

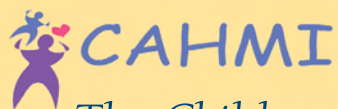


Children with Special Health Care Needs

A Profile of Key Issues in California



Prepared by



*The Child and Adolescent
Health Measurement Initiative*

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www.lpfch.org/specialneeds

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Foreword

The Lucile Packard Foundation for Children's Health is pleased to present this report on the status of California's 1.4 million children with special health care needs. The state's current systems of care for these children provide many valuable services, but often fall short of fulfilling the full range of needs faced by these children and their families. Problems include a broad range of issues, from a lack of family-centered and coordinated care to complicated and inefficient funding mechanisms, among other limitations. The challenge is immense, but improvements are within our reach.

Data for this report are drawn from two national surveys that provide rich, useful information about children with special health care needs. Our foundation commissioned this special analysis of California's results from these larger surveys to provide state policymakers and child health stakeholders with an accurate picture of how the state is faring, and to compel further action on needed changes.

The report offers in-depth information about this vulnerable population of children and their families. It describes the health status of children with special needs; the impacts of their conditions; their health care service utilization; and the quality of care they receive. Each chapter also notes policy and program implications.

Our foundation is committed to working with others to bring about the system improvements called for in this report. In the last two years, we have convened leaders across the state and nation to articulate a vision for an enhanced system of care for these children in California. This model of care calls for a high-performing system that provides high-quality, family-centered, culturally competent, and coordinated care within a medical home, funded by a unified, efficient, and comprehensive payment system. The model also calls for an adequate number of well-trained pediatric specialty care providers; focused training for general pediatricians in the management of children with special health care needs; and widely accepted and uniformly utilized quality measures. For more information on this vision, visit <http://www.lpfch.org/programs/cshcn>.

As part of this work, the foundation also is establishing the California Collaborative for Children with Special Health Care Needs, through which representatives from all parts of the system can advocate jointly for policy changes. For more information about this Collaborative, visit <http://www.lpfch.org/specialneeds>.

We are grateful to the Child and Adolescent Health Measurement Initiative for its diligent work on this report, and to the project advisors for offering expertise throughout the process. We hope that individuals and organizations across California will use this report and its companion piece to ensure that children with special health care needs reach their maximum health potential.

David Alexander, MD
President and CEO
Lucile Packard Foundation for Children's Health



Executive Summary

Children with *Special Health Care Needs: A Profile of Key Issues in California* is a comprehensive report on the health and well-being of the state's estimated 1.4 million children with special health care needs (CSHCN). This report draws on the most recently available data from the 2007 National Survey of Children's Health and the 2005-06 National Survey of Children with Special Health Care Needs. The report provides a profile of demographic characteristics, physical, mental, and social functioning, and health and community service needs of CSHCN in California. It also summarizes key aspects of health insurance coverage, health care system performance and the impact of having a special need on school engagement, and family health and well-being for CSHCN.

The report aims to assess California CSHCN in the context of national data, highlighting variations and disparities in care between California and the rest of the nation. In making these comparisons, the report notes areas where improvement is necessary, such as enrollment for insurance coverage, availability of services, care coordination, and family and community engagement.

Throughout the report, CSHCN are defined according to the widely endorsed federal Maternal Child and Health Bureau definition which sets forth that CSHCN are those with a physical, mental, developmental, or other type of ongoing health condition that requires an above routine need for or use of health and related services of a type or amount than required by children generally.¹ There is a long and compelling body of research supporting this consequences-based definition over a condition-specific, diagnostic-based definition of CSHCN.

Overall, the report shows that California has a particularly diverse and high-need population of CSHCN, and that many families are struggling to meet the basic needs of these children. Data also show that California ranks poorly compared to other states on numerous measures of quality health care for CSHCN, including adequacy of insurance, provision of basic preventive care, and meeting minimal criteria for having a medical home (ongoing, comprehensive, coordinated, and family-centered care).

The Report's Key Findings

Children with Special Health Needs Are Prevalent and Their Needs Are Complex

- About 1 in 7 California children has a special health care need.
- California's CSHCN are diverse: children of color represent approximately 52 percent of the CSHCN population in California compared to 33 percent in the rest of the nation.
- Nearly 60 percent of California's CSHCN have multiple chronic conditions, and 42 percent of CSHCN need at least five types of health services, many of which are complex services that go beyond primary care.
- 39 percent of California's CSHCN are overweight or obese—in addition to other health conditions they experience.
- CSHCN with the greatest complexity of needs are often those who experience the greatest challenges in accessing a variety of the high quality services they need.

Health Conditions Impact Daily Life for CSHCN and Their Families

- 21 percent of school-age CSHCN in California have repeated a grade compared to only 8 percent of the general child population.
- 15.4 percent of school-age CSHCN missed 11 or more days of school per year due to health conditions, compared with 4 percent of children without special health needs.
- Over 1 in 6 publicly insured California CSHCN has a family that spends 11 hours or more per week providing or coordinating care. In total, these families spend an estimated 3,780,000 hours per week coordinating their child's care, which is equivalent to 94,500 full-time employees.
- California has the highest percentage nationwide of CSHCN whose parents experience stress due to parenting.
- The parents of 36 percent of publicly insured CSHCN in California report having to stop work or cut back on their hours at work because of their children's needs. This percentage is much higher for CSHCN with higher levels of service needs and poor care coordination.

Health Care Quality Is Poor for Many California CSHCN

- Strikingly, California ranks last in the nation on a minimum quality of care index for CSHCN that assesses adequacy of insurance, provision of basic preventive care, and meeting minimal criteria for having a medical home (17 % California vs. 40% nationally).
- California children are significantly less likely to have parents who feel satisfied with care and feel like a partner in their child's care than children in other states. The state ranks second to last in the nation on the percentage of CSHCN who receive family-

centered care, a fundamental measure of quality care that represents a minimum level of effective communication and interaction with families.

- Only 4 in 10 of California's CSHCN are receiving care within a medical home—a minimum standard of quality that assesses whether care is ongoing, comprehensive, coordinated, and family-centered.
- Of CSHCN with health insurance, about 1 in 3 has insurance that is inadequate to meet his or her health care needs.
- About 2 in 5 CSHCN in California do not receive needed mental health care.
- Roughly 8 in 10 poor and publicly insured youth with special health care needs in California are not receiving appropriate services to support their transition to adulthood and the adult health care delivery system.

Health Care Disparities Affect California's CSHCN

- CSHCN who are low income, of color, or publicly insured are more likely than other children with special needs to have poor health status and sub-optimal health care experiences. For example, nearly 6 in 10 African American CSHCN and about 8 in 10 Latino CSHCN in primarily Spanish-language households are not receiving family-centered care, compared to almost 3 in 10 white CSHCN.
- Additionally, just 30 percent of publicly insured CSHCN receive coordinated, ongoing, comprehensive care within a medical home, compared to 50 percent of privately insured. And 94 percent of privately insured CSHCN in California have a usual source of sick and well care, compared to about 88 percent of publicly insured CSHCN.
- Approximately 107,000 CSHCN are uninsured. California ranks 40th out of the 50 states and the District of Columbia on the number of uninsured CSHCN.

Conclusions

It has been widely recognized within the state that California's system of care for CSHCN needs significant improvements and reform of some magnitude. These findings compel continued engagement and collaboration among policymakers and other stakeholders in addressing care for children with special needs in California.

The recent passage of federal health care legislation provides important opportunities for additional funding and incentives for securing access to quality care for CSHCN, and includes models for reforming financing and organization of services to optimize access and quality and to manage efficiency and costs of care. Successful reform will require the concerted efforts of the public and private sectors, purchasers, payers, providers, families, and youth themselves.

In support of such efforts, this report offers the following general conclusions regarding the health and well-being of California's CSHCN.

Since health insurance coverage is an essential component of any strategy to promote high quality care for children, all eligible children should be enrolled in public or private

programs. Medi-Cal and SCHIP play an important role in overall access to care for CSHCN. Close monitoring and evaluation of the impact of Medi-Cal and SCHIP reforms on CSHCN should be central to any health care reform strategy.

Since most California CSHCN have more than one type of health condition, policies and programs that focus on single conditions or only a few specific health problems will not adequately address care needs for California's CSHCN. Likewise, California's many health agencies and programs are often caring for the same CSHCN—emphasizing the importance of cross-agency and cross-sector collaboration and coordination in designing, implementing, and improving services. This is especially the case for integrating medical and mental and developmental health related services.

Additional services also should be provided to CSHCN with more complex health conditions and functional limitations, since these children have substantial unmet care needs, including a high proportion of parents having to cut back or stop working due to unmet needs. In addition, all programs should provide linguistically and culturally appropriate services for CSHCN of color, as these children represent the majority of CSHCN, and are most likely to have low quality of care.

Overall, there is much room for improvement in access to and delivery of high quality care for CSHCN. Effective improvement efforts currently under way by pediatric leaders in the state should be expanded. Policy and program attention should be directed toward improving the availability of medical homes for children and youth with special health care needs, particularly for CSHCN of color.

In addition, enhancing existing data about CSHCN in California is desirable. Though this report provides an important starting point for data about CSHCN, some analyses were limited due to small sample sizes. For example, interesting differences exist between CSHCN and non-CSHCN who have either public or private insurance (e.g., overweight/obese, problems with getting needed referrals), but sample sizes were too low to make confident determinations based on these multiple layers of stratification. Also, due to the diverse ethnic background of children within California, further efforts would need to be undertaken locally to determine health status differences between groups of Latino CSHCN (e.g., Mexican, El Salvadoran ancestry) or Asian CSHCN (Chinese, Vietnamese ancestry).

Finally, analyses were limited to data collected within national surveys and analyzed at the state level. More data collection would be required to compare specific communities within California regarding the health status, well-being, and health care needs of CSHCN. The well-being of CSHCN within California depends on the performance of a variety of health and educational systems, which vary across the state, between different counties and communities in the state, and even within local agencies and school districts. To assess differences in quality of care at those levels will require California to conduct further research on the health of its population of children with special health care needs.

References for Executive Summary

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 Pt 1):137-140.

Executive Summary Data Tables

Children with Special Health Care Needs (CSHCN) in California vs. Nation	Percent in California	Percent in Nation	California Ranking 1=best, 51=worst
Children with special health care needs ^b	14.5%	19.9%	*
CSHCN of color (Latino, African American, Asian, and Multiracial/Other) ^a	52.2%	32.9%	*
CSHCN with 2 or more conditions (from a list of conditions) ^a	57.0%	57.2%	*
CSHCN with 5 or more health service needs in the past 12 months ^a	42.4%	47.3%	*
CSHCN whose health care meets a minimum quality index ^{1†b}	17.1%	40.3%	51
CSHCN whose parents experience stress ^{†b}	26.6%	19.3%	51
CSHCN whose parents feel like partners in their child's care ^{†a}	46.6%	58.5%	51
CSHCN who receive family-centered care ^{†a}	59.6%	66.4%	50
CSHCN who have difficulty accessing community-based services ^{†a}	14.7%	10.5%	49
CSHCN who needed a referral and had problems getting one ^{†a}	27.6%	20.4%	49
CSHCN who receive effective care coordination ^a	54.5%	59.7%	48
CSHCN with inadequate insurance coverage ^b	34.7%	28.8%	46
CSHCN who receive needed transition services to adulthood ^a	37.1%	41.7%	45
CSHCN who receive needed mental health care ^b	59.2%	61.9%	43
CSHCN who receive coordinated care within a medical home ^{†a}	42.2%	47.7%	44
CSHCN who do not have a usual source of sick and well care ^a	8.9%	6.9%	44
CSHCN who are uninsured ^b	7.9%	5.9%	40
CSHCN who are overweight or obese (BMI for age \geq 85%) ^b	39.0%	36.0%	38
CSHCN who have repeated a grade in school ^b	20.9%	18.2%	36
CSHCN whose parents had to cut back or stop working due to the child's condition ^a	23.7%	23.8%	31
CSHCN with inconsistent insurance coverage (uninsured or not insured all of past 12 months) ^b	11.7%	12.4%	28
CSHCN whose families spend 11 or more hours on care per week ^a	9.2%	9.8%	23
CSHCN whose parents report the child's condition created a financial burden ^a	15.5%	18.4%	7

* Indicator cannot be ranked.

Note: Rankings are based on all states and the District of Columbia. National percentages include all states and the District of Columbia without California calculated into the estimate.

¹ Minimum quality index = CSHCN who have a medical home, have adequate health insurance coverage, and had at least one preventive visit in the past 12 months.

[†] Chi-square test is significant at the $p < 0.05$ level.

Data sources:

^a 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

^b 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Comparisons of Children with Special Health Care Needs (CSHCN) vs. Those without Special Health Care Needs within California	Percent of CSHCN	Percent of Non-CSHCN
Children whose health care meets a minimum quality index ^{*†b}	17.1%	42.4%
Children with inadequate insurance ^{†b}	34.7%	23.1%
Children with inconsistent insurance coverage (uninsured or not insured all of past 12 months) ^{†b}	11.7%	16.9%
Children who have repeated a grade in school ^{†b}	20.9%	7.8%
Children who missed 11 or more days of school ^{†ab}	15.4%	4.0%

*Minimum quality index = Children who have a medical home, have adequate health insurance coverage, and had at least one preventive visit in the past 12 months.

† Chi-square test is significant at the $p < 0.05$ level.

Data sources:

^a 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

^b 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Key Indicators by Race/Ethnicity in California	Percent White	Percent African American	Percent Latino
CSHCN who receive routine preventive care ^{†a}	68.8%	56.9%	53.9%
CSHCN who receive family-centered care ^{†a}	73.4%	43.9%	43.0%
CSHCN who receive coordinated care within a medical home ^{†a}	52.7%	28.3%	28.7%

† Chi-square test is significant at the $p < 0.05$ level.

Data sources:

^a 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

^b 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Key Indicators by Insurance Type in California	Percent Among Publicly Insured	Percent Among Privately Insured
CSHCN who have 4 or more functional difficulties (from a list of common difficulties) ^{†a}	33.9%	20.2%
CSHCN who receive routine preventive care ^{†a}	54.8%	69.1%
CSHCN who have a usual source of sick and well care ^{†a}	87.6%	94.3%
CSHCN who receive coordinated care within a medical home ^{†a}	29.7%	49.9%
CSHCN who needed a referral and had problems getting one ^a	34.7%	23.4%
CSHCN who have difficulty accessing community-based services ^{†a}	23.8%	9.6%
CSHCN who receive family-centered care ^{†a}	42.4%	68.9%
CSHCN whose parents feel like partners in their child's care ^{†a}	40.6%	52.0%
CSHCN whose parents had to cut back or stop working due to the child's condition ^{†a}	36.1%	16.1%
CSHCN whose parents spent more than \$1,000 on out of pocket expenditures ^{†a}	4.5%	23.0%
CSHCN whose families spend 11 or more hours on care per week ^{†a}	17.5%	5.5%

† Chi-square test is significant at the $p < 0.05$ level.

Data sources:

^a 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

^b 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org



Introduction

This report offers families, health care providers, health services agencies, and policy-makers a summary of the most recent data available about California's approximately 1.4 million children with special health care needs (CSHCN). As a resource for child health stakeholders across California, the report presents data on the characteristics, health status, health service needs, and system performance for California's CSHCN. The information provided here is intended to inform and expedite progress of existing efforts and jump-start new policy and program strategies to improve the system of care and, ultimately, the short- and long-term health outcomes for children and youth with special health care needs and the quality of life of these children and their families.

The Importance of Focusing on CSHCN

In its 2001 report, *Crossing the Quality Chasm*,¹ the Institute of Medicine defined high-quality health care as care that is safe, effective, patient-centered, timely, efficient, and equitable. The federal Maternal and Child Health Bureau sets forward a model of care for CSHCN that ensures the provision of comprehensive, community-based, coordinated, family-centered, and compassionate services. While many children with special needs in both California and the nation receive this type of high-quality care, multiple reports suggest that this is often not the case.^{2,3} In fact, recent studies suggest that all children and adolescents, on average, receive less than 50 percent of recommended care, and approximately four out of five children with special health care needs fail to receive one or more basic aspects of quality care.^{4,5} Clearly, improving care for our most vulnerable children should be a high priority in California.

Data Sources and Methods

Two primary data sources were used in this report: the 2007 National Survey of Children's Health (NSCH) and the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN). Both surveys are national, parent-reported telephone surveys funded by the Maternal and Child Health Bureau of the U.S. Department of Health Resources and Service Administration and conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). Both of these surveys

report representative national and state-level data for the non-institutionalized population of children ages 0-17. Child health indicators from the NSCH and the NS-CSHCN were selected and refined in consultation with California child health stakeholders. Standard statistical tests of differences are used throughout this report. For this report, national data include all states and the District of Columbia without California calculated into the estimate. A full description of data sources and methods can be found in the appendix.

Author and Funder Background

This report was commissioned by the Lucile Packard Foundation for Children's Health and produced by the Child and Adolescent Health Measurement Initiative (CAHMI). The Lucile Packard Foundation for Children's Health, an independent public charity based in Palo Alto, California, was founded in 1996. Its mission is to elevate the priority of children's health and increase the quality and accessibility of children's health care through leadership and direct investment. The CAHMI, founded in 1997, is a research and policy group based at Oregon Health & Science University that focuses on the development, implementation, and strategic dissemination of data based on measures of child and adolescent health and health care quality.

References for Introduction

1. Institute of Medicine, Committee on Quality of Health Care in America. *Crossing the Quality Chasm*. Washington, D.C.: National Academy Press; 2001.
2. Family Voices. California Survey of the Health Care Experiences of Families of Children with Special Health Care Needs. 2000.
3. Inkelas M, Smith KA, Kuo AA, Rudolph L, Igdaloff S. Health care access for children with special health care needs in California. *Maternal and Child Health Journal*. 2005;9(2):S109-16.
4. Mangione-Smith R, DeCristofaro AH, Setodji CM, et al. The quality of ambulatory care delivered to children in the United States. *The New England Journal of Medicine*. 2007;357(15):1515-1523.
5. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*. 2004;158(9): 884-890.



Chapter 1: Who Are Children with Special Health Care Needs?

Understanding the number and types of children who have special health care needs is an important first step toward developing policies that target children’s needs appropriately. This section has two parts. Part A reports on the prevalence of special health care needs among children in California, the specific conditions and types of conditions that California children have, and the overall health status and functioning of children with special health care needs (CSHCN). Part B reports on the composition of California’s CSHCN in terms of age, gender, race/ethnicity, language, income, and insurance status. Throughout this section, California CSHCN are compared to CSHCN in other states as well as to children without special needs.

Part A: Health Care Needs, Conditions, and Functioning of California’s CSHCN

Defining Special Health Care Needs

The Maternal and Child Health Bureau defines 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.”¹

This definition is broad and inclusive: instead of focusing on specific chronic health conditions, it defines special needs based on how children’s health conditions affect their lives and their need or use of health and health-related services. As a result, this definition of special needs incorporates children with a wide range of conditions and risk factors.

One of the major goals of the National Survey of Children’s Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN) is to determine the proportion of children who currently have a special health care need. Therefore, children *at risk* for a special health care need or difficulty are not included in the definition. To provide a real-time assessment of prevalence and current system performance for CSHCN, the screening tool used in the NSCH and NS-CSHCN—the CSHCN Screener²—focuses on children who currently have an ongoing health condition that has already resulted in a need for, or a use of, above routine and/or special health care services. Also included are the small minority of CSHCN whose condition results in a persistent and notable functional limitation but does not necessarily require an above routine need or use of health care services.

For a child to qualify as having a special need on the CSHCN Screener, a parent must report that the child has “a condition that has lasted or is expected to last at least one year,” and also must report that the condition resulted in *at least one* of the following consequences for the child:

- The need for or use of prescription medication for the child’s condition
- The need for or use of more health-related services than other children of the same age generally require, including:
 - ◆ medical care
 - ◆ mental health services
 - ◆ education services (including special education)
 - ◆ treatment or counseling for an emotional, developmental, or behavioral problem
 - ◆ special therapy, such as physical, occupational, or speech therapy
- A limitation in the child’s ability to do the things most children of the same age do (functional limitations)
- An ongoing emotional, behavioral, or developmental problem that requires treatment or counseling

A child who has both an ongoing condition that has lasted or is expected to last at least a year and also has resulted in one of the above consequences qualifies as a Child with Special Health Care Needs. While CSHCN experience many other needs and consequences not included in the CSHCN Screener, studies show that nearly all will experience at least one of the needs or consequences listed above. As such, the screener criteria used for identifying CSHCN provide a strong signal for having a special health care need.

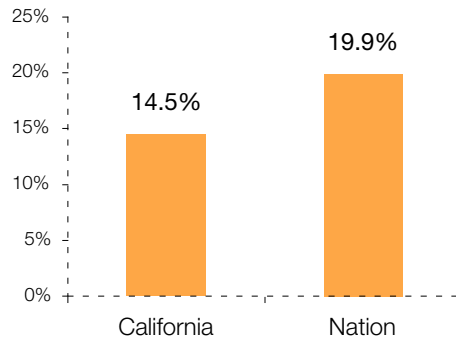
The Prevalence of Children with Special Health Care Needs in California

Based on the CSHCN Screener questions, 14.5 percent of children under 18 years of age in California, or approximately 1.4 million children, were estimated to have special health care needs in 2007. The percent of California children with special health care needs has not changed substantially since the last time the National Survey of Children’s Health was administered, in 2003.

IMPLICATIONS: California has a significantly lower prevalence of CSHCN compared to the rest of the country. The reasons for California’s lower rate of CSHCN are complex. National data suggest that Latino families who are recent immigrants are less likely to qualify on the screener as having a child with a special health care need due to their own health care practices and cultural norms related to health services use and perceptions of their child’s health.² As discussed in the race/ethnicity section of this chapter (below), Latino children are less likely to qualify as CSHCN primarily because they are less likely to be taking prescription medications, one of the prominent health services provided to CSHCN. Because California has a very large Latino population, it has a lower rate of CSHCN compared to other states. In fact, after statistical adjustment for the different racial/ethnic characteristics, health insurance status, and income of children in California, California’s rate of CSHCN is statistically similar to the rest of the country.

14.5 percent of children under 18 years of age in California, or approximately 1.4 million children, were estimated to have special health care needs in 2007.

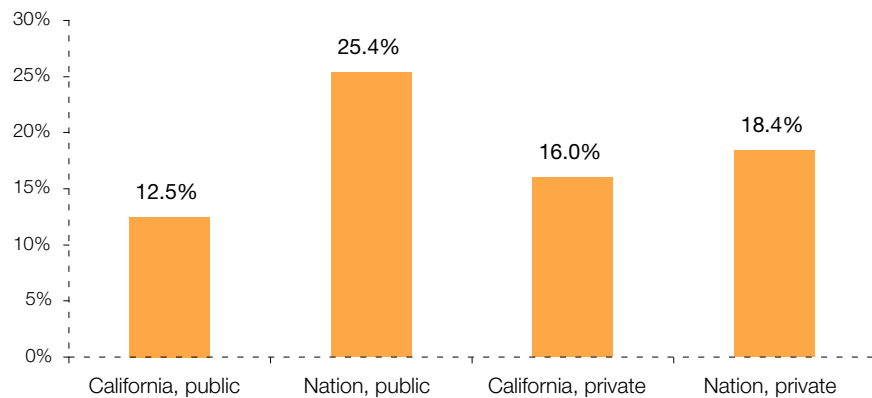
Figure 1.1: CSHCN as a Percentage of All Children Ages 0-17



Chi-square test $p = 0.002$; Statistical significance eliminated with control for differences in demographic characteristics between California and the rest of the nation.

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Figure 1.2: CSHCN as a Percentage of All Children Ages 0-17, by Type of Insurance



Chi-square test $p < 0.001$ for prevalence rate of CSHCN among children with public insurance, California vs. the nation.

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

California's CSHCN Have Complex Health Conditions

Because of the nature of the CSHCN Screener, children qualify as having a special health care need for different reasons. Given that many chronic conditions are treatable with medication, some CSHCN qualify based on a need that is primarily met by prescription medications. However, a majority of children qualifying as CSHCN require more than prescription medications. They need additional health services, such as above routine use of primary or specialty medical care, educational services, or specialized therapies. Some children also qualify based on having a notable and persistent functional limitation that goes beyond the many more routine difficulties CSHCN experience. Nearly all of these children with more serious functional limitations also require prescription medications and/or specialized services.

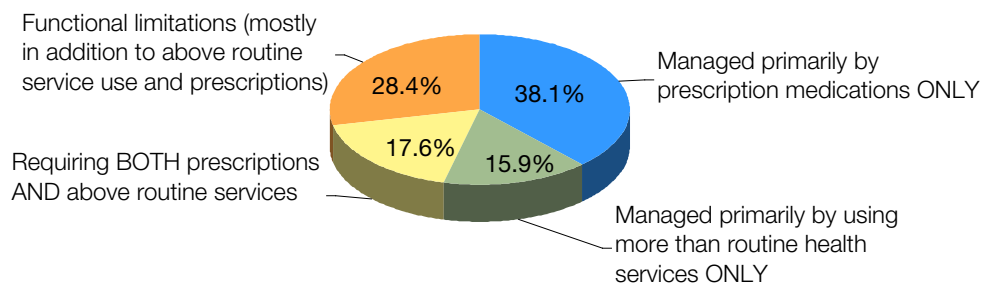
The diversity of health and service needs in the CSHCN population presents a special challenge for state and federal programs that must understand the specific needs of certain groups of CSHCN. As a result, researchers often divide CSHCN into sub-groups

of children who tend to have different health outcomes and service needs.³ Throughout this report, these four *mutually exclusive* groups of CSHCN are referred to as:

- Children whose needs are managed primarily by **prescription medications ONLY**
- Children whose needs are managed primarily by **above routine health services ONLY**
- Children whose needs are managed by **BOTH prescriptions AND above routine services**
- Children with **functional limitations** and (with some small exceptions) also requiring an above routine service use and prescriptions—the most complex of all CSHCN subgroups.

Among the California children who qualified on the CSHCN Screener, nearly 40 percent qualified based solely on the need for prescription medications (see Figure 1.3). However, nearly 30 percent of California CSHCN qualified based on having notable limitations in their ability to do the things most children of the same age do that go beyond the more routine functioning difficulties most other CSHCN experience. Children who qualify as CSHCN based on their need for prescription medications alone often can be well-managed by the provision of proper health care services. However, children who qualify as CSHCN based on their functional limitations often experience significant limitations despite the health care and related services that they receive.

Figure 1.3: Percentage of California CSHCN Ages 0-17, by CSHCN Screener Qualifying Criteria



Data source: 2007 *National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

California's rate of CSHCN with functional limitations is somewhat higher, though not statistically different, than rates in the nation as a whole. Nationwide, 22 percent of CSHCN have functional limitations, compared to 28 percent in California. California may have a slightly higher proportion of CSHCN with functional limitations because of California's large population of Latino children. National research suggests that while Latino children are less likely to qualify as CSHCN overall, when they qualify, they have more complex needs and are more likely to experience functional limitations.³ More information about categorization of CSHCN and the CSHCN Screener can be found in the appendix.

Most of California's CSHCN Have Multiple Health Conditions

The 2005-06 NS-CSHCN asks parents of CSHCN if their child has any one of 16 health conditions common among CSHCN (see table below). Of these 16 conditions, allergies were the most commonly reported health condition in California, at 48 percent. Other frequently reported conditions were asthma (42%), attention deficit disorder (24%), and

Asthma, allergies, attention deficit disorder (ADD/ADHD), and emotional problems were the most common health conditions reported among CSHCN in California.

emotional problems (20%). Notably, rates of ADHD among CSHCN in California are significantly lower than rates in the rest of the country (24% vs. 30%), consistent with research on a lower rate of reported ADHD within the Latino population.⁴ Other conditions do not vary significantly from national averages.

Table 1.1: Percentage and Population Estimate of California CSHCN with Specific Health Conditions

Condition	Percentage having this condition	Percentage with this condition and at least one other condition	2005/06 population estimate with this condition
Allergies	48%	84%	650,000
Asthma	42%	78%	573,000
Attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD)	24%	71%	324,000
Emotional problems	20%	86%	277,000
Migraine or frequent headaches	14%	93%	194,000
Mental retardation	10%	94%	139,000
Autism or autism spectrum disorder (ASD)	5%	88%	64,000
Arthritis or joint problems	5%	90%	63,000
Heart problem, including congenital heart disease	4%	72%	54,000
Blood problems, including anemia and sickle cell disease	3%	91%	37,000
Cerebral palsy	3%	100%	36,000
Epilepsy or seizure disorder	2%	96%	29,000
Diabetes*	1%	78%	15,000
Down syndrome*	1%	92%	11,000
Muscular dystrophy*	<1%	100%	4,000
Cystic fibrosis*	<1%	100%	4,000

*Estimates based on sample sizes too small to meet standards for reliability or precision.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

It is important to note that these figures represent the percentage of CSHCN who have these conditions, not the percentage of all California children with the condition. The percentages do not add up to 100 because most children have more than one condition. In fact, very few CSHCN experience only one of the conditions asked about in the survey. For example, 84 percent of children with allergies have at least one of the other conditions asked about. Additionally, those identified as having only allergies may also have another condition not asked about in the survey.

Nearly 60 percent of California CSHCN have two or more conditions from this list, as indicated in Table 1.2. This is especially true for children with functional limitations: Figure 1.4 shows that 78 percent have two or more conditions. However, even children

Nearly 60 percent of California's CSHCN have two or more common health conditions.

with less complex care needs are likely to have multiple conditions. As illustrated in Figure 1.4, approximately 52 percent of CSHCN qualifying only on the “prescription medication use” criterion have two or more conditions—further confirming that this is also an important group of CSHCN to continue to focus on in California.

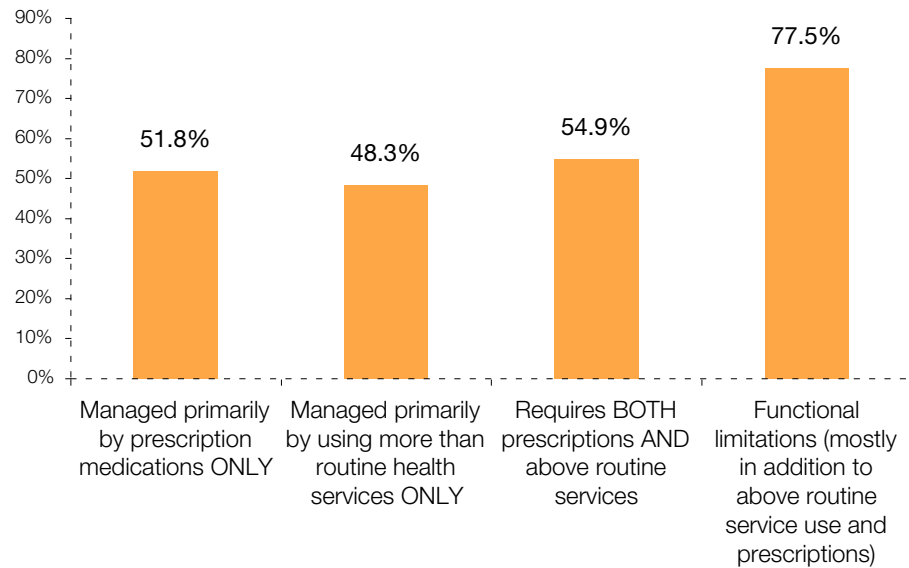
Table 1.2: Percentage and Population Estimate of California CSHCN, by Number of Conditions

Number of conditions*	Percentage	2005/06 population estimate
1 condition	31%	298,000
2 conditions	35%	337,000
3 conditions	13%	124,000
4 or more conditions	9%	88,000

*Data based on a list of 16 common health conditions. 12% of CSHCN had ongoing health conditions other than those asked about in the survey.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child Adolescent Health website. www.cshcndata.org

Figure 1.4: California CSHCN with Two or More Conditions, by CSHCN Screener Qualifying Criteria*



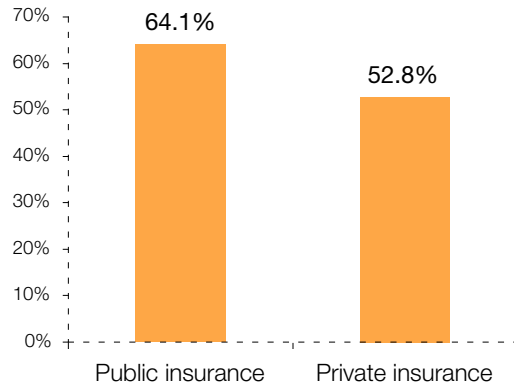
*Children with special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN in California with public insurance are significantly more likely to have two or more conditions, as children with more complex health conditions often have public insurance as their *secondary* payor. This can be because their private insurance does not adequately cover all of their medical needs, or that they routinely exceed the private insurance annual or lifetime cap.

Figure 1.5: California CSHCN with Two or More Health Conditions,* by Type of Insurance



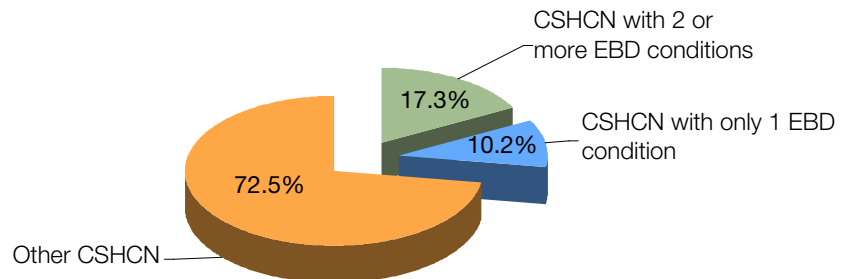
*Data based on a list of 16 common health conditions. 12% of CSHCN had ongoing health conditions other than those asked about in the survey.

Chi-square test $p = 0.03$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Emotional and behavioral issues are common among CSHCN, and those with these types of conditions frequently experience much poorer quality of care.⁵ More than one in four (27.5%) CSHCN in California has ongoing emotional, behavioral, or developmental problems, and of those children, 63 percent have two or more conditions (see below). These rates are similar to rates found in the nation overall.

Figure 1.6: California CSHCN by Whether They Have Ongoing Emotional, Behavioral, or Developmental (EBD) Conditions



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: The special needs of California’s CSHCN are complex and often require both physical, mental, and emotional health care services. Since most CSHCN in the state have more than one condition, policies and programs aimed at a single condition or type of condition do not serve the needs of most of California’s CSHCN. Integration across medical and mental health care systems is essential.

Functional Difficulties of CSHCN in California

One way to broadly assess a child’s health is to examine his or her functional difficulties, or difficulties doing things that other children his or her age do. The NS-CSHCN assesses specific types of functional difficulties sometimes experienced by children with special health care needs.

The functional difficulties include:

- Difficulty with ***emotional or behavioral issues***, such as:
 - ◆ anxiety or depression
 - ◆ behavioral problems
 - ◆ difficulty making or keeping friends
- Difficulty with ***participating in any activity***, such as:
 - ◆ difficulties with self-care activities, e.g., eating or dressing
 - ◆ coordination or movement difficulties
 - ◆ difficulties using hands
 - ◆ difficulty learning, understanding, or paying attention
 - ◆ difficulty speaking, communicating, or being understood
- Difficulty with ***bodily functions***, such as:
 - ◆ vision difficulties despite wearing glasses or contacts
 - ◆ hearing difficulties even with aids
 - ◆ breathing difficulties
 - ◆ swallowing, digestive, or metabolic difficulties
 - ◆ blood circulation difficulties
 - ◆ chronic physical pain, including headaches

Both national and California data suggest that most children with special health care needs experience at least one type of *functional difficulty*. However, in only a smaller subset do these difficulties lead to *functional limitations*, or *limitations* in the ability to do things that other children their age can do (a CSHCN screening criterion—see above). Functional difficulties are assessed in all CSHCN, regardless of whether they fall into the “functional limitations” category of the CSHCN Screener.

In California, 87.7 percent of CSHCN experience one or more of the above functional difficulties. Notably, 12.3 percent of CSHCN experience none of these functional difficulties, while more than twice that (25.3%) report four or more functional difficulties. This is similar to the national average—27.7 percent of CSHCN experience four or more of the functional difficulties.

As shown in the table below, children whose conditions are managed solely by prescription medications are the least likely to have four or more functional difficulties (5.1%) compared to all other groups. They also are least likely to have difficulty with emotional/behavioral issues and participating in activities. However, they are most likely to have difficulties with bodily functions (such as respiratory or digestive problems), more than likely due to conditions such as asthma and/or allergies.

As would be expected, children qualifying on the CSHCN Screener with functional limitations experience the broadest impact on their daily activities.²⁴ They are the most likely to experience four or more difficulties (56.8%) as well as problems participating in activities (83.7%). The majority also have difficulties with bodily functions and emotional issues.

Table 1.3: Number and Types of Functional Difficulties Among California CSHCN, by CSHCN Screener Qualifying Criteria*

CSHCN Screener qualifying criteria	Four or more functional difficulties	Difficulty with any bodily function	Difficulty participating in any activity	Difficulty with any emotional or behavioral issues
Managed primarily by prescription medications ONLY	5.1%	71.0%	19.6%	14.9%
Managed primarily by using more than routine health services ONLY	34.3%	35.5%	77.7%	57.0%
Requires both prescriptions AND above routine services	26.5%	51.7%	55.7%	63.1%
Functional limitations (mostly in addition to above routine service use and prescriptions)	56.8%	54.3%	83.7%	55.8%

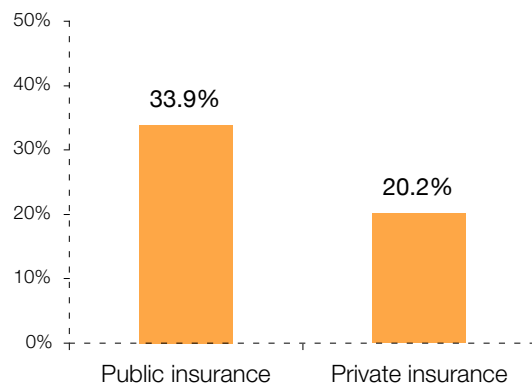
*Children with special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received.

Chi-square test $p < 0.001$ for all columns of data

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

California CSHCN with public insurance are significantly more likely than CSHCN with private insurance to experience four or more functional difficulties. This may be due to the fact that many CSHCN with complex health conditions are unable to find private health insurance plans that can adequately cover their medical needs.

Figure 1.7: Four or More Functional Difficulties, by Type of Insurance



Chi-square test $p = 0.003$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN with ongoing emotional, behavioral, or developmental issues also are significantly more likely to experience four or more functional difficulties (54.4%) compared with CSHCN who do not have such ongoing issues (14.2%).

IMPLICATIONS: California systems of care should ensure that all functional difficulties and needs are adequately assessed and addressed. Many CSHCN experience multiple functional difficulties that may stem from one or more conditions. Attention to these difficulties is often as important as the diagnosis and medical treatment of conditions. Children who experience functional difficulties often require services that cross multiple medical, mental, and educational systems of care, which may inhibit comprehensive access to services.

Overweight and Obesity: A Key Risk Factor Among California's CSHCN

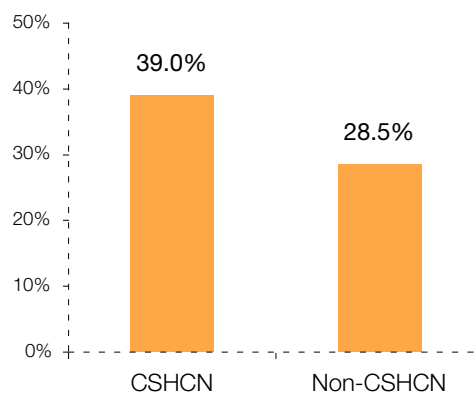
Childhood overweight and obesity is a major concern nationally and in California.⁶ Several recent studies suggest that children with chronic conditions are more likely to be overweight or obese.⁷

Among California CSHCN ages 10-17 (the ages for which reliable data were available), 26.6 percent are overweight (defined as 85-94 percentile body mass index for age), and 12.4 percent are obese (defined as 95 percentile or above body mass index for age).

As shown in the next figure, 39 percent of California CSHCN are overweight or obese, compared to 28.5 percent of children without special health care needs. While the difference between CSHCN and children without special health care needs is not statistically significant in California, it is consistent with national findings of higher rates of overweight and obesity among CSHCN.⁶

IMPLICATIONS: Since overweight and obesity are very common among CSHCN, programs for CSHCN should include primary prevention efforts as well as education and advice regarding pediatric nutrition and active lifestyle. California's special education system should pay particular attention to the weight status of CSHCN and work to improve it by providing appropriate education, food products, and opportunities for exercise for all children regardless of level of disability.

Figure 1.8: Percentage of California Children Who Are Overweight or Obese, by CSHCN Status



Chi-square test $p = 0.20$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

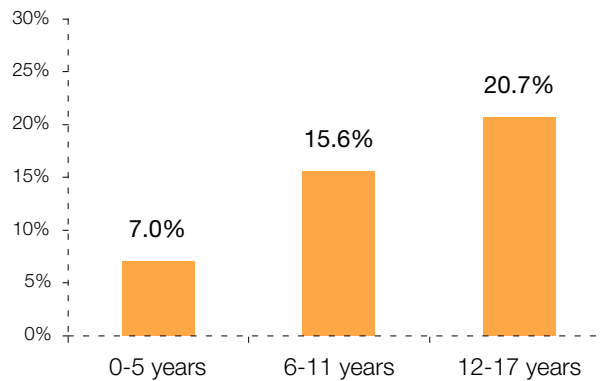
39 percent of California's CSHCN are overweight or obese.

Part B: Demographic Characteristics of California's CSHCN

By Age

As expected based on the epidemiology and accurate identification of ongoing health conditions in children, the prevalence of special health care needs within the child population increases with age.⁸ The youngest children (birth to 5 years) have the lowest prevalence of special health care needs, while the oldest age group (ages 12-17 years) has the highest prevalence. The higher prevalence among older children is partly attributable to conditions that do not develop until later in childhood, are not immediately diagnosed, or are not identified via early screening and assessment—either due to lack of valid screening methods or poor implementation of screening at earlier ages.

Figure 1.9: Percentage of CSHCN Out of Total California Child Population, by Age Group

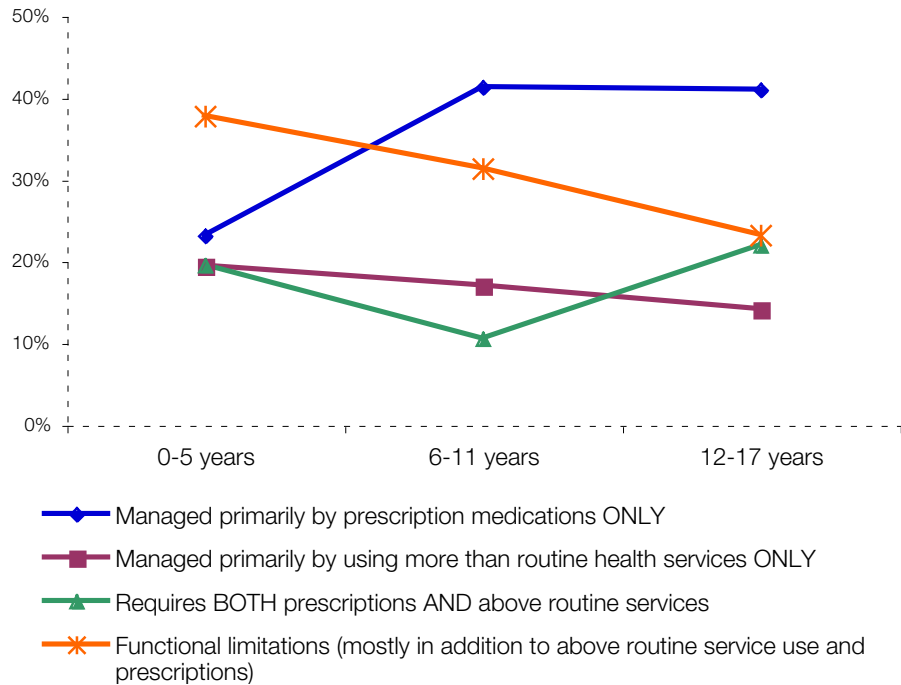


Chi-square test $p = 0.001$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

The complexity of special health care needs also changes according to a child's age. For instance, older children are more likely to have special needs that are managed by prescription medications alone than are younger children, and younger children are more likely to have functional limitations (Figure 1.10). This finding also reflects the fact that less-obvious and milder conditions may not be picked up by parents or health care providers until a child is older.

Figure 1.10: Prevalence of CSHCN by Age and CSHCN Screener Qualifying Criteria*



*Children with special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received.

Chi-square test $p = 0.75$

Data source: 2007 *National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

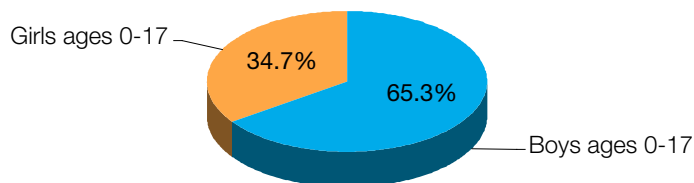
IMPLICATIONS: Programs and policies aimed at CSHCN should take into account their changing needs as they age. Since over two thirds of school-age CSHCN require or use prescription medications, health care and educational providers should work with these children and their families to be sure they understand how to use and manage their medications independently. Likewise, since functional limitations are most common among younger children, efforts should be made to ensure that parents of young children with more severe conditions are getting all necessary health services and information regarding their child's health condition, especially as it relates to their child's physical, cognitive, social, and emotional development, which are both rapid and most amenable in younger children.

By Gender

The prevalence of special health care needs among children also varies by gender.⁹ In California, 18.5 percent of boys and 10.3 percent of girls are diagnosed with a special health care need. Though more pronounced in California, this gender difference reflects a national trend, and may be related to the higher proportion of boys who are diagnosed with emotional, behavioral, or developmental problems. While male children represent 65.3 percent of CSHCN in California, they represent 78 percent of CSHCN with emotional, behavioral, or developmental problems. This disproportionate identification of such issues in male vs. female children is somewhat higher than in the rest of the nation (66.8% male).

More boys than girls are identified as having a special health care need.

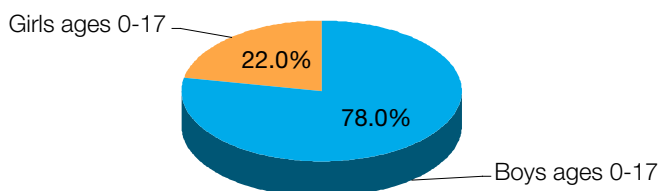
Figure 1.11: Percentage of California CSHCN Ages 0-17, by Gender



Chi-square test $p = 0.007$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Figure 1.12: Percentage of California CSHCN Ages 0-17 with Emotional, Behavioral, or Developmental (EBD) Problems, by Gender



Chi-square test $p = 0.052$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

These findings reflect the fact that the symptoms of some emotional, behavioral, and developmental disorders may vary by gender. Girls may exhibit fewer overt behavioral symptoms than boys for common disorders (such as attention deficit hyperactivity disorder), despite similar levels of impairment. Thus, parents and teachers may be more likely to bring boys' symptoms to medical attention.¹⁰ Additionally, it is also likely that gender influences whether parents, teachers, and providers identify a certain set of symptoms or findings as a health condition versus a normal behavioral variation. Ethnicity and culture also may affect whether parents identify emotional, behavioral, or developmental problems in boys versus girls.

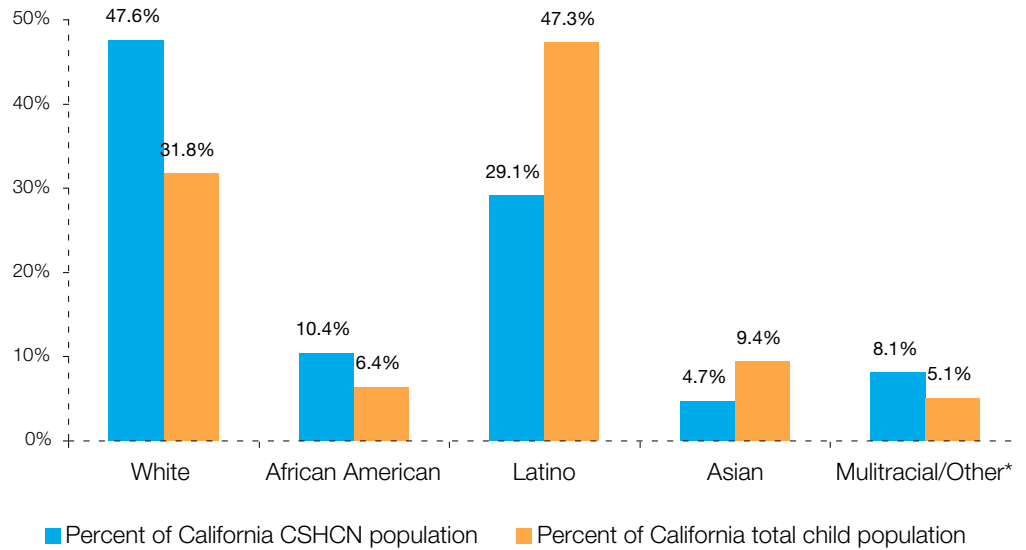
IMPLICATIONS: Health care providers may need to make special efforts to investigate emotional and behavioral conditions among girls, since they are disproportionately less likely to be diagnosed with emotional, behavioral, or developmental conditions.

By Race/Ethnicity and Language

Racial and ethnic differences are important when considering child health outcomes. In general, children of color have worse overall health status, lower rates of insurance coverage, and receive fewer recommended child health services, although individual outcomes differ greatly according to race/ethnicity.^{11,12}

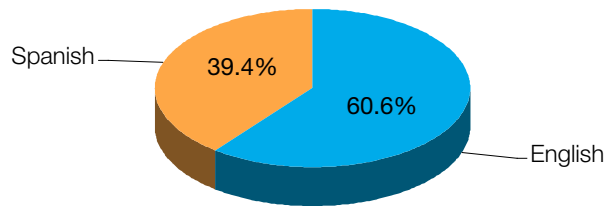
Because California has substantial racial/ethnic diversity, its CSHCN also are quite diverse. As the next figure shows, more than 50 percent of California's CSHCN are children of color. Latino children are the largest group of California's CSHCN of color. Among Latino CSHCN, about four in 10 live in a household where Spanish is the primary language.

Figure 1.13: Race and Ethnicity Distribution of CSHCN in California



* "Multiracial" includes two or more races. "Other" includes American Indian and Alaskan Native. These groups are not presented separately due to small sample size.
Data source: 2005-06 National Survey of Children with Special Health Care Needs (Screener File). Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Figure 1.14: Household Primary Language Among Latino CSHCN



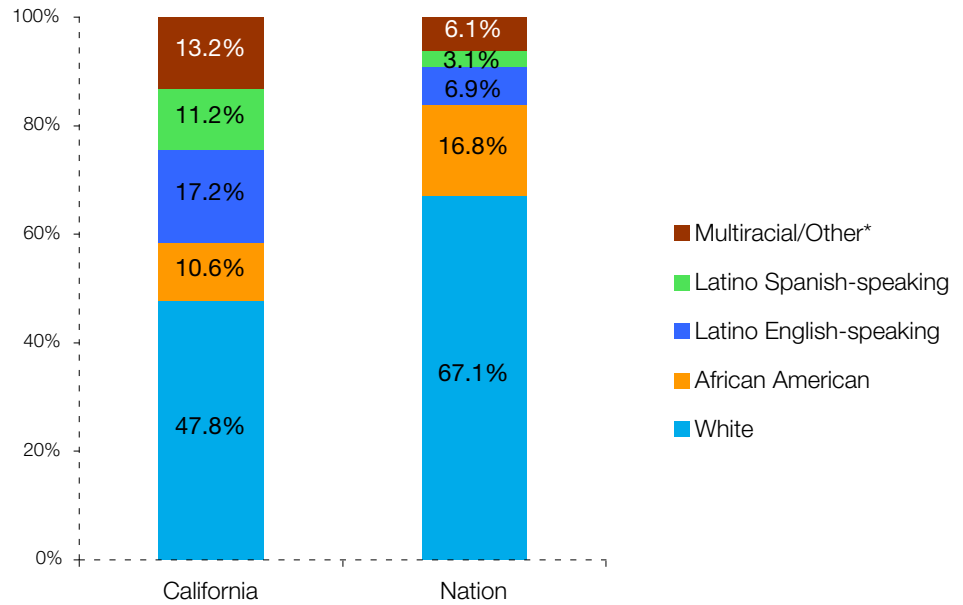
Data source: 2005-06 National Survey of Children with Special Health Care Needs. Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

As these data show, Latino children represent a smaller proportion of the CSHCN population than the general child population in California. Conversely, white children represent a larger proportion of the CSHCN population than they do of the overall California child population. These data are similar to national data that also show racial and ethnic differences in the prevalence of CSHCN, whether assessed based on parent report or through direct clinical assessment.⁹ Because the surveys are based on parent reports of health care needs and utilization, racial and ethnic differences may be due to different parental perceptions of health status. Some research suggests that racial and ethnic groups may vary in health care-seeking behavior, which may also contribute to disproportionately lower CSHCN prevalence.^{2,3} These prevalence findings may also be due to actual lower health problems for specific racial and ethnic groups, especially immigrant populations who some theorize may experience better overall health.

Although data are not available for California, national data also suggest that, like Latino families, Asian families are less likely to identify their child as having a special need.

As the next figure suggests, California's CSHCN are more diverse than CSHCN in the nation as a whole. In particular, California has more Latino CSHCN and fewer white CSHCN than do other states.

Figure 1.15 Racial/Ethnic Composition of CSHCN in California Compared with Other States



Whereas white children represent about two-thirds of CSHCN in the country, they represent less than half of CSHCN in California.

**"Multiracial" includes two or more races. "Other" includes American Indian, Alaskan Native, Asian, Native Hawaiian, or Other Pacific Islander. These groups are not presented separately due to small sample size.

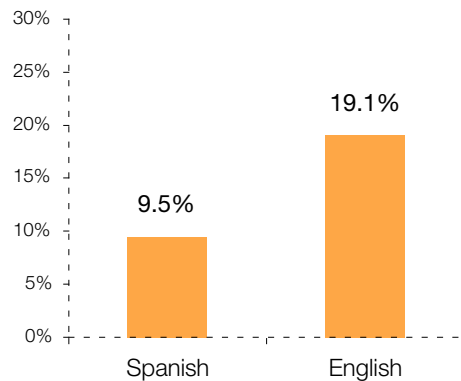
Note: Slight differences in racial/ethnic distribution between figures 1.13 and 1.15 are a result of sampling differences between the *National Survey of Children with Special Health Care Needs (Screener File)* and the *National Survey of Children with Special Health Care Needs (CAHMI Data File)*.

Data source: 2005-06 *National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

For confidentiality reasons, the National Center for Health Statistics releases the number of Asian CSHCN for only a few states with high Asian populations. Therefore, it is not possible to compare the numbers of Asian CSHCN in California to other states. In the above figure, Asian CSHCN are included in the "Multiracial/Other" category.

Race, ethnicity, and language may influence whether a child qualifies on the CSHCN Screener as having a special health care need.^{2,8} For instance, among Latino CSHCN, those in households with English as the primary language are more likely to qualify as a CSHCN than those in households with Spanish as the primary language.

Figure 1.16: Percentage of California Latino Children Meeting the CSHCN Screener Criteria, by Household Primary Language



Chi-square test $p = 0.032$

Data source: 2007 *National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

As a result, Latino children in Spanish-language households represent a smaller proportion of the CSHCN population than the general child population in California. Conversely, white children are the most likely to qualify as having a special health care need when compared to any other ethnic group.

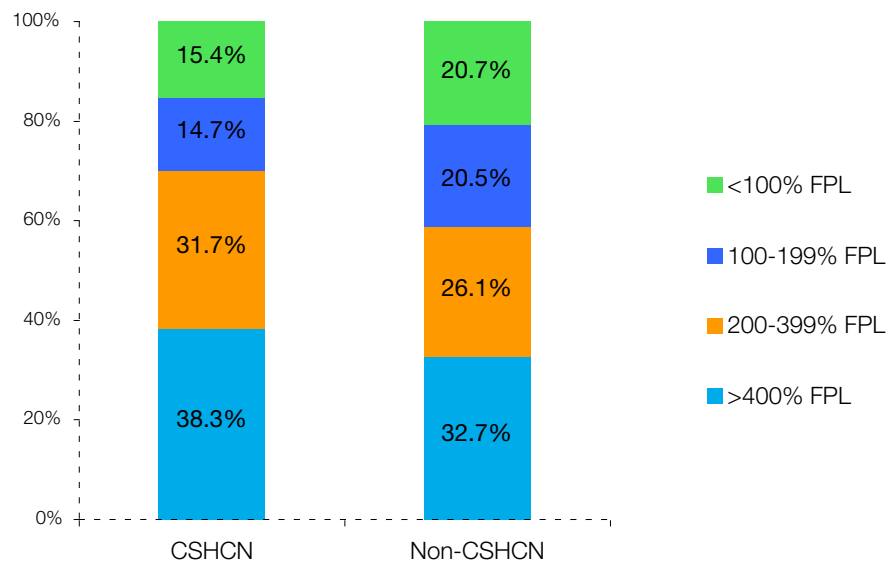
By Income

Household income is one of the strongest determinants of overall child health. Poor children face a wide variety of adverse health outcomes, including increased infant mortality and rates of chronic disease.¹³⁻¹⁵ In addition, low-income children are at higher risk for not receiving needed care or for receiving care that is lower in quality.^{8,16-18}

The federal government defines poverty according to the Federal Poverty Level (FPL), which in 2007 (the most recent year of the National Survey of Children's Health) was \$20,650 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.¹⁹ The FPL is a federal standard, and is the same across states, regardless of cost-of-living differences. Due to the high cost of living in California, many families have to earn at least twice the FPL (200% FPL) in order to cover their basic expenses.²⁰

In California, 15.4 percent of CSHCN lived in households below FPL in 2007, and an additional 14.7 percent of California CSHCN lived in households below 200 percent of FPL.²¹ There are no statistically significant income differences when CSHCN are compared to children without special needs. However, in general, there is a trend toward slightly more CSHCN than non-CSHCN in the higher income categories, and slightly more non-CSHCN than CSHCN in lower income categories. These differences may be attributable to other demographic differences between CSHCN and non-CSHCN, such as differences in age and racial/ethnic distribution.

Figure 1.17: Percentage of California Children by CSHCN Status and Income Level



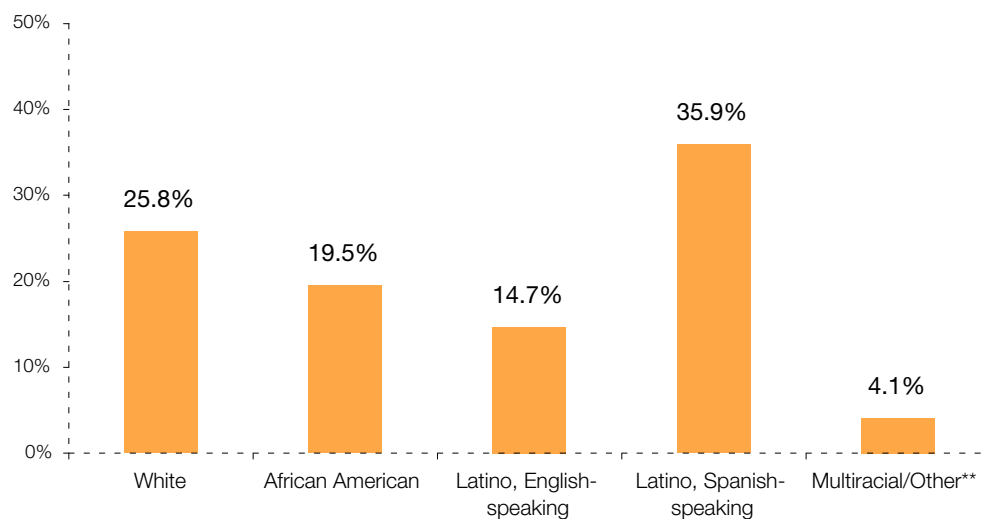
Chi-square test $p = 0.328$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Latino CSHCN in Spanish-language households are more likely to be living in poverty than any other racial/ethnic group for which data are available.

In particular, race/ethnicity is one of the strongest correlates of poverty.^{22,23} Similar to the general California child population, CSHCN of color are more likely to be living in poverty, with Latino children in Spanish-language households being at particular risk of poverty. This is the case even after adjusting for other socio-demographic differences.

Figure 1.18: Percentage of California CSHCN Living Below the Federal Poverty Level,* by Race/Ethnicity



* In 2006 the Federal Poverty Level (FPL) was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.

** "Multiracial" includes two or more races. "Other" includes American Indian, Alaskan Native, Asian, Native Hawaiian, or Other Pacific Islander. These groups are not presented separately due to small sample size.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs. Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Chapter 1 Conclusions

Children with special health care needs are numerous: more than one in seven California children has a special health care need. In addition, CSHCN in California are demographically diverse and have a high level of complex health conditions. Policymakers and program planners must consider this diversity and complexity when designing programs or systems to serve CSHCN. In addressing diversity, policymakers and program planners should consider not only CSHCN of different races/ethnicities, but also language differences, income limitations, the large spectrum of ages of CSHCN, and the variability in health conditions by gender.

Programs for CSHCN should accommodate a range of severity and complexity in health conditions and needs. Though nearly one in four CSHCN experience notable and persistent daily functional limitations and require special attention, most CSHCN do not. This is expected based on the diversity of health conditions in children—most of which will result in normal or near normal functioning if treated and managed properly. While some health conditions are most common, the majority of CSHCN have more than one health condition. Therefore, policies and programs aimed at specific health conditions may not fully encompass the needs of California's CSHCN, since many of them have multiple conditions.

Given the high prevalence of CSHCN, their diversity of social backgrounds, and their broad range of medical conditions and needs, caring for CSHCN can be a challenge. Parents, educational professionals, and health care providers need to be given adequate time, resources, and financial support to be able to offer CSHCN the broad range of services that they need.

References for Chapter 1

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 Pt 1):137-140.
2. Read D, Bethell C, Blumberg SJ, Abreu M, Molina C. An evaluation of the linguistic and cultural validity of the Spanish language version of the children with special health care needs screener. *Maternal and Child Health Journal*. 2007;11(6):568-585.
3. Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*. 2008;12(1):1-14.
4. Pastor PN, Reuben CA. Diagnosed attention deficit hyperactivity disorder and learning disability: United States, 2004-2006. *Vital and Health Statistics [10]*. 2008(237):1-14.
5. Centers for Disease Control and Prevention (CDC). Mental health in the United States: health care and well being of children with chronic emotional, behavioral, or developmental problems—United States, 2001. *MMWR. Morbidity and Mortality Weekly Report*. 2005;54(39):985-989.
6. Bethell C, Simpson L, Stumbo S, Carle AC, Gombojav N. National, state, and local disparities in childhood obesity. *Health Aff (Millwood)*. 2010;29(3):347-356.
7. Chen AY, Kim SE, Houtrow AJ, Newacheck PW. Prevalence of obesity among children with chronic conditions. *Obesity (Silver Spring)*. 2009.
8. Newacheck PW, Kim SE, Blumberg SJ, Rising JP. Who is at risk for special health care needs: findings from the National Survey of Children's Health. *Pediatrics*. 2008;122(2):347-359.
9. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Archives of Pediatrics & Adolescent Medicine*. 2004;158(9):884-890.
10. Sassi RB. Attention-deficit hyperactivity disorder and gender. *Archives of Women's Mental Health*. 2010;13(1):29-31.
11. Flores G, Olson L, Tomany-Korman SC. Racial and ethnic disparities in early childhood health and health care. *Pediatrics*. 2005;115(2):e183-93.
12. Ngu EM, Flores G. Unmet needs for specialty, dental, mental, and allied health care among children with special health care needs: are there racial/ethnic disparities? *Journal of Health Care for the Poor and Underserved*. 2007;18(4):931-949.
13. Victorino CC, Gauthier AH. The social determinants of child health: variations across health outcomes—a population-based cross-sectional analysis. *BMC Pediatrics*. 2009;9:53.
14. Fulda KG, Lykens K, Bae S, Singh K. Factors for accessing a medical home vary among CSHCN from different levels of socioeconomic status. *Maternal and Child Health Journal*. 2008.
15. Lykens KA, Fulda KG, Bae S, Singh KP. Differences in risk factors for children with special health care needs (CSHCN) receiving needed specialty care by socioeconomic status. *BMC Pediatrics*. 2009;9:48.

16. Larson K, Halfon N. Family income gradients in the health and health care access of U.S. children. *Maternal and Child Health Journal*. 2009.
17. Newacheck PW, Hughes DC, Hung YY, Wong S, Stoddard JJ. The unmet health needs of America's children. *Pediatrics*. 2000;105(4 Pt 2):989-997.
18. Newacheck PW, McManus M, Fox HB, Hung YY, Halfon N. Access to health care for children with special health care needs. *Pediatrics*. 2000;105(4 Pt 1):760-766.
19. Centers for Medicare and Medicaid Services. Income and Resource Guidelines. http://www.cmms.hhs.gov/MedicaidEligibility/07_IncomeandResourceGuidelines.asp#TopOfPage. Accessed March 10, 2010.
20. Insight Center for Community Economic Development. California Family Economic Self-Sufficiency Standard by County. <http://www.insightcced.org/communities/cfess/ca-sss.html>. March 10, 2010.
21. U.S. Department of Health and Human Services. The 2007 HHS Poverty Guidelines. <http://aspe.hhs.gov/POVERTY/07poverty.shtml>. Updated 2008. Accessed January 25, 2010.
22. Raphael JL, Guadagnolo BA, Beal AC, Giardino AP. Racial and ethnic disparities in indicators of a primary care medical home for children. *Academic Pediatrics*. 2009;9(4):221-227.
23. Larson K, Russ SA, Crall JJ, Halfon N. Influence of multiple social risks on children's health. *Pediatrics*. 2008;121(2):337-344.
24. Stein RE, Silver EJ. Are rates of functional limitations associated with access to care? A state-level analysis of the national survey of children with special health care needs. *Maternal and Child Health Journal*. 2005;9(2):S33-9.



Chapter 2: Service Needs and Access to Care

Children with special health care needs (CSHCN) require a broad range of services. These needs include, but are not limited to, primary and specialty medical care, prescription medications, and medical equipment and therapies. In addition, many families of CSHCN have important needs for support services, such as respite care, family counseling, or genetic counseling. Access to basic and specialized services is a fundamental measure of health care quality for CSHCN.

This section describes the percent of CSHCN who need a variety of medical and ancillary services, and the percent whose families need support services. In addition, this section presents data on CSHCN whose parents report that their children needed services during the past year but did not receive them.

The Fundamentals of Access to Care: Having Usual Source of Care and a Personal Doctor or Nurse

A consistent source of primary care is an important indicator of health care access and quality. Children who have a personal doctor or nurse and a usual place that they go for their medical care are more likely to get the basic components of pediatric preventive care such as immunizations and well-child visits.¹ In addition, regular screening of children for health conditions in the primary care setting allows for early identification and treatment of chronic health problems.^{2,3}

In the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN), parents were asked whether their children have an identified place to go for sick care and for well-child care.

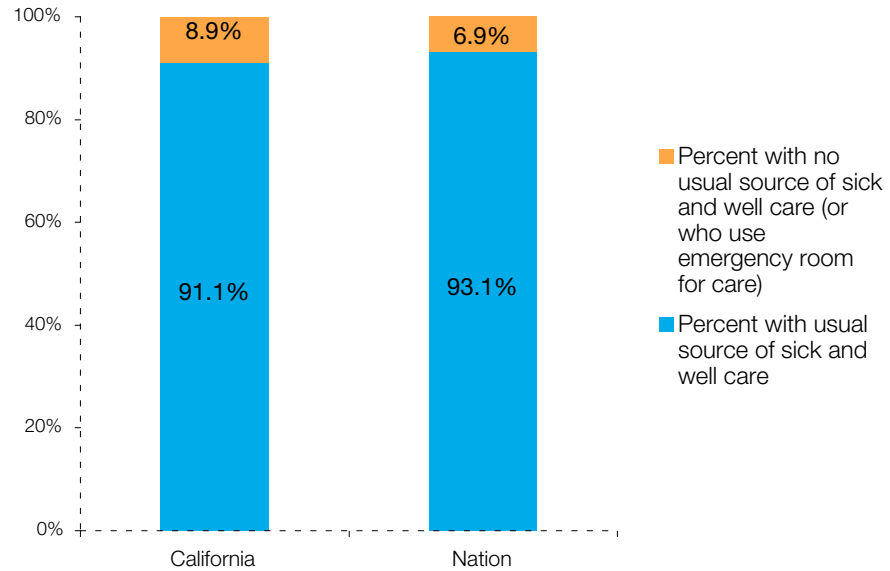
Children were defined as having *no usual source of care* if:

- Parents could not identify a place that their child usually went for sick and well care
- OR IF
- Parents said that an emergency room was the place that their child usually went for sick and well care

Compared to other states, CSHCN in California are less likely to have a usual source of sick and well care. In fact, of all the states and the District of Columbia, California ranks in the bottom quarter (#44) in terms of the percent of CSHCN having a usual source of care.

Of all the states and the District of Columbia, California ranks in the bottom quarter (#44) in terms of CSHCN having a usual source of care.

Figure 2.1: Usual Source of Sick and Well Care Among CSHCN in California Compared with Other States



Chi-square test not significant.

Data source: 2005/06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cschndata.org

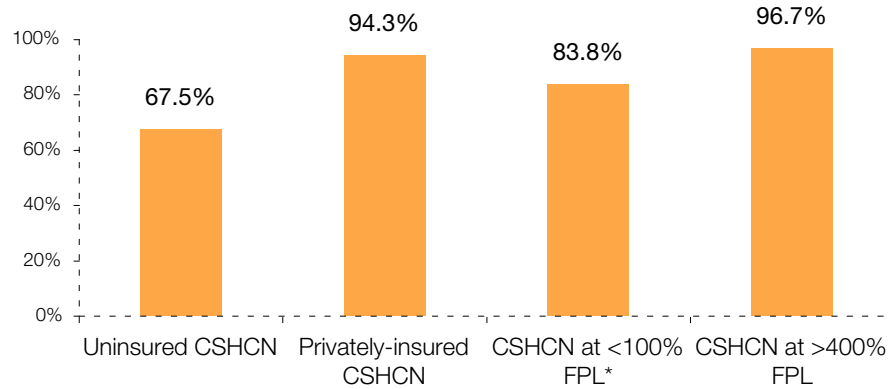
Health care disparities exist in access to a usual source of care. Having a usual source of care varies by income, with very poor California CSHCN—those living below the Federal Poverty Level (FPL)—being less likely to have a usual source of care than wealthier children; only 83.8 percent of children with household incomes below the FPL have a usual source of care, compared to 96.7 percent of children with household incomes more than 400 percent of the FPL.

This finding may reflect multiple factors. First, California has a large population of immigrant children who may not be eligible to enroll in low-cost state health care programs such as Medi-Cal. As a result, these children may not be able to afford regular health care. Additionally, some children who are eligible for Medi-Cal may not be enrolled, or may be enrolled but have not been connected with a health care provider.

Of all groups, uninsured children are least likely to have a usual source of care; only 67.5 percent of uninsured CSHCN in California have a usual source of sick and well care (see Figure 2.2). This may be due to financial barriers in seeking care (such as high costs for care and lack of providers offering free or low-cost care) or to problems in eligibility and access to public or private insurance programs.

Disparities in access to a usual source of care are not unique to California. In the nation as a whole, poor and uninsured children are less likely to have a usual source of care, even after adjusting for differences such as race/ethnicity.

Figure 2.2: Percentage of California CSHCN with a Usual Source of Sick and Well Care, by Insurance Status and Income Level



*FPL = Federal Poverty Level. In 2006 (the year of the most recent National Survey of Children with Special Health Care Needs), the FPL was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.

Chi-square test: Insurance Type ($p < .001$) and Household Income Level ($p = .006$)

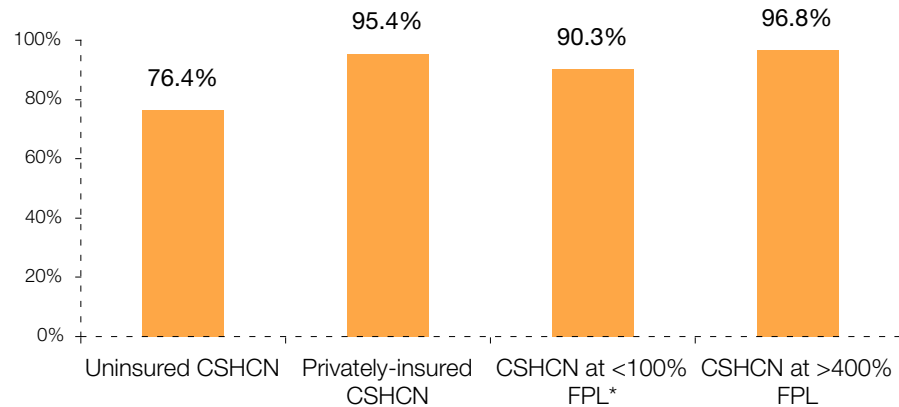
Note: This figure highlights the differences between the groups with the lowest and highest percentages; public insurance and middle income groups are excluded, as their percentages fall in the middle range.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Every CSHCN should have a doctor or nurse who knows him/her and is familiar with his/her health history and health care needs. In the 2005-06 NS-CSHCN, parents were asked if their child had “a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician’s assistant” who knew the child well and was familiar with his or her health history. According to this definition, about 8 percent of CSHCN in California do not have a personal doctor or nurse. This rate was similar to rates in other states (5%). More CSHCN had a personal doctor or nurse than a usual source of care, perhaps suggesting that some parents think of their child’s specialist doctor as the personal care provider.

As with usual source of care, having a personal doctor or nurse varied by income and insurance status, with poor and uninsured children being significantly less likely to have a personal doctor or nurse (see Figure 2.3). Once again, these income and insurance disparities found in California were similar to findings in the rest of the nation.

Figure 2.3: Percentage of California CSHCN with a Personal Doctor or Nurse, by Insurance Status and Income Level



*FPL = Federal Poverty Level. In 2006, the FPL was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia.

Chi-square test $p = 0.008$

Note: This figure highlights the differences between the groups with the lowest and highest percentages; public insurance and middle income groups are excluded, as their percentages fall in the middle range.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: All CSHCN, at minimum, should have access to basic health care. California performs worse than other states in terms of access to basic services, and access is especially lacking for poor and uninsured children. Expanding eligibility and improving access to public programs, informing parents about their eligibility for services, encouraging employer-based private insurance, and providing opportunities for free or low-cost care will be important steps toward improving the overall number of CSHCN who have access to the fundamentals of care.

Specific Care Needs

CSHCN have needs for a variety of specific services that vary according to their health conditions and social circumstances. As children's health care needs change over time, their specific service needs also vary.

In the 2005-06 NS-CSHCN, parents were asked whether their child had a need for specific health care services. Children were considered to have a need for a service regardless of whether they were actually able to use the service. The specific services asked about include:

- **Basic health care services**, such as:
 - ◆ preventive care
 - ◆ dental care
 - ◆ prescription medicine
- **More specialized health care services**, such as:
 - ◆ specialty care
 - ◆ physical, occupational or speech therapy
 - ◆ mental health care or counseling
 - ◆ substance abuse treatment or counseling
 - ◆ home health care services

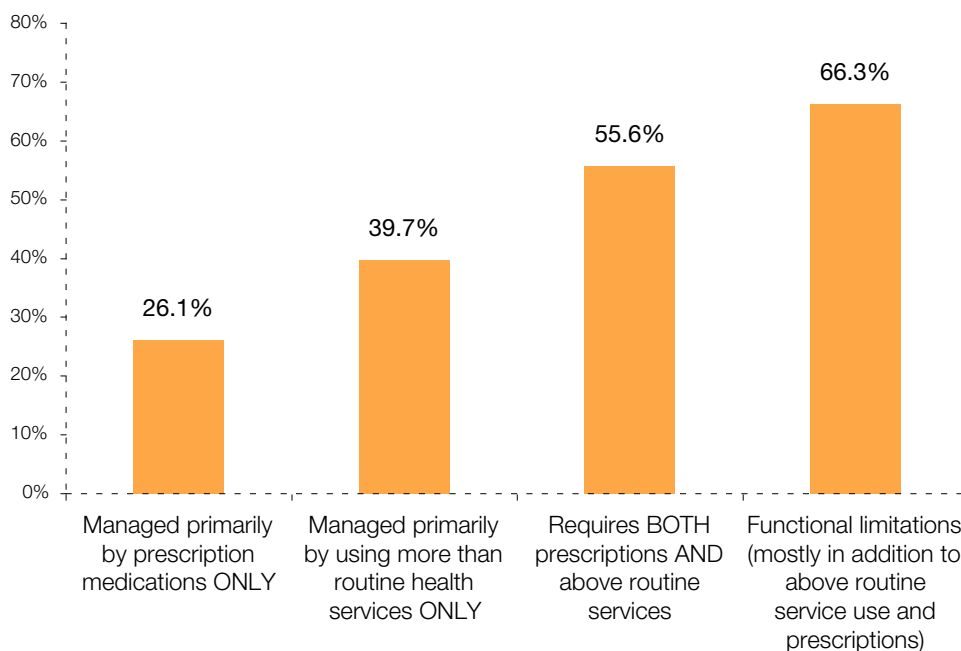
In California, 42 percent of CSHCN need at least five types of health services.

- **Equipment**, such as:
 - ◆ eyeglasses or vision care
 - ◆ hearing aids
 - ◆ mobility aids (wheelchairs, walkers, orthoses, etc.)
 - ◆ communication aids (communication boards, augmentative devices)
 - ◆ medical supplies
 - ◆ durable medical equipment (non-disposable equipment such as nebulizers, feeding pumps, hospital beds, etc.)

The most common services parents reported their child needed were basic services: preventive dental care (81.6% of California CSHCN), prescription medications (81.4%), and routine preventive care (77.1%). More than half of California CSHCN also had a need for specialist care (51.5%).

Many CSHCN need multiple services; in fact, 42 percent of CSHCN need at least five of the above services. As expected, CSHCN with functional limitations are most likely to need five or more types of services, even after adjustment for socio-demographic differences.

Figure 2.4: Percentage of California CSHCN Who Need 5 or More Types of Services,* by CSHCN Screener Qualifying Criteria**



*Services included: preventive care; specialty care; preventive dental care; other dental care; prescription medicine; physical, occupational or speech therapy; mental health care or counseling; substance abuse treatment or counseling; home health care services; eyeglasses or vision care; hearing aids; mobility aids; communication aids; medical supplies; and durable medical equipment.

**Children with special needs who meet the criteria for "functional limitations" differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: Since many CSHCN need multiple types of services, care coordination is important to assure that these service needs are effectively met. Streamlining care processes and decreasing geographical and bureaucratic silos of care may improve access to specific health care services. Improving parent and family knowledge of the health care system and ensuring they have the information they need to access specific health services are also essential to ensure that children’s complex health care needs are met.

Services Needed But Not Received

Nationwide, CSHCN have frequent unmet needs for medical services, and more unmet service needs than the general pediatric population.⁶⁻¹¹ This also is the case among CSHCN in California. Children may not receive services they need for a variety of reasons, such as difficulty paying for services, lack of access to providers, and competing demands on families’ time. Nationally and in California, health care disparities also affect whether a child will receive all of the care that he or she needs: children who are poor, uninsured, or of color are less likely to receive needed care.¹²⁻¹⁵

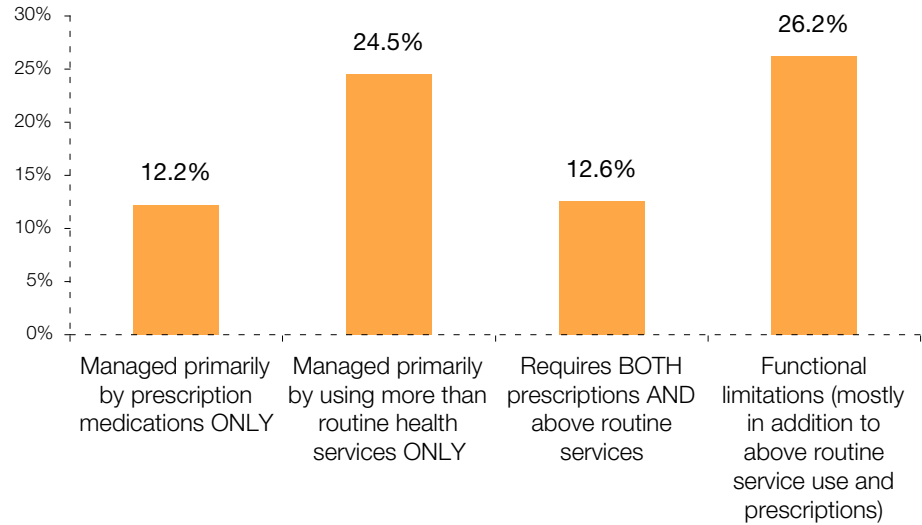
Unmet needs are assessed in a variety of ways in the NS-CSHCN and the NSCH. One way is by asking parents if their child received all of the care that he or she needed for each type of health care service in the list of specific services shown above. Generally speaking, parents tend to report getting all needed care unless an obvious negative consequence resulted from an unmet need. Even when getting needed care was challenging, parents will tend to report getting such care as long as the difficulty was resolved over time. As such, this way of asking about unmet needs is likely conservative. Asked in this way, 17.5 percent of CSHCN have one or more unmet care needs. Of the services in the list, the survey shows that unmet needs for therapy were particularly high: 16.4 percent of CSHCN do not receive all needed physical, occupational, or speech therapy. Additionally, about one in 10 California CSHCN does not receive all needed non-preventive dental care.

California CSHCN living below 200 percent of the FPL were more likely to have parents who reported unmet service needs compared to higher income children, even after adjustment for other socio-demographic factors such as race and insurance status. Finally, CSHCN with notable functional limitations—who have the greatest need for services—also are the most likely to have unmet needs for services (Figure 2.5).

Notably, there was no difference between children with public insurance versus those with private insurance.

CSHCN with the highest service needs also are the most likely to have unmet needs for services.

Figure 2.5: Percentage of California CSHCN with At Least One Unmet Service* Need, by CSHCN Screener Qualifying Criteria**



*Services included: preventive care; specialty care; preventive dental care; other dental care; prescription medicine; physical, occupational or speech therapy; mental health care or counseling; substance abuse treatment or counseling; home health care services; eyeglasses or vision care; hearing aids; mobility aids; communication aids; medical supplies; and durable medical equipment.

**Children with special needs who meet the criteria for "functional limitations" differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

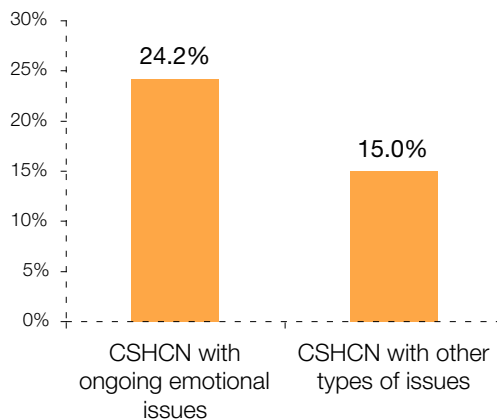
Chi-square test $p = 0.005$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

California CSHCN Have High Unmet Mental Health Needs

The NS-CSHCN and NSCH have different ways of measuring unmet mental health needs. In the NS-CSHCN, overall unmet service needs are assessed among children with emotional and behavioral issues. Based on this survey, children with ongoing emotional or behavioral issues are more likely to have unmet service needs than children with other conditions (24.2% versus 15.0%), as shown below.

Figure 2.6: Percentage of California CSHCN with At Least One Unmet Service Need, by Whether Children Have Ongoing Emotional, Behavioral, or Developmental (EBD) Issues



Chi-square test $p = 0.024$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

About 2 in 5 CSHCN in California did not receive needed mental health care.

In contrast, the 2007 NSCH assesses unmet needs for mental health services somewhat differently and more directly than outlined above. Here, provision of any mental health services is assessed among children qualifying as having a mental, emotional, or developmental problem based on their CSHCN Screener results. Assessed in this way, 40.9 percent of CSHCN in California do not receive needed mental health care.

IMPLICATIONS: Unmet service needs are common among California's CSHCN. The fact that the most unmet needs are found for mental health services, other therapy services, and for dental care suggests that extra efforts should be made toward improving coverage and accessibility in these areas, particularly for underserved children.

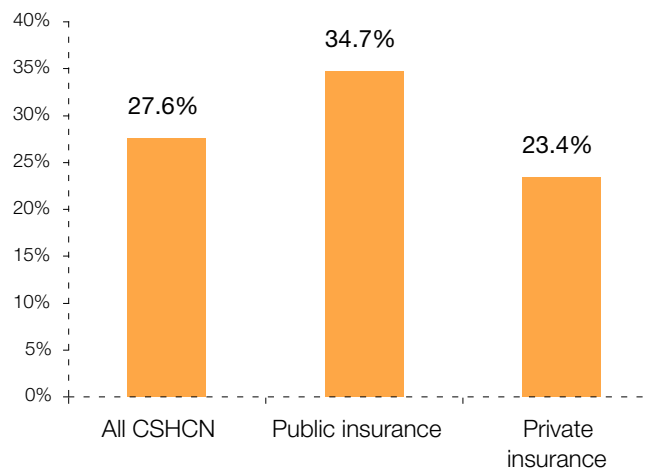
Access to Referrals

CSHCN often need a referral from a primary care provider in order to see a specialty provider, a therapist, or to obtain medical equipment. However, referrals can be difficult to get because of paperwork issues, insurance barriers, or provider reluctance to make a referral. Access to appropriate referrals, when needed, is an important health care access measure for CSHCN, and previous data collected in California suggest that the state's CSHCN frequently have difficulty obtaining referrals.¹⁶

The 2005-06 NS-CSHCN shows that more than one in four California CSHCN needing a referral has difficulty getting one. This rate is higher, but not significantly different from rates for CSHCN in other states. The rate is also higher, but not significantly different from the overall rate of unmet needs for medical services (27.6% versus 17.5%), suggesting that access to referrals is an important area for quality improvement in California. Rates of unmet referrals are higher for California CSHCN with public versus private sector insurance.

More than 1 in 4 California CSHCN who need a referral has difficulty getting one. This is higher for CSHCN with public vs. private sector insurance.

Figure 2.7: Percentage of California CSHCN Who Had Problems Getting Needed Referrals, by Public Versus Private Health Insurance Coverage*



*While meaningful, the difference in having unmet need for referrals for publicly insured children versus privately insured children was not statistically significant due to sample size limitations.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

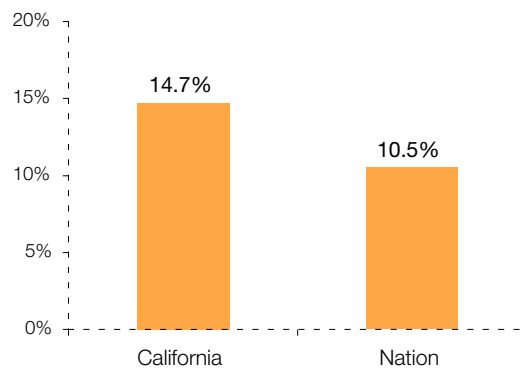
CSHCN in California have more difficulty accessing community-based services than CSHCN in other states.

Access to Community-Based Services

Caring for a child with a special health care need involves use of a broad variety of services throughout the community, including medical services, educational services, child care, and other community programs. These services are often geographically spread out and usually have different administrative systems. Getting different community agencies to cooperate in a child's care is a challenge for families of CSHCN.

In the 2005-06 NS-CSHCN, parents were asked if they had difficulty trying to use community-based health services for their child, such as medical care, early intervention, special education, child care, rehabilitation programs, and other community programs. In California, 14.7 percent of parents of CSHCN say they have difficulty accessing some of these services. This figure is significantly higher than rates in other states. In addition, publicly insured CSHCN in California are much more likely than privately insured CSHCN to report difficulty accessing community-based services.

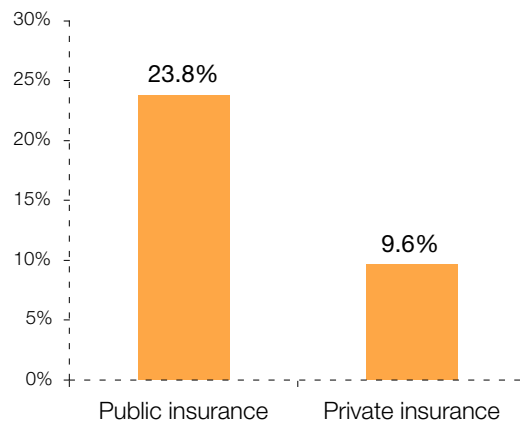
Figure 2.8: Percentage of Families of CSHCN Who Have Difficulty Accessing Community-Based Health Services



Chi-square test $p = 0.002$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Figure 2.9: Percentage of Families of CSHCN Who Have Difficulty Accessing Community-Based Health Services in California, by Insurance Type



Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Publicly insured CSHCN in California are much more likely to report difficulty accessing community-based services.

IMPLICATIONS: Community-based services in California are not always easy for families to use. Service accessibility would likely improve if organizations did more to collaborate and communicate regarding a child's needs. These efforts might include reducing paperwork and care coordination demands on families, streamlining administrative systems, arranging collaborative care coordination meetings, and improving provider knowledge of other community resources available to families. It is also essential that families be provided with information in order to understand how to access services and how to assess their child's service eligibility. "One-stop shopping" opportunities to obtain such information and care coordination could be very helpful.

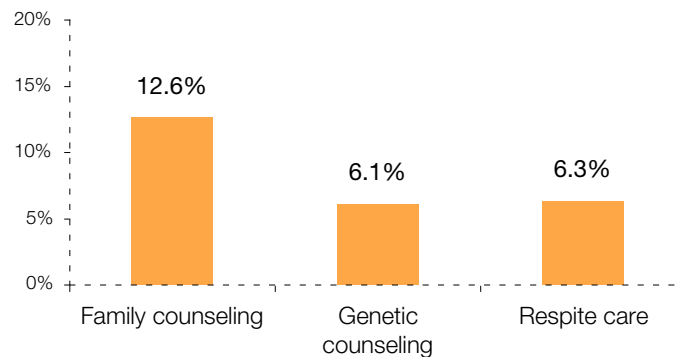
Nearly one-third of CSHCN whose parents report needing respite care, family counseling, or genetic counseling do not receive one of these services.

Family Support Service Needs

Support for a child with special health care needs requires family involvement, and can create additional stresses and information needs among parents and caregivers.^{4,5} Families of CSHCN benefit from services that help them to cope with the challenges associated with their children's conditions. These services include family counseling (mental health care for family members), respite care (having someone else care for the child so the parents or family members can take a break), and genetic counseling (for advice on inherited conditions related to the child).

Of these services, family counseling is the most common family support service needed, with about one in nine parents of California CSHCN needing family counseling.

Figure 2.10: Percentage of California CSHCN Whose Families Need Each Support Service



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Many families of CSHCN who need support services face difficulties when trying to get them.^{11,17} Overall, 28.8 percent of CSHCN whose parents need respite care, family counseling, or genetic counseling do not receive one of these services.

IMPLICATIONS: Parents are best able to take care of their child's special health care needs when their own needs and other family members' needs are met. These data suggest that more efforts are needed to support parents and families of CSHCN in California.

Chapter 2 Conclusions

Many California CSHCN have difficulty accessing both basic services (such as a usual place to go for health care) and more specialized services (such as mental health care, referrals, community-based services, and family support services). Without these fundamental building blocks of care, California CSHCN are precluded from having a medical home and the continuity of care necessary to meet their health care needs. In the long run, these children are at risk for progression and worsening of their medical conditions, dissatisfaction with care, and decreased quality of life for themselves and their families.

In order to improve care for these children and their families, policymakers, program managers, and researchers need to invest in solutions to improve service accessibility and eligibility. In particular, efforts should be made to lower enrollment barriers and inform families and providers about service availability so that existing services are used more comprehensively. Policymakers and program managers should also work to streamline and consolidate care, which would reduce bureaucratic barriers and care coordination burdens on families and providers. Where consolidation or streamlining is not possible, better communication within and among organizations and health care systems will enable more CSHCN to get the specific types of care they need. Achieving this may require substantial modifications to existing administrative structures and requirements related to cross-agency coordination.

References for Chapter 2

1. Chung PJ, Lee TC, Morrison JL, Schuster MA. Preventive care for children in the United States: quality and barriers. *Annual Review of Public Health*. 2006;27:491-515.
2. American Academy of Pediatrics. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1):405-420.
3. American Academy of Pediatrics. *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*. Elk Grove Village, IL: American Academy of Pediatrics; 2008.
4. Coffey JS. Parenting a child with chronic illness: a metasynthesis. *Pediatric Nursing*. 2006;32(1):51-59.
5. Ray LD. Parenting and Childhood Chronicity: making visible the invisible work. *Journal of Pediatric Nursing*. 2002;17(6):424-438.
6. Mayer ML, Skinner AC, Slifkin RT, National Survey of Children with Special Health Care Needs. Unmet need for routine and specialty care: data from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2004;113(2):e109-15.
7. Inkelas M, Raghavan R, Larson K, Kuo AA, Ortega AN. Unmet mental health need and access to services for children with special health care needs and their families. *Ambulatory Pediatrics*. 2007;7(6):431-438.
8. Warfield ME, Gulley S. Unmet need and problems accessing specialty medical and related services among children with special health care needs. *Maternal and Child Health Journal*. 2006;10(2):201-216.

9. Dusing SC, Skinner AC, Mayer ML. Unmet need for therapy services, assistive devices, and related services: data from the National Survey of Children with Special Health Care Needs. *Ambulatory Pediatrics*. 2004;4(5):448-454.
10. Newacheck PW, Hughes DC, Hung YY, Wong S, Stoddard JJ. The unmet health needs of America's children. *Pediatrics*. 2000;105(4 Pt 2):989-997.
11. Ganz ML, Tendulkar SA. Mental health care services for children with special health care needs and their family members: prevalence and correlates of unmet needs. *Pediatrics*. 2006;117(6):2138-2148.
12. Flores G, Tomany-Korman SC. The language spoken at home and disparities in medical and dental health, access to care, and use of services in U.S. children. *Pediatrics*. 2008;121(6):e1703-14.
13. Flores G, Tomany-Korman SC. Racial and ethnic disparities in medical and dental health, access to care, and use of services in U.S. children. *Pediatrics*. 2008;121(2):e286-98.
14. Shi L, Stevens GD. Disparities in access to care and satisfaction among U.S. children: the roles of race/ethnicity and poverty status. *Public Health Reports*. 2005;120(4):431-441.
15. Yu SM, Huang ZJ, Schwalberg RH, Nyman RM. Parental English proficiency and children's health services access. *American Journal of Public Health*. 2006;96(8):1449-1455.
16. Doksum T, Irvin C, Norman J, Johnson K, Connor P. California survey of the health care experiences of families of children with special health care needs. 2000.
17. Chung PJ, Garfield CF, Elliott MN, Carey C, Eriksson C, Schuster MA. Need for and use of family leave among parents of children with special health care needs. *Pediatrics*. 2007;119(5):e1047-55.



Chapter 3: Health Insurance

Access to health insurance is an essential step in receiving needed pediatric health care. National studies suggest that children without health insurance are less likely to receive necessary preventive and acute care.¹⁻³ Having health insurance is particularly important for children with special health care needs, who have increased ongoing medical needs. Among CSHCN, having health insurance is associated with improved health care quality, fewer unmet needs, and having a usual source of care.⁴⁻⁶

Having health insurance also is a financial safeguard for families. Uninsured CSHCN are more likely to experience high levels of family financial stress,⁴ and having health insurance has been shown to reduce burdensome out-of-pocket costs and financial stress among families of all income levels.^{7,8}

For children who have insurance, the type and quality of insurance matter. For instance, privately insured CSHCN are known to have higher out-of-pocket expenses than publicly insured CSHCN.⁹ Likewise, children with continuous insurance fare better than those who have gaps in their coverage.¹⁰

With recent passage of health care reform legislation, important changes will be made to child health insurance nationwide, including improved coverage of preventive services, increases in coverage of mental health services, and prohibition of insurance exclusion for children with pre-existing conditions.¹¹ Health care reform offers an important opportunity for California's policymakers and stakeholders to rethink how health insurance should optimally be delivered to CSHCN.

This chapter reviews survey findings on insurance coverage among CSHCN in California, including the proportion that have health insurance, the type of coverage they have, and potential problems such as cost, inclusivity, and continuity of coverage. In addition, the chapter points to important opportunities to improve insurance coverage and quality for California's CSHCN.

Health Insurance Status

In California, children access health insurance through private insurers or through public programs such as Medicaid (called Medi-Cal in California) and the State Children's Health Insurance Program (SCHIP, called the Healthy Families program in California). Low-income CSHCN, publicly-insured CSHCN, and CSHCN with high medical expenses also may qualify for California Children's Services (CCS), a statewide Title V program that coordinates services for CSHCN with certain health conditions. Other

About 1 in 12 California CSHCN is uninsured—more than 107,000 children. California ranks 40th out of the 50 states and the District of Columbia on the number of uninsured CSHCN.

public benefits include Medicaid’s Supplemental Security Income (SSI) program, which provides additional income to families of qualifying CSHCN.

Some children, particularly CSHCN with more severe health conditions, have both public and private insurance. In this case, public insurance serves as a supplement for some health care expenses that private insurance does not cover for the small subset of CSHCN who qualify for this coverage.

In the 2007 National Survey of Children’s Health (NSCH), parents were asked what kind of health insurance their child had. Children who had both private and public insurance are considered to be publicly insured, since they received at least some public benefits.

The survey shows that, as with most of the country, a majority of California CSHCN have private insurance (see table below). However, nearly one in three California CSHCN has public insurance. CSHCN in this state are about equally likely to be publicly insured as are children without special needs, even after adjusting for socio-demographic differences between CSHCN and non-CSHCN.

About one in 12 California CSHCN is uninsured—more than 107,000 children. Compared to other states, California has a large number of uninsured CSHCN: California ranks 40th out of the 50 states and the District of Columbia. However, differences between California and other states are small, especially considering the substantial racial/ethnic differences between children in California and in other states.

Table 3.1: Insurance Status of CSHCN and Non-CSHCN in California and the U.S.

Insurance status	Percent of CSHCN in California	Percent of CSHCN in the U.S.	Percent of non-CSHCN in California	Percent of non-CSHCN in the U.S.
Privately insured	63.9%	57.6%	56.8%	63.5%
Publicly insured	28.2%	36.5%	33.3%	26.6%
Uninsured	7.9%	5.9%	9.9%	9.9%

Chi-square test $p = 0.51$ for insurance status of CSHCN in California versus non-CSHCN in California, and $p = 0.30$ for insurance status of CSHCN in California vs. CSHCN in other states

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Complexity of health conditions affects a child’s type of health insurance. Though CSHCN with functional limitations represent only about 1/3 of CSHCN in California, nearly half have public sector health insurance. Likewise, among CSHCN with an above routine need for specialized services, more than two in five are publicly insured. These findings suggest that while most CSHCN are privately insured, the public sector insures a disproportionate number of the most medically needy groups of CSHCN. Thus, the needs of CSHCN should be a primary focus of insurers in both the public and private sectors.

Income, Insurance Status, and Insurance Eligibility

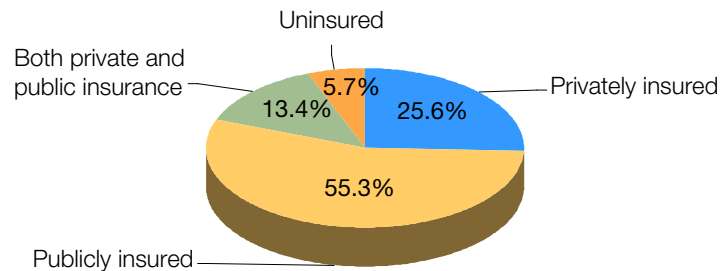
In California, the public insurance programs Medicaid (Medi-Cal) and SCHIP (Healthy Families) provide free or low-cost health insurance to children in families with incomes less than 250 percent of the Federal Poverty Level (FPL). In 2010, 250 percent of the FPL translates into an annual household income of \$55,125 for a family of four in the 48 contiguous states and the District of Columbia.¹²

The majority of California's most complex CSHCN have private sector health insurance.

However, as in other states, not all California families that are eligible for public programs have children who are enrolled in these programs. Families may not enroll their children in public insurance programs for a variety of reasons. Some eligible families may receive private insurance from their employer. Other families may not meet immigration or citizenship requirements. Some may not be aware that they are eligible for the program, may not be able to complete the necessary paperwork, or may not feel the program is a good value.³

In California, all citizen children in households with incomes less than 200 percent of the Federal Poverty Level should be eligible for public programs (while these programs cover households up to 250% of FPL, per above, the National Survey of Children with Special Health Care Needs assesses poverty at the 200% level). The figure below shows that a majority (68.7%) of CSHCN living below 200 percent of FPL are enrolled in public programs. However, about one in four has private insurance, and about one in 20 is uninsured.

Figure 3.1: Insurance Status of CSHCN Living in Households Making Less than 200 Percent of the Federal Poverty Level*



*In 2006, the most recent year of this survey, the Federal Poverty Level was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.
Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: Although most eligible low-income CSHCN are enrolled in public insurance programs, a significant minority are not. Continued efforts need to be made to increase outreach to low-income communities, reduce paperwork barriers to enrollment, make enrollment possible at multiple sites of care, and improve family awareness of public insurance benefits.

Adequacy of Insurance

Children who have health insurance may experience problems getting coverage that meets their health care needs. A child's health insurance may be inadequate for a number of reasons. Employers and the public sector often primarily focus on the needs of adults when deciding on a plan's benefits, so a plan that covers a CSHCN's particular needs may not be available through the parents' workplace or through the public sector. When selecting a plan, families also may not be able to find out the information they need to make an informed decision about benefits for their special needs child. Additionally, families may not have anticipated having a CSHCN at the time they selected their insurance, and may have opted for a more restrictive but lower cost plan.

In the 2007 National Survey of Children's Health, parents of children with health insurance were asked three questions about their children's coverage:

Inadequate insurance is a far greater problem than lack of insurance for CSHCN in California. More than 1 in 3 CSHCN has insurance that is inadequate to meet his or her health care needs.

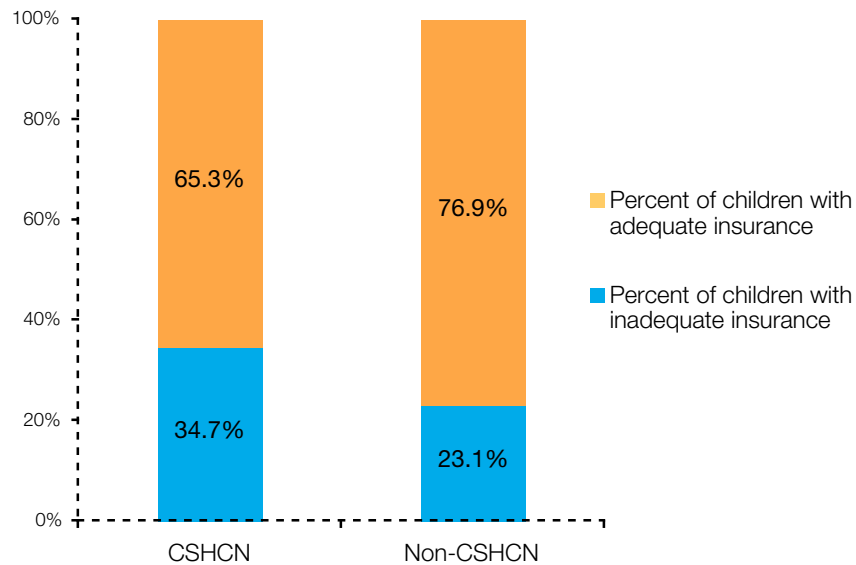
- Does the plan allow the child to see the health care providers that he/she needs?
- Does the plan offer benefits and cover services that meet his/her needs?
- Are the costs not covered by the plan reasonable?

If parents answered “usually” or “always” for all three of these questions, then the child’s coverage is considered to be adequate. All other children were considered to have insurance that was in some way inadequate to meet their needs.

Overall, among California CSHCN who had health insurance, 35 percent had insurance that was inadequate according to this definition. Inadequate insurance is a much more common problem than uninsurance among California’s CSHCN: more than one in three California CSHCN had inadequate insurance, whereas one in 12 had no insurance.

About 35 percent of CSHCN and 23 percent of children without special needs had coverage that was inadequate. These figures are statistically different, but they become similar when one considers differences between CSHCN and children without special needs, such as age differences and difference in racial/ethnic distribution.

Figure 3.2: Percentage of California CSHCN and Non-CSHCN, by Adequacy of Insurance



Chi-square test p= 0.05

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Nearly 40 percent of privately insured CSHCN have insurance that does not adequately meet their needs.

The type of special health care need may affect whether a child has inadequate insurance. For instance, children with emotional, behavioral, or developmental issues are more likely to have inadequate insurance than children with other types of special health care needs (51.0% versus 29.7%). This finding may relate to the fact that many health insurance plans limit mental health coverage, or cover mental health services at a lower level than other services.

Inadequate insurance was high, regardless of insurance type: 26.4 percent of publicly insured children and 37.9 percent of privately insured children had coverage that was inadequate in at least one of the three ways assessed.

More than 1 in 9 CSHCN is currently uninsured or lacked coverage for at least part of the year.

IMPLICATIONS: A large number of California CSHCN have inadequate insurance. This finding suggests that while expanding insurance coverage is an important goal, improving the quality of health care coverage may be even more important. Insurance quality was a problem for children regardless of the type of insurance, suggesting that both private and public plans in California need to do more to meet children’s needs. Since inadequate insurance is particularly a problem for children with mental health issues, giving equal coverage to mental and physical health conditions (also known as mental health parity) should be a priority.

Insurance Gaps

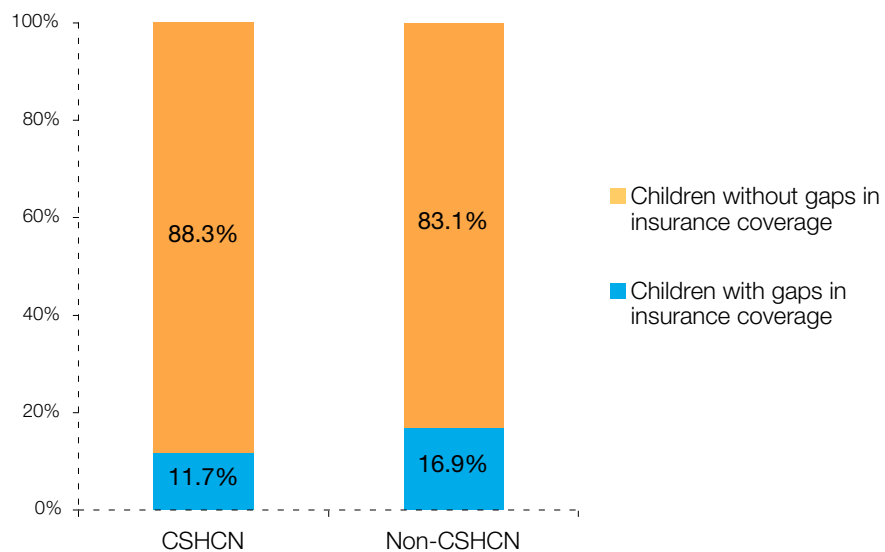
Families also can experience problems due to gaps in a child’s health insurance. When coverage is not continuous, children have difficulty accessing basic health care services.³ Discontinuous coverage also can put significant financial and paperwork burdens on the families of CSHCN.

Insurance coverage may be disrupted for a number of reasons. Families may temporarily lose private insurance due to loss of employment or due to a change in employer. Families who switch insurance carriers may be denied coverage for a CSHCN if he or she has pre-existing conditions. An increase in household income may result in loss of eligibility for public programs. Limited financial resources may lead families to drop children’s coverage because it is not affordable.

In the 2007 NSCH, parents were asked if in the previous 12 months there was any time when their child did not have health insurance. When added to the uninsured rate among CSHCN, 11.7 percent of CSHCN in California are either currently uninsured or experienced gaps in their health insurance coverage for at least part of the year.

The rate of insurance gaps in California is similar to rates found in other states. In addition, insurance gaps affect CSHCN and non-CSHCN similarly, especially when taking into account age, gender, and other differences between the two groups.

Figure 3.3: Percentage of California Children with and without Gaps in Insurance, by CSHCN status



Chi-square test $p = 0.24$

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Continuity of insurance is a critical component of assessing access to care. A substantial number of California children are currently uninsured or have discontinuous coverage. Health care reform legislation holds the promise of improving continuity of coverage by expanding employer based insurance, improving eligibility for public programs, and by halting insurance exclusion for children with pre-existing conditions.

Chapter 3 Conclusions

Due to their ongoing health issues, all CSHCN should have access to high-quality, continuous health insurance. Unfortunately, some California CSHCN have no insurance, and others have insurance that is unstable or insufficient. Since problems with insurance adequacy are exceedingly common for CSHCN, policymakers need to focus efforts on improving the quality of insurance plans by reducing out-of-pocket costs, improving access to providers, and expanding service coverage. Expanded coverage is particularly needed in the area of mental health and developmental services, since more than half of children with emotional, behavioral, and developmental issues experience insurance inadequacy.

Health care reform holds the promise of improving health insurance coverage and quality for CSHCN: the recently approved federal health care reform law (the Patient Protection and Affordable Care Act) legislates that many recommended preventive services for children, including immunizations and well-child visits, be covered by private and public plans as an immediate benefit with no co-pay.¹³ This important reform ensures that preventive care, a cornerstone of health for CSHCN, will no longer be prohibitively expensive for CSHCN and their families.

Additionally, the bill ensures that no child with pre-existing conditions will be denied coverage, and prohibits a lifetime or annual cap on insurance payments.^{11,13} This reform is particularly important for CSHCN in California, since the state has a high rate of uninsured CSHCN, and since many California CSHCN have unreasonable out-of-pocket expenses once coverage is obtained.

Finally, improved pediatric provider payment for Medicaid services will make it more financially feasible for health care providers to offer care to underserved children.¹³ Increasing the number of pediatric health care providers who accept Medicaid (Medi-Cal) services is another important way to improve health care access to California's CSHCN.

California policymakers, program managers, health care providers, and advocates understand that 2010 is a critical juncture in health insurance for CSHCN. Improving health insurance for CSHCN will require all stakeholders to examine the current health insurance system, take advantage of the reforms promised by new legislation, assess whether current reforms are actually helping CSHCN, and continue to push for health insurance improvements for CSHCN.

References for Chapter 3

1. Cummings JR, Lavarreda SA, Rice T, Brown ER. The effects of varying periods of uninsurance on children's access to health care. *Pediatrics*. 2009;123(3):e411-8.
2. Kenney G, Rubenstein J, Sommers A, Zuckerman S, Blavin F. Medicaid and SCHIP coverage: findings from California and North Carolina. *Health Care Financing Review*. 2007;29(1):71-85.
3. Stevens GD, Seid M, Halfon N. Enrolling vulnerable, uninsured but eligible children in public health insurance: association with health status and primary care access. *Pediatrics*. 2006;117(4):e751-9.
4. Honberg LE, Kogan MD, Allen D, Strickland BB, Newacheck PW. Progress in ensuring adequate health insurance for children with special health care needs. *Pediatrics*. 2009;124(5):1273-1280.
5. Szilagyi PG, Shone LP, Klein JD, Bajorska A, Dick AW. Improved health care among children with special health care needs after enrollment into the State Children's Health Insurance Program. *Ambulatory Pediatrics*. 2007;7(1):10-17.
6. Jeffrey AE, Newacheck PW. Role of insurance for children with special health care needs: a synthesis of the evidence. *Pediatrics*. 2006;118(4):e1027-38.
7. Chen AY, Newacheck PW. Insurance coverage and financial burden for families of children with special health care needs. *Ambulatory Pediatrics*. 2006;6(4):204-209.
8. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics*. 2004;114(1):79-85.
9. Bumbalo J, Ustinich L, Ramcharran D, Schwalberg R. Economic impact on families caring for children with special health care needs in New Hampshire: the effect of socioeconomic and health-related factors. *Maternal and Child Health Journal*. 2005;9(2):S3-11.
10. Kogan MD, Newacheck PW, Honberg L, Strickland B. Association between underinsurance and access to care among children with special health care needs in the United States. *Pediatrics*. 2005;116(5):1162-1169.
11. Association of Maternal and Child Health Programs. The Patient Protection and Affordable Care Act: Maternal and child health related highlights. <http://www.amchp.org/Advocacy/health-reform/Documents/Senate%20Bill%20-%20MCH%20Highlights%203%2022%2010.pdf>. Accessed April 8, 2010.
12. U.S. Department of Health and Human Services. The 2007 HHS Poverty Guidelines. <http://aspe.hhs.gov/POVERTY/07poverty.shtml>. Updated 2008. Accessed January 25, 2010.
13. Palfrey JS, American Academy of Pediatrics. Press Statement on Final Passage of Health Reform Legislation. <http://www.aap.org/pressroom/AAPStatementHCRFinalPassage32510.pdf>. Accessed April 8, 2010.



Chapter 4: Quality of Care for Children with Special Health Care Needs

Due to their increased medical service use, children with special health care needs (CSHCN) interact frequently with multiple systems in order to receive all needed services—educational services, developmental services, and multiple components of the health care delivery system—so they are especially vulnerable to any health care quality weaknesses in the system. In fact, multiple studies show that health care quality for CSHCN differs substantially from that of children without special health care needs; that quality of care varies greatly depending on the health condition type, severity, or complexity; and that it also depends on demographic characteristics such as race/ethnicity and income.¹⁻⁴

This chapter outlines several components essential to any assessment of health care quality for CSHCN.⁵⁻⁸ First, preventive care and screening are known to identify emerging health issues in children generally and CSHCN especially.^{9,10} Second, engaging families as partners in decision-making is an important aspect of quality health care delivery. Finally, receiving care within a medical home¹¹—which includes coordination across services¹² and family-centered care—is another key component of quality health care for CSHCN.

Screening and Preventive Care

Preventive care reduces both avoidable hospitalization and unmet health care needs.¹³ Screening, an important component of primary preventive care, is used to identify children at risk for future morbidity. A comprehensive approach to screening includes:

- Examining all children to identify emerging special needs, and
- Ongoing monitoring and assessment of children with special needs to identify any new or secondary complications.

In this comprehensive view, screening is best accomplished through deliberate, ongoing preventive care and not left to visits dependent on illness. Racial/ethnic disparities in delivery of quality primary and preventive care also must be addressed.^{14,15}

In the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN), a child's receipt of routine periodic screening is evaluated using two survey questions:

- Whether CSHCN receive routine preventive medical care, and
- Whether they receive routine preventive dental care.¹⁶

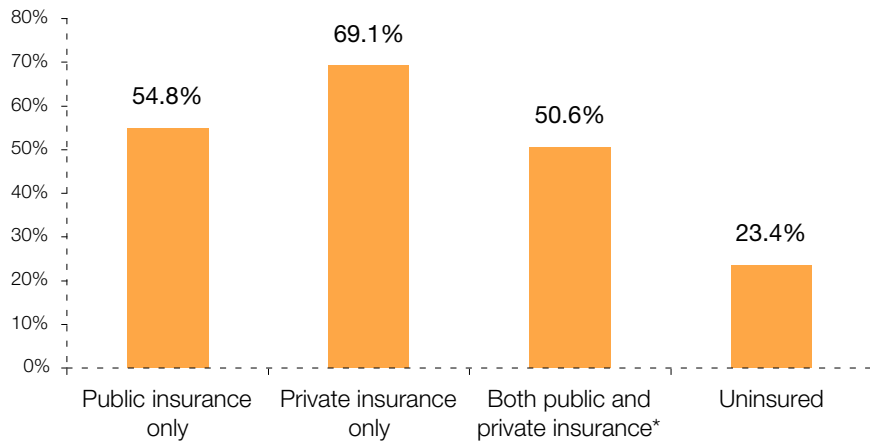
Neither of these questions specifies whether recommended screening occurred during

visits; however, they serve as a signal regarding whether opportunities for screening were present for CSHCN.

Overall, this outcome is successfully achieved for 63.9 percent of CSHCN nationally and 62.7 percent of CSHCN in California. Children's likelihood of achieving this outcome does not vary substantially based on the type of special health care need or whether the child has ongoing emotional, behavioral, or developmental issues. However, CSHCN with private insurance are more likely to have preventive medical and dental visits where screening may occur: 69.1 percent of children with private insurance, compared to 54.8 percent of children with public insurance (see Figure 4.1). As shown in Figure 4.2, there also is a substantive difference on this indicator by race/ethnicity: 68.8 percent of white CSHCN meet this outcome, compared with only 53.9 percent of Latino CSHCN.¹⁷

In California and nationwide, privately insured CSHCN are more likely than publicly insured children to receive routine preventive services and screening.

Figure 4.1: Percentage of California CSHCN Who Receive Routine Preventive Medical and Dental Care, by Type of Insurance

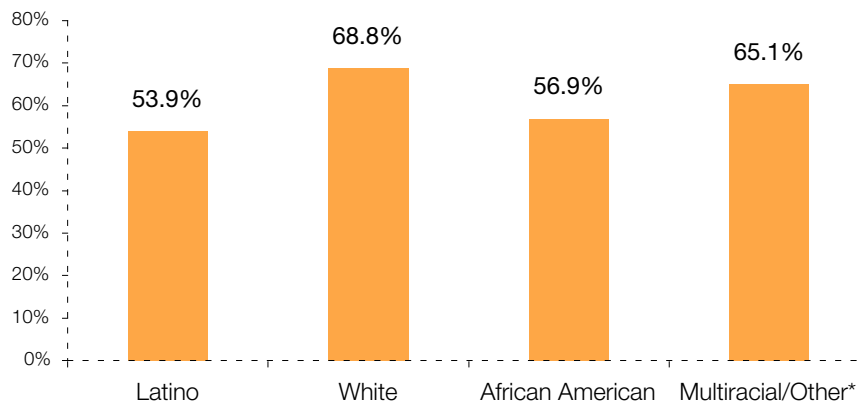


*Children living in higher income households with serious medical conditions and extensive service needs may qualify for public health insurance coverage to cover costs not covered through their private insurance coverage.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Figure 4.2: Percentage of California CSHCN Who Receive Routine Preventive Medical and Dental Care, by Race/Ethnicity



* "Multiracial" includes two or more races. "Other" race includes American Indian, Alaskan Native, Asian, Native Hawaiian, or Other Pacific Islander. These groups are not presented separately due to small sample size.

Chi-square test $p = 0.036$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Among the 30.5 percent of California children at moderate to high risk for developmental disorders, only 9 percent received standardized screening.

The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children at 9 months, 18 months, and 24-30 months using a standardized screening tool.⁹ Screening children in early childhood for risk of developmental delays is a cornerstone of preventive health care. In California in 2007, only 14 percent of all children under age 6 received standardized development and behavioral screening as recommended by the AAP. Among the 30.5 percent of California children at moderate to high risk for developmental disorders, only 9 percent received standardized screening, making California among the poorest performing states in the nation for this measure.

IMPLICATIONS: California must promote timely access and remove all barriers to preventive care, including preventive dental care,¹⁸ in order to identify newly emerging primary health issues and address secondary issues among children already experiencing health conditions.

In addition, California should commit to consistent developmental screening of children ages 0-5 with standardized tools. This will require addressing payment for screening in both public and private sectors, as well as addressing the shortage of early intervention services, particularly for children who do not meet new limited-eligibility criteria for Regional Centers (the contracted providers of early intervention services with the state Department of Developmental Services). Children at risk for missed developmental evaluation include infants born prematurely, infants known to have had prenatal alcohol/drug exposure or other high-risk neonatal conditions, and other children who are no longer eligible for early intervention services through Regional Centers.

Engaging Families of Children with Special Health Care Needs

Partnering in Care and Satisfaction with Services

In developing community-based systems of care, a child's family structure and values should be of primary importance.¹⁹ Family-centered care delivery fosters an engaged partnership between families and professionals and recognizes that families are the ultimate decision-makers for their children.^{20,21}

Shared decision-making is evaluated using two questions from the 2005-06 NS-CSHCN:

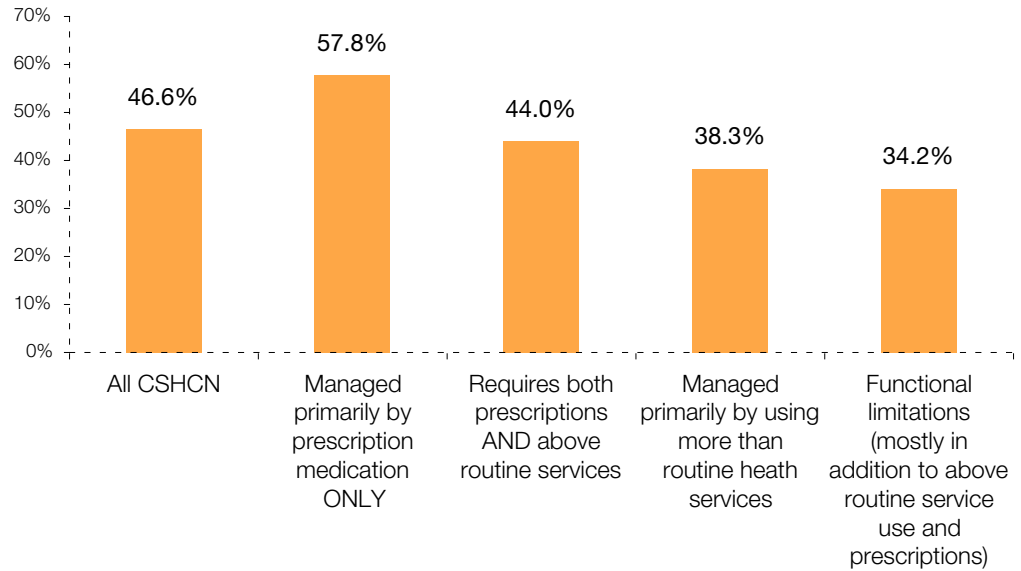
- Whether the doctor makes the parent feel like a partner in the child's care, and
- The parent's level of satisfaction with the child's health care services.¹⁶

Children whose parents report that they "usually" or "always" feel like a partner and that they are "very" or "somewhat" satisfied with care are considered to meet the overall criterion. This outcome was achieved by 46.6 percent of California CSHCN, significantly less than the proportion of CSHCN nationally meeting this indicator (58.5%).

As shown in the figure below, parents of children with more complex needs are even less likely to feel they are partners in decision-making and satisfied with the care their children receive. Children who experience functional limitations (those limited or prevented in their ability to do things most children of the same age can do) or who have ongoing emotional, behavioral, or developmental issues are the least likely to have parents who feel they are partners in their child's care (34.2% and 30.1%, respectively). It is important to note that more than four in 10 CSHCN in California with less complex special needs also fail to meet this very fundamental measure of health care quality. In addition, CSHCN with public insurance are significantly less likely to meet this measure

than CSHCN with private insurance (40.6% and 52.0%, respectively), as shown in Figure 4.5.

Figure 4.3 Percentage of CSHCN Whose Families Are Engaged in Decision-Making and Satisfied with Care, by CSHCN Screener Qualifying Criteria*



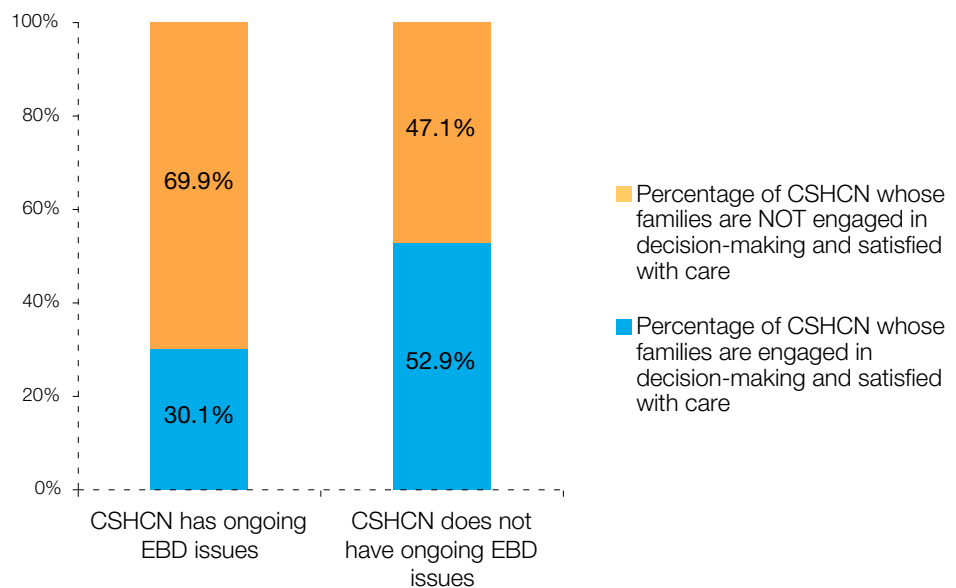
*Children who qualify as having special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

Chi-square test $p = 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Even after adjusting for socio-demographic differences, California CSHCN were significantly less likely to have parents who feel satisfied with care and feel like a partner in their child’s care than CSHCN in all other states.

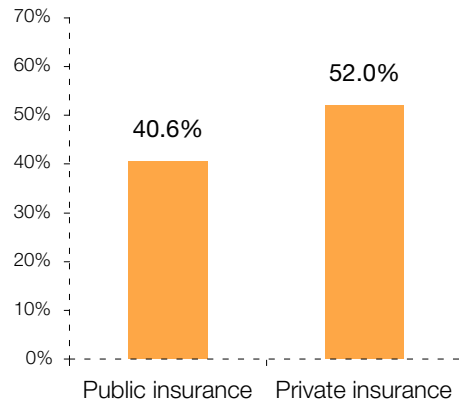
Figure 4.4: Percentage of CSHCN Whose Families Are Engaged in Decision-Making and Satisfied with Care, by Whether the Child Has Ongoing Emotional, Behavioral, or Developmental Issues



Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Figure 4.5: Percentage of CSHCN Whose Families Are Engaged in Decision-Making and Satisfied with Care, by Type of Insurance



Chi-square test $p=0.04$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

The Medical Home as a Key Component of Quality Health Care

Many CSHCN in California fail to receive care within a medical home—a basic measure of quality health care. Only 42.2 percent of California CSHCN are receiving such care, compared to 47.7 percent nationally.

Ensuring CSHCN Receive Quality Care

The American Academy of Pediatrics describes the “medical home” as 37 positive elements comprising excellent health care for children.¹¹ These elements serve as guidelines for care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.^{22,23} Ideally, these seven components are delivered in a comprehensive health care system designed to meet the overall well-being of the child, and delivered by health care professionals—in conjunction with educator and ancillary providers working with the child—who know the child well. Six of the seven components of medical home are assessed by the two national surveys used in this report.

While the medical home approach is central to caring for all children, it is particularly critical for ensuring quality care and good health outcomes for CSHCN.^{22,24,25} A medical home helps to ensure that CSHCN not only receive ongoing health care from a doctor and team who know the child well, but that they also receive necessary information to promote and protect the child’s health and functioning. Additionally, a medical home provides care coordination among a child’s providers and help from a personal doctor or nurse to ensure their needs are met in a high quality manner.

Whether a child has a medical home was evaluated using a series of questions from the NS-CSHCN:

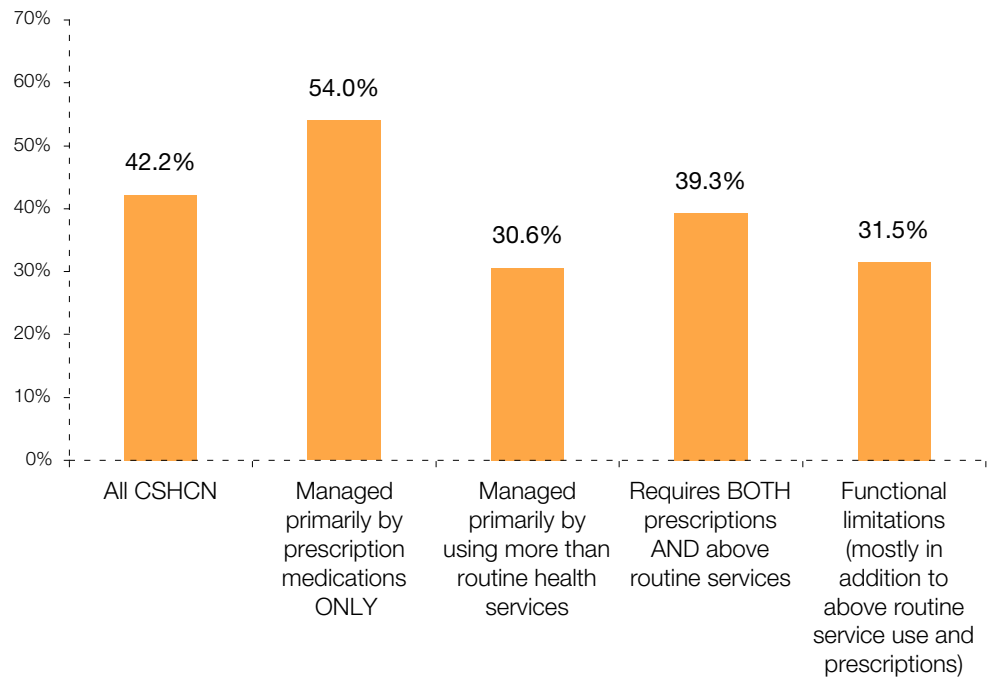
- Whether the child has a personal doctor or nurse
- Whether he or she has a usual source of sick care
- Whether the child has had problems obtaining needed referrals
- Whether the health care provider spends enough time with the family, listens carefully to the parent, and is sensitive to the family’s customs

- Whether the health care provider supplies the family with enough information
- Whether the parent feels like a partner in the child's care
- And whether the family receives interpreter services, if needed

In the 2005-06 NS-CSHCN survey, 47.7 percent of CSHCN nationally and 42.2 percent of California CSHCN met all of these criteria. In contrast, according to the 2007 National Survey of Children's Health, 52.8 percent of children without special health care needs in California met all of the criteria for receiving care within a medical home.

As shown below, those CSHCN most likely to need a medical home—those whose conditions limit their ability to function or those who require specialized services—are the least likely to have a medical home in California (31.5% and 30.6%, respectively). Nearly half (46%) of children whose conditions are managed primarily through prescription medications—arguably the least medically complex CSHCN—do not meet these criteria.

Figure 4.6: California CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home, by CSHCN Screener Qualifying Criteria*



*Children who qualify as having special needs who meet the criteria for "functional limitations" differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

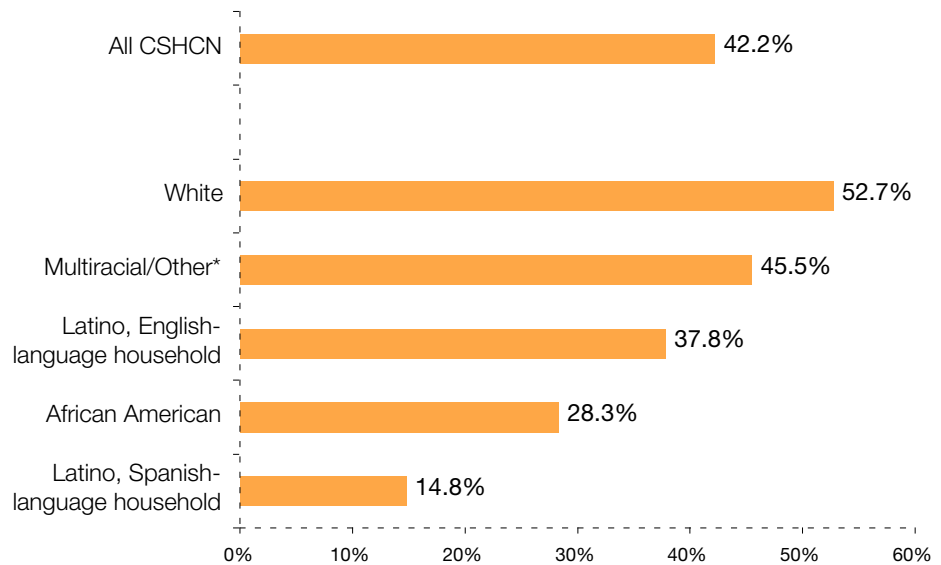
Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Receipt of care in a medical home varies substantially by the child's race/ethnicity and by the primary household language. As shown in the next figure, only 14.8 percent of Latino children living in a Spanish primary language household met all of the criteria for a medical home. African American children in California are doing marginally better at 28.3 percent. White children have the highest rate at 52.7 percent. These differences are significant even after adjusting for income and type of insurance.

Figure 4.7: California CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home, by Race/Ethnicity and Primary Language of Household

African American and Latino CSHCN, particularly Latino CSHCN who live in primarily Spanish-language households, are significantly less likely to receive care within a medical home, even after adjusting for other factors.



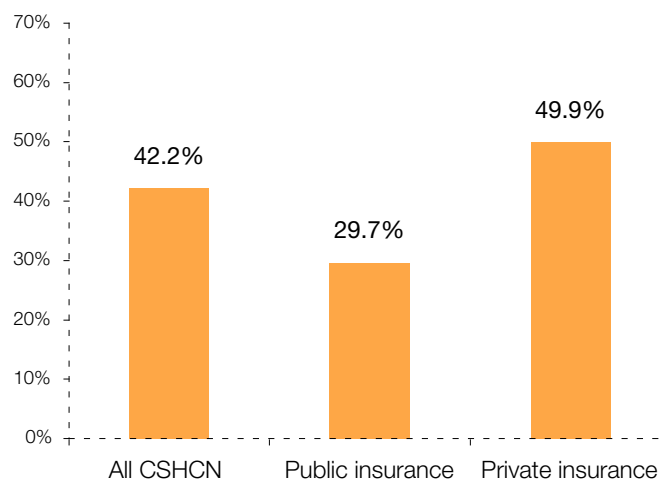
* "Multiracial" includes two or more races. "Other" race includes American Indian, Alaskan Native, Asian, Native Hawaiian, or Other Pacific Islander. These groups are not presented separately due to small sample size.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN in California with public insurance are much less likely to receive ongoing and coordinated care within a medical home. As shown below, fewer than one in three CSHCN in California who are publicly insured are receiving such care.

Figure 4.8: California CSHCN Who Receive Coordinated, Ongoing, Comprehensive Care Within a Medical Home, by Type of Insurance



Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN in California with public insurance are much less likely to receive ongoing and coordinated care within a medical home.

IMPLICATIONS: Many California CSHCN lack a medical home, and disparities exist in medical home provision. Policy and program attention should be directed toward improving the availability of medical homes—including accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care—for all children in California, but should pay particular attention to those with complex conditions, children of color, and children with public insurance.

Coordinating Care for Children with Special Health Care Needs

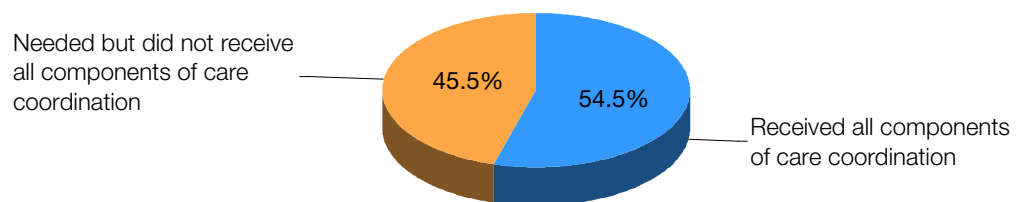
Care coordination is the organization of patient care activities among two or more providers (including the patient’s family) involved in children’s care to facilitate the appropriate delivery of medical and family support services.¹² Care coordination for CSHCN is often complex, as these children are involved in multiple systems of care such as schools, hospitals, community providers, therapists, and government agencies, without a single point of entry. As a result, family members are often their child’s primary care coordinators. Access to care coordination is an important measure of high quality pediatric health care in general, and especially for CSHCN.²⁶⁻²⁸

The 2005-06 National Survey of Children with Special Health Care Needs used several questions to determine whether CSHCN were receiving coordinated care:

- How often do you get as much help as you want with arranging or coordinating care, if needed?
- How satisfied are you with the communication among your child’s doctors and other health care providers, if needed?
- How satisfied are you with communication between your child’s health care providers and his/her school, early intervention program, child care providers, or vocational education or rehabilitation program, if needed?

To qualify as having coordinated care, the parent had to report “usually” regarding receiving help when needed *and* being “very satisfied” with communication among providers and communication between providers and other programs.

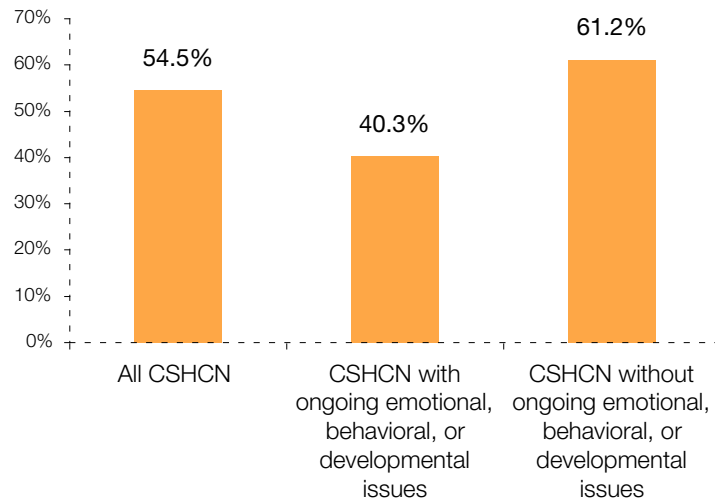
Figure 4.9: Receipt of Care Coordination Among California CSHCN Who Needed* It



*“Needed” care coordination is defined as CSHCN who required more than one type of health care visit in the past 12 months and whose parents indicated that they got help with or would have liked help with care coordination services. Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Due to the complexity of their conditions, and perhaps due to their need to access multiple service providers (e.g., mental health specialists, primary care physicians, special education, etc.), CSHCN with ongoing emotional, behavioral, or development issues may be more likely to need care coordination. However, the survey data suggest that these children are significantly less likely to meet the care coordination criteria, as shown below

Figure 4.10: Percentage of California CSHCN Who Receive Needed Care Coordination, by Ongoing Emotional, Behavioral, or Developmental Issues



Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Whether or not CSHCN receive care coordination does not vary by the type of insurance they have.

IMPLICATIONS: The burden of integrating information and coordinating care often falls on the parents, particularly of children with highly complex needs. California should further assess how care coordination might benefit both parents of CSHCN and the health care system within the state. Providers, health care professional associations, and professional schools should enhance their educational content to focus on coordinating care for CSHCN and the interface of primary and specialty care.

Family-Centered Care

The provision of family-centered care involves designing and implementing health care services that ensure effective communication and interaction with families and children. Family-centered care supports the family's relationship with the child's health care providers, recognizes the importance of the family's customs and values, and leads to improved care delivery and child health outcomes.²⁹

The National Survey of Children with Special Health Care Needs asked several questions to determine whether CSHCN were receiving family-centered care:

- How often did your child's doctors and other health care providers spend enough time with him/her?
- How often did you get the specific information you needed from your child's doctors and other health care providers?
- How often did your child's doctors or other health care providers help you feel like a partner in his/her care?
- When your child is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?

26.4 percent, or approximately 350,000 CSHCN, have parents who feel that health care providers do not spend enough time with their child.

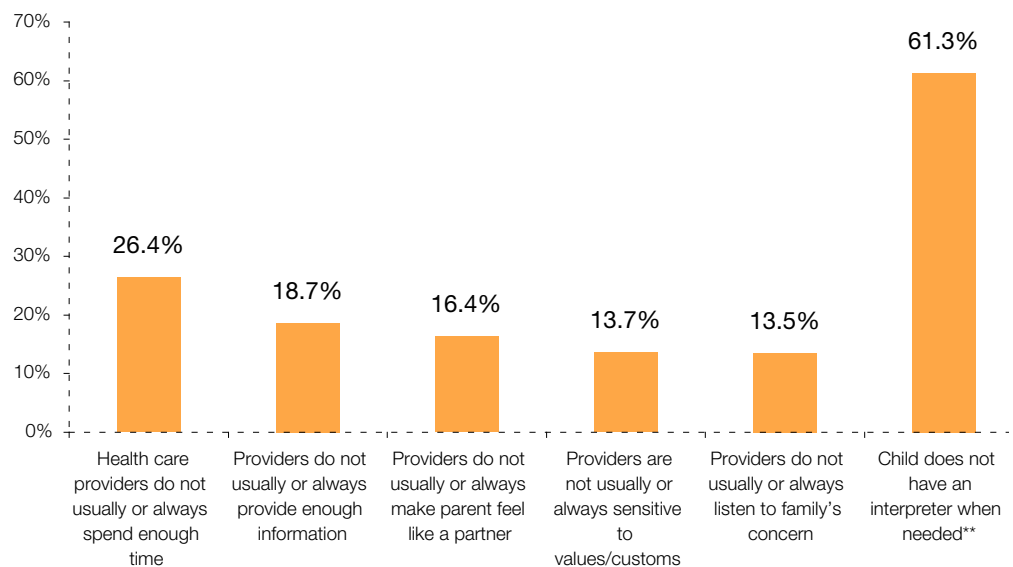
- How often did your child's doctors and other health care providers listen carefully to you?
- How often were you able to get someone other than a family member to help you speak with your child's doctors or other health care providers when an interpreter was needed?

To qualify as having family-centered care, the parent needed to answer "usually" or "always" to each of the above elements.

Overall, 59.6 percent of California CSHCN receive care that meets all of the essential components of family-centered care. This is significantly lower than the 66.4 percent national figure.

Aside from interpretation, the most commonly lacking component of family-centered care across all CSHCN is the health care provider spending enough time with the child: more than one in four parents of CSHCN report that their child's care does not meet this criterion.

Figure 4.11: Percentage of California CSHCN Who Did Not Receive Individual Components of Family-Centered Care*



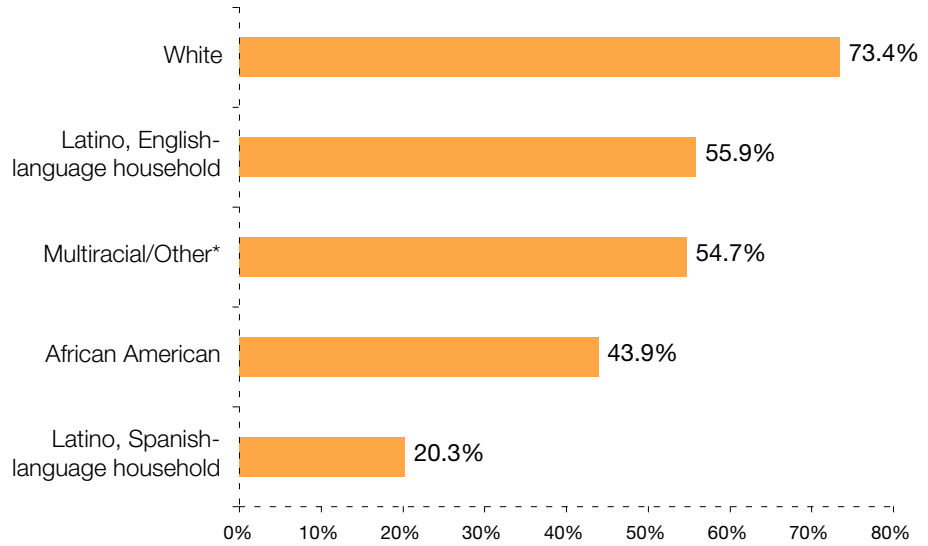
*Parents who report that care "sometimes" or "never" meets this criterion.

**Interpretation data are based on those who needed interpretation and were not able to get that interpretation from someone other than a family member.

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Race/ethnicity, language, and culture are important to the delivery and receipt of family-centered care.³⁰ As shown below, nearly six in 10 African American CSHCN in California are not receiving family-centered care, and nearly eight in 10 Latino CSHCN living in primarily Spanish-language households are not receiving family-centered care. More than 25,000 of California CSHCN do not receive an interpreter when needed, an obvious hindrance to the delivery of effective family-centered care.^{3,31}

Figure 4.12: Percentage of California CSHCN Receiving All Components of Family-Centered Care, by Race/Ethnicity* and Primary Language of Household

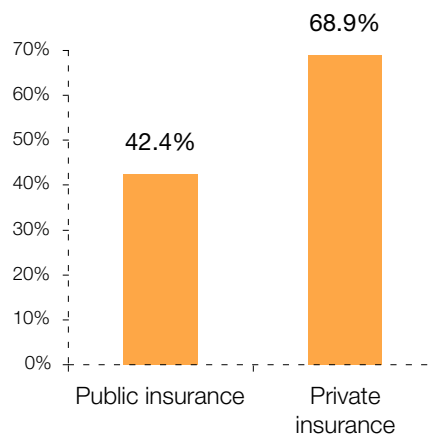


* "Multiracial" includes two or more races. "Other" race includes American Indian, Alaskan Native, Asian, Native Hawaiian, or Other Pacific Islander. These groups are not presented separately due to small sample size.
 Chi-square test $p < 0.001$
 Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Even after adjusting for all other factors, CSHCN of color in California are significantly less likely to receive family-centered care than white CSHCN. Latinos living in households where the primary language is Spanish are least likely to receive such care.

Children with public insurance are less likely to receive family-centered care than privately insured children (42.4% vs. 68.9%, respectively), and children from lower income households also are much less likely to receive such care (35.8% among children living below FPL vs. 72.8% among children above 400% FPL).

Figure 4.13: Percentage of California CSHCN Receiving All Components of Family-Centered Care, by Type of Insurance



Chi-square test $p < 0.001$
 Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: All children should receive care in a family-centered environment that respects the child's and family's culture and primary language; providers should listen to family concerns and offer specific information to address concerns. California must particularly address language barriers which inhibit the delivery of family-centered care.

Children in families with a primary language other than English should have consistent access to appropriate professional interpreters in the medical setting. Providers should receive continuous training in the delivery of family-centered care and assistance with strategies for increasing the family-centeredness of their services. Providers should also be trained in the delivery of culturally competent care to all families with CSHCN in California, regardless of race/ethnicity, primary household language, or other characteristics.

Family Resource Centers, currently under the Department of Developmental Services, only offer family support services to families with children identified with developmental issues. The Family to Family Information Center is in place to assist families with CSHCN more generally. However, there is no integrated family support system for all CSHCN.

Overall System Performance: Minimum Quality Composite Index

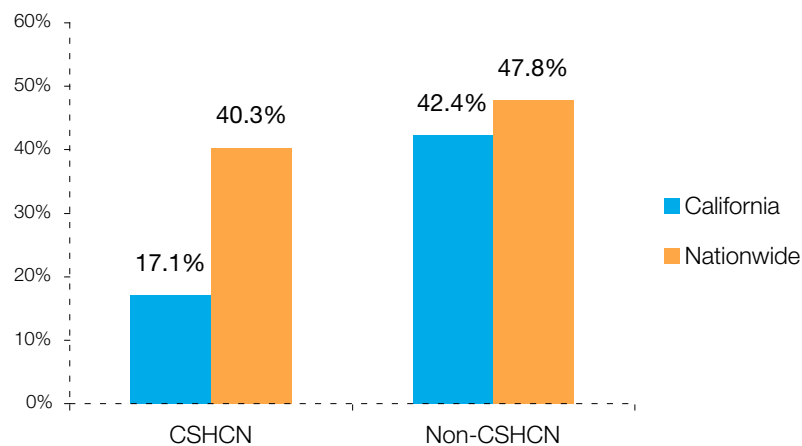
All children with special health care needs should receive the following in their ongoing health care:

- Care that meets all of the criteria for a medical home (ongoing, coordinated)—see above
- At least one preventive visit annually—see above
- Insurance coverage that is adequate to meet all of their health care needs—see Chapter 3

This definition of a minimum quality index is useful for understanding the disparities between children with special health care needs versus those children who are not identified with special needs. This relatively low bar of measuring the quality of health care delivery is met by only 17.1 percent of California’s CSHCN population. In contrast, over 42 percent of children without special health care needs in California are meeting these minimum criteria.

At 17 percent, California CSHCN are doing the worst in the nation on a minimum quality of care index.

Figure 4.14: Percentage of California Children Who Meet the Minimum Quality of Care Index,* by CSHCN Status



*Minimum quality index is met if child (1) receives ongoing and coordinated care within a medical home, (2) had at least one preventive visit in the past 12 months, and (3) has insurance coverage which is adequate for their needs.

Chi-square test $p < 0.001$ for within California comparisons and national vs. California comparisons.

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Chapter 4 Conclusions

All children need to be screened early and often to identify emerging health issues. Screening begins with prenatal care and continues even among children already identified as having a chronic illness or ongoing condition. All children in California, especially those who have been identified with ongoing conditions or as having special needs, must receive coordinated and comprehensive care within a stable medical and health care delivery environment. A medical home is a model for the provision of quality health care, providing ongoing and comprehensive care while engaging parents and families as partners in the care of their children. California should invest in medical home strategies to improve care delivery and coordination across services.

References for Chapter 4

1. Chung PJ, Lee TC, Morrison JL, Schuster MA. Preventive care for children in the United States: quality and barriers. *Annual Review of Public Health*. 2006;27:491-515.
2. Chin MH, Alexander-Young M, Burnet DL. Health care quality—improvement approaches to reducing child health disparities. *Pediatrics*. 2009;124 Suppl 3:S224-36.
3. Flores G, Tomany-Korman SC. The language spoken at home and disparities in medical and dental health, access to care, and use of services in U.S. children. *Pediatrics*. 2008;121(6):e1703-14.
4. Flores G, Tomany-Korman SC. Racial and ethnic disparities in medical and dental health, access to care, and use of services in U.S. children. *Pediatrics*. 2008;121(2):e286-98.
5. Dougherty D, Simpson LA. Measuring the quality of children's health care: a prerequisite to action. *Pediatrics*. 2004;113(1):185-198.
6. Simpson L, Dougherty D, Krause D, Ku CM, Perrin JM. Measuring children's health care quality. *American Journal of Medical Quality*. 2007;22(2):80-84.
7. Simpson L, Lawless S. Quality measurement: is the glass half full yet? *Ambulatory Pediatrics*. 2005;5(5):279-280.
8. Mangione-Smith R. Bridging the quality chasm for children: need for valid, comprehensive measurement tools. *Archives of Pediatrics & Adolescent Medicine*. 2007;161(9):909-910.
9. American Academy of Pediatrics. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118(1):405-420.
10. Halfon N, Regalado M, Sareen H, et al. Assessing development in the pediatric office. *Pediatrics*. 2004;113(6 Suppl):1926-1933.
11. American Academy of Pediatrics. The medical home: Medical Home Initiatives for Children with Special Needs Project Advisory Committee. American Academy of Pediatrics. *Pediatrics*. 2002;110(1 Pt 1):184-186.
12. Agency for Healthcare Research and Quality. *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies: Volume 7-Care Coordination*. 2007;Structured Abstract. Publication No. 04(07)-0051-7. <http://www.ahrq.gov/clinic/tp/caregapt.htm>.
13. Van Cleave J, Davis MM. Preventive care utilization among children with and without special health care needs: associations with unmet need. *Ambulatory Pediatrics*. 2008;8(5):305-311.

14. Stevens GD, Shi L. Racial and ethnic disparities in the quality of primary care for children. *The Journal of Family Practicet*. 2002;51(6):573.
15. Raphael JL, Guadagnolo BA, Beal AC, Giardino AP. Racial and ethnic disparities in indicators of a primary care medical home for children. *Academic Pediatrics*. 2009;9(4):221-227.
16. Lewis CW. Dental care and children with special health care needs: a population-based perspective. *Academic Pediatrics*. 2009;9(6):420-426.
17. Dietrich T, Culler C, Garcia RI, Henshaw MM. Racial and ethnic disparities in children's oral health: the National Survey of Children's Health. *Journal of the American Dental Association*. 2008;139(11):1507-1517.
18. Kane D, Mosca N, Zotti M, Schwalberg R. Factors associated with access to dental care for children with special health care needs. *Journal of the American Dental Association*. 2008;139(3):326-333.
19. Looman WS, Lindeke LL. Children and youth with special health care needs: partnering with families for effective advocacy. *Journal of Pediatric Health Care*. 2008;22(2):134-136.
20. Hart CN, Kelleher KJ, Drotar D, Scholle SH. Parent-provider communication and parental satisfaction with care of children with psychosocial problems. *Patient Education and Counseling*. 2007;68(2):179-185.
21. Ridd M, Shaw A, Lewis G, Salisbury C. The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *The British Journal of General Practice*. 2009;59(561):e116-33.
22. Bethell CD, Read D, Brockwood K, American Academy of Pediatrics. Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics*. 2004;113(5 Suppl):1529-1537.
23. Cooley WC, McAllister JW, Sherrieb K, Kuhlthau K. Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*. 2009;124(1):358-364.
24. Homer CJ, Klatka K, Romm D, et al. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008;122(4):e922-37.
25. McPherson M, Weissman G, Strickland BB, van Dyck PC, Blumberg SJ, Newacheck PW. Implementing community-based systems of services for children and youths with special health care needs: how well are we doing? *Pediatrics*. 2004;113(5 Suppl):1538-1544.
26. Stille CJ, Antonelli RC. Coordination of care for children with special health care needs. *Current Opinion in Pediatrics*. 2004;16(6):700-705.
27. Cooley WC. Redefining primary pediatric care for children with special health care needs: the primary care medical home. *Current Opinion in Pediatrics*. 2004;16(6):689-692.
28. Ziring PR, Brazdziunas D, Cooley WC, et al. American Academy of Pediatrics. Committee on Children with Disabilities. Care coordination: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 1999;104(4 Pt 1):978-981.
29. McAllister JW, Sherrieb K, Cooley WC. Improvement in the family-centered medical home enhances outcomes for children and youth with special healthcare needs. *The Journal of Ambulatory Care Management*. 2009;32(3):188-196.
30. Ochieng BM. Minority ethnic families and family-centered care. *Journal of Child Health Care*. 2003;7(2):123-132.
31. Javier JR, Huffman LC, Mendoza FS, Wise PH. Children with special health care needs: how immigrant status is related to health care access, health care utilization, and health status. *Maternal and Child Health Journal*. 2009.



Chapter 5: Impact on the Child: Functioning, School, and the Transition to Adulthood

Children with special health care needs (CSHCN) are children first and foremost. CSHCN desire to engage in the same activities as all children—school, play, sports, and clubs. Participation and inclusion are goals for most CSHCN, though due to conditions and functional limitations, some CSHCN have a harder time engaging in activities than other children.^{1,2}

The population of CSHCN includes children with a wide range of conditions. These conditions affect their daily lives in a number of different ways. Some CSHCN experience great limitations while others experience their daily lives in a manner that differs little from the general child population.^{2,3} When CSHCN receive proper health care and related services, their functional limitations can be significantly minimized or eliminated.

The goal of this section is to provide a sense of how children with special needs experience their daily lives, and how those experiences differ by complexity of need and functional ability. It explores the impact of children's conditions on their ability to do the things that most children of the same age do. Full engagement in school and ancillary activities is particularly important to all school-age children; therefore this section specifically addresses school engagement, repetition of grades, and number of missed school days. In addition, the transition from adolescence to adulthood can be a particularly challenging time for CSHCN. Preparing youth with special needs for the transition to adulthood should be a major priority for California's health system.

Impact of Special Health Care Needs on Children

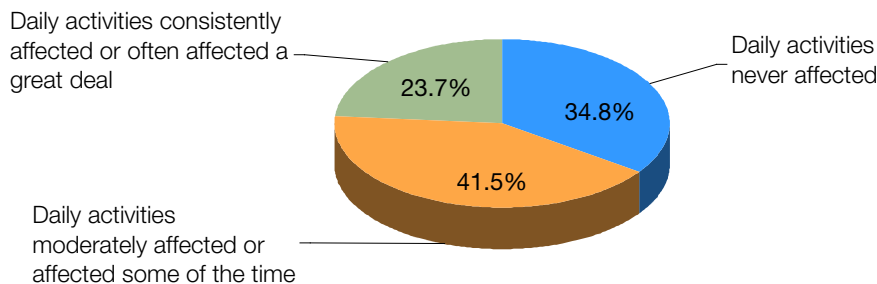
How children's special needs affect their daily lives was measured in the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN) in a number of ways. Detailed information on functional difficulties experienced by CSHCN was set forth in Chapter 1. Here, we draw on other items from the survey that provide a summary of how much CSHCN are impacted by their conditions in their daily lives. The NS-CSHCN assesses this through two questions:

- How often does the child's condition affect his or her ability to do the things other children of the same age do?
- Does his/her condition affect his or her ability to do things a great deal, some, or very little?

Almost 1 in 4 children with special needs in California (nearly 322,000) is consistently affected and/or often affected a great deal by their conditions.

As shown in Figure 5.1, almost one in four children with special needs in California (nearly 322,000) are consistently affected and/or often affected a great deal by their conditions—this is the same rate as the national average among CSHCN. California ranks in the middle of all states on this measure.

Figure 5.1: Impact of Condition on Daily Activities Among CSHCN in California

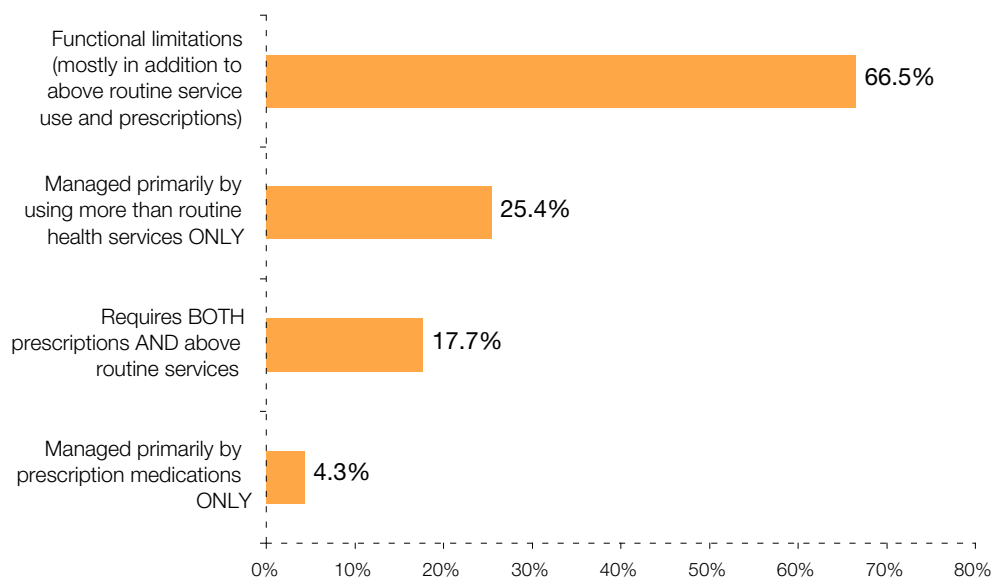


Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

However, not all California CSHCN are affected equally. As would be expected, even after adjusting for demographic differences, CSHCN with more serious functional limitations experience disturbances to their daily activities at a much higher rate, compared to CSHCN with less complex conditions managed solely by prescription medications (66.5% vs. 4.3%, respectively).²

Children with functional limitations experience the greatest impact on their daily lives. By contrast, CSHCN whose conditions can be managed solely by prescription medications experience significantly less disruption in their daily activities.

Figure 5.2: Percentage of California CSHCN Whose Conditions Consistently or Greatly Affect Their Daily Lives, by CSHCN Screener Qualifying Criteria*



*Children who qualify as having special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN with ongoing emotional, behavioral, or developmental issues also are significantly more likely to experience limitations on their activities (40.7%) compared with CSHCN who do not have such ongoing issues (17.2%).^{3,4}

IMPLICATIONS: California should adequately insure all CSHCN because adequate coverage can lessen the impact of special needs on the daily lives of children. As children with ongoing emotional and mental health issues experience more impact on their daily activities than children without such conditions, California should ensure that mental health coverage is as comprehensive as standard medical coverage, particularly for children who are not Medi-Cal eligible.

School and Related Activities Among CSHCN

More than one-third of California CSHCN ages 6-17 require special services through the education system, in addition to the health care system—35 percent have an individualized educational plan (IEP) to assist in their educational needs.

School is a large part of any child's life from age 6 to 17. The importance of school to children cannot be underestimated; it is a hallmark of childhood and one of the key components to successfully transitioning from adolescence into adulthood. School also serves as a primary avenue for the delivery of a range of services for children with special needs.

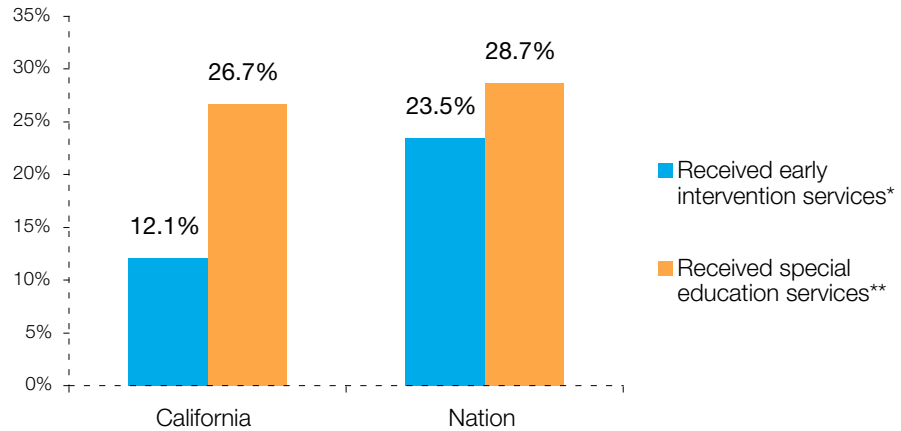
This section explores several elements of children's educational experiences, including program participation, school engagement, missed school days, participation in activities outside of school, and repetition of a grade. CSHCN often require additional support in several of these areas, and/or experience gaps in achievement due to their conditions.^{6,7}

Educational Program Participation

Early intervention services provide specialized therapies to children up to age 3 with developmental delays. These services include counseling, occupational and physical therapy, service coordination, and speech-language therapy. Nationally, 23.5 percent of CSHCN ages 0-3 receive these types of services, but only 12.1 percent in California do so.⁸

Special education programs provide educational and education-related health care services to children age 3 and older. As shown below, 26.7 percent of California CSHCN in this age group received these services. It is unclear whether these numbers reflect all CSHCN who needed the services or if there is still unmet need for special education services in California.

Figure 5.3: CSHCN Who Receive Early Intervention and Special Education Services



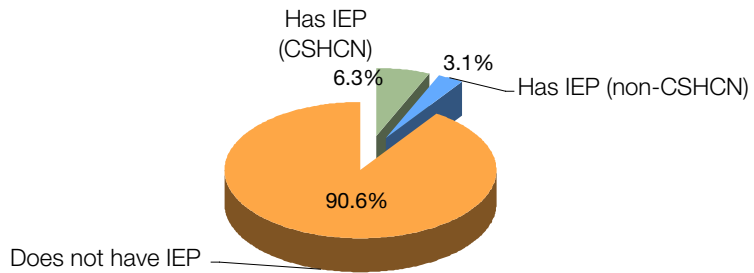
* Early Intervention Services go up to age 3. Chi-square test $p=0.14$

** Special Education Services are among age 3 or older. Chi-square test $p=0.35$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

In the 2007 National Survey of Children’s Health, parents of all children were asked if their child received special education services or had an individualized educational plan (IEP). Among all children in California, 9.4 percent have an IEP. However, CSHCN are much more likely than non-CSHCN to have an IEP (35.1% vs. 3.7%, respectively).

Figure 5.4: Children Ages 6-17 in California with Individualized Educational Plans, by CSHCN Status



Chi-square test $p<0.001$

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

IMPLICATIONS: In California, early intervention services are provided through the Regional Centers under contract with the state Department of Developmental Services. The different points of access for children ages 0-3 and children age 3 and older who receive services through special education pose a barrier and should be addressed. Children 2-1/2 to 3 years old, who are often too old to begin early intervention services through the Regional Centers, frequently experience a delay in waiting for special education services.

In order to promote educational opportunities for all, children with special needs that directly impact educational attainment should be addressed through early intervention and specialized educational services. Attention to gaps in early intervention access among vulnerable populations—especially Latino and poor families—can help in advancing educational achievement and improved well-being for all CSHCN.^{9,9a}

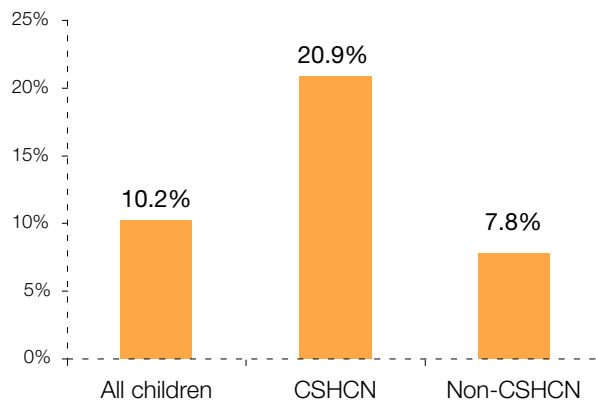
Repeating a Grade

In the National Survey of Children's Health, parents of school-age children were asked if their children had repeated one or more grades since starting school. In California, 10.2 percent of all children ages 6-17 have repeated a grade, similar to the national rate of 10.6 percent.

CSHCN are much more likely to repeat a grade than children generally. As shown below, 20.9 percent of CSHCN in California have repeated a grade compared to only 7.8 percent of the general child population—a result which holds even after adjusting for other demographic characteristics. The states range from 3 percent to 40 percent of CSHCN ever repeating a grade, with California falling in the middle, at 20.9 percent.

About 1 in 5 CSHCN in California has repeated a grade, compared to only 7.8 percent of the non-special needs population—a result that holds even after adjusting for other demographic characteristics.

Figure 5.5: Children Ages 6-17 Who Have Repeated a Grade in California, by CSHCN Status



Chi-square test $p=0.003$

Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

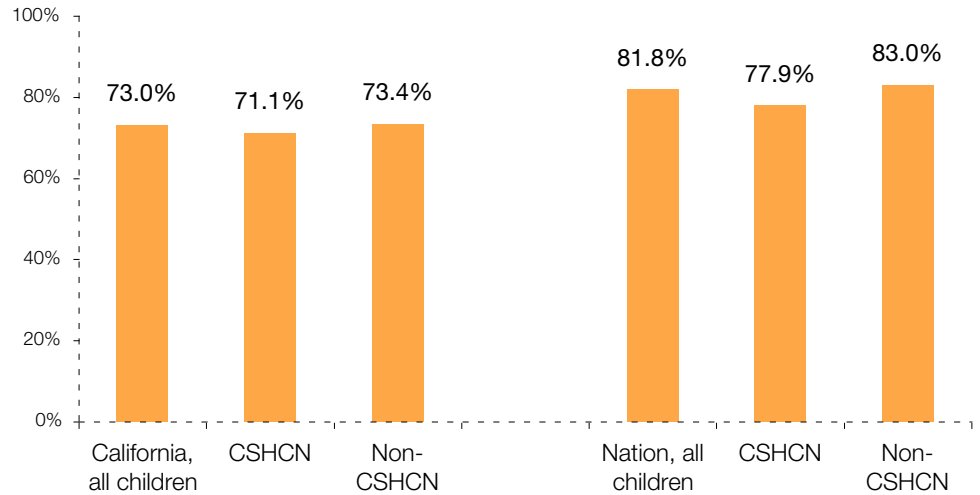
IMPLICATIONS: Strengthening support and early intervention services for CSHCN in California may lessen the need for grade repetition later in the educational cycle. California should empower families to be informed of their right to special educational services for their children's special needs.

Activities Outside of School

For school-age children, participation in activities after school or on the weekends—such as sports teams, recreational leagues, music lessons, Scouts, religious groups, or Boys'/Girls' Clubs—can play an important role in the development of their overall emotional and behavioral health.^{10,11} In the National Survey of Children's Health, parents of children ages 6-17 were asked if their children had participated in any of these types of activities in the past year. California has the lowest rate of participation in out-of-school activities in the nation (73% vs. 81.8% nationally and 91% in the highest state).

As shown in the figure below, participation in activities outside of school within California did not vary much by CSHCN status. Though California has a lower rate than the nation in youth ages 6-17 participating in activities, CSHCN within California are participating at roughly the same rate—even after adjusting for other demographic factors—as California children generally.

Figure 5.6: Participation in Activities Outside of School Among Children Ages 6-17, by CSHCN Status



Chi-square test $p < .001$ for California vs. national overall rate. California CSHCN vs. national CSHCN $p = 0.71$.
 Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

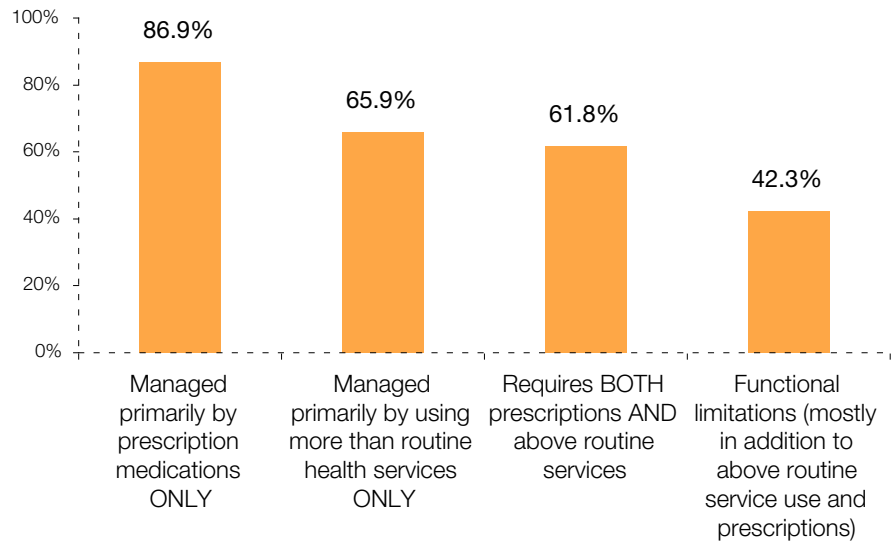
School Engagement

Given that school takes up a large portion of any school-age child's day, being engaged in that core activity is extremely important. School engagement, though measured in a variety of ways, is associated with more successful academic performance, less depression, and better peer relationships.¹²

Parents of school-age children were asked two questions in the National Survey of Children's Health to assess their child's engagement in school: whether the child cares about doing well in school and whether the child does all required homework. Children were considered to be engaged in school if their parent responded "usually" or "always" to both of these items. Overall, 76.6 percent of children ages 6-17 in California are engaged in school.

However, fewer than 68 percent of CSHCN are reported to be engaged in school, compared to 78.6 percent of children without special needs. As shown below, among CSHCN, the most likely to be engaged in school are those whose conditions are managed solely by prescription medications (86.9%) while the least likely to be engaged are those CSHCN experiencing functional limitations (42.3%). These differences hold even after adjusting for other demographic characteristics. CSHCN with functional limitations encounter a number of challenges—such as a greater likelihood of not being able to attend school—that inhibit their school experience and success.¹³

Figure 5.7: Percentage of California CSHCN Ages 6-17 Engaged in School, by CSHCN Screener Qualifying Criteria*



*Children who qualify as having special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

Chi-square test $p=0.016$

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

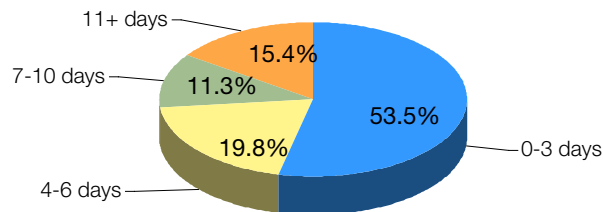
IMPLICATIONS: Educational services must remove barriers to school engagement. Children with complex conditions often require greater services in order to meet academic achievements, but may also require more services in order to actively engage in school and in school-based learning.

Only 4 percent of children without special health care needs missed more than 11 days of school in a year, compared to 15.4 percent of CSHCN. Missing that much school in one year can have serious effects on a child’s ability to succeed in school.

Missed School Days

The number of school days missed is another measure of the impact of a child’s condition on his or her ability to function normally. In general, the average child misses three days of school per year due to acute conditions.^{13,14} By comparison, among school-age CSHCN, the average is seven school days missed (due to both chronic and acute conditions). Among CSHCN, there is a substantial minority (15.4%) who miss 11 or more school days per year due to their condition(s); this compares to only 4 percent of children without special needs.

Figure 5.8 Percentage of California CSHCN Ages 6-17 Who Missed Each Amount of School Days Due to Illness



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Transition to Adulthood: A Core Goal for All Youth with Special Health Care Needs

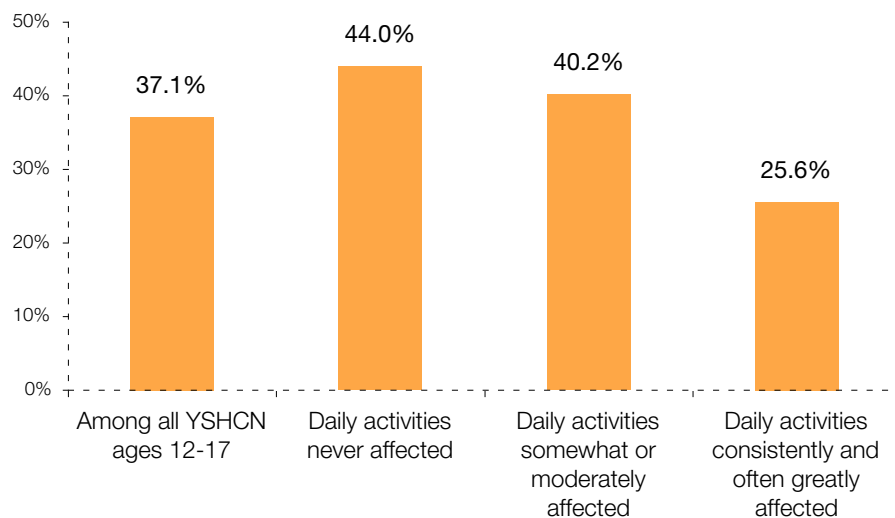
Poor and publicly insured youth with special health care needs in California are not receiving appropriate services to transition to adulthood. They are in danger of not receiving the care needed to successfully navigate life as an adult.

Youth with special health care needs (YSHCN) are much less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently.^{15,16} One of the greatest challenges families and their children face in planning is how to make a successful transition from the pediatric to adult health care system for youth with special health care needs.¹⁷⁻¹⁹ Health care professionals, both pediatric and adult, may lack the training to help YSHCN successfully transition; some adult health care providers may not be prepared to treat patients with complex medical conditions that began in childhood.²⁰ YSHCN may find themselves with a different form of health care coverage, geared toward adult health outcomes, that no longer meets their needs.

Whether youth receive transition services was evaluated for YSHCN ages 12-17 using three questions from the NS-CSHCN about whether doctors had discussed: (1) the shift to adult providers, (2) the child's changing needs as he or she approached adulthood, and (3) insurance coverage in adulthood. In California, 37.1 percent of YSHCN received this level of transition planning, compared to 41.7 percent nationwide.

Adolescents whose conditions consistently or greatly affect their daily activities are considerably less likely to achieve this objective than those whose daily activities are never affected (26% versus 44%)—most likely due to the complexity of their health needs and therefore the complexity of the need for their transition planning. More complicated conditions that require a wider variety of health services will require a stronger case manager or care coordinator to ensure uninterrupted health management.

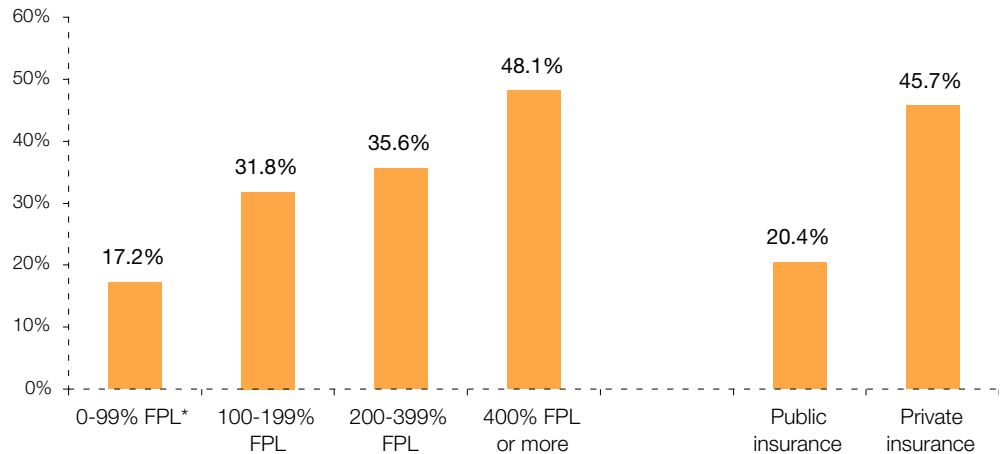
Figure 5.9: Percentage of California YSHCN Ages 12-17 Who Receive Services to Help Them Transition to Adulthood, by Impact of Condition(s)



Chi-square test $p=0.15$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Figure 5.10: Percentage of California YSHCN Ages 12-17 Who Receive Services to Help Them Transition to Adulthood, by Income Level and Type of Insurance



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Chi-square test for income level $p=0.06$; Chi-square test for type of insurance $p=0.002$

*FPL = Federal Poverty Level. In 2006 (the year of the most recent National Survey of Children with Special Health Care Needs), the FPL was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.

More training and system assistance is needed for pediatricians and other practitioners who work with and interact intensively with youth in transition.

IMPLICATIONS: Youth with special health care needs must be able to expect a degree of independence, good health care, and employment with benefits as adults. Systems of care that guide youth into adulthood should focus on securing continuous, uninterrupted care. They also should assist in fostering independent living or direct youth toward appropriate assistive services. Transition planning should begin at least by the age of 12, and perhaps much younger for children with more severe limitations. Transition planning also requires that a number of providers and agencies work together in a coordinated effort.

California should develop and train more practitioners who specialize in treating adults who have had chronic and complex health conditions since childhood. Further, there is a large problem with YSHCN “graduating out” of the child health insurance system and experiencing problems acquiring insurance for pre-existing conditions. Recently enacted health care legislation reform is expected to remedy this situation, but in the meantime California should provide assistance to YSHCN in accessing high-risk pool state insurance.

Conclusions for Chapter 5

CSHCN desire to engage in and enjoy all of the same activities as other children who are not living with the burden of illness. A coordinated system of care which monitors CSHCN and their needs for health care and educational assistance without service access barriers will go a long way to greatly improve the daily lives of children with special needs. As children grow into adolescents with special needs, California must do more to promote their academic achievement, engage them in learning, and work with primary and specialist providers to prepare youth for the transition to adult health care. California should attempt to ameliorate the disproportionate burden of illness and activity limitations which fall upon the most vulnerable—those with complex chronic conditions, CSHCN of color, and those with public insurance.

References for Chapter 5

1. Murphy NA, Carbone PS, American Academy of Pediatrics Council on Children with Disabilities. Promoting the participation of children with disabilities in sports, recreation, and physical activities. *Pediatrics*. 2008;121(5):1057-1061.
2. Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. *Maternal and Child Health Journal*. 2009;13(2):151-163.
3. Boulet SL, Boyle CA, Schieve LA. Health care use and health and functional impact of developmental disabilities among U.S. children, 1997-2005. *Archives of Pediatrics & Adolescent Medicine*. 2009;163(1):19-26.
4. Halfon N, Newacheck PW. Prevalence and impact of parent-reported disabling mental health conditions among U.S. children. *Journal of the American Academy of Child and Adolescent Psychiatry*. 1999;38(5):600-9; discussion 610-3.
5. Stein RE, Silver EJ. Are rates of functional limitations associated with access to care? A state-level analysis of the national survey of children with special health care needs. *Maternal and Child Health Journal*. 2005;9(2):S33-9.
6. Currie J. Health disparities and gaps in school readiness. *The Future of Children*. 2005;15(1):117-138.
7. Fiscella K, Kitzman H. Disparities in academic achievement and health: the intersection of child education and health policy. *Pediatrics*. 2009;123(3):1073-1080.
8. Rosenberg SA, Zhang D, Robinson CC. Prevalence of developmental delays and participation in early intervention services for young children. *Pediatrics*. 2008;121(6):e1503-9.
9. McManus B, McCormick MC, Acevedo-Garcia D, Ganz M, Hauser-Cram P. The effect of state early intervention eligibility policy on participation among a cohort of young CSHCN. *Pediatrics*. 2009;124 Suppl 4:S368-74.
- 9a. National Research Council and Institute of Medicine (2000) *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Committee on Integrating the Science of Early Childhood Development. Jack P. Shonkoff and Deborah A. Phillips, eds. Board on Children, Youth, and Families, Commission on Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.
10. Grossman JB, Price ML, Fellerath V, et al. *Multiple Choices After School: Findings from the Extended-Service Schools Initiative*. Philadelphia: Public/Private Ventures; 2002.
11. Mahoney JL, Larson RW, Eccles JS. *Organized Activities as Contexts of Development: Extracurricular Activities, After-School, and Community Programs*. New Jersey: Lawrence Erlbaum Associates; 2005.
12. Battistich V, Hom A. The relationship between students' sense of their school as a community and their involvement in problem behaviors. *American Journal of Public Health*. 1997;87(12):1997-2001.
13. Msall ME, Avery RC, Tremont MR, Lima JC, Rogers ML, Hogan DP. Functional disability and school activity limitations in 41,300 school-age children: relationship to medical impairments. *Pediatrics*. 2003;111(3):548-553.
14. Bethell CD, Read D, Blumberg SJ, Newacheck PW. What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*. 2008;12(1):1-14.
15. Wagner MM, Blackorby J. Transition from high school to work or college: how special education students fare. *The Future of Children*. 1996;6(1):103-120.

16. Thurlow ML, Ysseldyke JE, Reid CL. High school graduation requirements for students with disabilities. *Journal of Learning Disabilities*. 1997;30(6):608-616.
17. Kane DJ, Kasehagen L, Punyko J, Carle AC, Penziner A, Thorson S. What factors are associated with state performance on provision of transition services to CSHCN? *Pediatrics*. 2009;124 Suppl 4:S375-83.
18. Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *Journal of Adolescent Health*. 2008;43(1):23-29.
19. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005;115(6):1562-1568.
20. Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health*. 2003;32(3):225-233.



Chapter 6: Impact on the Family: Time, Employment, Finances, and Physical and Mental Health

Children with special health care needs (CSHCN) live within families and communities. Their siblings, parents, and guardians have complex relationships with their health care needs. Though all families experience health and financial related stress when raising children, the families of CSHCN may often experience extra stress due to their children's conditions.¹

Having a child with special health care needs can affect a family's finances,² employment status,³ and mental and physical health.⁴ The demands on families may require that parents cut down their work hours or give up a job,^{5,6} at the same time that they face higher than average out-of-pocket health care costs.⁷ As important as the financial considerations, having a child with special needs also is a significant time commitment. Families of CSHCN may spend large amounts of time directly providing care, learning about their child's condition, learning about services, or coordinating their child's care.

This chapter describes the family impact of caring for CSHCN, including comparisons to families caring for children without special needs. The second part of the chapter describes the parental stress associated with caring for CSHCN, especially those with ongoing emotional, behavioral or developmental issues. Finally, the chapter describes how caring for children with special or complex needs affects parents' physical and mental health.

The Impact of Caring for Children with Special Health Care Needs

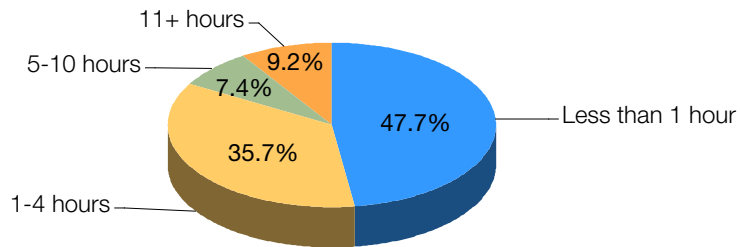
Time Spent Providing Care

For families with children who have special health care needs, providing direct care or coordinating care—in addition to routine child-raising activities—can be quite time-consuming. Families spend time on such tasks as administering medications and therapies, maintaining equipment, and providing transportation to appointments. Families also spend time arranging or coordinating care for their children by making appointments, making sure that care providers are exchanging information, and following up on their children's health care needs.^{1,8}

Almost 1 in 10 (approximately 125,000) California CSHCN have families who spend 11 hours or more per week providing or coordinating their care.

As shown in Figure 6.1, 47.7 percent of California CSHCN have families who spend less than one hour per week on these activities. However, at the other end of the spectrum, almost one in 10 (approximately 125,000) California CSHCN have families who spend 11 hours or more per week providing or coordinating care. This is similar to the national average.

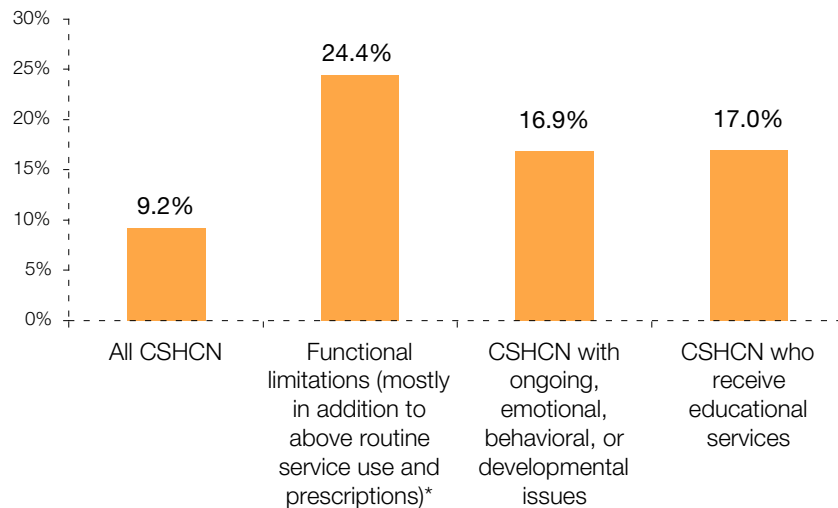
Figure 6.1: Time Spent Providing, Arranging, or Coordinating Care for California CSHCN, per Week



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

The burden of care is more acute among certain groups of CSHCN. Those with functional limitations (those who are limited or prevented in their ability to do things most children of the same age can do) or who have ongoing emotional, behavioral, or developmental issues, or who receive educational services (such as having an IEP) are significantly more likely to require additional hours of care from parents and family.⁸

Figure 6.2: Percentage of California CSHCN Whose Families Spend 11 Hours or More per Week Providing, Arranging, or Coordinating Care, by Various Groups with Higher Levels of Need



*Children who qualify as having special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

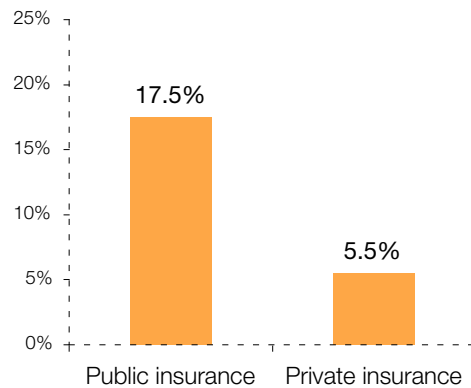
Chi-square test $p=0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Additional strain on family time and resources can result from the need for specialized services or parental involvement in meetings with school counselors and IEP providers. The challenges of having to learn about their child's condition and simultaneously navigate and negotiate for services can be debilitating.

CSHCN with public insurance are also more likely to receive 11 or more hours of care from their family.

Figure 6.3: Percentage of California CSHCN Whose Families Spend 11 Hours or More per Week Providing, Arranging, or Coordinating Care, by Type of Insurance



Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org
Chi-square test $p < 0.001$

Parental Stress Involved with Caring for CSHCN

Overall, the parents of nearly 24 percent of CSHCN in California report having to stop work or cut back on their hours at work because of their children's needs. This affects nearly 325,000 children and their families in California.

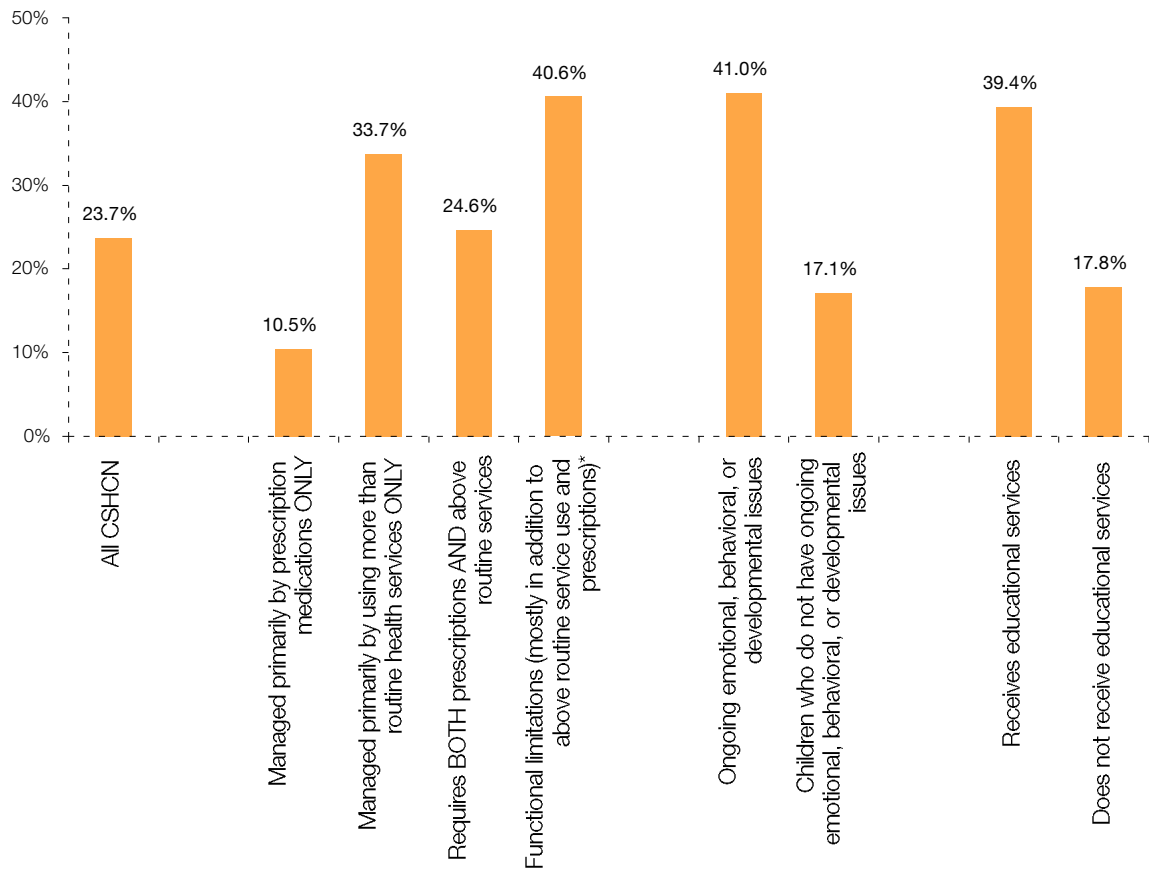
Impact on Parental Employment

Due to the complexity of caring for a child with special needs and the amount of time it often takes, familial employment may sometimes be affected. This may require that parents cut back on the number of hours they work or stop working completely to care for their child.^{10,11}

The complexity of caring for children with special needs tends to rise with the complexity of their conditions. Though 24 percent of children with special health care needs have families who have had to cut back or stop working, children with more complex conditions have an even higher rate of such effects on employment.

As the next figure shows, approximately 4 out of 10 CSHCN who have functional limitations, or who have ongoing emotional, behavioral, or developmental issues, or who receive special educational services have parents whose employment has been affected by their conditions.

Figure 6.4: Percentage of California CSHCN Whose Parents Stopped or Cut Back on Work, by Subgroups of CSHCN



*Children with ongoing special needs who meet the criteria for "functional limitations" differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

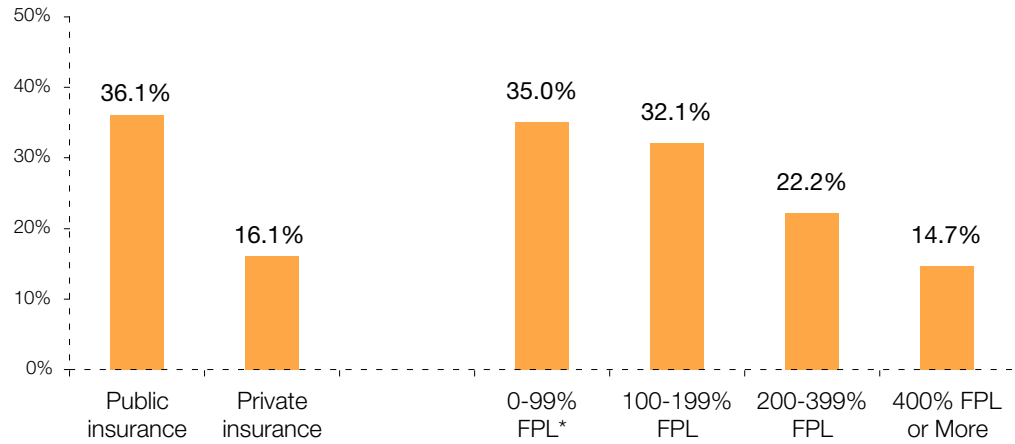
Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN who are living in poverty or who have public insurance are much more likely to have parents who cut back or gave up their jobs.

Families of CSHCN who are living in poverty or who have public insurance are disproportionately affected by caring for children with special needs.¹¹ Children in lower-income families are more likely to have parents who have given up their jobs—more than one-third of CSHCN in poverty in California compared to less than 15 percent at the highest income level. Families with public insurance also are much more likely to cut back or stop working (36.1% vs. 16.1% with private insurance).

Figure 6.5: Percentage of California CSHCN Whose Parents Stopped or Cut Back on Work to Care for Their Child, by Income and Type of Insurance



*FPL = Federal Poverty Level. In 2006 (the year of the most recent National Survey of Children with Special Health Care Needs), the FPL was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.

Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: California can (1) strengthen medical leave policies, (2) strengthen child care resources for families with CSHCN in order to help parents maintain their employment, and (3) ensure that every child has insurance so families do not have to quit their jobs in order to qualify for Medi-Cal.^{5,12}

Financial Impact of Caring for Children with Special Health Care Needs

Nearly 1 in 7 California CSHCN families reported that their child's condition had created a financial burden.

The financial impact of children's ongoing conditions on their families was assessed in a few ways in the 2005-06 National Survey of Children with Special Health Care Needs (NS-CSHCN). First, the survey asked whether a child's condition or need had caused a financial problem. The survey also assessed whether families of CSHCN had to pay more than \$1,000 in out-of-pocket expenses for services related to their children's conditions.

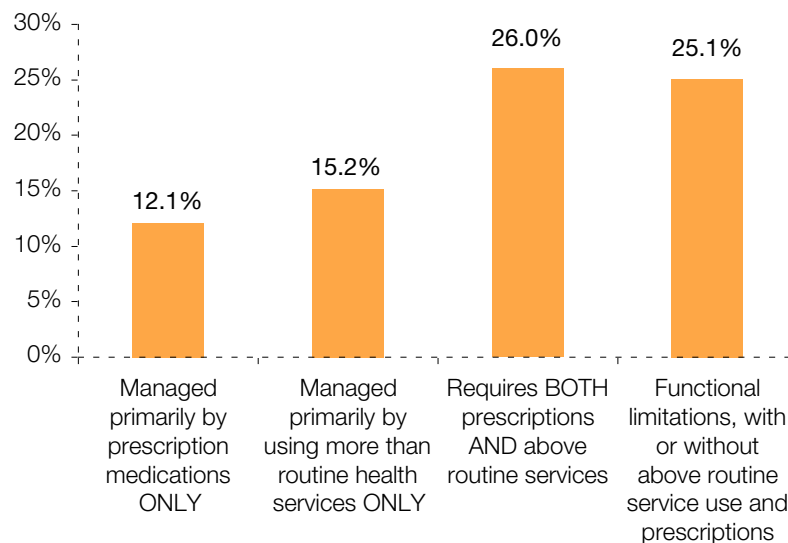
Nearly one in seven California CSHCN families reported that their child's condition had created a financial burden. However, when looking at children with functional limitations, the number jumps to nearly one in four CSHCN. The financial burden is comparatively much less for families whose children are managed solely by prescription medications; only 6 percent of such children have families who report financial problems. California ranks seventh (with one being the best) among all states for parents who report that they are under undue financial burden in caring for their child with special needs.

Out-of-Pocket Expenditures

Families are often required to pay for health care services which are not covered by their insurance plans. These services may include certain types of therapy, home health care, prescription drugs, mental health care, medical equipment, and dental services. Families of almost 250,000 CSHCN in California (17.9%) report spending more than \$1,000 in the past year on medical expenses.

Families of children with more complex conditions, such as those who require prescription medication along with higher than average service use, are more likely to have annual out-of-pocket expenditures over \$1,000. Children whose conditions are managed solely by prescription medications are the least likely to expend more than this amount annually.

Figure 6.6: Percentage of California CSHCN Families with Annual Out-of-Pocket Expenditures of More than \$1,000, by CSHCN Screener Qualifying Criteria*



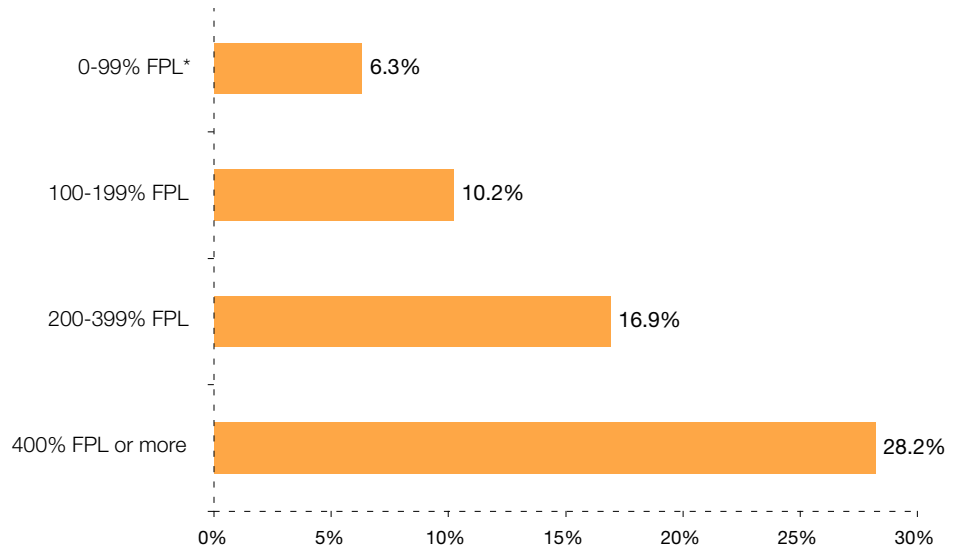
*Children who qualify as having special needs who meet the criteria for “functional limitations” differ qualitatively from other CSHCN. While nearly all CSHCN experience functional difficulties of some kind, children with functional limitations are typically those with complex conditions that result in daily limitations despite health care services received. Please see chapter 1 for more on functional difficulties and functional limitations.

Chi-square test $p=0.03$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

Children in low-income families or with public health insurance are less likely to have high levels of expenditures than are children from families with higher incomes or with private health insurance.^{7,13} Given that children in low-income families are more likely to be covered by Medicaid (Medi-Cal) and SCHIP (Healthy Families), which limit the co-pays charged to families, the burden of out-of-pocket expenditures is comparatively lower—6.3 percent vs. 28.2 percent among the highest income level, as shown below. However, for lower income families, any out-of-pocket expenses, even those less than \$1,000 per year, can be quite burdensome.

Figure 6.7: Percentage of California CSHCN Families with Annual Out-of-Pocket Expenditures of More than \$1,000, by Federal Poverty Level (FPL)*



*In 2006 (the year of the most recent National Survey of Children with Special Health Care Needs), the Federal Poverty Level was \$20,000 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2010), the FPL is \$22,050 for a family of four.

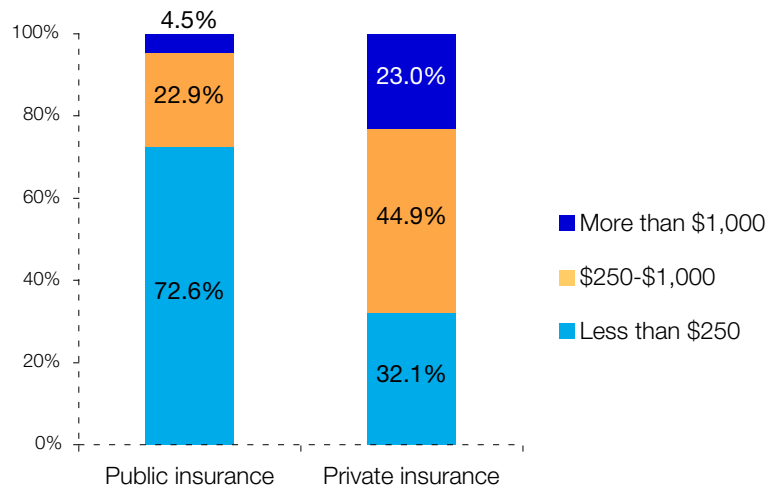
Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

CSHCN in families with private insurance are significantly more likely to expend \$1,000 or greater annually to care for their children, compared with children on public insurance.

CSHCN in families with private insurance are significantly more likely to expend \$1,000 or greater annually to care for their children, compared with children on public insurance (23.0% vs. 4.5%). California ranks 16th for expenditures over \$1,000 among publicly insured children. Illinois is the lowest at 1.4 percent and New Jersey is the highest at 13 percent.

Figure 6.8: Percentage of California CSHCN Families with Each Amount of Annual Out-of-Pocket Expenditures, by Type of Insurance



Chi-square test $p < 0.001$

Data source: 2005-06 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

IMPLICATIONS: Public insurance often is more successful than private insurance at reducing out-of-pocket expenses for families with CSHCN.¹⁴ State policies, such as SCHIP (Healthy Families) eligibility guidelines, also can play a role in reducing the total burden for families caring for CSHCN.¹⁵ Likewise, broader coverage of therapeutic services (occupational and physical therapies), alternative medicine, and mental health services—especially by private insurance providers—would help reduce the costs associated with caring for children with complex conditions.

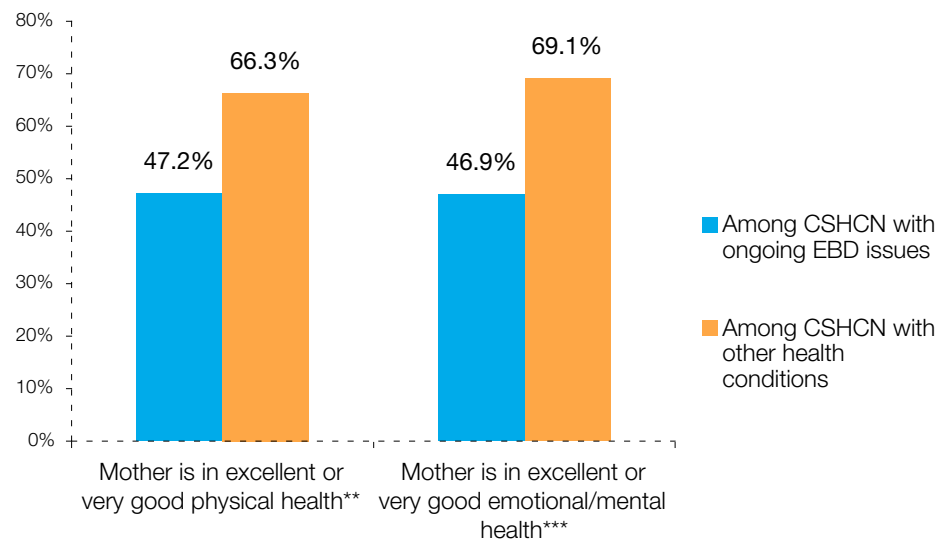
Parent’s Physical and Mental Health

Parental Health

The physical and emotional health of a child’s parents can affect a family’s overall well-being as well as their ability to care for their child. In addition, stress may affect parental health. Parenting stress is greater when children need more intensive levels of care.

The 2007 NSCH shows that the health of California parents with special needs children does not differ substantially from the health of parents of children without special needs. However, among CSHCN, those who have ongoing emotional, behavioral, or developmental issues are much more likely to have mothers in mediocre health than CSHCN with other types of conditions.^{16,17} Differences among fathers do not vary substantially.

Figure 6.9: Percentage of California CSHCN with Mothers* in Excellent or Very Good Health, by Whether Children Have Ongoing Emotional, Behavioral, or Developmental (EBD) Issues



*Among children with a biological, step, foster, or adoptive mother in the household.

**Chi-square test $p=.11$

***Chi-square test $p=.07$

Data source: 2007 National Survey of Children’s Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Parental Stress

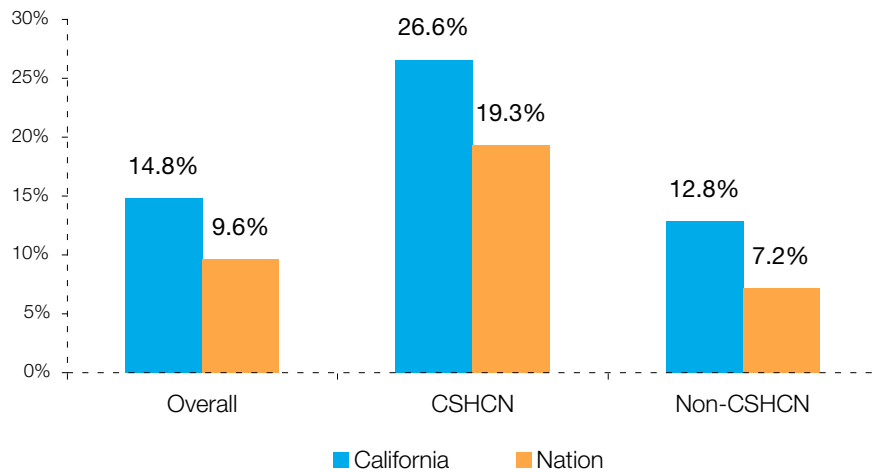
The general demands of parenting, and caring for CSHCN in particular, can cause considerable stress for families.^{18,19}

Parents were asked several questions in the 2007 NSCH to determine stress related to parenting during the prior month:

- How often they felt their child was much harder to care for than others of his or her age
- How often the child did things that really bothered them a lot
- How often they had felt angry with the child

Parents were considered to feel parental stress if they answered “usually” or “always” to at least one of these measures. As shown in the next figure, parents of 14.8 percent of children in California report parental stress—higher than the national rate of 9.6 percent. Additionally, CSHCN have parents who are significantly more stressed from parenting than children without special needs.

Figure 6.10: Percentage of Children with Parents Who Feel Stress Due to Parenting, by CSHCN Status



Chi-square test for California CSHCN vs. non-CSHCN $p=.003$; for national CSHCN vs. non-CSHCN $p<0.001$
Data source: 2007 National Survey of Children's Health, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

Finally, nearly half of children with ongoing emotional, behavioral, or developmental problems have parents who feel stress due to parenting (47.7%), compared with only 16.6 percent of children with other types of special health care needs.

California has the highest rate of parents of CSHCN reporting stress due to parenting than any other state.

Conclusions for Chapter 6

Caring for a child with special health care needs can be very challenging for many families. Providing and arranging care often takes a toll—in the amount of time spent providing care for the child, above average out-of-pocket expenses, effects on parental employment, and much greater burden of parental stress. California families need support to be able to provide the care their children require.

One source of assistance in California is the statewide network of Family Resource Centers (FRC), which are staffed by parents who have children with special needs. These centers, funded by the state Department of Developmental Services, provide information and parent-to-parent support regarding early intervention services. Another statewide resource is the federally funded Family to Family Health Information Center, which operates through Family Voices, a nonprofit group that provides services and information to families with CSHCN. The state Department of Health Care Services also offers information to assist families. However, a closer partnership between governmental agencies and nonprofit advocacy groups is essential to ensure that families receive the support they need to care successfully for their children.

References for Chapter 6

1. Family Voices. California Survey of the Health Care Experiences of Families of Children with Special Health Care Needs. 2000.
2. Kuhlthau K, Hill KS, Yucel R, Perrin JM. Financial burden for families of children with special health care needs. *Maternal and Child Health Journal*. 2005;9(2):207-218.
3. Looman WS, O'Conner-Von SK, Ferski GJ, Hildenbrand DA. Financial and employment problems in families of children with special health care needs: implications for research and practice. *The Journal of Pediatric Health Care*. 2009;23(2):117-125.
4. Witt WP, Gottlieb CA, Hampton J, Litzelman K. The impact of childhood activity limitations on parental health, mental health, and workdays lost in the United States. *Academic Pediatrics*. 2009;9(4):263-269.
5. Schuster MA, Chung PJ, Elliott MN, Garfield CF, Vestal KD, Klein DJ. Perceived effects of leave from work and the role of paid leave among parents of children with special health care needs. *American Journal of Public Health*. 2009;99(4):698-705.
6. Loprest P, Davidoff A. How children with special health care needs affect the employment decisions of low-income parents. *Maternal and Child Health Journal*. 2004;8(3):171-182.
7. Honberg LE, Kogan MD, Allen D, Strickland BB, Newacheck PW. Progress in ensuring adequate health insurance for children with special health care needs. *Pediatrics*. 2009;124(5):1273-1280.
8. Maes B, Broekman TG, Dosen A, Nauts J. Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*. 2003;47(Pt 6):447-455.
9. Montes G, Halterman JS. Child care problems and employment among families with preschool-aged children with autism in the United States. *Pediatrics*. 2008;122(1):e202-8.
10. Okumura MJ, Van Cleave J, Gnanasekaran S, Houtrow A. Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics*. 2009;124 Suppl 4:S392-8.

11. Derigne L, Porterfield S. Employment change and the role of the medical home for married and single-mother families with children with special health care needs. *Social Science & Medicine*. 2009.
12. Schuster MA, Chung PJ, Elliott MN, Garfield CF, Vestal KD, Klein DJ. Awareness and use of California's Paid Family Leave Insurance among parents of chronically ill children. *Journal of the American Medical Association*. 2008;300(9):1047-1055.
13. Chen AY, Newacheck PW. Insurance coverage and financial burden for families of children with special health care needs. *Ambulatory Pediatrics*. 2006;6(4):204-209.
14. Yu H, Dick AW, Szilagyi PG. Does public insurance provide better financial protection against rising health care costs for families of children with special health care needs? *Medical Care*. 2008;46(10):1064-1070.
15. Parish SL, Shattuck PT, Rose RA. Financial burden of raising CSHCN: association with state policy choices. *Pediatrics*. 2009;124 Suppl 4:S435-42.
16. Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. *Pediatrics*. 2007;119 Suppl 1:S114-21.
17. Busch SH, Barry CL. Mental health disorders in childhood: assessing the burden on families. *Health Aff (Millwood)*. 2007;26(4):1088-1095.
18. Churchill SS, Villareale NL, Monaghan TA, Sharp VL, Kieckhefer GM. Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. *Maternal and Child Health Journal*. 2010;14(1):47-57.
19. Kerr SM, McIntosh JB. Coping when a child has a disability: exploring the impact of parent-to-parent support. *Child: Care, Health and Development*. 2000;26(4):309-322.



Appendices

Appendix A: Methodology Overview

This methodological brief provides an overview of the methods utilized in preparing *Children with Special Health Care Needs: a Profile of Key Issues in California*. Two major sources of data—the 2005-06 National Survey of Children with Special Health Care Needs and the 2007 National Survey of Children’s Health—were used as the analytic base of this report. The California Health Interview Survey, though extremely rich in California-specific data, does not contain a standardized way of identifying children with special health care needs and therefore did not provide an appropriate source of analysis for this report.

The two national surveys, described in more detail below, both use the validated *Children with Special Health Care Needs (CSHCN) Screener*. The screener identifies children with special needs using the Maternal and Child Health Bureau definition of CSHCN as...

“those [children] 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.”¹

For more information about the CSHCN screener, please visit the CAHMI website at <http://www.cahmi.org/pages/Sections.aspx?section=10> or review the screener at <http://cahmi.org/ViewDocument.aspx?DocumentID=115>.

2005-06 National Survey of Children with Special Health Care Needs

The National Survey of Children with Special Health Care Needs (NS-CSHCN) is sponsored and funded by the Maternal and Child Health Bureau of the U.S. Department of Health Resources and Service Administration and is conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). The purpose of the 2005-06 NS-CSHCN is to assess the prevalence and impact of special health care needs among children younger than 18 years of age in all 50 states and the District of Columbia, and to evaluate changes since 2001. The central focus of the survey is the extent to which children with special health care needs (CSHCN) have medical homes, adequate health insurance and access to needed services. Functional difficulties, chronic medical conditions, care coordination, satisfaction with care, and adolescent transition services also are addressed in the survey questionnaire.

During the 2005-06 NS-CSHCN, 364,841 children nationwide in 192,083 households were screened, resulting in 40,723 completed interviews for CSHCN. In California, 11,292 children in 5,769 households were screened, to obtain a total of 945 in-depth CSHCN interviews.²

For each CSHCN selected as a participant in the 2005-06 NS-CSHCN, an in-depth telephone interview was conducted with the parent or guardian who is most familiar with the child's health and health care. Interviews were performed in English, Spanish, Mandarin, Cantonese, Vietnamese, or Korean.

Survey respondents were selected according to scientific random sampling methods designed to provide a sample that is representative of the entire population of non-institutionalized children with special needs from birth to age 17 within each state and the District of Columbia. As a result, the NS-CSHCN provides estimates of the number and percentage of all CSHCN in each state, which can be compared with results for other states, regions, and the nation. The National Center for Health Statistics creates sampling weights that are included in all public release dataset files. The sampling weights account for non-response bias (e.g., no telephone) and create individual child-level weights based on race, number of children in household, and a host of other demographic information. The result is that weighted estimates represent the population of non-institutionalized CSHCN ages 0-17 in the United States and in each state. For more information, please see the 2005-06 NS-CSHCN Design and Operations Manual.²

Results for individual survey items have been analyzed and combined to create measures of the six Maternal and Child Health Bureau (MCHB) Core Outcomes that pertain to CSHCN, and 15 child health indicators for the national NS-CSHCN Chartbook 2005-2006 (<http://mchb.hrsa.gov/cshcn05/>).

For more information on the 2005-06 NS-CSHCN, visit www.cshcndata.org.

2007 National Survey of Children's Health

The National Survey of Children's Health (NSCH) is sponsored and funded by the Maternal and Child Health Bureau of the U.S. Department of Health Resources and Service Administration and is conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). The Maternal and Child Health Bureau appointed and facilitated a National Technical Expert Panel to oversee the content, methods, and construction of indicators using the NSCH. Topics and survey items included in the NSCH underwent extensive review. Where available, the NSCH incorporated existing and validated survey items. In cases where relevant topics lacked such validated items, new items were developed and underwent cognitive testing and in-depth review by Technical Expert Panel members and consultants. The NSCH used random-digit-dial methods to identify a sample of households with children less than 18 years of age from each of the 50 states and the District of Columbia. One child was then randomly selected from all children in each identified household to be the subject of the survey. The respondent was a parent or guardian who knew about the child's health and health care. A total of 91,642 interviews were completed from April 2007 to July 2008. Nearly 80% of the interviews were completed in 2007. Interviews were completed in 66 percent of identified households with children. In California, 1,751 interviews were completed with parents or guardians of children ages 0-17.

The National Center for Health Statistics creates sampling weights that are included in all public release dataset files. The sampling weights account for non-response bias (e.g., no telephone) and create individual child-level weights based on race, number of children in household, and a host of other demographic information. The result is that weighted estimates represent the population of non-institutionalized children ages 0-17 in the United States and in each state. For more information, please see the 2007 NSCH Design and Operations Manual.³ In addition, a national chartbook, *The Health and Well-Being of Children: A Portrait of States and the Nation 2007*, is available at <http://mchb.hrsa.gov/nsch07/index.html>.

For more information on the 2007 NSCH, visit www.nschdata.org

Analytic Methods

This report uses the 2005-06 NS-CSHCN data to look at key measures and MCHB Core Outcomes for CSHCN in California and the 2007 NSCH to look at all children in California for comparison with CSHCN when appropriate. National data from both datasets also are presented when findings highlight consistencies or disparities between California's children and children in the rest of the nation. For this report, national data include all states and the District of Columbia without California calculated into the estimate. Subpopulations of interest are age groups, race and ethnicity, income level, insurance status and type, and complexity of special health care needs. Data from the 2001 NS-CSHCN and the 2003 NSCH were used for a small number of measures and outcomes that could be meaningfully tracked over time. Frequencies and cross tabulations with 95% confidence limits were generated using statistical software designed for analysis of complex survey samples.

Population prevalence and count estimates for all variables were weighted to represent the population of non-institutionalized children in the United States. Weights are calculated at the child level; therefore estimates represent "the percentage of children who..." rather than "the percentage of parents who..." or the "percentage of families who..." Point values, standard errors, and 95% confidence limits were calculated for all data presented in this report. Weighted population estimates were generated by using the rate of CSHCN from the 2007 National Survey of Children's Health (14.5% for California) as the baseline rate of CSHCN within the state. This baseline rate is used for calculating population estimates generated from weighted estimates derived from the 2005/06 National Survey of Children with Special Health Care Needs as well. Additional information on weighted population estimates is available from our websites or by contacting CAHMI (see contact information below).

The statistical significance of differences observed between groups was assessed in two ways:

1. Using standard chi-square tests of independence to assess bivariate relationships among findings, employing a 0.05 level of significance. A chi-square test demonstrates whether variation between groups could be explained by random chance. A chi-square test p-value of <0.05 indicates that there is less than a 5 percent chance that the difference observed was due to random variation. This is an accepted standard for statistical significance. In multi-group comparisons, a p-value of <0.05 means that at least one group is statistically different from the others.

2. By conducting a series of logistic regressions to assess multivariate relationships among findings. Sociodemographic factors such as age, sex, race/ethnicity and language, health insurance status, household income, state, and CSHCN status were included as covariates in logistic regression models.

All analyses employed datasets coded by CAHMI⁴⁻⁵ and used SPSS's Complex Sample Module⁶ with adjustment of standard errors to account for weighting, clustering, stratification, and increased variability that result from the complex sampling design of the NSCH and the NS-CSHCN. Detailed methods and findings from prevalence, variations, and regression analyses are available upon request. See contact information below.

The Data Resource Center for Child and Adolescent Health provides access to survey results at the state, regional, and national levels, overall and by age, race, income, insurance status, and other characteristics (<http://childhealthdata.org/>). The website also offers background information on both national surveys in easy-to-understand formats, examples of publications and presentations using data from the survey, and links to relevant materials such as the National Chartbook for the 2005-06 NS-CSHCN, the National Chartbook for the 2007 NSCH, National Center for Health Statistics information, documentation of survey methods and results, and resources for families with CSHCN.

For further information on any data sources, analytic methods, or regression analysis results used in this report or to request a copy of the 2005-06 NS-CSHCN or 2007 NSCH datasets, please contact the Child and Adolescent Health Measurement Initiative at the email or phone number provided below.

Contact Information

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Methodological References

1. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs, *Pediatrics*. 1998; 102: 137-140.
2. Blumberg SJ, Welch EM, Chowdhury SR, Upchurch HL, Parker EK, Skalland BJ. Design and operation of the National Survey of Children with Special Health Care Needs, 2005-06. Advance Access Online Version (November 28, 2007). Retrieved Nov. 21, 2008, from: http://www.cdc.gov/nchs/data/series/sr_01/sr01_045.pdf
3. Blumberg SJ, Foster EB, Frasier AM, et al. *Design and Operation of the National Survey of Children's Health, 2007*. National Center for Health Statistics. Vital Health Stat 1. 2009 (Draft May 2009).

4. Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health, 2007 National Survey of Children's Health. Available from: www.nschdata.org/Content/Default.aspx.
5. Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health, 2005-06 National Survey of Children with Special Health Care Needs. Available from: www.cshcndata.org/Content/Default.aspx.
6. SPSS version 15.0.1. (2006). Chicago, IL: SPSS Inc. 2006.

Appendix B: Additional Details and Links to Measures of Health and System Performance from the 2007 National Survey of Children’s Health and 2005-06 National Survey of Children with Special Health Care Needs.

Chapter 1

Indicator or Measure	Link	Method Notes	Additional Resources
Children with Special Health Care Needs (CSHCN) status: measured using the CSHCN Screener	Link to NSCH Link to NS-CSHCN	<p>Questions K2Q10-K2Q23 comprise the CSHCN Screener, a validated screening instrument for identifying children with special health care needs as defined by the federal Maternal and Child Health Bureau. The CSHCN Screener asks whether a child currently experiences any of five different health consequences, and if so, whether that specific health consequence is due to a medical, behavioral, or other type of health condition that has lasted or is expected to last 12 months or longer. A child must have affirmative responses on all 3 parts (or 2 parts in the case of a screening question for the ongoing emotional, developmental, or behavioral conditions criteria) of a screening question in order to qualify on that particular screening criterion.</p> <p>Some children with chronic conditions are not identified by the CSHCN Screener. This is acknowledged and expected.</p>	<p>Link to more information about the CSHCN Screener Identifying Children With Special Health Care Needs: Development and Evaluation of a Short Screening Instrument: http://www.ncbi.nlm.nih.gov/sites/entrez/11888437</p>
Count of chronic conditions	Link to NSCH	<p>One or more of the following chronic conditions: learning disability, ADD/ADHD, depression, anxiety, behavioral problems, autism, developmental delay, speech problems, Tourette, asthma, diabetes, epilepsy, hearing problems, vision problems, joint problems, brain injury, environmental allergies, food allergies, migraines, or chronic ear infections</p>	
Severity of child’s chronic condition(s): parents report if condition is mild, moderate or severe	Link to NSCH	<p>Asked only of children with a current chronic condition. Moderate and severe combined to differentiate from mild. Testing shows parents select “mild” unless functioning impact exists.</p>	
Overweight or obese: children whose BMI is at the 85th percentile or above	Link to NSCH	<p>Variable is available for children ages 10-17 only. Based on age/sex-specific BMI calculations on height and weight of child.</p>	<p>For more information on BMI: http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/about_childrens_bmi.html</p> <p>A look at social inequalities and change in obesity from 2003-2007: http://www.ncbi.nlm.nih.gov/pubmed/20006275</p>
Child has two or more ongoing emotional, behavioral or developmental conditions		<p>Eight conditions are used in this variable. The eight emotional, behavioral, or developmental conditions include: learning disability, developmental delay, ADHD/ADD, Tourette Syndrome, autism/ASD, depression, anxiety, and conduct problems/ODD.</p>	

Chapter 2

Indicator or Measure	Link	Method Notes	Additional Resources
Usual source of care	Link to NSCH Link to NS-CSHCN	In 2007 the question asks if a child has a usual source of care when sick or needs health advice. In 2005 the variable includes two items—usual source for sick care and usual source for preventive care.	
Personal doctor or nurse (PDN)	Link to NSCH Link to NS-CSHCN	A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history.	
Problems getting referrals	Link to NSCH Link to NS-CSHCN	Only asked of children who needed a referral in the past 12 months.	
Any unmet need	Link to NSCH	Two questions: (1) whether a child had any health care that was delayed or not received and (2) follow-up question about the type of care (medical, dental, etc.).	
Needed and did not receive mental health care	Link to NSCH	Asked of children ages 2-17 only who reported needing mental health care. An item from the CSHCN Screener asks about ongoing emotional, behavioral, or developmental issues. This item is then analyzed in conjunction with whether or not the child actually saw a mental health professional.	
Ease of access to community-based health services	Link to NS-CSHCN	Focused on child's health needs and all the services he/she needs, including early intervention programs, child care facilities, vocational education and rehabilitation programs, and other community programs.	
Needed 5 or more services or equipment	Link to NS-CSHCN	The 15 different services asked about include: routine preventive care; specialist care; preventive dental care; other dental care; prescription medicines; OT, PT or speech therapy; mental health care or counseling; substance abuse treatment or counseling; home health care; vision care or eyeglasses; hearing aids or hearing care; mobility aids or devices; communication aids or devices; disposable medical supplies; and durable medical equipment.	
Unmet needs for services or equipment	Link to NS-CSHCN	Services or equipment are same as listed above.	
Unmet needs for family services, including respite care, genetic counseling and mental health counseling	Link to NS-CSHCN		

Chapter 3

Indicator or Measure	Link	Method Notes	Additional Resources
Gaps in insurance coverage. Consistency of insurance.	Link to NSCH Link to NS-CSHCN	Inconsistency involves currently uninsured children or children without insurance for any period of time over the past 12 months. Children with coverage over all 12 months are coded as having consistent insurance.	
Adequacy of health insurance	Link to NSCH Link to NS-CSHCN	Composite measure including: benefits meet child's needs, coverage allows child to see needed providers, and out of pocket expenses are reasonable. If child has insurance that does not meet needs, cover all providers, and/or has unreasonable expenses, then he/she is coded as having inadequate insurance.	

Chapter 4

Indicator or Measure	Link	Method Notes	Additional Resources
Standardized Developmental and Behavioral Screening (SDBS)	Link to NSCH	Asked of children ages 0-5 only. The Standardized Developmental and Behavioral Screening (SDBS) items in the NSCH are meant to assess whether the parent completed a standardized, validated screening tool used to identify children at risk for developmental, behavioral, or social delays. Examples of parent-completed SDBS tools include the Parents Evaluation of Developmental Status® and the Ages and Stages Questionnaire®. In July 2006 the American Academy of Pediatrics issued the Statement on Identifying Infants and Young Children with Developmental Disorders in the Medical Home, calling for pediatric clinicians to routinely screen children for developmental delays using standardized and validated tools. The Child and Adolescent Health Measurement Initiative (CAHMI), with funding from the Commonwealth Fund and in conjunction with the Maternal and Child Health Bureau, led the development and testing of the items. The findings from the cognitive testing yielded this 3-item, stand-alone measure that is also part of the Promoting Healthy Development Survey® (PHDS) or can be administered as part of an existing survey.	Development and testing of SDBS items: http://cahmi.org/ViewDocument.aspx?DocumentID=70 Link to SDBS items: http://www.cahmi.org/pages/Topics.aspx?section=12&topic=127&parent=25
At least one preventive care visit in past 12 months	Link to NSCH		
At least one preventive dental care visit in past 12 months	Link to NSCH		
Received at least one preventive medical care visit and one preventive dental care visit in past 12 months	Link to NSCH		
Met 3-part Medical home criteria: 1. Has personal doctor/nurse and usual source of care for sick and well care (2 items) 2. Received family centered and culturally sensitive care (6 items) 3. Met Care Coordination measure criteria (got all care coordination wanted and satisfied with cross-provider communications)	Link to NSCH Link to NS-CSHCN	The American Academy of Pediatrics' description of a "medical home" lists 7 defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Ideally, these 7 components are delivered by a doctor or other health professional who knows the child well. Five of the 7 components of medical home and the presence of a personal doctor or nurse are assessed by the National Survey of Children's Health. The overall medical home measure is a composite score derived from five different subparts based on 19 different survey items. To qualify as having a medical home, a child must have a personal doctor or nurse and meet the criteria for adequate care on every needed component.	For more information on the history, development, and scoring of the Medical Home Measure, look at the Medical Home Manual: http://medicalhomedata.org/ViewDocument.aspx?item=436
Met family-centered care criteria	Link to NSCH Link to NS-CSHCN	A component of medical home. Includes several questions about whether the doctor listens to patients, is culturally sensitive, etc. Must have answers of "usually" or "always" to all items to receive family-centered care.	
Received all needed care coordination (among those needing it)	Link to NSCH Link to NS-CSHCN	Only asked of children who needed coordination because they needed 2 or more services during the past 12 months.	
CSHCN who are screened early and continuously for special health care needs	Link to NS-CSHCN	Preventive care, as measured in the 2005-06 NS-CSHCN.	
CSHCN whose families are partners in decision-making at all levels and are satisfied with the services they receive	Link to NS-CSHCN		
CSHCN who met all 5 MCHB Outcomes	Link to NS-CSHCN	Met outcomes #1-5.	Information about the MCHB Outcomes: http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm

Chapter 5

Indicator or Measure	Link	Method Notes	Additional Resources
Missed school days (11 or more in past 12 months)	Link to NSCH Link to NS-CSHCN	Asked only of children ages 6-17 on the NSCH, and only of ages 5-17 on the NS-CSHCN.	
Repeated a grade in school since kindergarten	Link to NSCH	Asked only of children ages 6-17.	
Consistently engaged in school	Link to NSCH	Asked only of children ages 6-17. Two questions about whether child cares about doing well in school and does all required homework.	
Individualized Education Program (IEP) or Individualized Family Services Plan (IFSP)	Link to NSCH	Children ages 1-5.	
Individualized Education Program (IEP)	Link to NSCH	Children ages 6-17.	
CSHCN who experience activity limitations due to their illness	Link to NSCH	Subset only to children ages 6-17. Only children who qualified as having special health care needs were asked questions about limits on social participation and activities. The functional limitations asked about include attending school on a regular basis, participating in sports, clubs or activities, or making friends.	
Participation in organized activities outside of school	Link to NSCH	Children ages 6-17 only. Activities outside of school are defined as: sports teams or lessons, clubs or organizations, or any other organized event or activity that takes place after school or on weekends.	
Children whose activities are greatly affected by their health condition(s)	Link to NS-CSHCN		
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	Link to NS-CSHCN	Asked only of CSHCN ages 12-17.	

Chapter 6

Indicator or Measure	Link	Method Notes	Additional Resources
Out of pocket expenses were sometimes or never reasonable	Link to NSCH		
Parental stress	Link to NSCH	Measure combines three items. If parent answered “usually” or “always” to one of the items he/she was coded as experiencing parental stress.	
Mothers in very good/excellent health	Link to NSCH	Only asked of children who currently live with their mothers.	
Fathers in very good/excellent health	Link to NSCH	Only asked of children who currently live with their fathers. Please keep in mind that approximately 20% of children in the survey were not currently living with a father in the household.	
Families pay more than \$1,000 for out of pocket medical expenses	Link to NS-CSHCN	“Out of pocket” expenses for CSHCN health care includes payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modifications, and any kind of therapy. Health insurance premiums or costs that were reimbursed by insurance or other sources not included.	
Families experience financial problems due to condition(s)	Link to NS-CSHCN		
Child’s conditions caused family members to cut back or stop working	Link to NS-CSHCN		
Families spend 11 or more hours per week coordinating and/or providing care	Link to NS-CSHCN		
Families receiving respite care	Link to NS-CSHCN		
Families receiving mental health care	Link to NS-CSHCN		

Stratifying and Independent Variables

Indicator or Measure	Link	Method Notes	Additional Resources
Children with Special Health Care Needs (CSHCN) Status	Link to NSCH Link to NS-CSHCN	See Chapter 1 above.	See Chapter 1 above
Type of health insurance (public, private, uninsured)	Link to NSCH Link to NS-CSHCN	In the NS-CSHCN, responses were coded as public insurance, private insurance, both public and private insurance, and uninsured. In the NSCH, responses were coded as public insurance, private insurance, or uninsured.	
Race and ethnicity/primary household language: White_NH; Black_NH; Hispanic, English; Hispanic, Spanish; Other_NH (NH: Non-Hispanic)	Race link to NSCH Language link to NSCH Race link to NS-CSHCN Language link to NS-CSHCN	Children reporting Hispanic or Latino ethnicity are grouped as Hispanic, regardless of reported race. This divides children into Hispanic children with Spanish-speaking households and Hispanic children with English-speaking households. All other categories do not include Hispanics.	
Race and ethnicity including Asian: Hispanic, White_NH, Black_NH; Asian_NH; Other_NH	Link to NSCH	Due to a very low sample size of Asian American children in California in the two surveys, this variable is used only in initial demographics chapters. There is no ability to further explore the category of Asian American by additional ethnicity. For most other states in the surveys, and in most of the variables used throughout this report, Asian American children are in the “Other_NH” category.	
Age of child: three categories (0-5, 6-11, 12-17)	Link to NSCH Link to NS-CSHCN		
Type of special health care need	Link to NSCH Link to NS-CSHCN	<p>Researchers have used responses from the CSHCN Screener questions to develop a measure of special needs type based on the following mutually exclusive categories:</p> <ul style="list-style-type: none"> • Managed primarily by prescription medications: Children in this group experience chronic health conditions that are managed solely through prescription medication—often quite successfully as long as they have access to medical care and needed medication. • Managed primarily by using more than routine health services: Children in this group qualify on one or more of the three screening criteria addressing elevated need or use of specialized services or therapies. These children rely on one or more of a wide array of services—such as pediatric specialist care; early intervention; mental health care; developmental disabilities; special education; physical, occupational, or speech therapies—to manage their chronic health conditions. • Requires BOTH prescriptions AND above routine services: Children in this group experience health needs that require both medication management and specialized services or therapies. These children qualify on one or more of the three screening criteria addressing elevated service use AND on the prescription medication screening criteria. • Functional limitations, with or without above routine service use and prescriptions. Children in this group qualify on the functional limitations criteria, nearly always in conjunction with one or more other screening criteria. In addition to other types of special needs, these children currently experience one or more functional limitations as result of their ongoing health conditions. 	Bramlett MD, Read D, Bethell C, Blumberg SJ. Differentiating subgroups of children with special health care needs by health status and complexity of health care needs. <i>Matern Child Health J.</i> 2009; 13(2): 151-163.
Ongoing emotional, behavioral, or developmental issue	Link to NSCH Link to NS-CSHCN	One component of the CSHCN Screener. Children are coded as EBD if they have emotional, developmental, or behavioral problems which have lasted or are expected to last at least 12 months.	
Moderate or high risk for developmental or behavioral problems: parental concerns about child’s learning, development, and behavior	Link to NSCH	Eight items asking about specific parental concerns, derived from the Parents’ Evaluation of Developmental Status® (PEDS), are included in the 2007 National Survey of Children’s Health (NSCH).	Details on scoring of PEDS: http://nschdata.org/Viewdocument.aspx?item=316
Receives educational services, including Individualized Education Plan (IEP) or Individualized Family Service Plan (IFSP)	Link to NSCH ages 1-5 Link to NSCH ages 6-17	Combined variable in both surveys of children receiving Individualized Family Service Plans (IFSP) or Individualized Education Program (IEP). Only asked of children ages 1-17.	