child's doctor's office gave me the login info 5 minutes before the appt - the appointment was then cut short because they only give you a specific time and then when time is up it's up.

– MOTHER OF DAUGHTER WITH DOWN SYNDROME

They would give me the links and passwords to get on the call, not more than that. they probably thought I didn't need it because the rest of the world was using it.

– MOTHER OF SON WITH A GENETIC CONDITION

Some families were even asked to weigh their child or take their child's temperature during telehealth visits but lacked the tools to be able to do so.

In a telehealth appointment, my doctor asked me to take my daughter's temperature and weight but I didn't have a scale or thermometer. The doctor hadn't told me that I would need these tools before the telehealth appt. I was three months pregnant and had a 3 year old running around.

– MOTHER OF DAUGHTER WITH DOWN SYNDROME



Additionally, providers are using various telehealth platforms which may have different software, browser requirements, or methods for how to initially log in and use the platform for a visit.



Moving to telehealth was a huge challenge. It was difficult to understand. I started learning more to get more informed to understand how to use the technology. Not all doctors used Zoom, some used other programs. My son has a speech therapist once a week and we had to adapt to using telehealth for those visits. It was difficult.

– MOTHER OF SON WITH DYSLEXIA

Families had more positive experiences using telehealth when their doctor's office explained telehealth and how to access care for their children using it ahead of time.

“

Yes, I was satisfied with my experience with telehealth because my doctor's office explained everything to me and asked me if using telehealth to access care for my child was convenient for me.

— MOTHER OF DAUGHTER WITH EPILEPSY

“

The doctor explained telehealth to me and asked if I needed support with anything before our telehealth appointment. They also asked me which they explained and also asked her if she needed support. I also received a letter that asked about what modes of communication I used like video or phone and that I could call a phone number with an orientation about telehealth if I had any questions or needed help.

— MOTHER OF DAUGHTER WITH DYSLEXIA

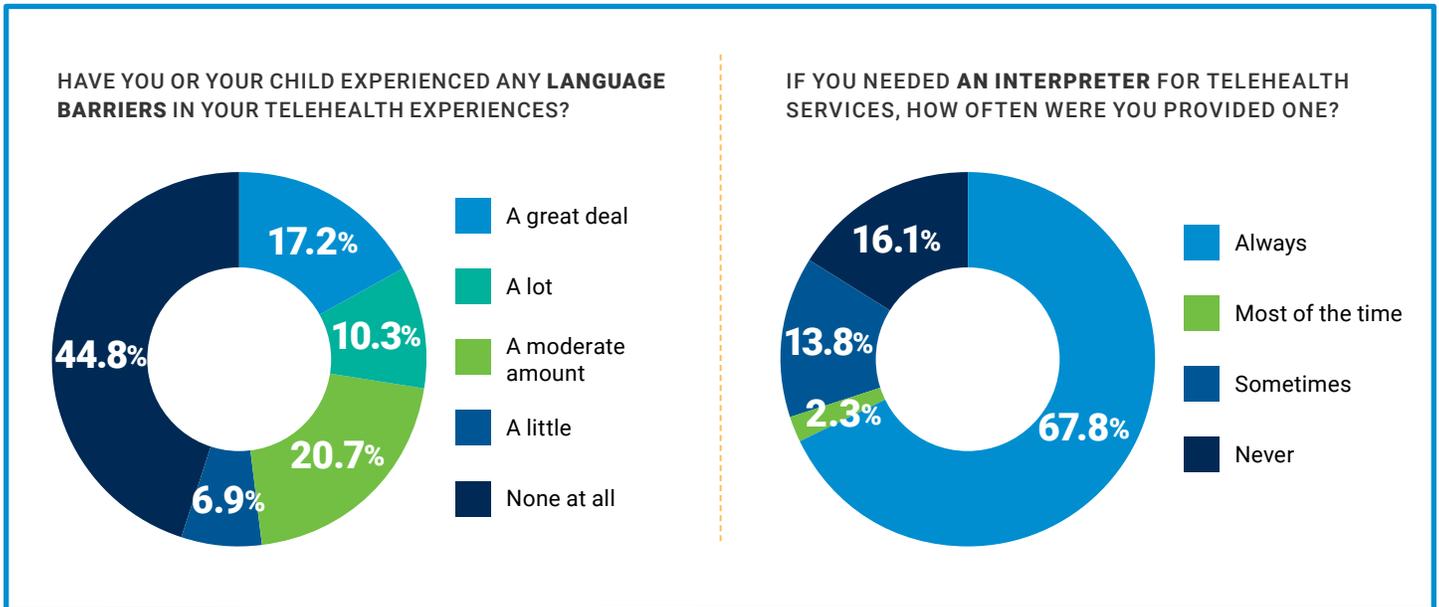
“

The doctor's office explained telehealth to me in Spanish. When it was a planned visit, they would send me a pamphlet ahead of the appointment that explained telehealth. That really helped me – that my doctor's office explained to me what telehealth is and how to use it.

— MOTHER OF DAUGHTER WITH EPILEPSY



Families experienced language barriers in accessing care and services for their children using telehealth.



Families of color with CSHCN noted facing language barriers, including difficulty accessing translated materials, interpreters and providers who speak their language. **52% of families reported experiencing language barriers in their telehealth visits, and over 1 in 3 (39%) of families sometimes or never were provided an interpreter for a telehealth appointment when they needed one.** Parents who do not speak English fluently repeatedly emphasized the difficulty they face in getting access to care and services in a language they and their child understand, both in providers who speak their native language as well as interpreters. **Multiple families noted asking neighbors or other family members (often siblings/other children) to translate for them during health appointments because they could not access an interpreter.**

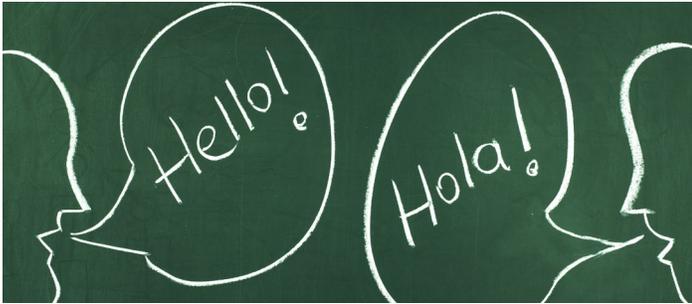
“*CCS [California Children’s Services] has never provided [me] a report in Spanish in 25 years. My child’s doctors will take notes with codes and it’s sometimes difficult to understand the next steps. Every health or social service professional speaks a lot in code which is not easy for parents to understand.*

– MOTHER OF THREE YOUNG CHILDREN WITH CEREBRAL PALSY

“*I think non-english speakers should be given more time for telehealth appts. I have translated for my mom during telehealth appointments with my sibling [who has a special need] at least 7 times. The doctor has never once asked my mom if she needs translation services, there’s an expectation that me or my siblings will translate for my mom.*

– MOTHER OF YOUNG DAUGHTER WITH DOWN SYNDROME WHO HAS A SIBLING WITH A SPECIAL HEALTH NEED

Some families also reported having to wait much longer for telehealth appointments when they requested interpretation services.



Families need access to interpreters. It takes a long time to get a telehealth appointment when I request Spanish interpretation, longer than if I don't [request an interpreter].

– MOTHER OF TEENAGE SON WITH DOWN SYNDROME

For those who had an interpreter during the telehealth visit, parents reported mixed results in how well interpretation worked during a telehealth visit compared to an in-person visit.



I don't speak English and sometimes when I tell the interpreter what to ask the doctor the doctor never responds to my question and I don't know if it's because I am not explaining myself well or if the interpreter is not translating what I am asking.

– MOTHER OF TEENAGE DAUGHTER WITH BEHAVIORAL HEALTH NEEDS

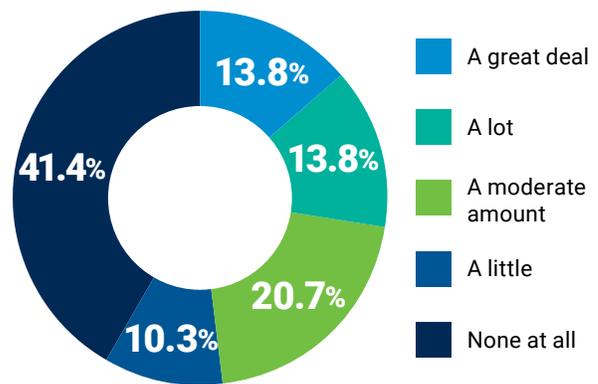


Lack of providers who reflect the identities of the families they serve.

Children of color with special health care needs, including those from immigrant communities, face barriers accessing culturally concordant/competent providers (providers who meaningfully understand or reflect families' racial/ethnic, cultural and linguistic identities), which continued in a virtual environment. 56% of families reported experiencing cultural barriers using telehealth.



HAVE YOU OR YOUR CHILD EXPERIENCED ANY **CULTURAL BARRIERS** IN YOUR TELEHEALTH EXPERIENCES?





Parents expressed a need for providers with a greater understanding of the immigrant experience and its impact on access to care and services.

“ We need programs that are focused in the Latino community that respond to issues facing documented and undocumented immigrant communities. ”
— MOTHER OF SON WITH AUTISM

“ [We] need more supports for immigrant families. It’s important to provide undocumented people with information and presentations [which] clarify that undocumented people can qualify for help for their kids who have special needs. Even though the parents don’t have documents, the kids can still qualify for certain services. ”
— MOTHER OF DAUGHTER WITH SPEECH IMPAIRMENT



Stakeholders also shared that there are sub-populations among their communities who remain hidden, making it a challenge to accurately identify the needs of the community. Listening session participants from Pomona in Los Angeles County shared that there is a lack of a cultural hub for Native American and Asian American and Pacific Islander youth, leading to a larger gap of culturally competent providers for these communities. Participants living in Tulare County mentioned the growing indigenous population of the community and the lack of services that exist that are specific to their needs.



PERSISTENT CHALLENGES CSHCN AND THEIR FAMILIES FACE

Throughout the listening sessions, parents shared a number of persistent barriers that children of color with special needs perpetually face. The barriers and quotes described in this box persist regardless of whether services are accessed in person or through telehealth. When discussing the accessibility of the system overall, families of color with children with special health care needs raised concerns that their children often face long wait times to access care. For some parents, the nature of their employment, such as agricultural work, does not align well with traditional health delivery schedules.

“ I am still waiting a long time for appointments to access my child’s doctor. It can take 1 month or 3 months waiting for my child to get an appointment. The [wait time] is three months to get an evaluation.

– MOTHER OF SON WITH AUTISM

“ Agricultural workers have long hours and can’t make the available appointments [to conduct initial intake for child with special health care needs].

– COMMUNITY STAKEHOLDER IN LOS ANGELES COUNTY (POMONA)

“ To get a doctor’s appointment, it takes a really long time. There is no help available to parents.

– MOTHER OF TWO SONS WITH SPECIAL HEALTH CARE NEEDS (ADHD AND DEVELOPMENTAL DELAY)

“ Wait time is a barrier. [We] have to go through referrals and get on a waiting list for actual services. Timing is a barrier – often [the doctor] does not accommodate parents’ schedules and [as a result] working parents have to request time off [from work] for [their child’s] appointments.

– MOTHER OF DAUGHTER WITH EPILEPSY

Finally, families also face transportation challenges when trying to access the health care system. Parents in all three regions identified the lack of adequate transportation as a barrier to their child accessing health care. Families shared that they may not have their own reliable transportation, or it is not available for all appointment times. Participants in Tulare County identified lack of adequate transportation as a significant barrier for children of color with special health care needs to access health care services.

“ Transportation is also a barrier because lot of families are farmworkers. They are often working in fields [and] may only have one car per family and they’re using it to go to work. The county’s bus system [only runs] every hour, not like in the city where buses run every 15 mins. There are clients in Porterville but [they] need services in Visalia or Tulare, which is an all-day trip for them, even though there is transportation available.

During the pandemic, there’s been an increase in the number of youth and adolescents being psychiatrically hospitalized. The nearest acute facility is Fresno, but most get sent to Ventura or San Jose Behavioral Health. Fresno is 45 minutes away when they have vacancies, which they don’t often have. Ventura or San Jose are both 4 hours away and some other facilities are even further away. It becomes difficult for parents to transport their children for health services. Youth can do telehealth while they are in psychiatric facility, but being in person would be much better to minimize symptoms. In our county, this is one of most urgent needs.

– TULARE COMMUNITY STAKEHOLDER



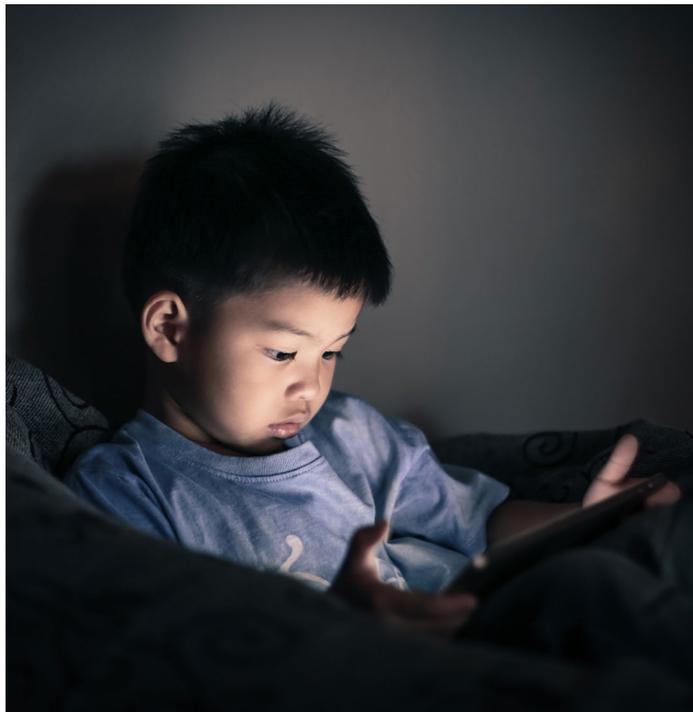
5. The pandemic caused instability, compounding and creating mental health issues and challenges for children of color with special health care needs and their families.

The pandemic confronted children and youth of color with special health care needs and their families with unprecedented interruptions, challenges and trauma, disrupting major elements of their daily lives. School closures not only disrupted daily activities and learning, but they also led to less physical activity, more screen time, and social isolation from peers. Stakeholders who work with children with special health care needs noted seeing an increase of depression, anxiety and suicidal ideation.

“

My son who is 7 years old was referred to a therapist because of his behavior. I feel that students who have behavioral issues do not receive a lot of resources and there is no empathy or understanding on behalf of the school. My son does not have friends. Sometimes he throws himself on the floor or has a tantrum not because he wants to but because he doesn't feel well. Sometimes students don't understand.

– MOTHER OF SON WITH AUTISM



“

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

– MOTHER OF DAUGHTER WITH AUTISM

“

Social isolation a contributing factor [to an increase in depression, anxiety]. Teens and children [are] missing their friends [and are also] isolating [themselves] from family. Parents [are] concerned and want to help their teens, especially [because of] so much screen time.

– COMMUNITY HEALTH CLINIC
STAKEHOLDER IN TULARE

Due to the impact of social isolation that children had faced for over a year, families repeatedly brought up the need to provide mental health services for children when they returned to school for in-person instruction. However, families and other stakeholders reported experiencing numerous hurdles when attempting to access mental health services. Parents expressed frustration with the lack of information, support or knowledge about existing mental health resources for their children with special health care needs. In particular, parents did not know which mental health resources may exist in their communities or how to access them, noting the need for better community outreach and engagement from their schools, districts and community providers.

“

There's a lot of people in our community who don't know that there are mental health resources and that there are free programs. Parents think that they need to decide between paying rent or paying for a doctor.

– MOTHER OF SON WITH DYSLEXIA

“

Children are very vulnerable and being locked inside all the time affects them. I am fighting for my daughter to get the professional therapy she used to get [at the school] before the pandemic [which] the school took away. I am also fighting [the school] to give her an hour and a half of speech therapy [like before the pandemic] because the school took away half an hour.

– MOTHER OF DAUGHTER WITH SPEECH DELAY

Parents also identified that it was rare to find a therapist who understood their culture and/or spoke their language and was easily accessible.

Even after the correct resources were identified, parents and other stakeholders who worked with children of color with special health care needs found it a challenge to navigate the different eligibility rules or requirements of each program or obtain referrals within and across silos that may exist between health providers, schools and other social services. If a referral was obtained, the lack of a warm handoff often prevented access to needed services. Even more frustrating was after learning about and trying to obtain a particular service for their child, they sometimes found that the resources no longer existed. Families felt like they were being tested, continually trying but often failing to get the services they needed.

“

From one day to the next, my son began to develop a lot of acne because of all the stress and anxiety he was going through. In schools, there isn't a lot of information about mental health. We need programs that are focused in the Latino community that respond to issues facing documented and undocumented immigrant communities. My son was affected a lot physically and emotionally. We need mental health programs that are consistent and aren't reliant on teachers wanting to participate.

– MOTHER OF SON WITH ANXIETY

“

My youngest daughter was diagnosed with depression. The school counselor guided me [to other resources], but I felt that I didn't get much support [helping my daughter with her diagnosis]. I had to go through [my] private insurance [for help]. It was upsetting [to get] no help at the school. What about other families [to find resources for their children]?

– MOTHER IN LOS ANGELES COUNTY (POMONA)

Policy Recommendations

All children of color with special health care needs and their families should have a fair and just opportunity to be as healthy as possible and thrive throughout their lives without discrimination and regardless of the circumstances in which they were born or live. Alarming, our learnings indicate that this is not the reality for many children and families. These high-level policy recommendations are rooted in the experiences and recommendations of families of color with children who have special health care needs. They intentionally seek to mitigate structural barriers that make it more difficult for these children and families to use telehealth and access care.

The policy recommendations are grounded in the learnings and recommendations shared by families who participated in this project. They are further supported by academic and policy research as key areas to address in order to advance child health equity for children of color with special health care needs. They are directed to and can be implemented by all systems and people that serve children of color with special health care needs. Ultimately, the recommendations seek to help ensure that children of color with special health care needs enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health and emotional needs, ensuring dignity, autonomy, independence and active participation in their communities.



1. Treat families of color with CSHCN as experts and center them in their children's care.



2. Allow CSHCN of color and their families to use multiple telehealth modalities to access health care.



3. Expand use and coverage of telehealth services to trusted places in the community including schools and early learning and care centers.



4. Provide families with outreach, education and resources that make it easier for them to use telehealth to access services and care for their children.



5. Use community health workers and promotores (CHW/Ps) to help families navigate telehealth and ensure CHW/Ps can leverage telehealth to provide outreach, education, navigation and other services to children and their families.



6. Ensure telehealth is racially, culturally and linguistically concordant.



7. Increase access to mental health services using telehealth.



In June 2022, the U.S. Department of Health and Human Services (HHS), through the Health Resources and Services Administration (HRSA), released [*The Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs*](#). The framework provides systemic recommendations to improve equitable access to care for children with special health care needs and their families. **The policy recommendations presented in this brief are supported by and advance the framework's four critical areas and**

key principles: health equity, family and child well-being and quality of life, access to services, and financing of services. This brief's policy recommendations further these areas and key principles by aiming to ensure that:

- ▶ All services and supports for children with special health care needs are designed and implemented to reduce health inequities and improve health outcomes. This includes addressing the upstream and downstream factors that inhibit CSHCN from a fair and just opportunity to be healthy.
- ▶ All services and supports for CSHCN at the individual, family, community and provider levels are easy for families to navigate when, where and how they need them.
- ▶ Child-serving systems should center and be responsive to the needs of children and families, not just diagnosis or treatment.
- ▶ Child-serving systems increase the ability of CSHCN and their families to access services by addressing administrative and other processes that hinder access.





1. Treat families of color with CSHCN as experts and center them in their children's care.



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 CHILD WITH AUTISM

Families of children of color with special health care needs should be seen as equal partners in their child's care, as well as in developing services and supports designed for their benefit. Family-centered care is care where the central role of the family is recognized and respected in the lives of children with special health needs.⁴⁹ Within this philosophy is the idea that families should be supported in their caregiving and decision-making roles by identifying, centering and building on their unique strengths.⁵⁰ Yet, learnings from our listening sessions highlight that families of color with CSHCN in California do not receive family-centered care.



California ranks last

in the nation in the percentage of children with special health care needs whose families experience shared decision-making with health care providers.⁵¹

Studies across the U.S. have found that parents of CSHCN who are Latinx or Black, or who have a primary language other than English, are significantly less likely to report having family-centered care or feeling like partners in their children's health care.⁵² Parents of Latinx and Black children have significantly lower odds of reporting that they feel that their providers spend enough time with their child, provide culturally

sensitive care, and help them feel like a partner in care, compared with parents of white CSHCN.⁵³ As broad changes that continue to allow additional Medi-Cal covered benefits and services to be provided via telehealth are implemented post-PHE, family-centered care should be recognized as a necessary component of the telehealth policy landscape.

Policies that recognize the importance of family-centered care and the need for children of color with special health care needs and their families to be active partners within care sectors include those that:

- ▶ Incorporate shared power and decision-making at all levels, including direct services and patient care, organizational design and governance, and systems-level programs and policies.
- ▶ Are directly informed by the families who are using those services to access health care while at the same time acknowledging the important role of providers.
- ▶ Offer families their choice of receiving health care services in person or using telehealth and retain the right to receive health care for their children in person. This includes creating reasonable limits on the length of time children and families have to wait to see specialty doctors in person or through telehealth appointments to address the long wait times CSHCN of color and their families often experience.
- ▶ Give children with special health care needs and their families more time in telehealth appointments so that they have more room to ask questions and engage in discussions with their child's provider.

“

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

“

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

– MOTHER OF DAUGHTER WITH DOWN SYNDROME

California should also create new forums or at a minimum add to existing stakeholder workgroups to actively seek feedback from families of color with special health care needs as a key consumer population from which to actively recruit feedback. For example, California will create a stakeholder advisory group of Medi-Cal beneficiaries (not targeted to specific populations) in late 2022 to help inform Medi-Cal policies specifically for children and families.⁵⁴ This group should include direct input from families of CSHCN of color who can illuminate various interventions or promising practices to test and tweak how telehealth services and policies can be more family-centered and best serve children of color with special health care needs. The California Children's Services program could also convene a telehealth stakeholder workgroup for families of color of CSHCN to identify policy barriers to wider adoption of telehealth and pursue solutions to these barriers. In addition, schools, health plans and providers can partner with community-based groups to bring the perspectives of families on utilizing telehealth to increase access to care and services.

NEW MEDICAID "HEALTH HOME" BENEFIT



In August 2022, the U.S. Department of Health and Human Services, through the Centers for Medicare & Medicaid Services (CMS), published guidance on a new Medicaid health home benefit for children with medically complex conditions like cerebral palsy, cystic fibrosis, epilepsy, blood diseases, and mental health conditions that can severely impact a child's ability to function. Children with medically complex conditions often require tremendous care coordination and highly specialized treatment. Finding needed services often requires traveling well beyond a family's home, and often care is only available for these children out-of-state. This new optional benefit provides children who have medically complex conditions with person-centered care management, care coordination, and patient and family support.





2. Allow CSHCN of color and their families to use multiple telehealth modalities to access health care.

Families should be able to use multiple telehealth modalities to access care and services for their children depending on the needs of their child and their access to high-speed broadband and technology. This includes video, audio or texting. Policies should be explicit that telehealth services can be offered through various types of technology and that the patient, not the provider, should be able to choose which type of technology he/she wants for every visit. Patients should be allowed to choose what method they would like to use for a telehealth visit well in advance of the appointment – such as at the time of scheduling the appointment – and be able to change the modality easily if needed.

To help encourage providers to offer a full range of modalities for a telehealth visit, policies should be updated to ensure that coverage exists for all modalities, and that reimbursement rates for

all telehealth visits are the same, regardless of which modality is used. For example, audio-only telehealth services were not reimbursable under Medicaid prior to the pandemic, and they only became more common when states reimbursed audio-only visits for at least some services as part of their post-pandemic flexibilities.⁵⁵ Most states made permanent their temporary Medicaid policies to reimburse providers for audio-only visits for certain services.⁵⁶ California's forthcoming updates to Medi-Cal telehealth policy is in some ways a promising policy because it not only allows payment parity between video and audio-only modalities, but it also requires that patients be able to choose their preferred modality.⁵⁷ However, certain reimbursement policies that limit the ability of providers to establish patients using telehealth and require providers to have live video capabilities may impede access to care.





3. Expand use and coverage of telehealth services to trusted places in the community including schools and early learning and care centers.

“

Parents value their school, so if more issues are addressed there, schools could be a central place of access. Even if telehealth is an option not all families would be able to use it because not all families have high-speed internet at home. During the pandemic, migrant families struggled and went to Starbucks and sat outside just to get internet.

— STAKEHOLDER FROM TULARE COUNTY

“

School based telehealth is the door to many more children having access to health and mental health services.

— STAKEHOLDER FROM POMONA



Another way to ensure equal access to health services offered using telehealth is to expand where children with special health care needs access telehealth services to community spaces. Ensuring telehealth services are accessible from locations where the necessary broadband and technology infrastructure is already in place, including schools, early learning centers and libraries, can help address the digital inequities experienced by families of color who have children with special health care needs that were highlighted in our learnings. These spaces are a common-sense place within communities to provide health care. Since the late 1960s, school-based health centers in the United States have been providing care in school settings, helping children and adolescents and their families overcome barriers that may prevent them from receiving needed health care services, including transportation, time, cost and lack of continuity of care.⁵⁸ School-based telehealth can deliver a variety of health care and subspecialty services including audiology, acute and chronic illness management, speech language therapy, psychiatric consultations, and dental examinations.⁵⁹





4. Provide families with outreach, education and resources that make it easier for them to use telehealth to access services and care for their children.



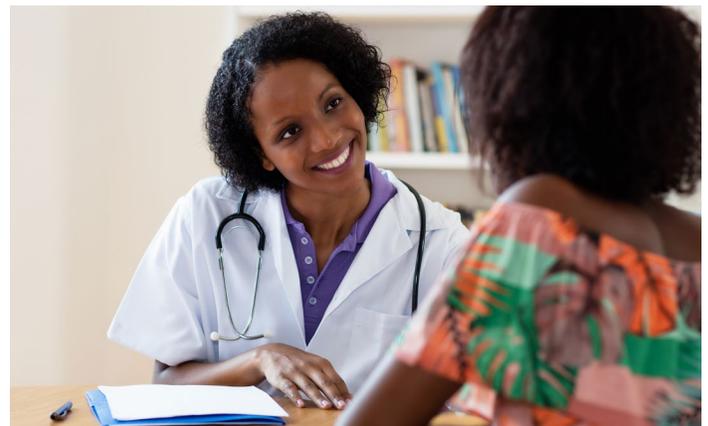
Cannot give technology without training, otherwise it's useless to families.

— MOTHER OF CHILD WITH A DEVELOPMENTAL DELAY

Education is a fundamental social driver of health that gives families the tools they need to be healthy and thrive.⁶⁰ Public health policymakers, health practitioners and educators, health care providers, health plans, and departments of health and education and school districts can collaborate to implement educational programs that help families navigate telehealth. Policies should require that families receive some kind of tutorial or educational guide — available in multiple languages — on the logistics of how to access the specific telehealth platform that the provider will use instead of assuming all telehealth platforms are the same or well understood.⁶¹ For example, families should be provided with step-by-step instructions on how to access telehealth via a mobile phone is included along with instructions for accessing service from a computer. The instructions should be in an easy-to-understand format that is vetted and designed by families

themselves rather than a dense, written manual. Where families do not have the correct tools or resources, they should be provided with a referral/warm handoff to organizations that can help. Extra time should be included in the initial telehealth visit to account for technological problems and to answer other logistical questions before beginning the clinical part of the visit. Providers should also notify families ahead of time if they will need to weigh their children, measure their temperature, or engage in other health-related activities during a telehealth visit that require families to have certain tools and provide them with those tools.

Policies can also require health plans or providers to inform CSHCN and their families regarding how and when they can request telehealth visits. Once an appointment for a telehealth visit is made, patients should receive both verbal and written information about what to expect before, during and after the visit. Finally, policies should require plans and providers to ask for feedback from patients after any telehealth visit on what challenges they experienced and what can be improved.





5. Use community health workers and promotores (CHW/Ps) to help families navigate telehealth and ensure CHW/Ps can leverage telehealth to provide outreach, education, navigation and other services to children and their families.

A number of the families we spoke with noted how they resorted to forming their own communities of support made up of parents who also had children with special health care needs when they found themselves facing difficulty navigating the health care system. They turned to these support groups – their peers – when they had questions or needed help, trusting and providing each other with information after the health care system had failed to do so. These experiences reflect the importance of integrating into the health care system a workforce made up of people who share the identities and experiences of children of color with special health care needs and their families.



There's a facebook support group for families with children with special needs called "capacidad diferentes" where we share important information and events.

– MOTHER OF SON WITH AUTISM



Promotoras have been so helpful in supporting 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

California has created a new benefit in Medi-Cal⁶² where CHWs/Ps will be able to provide services to children and families that focus on child health and development and will include many supports to help address several systemic barriers families mentioned during the listening sessions. CHW/Ps should be able to leverage this benefit to provide services utilizing telehealth that support children of color with special health care needs and their families, including:

- ▶ Health navigation to provide information, training and referrals that help children of color with special health care needs with accessing health care, understand the health care system, or engage in their own care, including understanding telehealth appointments.
- ▶ Connecting families to community resources necessary to promote the health of a child of color who has special health care needs, address health care barriers, or address health-related social needs.
- ▶ Serving as a “cultural liaison” and assisting a licensed health care provider to create a care plan for children of color with special health care needs and their families.
- ▶ Providing outreach and resource coordination to encourage and facilitate the use of appropriate preventive services.
- ▶ Providing screenings and assessment that do not require a license and that assist children of color with special health care needs in connecting to appropriate services to improve their health.
- ▶ Helping children of color with special health care needs enroll or maintain enrollment in government programs or insurance that is related to improving their health.
- ▶ Providing individual support or advocacy that assists children of color with special health care needs in preventing a health condition, injury or violence.

As part of this new benefit, CHWs should be able to provide these services using telehealth if needed as well as offer support for the use of telehealth to provide services to children and families more broadly. This would include providing CHWs with laptops and other hardware, dedicated training on new digital tools, technical support, reliable internet connectivity, and other administrative supports.



6. Ensure telehealth is racially, culturally and linguistically concordant.

“

Non-English speakers should receive additional support for telehealth visits. If they need translation, they should be guided step by step on how to get it. They should also be given additional time in telehealth appointments.

— MOTHER OF CHILD WITH DOWN SYNDROME

Racial, ethnic, and language concordance — the shared identity between patients and their health care providers — is a critical component of advancing child health equity by improving the patient-provider relationship and fostering trust and better communication.⁶³ Families and children having a health care provider of the same race, ethnicity, culture and language has been associated with a greater likelihood of patients agreeing to and receiving preventive care.⁶⁴



Telehealth policies can be made more concordant in several ways:

- ▶ Create programs that recruit providers and community health workers from communities of color who speak multiple languages.
- ▶ Policies should clarify that all existing health care requirements for providing culturally competent or concordant services also apply to telehealth services.
- ▶ Any written material provided to families with special health care needs regarding the needs of their child should be translated into the parent's primary language (e.g., CCS reports about a child's health care need).
- ▶ Co-create “Know Your Rights” materials and outreach campaigns with non-English families of color whose children have special health care needs regarding their rights to translation and interpretation.
- ▶ Allocate more time for a telehealth visit when an interpreter is used without additional cost to the family.
- ▶ Make requesting and obtaining an interpreter prior to a telehealth visit clear, easy and without causing unnecessary delay.

As use of telehealth expands, addressing structural barriers to care such as cultural and linguistic barriers in telehealth services will be critical for telehealth to fulfill its promise of a more equitable way to access and provide health care.



7. Increase access to mental health services using telehealth.

Traditionally, health care for children with special health care needs does not include a proactive focus on patient and family well-being and quality of life. Yet, our research and other studies revealed that parents and families of CSHCN often experience disruptions to family life, social isolation, and chronic stress, and have significant mental health and psychosocial support needs.

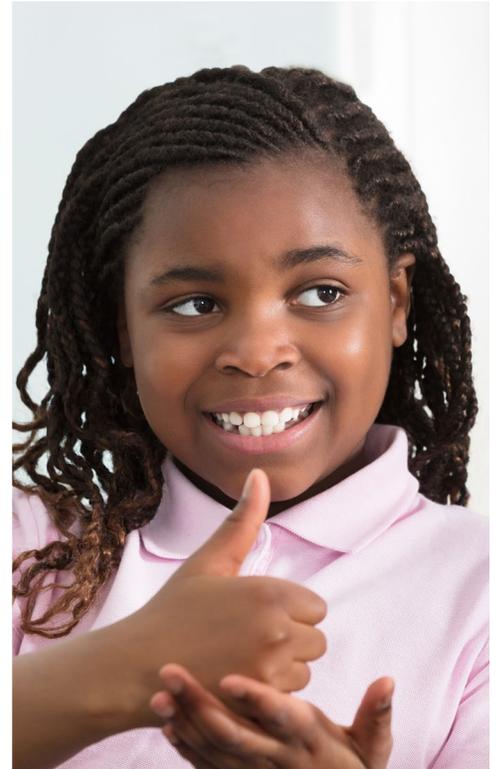
One way to increase mental health services for CSHCN is to increase the availability and funding for mental health services that are provided at school locations.⁶⁵ This may also have the benefit of normalizing the need to seek mental health care and avoiding some of the stigma currently experienced. Any new policy or funding that helps increase mental health access through telehealth must look closely at the mental health outcomes for CSHCN of color. In addition, more investment should be made to create both the pipeline as well

as training to increase the number of mental health providers who are also culturally and linguistically competent, work with CSHCN and are trained on telehealth best practices.

Expanded investments in telehealth and mental health services for CSHCN should also be coordinated with but not exclusively provided through a child's behavioral health or individualized education plan. CSHCN may very well be receiving services related to a disabling condition in order to ensure they can access and benefit from the learning environment. However, given what we have heard from families about their desires for improved quality of life, CSHCN and their families could benefit greatly from mental health services and dyadic care that serve to prevent child and family distress or mitigate the impacts of their health conditions on their social-emotional development and well-being.



Conclusion



Our work with families of color of CSHCN found multiple challenges facing families, hindering their ability to support the well-being of their children. While California has taken a number of important steps to reform its health care system to better serve its constituents, many of these reforms are not reaching those most marginalized, such as families of color of CSHCN. The recommendations presented in this report offer an opportunity to lead with equity by centering the experiences of these families. As the adoption of telehealth continues to grow, including families in telehealth policymaking and advocacy will help us create a more equitable health system that is responsive to the needs of children and families from marginalized communities.

As we observed and heard from the families in our work, making space for families:

- ▶ Shifts and shares power with people who have historically been excluded from the policymaking process.
- ▶ Encourages civic engagement such as self-advocacy that has positive and protective health benefits.
- ▶ Fosters structural and community competency among child-serving systems.

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. California has served as a leader in advancing telehealth policy and can continue to be by responding to and incorporating these family-centered learnings and policy recommendations.

Acknowledgments

The Children’s Partnership (TCP) is especially thankful to the families of children of color with special health care needs who participated in our listening sessions in English and Spanish, reviewing this report, and continue to engage with TCP to support all children of color with special health care needs in California. We are grateful for their willingness to share their stories and for the opportunity to center their voices in this report. It is their experiences, recommendations and advocacy that is the heart of this report.

We’d like to provide a special appreciation to our community partners who helped plan and also participated in our listening sessions: [East Los Angeles Family Resource Center](#), [Parents’ Place Family Resource Center](#), [Padres Con Poder](#), [Vision y Compromiso](#), [Gente Organizada](#), [Uncommon Good](#), [St. Lourdes Church - Special Needs Children Support Group](#), [Lugonia Family Resource Center](#), [Franklin Family Resource Center](#), [Mentone Family Resource Center](#), and [Early Start Family Resource Network](#) Thank you for all the work you do supporting families and children of color and working with TCP on this project.

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

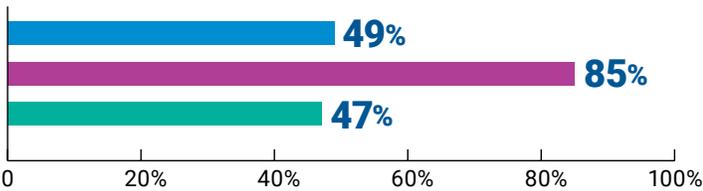
Regional Data

Identifying Participants by Region

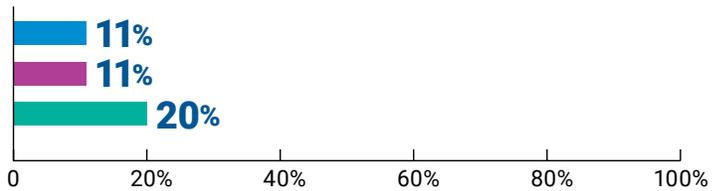
Based on the data below, TCP chose to talk with families from the following three regions: Los Angeles County (City of Pomona), Tulare County and San Bernardino County. All three counties had indicators of significant health care inequities and included children and families with identities that have been historically oppressed.

CITY OF POMONA **TULARE COUNTY** **SAN BERNARDINO COUNTY**

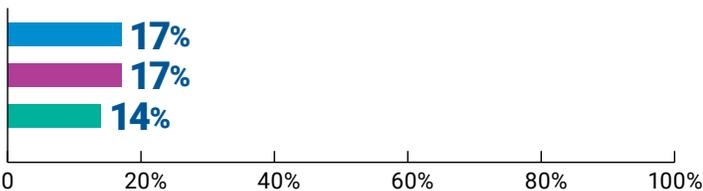
PERCENTAGE OF BLACK, LATINX, NATIVE AMERICAN, AAPI AND MULTIRACIAL CHILDREN THAT ARE ENROLLED IN MEDI-CAL



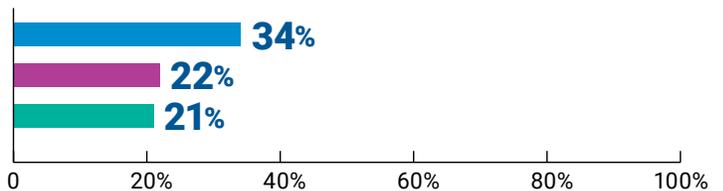
PERCENTAGE OF RESIDENTS THAT AVOIDED GOVERNMENT BENEFITS DUE TO CONCERN OVER SELF OR FAMILY MEMBER DISQUALIFICATION FROM GREEN CARD [VS. 9% AT STATE LEVEL (CHIS)]



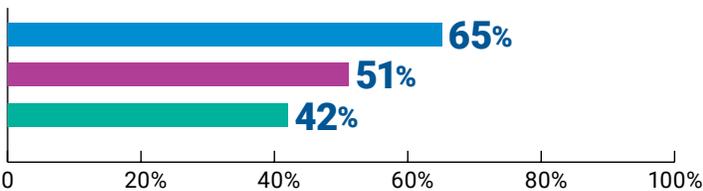
PERCENTAGE OF RESIDENTS LIVING IN POVERTY



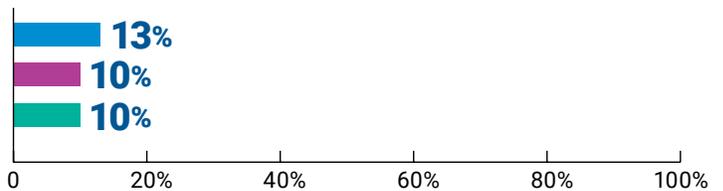
PERCENTAGE OF RESIDENTS THAT WERE BORN OUTSIDE OF THE UNITED STATES (2016-2020)



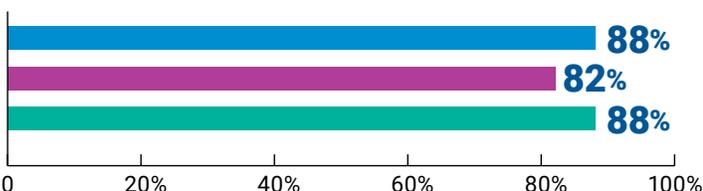
PERCENTAGE OF RESIDENTS OLDER THAN 5 YEARS THAT SPEAK A LANGUAGE OTHER THAN ENGLISH AT HOME



PERCENTAGE OF RESIDENTS UNDER 65 YEARS OLD THAT ARE UNINSURED



PERCENTAGE OF RESIDENTS THAT HAVE BROADBAND ACCESS



Data Sources: CA Health Insurance Survey 2020 and [U.S. Census](#)

Details of Listening Sessions

Listening Sessions

POMONA - MAY 2021

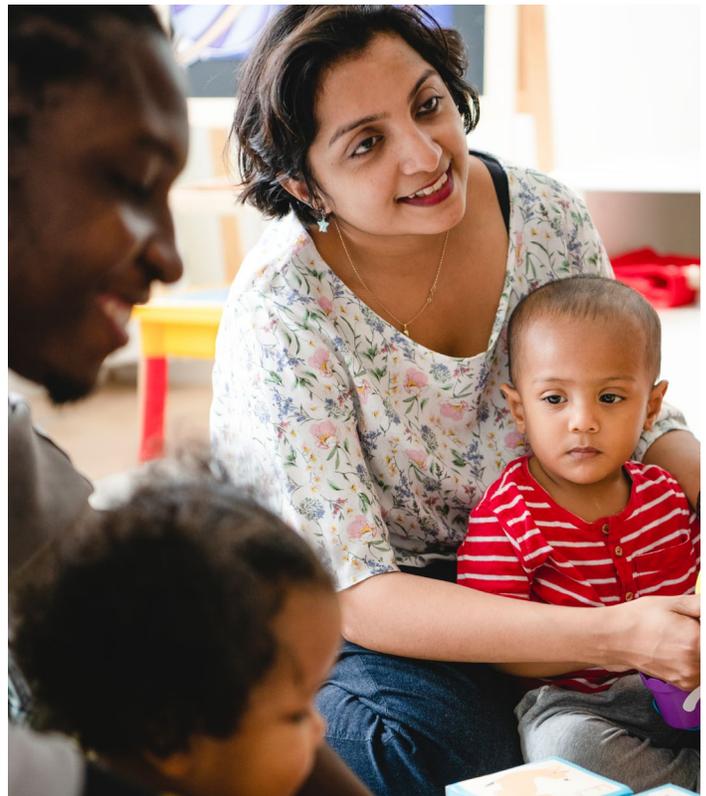
-  **37**
total participants
-  **25**
family stakeholders
-  **12**
CBOs / schools / providers

TULARE COUNTY – JULY 2021

-  **32**
total participants
-  **20**
family stakeholders (4 Spanish speaking)
-  **12**
CBOs / schools / providers

INLAND EMPIRE – SEPTEMBER 2021

-  **19**
total participants
-  **13**
family stakeholders (13 Spanish speaking)
-  **6**
CBOs / schools / providers



Survey Questions

Listening Session Survey Questions

TCP Telehealth for Children with Special Health Care Needs

DEMOGRAPHICS

What county are you located in?

- ▶ Los Angeles
- ▶ Riverside
- ▶ San Bernardino
- ▶ Tulare
- ▶ Ventura
- ▶ Other

What is your gender?

- ▶ Male
- ▶ Female
- ▶ Transgender / Gender Expansive / Intersex
- ▶ Prefer not to say

How many children do you have?

- ▶ (open)

How many of your children have special needs?

- ▶ 1
- ▶ 2
- ▶ 3 or more

What is your child's gender, with special needs? (check boxes)

- ▶ Male
- ▶ Female
- ▶ Transgender / Gender Expansive / Intersex
- ▶ Prefer not to say

What is your age?

- ▶ (open)

What is your child's age?

- ▶ (open)

What is your child's grade level?

- ▶ (open)

What is your race?

- ▶ White/Caucasian
- ▶ Hispanic/Latino
- ▶ Black/African American
- ▶ Native American/American Indian
- ▶ Asian/Pacific Islander
- ▶ Other

What is your child's race?

- ▶ White/Caucasian
- ▶ Hispanic/Latino
- ▶ Black/African American
- ▶ Native American/American Indian
- ▶ Asian/Pacific Islander
- ▶ Other

What is your current employment status?

- ▶ Employed full-time (40+ hours a week)
- ▶ Employed part-time (less than 40 hours a week)
- ▶ Unemployed (currently looking for work)
- ▶ Unemployed (not currently looking for work)
- ▶ Student
- ▶ Retired
- ▶ Self-employed

CHILD HEALTH CARE NEEDS

What kind of special health care needs does your child have?

Please check all that apply.

- ▶ Physical Health (cerebral palsy, cystic fibrosis, spina bifida, muscular dystrophy, amputations and loss of limbs, epilepsy)
- ▶ Developmental Health (autism, Down syndrome, Fragile X syndrome, any other genetic or chromosomal conditions)

- ▶ Mental and Behavioral Health (ADHD, anxiety, depression, Oppositional Defiant Disorder (ODD), Conduct Disorder, substance abuse, addictions, eating disorders, etc.)
- ▶ Complex Medical Needs (asthma, diabetes, etc.)
- ▶ Other

Please specify the specific health care needs of your child:

- ▶ (open)

Have you used telehealth to support the health care needs of your child?

- ▶ Yes
- ▶ No
- ▶ If yes, what kinds of services?

TELEHEALTH ENGAGEMENT

How familiar are you with telehealth?

- ▶ Extremely familiar
- ▶ Very familiar
- ▶ Moderately familiar
- ▶ Slightly familiar
- ▶ Not familiar at all

How many years have you and your child used telehealth?

- ▶ Zero, never used telehealth
- ▶ Less than 1 year
- ▶ 1 year to 2 years
- ▶ 2 or more years

Did you first use telehealth to access services for your child during the pandemic beginning in March 2020?

- ▶ YES
- ▶ NO
- ▶ I used telehealth before the pandemic
- ▶ I haven't used telehealth at all

How likely did COVID-19 encourage you and your child to use telehealth?

- ▶ Extremely likely
- ▶ Somewhat likely
- ▶ Neither likely nor unlikely
- ▶ Somewhat unlikely
- ▶ Extremely unlikely

TELEHEALTH NAVIGATION

How easy is it for you and your child to use telehealth?

- ▶ Extremely easy
- ▶ Somewhat easy
- ▶ Neither easy nor difficult
- ▶ Somewhat difficult
- ▶ Extremely difficult

What technology have you used to access telehealth services? (check boxes/not required)

- ▶ telephone
- ▶ laptop
- ▶ iPad/tablet/Microsoft notebook

Have you or your child experienced any technological barriers in your telehealth experiences?

- ▶ A great deal
- ▶ A lot
- ▶ A moderate amount
- ▶ A little
- ▶ None at all

Do telehealth visits with providers explain all the information about your child's healthcare needs to you?

- ▶ Always
- ▶ Most of the time
- ▶ About half the time
- ▶ Sometimes
- ▶ Never

Have you or your child experienced any cultural barriers in your telehealth experiences?

- ▶ A great deal
- ▶ A lot
- ▶ A moderate amount
- ▶ A little
- ▶ None at all

Have you or your child experienced any language barriers in your telehealth experiences?

- ▶ A great deal
- ▶ A lot
- ▶ A moderate amount
- ▶ A little
- ▶ None at all

If you needed an interpreter for telehealth services, how often were you provided one?

- ▶ Always
- ▶ Most of the time
- ▶ About half the time
- ▶ Sometimes
- ▶ Never
- ▶ Does not apply

If yes, how often do you prefer telehealth over in-person health appointments? (not required)

- ▶ Always
- ▶ Most of the time
- ▶ About half the time
- ▶ Sometimes
- ▶ Never

TELEHEALTH PREFERENCES

How satisfied are you with telehealth services currently?

- ▶ Extremely satisfied
- ▶ Somewhat satisfied
- ▶ Neither satisfied nor dissatisfied
- ▶ Somewhat dissatisfied
- ▶ Extremely dissatisfied

Are there times when you prefer in-person visits instead of using telehealth?

- ▶ Yes
- ▶ No
- ▶ Maybe
- ▶ Sometimes

If yes, how often do you prefer telehealth over in-person health appointments? (not required)

- ▶ Always
- ▶ Most of the time
- ▶ About half the time
- ▶ Sometimes
- ▶ Never

How do you best like to be communicated with about specific information regarding your child's health care needs?

- ▶ In-person
- ▶ Phone call or telehealth
- ▶ Letter by mail or e-mail

Endnotes

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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.