

Report

Realizing the Promise of Telehealth for Children with Special Health Care Needs



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The Children's Partnership (TCP) is a national, nonprofit child advocacy organization, with offices in Santa Monica, CA and Washington, DC, that focuses on ensuring that all children have the health care they need and that the opportunities afforded by technology benefit all children and families. TCP advances its goals by combining national research with community-based pilot programs and developing policy and advocacy agendas to take these demonstrated solutions to scale. For more information, visit www.childrenspartnership.org

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Executive Summary

or children with complex and chronic health conditions, access to the right health care is critical but often comes with an array of challenges. Obtaining access to timely coordinated care and necessary resources is often difficult, especially for families who grapple with financial or other types of challenges.

Telehealth—the use of technology to provide and coordinate health care at a distance—has proven to be an effective tool in making the types of specialized care and coordination needed by children

Telehealth holds considerable promise for meeting the diverse and unmet needs of CSHCN.

with special health care needs (CSHCN) more accessible. Telehealth is being used to provide quality care in areas such as behavioral health, neonatal care, disease management, and coordination of care.

Telehealth holds considerable promise for meeting the diverse and unmet needs of CSHCN. However, in California, providers and families are not using telehealth to its full potential. Given the needs of CSHCN

for specialty services, telehealth can often be an ideal option for bringing required care to children when available providers are scarce or mal-distributed, an issue that is especially acute in rural areas. In addition, telehealth can be used to assist in care coordination for children who have multiple needs for health care and support services. Finally, telehealth can play a critical role in helping children and their families monitor and manage chronic conditions on a regular basis.

Recognizing that telehealth is relatively underutilized and is not well understood by families and providers in California, The Children's Partnership, the Center for Connected Health Policy, and University of California, Davis, Children's Hospital developed this report to:

- 1. Outline how telehealth can be used to better meet the needs of CSHCN;
- 2. Understand how telehealth is currently being used to meet the needs of California's CSHCN;
- 3. Identify barriers to wider adoption of telehealth to better meet the needs of CSHCN; and
- 4. Provide recommendations to facilitate wider inclusion of telehealth as a care delivery option to improve the health and lives of CSHCN and their families.

Key barriers to wider adoption of telehealth include:

- Providers' lack of knowledge about and/or how to use and bill for telehealth;
- Families' lack of knowledge about the option to use telehealth;
- Lack of a mechanism for providers to bill for some services delivered through telehealth;
- Concerns by providers related to the costs and maintenance of telehealth equipment; and
- Concerns related to ensuring patient privacy.

Recommendations to overcome these barriers and further integrate telehealth into California's delivery system for CSHCN include:

Provide comprehensive telehealth information to providers

California Children's Services (CCS), the primary state program responsible for coordinating care for children with chronic medical conditions, should continue efforts to clarify, consolidate, and centralize information on telehealth for providers and conduct outreach to inform providers of its policies. Additionally, CCS should provide ongoing updates and training to providers on telehealth reimbursement policies, how to bill, and other issues that may arise when providing care to children enrolled in CCS via telehealth.

• Facilitate efforts to educate families about telehealth as an option for care

CCS should partner with community-based providers and family advocates who work with families of CSHCN to provide information to them regarding telehealth. CCS should also partner with other state entities that reach families with CSHCN to distribute information on telehealth.

• Expand the list of eligible billing codes for telehealth

Only a limited number of Medi-Cal/CCS codes associated with clinical services are eligible for reimbursement when delivered using telehealth. This leaves many services that providers are legally eligible to provide via telehealth ineligible for reimbursement. CCS should create a process that includes stakeholders to evaluate clinical services that can be delivered using telehealth and approve additional codes for telehealth reimbursement.

• Expand locations eligible for telehealth payment to include the patient's home

Because of the complex medical needs of CSHCN, home-based care is particularly critical. When feasible, administering clinical services in the home can alleviate a significant burden on families. CCS should make patients' homes eligible originating sites for telehealth reimbursement.

• Expand the number of telehealth modalities that are reimbursable by Medi-Cal and the CCS program

The Legislature and Administration should assess and update Medi-Cal/CCS reimbursement policies on an annual basis to include reimbursement for clinically appropriate telehealth applications. For example, store-and-forward and remote patient monitoring applications may be clinically appropriate in a variety of health care services; therefore, providers should be reimbursed for using these modes of telehealth to deliver such services.

Convene a telehealth stakeholder workgroup

CCS should convene a stakeholder workgroup to serve as a forum for CCS and stakeholders to identify policy barriers and pursue solutions to these barriers to wider adoption of telehealth for CCS-enrolled children.

• Implement local demonstration projects to identify best practices for how telehealth can be used to improve care for children enrolled in CCS

The State CCS program should work with county CCS programs and stakeholders to implement demonstration projects to bring care to children, identify lessons and best practices, and explore ways to make such applications of telehealth scalable.

Introduction

hildren with special health care needs (CSHCN) represent one out of every seven children in California, or about 1.4 million.¹ CSHCN are children who have, or are at risk for, chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that typically required by children.² As such, they often require multiple specialists, coordinated health care, and related services on an ongoing basis from a multidisciplinary set of providers.³ Additionally, because children with complex and multiple health care needs are often involved in multiple arenas of care such as schools, hospitals, government agencies, and community-based organizations, care coordination is a critical component of the care of CSHCN.

CSHCN often find their health care needs unmet due to a variety of reasons, such as provider shortages, lack of access to specialists, lack of affordable transportation, and other barriers. Further,

complications related to CSHCN's health care conditions often make it difficult for families to transport their children long distances. Finally, while care coordination is critical to effective care for CSHCN, nearly half of California's CSHCN who need such coordination do not receive it.⁴

Telehealth—the use of technology to provide and coordinate health care at a distance—has proven to be an effective tool in making the types of specialized care and coordination needed by CSHCN more accessible. Telehealth is being used to provide quality care in areas such as behavioral health, neonatal care, disease management, and coordination of care. Telehealth makes it possible for CSHCN to get the care they may otherwise go without, which is particularly important for families who live in rural areas far from large medical centers or pediatric specialist practices.

By allowing families to stay in their communities, telehealth makes it possible for CSHCN to get the care they may otherwise go without. This benefit is particularly important for families who live in rural areas far from large medical centers or pediatric specialist practices. Telehealth can be a cost-effective alternative to the traditional face-to-face model of care delivery. It can allow health care appointments to be more efficient—without compromising quality—while also reducing patient costs for travel and limiting absences from school and work for medical appointments.

Telehealth also can play an important role in facilitating coordination between and among providers, for example, by allowing a specialty provider in one location to connect and consult with a primary

3 Merle McPherson et al., "A New Definition of Children With Special Health Care Needs," Pediatrics 102 (1) (1998): 137-139.

¹ Children and Adolescent Health Measurement Initiative, *Children with Special Health Care Needs: A Profile of Key Issues in California* (Palo Alto: Lucile Packard Foundation for Children's Health, 2010); Dian Baker, Linda Davis-Alldritt, Kathleen Hebbeler, "Children with Special Health Care Needs: Lost at School?," (fact sheet, Sacramento State School of Nursing, California School Nurses Organization, Lucile Packard Foundation for Children's Health, March 2014).

^{2 &}quot;Maternal and Child Health Bureau Division of Services for Children with Special Health Needs," (fact sheet, US Department of Health and Human Services Health Resources and Services Administration), retrieved July 2014, http://mchb.hrsa.gov/about/factsheets/dschenfacts.pdf

⁴ Child and Adolescent Health Measurement Initiative, *Children with Special Health Care Needs in California: A Profile of Key Issues* (Palo Alto: Lucile Packard Foundation for Children's Health, 2013); Association of Maternal and Child Health Programs, "Models of Care for Children with Special Health Care Needs: Promising Models for Transforming California's System of Care," (Palo Alto: Lucile Packard Foundation for Children's Health, November 2009).

care provider who may be in another location closer to where the family lives. Telehealth has the potential to facilitate coordination and communication among all members of the care delivery

team. For instance, video conferencing can be used to connect a specialist, a primary care provider, a social worker, the child's school, and any other relevant providers to help improve a child's health and well-being. Finally, telehealth can help facilitate disease management by using computers, cell phones, and other devices to collect and track health indicators.

Telehealth holds considerable promise for meeting the diverse and unmet needs of CSHCN. However, in California, providers and families are not using telehealth to its full capacity. Recognizing that the telehealth option is neither widely available to families nor well understood by families and providers in California, The Children's Partnership, the Center for Connected Health Policy, and University of California, Davis, Children's Hospital conducted online surveys and interviews with key stakeholders and a literature review to:

- 1. Understand how telehealth is currently being used to meet the needs of California's CSHCN;
- 2. Highlight best practices for how telehealth can be used to better meet the needs of CSHCN;
- Clarify current policies related to the delivery of services through telehealth to treat enrollees in the California Children's Services (CCS) program (the primary funder and coordinator of health care for CSHCN in California);
- 4. Document where policy constraints exist in the CCS program that impede the wider adoption of telehealth to better meet the needs of CSHCN; and

Figure 1. Modes of Telehealth Delivery

- Live video conferencing (synchronous or "real-time"): Live, two-way interaction between a person (patient, caregiver, or provider) and a provider using audiovisual telecommunications technology.
- Store-and-forward (asynchronous): Transmission of recorded health history (for example, pre-recorded videos; audio files; and digital images, such as X-rays and photos) through a secure electronic communications system from the patient's location to a practitioner, usually a specialist, who uses the information to evaluate the case and provide consultation or diagnosis and treatment recommendations.
- Remote patient monitoring (RPM): Personal health and medical data can be collected from an individual in one location—via a smart phone or wearable device—and transmitted to a provider (sometimes via a data processing service) in a different location.
- **Mobile health (mHealth)**: Mobile devices—such as cell phones, tablet computers, and wearable devices— can also be used to promote, share, and expand health care, public health practice, and education.
- 5. Provide recommendations to facilitate wider inclusion of telehealth as a care delivery option to improve the health and lives of CSHCN.

What Is Telehealth?

California law defines telehealth as:

"The mode of delivering health care services and public health via information and communication technologies to facilitate the diagnosis, consultation, treatment, education, care management, and self-management of a patient's health care while the patient is at the originating site and the health

Ethan's Story

than, a 19-year-old man with autism living in Redding, California, has experienced improved quality of life due to the benefits of telehealth. Ethan began receiving psychiatry services via telehealth in 2002 at the age of six from a psychiatrist located in Los Angeles. Prior to this, Ethan's mother, Gina, drove Ethan great distances for in-person appointments. These long drives exacerbated Ethan's behavioral difficulties; and when he finally saw the psychiatrist, he would be overwhelmed and over-stimulated, often to the point of requiring medication. Gina said that the psychiatrist "just wouldn't really be able to see the true picture of who Ethan was in his normal setting or situation because he was so overwhelmed by the time we got there." Ethan's regular appointments became increasingly difficult and expensive due to travel, the cost of hotels, and time off work.

After the family was introduced to telehealth by a service coordinator from an organization that supports individuals with developmental disabilities, Ethan's experience dramatically improved. Gina and Ethan's trip to the clinic in Redding, where the telehealth session with the psychiatrist in Los Angeles would occur, now took less than 10 minutes. Gina recalls how much better this arrangement was for Ethan's progress in treatment. She feels that the interventions became much more appropriate because the doctors could see Ethan in a relaxed and natural state.

Ethan's telehealth arrangement also allows for effective collaboration and coordination between his psychiatrist and primary care physician. The psychiatrist conducts evaluations and sends the recommendations for medication to his local physician in Redding, who then writes the prescription. Ethan's physician orders the labs that are needed for medication management.

Ethan graduated high school and currently works in an inclusive competitive employment environment with a job coach assisting him as needed. With the consistent telepsychiatry appointments, medication management, and collaboration and coordination among his doctors, Ethan has been able to live his life as independently as he can.

(Interview with Gina Grecian, mother of Ethan, December 2014)

care provider is at a distant site. Telehealth facilitates patient self-management and caregiver support for patients and includes synchronous interactions and asynchronous store-and-forward transfers."⁵

Telehealth generally encompasses four distinct types of applications: live video conferencing, store-and-forward transmission of health information, remote patient monitoring, and mobile health (mHealth) (See Figure 1).

⁵ California Business and Professions Code, Sec. 2290.5.

California's System of Care for CSHCN

Various systems of care in California are designed to serve different segments of the CSHCN population. This report will focus on a narrower segment of the CSHCN population—those enrolled in the California Children's Services (CCS) program. The CCS program is the primary state program responsible for coordinating care for children with chronic medical conditions and primarily serves children in low-income families who have fewer resources to help them access care. Because CCS has the same telehealth reimbursement policies as Medi-Cal, this report will examine the policies of both programs. Private health plans and other payers set their own policies regarding the use of telehealth, which are beyond the scope of this report. Additionally, given that decisions about telehealth reimbursement in Medicaid programs are under the purview of states, federal policies are not addressed directly in this report. However, further exploration into the role the federal government could play in encouraging the use of telehealth to meet the needs of these children or providing more grant opportunities to spur movement would be useful.

Children with developmental or behavioral conditions are not included in the criteria for eligibility for CCS. Other agencies and systems—such as the Regional Centers administered by the California Department of Developmental Services—are dedicated to children with developmental care needs. As the primary payer for health care for CSHCN in California, CCS is in a unique position to promote the utilization of telehealth to meet the needs of this population.

California Children's Services: An Overview

California Children's Services (CCS), which serves approximately 184,000 children from birth to age 21, is a state-based program established to provide medical care for children with serious medical conditions as well as to ensure CSHCN are connected to the unique services they need.⁶ Examples of CCS-eligible conditions include cancer, congenital heart diseases, hemophilia, sickle cell anemia, infectious disease, cerebral palsy, spina bifida, cystic fibrosis, and diabetes (See Figure 2 for other eligibility criteria).⁷ CCS pays for services such as doctor visits, hospital stays, surgery, physical and occupational therapy, tests, medical equipment, and medical supplies. Case management also is provided, which includes coordinating care and referrals to other services.⁸

The CCS program is administered as a partnership between the California Department of Health Care Services (DHCS) and local CCS programs, which are housed at county health departments. CCS county-level administrators determine patient eligibility, evaluate needs for specific services, determine the appropriate providers, and authorize medically necessary care.⁹

Services for children enrolled in CCS are paid for by the county, state, and federal governments. Ninety percent of CCS-enrolled children also are enrolled in Medi-Cal, California's Medicaid program.¹⁰ CCS-enrolled children typically receive care for their CCS-eligible condition under CCS and primary health care services through Medi-Cal or private insurance plans.

CCS Providers and Facilities

All providers who treat children enrolled in CCS must be approved to do so by the CCS program.¹¹ Additionally, children enrolled in CCS may receive care only at a CCS-

Figure 2. CCS Eligibility Criteria

To receive services under CCS, a child must:

- Be under age 21.
- Be a resident of California.
- Be diagnosed with one or more eligible conditions such as: cancer; congenital heart diseases; hemophilia; sickle cell anemia; infectious diseases; cerebral palsy; spina bifida; cystic fibrosis; and diabetes.
- Have an annual family adjusted gross income under \$40,000 or out-of-pocket medical expenses exceed 20 percent of the family's adjusted gross income, or be enrolled in Medi-Cal.

Sources: California Department of Health Care Services, "California Children's Service Eligible Medical Conditions," accessed on February 12, 2015, http://www.dhcs.ca.gov/ provgovpart/Documents/CCS%20 eligible%20medical%20 conditions.pdf; California Department of Health Care Services, "Find Out if I Qualify," accessed February 12, 2015, http://www. dhcs.ca.gov/services/ccs/Pages/qualify.aspx

approved facility. Special Care Centers are one of the most common CCS-approved facilities. They are designed to meet the multiple and complex needs of CSHCN and employ multi-disciplinary, multi-specialty teams that develop and implement coordinated, family-centered care plans tailored to CSHCN's particular conditions and circumstances.¹² Special Care Centers are usually located within hospitals, particularly children's hospitals.

⁶ Family Voices of California, "CCS—The Nuts and Bolts of California Children's Services," (webinar presentation, September 10, 2014).

⁷ California Department of Health Care Services, "California Children's Services Eligible Medical Conditions," retrieved February 12, 2015, http://www.dhcs.ca.gov/provgovpart/Documents/CCS%20eligible%20medical%20conditions.pdf.

^{8 &}quot;Know the Benefits," California Department of Health Care Services, accessed August 1, 2014, http://www.dhcs.ca.gov/services/ ccs/Pages/benefits.aspx.

^{9 &}quot;Program Overview," California Department of Health Care Services, accessed August 1, 2014, http://www.dhcs.ca.gov/services/ ccs/Pages/ProgramOverview.aspx#description.

¹⁰ Family Voices of California, "CCS—The Nuts and Bolts of California Children's Services" (webinar presentation, September 10, 2014).

^{11 &}quot;CCS Provider Lists," California Department of Health Care Services, accessed August 1, 2014, http://www.dhcs.ca.gov/services/ccs/Pages/CCSProviders.aspx.

¹² Daphna Gans, Molly Battistelli, Mark Ramirez, Livier Cabezas, and Nadereh Pourat, "Assuring Children's Access to Pediatric Subspecialty Care in California," UCLA Center for Health Policy Research, April 2013.

California's Telehealth Policies

The CCS program is subject to the same parameters related to telehealth as Medi-Cal, necessitating a brief examination of Medi-Cal's telehealth policies to determine if there are any potential policy barriers to using the technology.

California was one of the first states to establish telehealth reimbursement through its Medicaid program, as a result of the Telemedicine Development Act of 1996. At the time, only live video conferencing was reimbursed by Medi-Cal until 2005, when store-and-forward telehealth consults for teleophthalmology and teledermatology were also made reimbursable. In 2011, the Telehealth Advancement Act of 2011 was enacted, which overhauled California's telehealth laws to keep pace with the rapidly evolving technology (See Figure 3). Most recently, in 2014, California authorized Medi-Cal payment for teledentistry via store-and-forward, through the enactment of AB 1174.

In order for providers to receive reimbursement under Medi-Cal and CCS for providing care via telehealth, they bill according to standard Medi-Cal practices, with the exception that they must add a special billing modifier to indicate that they provided the service via telehealth. In addition, the originating site—where the patient is, such as a rural clinic—is eligible to receive an originating site facility fee when telehealth is used. The facility fee was

Figure 3. Summary of Medi-Cal Telehealth Policies

For Medi-Cal patients (and by extension CCS):

- Services delivered via interactive audio, video, or data communication are reimbursed.
- Store-and-forward teledermatology, teleophthalmology, a narrow set of teleoptometry services, and teledentistry are reimbursed.
- Limitation on types of providers reimbursed.
- A specific set of codes are reimbursed.
- Remote patient monitoring is not reimbursed.

created to compensate for additional costs related to a telehealth visit, such as scheduling, setting up the equipment, and other related costs. Originating sites may also bill for a transmission fee to compensate for the telecommunications costs associated with a telehealth visit.¹³ Typically, the provider at the distant site (the specialist) will bill separately.

The Telehealth Advancement Act also allows the Department of Health Care Services (DHCS)—the state entity that administers Medi-Cal and CCS—to decide to apply certain restrictions around telehealth reimbursement, such as limiting the types of services that can be reimbursed. For example, Medi-Cal does not reimburse for care provided by telephone calls, electronic mail messages, or facsimile transmissions.¹⁴ Medi-Cal also has a specific list of types of providers who are eligible to receive Medi-Cal reimbursement and, therefore, who are eligible to receive reimbursement if they provide services via telehealth (See Figure 4). Unfortunately, as discussed later in this report, only certain services are eligible to be reimbursed through telehealth.

California Department of Health Care Services, "Medi-Cal Part 2 General Medicine Manual: Telehealth," (December 2013): 1.
Ibid.



* Not eligible to bill Medi-Cal for services, although some practitioners may provide Medi-Cal services under the supervision of a physician.¹⁵

While an examination of the state laws and regulations as they pertain to the CCS program and discussions with CCS state program administrators did not show legal or regulatory barriers to utilizing telehealth to deliver services to the CSHCN population, there appeared to be a lack of understanding about these laws and regulations by providers. Therefore, in December 2013, the CCS state office released official guidance to CCS program administrators, clarifying that services provided via telehealth are reimbursable under the CCS program through Medi-Cal's telehealth reimbursement policies.¹⁶

¹⁵ California Department of Health Care Services, "Medi-Cal and Telehealth," (webinar presentation, December 26, 2013).

¹⁶ Robert J. Dimand, "Telehealth Services for CCS and GHPP Programs," (Numbered letter 14-1213, California Department of Health Care Services, December 31, 2013).

How Telehealth Is Being Used to Meet the Needs of CSHCN in California

Methodology

To assess why the utilization of telehealth to meet the needs of CSHCN has not been more fully realized and to assess the experiences with telehealth of families, providers, and CCS county administrators, online surveys were administered to: one California chapter of the American Academy of Pediatrics; members of the Children's Specialty Care Coalition (CSCC)—a non-profit representing more than 2,000 California pediatric subspecialists; and county-level CCS administrators. In addition, interviews were conducted with more than 40 stakeholders—including health care providers, family advocates, families with CSHCN, state and local administrators, health plans, children's hospitals, and community-based support organizations. A full list of interviewees can be found in the Appendix.

Results

Provider Surveys

The majority of the 151 total respondents were pediatric physicians, either primary care providers or subspecialists. Of the 151 respondents to the provider surveys, 142 identified as clinicians, and 53 of those (37 percent) indicated that they were utilizing telehealth in some way. The over-whelming majority are using live video conferencing as their mode of delivery. Several common themes emerged from both the surveys. Most providers understood that telehealth has the potential to bridge gaps in care for CSHCN. However, of survey respondents who responded to the question regarding the barriers to using telehealth, over 50 percent felt that lack of time, information, payment, understanding of billing, and availability of specialists, as well as the the expense of equipment, limited the adoption of telehealth in their practice (See Graph 1).



CCS Program Administrator Survey

A total of 44 respondents filled out the survey, representing 32 counties. Like providers, administrators were interested in learning more about how telehealth can be used to meet the health care needs of CSHCN in their communities. CCS administrators in rural counties consistently stated that telehealth would provide a great benefit, citing the prohibitive costs and inconvenience of travel to the nearest Special Care Center to access care.

However, many county CCS administrators do not even know if telehealth is being used. The survey indicated that a majority—over 60 percent—of county CCS administrators were not sure if their county is able to determine if a service is delivered through telehealth. Twenty percent indicated that they are not able to determine this (See Graph 2).

CCS administrators also cited lack of sufficient information about CCS policies regarding telehealth as an issue. In fact, many CCS county administrators were unaware of the billing guidelines in the Medi-Cal provider manual on telehealth, with 22 out of 39 respondents to the question stating that they were not aware of the document.

A higher percentage of respondents knew of two other policy documents released on the subject by DHCS: a letter to CCS administrators providing general information to CCS county programs about telehealth policies and information on relevant changes to the Medi-Cal provider manual section

on telehealth; and an informational bulletin on telehealth codes and modifiers¹⁷ (See Graph 3). The survey revealed that the overwhelming majority of respondents (32 out of 39) would be interested in state-sponsored training to learn more about telehealth and CCS-related reimbursement policies.





¹⁷ Ibid.; California Department of Health Care Services, Department of Health Care Services Children's Medical Services Network, "This Computes" (information bulletin 446), accessed February 1, 2015, http://www.dhcs.ca.gov/services/ccs/cmsnet/Documents/thiscomputes446.pdf.

Interviews with Stakeholders

Nearly 40 stakeholders were interviewed for this report. There was broad agreement among stakeholders that telehealth could offer many potential benefits to children with special health care needs. Much of the information obtained from these interviews focuses on the barriers to care faced by CSHCN and barriers to the adoption of telehealth. These issues are discussed in more detail later in this report. Stakeholders interviewed for this report emphasized the importance of providing information to and proper training on telehealth for health care providers as well as education on the telehealth option for families of CSHCN. There was also widespread agreement that billing issues were a significant challenge to the wider use of telehealth.

If there was broader communication about the availability of a telehealth alternative, I know many of the families of CCS children in Monterey County would choose that over their current choice of a half-day or full-day trek to Packard or UCSF (hospitals) for a 30-minute office visit.

> - Dyan Apostolos, California Community Care Coordination Collaborative, Monterey County

Telehealth in Action

Coordination of Care

The need:

Due to the complex, chronic, and potentially disabling nature of the medical conditions of CSHCN, this population often requires multiple coordinated health and related services on an ongoing basis from a multidisciplinary set of providers.

A telehealth solution:

The TeleFamilies Project, run by the University of Minnesota and Children's Hospitals and Clinics of Minnesota, used video conferencing to expand care coordination to children with high levels of medical complexity, including children with neurological impairment, heart conditions, and Down syndrome. TeleFamilies recruited 163 families of children with medical complexity from the children's hospital to participate in a randomized controlled trial. Families in one intervention group received care coordination services from a nurse practitioner via telephone; families in a second intervention group also could connect with the nurse practitioner using web-based video conferencing—telehealth. A control group received usual care, which included telephone triage by registered nurses.

Preliminary findings indicated that the families who received care coordination through telehealth from the nurse practitioner obtained more planned care, relative to emergency care, than the control group. The telehealth encounters with the nurse practitioner prevented 277 clinic visits and 27 Emergency Department visits over the course of the study. In some cases, families began accessing additional services because they were receiving care coordination, which led to the identification of unmet needs. Families who worked with the nurse practitioner via video conferencing indicated that they were getting their care coordination needs met more adequately than those in the control group (who received traditional triage services via phone). Benefits of video conferencing included involving more family members at the same time; in comparison to phone, video allowed for more involvement of fathers; and for the nurse, the technology was easy to use and it was helpful to be able to see the children in their home environment with family members present.

Citations:

Merle McPherson et al., "A New Definition of Children With Special Health Care Needs," Pediatrics 102 (1) (1998): 137-139.

Child and Adolescent Health Measurement Initiative, *Children with Special Health Care Needs in California: A Profile of Key Issues* (Palo Alto: Lucile Packard Foundation for Children's Health, 2013); Association of Maternal and Child Health Programs, "Models of Care for Children with Special Health Care Needs: Promising Models for Transforming California's System of Care," (Palo Alto: Lucile Packard Foundation for Children's Health, November 2009).

Wendy Looman (Associate Professor, University of Minnesota School of Nursing) in discussion with the authors, October 2014.

Wendy Looman et. al., "Care coordination for children with complex special health care needs: the value of the advanced practice nurse's enhanced scope of knowledge and practice," *Journal of Pediatric Health Care* 27 (4) (2013): 293-303.

Access to Subspecialty Care

The need:

The shortage of pediatric subspecialists can present a major barrier to care for CSHCN in California, particularly in rural areas. In addition, there is an uneven distribution of providers, as pediatric subspecialists tend to be concentrated in specialty care centers, which are usually located in high-density population areas.

A telehealth solution:

The California Tele-audiology Program (CTP) was established by the University of California, Davis to provide remote diagnostic audiology evaluations for infants who do not pass their newborn hearing screening. Using video conferencing, a pediatric audiologist performs evaluations while the infant remains in or near their home community. Specifically, the Northern California Hearing Coordination Center (HCC) identifies and refers all infants who do not pass their newborn hearing screen to the CTP. The audiologist uses a video conferencing unit and laptop computer to access and run the audiology equipment remotely to test the child. Trained assistants place probes, electrodes, an otoscope, or any other necessary equipment in the baby's ear, while the audiologist at UC Davis controls the equipment and conducts the testing.

Prior to the Tele-audiology Program, the HCC referred patients to the closest pediatric audiologists, which sometimes required up to 6 hours of one-way travel from the infants' local communities. The CTP provides this clinical service in a centrally located city in Northern California where services were previously unavailable.

Citations:

Daphna Gans, Molly Battistelli, Mark Ramirez, Livier Cabezas, and Nadereh Pourat, "Assuring children's access to pediatric subspecialty care in California," UCLA Center for Health Policy Research, April 2013.

Ann Simon (Audiologist, UC Davis Medical Center Tele-audiology program) in discussion with the authors, November 2014.

[&]quot;Pediatric Subspecialist Physician Shortages Affect Access to Care," National Association of Children's Hospitals and Related Institutions, accessed February 10, 2015, https://www.childrenshospitals.org/issues-and-advocacy/graduate-medical-education/factsheets/2012/pediatric-specialist-physician-shortages-affect-access-to-care.

Distance and Travel

The need:

For children with complex or chronic conditions, travel and mobility can present considerable challenges when it comes to getting care. Since most pediatric subspecialists are located in urban areas, families living in more remote areas often have to travel, accruing burdensome travel costs and missed work and school days. In addition, many children with CSHCN have behavioral or physical conditions that make traveling difficult.

A telehealth solution:

Connecting to Care in Redding, California has been using telehealth to meet the mental health care needs of children and adults who live in rural parts of the state that lack psychiatrists for the past seven years. In partnership with a Los Angeles-area medical center, Connecting to Care supports a local clinic in providing consultations via video conferencing with pediatric psychiatrists for high-risk children with autism spectrum disorder, bipolar disorder, seizure disorders, and other special health care needs. The partnership also developed a behavioral health program that brings in social workers, psychologists, and board-certified behavior analysts to observe children's behavior in a controlled setting via webcam. The providers observe the children, identify issues, and provide recommendations for their local provider to carry out. This collaborative model also includes case management services, and is able to provide up to 1000 consultations per year, without the children and their families having to travel great distances.

Citation:

Suzi Coleman and Mark Schweyer (Co-Executive Directors, Connecting to Care) in discussion with the authors, November 2014.

Remote Patient Monitoring

The need:

For children with chronic conditions, medical care often has to be frequent and consistent. Frequent doctor visits and tests can be prohibitive due to costs and related stress, especially for families with limited means. The ability to track and monitor diseases remotely offers numerous potential benefits, including reduced use of emergency care, cost savings, and improved quality of life.

A telehealth solution:

A randomized controlled trial studied the effectiveness of using smartphones to help patients manage their asthma. The program—called the Propeller mobile respiratory management plat-form—involves patients using sensor-equipped inhalers. For patients (adults and children) assigned to the intervention group, the sensors tracked inhaler use and data from the sensor, which was then synced to the patients' smartphone. The data could be accessed by the patients but was also transmitted to a server that allowed real-time monitoring by physicians. Automatic text or email alerts were transmitted directly to physicians and patients about any increase in inhaler use. The ability for physicians to do real-time monitoring helped them see immediate changes in the patients' conditions and make adjustments to their treatment plan accordingly. The study demonstrated marked improvements in physicians' ability to observe and respond to changes in patients' symptoms and make adjustments to treatment before any emergency care was necessary. For example, physicians were able to directly send notifications and messages to patients through the smartphone app. Patients also demonstrated a deeper understanding of their health condition and learned better self-management using the remote feedback. The program resulted in reduced asthma symptoms and improved asthma control.

Citation:

Rajan Merchant, Rubina Inamdar, Robert Quade et al., "Interim Results From A Randomized, Controlled Trial Of Remote Monitoring Of Inhaled Bronchodilator Use On Asthma Control, Symptoms And Management," *American Journal of Respiratory and Critical Care Medicine* 189 (2014), accessed April 29, 2015, doi:10.1164/ajrccm-conference.2014.189.1_MeetingAbstracts.A1386.

Barriers to Wider Adoption of Telehealth for CSHCN

Providers' Lack of Understanding of How to Use, Bill for Telehealth

Health care and other support providers reported that a lack of knowledge regarding telehealth as an option for care was one of the main barriers to using telehealth (See Graph 1). For providers who are familiar with telehealth and are considering integrating it into their practice, a lack of understanding and clarity around billing is a major concern, as indicated by the provider surveys. This lack of understanding and clarity persists, despite the steps CCS has taken to disseminate information to providers regarding telehealth reimbursement.

Providers may lack information because there is no one centralized source of information for telehealth policies in the CCS and Medi-Cal programs. Recently, the California Department of Health Care Services (DHCS) updated its website (http://www.dhcs.ca.gov/provgovpart/Pages/Telehealth. aspx) to include more information regarding telehealth and Medi-Cal, but information still remains difficult for providers to find. The documents issued by CCS for guidance on telehealth provide general information and refer to the telehealth section in the Medi-Cal provider manual for the detailed policy. While most information is located in the telehealth section of the Medi-Cal provider manual, the information is not complete. For example, providers relying solely on information from the manual would not have a complete list of the types of providers who may utilize and receive payment for telehealth services in the Medi-Cal program.

Families' Lack of Understanding of Telehealth as an Option to Serve CSHCN

Families have even fewer resources to access information regarding telehealth than providers. Many do not know what telehealth is or that it is an option for receiving some types of care. CCS state and county programs do not distribute any information regarding telehealth directly to families. Representatives from several family advocate organizations indicated that they were unaware that telehealth was an option for receiving services or that telehealth services could be available through the CCS program. Families who are familiar with telehealth tend to learn about it from their providers.

I do not believe families are aware. I think what may be the best way to get them involved is if the physicians are also on board and can be as informative to families as possible on the benefits and/or convenience [of telehealth]. It is a decision that families and physicians both need to be comfortable with for this to be successful.

- Kausha King, Parent Liaison, CARE Parent Network, Contra Costa County

Barriers Related to Provider Reimbursement

Surveys and anecdotal information from various providers reveal constraints to receiving reimbursement for telehealth provided to children enrolled in CCS, with the two primary barriers being "lack of payment" and "lack of understanding and clarity around billing."¹⁸

Billing Codes

The biggest barrier to providers using telehealth is the lack of a mechanism to bill for services delivered via telehealth. For the most part, submitting a claim for a telehealth service in Medi-Cal/CCS should be quite similar to submitting a claim for a service performed in person.¹⁹ The same Current Procedural Terminology (CPT) and Healthcare Common Procedure Coding System (HCPCS) codes are used to describe the services, products, or supplies used. The only difference when using telehealth is that a modifier must be included to indicate telehealth was used.

However, Medi-Cal's telehealth section of the provider manual only lists a limited number of CPT codes that are reimbursed if a service is provided via telehealth.²⁰ These codes are only a small fraction of the many codes that a provider may bill for in the Medi-Cal and CCS program. Therefore, if a provider attempts to bill for a service provided via telehealth using a code that is not one of the eligible codes under the telehealth section, the claim will be rejected. DHCS has indicated that providers can use an office visit or consultation code to bill for that specialty visit if that specific code is not one of the approved codes for telehealth. However, often the office visit or consultation code pays a lesser amount than a specific specialty code, which not only results in a smaller payment to the provider, but also inaccurate documentation of the visit.

This situation creates especially complicated issues for those specialists who must use very specific codes to bill for their professional services. Audiologists, for example, are providers whom Medi-Cal has stated are eligible to use telehealth to deliver services. However, their codes are not among the listed eligible telehealth codes that may be reimbursed if the services are provided via telehealth. This situation presents an audiologist with a challenge. Audiologists are eligible to use telehealth to provide services, but they are prevented from claiming reimbursement for these services because their billing codes are not among the eligible codes that are used when submitting a Medi-Cal claim. The alternative may be to submit billing as an office visit and get paid far below cost, something which providers are unlikely to do.

Representatives from CCS have indicated that they are examining this issue as it relates to audiologists, but they have not provided a timetable as to when this situation may be resolved and currently note that this service will not be covered at this time if it is delivered via telehealth.²¹ While the fact that CCS is examining the issue is encouraging for audiologists, other subspecialties have also confronted similar challenges.

^{18 &}quot;Use of Telehealth and CSHCN" (online survey administered to the Children's Specialty Care Coalition by the authors, July 2014).

California Department of Health Care Services, "Medi-Cal Part 2 General Medicine Manual: Telehealth," (December 2013): 1.
Ibid.

^{21 &}quot;Medi-Cal Special Program FAQs," California Department of Health Care Services, accessed February 1, 2015, http://www. dhcs.ca.gov/provgovpart/Pages/FAQ-Telehealth-Programs.aspx.

Ambiguity Around Where Services Can Be Provided

The law does not limit the type of setting where services are provided via telehealth, but there has been confusion over whether the home is an eligible location without the presence of a provider.²² No location restrictions are listed in the Medi-Cal provider manual, but DHCS has verbally indicated that telehealth cannot be reimbursed in a patient's home unless a provider is present with the patient. This lack of clarity has made providers hesitant to use telehealth to treat patients who are at home. Home care is especially important for children with complex and multiple health care needs, which often present formidable barriers to travel. Having this care delivered through telehealth can be a particularly useful, efficient, and cost-effective model of delivery.

Barriers Related to Equipment and Technology

Providers also expressed concerns related to the cost and maintenance of telehealth equipment such as digital cameras, video conferencing equipment, software, and electronic clinical instruments—as reasons for not using telehealth. In addition, some providers expressed the lack of high speed Internet, an essential component of telehealth, as a barrier. Finally, some survey respondents indicated the need for training on using telehealth technology and successfully incorporating it into their practice.

Concerns About Privacy

Many providers and families are unaware of how medical privacy laws might apply to telehealth and are wary of using telehealth because of such concerns. While there is no section of the federal Health Insurance Portability and Accountability Act (HIPAA) that specifically addresses telehealth,²³ providers are subject to the same HIPAA rules as they would be for in-person care. Unfortunately, there appears to be a lack of understanding about how providers can safely do this and protect patients' privacy. For example, providers are unaware of how to ensure that the technology used has proper encryption and that personal health information (PHI) is being treated with the same degree of care, according to the HIPAA rules, as would otherwise be required.

There is an unfortunately high level of confusion about HIPAA and telemedicine (another term used for telehealth). Education on this would be helpful.

- Anonymous respondent, AAP provider survey

²² California Department of Health Care Services, "Medi-Cal and Telehealth," (webinar presentation, December 26, 2013).

²³ Telehealth Resource Centers, "HIPPA and Telehealth," retrieved March 19, 2015, http://www.telehealthresourcecenter.org/sites/main/files/file-attachments/hipaa_for_trcs_2014_0.pdf.

Recommendations

Pelehealth has the potential to improve the lives of CSHCN and their families, while helping health care providers and support systems better serve their patients. It also has the potential to reduce costs both for the health care system and for patients. Where appropriate, providers and families should have the option to utilize telehealth to address health care and other support needs.

However, if the challenges to using telehealth are not addressed, this important tool will not fulfill its potential. While the CCS state office has a critical role in improving how it educates families and educates and supports local CCS administrators and providers, other stakeholders, such as health care providers, family advocates, children's advocates, and philanthropists—in partnership with CCS—also have a role to play in helping to ensure telehealth is integrated into health care and support systems for CSHCN and their families.

Provide comprehensive telehealth information to providers

CCS should continue efforts to clarify, consolidate, and centralize information on telehealth for providers and conduct outreach to inform providers of their policies. Placing all the information in a single, easily accessible location—such as the Medi-Cal provider manual—would give providers a constant point of reference. This should be done as soon as possible so that providers have the information they need to start billing for services.

Additionally, CCS should provide ongoing updates and training to providers on telehealth reimbursement policies, how to bill, and other issues that may arise when providing care to children enrolled in CCS via telehealth. For examples, CCS should consider providing information about telehealth to CCS administrators and providers on a regular basis—whether updates on policies or reminders and tips about how to bill for services provided via telehealth. This could be in quarterly newsletters or incorporated into information already provided to CCS administrators and providers. CCS also ought to explore conducting quarterly webinars for CCS providers and administrators about telehealth and to respond to questions providers may have about billing. Such outreach and education may prove especially useful in connecting rural providers with the resources they need to integrate telehealth into their practices.

As part of regular updates and webinars, CCS should share information with its network about resources that are available to help providers incorporate telehealth into their practices. For example, the California Telehealth Resource Center²⁴ can provide technical assistance to providers at no cost to assess how best to integrate telehealth into their care delivery systems. Additionally, The California Telehealth Network—a nonprofit entity supported by federal grants—helps providers in rural and underserved areas obtain subsidized broadband connectivity.²⁵

²⁴ The California Telehealth Resource Center (CTRC) is a federally funded program that can provide providers with technical assistance and information around developing and implementing telehealth programs. The CTRC can also provide onsite help in planning and training on the use of equipment. Their services are free as they are federally funded.

²⁵ California Telehealth Network, "2013 Annual Report," retrieved February 12, 2015, http://www.caltelehealth.org/sites/main/files/file-attachments/annual_report_final_12-11-13.pdf.

Facilitate efforts to educate families about telehealth as an option for care

CCS should partner with community-based providers and family advocates who work with families of children with special health care needs on a daily basis to provide information to families regarding telehealth. These are organizations that understand the unique needs of families and that families trust as sources of information about their children's care. Currently, CCS issues no information to families with children enrolled in CCS about the option of telehealth as a way to receive health care services. CCS also should partner with other state entities that reach families with CSHCN, such as the California Department of Developmental Services, to distribute information to families regarding telehealth.

Expand the list of eligible billing codes for telehealth

Many Medi-Cal codes associated with clinical services are not eligible for reimbursement if the service is delivered using telehealth. This presents a challenge for many providers who are legally eligible to provide services via telehealth, but either cannot get paid or have to bill a different code that results in a payment less than if the services were provided face-to-face. Medi-Cal should increase the number of codes that can be reimbursed if the service is provided via telehealth by working with stakeholders to assess the appropriateness of a service provided via telehealth and create a process to approve additional CPT/HCPCS codes as eligible for telehealth reimbursement.

Expand eligible locations to include the patient's home

According to the research conducted for this report, families of CSHCN are enthusiastic about using telehealth to allow greater access to services from a local community site or their homes. Because of the complex medical needs of CSHCN, home-based care is particularly critical. While not all clinical services can or should be administered in the home via telehealth, there are some that can be, while alleviating a significant burden on families. The Telehealth Advancement Act of 2011 gave Medi-Cal the authority to expand the originating site locations where patients can receive treatment. DHCS and, thus, CCS should consider making patients' homes eligible originating sites for appropriate health care and other support services.

Expand the number of telehealth modalities that are reimbursable by Medi-Cal and the CCS program

The Telehealth Advancement Act of 2011 was designed to recognize that technologies to improve the quality and access to care for individuals are growing at a rapid pace. However, the benefits of these technologies cannot be realized if there is no payment mechanism. The Legislature and Administration should assess and update Medi-Cal reimbursement policies on an annual basis to include reimbursement for clinically appropriate telehealth applications. Specifically, the services/ specialties that can be reimbursed through store-and-forward technology should be expanded, and reimbursement for remote patient monitoring (RPM) should be added.

Currently, store-and-forward teleophthalmology, teledermatology, and teledentistry are reimbursable by Medi-Cal. However, store-and-forward can also be used in other specialties that could greatly benefit CSHCN, such as endocrinology and neurology. Yet services in these specialties delivered via store-and-forward telehealth are not currently reimbursed, despite there being nothing in California law prohibiting Medi-Cal/CCS from doing so.

Additionally, RPM also can be a valuable tool to track the health of children with certain conditions and prevent unnecessary hospitalization by treating issues before they escalate into more serious conditions. However, RPM also is not currently reimbursed by Medi-Cal/CCS, and many telehealth providers do not utilize it in their practices. Reimbursing these forms of service delivery will encourage providers to utilize the technology to improve CCS-enrolled children's health.

Convene a telehealth stakeholder workgroup

There is great interest among providers, advocates, family representatives, CCS administrators, and other stakeholders to identify ways to use telehealth to bring health care and other services to CSHCN and their families. CCS should convene a stakeholder workgroup to serve as a forum to identify policy barriers and pursue solutions to these barriers to wider adoption of telehealth for CCS-enrolled children. The workgroup could be instrumental in advising and assisting CCS in educating providers, CCS administrators, and family advocates about telehealth. The workgroup should be used to explore the access needs of CSHCN, such as those living in rural areas, and how telehealth can address those needs. Finally, as members meet and share ideas, the workgroup will inevitably serve to spur innovation—such as ways to better use telehealth to coordinate care and monitor chronic conditions—as well as collaboration, with the goal of spreading the use of telehealth in ways that can truly make a difference for CSHCN and their families.

Implement local demonstration projects to identify best practices for how telehealth can be used to improve care for children enrolled in CCS

The State CCS program should work with county CCS programs and stakeholders to implement demonstration projects to bring care to children, identify lessons and best practices, and explore ways to make such applications of telehealth scalable. The stakeholder workgroup would advise the development and monitor the outcomes of these projects. The State, local CCS programs, and the stakeholder workgroup should work together to identify best practices and barriers from the pilots and work together to address the barriers so that telehealth can be used more widely to support the care of CCS-enrolled children.

Conclusion

Telehealth holds considerable promise as an effective and proven tool to help address the myriad of challenges families with CSHCN face in getting needed services and coordinated care—especially with the experience, technology expertise, and policy foundation in California on which to build. However, several components are missing: forward-looking reimbursement policies; education to providers, CCS administrators, and families about telehealth as a high-quality alternative to in-person care; and information and education about available resources for providers to receive assistance in adopting telehealth as a tool in serving CSHCN. By addressing the barriers outlined in this report, the State and stakeholders can help make sure that CSHCN and their families will be able to take full advantage of the benefits offered by these technologies that are transforming the broader health care system.

Now more than ever technology is available that can be utilized to benefit children with complex health needs and their families, while at the same time reducing health care costs. It is up to CCS, DHCS, and the Legislature—in partnership with stakeholders—to build on this momentum to help integrate telehealth into the health care delivery system for children with special health care needs and, as a result, improve the effectiveness of their care and their health outcomes.

Appendix: List of Stakeholder Interviews

Contact Name	Title	Organization
Bernardette Arellano	Director of Government Rela- tions	California Children's Hospital Association
Gary Baldwin	Deputy Director for Plan & Provider Relations	California Department of Managed Care
Angela Blanchard	Interim Executive Director	Children's Specialty Care Coalition
Janis Burger	Executive Director	First 5 Alameda County
Lisa Chamberlain	Assistant Professor of Pediat- rics (General Pediatrics)	Lucile Packard Children's Hospital Stanford
Kathy Chorba	Executive Director	California Telehealth Resource Center
Elizabeth Clark	Analyst	UC Davis Health System Patient Financial Services
Carol Cohen	Project Manager	Family Resource Network of Alameda County
Debbie Corlin	Chief Administrative Officer	Department of Pediatrics, Mat- tel Children's Hospital UCLA
Robert Dimand, MD	Chief Medical Officer	California Department of Health Care Services, Systems of Care Division (Cal- ifornia Children's Services)
Mary Doyle, MD	Associate Medical Director	California Children's Services, Los Angeles County Department of Public Health
Juno Duenas	Executive Director	Family Voices of California
Amy Durbin	Associate Director (Center for Government Relations)	California Medical Association
Chris Dybdahl	Senior Health Services Man- ager	Child Health and Disability Prevention Program and California Children's Ser- vices, County of Santa Cruz
Lishaun Francis	Associate Director	California Medical Association
Patsy Hampton	Project Director	California Project LAUNCH; WestEd Center for Prevention and Early Intervention

Contact Name	Title	Organization
Holly Henry	Research Program Manager	Lucile Packard Foundation for Children's Health
Patrick Johnston	President & CEO	California Association of Health Plans
Bill Kennedy, MD	Associate Professor of Urol- ogy	Stanford University Medical Center
Moira Kenney	Executive Director	First 5 Association
Kausha King	Parent Health Liaison	Parent Liaison, CARE Parent Network, Contra Costa County
Jim Knight	Assistant Deputy Director, Office of Federal Programs & Fiscal Support	Community Services Divi- sion, California Department of Developmental Services
Wendy Longwell	Parent Consultant	Rowell Family Empowerment of Northern California, Inc.
Pip Marks	Manager	Family Voices of California
Alyce Mastrianni	Program Development & Evaluation Director	Help Me Grow Orange County; Children & Families Commission of Orange County
Lisa Matsubara	Attorney	California Medical Association
Sunshine Moore	Senior Policy Analyst	California Association of Health Plans
Shelley Rouillard	Director	California Department of Managed Care
Christy Sandborg, MD	Vice President of Medical Af- fairs; Professor of Pediatrics; Associate Chair of Pediatrics	Lucile Packard Children's Hospital Stanford
Lee Sanders	Associate Professor of Pedi- atrics; Co-Director, Center for Policy, Outcomes and Preven- tion	Stanford University
Tim Shannon	Lobbyist, Government Rela- tions	Children's Specialty Care Coalition
Kathryn Smith	Associate Director for Admin- istration	USC University Center for Excellence in Developmental Disabilities, Children's Hospital Los Angeles

Contact Name	Title	Organization
Laurie Soman	Project Director	Children's Regional Integrated Service System (CRISS)
Barbara Swan	Program Manager, Assess- ment Center for Children	Exceptional Parents Unlimited Children's Center; Help Me Grow Fresno
Abbie Totten	Director of State Programs	California Association of Health Plans
Seleda Williams, MD	Public Health Medical Officer III	California Department of Health Care Services, Systems of Care Division (Cal- ifornia Children's Services)
Brian Winfield	Assistant Deputy Director, Of- fice of Community Operations	Community Services Divi- sion, California Department of Developmental Services
Jody Winzelberg, MD	Administrative Director, Pro- gram Growth and Innovation	Lucile Packard Children's Hospital Stanford

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