

Issue Brief

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Challenges and Joys: Pediatricians Reflect on Caring for Children with Special Health Care Needs

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Introduction

How can families of children with special health care needs (CSHCN) be assured that their children are receiving appropriate care?

Research shows that when these children receive their care in a medical home, they have better access to services, improved quality of care, and reduced healthcare costs.¹ Yet only 38% of families in California report that their child with special needs has a medical home.

The concept of the “medical home” was introduced by the American Academy of Pediatrics as a way to assure better care for children with chronic health conditions.² It was first described as a centralized, physical location for a child’s medical records, but has evolved to a model of team-based care designed to address the totality of care a child needs, and as such is accessible, family-centered, coordinated, comprehensive, continuous, compassionate, and culturally effective.³

To better understand what is preventing greater availability of medical homes, a collaboration of pediatric organizations in California,⁴ along with representatives from family organizations and children's advocacy groups, conducted a two-phase study asking the state’s pediatricians about their experience and willingness to care

for children with special health care needs, and about systemic changes that would facilitate their future participation in medical homes for these children.

Research Overview/Methods

The first phase of the study involved focus groups and individual interviews with key informants regarding pediatric care for children with special health care needs. (The second phase was a quantitative survey of California’s board-certified pediatricians, the results of which are reported in [Survey: Quantifying Pediatricians’ Views on Caring for Children with Special Health Care Needs](#).)

Participants

A total of 39 purposively selected key informants representing important stakeholder categories across California participated in the focus groups or interviews. Twenty-eight of the 39 participants were pediatricians; the remaining 11 were parents, nurses, and other experts in the care of children with special health care needs. Thirty-one individuals participated in one of nine hour-long focus groups; eight of the informants were interviewed individually for 30-45 minutes.

The majority of pediatrician participants (who included equal representation of men and women) were practicing in primary care. Seven had practices comprising 50 percent or more children with special health care needs; 9 reported 15-35 percent CSHCN; 6 reported 10 percent or less. Most had been in practice for between 10 and 25 years. The majority of pediatrician participants practiced in urban communities, with five in suburban areas. Two identified as practicing in rural areas. Practice settings, incompletely reported, included hospital and medical schools (6), small group of 3-10 MDs (4), HMO (3), large groups of >10 MDs (2), community health centers (2), and a multispecialty group (1).

Interview Guide

The focus groups and interviews were semi-structured. Core areas of focus for policy development were offered as prompts, with interactive discussion among participants encouraged.

1. What are key (essential) elements needed to provide high-quality care for children with special health care needs?
2. What are barriers to providing high-quality care for children with special health care needs?
3. What are solutions, facilitators, and supports for providing high-quality care for children with special health care needs?
4. What do you feel is the appropriate “lead provider” for a medical home/locus of care for a child with special health care needs?

5. Do you know of any model practices that provide high-quality care for CSHCN and if so, what makes them model practices?

Analysis

All focus groups and interviews were conducted via webinar or by phone, recorded (with permission of the participants), and transcribed.

Key Findings

Participant responses yielded considerable overlap in discussion across prompts. For example, “time”—for visits, for care coordination, for all the things a pediatrician and practice must do to provide quality care for children with special health care needs—came up in discussions of key elements, barriers, and resources. That is, “time” was clearly on pediatricians’ minds regarding care for this population, regardless of how the question was framed. This was true of other frequently mentioned themes as well. For this reason, major themes/key findings are presented in terms of topic area rather than organized by prompt.

Reimbursement Rates

One key barrier noted by respondents is reimbursement rates for primary care physicians, which are often set at levels that incentivize high-volume practice—discouraging practices from assuming care for patients whose conditions require above average visit times and the assistance of additional staff.¹ At the same time, pediatric subspecialists have increased as a proportion of all pediatricians, and the differential between their fees and those of primary care providers has grown.

Diminution of the role of community physicians in hospitals also has changed how primary care physicians spend their time, reducing their opportunities to interact with hospital-based specialists, especially in tertiary care centers. These changes raise questions about what the roles and relationships should be between primary care and subspecialist pediatricians in the care of children with chronic health conditions today, and how the system must change to support and strengthen that partnership.

Time and Care Coordination Resources

Time

Two elements repeatedly emerged as essential for the provision of quality comprehensive health care for CSHCN:

- Sufficient time for visits and administrative needs
- Robust care coordination/communication

Several primary care pediatricians reported that practices increasingly must maintain high visit volume in order to remain financially viable. Children with special health care needs do not fit easily into this business model because their visits may take longer, yet providers are not reimbursed for more than the “usual visit.” Striving to provide good care, pediatricians may extend the visits and lose revenue, or, in academic settings, “steal time” designated for other responsibilities; neither approach is sustainable. In addition to the need for longer visits to address multiple issues in sufficient depth, added administrative time was noted as essential to handle referrals,

“What makes it difficult as a pediatrician to provide this care? Lack of time, number one.”

fit easily into this business model because their visits may take longer, yet providers are not reimbursed for

track follow-up care, and complete paperwork, billing, and coding.

Care Coordination

Respondents reported that it is essential that someone on staff be able to devote the time needed to know all aspects of the child’s care, including medical, developmental, educational, and social service needs, and to communicate and coordinate among all those serving the child and family. This capacity was identified as one of the most important facilitators of high-quality care for children with special health care needs. Respondents emphasized that this person does not need to be a pediatrician or even a medical provider. Small group and solo practices (approximately 20% of California pediatricians), in particular, lack sufficient resources to hire dedicated care coordinators. In these practices, care coordination falls to the physician and existing staff, who rarely can devote the time needed.

Medical Record Systems

Medical Record Systems that “talk to one another” often were noted as an important feature of care coordination. Respondents praised electronic medical record (EMR) systems that are easy to access, both on- and off-site, and allow for the seamless and instantaneous two-way transfer of information between different care providers. This facilitates “real-time” access to medical records by the primary care provider and care coordinator, alleviating problems such as delayed specialty visit reports and the resulting dependency on parents to recount subspecialty visits.

“I don’t know how we did this before electronic medical records.”

The best EMR systems also allow pediatricians to follow up with patients immediately after hospitalizations, respondents said. They also noted that enhanced EMR systems allow pediatricians to share lab results, images, and EKGs. Such systems facilitate informal and formal consultations with subspecialists, allowing the subspecialist to respond to or ask for clarification from a general pediatrician's consultation request without having to bring the patient in for a visit.

Locus of Care/Team Leader

Having a pediatrician lead the child's health care team in a medical home was deemed highly important. Given that respondents were largely pediatricians, it is not surprising that they identified access to "one of their own" as essential (as opposed to, for example, a family physician or general practitioner). However, respondents also repeatedly emphasized the need for that pediatrician to be knowledgeable, comfortable, and interested in caring for children with special needs, i.e., *not just any pediatrician would do*. To broaden the availability of qualified pediatricians, respondents stressed the importance of continuing medical education for pediatricians in the skills and knowledge needed to care for CSHCN, including when (and when not) to refer to subspecialists.

Respondents also differed as to who would be the optimal team leader for the medical home for children with special health care needs. Most primary care pediatricians indicated that, given the right support, they should be the medical home for *all* children, including those with complex special needs. They stated that they are trained to "quarterback" the health care team. Others recommended that university- and

hospital-based special clinics, or integrated systems like Kaiser, are the optimal medical home for most children with complex medical needs, arguing that "no amount of money is going to solve the problems of caring for children with special health care needs in the community." They noted, however, that some geographic regions, particularly rural settings, cannot support a children's hospital or special needs clinic, so community pediatricians must be equipped and supported to take on the care coordination role.

None of the respondents suggested that subspecialty pediatric providers should be the "default" medical home for CSHCN. They reasoned that subspecialists are not prepared or trained to be primary care providers, and that they lack the necessary infrastructure for well-child care such as vaccination. Their focus tends to be narrowly on the child's medical issues that fall within their subspecialty expertise. However, respondents acknowledged that there are specific situations in which the subspecialist could or should serve as the medical home, such as when a child has one specific overriding health need, and spends most of his/her time in the subspecialist's office. Several pediatricians supported this notion particularly for children with cancer, who may then return to the care of the primary care pediatrician when their need for intensive subspecialty care has resolved, diminished or stabilized.

Respondents strongly agreed that the family, in consultation with their child's health care providers, should have the ability to choose the

"For families, it's not fair if they don't have a generalist physician to ask about everything in one place."

type of provider and the setting in which their child's needs will best be met, to the extent possible.

Respondents offered competing explanations regarding why pediatricians might lack interest in caring for CSHCN. In some cases, this may be due to the considerable system barriers that need to be overcome, e.g., time, care coordination, availability of subspecialists, and so on. Were these addressed, additional pediatricians might want to be the medical home for children with special health care needs. However, a subset of pediatricians reported going into primary care because they are most interested in preventive care and serving typical children, and feel CSHCN are better served in specialty care clinics. Respondents differed as to whether “resources” or “interest” is the dominant root of the problem.

Model Practice

Respondents were asked to identify model practices that serve special needs populations. Many small and solo community primary care practitioners were unable to name any such practices; some were unaware of existing models close to them. Pediatricians who were

able to identify a model system or practice almost universally cited integrated systems of care: university- or hospital-based clinics established specifically for children with special

“For complex children, the right team working together is really important but it's a struggle for a community doctor to get there.”

health care needs, including clinics at University of California, Los Angeles (UCLA); University of California, San Francisco (UCSF); Lucile Packard Children's Hospital Stanford; UCSF Benioff Children's Hospital Oakland;

University of California, Irvine (UCI); and University of California, San Diego (UCSD). These systems share common elements such as a whole child focus, and utilize a health care team incorporating not only primary care and subspecialty physicians, but also allied health and other non-physician professionals such as social workers, education specialists, and legal aides. Although some of these clinics are advanced primary care medical homes, many are disease- or condition-specific, caring for children with spina bifida, autism, cystic fibrosis, hematologic or oncologic disorders.

Kaiser Permanente was highlighted by pediatricians both within and outside of that system as an example of a care model that is designed to provide comprehensive care. It was lauded for its “universal coverage” system, in which a general pediatrician doesn't have to seek out referrals and can access almost all services “in-house”—greatly reducing access barriers to both subspecialty and mental health providers. A few free-standing practices in Northern and Southern California also were identified as model practices, but seemed to be chosen only for the willingness of the providers to care for CSHCN, not the practice characteristics that made it a model.

Subspecialists: Availability, Relationships, and Professional Cultural Divide

Subspecialty access concerns fell primarily into three categories: (1) health plans that seem not to appreciate the need for pediatric subspecialists and limit their provider networks almost exclusively to adult specialists; (2) inadequate numbers of available pediatric subspecialists in a region, especially in rural areas; and (3) reimbursement inadequacy for pediatric subspecialty care in public programs,

leading to shortages in the pipeline for California pediatric subspecialists and, therefore, long-term structural shortages.

“There’s nothing in the system today that fosters informal or ongoing interaction between subspecialists and primary care pediatricians.”

One ongoing source of frustration and concern expressed about quality of care was the lack of communication between subspecialists

and primary care pediatricians and the child’s medical home. Inconsistent record-keeping methods and incompatible electronic medical record systems were cited as problematic. But beyond these specific communication issues, more broadly speaking it was reported that there is little in the current structure of health care delivery to facilitate, foster, or incentivize the interaction of general and subspecialty pediatricians in the community. Most pediatric subspecialists participate in separate continuing medical education from their primary care colleagues, and identify largely with their individual subspecialist professional associations. Over time, this has meant informal communication and “collegiality” between subspecialists and primary care pediatricians have diminished.

This “culture-communication gap” has made formal relationships between primary care pediatricians and subspecialists more difficult to establish and maintain. Respondents suggested that joint continuing medical education could be used to start conversations between general and subspecialty pediatricians about how to better collaborate, when general pediatricians should make referrals for subspecialty care, and what new treatments are available for CSHCN. Primary care pediatricians emphasized that

personally knowing subspecialists and other care providers can facilitate referrals and consultations, especially if these activities are enabled and incentivized or reimbursed.

Primary care pediatricians also suggested that having access to practice guidelines and authoritative answers to frequently asked questions about chronic conditions would be helpful, perhaps via a user-friendly website and/or telephonic expert hotline. Availability of such resources could help primary care pediatricians know when to seek subspecialty advice and to whom to make referrals.

Obtaining mental/behavioral health services for their patients and communicating with those providers was

“Half of what I do in primary care with these kids is to interpret for the family what was said at the specialist’s office.”

identified as especially problematic. This situation seemed to be aggravated by health insurers carving out mental health coverage and excluding primary care pediatricians from providing reimbursable behavioral/mental health services. These circumstances combined prevent pediatric patients from accessing specialty care and interfere with primary care pediatricians’ ability to fill the gap of inaccessible child and adolescent mental health services. Given the high rate of co-morbidity among CSHCN, problems accessing behavioral/mental health care are especially important.

Non-Medical Resources

Formal linkages and positive relationships between the child’s medical home and other community services providers—schools, Regional Centers, family resource centers, and

support groups—often are essential for quality care for children with special health care needs. This support was especially critical for children from families with fewer resources. Respondents said repeatedly that, in addition to funding, effective care coordination requires strong personal relationships across these entities, and the ability to communicate across health and service agencies. Knowing whom to call and being assured that the person will return your calls are two equally important prerequisites.

In California, many CSHCN access services and resources through Regional Centers and California Children's Services (CCS). Pediatric providers highly value these programs. However, variations in eligibility guidelines and service availability make it difficult for pediatricians to know which children qualify for which services. Respondents also reported barriers for children in obtaining timely access to Regional Center services. In addition, denying responsibility for providing or paying for services leads to children being bounced among schools, Regional Centers, CCS, and insurers, and frustrates families and health care providers who are endeavoring to provide high-quality care and a medical home.

Family Education and Support

Multiple informants noted that practices benefit when they educate and empower parents to be active participants in their child's care, encourage them to speak up about their concerns, and educate providers about community resources with which they have interacted.

Respondents suggested that pediatricians can support families' capacity to manage their

children's health conditions in a variety of ways. They can provide organizational tools such as calendars, "passports," and clinical notebooks, and suggest other ways to organize home care. Further, providers can facilitate communication with families via telephone and email, and telehealth systems can help to determine whether an in-person visit is needed, potentially avoiding stress for the family.

"The primary care pediatrician gets to know each child and family over time, it's that continuity that matters."

Similarly, providing information such as appointment reminders by mail or email, and printed care guidelines and information sheets was identified as helpful, as long as such assistance is in the language and at the educational level appropriate for the family. In addition, respondents noted that the health care team needs to take into account the families' social circumstances, including cultural values and beliefs, access to various resources and supports, employment and income, ability to cope with stress, need for respite services, and distance to sources of care.

Insurance, Health Plans, and Reimbursement

Respondents stressed that health plans that are streamlined in approval processes, have adequate networks of pediatric subspecialists, and that cover support services, durable medical equipment, and needed medications contribute to achieving quality care for children with special health care needs. Respondents reported that some health plans do much better in this regard than others. Bringing all health plans up to the level of the highest performers would do a great deal to improve the system in California and the quality of care provided.

Respondents disagreed over whether insurance coverage and benefits for CSHCN are generally better in private sector plans or public sector programs. Some argued that while benefits and coverage may be richer in Medi-Cal and some

“The kind of insurance a child has determines what referrals I can make.” other public programs, reimbursement is inadequate and impedes access. Respondents also discussed the need to make sure benefits are appropriately designed, and that children’s hospitals and all child health care providers are reimbursed adequately for the care they provide for special needs populations.

Conclusion

Pediatricians were open and thoughtful in responding to this opportunity to express their views regarding the system of care for children with special health care needs, including the role they feel they should play and the challenges they face.

Increased and dedicated resources for care coordination at the practice level topped the list of systemic improvements that pediatricians said are needed to assure all CSHCN had access to high-quality medical homes in their community. This conclusion from the

qualitative phase of this study was supported by the results from the survey phase. But in addition, within the private and collegial setting of small focus groups and interviews, pediatricians were willing to take their analysis to a more personal level, and to consider what might be done in their own profession to increase medical home access. This included addressing the gap between primary care pediatricians and pediatric subspecialists that has occurred in continuing education and professional networking activities. Pediatricians also reflected on whether and to what extent their provision of medical homes for CSHCN might be increased were more resources made available, versus enhancing the knowledge, skills, and expectations of pediatricians more comfortable in a “wellness-based” practice.

In this study, pediatricians and other key stakeholders identified a number of themes central to providing medical homes to CSHCN. Many of these topics merit further research and discussion on how to best utilize existing resources and to craft new policies that would substantially improve the system of care for this important and especially vulnerable group of children and their families.

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