



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