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OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## **What Will Open the Doors for Children and Youth With Special Health Care Needs From Traditionally Underserved Communities?**

Thomas Chapman and Fan Tait  
*Pediatrics* 2010;126;S194-S196  
DOI: 10.1542/peds.2010-1466Q

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# What Will Open the Doors for Children and Youth With Special Health Care Needs From Traditionally Underserved Communities?

The articles in this supplement to *Pediatrics* raise serious questions about the current policies and practices that affect children and youth with special health care needs (CYSHCN) from traditionally underserved communities and are a call to action at a time when the United States is experiencing both unprecedented demographic shifts and a serious economic downturn. Although CYSHCN from underserved communities do confront persistent and even worsening barriers to community-based health and developmental services, the articles in this supplement also describe methods for meeting these issues head-on. In the face of these complex conditions, the supplement authors offer practical information and provide guidance that can steer child health care professionals, communities, parents, and policy-makers alike as they work together to form partnerships and take advantage of new models of interaction as well as the new rights and policies that are embedded within the Affordable Care Act of 2010.

## HEALTH AND HEALTH CARE INEQUITY

Children with special health care needs are living longer and better lives because of improved health care through early identification of problems and new medical and surgical treatments. However, the report by Berry et al, "Children and Youth With Chronic Health Conditions: Another Case of Health Inequity,"<sup>1</sup> is a remarkable documentation of the current status of childhood chronic disease disparity patterns and documents a wide gap in chronic disease severity and outcomes for black, Hispanic, and white children. The gap in incidence and prevalence of disease among white, Hispanic, and black children is essentially consistent across the clinical conditions researched. These findings are especially troublesome, because they reflect a worsening of conditions and complex issues for this vulnerable and often fragile population.

Social determinants such as poverty, substandard housing, poor nutrition, and undesirable social and environmental conditions are strongly influential factors in many minority communities and may heavily contribute to poor outcomes. The disparity in rates of better health and health care for white children versus black and Hispanic children is significant and striking. Gaps in access to care are particularly critical for CYSHCN, because many of their families are supported by state and federal agencies and their needs are often extensive, protracted, and/or permanent.

In addition, the other research articles in this supplement underscore and verify significant underreporting of needs, transition obstacles, primary care access issues, social and cultural barriers, and funda-

**AUTHORS:** Thomas Chapman, MPH, EdD<sup>a</sup> and Fan Tait, MD<sup>b</sup>

<sup>a</sup>HSC Foundation, Washington, DC; and <sup>b</sup>Associate Executive Director, American Academy of Pediatrics, Elk Grove Village, Illinois

### ABBREVIATION

CYSHCN—children and youth with special health care needs

[www.pediatrics.org/cgi/doi/10.1542/peds.2010-1466Q](http://www.pediatrics.org/cgi/doi/10.1542/peds.2010-1466Q)

doi:10.1542/peds.2010-1466Q

Accepted for publication Sep 1, 2010

Address correspondence to Thomas Chapman, MPH, EdD, HSC Foundation, 1808 I St NW, 600, Washington, DC 20006-5429.

E-mail: [tchapman@cscn.org](mailto:tchapman@cscn.org)

PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** *The authors have indicated they have no financial relationships relevant to this article to disclose.*

mental racial and ethnic inequities for children and youth with special needs. There is documentation of gaps in physical and mental health needs and treatment in a wide range of ethnic cultures in the United States (Hispanic, black, Chinese, Haitian, Southeast Asian American, Ethiopian, Pacific Islander, etc). The authors point out many factors that influence the disparities and inequities: uncoordinated government social systems; inadequate medical education and training; family and cultural norms; a lack of community understanding of special needs; and fragmented social, educational, and health systems in communities.

Although children and youth with special needs and circumstances often are not highly visible in the larger society, their growing psychosocial needs and related conditions challenge local and state governments as well as most school systems. Poverty seems to drive or exacerbate most of these problems. Poor communities frequently have higher percentages of Supplemental Security Income (SSI) beneficiaries and children and youth with related chronic illness and special needs. The prevalence of these conditions of poverty undermine and complicate the ability and capacity of families to negotiate and coordinate so many service and care needs simultaneously, especially when resources are frequently organized in separate agencies that are not integrated. Agencies and resources are often limited by variable but ongoing financial constraints, often without the ability to develop an appropriate maintenance strategy plan. Transition planning is a particularly salient example of a service area that requires extensive new funding and resources.

The supplement authors provide telling descriptions of convoluted challenges, high needs and demand, un-

derreporting of problems, multitudes of barriers, stretched or limited family capacity, and inadequate professional knowledge for a population that depends on and interacts with the medical, educational, and social systems in the community on a highly frequent basis. Their voices document the concerted and widespread interest in finding ways to address these longstanding problems that families face.

### LISTENING TO PARENTS AND COMMUNITIES

Repeatedly in the supplement the authors point to the enormous power that is present in communities and to the value of seeking and acting on the suggestions of parents and communities. In past years, the HSC Foundation conducted on-site interviews with families, providers, and health officials responsible for, and involved with, childhood chronic illness and disability. Three important messages were consistently stated by the participants interviewed: (1) increase primary care access; (2) improve quality; and (3) achieve cost-efficiency. Their requests were for “one-stop shopping” (a medical home), care management and coordination systems, and aggregation of payments for health, mental health, and socially enabling resources into a single package.

### SUGGESTING A WAY FORWARD

For more than 30 years, the Maternal and Child Health Bureau, Family Voices, and the American Academy of Pediatrics have promoted the concept of a “medical home” in which care is family-centered, accessible, compassionate, coordinated, continuous, comprehensive, and culturally effective. A medical home is a community-based system of care that includes families, physicians, and interdisciplinary health clinicians, specialists and subspecialists, hospitals, public health agencies, and community organizations.

This care requires acute, subacute, community-based, home-based, and school systems to organize comprehensive and integrated connected networks that can communicate, maintain comprehensive record systems, and conduct treatment, training, and education for the children and their families.

Over the past few years, payers, purchasers of health care, providers, patients and families, federal agencies, and businesses have realized the value of care within a medical home. The recently passed Affordable Care Act includes provisions that reinforce preventive, acute, and chronic care within medical homes. Although a medical home is the kind of care we all want and deserve, it is even more critical for CYSHCN, especially those with racial, socioeconomic, and ethnic diversity.

### ROLES FOR EVERYONE TO PLAY

What is clear from the articles in this supplement is that improving the health and developmental outcomes for children and youth with disabilities and special health care needs depends on increasing opportunities for the children and their families in their communities and the greater society around them. To open the doors to those opportunities, professionals, community leaders, parents, and policy-makers all have specific and valuable roles to play. The following is a short list of suggestions from the articles in this supplement of the types of activities in which each of the players can engage.

Through the establishment of true medical homes, primary care providers can:

1. Review their patient panel by using the Children With Special Needs Screener<sup>2</sup> to identify CYSHCN in their practice. They can then reach out to families and youth in the group who are at double risk because of socioeconomic stresses, language issues, immigration con-

- cerns, parental death, absence or loss of a job, teen pregnancy, or foster care status.
2. Name this panel of patients and give them the benefit of having a special status in the primary care office (receiving a designation on their charts and increased attention by the receptionist and nursing staff at visits).
  3. Work with insurers and Medicaid to obtain per-member per-month enhancement for case coordination and assign a coordinator to provide linkage to community-based services for CYSHCN.
  4. Establish a family council for the practice.
  5. Periodically meet with community leaders, agency heads, and school personnel.
  6. Work with the American Academy of Pediatrics state chapter on initiatives for CYSHCN.

Pediatric specialists can:

1. Review their patient population to identify compounding factors such as poverty, language issues, and immigrant status.
2. Assign a social worker or case coordinator to help the patients access community-based services.
3. Create a family council to help identify common concerns and barriers that the families in the subspecialty practice are facing.

4. Periodically meet with community-based organizations, agencies, and schools.
5. Participate in American Academy of Pediatrics chapter activities that address concerns of CYSHCN.

Community-based organizations and agencies can:

1. Identify families with CYSHCN.
2. Invite health care providers to visit the community-based organization or make regularly scheduled visits to nearby practices, clinics, and hospitals.
3. Hold open family and youth forums on issues related to children and youth with disabilities and special health care needs.
4. Identify and publicize resources for CYSHCN by using community-based communication media such as local radio, newsletters, newspapers, and social media.
5. Participate in partnership activities with child health professionals (eg, through programs sponsored by state American Academy of Pediatrics chapters).

Families can:

1. Offer to meet with health care providers and agencies to offer suggestions on resources for other families of CYSHCN.
2. Create support groups and family-to-family networks, particularly for

marginalized and traditionally underserved parents.

3. Create leadership opportunities for parents from traditionally underserved communities.
4. Communicate to other parents through radio, newsletters, social media, and telephone networking.

Policy-makers can:

1. Ensure that the promises of the Affordable Care Act become realities through meaningful regulations and monitoring of the new insurance provisions, particularly as they relate to the medical home.
2. Support and reinforce provisions of the Individuals With Disabilities Education Act that provide increased services for non-English speakers.
3. Support health literacy interventions.
4. Continue to emphasize quality improvement and outcome orientation as well as payment for coordination services and prevention.

Opening the doors for CYSHCN will not be easy. But, there are tools. There are models. And, there are roadmaps to follow. This supplement to *Pediatrics* certainly does not lay out all the answers, but the authors call for action, partnerships, and continued forward movement to improve the opportunities for children and youth with disabilities and special health care needs.

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