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Assuring Children's Access to Pediatric Subspecialty Care in California

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SUMMARY: This policy note explores disparities in access to pediatric subspecialty care in California by insurance coverage, geographic location, race/ethnicity, and language. Using the available literature and interviews with stakeholders, it identifies barriers to access, which include a potential shortage of trained pediatric subspecialists, gaps in care delivery, low reimbursement rates and payment levels, and lack of care integration. Innovative care delivery models for improving the capacity of pediatric subspecialty care, including expanded use of technology, team models of care, and standard care processes, are also examined.

The following recommendations are proposed to ensure adequate access to pediatric subspecialty care: increase the number of pediatricians specializing in pediatric subspecialties; address payment and reimbursement issues that impede the access of children with special health care needs (CSHCN) to pediatric subspecialty care; increase the capacity of pediatric subspecialists by better utilizing physician extenders and general pediatricians; improve access to telehealth services for pediatric subspecialty providers; improve the availability of pediatric subspecialty services to underserved populations; improve communication between general pediatricians and providers; develop benchmarks and collect accurate data on workforce supply; and assess the standards of care available to CSHCN in California.

The Importance of Pediatric Subspecialty Care

Given the unique developmental and emotional needs of children and adolescents, providing specialized care to pediatric populations presents a distinct challenge. Pediatric subspecialists are highly trained to treat children with complex, serious, rare, or chronic conditions. The view that adult subspecialists are an acceptable alternative

to pediatric subspecialists is based on the flawed idea that “children are simply small adults.”¹

Research continues to highlight the distinct characteristics of pediatric care.^{2,3} In addition to the physiological and cognitive differences between children and adults,³⁻⁵ recent research has documented the unique psychosocial, disease progression, and pharmacokinetic aspects of pediatric patients.⁶⁻⁸

Access to Pediatric Subspecialty Care Is Associated with Higher Quality of Care, Improved Outcomes, and Reduced Costs

A plethora of research indicates a link between ensuring access to pediatric subspecialty care for children and adolescents who have complex, severe, acute, or chronic conditions and improved quality of care. When compared to the care given by general (adult) specialists, studies demonstrate that care provided by pediatric subspecialists can reduce the length of hospital stays, the number of readmissions, and the likelihood both that a secondary surgery or intervention will be required and that, if required, it will result in fewer complications. Care provided by pediatric subspecialty providers is therefore less expensive.⁹⁻¹⁴ This is consistent with the evidence that surgeon specialization and volume of surgeries performed positively affect patient outcomes.¹¹ Pediatric specialization has been found to be especially important in complex cases and in cases involving younger patients.^{10,13} Additionally, there is increasing evidence that pediatric subspecialty care results in improved quality of life and survival rates for children with complex and chronic health conditions.^{11,12,14}

The Unique Population of Children with Special Health Care Needs

More than 1 million Californians ages 0 - 17 are estimated to have special health care needs (about 10 percent of children in the state).¹⁵ The Maternal and Child Health Bureau (MCHB) of the U.S. Department of Health and Human Services defines children with special health care needs (CSHCN) as those “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.”¹⁶ While children’s conditions vary by type and severity, almost half of the state’s CSHCN have four or more functional difficulties, and about a quarter are living with three or more diagnosed co-morbid health conditions.¹⁵ The most common conditions among California’s CSHCN are chronic allergies, asthma, attention deficit hyperactivity disorder, developmental delays, anxiety, behavioral problems, and autism spectrum disorder.¹⁵ The unique needs of these

children lead to frequent visits to medical providers, necessitating easy access as well as intensive care management and coordination by providers with adequate and specialized training. With advanced medicine, more children are surviving conditions that were once life-threatening. This results in increased numbers of CSHCN and increased demand for subspecialty care.¹⁷

Who Are Children with Special Health Care Needs?

According to the Child and Adolescent Health Measurement Initiative (CAHMI), children with special health care needs experienced one or more of the following health-related consequences as a result of a health condition that has lasted (or is expected to last) at least 12 months:¹⁸ limited ability to do things most children of the same age are able to do; need for or use of prescription medication; need for or use of specialized therapies (e.g., physical, occupational, speech); need for or use of medical, mental health, or educational services beyond those required by most children of the same age; or need for or use of treatment or counseling for emotional, behavioral, and/or developmental problems.

California Children’s Services

In accordance with Title V of the Social Security Act, California has partnered with the counties to create California Children’s Services (CCS) to provide care coordination services and insurance coverage to children with complex health problems and specific diseases. Eligible children and youth have complex, chronic, and potentially disabling medical conditions, such as cancer, diabetes, cystic fibrosis, cerebral palsy, congenital anomalies, and conditions secondary to premature birth; their families must also satisfy specific financial requirements. The program has specific regulated care standards that are implemented and enforced by the state’s Children’s Medical Services. Providers are required to be Medi-Cal providers and must apply for approval (paneling). The CCS program annually serves 175,000 to 200,000 children, 75 percent of whom are also

eligible for Medi-Cal (California's Medicaid program).¹⁹

Centralizing Care: Specialty Care Centers

Regionalization of subspecialists in specialty centers is logical, given that highly specialized physicians would be unlikely to have enough patients to attend to in any single community. Additionally, there is increasing evidence of, and support for, centralized integrated services for critically ill children in a highly specialized health care setting.²⁰ Accordingly, California has developed Specialty Care Centers (SCCs), facilities that provide comprehensive specialty care for children using multi-disciplinary, multi-specialty teams that develop a unique, comprehensive, family-centered, and coordinated care plan and treatment for each child with designated conditions.²¹ Such conditions include, for example, neonatal intensive care,²² pediatric trauma care,²³ pediatric intensive care,^{24,25} and clinical services for sickle cell disease,²⁶ cystic fibrosis,²⁷ cancer,²⁸ and congenital heart defects.¹⁹ The centers operate under regulated care standards and provide cohesive, highly specialized, integrated care.

Section 1: Access to Pediatric Subspecialty Care: A Multifaceted Concept

Access to medical care is a multidimensional concept involving affordability, timeliness and frequency, geographic proximity, and cultural sensitivity.²⁹ Stakeholders interviewed for this policy note, including health care providers and advocacy organizations, defined access in the following ways: 1) universal guaranteed access to affordable pediatric subspecialty care across all types of public and private insurance; 2) continuous access to a regular source of care, availability of consultations with and referrals to pediatric subspecialists when appropriate, and access to urgent or emergency care when needed; 3) availability of timely care within a reasonable time period (generally 10-14 days); 4) availability of providers within a reasonable geographic distance from the family's residence; and 5) availability of linguistically and culturally

appropriate care that is aligned with the family's needs and belief system. Achieving such high standards, a challenge in the general population, is especially challenging in the highly complex CSHCN population.

Some California Families Report Barriers to Subspecialty Care Access

Thirty-four percent of California families with CSHCN report difficulties accessing pediatric subspecialty care.¹⁵ According to the National Survey for Children with Special Health Care Needs, Californians experience more problems accessing pediatric subspecialty care than residents of any other state.¹⁵ Difficulties securing referrals and accessing subspecialty care are especially prominent among families who live at or below 200 percent of the Federal Poverty Level and among those with children who have more complex health care needs.^{i,15,30}

In the following sections, we assess the validity of these concerns and examine the various factors that affect access to pediatric subspecialty care in California. We examine insurance coverage and reimbursement, supply of providers and their geographic distribution, racial/ethnic and language disparities, and other barriers to access. We then address the future landscape of care and provide recommendations to ensure universal access to quality subspecialty care in California.

Access by Health Insurance Coverage and Insurance Type

Almost all of California's CSHCN have health insurance: 60 percent have private insurance, 28 percent are publicly insured, and 8 percent have dual coverage.¹⁵ However, nearly 40 percent of CSHCN in California have health insurance that is inconsistent or inadequate to meet their needs.¹⁵ As with most health care services, access to pediatric subspecialty services varies by type of insurance coverage. Yet, current research is inconclusive about the overall favorability of any one insurance type.

On one hand, research consistently demonstrates that children with private insurance have more timely access to subspecialists than children with public or no insurance. Significant disparities by insurance type in timely access to care have been

found in urology, orthopedics, otolaryngology, dermatology, pulmonology, endocrinology, neurology, and psychiatry.³¹⁻⁴⁰ For example, one analysis showed that Medi-Cal patients had fewer than half the number of appointment slots that were available to their privately insured counterparts.⁴¹ Similarly, there is some evidence that publicly insured CSHCN in Southern California experience substantial inequities in accessing surgical care compared with privately insured children.³¹ Disparities in access by payer extend beyond the clinical encounter; publicly insured CSHCN with more complex conditions report significantly less access to community-based services.¹⁵

A major contributor to the relatively less timely access for children with Medi-Cal coverage is the unwillingness of providers, particularly subspecialists, to participate in the program due to low payments, excessive paperwork, payment delays, and poor responsiveness from fiscal intermediaries, who are often challenged by processing complex medical payments.^{31,32,42-44} Nationally, a pediatrician treating a child on Medicaid receives, on average, 70 percent of what an adult provider treating a Medicare patient would receive for the same illness.⁴⁵ This problem is more pronounced in California, where Medi-Cal pays an average of 54 percent of the Medicare rates for pediatric services—rates lower than Medicaid physician payment levels in many other states.^{32,36,45-48}

Despite timeliness issues for publicly insured children, there is some evidence that these children are provided with high-quality care. CCS-eligible children are routinely referred for pediatric subspecialty care at the highly qualified SCCs.^{36,49} Stakeholders further emphasized that CCS has comprehensive defined benefits which guarantee coverage for durable medical equipment and medical supplies, and allows providers to quickly obtain the necessary authorizations for care in SCCs.

On the other hand, private health insurance coverage does not guarantee access to high-quality care. The SCC referral criteria do not apply to all insurance types; as a result, privately insured CSHCN are significantly less likely to be cared for in SCCs than publicly insured children.⁵⁰ Stakeholders further emphasized that many

private insurers do not explicitly include access to pediatric subspecialists as part of their defined benefits packages. When they do, the access granted rarely meets the standards set by public insurance plans. While private insurance plans offer higher reimbursement rates to ensure physician participation, they often vary in their network size and frequently charge enrollees a fee to see providers outside of the network or to receive care from a large academic medical center. Additionally, private insurance plans may refer to contracted adult subspecialists or pediatric subspecialists who are within the network but lack the specific needed expertise. This is especially problematic if the condition is rare. These issues may contribute to the documented decrease in access to pediatric subspecialty care among privately insured children over the past 10 years.⁵¹

Uninsured children face the most significant access challenges. In 2009, approximately 481,000 California children were uninsured,⁵² and of these approximately 34,000 were uninsured CSHCN. Uninsured CSHCN in California are four times more likely than insured children to have unmet health care needs.^{52,53} Most of the care provided to California's uninsured population occurs at community clinics and hospitals.⁵⁴ However, almost all specialty care for the state's uninsured is provided at urban hospitals,⁵⁵ which may present additional obstacles for rural families of CSHCN.^{35,56} Among the pediatric subspecialties, uninsured children have the greatest and the most difficulty in accessing allergy/immunology, dermatology, neurology, and psychiatry services.⁵⁵ Additionally, children from undocumented immigrant families are at the highest risk of having poor access, according to stakeholders.

Pediatric Subspecialty Workforce May Be Inadequate

Few physician workforce supply studies consider the supply of subspecialty care providers, and those that do rarely differentiate between adult and pediatric subspecialists.^{57,58} This lack of specificity has resulted in an insufficient understanding of the availability of pediatric subspecialty services.^{1,59}

According to 2010 data from the American Medical Association, 16,962 physicians identified

themselves as pediatric subspecialists,ⁱⁱ of whom 1,701 were practicing in California.⁵⁹ According to the 2010 U.S. Census, there are 74,181,467 children ages 0-17 in the entire country, and 9,295,040 in California.⁶¹ There is no established gold standard for the ratio of pediatric subspecialists to the overall child population, but these numbers suggest a lower ratio in California (1 to 5,464) than in the U.S. as a whole (1 to 4,373). The ratio of pediatric subspecialist physicians to CSHCN in California is 1 to 588, based on an estimated 1 million CSHCN in the state.

The adequacy of the subspecialty pediatrician supply cannot be assessed based on these supply measures, because they do not incorporate the level of demand for care. However, multiple studies have found a shortage in such subspecialties as child/adolescent psychiatry, developmental behavioral pediatrics, pediatric anesthesiology, pediatric dermatology, pediatric gastroenterology, pediatric radiology, pediatric rheumatology, pediatric neurology, and adolescent health.⁶²⁻⁶⁹ Some studies have found supply to be adequate in other subspecialties, most notably neonatal care.^{1,62,67,70,71}

The majority of pediatric subspecialists in the United States are affiliated with academic medical centers.^{70,72-74} Many pediatric departments experience difficulty filling subspecialty positions, while subspecialists interested in nonacademic practices report fierce competition for few positions.^{62,67} Although there are variations among subspecialties, most pediatric subspecialists spend the majority of their professional time providing patient care. The additional demands of research and education within an academic practice may account for some of the subspecialty shortages reported by academic medical centers.⁷² These shortages may be exacerbated by shifting demographic trends and work-life balance preferences seen among all physicians. Most notably, more women are entering the physician workforce, but most are likely to opt for part-time rather than full-time work.^{65,75,76}

The role of medical student incentives and postgraduate debt in influencing physician career intention is frequently discussed in the pediatric subspecialty workforce literature. Typically, a three-year, post-residency fellowship training is

required to become a pediatric subspecialist.⁷⁷ However, this additional training time and cost in forgone salary and fees may not be rewarded by increased pay for the trained specialist. As a result, more pediatricians are opting for general practice or hospitalist tracks over further specialization.^{75,78,79} Pediatric subspecialists are generally paid at lower rates than their adult medicine counterparts, according to stakeholders, possibly pushing physicians out of pediatrics altogether. Stakeholders further noted that the return on investment is lower in California than in other states due to higher costs of living and lower reimbursement rates.

Other factors associated with choice of pediatric subspecialty include exposure to pediatric subspecialties during medical school and through residency electives;^{19,80} the number of pediatric subspecialists on faculty at residency locations;^{19,68} and awareness and understanding of the subspecialty (especially relevant to newer pediatric subspecialties, such as pediatric hospitalist and pediatric trauma care).^{81,82} Currently, each resident must complete a minimum of seven months of pediatric subspecialty rotations during residency.⁸³ However, some residency programs are considering reducing the availability of subspecialty rotations as a cost-saving measure, a move that may cause even fewer pediatric residents to subspecialize.⁸⁰

Geographic Disparities

Studies demonstrate an uneven distribution of providers nationally in urban and rural areas and according to community wealth.^{56,59,84} The majority of pediatric subspecialty care is provided at large metropolitan academic medical centers,⁷⁰ where subspecialists can serve the appropriate volume of patients. However, there is evidence that some pediatric subspecialists (e.g., neonatologists and cardiologists) are expanding their practice settings to include community hospitals and private practices.⁸⁵

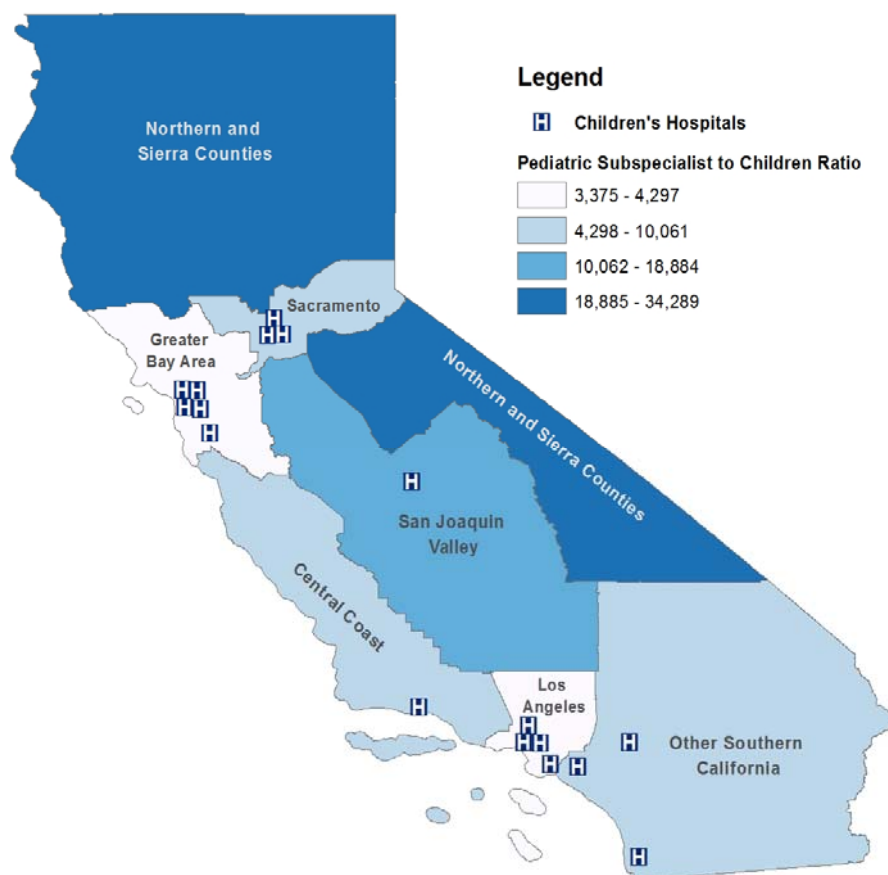
In California, pediatric subspecialty care delivery is centralized by design to allow for optimal specialization by condition. However, access to pediatric subspecialty care and utilization of pediatric specialty care facilities are also adversely impacted by the uneven distribution of providers and potentially the availability of non-

specialty care facilities.^{36,41,47} There is evidence of geographic variation and fluctuation in the utilization of pediatric subspecialty ambulatory and inpatient care over time.⁵⁰ For example, variation in the supply of pediatric subspecialty hospital beds has resulted in a relatively high use of pediatric specialty care facilities in some areas of the state (Fresno and Madera counties). However, Los Angeles County referred only 60 percent of CSHCN to pediatric specialty care centers while others received care in non-specialty care facilities.⁵⁰ Furthermore, there is a generally inadequate supply of pediatric trauma services across the state due to California's lack of a

statewide trauma system and inconsistent pediatric transfer guidelines.^{20,86}

A regional comparison of ratios of pediatric subspecialists to childrenⁱⁱ indicates that Northern and Sierra counties, San Joaquin, and Central Coast counties have the lowest supplies. Sacramento, Los Angeles, and other Southern California counties have comparatively more providers, and the Greater Bay Area has the highest supply. Similarly, children's hospitals mimic this trend, with pediatric subspecialists heavily concentrated in areas of denser population, such as the Greater Bay Area and Los Angeles (Exhibit 1).

Exhibit 1: Relative Distribution of Pediatric Subspecialists per Child by Region in California (2010) and Location of Children's Hospitals



Note: Data are presented as one pediatric subspecialist per number of children ages 0-17 by California region.

Source: Authors' analysis of the number of pediatric subspecialists per child by California region. Data on pediatric subspecialists are from the National Center for Health Workforce Analysis by the Bureau of Health Professions of the Health Resources and Services Administration, U.S. Department of Health and Human Services (2012).⁶⁰ Data on the total population of children per region are from the U.S. Census Bureau, 2010 Census of Population and Housing, Demographic Profile Summary File [machine-readable data files] prepared by the U.S. Census Bureau (2011), provided by the Demographic Research Unit of the California Department of Finance. Data on children's hospitals are from the National Association of Children's Hospitals, retrieved on February 19, 2013, from www.childrenshospitals.net.⁸⁷

Racial/Ethnic, Socioeconomic, and Language Barriers to Access

Differences in access to pediatric subspecialty care are also found along socioeconomic and racial lines.⁸⁸ Low socioeconomic status is a strong predictor of greater severity of cystic fibrosis disease, and access to and utilization of care are exacerbated by socioeconomic and racial differences.⁸⁹ The majority (64%) of California's CSHCN are children of color,¹⁵ so it is important to understand potential racial disparities. Language barriers also can decrease access to care,^{90,91} impede patient understanding,⁹²⁻⁹⁴ decrease patient adherence to treatment,^{93,95} and reduce patient satisfaction.^{90,94} Limited English proficient (LEP) families with CSHCN face greater obstacles than English-speaking families due to the complexity of the needed care.⁹¹ This is a particularly relevant issue in California, where in 2009 approximately 11.6 percent of children (1,142,000) lived in households where a language other than English was spoken, and an additional 39.4 percent (3,871,000) lived in households where both English and another language were spoken.⁵² Health care disparities attributed to race/ethnicity are partially caused by language barriers.^{44,91,96} Further, families of CSHCN with language access barriers often have inadequate insurance coverage.⁵⁵

Stakeholders also identified lack of diversity among pediatric subspecialists as an access barrier, which is also a problem in the greater medical field. Children and families may have difficulty developing trust with physicians who do not speak their language or understand their culture.⁷²

Inadequate Referral Process and Communication

Access to pediatric subspecialty care can be adversely affected by poor communication between the referring general pediatrician and the pediatric subspecialist.⁹⁷⁻⁹⁹ Appropriate communication is crucial in making appropriate referrals for transfer of care from the general pediatrician to the specialist, in using a consultation approach when the physician is referring the patient for a one-time visit with a subspecialist, and in ongoing patient management when the pediatrician and subspecialists share the care for a patient.^{100,101} Stakeholders attributed

observed communication challenges to the fragmented nature of the health care system. Additionally, they emphasized that time constraints and low or no reimbursement rates for care coordination efforts may impede general pediatricians from referring on time and may also disrupt care integration for patients who require ongoing shared care. Lack of time and support personnel on the specialist's side may in turn lead to delays in sending information back to the referring physician. Care coordination is a crucial component of access to appropriate care, especially for CSHCN, yet there are not always sufficient resources to designate case managers or care coordinators, and their training may not be sufficient. In many cases, parents take over the care coordination role, in which case care coordination varies according to the abilities of the parents. Moreover, inconsistencies in availability of electronic health records further inhibit effective communication. Even for those using electronic health records, privacy and data security settings (log-ins, encryption, etc.) require additional time.

Section 2: Innovative Care Delivery Models

Expanded use of technology, team-based care delivery models, and standardized evidence-based protocols are a few examples of emerging innovations aimed at improving access to pediatric subspecialty care.^{102,103}

Telehealth, E-Consults, and Other Technological Applications

Telehealthⁱⁱⁱ consultations have been successfully implemented in dermatology, psychiatry, cardiology, and home health care.^{54,104,105} There is increasing evidence that pediatric subspecialty services delivered through telemedicine can improve health outcomes, care coordination, access to care, and quality of care.¹⁰⁵⁻¹⁰⁹ Several analyses of the use of telemedicine by pediatric subspecialists in California demonstrated high provider and family satisfaction, reduced emergency room utilization, and improved access to care.^{102,106} Consistent with the literature, stakeholders confirmed the positive effects of

telehealth and of various other technological applications including but not limited to e-consults, videoconferencing, phone consults, and social media for communication with patients and families as well as among providers. Telehealth allows for ongoing monitoring (e.g., using blood monitors to transmit data to the medical records of patients with diabetes) and overall improved communication between the referring physician and the subspecialist. If the general pediatrician is involved in the telehealth consultation, this provides an educational opportunity for the provider. Telehealth further improves access to pediatric subspecialty care for children in rural and underserved areas. The use of technology allows for community- and home-based treatment and reduces the need for travel, resulting in fewer missed days of school for children and missed work for parents, saving money and time.

California was among the first states to establish a comprehensive policy to facilitate and encourage the use of telehealth, enacting the Telemedicine Development Act in 1996.¹¹⁰ California law mandates that all public and private health care service plans cover services that can be adequately provided through telemedicine.¹¹¹ However, stakeholders mentioned several barriers to the use of this technology. The reimbursement structure, especially in the case of private insurers, is complicated by the fragmented payer market, making it difficult for providers to bill for these services. Additionally, there is no support for the initial and ongoing costs of infrastructure (including access to broadband connections with sufficient bandwidth) and of adequate training. Finally, there are privacy and confidentiality concerns in this care setting that need to be legally addressed.

Innovative Team-Based Models of Care

Several delivery models employ pediatric subspecialists as consultants who collaborate remotely with primary care providers in their network or health care system to manage the unique needs of children.⁹⁹ Other approaches include pediatric group visits and emphasize the importance of medical homes^{iv} and care coordination.^{108,112,113} Increasingly, researchers are recognizing the importance of integrating non-clinical health care activities, such as a pediatric transport team, in providing high-quality,

accessible health care to CSHCN.^{114,115} Some team models use nonphysician providers (e.g., nurse practitioners, clinical nurse specialists, or physician assistants) in the provision of direct care, with these providers often working as a team in a pediatric subspecialty practice.^{108,116-118} However, research indicates that these physician extenders are underutilized.⁴⁸

Standard Care Protocols

Evidence-based clinical guidelines and standardized clinical protocols, increasingly viewed as essential quality assurance measures, have the potential to increase access to care. Such measures have led to the identification of specific treatments for many diseases, and they can also increase consistent delivery of effective care.¹¹⁹ The standardization of care has been shown to improve health outcomes and can improve access to pediatric subspecialty care through the training of such alternative providers as general pediatricians, nurse practitioners, and physician assistants.¹²⁰ The development of standard referral protocols describing exact thresholds for when referrals are needed may prevent unnecessary referrals and ensure the timeliness of appropriate ones.⁷²

Section 3: The Future Landscape of Pediatric Subspecialty Access

Upcoming changes in care delivery and payment methods, specific changes to CCS, and legislative changes brought on by the Affordable Care Act are likely to impact access to pediatric subspecialty care in California.

Changing Care Delivery Models and Payment Structures in California

Based on Governor Brown's 2012/2013 budget, all California Medi-Cal beneficiaries (including residents of rural counties) will be enrolled in managed care arrangements by January 1, 2014. In addition, the Children's Health Insurance Program of California's Healthy Families Program will be transitioned into Medi-Cal. The mandatory transition of Medi-Cal enrollees into managed care in California has raised concerns about access to specialty care.^{121,122} On one hand, managed care organization (MCO) networks may

improve access to subspecialty care, because their networks include contracted specialists or have special arrangements for covering needed providers outside the network. MCOs frequently have disease and case management services for CSHCN or chronic conditions and facilitate referrals to specialists.¹²³ Quality improvement initiatives in MCOs may improve the appropriateness of referrals and increase delivery of guideline-concordant care by primary care providers and specialists alike, but more research needs to be done on the subject.¹²⁴

On the other hand, MCO enrollment may create barriers to subspecialty care. Primary care medical groups will have to take on the capitated risk in MCO agreements, incentivizing the use of primary care physicians and preventive care. Additionally, quality improvement initiatives and increased accountability may lead to an overall reduction in subspecialty care by shifting some care back to the primary care setting.¹²⁴ There is evidence of delays in referrals in MCOs, but streamlining of referral processes and increased availability of health information technology may reduce such delays.¹²⁴ The reluctance of subspecialists to participate in Medicaid MCOs is a concern, although specialty services are frequently not reimbursed on a capitated basis.

Changes to CCS Payment and Care Delivery Methods

There are several financial and structural barriers in the current fee-for-service (FFS) structure of the CCS program, including limited opportunities to incentivize providers to use lower-cost settings of care when appropriate. Additionally, the current program covers only CCS-related conditions and not the other medical needs of enrollees. This care delivery model creates administrative barriers for providers, potentially leading to inefficiencies as well as obstacles to coordinated, comprehensive care delivery. In the next few months, a handful of new pilot programs across California will be implemented, shifting CCS from the FFS payment structure in some locations to managed or accountable care delivery models aimed at reducing cost growth and improving integration of care.^v Several stakeholders have expressed concern over the upcoming changes, fearing that lower

reimbursement rates may lead to reduced use of SCCs, which could result in poorer patient outcomes and threaten the financial viability of these facilities.

The Patient Protection and Affordable Care Act (ACA) of 2010

The ACA includes efforts designed to improve access to pediatric subspecialty care through the use of various financial incentives and measures aimed at rightsizing the health care workforce.

Payment and Rates: §1202 of the ACA authorizes state Medicaid agencies to increase payment rates for primary care providers (including family practice, internal medicine, and pediatrics) to at least 100 percent of the Medicare rate for specific primary care services in 2013 and 2014, with full federal matching from CMS.^{95,125} CMS has included pediatric subspecialists among the providers qualified for the payment increase, recognizing the mix of primary and specialty care services often provided by pediatric subspecialists.¹²⁶

New Initiatives: §4002 created the Prevention and Public Health Fund¹²⁷ to support community-led programs aimed at improving access to health information, education, screening services, and ancillary health care programs (e.g., transportation, care coordination, and family support systems). While focused on prevention, the fund includes a number of programs that will benefit CSHCN and improve access to pediatric subspecialty care. These include efforts to expand the health care workforce, improve ancillary health care services at the local and state levels, and increase the collection, analysis, and dissemination of workforce and chronic disease data and information.^{128,129}

Community Grants: §4201 authorized funding for the Department of Health and Human Services (HHS) to award grants to community organizations and state and local government agencies for implementation, evaluation, and dissemination of evidence-based preventive health services at the community level.¹²⁷ The aims of these grants include the reduction of health disparities and the improvement of the well-being of those with chronic illnesses. The grants could prove to be a valuable resource in enhancing

access to the subspecialty care and services required by CSHCN.

Workforce Initiatives: §5101 mandates the creation of a National Health Care Workforce Commission charged with making annual reports and recommendations to Congress on national health workforce goals, priorities, and policies. The commission has the authority to evaluate the adequacy of the health workforce, to coordinate federal, state, and local health workforce initiatives, and to prioritize workforce investment based on population needs.

Data on Workforce: §5103 establishes national and regional centers responsible for collecting, analyzing, and disseminating health workforce data and policy recommendations to the national commission and to regional and state stakeholders.^{125,130}

Student Loan Repayment Program: §5203 of the law authorizes \$50 million annually to establish a pediatric subspecialty loan repayment program for qualified individuals who agree to work in health professional shortage areas post-training, working with medically underserved populations and/or in medically underserved areas.¹²⁵ To date, this remains an unfunded mandate.

In accordance with §1302 of the ACA, each state must adopt one of the seven template essential health benefit packages outlined by the federal government to be sold in a health benefit exchange. Once chosen, this benchmark plan will serve as the minimum defined health benefits package for all individual and small group health care plans in a given state.¹²⁷ California Health Benefit Exchange, now named Covered California, has adopted the Kaiser Foundation Health Plan’s Small Group HMO 30 package as its minimum benchmark.¹³¹ While ACA mandates that the benefits must include pediatric services, it does not explicitly include pediatric subspecialty care coverage, nor does California’s benchmark package.^{131,132} As a result, several stakeholders have expressed concern over the availability of appropriate pediatric subspecialty services under this plan.

Additionally, the ACA authorized payment reductions of \$14.1 billion to Medicaid’s

Disproportionate Share Hospital (DSH) program by 2019. These reductions will significantly impact California’s public hospitals, which receive approximately \$1.1 billion in annual support in DSH payments.¹³³ DSH payments are given to states by the federal government for distribution to hospitals to help defray the costs of uncompensated care. Currently, California further provides DHS-like funding to support private community hospitals—including the state’s eight children’s hospitals—which care for 49 percent of the state’s Medi-Cal beneficiaries and provide the greatest volume of care for California’s uninsured and publicly insured children.¹³⁴ DSH-like funding remained intact under the current budget.

Recommendations

The evidence provided in this policy note supports a wide range of policy actions that will ensure improved access to pediatric subspecialty care. The ACA makes significant steps toward this goal, but additional policy measures are needed. The following recommendations are proposed:

Increase the number of pediatricians specializing in pediatric subspecialties.

Efforts focused on reducing the cost of subspecialty training and evaluating and instituting innovative education and training models should be undertaken.

- Congress should fund the ACA-mandated expansion of Title XII to support the loan repayment program’s inclusion of pediatric subspecialists. Combined with increased reimbursement rates, loan repayment may encourage more medical students to view pediatric subspecialties as an attractive career choice. This would support a documented recent increase in pediatric subspecialty training and career interest.^{70,135}
- The National Health Care Workforce Commission, in partnership and collaboration with the Accreditation Council for Graduate Medical Education (ACGME), should establish early entry pediatric subspecialty pilot residency/fellowship programs that recognize the subspecialty training many physicians currently receive in their residency programs. ACGME should also explore “tracking” models

for pediatric subspecialty training programs that focus on either research or patient care.

- Congress should reinstate the \$22 million in funding that was cut from the 2013 budget's Children's Hospital Graduate Medical Education (CHGME) funds as a result of sequestration. CHGME funds support 43 percent of the nation's pediatric subspecialty training slots; the cuts may result in 465 fewer pediatric subspecialty residency positions annually, further jeopardizing children's access to critical health care services.¹³⁶
- ACGME should exempt pediatric subspecialty fellowship training from graduate medical education funding caps.
- The American Association of Medical Colleges (AAMC) and ACGME should include pediatric chronic and acute care symptom recognition, communication, and referral management competencies as routine components of graduate and continuing medical education and training.

Address payment and reimbursement issues that impede CSHCN's access to pediatric subspecialty care.

- Congress should extend the ACA-allowed payment rate increases to Medicaid providers (to the equivalent of Medicare rates) beyond their December 31, 2014, sunset date to ensure appropriate payment to pediatric subspecialists for the primary care evaluation and management services they provide. California should finalize the state plan amendment and pay the highest rate for retroactive claims.
- Medicaid rate increases for health care services should be extended beyond those specified by the ACA to include pediatric subspecialty procedures, consultations, and other subspecialty services needed by California's CSHCN.
- The American Medical Association (AMA) should work with CMS and private payers to simplify reimbursement codes for care and care coordination provided to CSHCN. Pediatric subspecialists and other stakeholders have worked closely with the AMA and CMS to develop appropriate billing codes for the care provided to children with complex health care needs (some of these codes are new in 2013).¹³⁷ Additional work is needed to ensure that

reimbursement codes accurately reflect the resource demands and complexity of care required by CSHCN, with specific focus on developing codes that have greater flexibility with regard to the frequency of communication and care provision.

- Congress should overturn the \$76 million cuts to the ACA-instituted Prevention and Public Health Fund imposed by sequestration and protect the fund from future budget reductions.¹³⁸ These cuts will adversely impact access to pediatric subspecialty care through budget reductions in a number of programs, including the Centers for Disease Control and Prevention's (CDC) community and prevention programs aimed at conducting chronic disease research and providing evidence-based recommendations and interventions to improve public health at the community level; Community Transformation Grants, which were enacted to support community-level efforts to reduce chronic diseases and improve the lives of individuals with these diseases; CDC-administered public health workforce education, development, and training programs; and data collection, analysis, and dissemination efforts.¹²⁸

Increase the capacity of pediatric subspecialists by better utilizing physician extenders and general pediatricians when appropriate.

- Increase the capacity and scope of practice of physician extenders such as nurse practitioners and physician assistants. State Senator Ed Hernandez (D-West Covina) plans to introduce legislation in 2013 that would expand the roles of nonphysician clinicians in an effort to ease the shortage of primary care physicians in the state and provide adequate levels of care to the newly insured in 2014. The American Academy of Pediatrics (AAP) has encouraged the AAP state chapters, along with state medical and specialty societies, to develop a forum to address expanding the scope of work of nonphysicians in pediatric care.¹³⁹ In addition to addressing the ability of physician extenders to work independently, this forum should address reimbursement rates for nonphysicians. Even if California does not permit independent practice of nonphysicians, more physician extenders should be included in pediatric subspecialty care, as they can improve coordination of care,

contribute to team-based approaches to care, and improve efficiency.

- The California AAP chapter, along with state medical and specialty societies, should develop education and training efforts to increase the expertise of general pediatricians in using standard treatments. Pediatricians could then practice at the top of their skill sets and treat the more simple cases, freeing up subspecialists' time and allowing them to treat the more complex patients.

Improve access to telehealth services for pediatric subspecialty providers.

- Create a Telehealth Advocacy Advisory Board (TAAB) to monitor state legislation and identify gaps in effectively operating telehealth services. The California Telehealth Resource Center can identify potential board members who would represent all stakeholders.
- The state should make additional funding available to existing vendors for telehealth technical support. The California Telehealth Network provides services to assist with finding reduced rates for broadband services, and provides 24/7 technical support, free online training, and webinars.¹⁴⁰
- The subspecialty care coalition should collaborate with the California Telehealth Network and the American Telemedicine Association to develop appropriate security measures for transmitting sensitive health information through telehealth services. Such measures can include training on best practices of protecting health data and establishing secure electronic connections.^{141,142}

Improve the availability of pediatric subspecialty services to underserved populations.

- SCCs should develop and implement destination care models, whereby centers with a particular expertise would coordinate a day's worth of visits for a child coming from a remote location. Condensing care into one day would save the family time and money and would also be cost-effective for the providers.
- Increase workforce diversity by recruiting minority individuals in medical school and

offering financial incentives. Evidence shows that increasing diversity in the workforce increases patient satisfaction and trust.¹⁴³ Given that the majority of CSHCN in California are children of color and that racial/ethnic disparities in care persist, diversifying the pediatric workforce can help strengthen the patient-provider relationship among underserved populations. There are ongoing efforts to recruit minority students into the medical field through targeted outreach to diverse populations and through financial incentives (such as loan forgiveness and tuition reimbursement) to minority students, who often come from low-income families.¹⁴³ Children's hospitals and other health care institutions providing subspecialty pediatric care should oversee the implementation of diverse workforces, which would include the hiring and retention of minority workers.¹⁴³

- California's DHCS should partner with community organizations and apply for Community Transformation Grants focused on improving access to services for underserved CSHCN.
- Children's hospitals should consider partnering with community clinics to provide subspecialty services in community clinics, either in person or through telehealth. Recently, Children's Hospital Los Angeles, University Children's Medical Group (UCMG), and AltaMed Health Services Corporation announced a joint initiative to support the provision of primary and preventive care in clinics. This may serve as a model for future initiatives in subspecialty care.

Improve communication between general pediatricians and subspecialists.

- The health care delivery system as a whole would benefit from a commitment to greater cooperation and collaboration among general pediatricians, subspecialists, and nonphysicians across organizations. Research consistently points to opportunities for improvement in the coordination and communication of care, especially for CSHCN.^{71,90,144-146} Care facilities should promote care coordination and fluid communication through weekly team meetings in co-located facilities, along with webinars, videoconferences, meet-and-greet events, or

meetings for general and subspecialty pediatricians across organizations.

- Create an infrastructure to enhance collaboration between primary care providers and subspecialists. Primary care providers should have access to accurate data on subspecialty providers and their contact information through the integration of claims and licensure data sets across services systems, thereby enhancing network development and communication among providers.

Develop benchmarks and collect accurate data on workforce supply.

- Establish criteria for determining pediatric subspecialty shortage areas. HHS recently released the Health Resources and Services Administration (HRSA) determination of health professional shortage areas in the areas of primary medical care, dental care, and mental health services.¹⁴⁷ HRSA, in partnership with the National Health Care Workforce Commission (NHCWC) and ACGME, should perform a similar assessment to identify areas of pediatric subspecialties shortages.
- Objective data should be collected to validate parent survey data indicating long wait times for appointments and other access concerns. Pediatric professional organizations should partner with children's hospitals and the National Healthcare Workforce Commission to (1) develop measures of hospital capacity for the delivery of high-quality pediatric subspecialty-specific services, (2) develop claims-based measures to determine the appropriate number of referrals to pediatric subspecialty providers by type of subspecialty, and (3) assess actual time to appointment by tracking referrals and authorization patterns.
- DHCS Children's Medical Services, which oversees CCS, should work with representatives of commercial health plans to develop guidelines for adequate times for appointments and appropriate mechanisms to track adherence to these guidelines.
- Promote research to provide data about the pediatric workforce in order to plan for current and future health care needs. The AAP Workforce Committee should partner with the NHCWC and other appropriate groups to

develop realistic, scientifically based workforce models for both primary and subspecialty pediatric care. This would involve the regular collection of data on the supply of pediatricians and pediatric residents, including specialty geography and employment and practice arrangements. To facilitate this effort, specialty societies, state medical societies, child advocacy groups, and others should share subspecialty-specific data with legislators and policymakers at the national, state, and local levels.

Assess the standards of care available to CSHCN in California.

- Data should be collected regarding cost drivers and savings opportunities within the CCS program at the patient, county, and state levels. As the state moves forward with its 1115 Medicaid waiver that includes CCS program redesign, it is important that both quantitative and qualitative data be collected to identify successful elements and areas of deficiency in the program and to determine the program's cost-effectiveness. These data should be utilized by DHCS to develop new solutions, select priorities, and allocate resources to improve patient satisfaction and health outcomes. Comparable standards of scientific evidence should be applied to assess the outcomes in all areas of clinical practice delivered by all providers of pediatric subspecialty care. This information should be leveraged to educate legislators on the standards of care that all insurance plans should offer to cover the needs of CSHCN.
- A stakeholders' workgroup should be established to ensure that new models of care delivery do no harm to patients and do not erode program provider participation, and that they serve the whole child in a well-coordinated system for primary and subspecialty services. The work group should support the development of clear responsibilities among providers, counties, and the state to minimize variation in administration and increase financial flexibility. The workgroup should include county CCS administrators, hospital health executives, physicians, health plan representatives, advocacy groups, and state agency representatives.

- DHCS should monitor the implementation of CCS pilot programs according to established quality and outcome benchmarks. Statewide timely dashboard reports may be used across all sites to ensure oversight.
- The California State Legislature should require Covered California (the California Health Benefits Exchange) to include pediatric subspecialty care as an essential insurance benefit of all health insurance provided to children through the state's insurance exchange.
- Beyond California, nationwide demonstration projects should be funded and established for CSHCN to assess the effects of patient-centered medical home models and community care transition programs on improved access to quality care, reduced costs, and reduced unnecessary hospital readmissions. The ACA has authorized such demonstration programs, including the Federally Qualified Health Centers (FQHC) and the Community-Based Care Transitions Program demonstrations, which are overseen by HRSA and CMS.^{148,149}

Methodology

The development of this policy note was informed by a thorough literature review and a set of semistructured interviews. Key research regarding access to care for children with special health care needs (CSHCN) was first identified by the authors. Additional literature was identified through a “snowball” approach, using the references of these key studies to identify detailed information regarding access to care for this population. Also, a comprehensive review of the literature concerning access to care for CSHCN was conducted using PubMed and Google Scholar. In addition to the exhaustive literature search, we conducted semistructured interviews with 11 key stakeholders, including children’s hospital executives, pediatric subspecialists involved in workforce issues, CCS and pediatric subspecialty care workgroups, and children’s health advocacy groups. Discussions were recorded, transcribed, and analyzed to support and confirm findings from our extensive literature review.

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Notes

ⁱ The survey further revealed that some families experienced difficulties or delays in receiving necessary services. 12.6 percent of families reported delays due to ineligibility; 12.6 percent reported that the services they needed were not available in their area; 16.3 percent had cost-related issues; and 12.5 percent lacked the information they needed to access care. Even when CSHCN families had a subspecialist they could see, approximately 18.4 percent were on waitlists or in backlogs or experienced other problems getting appointments.

ⁱⁱ Northern and Sierra counties include Alpine, Amador, Butte, Calaveras, Colusa, Del Norte, Glenn, Humboldt, Inyo, Lake, Lassen, Mariposa, Mendocino, Modoc, Mono, Nevada, Plumas, Shasta, Sierra, Siskiyou, Sutter, Tehama, Trinity, Tuolumne, and Yuba. Greater Bay Area counties include Alameda, Contra Costa, Marin, Napa, San Francisco, San Mateo, Santa Clara, Solano, and Sonoma. Sacramento region counties include El Dorado, Placer, Sacramento, and Yolo. San Joaquin counties include Fresno, Kern, Kings, Madera, Merced, San Joaquin, Stanislaus, and Tulare. Central Coast counties include Monterey, San Benito, San Luis Obispo, Santa Barbara, Santa Cruz, and Ventura. Other Southern California counties include Imperial, Orange, Riverside, San Bernardino, and San Diego. The following hospitals are included: Loma Linda University Children's Hospital; Miller Children's Hospital Long Beach; Shriners Hospitals for Children - Los Angeles; Children's Hospital Los Angeles; Mattel Children's Hospital UCLA; Children's Hospital Central California; Kaiser Permanente - Oakland Medical Center; Children's Hospital & Research Center at Oakland; Children's Hospital of Orange County (CHOC Children's); Lucile Packard Children's Hospital at Stanford; Shriners Hospitals for Children - Sacramento; Sutter Children's Center, Sacramento; University of California Davis Children's Hospital; Rady Children's Hospital - San Diego; California Pacific Medical Center; and Cottage Children's Hospital.

ⁱⁱⁱ Telehealth uses software, computers, telephone lines, medical cameras, and videoconferencing equipment to connect a physician's office to an SCC in a different location. Telehealth encounters can be done using live video, where the physician, patient, and specialist meet at the same time using video and telephone equipment, or they can be conducted using "store and forward," where an image of the patient's condition is taken and sent electronically to the specialist for review.

^{iv} Care coordination in which physicians and other health care providers work as a team with families to develop and implement a specific, culturally sensitive, family-centered care plan, along with continuous availability of comprehensive care, are the core principles of the pediatric "patient-centered medical home" for children with special health care needs.

^v The CCS Program currently uses an FFS payment structure administered through the department's Fiscal Intermediaries. In April 2011, the Office of Medi-Cal Procurement (OMCP) of the California Department of Health Care Services (DHCS) released a Request for Proposals (RFP) (#11-88024) to provide CCS services under one of four proposed pilot models, including: (1) Enhanced Primary Care Case Management (EPCCM) Program; (2) Provider-Based Accountable Care Organization (ACO); (3) Specialty Health Care Plan (SHCP); and (4) Utilization of Existing Medi-Cal Managed Care Plans.

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