

Issue Brief

March 2017

Survey: Quantifying Pediatricians' Views on Caring for Children with Special Health Care Needs

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Introduction

Children, especially those with chronic health conditions, benefit from receiving pediatric care that comprehensively addresses their medical, behavioral, and psycho-social needs.

Children with special needs who receive this type of coordinated care in a family-centered medical home¹ have better access to needed services, improved quality of care, and reduced health care costs.

However, most children with special health care needs (CSHCN) are not cared for in a medical home. California does especially poorly in this regard, with only 38.3% of families reporting their child with special needs having a medical home.²

Ample evidence, both qualitative and quantitative, indicates that what parents and guardians desire for their children with special needs matches precisely what a medical home can offer. Unfortunately, insufficient numbers of pediatric and other physician practices operate on the medical home model.

Numerous explanations for this shortage have been proposed, including a fragmented system, legal and policy barriers, low levels of physician reimbursement, and inadequate supports for practices. But little research has queried

physicians themselves about what prevents them from providing medical homes for children with special health care needs.

To address this issue, a collaboration of pediatric organizations in California, along with representatives from family organizations and children's advocacy

groups, conducted a research study to define and better understand pediatrician-identified barriers to caring for these children.

Participating organizations included the American Academy of Pediatrics, California Foundation; the American Academy of Pediatrics, California; the Children's Specialty Care Coalition; and the University of California, San Francisco.

Research Overview/Methods

The researchers first conducted a literature review of pediatric care of CSHCN. The findings indicated that few studies have looked at the proportion of pediatric patients with special health care needs who are cared for in

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individual practices, or the way practices that successfully care for CSHCN are structured.

Subsequently, focus groups and semi-structured interviews were conducted with 39 purposively selected key informants to identify additional issues and to prioritize those that should be studied further.

The focus group participants were predominantly primary care pediatricians, but also included pediatric subspecialists, nurses, and others. They identified a number of interrelated themes affecting practices' and practitioners' ability to serve CSHCN. The most common issues were: (1) time for visits, (2) staffing needs, and (3) care coordination capacity, both in terms of systems of communication (e.g., shared Electronic Medical Records) and designated staff. These topics formed the basis of a statewide survey of active California AAP member fellows. That 10-minute survey was administered between May 2014 and January 2015 via email and mail.

A unique aspect of the survey was the inclusion of one of four randomly assigned vignettes of a child with special health care needs, along with a series of questions to respondents about their comfort level and ability in providing care for the child in the vignette they received. Vignettes included a 10-year-old with a medical condition (neurofibromatosis) or a behavioral condition (autism). In each, the child had either adequate or inadequate social resources, in terms of the family's functioning and access to community services and other support. Respondents also were asked to identify those resources that they deem most important to their practice's ability to provide care for a child with special health care needs.

Key Findings

Over half (50.2%) of the pediatricians responded to the survey (1290/2569). Analysis of the data yielded six key findings:

- The CSHCN cared for in California pediatric practices represent a wide range of conditions and severity. University-affiliated practices provide a higher proportion of the care for CSHCN. Somewhat unexpectedly, many non-university-affiliated practices also care for children with complex medical conditions, including some who are technology dependent and some with serious behavioral disorders. (Primary care physicians reported an average of approximately 5% of CSHCN in their practice with technology dependence.).
- Primary care pediatricians overwhelmingly (>90%) responded that the primary medical home should be with the general pediatrician, with some rare exceptions. These exceptions included views that the primary care medical home should be nested within specialty care centers or be the joint responsibility between primary care and subspecialty care.
- Although the majority of general pediatricians report being fully comfortable caring for children with special health care needs, depending on the vignette a significant number reported being only somewhat comfortable (18-37%) or being somewhat or strongly uncomfortable (8-16%), depending upon the types of service needs and the family's circumstances.

Families' circumstances were an important factor. The proportion of pediatricians

stating they were comfortable being the medical home for the child in each vignette (neurofibromatosis or autism) dropped by 10-13% when there were fewer social resources available to the child.

- Less than half of the primary care pediatricians (46%) and subspecialists (38%) strongly agree with the statement “I am satisfied with the care I am able to deliver to most of the children with special health care needs in my practice.”
- Subspecialty access was identified as a barrier to primary care pediatricians’ delivery of care to children with special health care needs; the magnitude of the barrier varied by subspecialty.

Nearly two-thirds of primary care pediatrician respondents report that developmental/behavioral pediatricians and pediatric psychiatrists/psychologists are not easily available to their patients. Close to half report that referrals to pediatric subspecialists in genetics and dermatology are difficult. One-third report that pediatric pulmonologists are not easily available to their patients. In addition, a significant proportion of pediatricians report that the following pediatric subspecialties are not easily available to their patients: pediatric endocrinologist (26%); pediatric gastroenterologist (25%); pediatric infectious disease (27%); pediatric neurologist (30%). Pediatrician access for consultation to all types of subspecialists is difficult for pediatricians who practice in rural areas (depending on the subspecialty, 10-59% of respondents reported having no access). Overall, patients had greater access

to subspecialty consultation than their pediatricians had.

- Care coordination was the resource most often cited by respondents as necessary to care for children with special health care needs. This was true for both case vignettes, i.e., complex medical issue or behavioral issue. The rank order of resources needed to facilitate care for the complex medical case was as follows:
 - Support staff for case management/care coordination;
 - Reimbursed time for longer visits;
 - Ability to make informal consults and contacts with subspecialty providers (email, phone consultation or telemedicine);
 - Electronic medical record system that links with pediatric subspecialty providers.

The rank order of resources needed to facilitate care for the behavioral case was as follows:

- Support staff for case management/care coordination;
- Readily available community level resources (e.g., Regional Center, Family Voices) for patients and their families to meet their social/home needs;
- Reimbursed time for longer visits;
- Readily available treatment guidelines for patients with specific diagnoses/conditions, e.g., autism, developmental delay.

While support staff for care/case management and adequate reimbursement for longer visits are deemed important

resources for both the autism and neurofibromatosis vignettes, facilitating access to, and communication with, subspecialists is identified as essential for management of the complex medical case. Community resources and treatment guidelines are considered core elements in the support of case management for behavioral cases.

Put another way, for children with chronic medical problems, pediatricians look to their medical colleagues (subspecialists) for support, while for behavioral issues they prefer community resources and standardized guidelines.

Policy Recommendations

Primary care pediatrician respondents reported overwhelmingly that they want to be the medical home for children with special health care needs.

- Recommendation: Include primary care pediatricians in policy conversations and decisions regarding systems of care so that they can contribute to solutions that permit them to fulfill that role and, in so doing, make it possible for more CSHCN to have their care coordinated locally, where they live and go to school.

Enhanced resources for care coordination was identified by both primary care and subspecialty pediatricians as the most important factor in permitting them to provide family-centered medical homes for CSHCN.

- Recommendation: Pilot and implement on a broad scale care coordination and subspecialty supports for community-based

pediatric practices to ensure that subspecialty access and the case management required for specialty needs can be uniformly available to all CSHCN across the state.

Lower levels of families' social resources (family support) adversely affect how comfortable a pediatrician feels in being the primary medical home for a child with special needs.

- Recommendation: Identify and address families' non-medical needs as part of any care coordination process offered through the state and federal CSHCN programs or private insurance plans, particularly for families in poverty/low-income, to enhance support for families and their pediatricians in caring for their child.

Access to developmental and behavioral pediatricians and mental health care providers for CSHCN is clearly lacking across California.

- Recommendation: Develop and implement ways to integrate behavioral and developmental health care into medical care settings for children with special health care needs, including in primary care pediatric practices.

Rural pediatric practices disproportionately lack subspecialty and medical support resources to provide care for the children with special needs in their communities.

- Recommendation: Develop telemedicine and regionalized, shared supports to improve access to subspecialty resources and complex medical care in rural areas that have limited access to pediatric-specific resources.

Primary care and subspecialty pediatricians report the need for readily available community resources for their patients. Currently, communications between primary care practices and outside entities, such as schools and Regional Centers, are inadequate.

- Recommendation: Develop innovative practices and policies to facilitate cross-disciplinary communication and care coordination, such as with school nurses or administration.

The range of complexity and needs of children with special needs is wide, with many primary care physicians taking care of medically complex children outside of a

tertiary care center system; to care for these children requires a financing mechanism that aligns with the severity of the child's illness and/or the time required for care.

- Recommendation: Develop coverage and payment policies that are sufficiently flexible (such as case mix adjustment for payment or resource allocation) to allow practices to individualize the care of CSHCN to achieve better quality of care, health outcomes, and family satisfaction.

Also see: [*Challenges and Joys: Pediatricians Reflect on Caring for Children with Special Health Care Needs*](#)

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