



## Executive Summary

California's approximately 1 million children with special health care needs depend on an array of health care providers, institutions and programs to obtain the best possible care and reach their maximum health potential. Unfortunately, health care in California is not meeting the needs of many of these children, especially those whose families have fewer resources and whose medical conditions are complex.

Children with special health care needs are those who have chronic physical, developmental, behavioral, or emotional conditions, and require health and related services of a type or amount beyond that required by children generally.

**This report provides a summary of the most recent data on California's children with special health care needs.**

Compared with their national counterparts, children with special health care needs in California are receiving care that is less coordinated, less family-centered, and fails to meet a number of key quality indicators set forth by the Federal Maternal and Child Health Bureau. The cumulative impact felt by families—on employment, on time spent caring for their children, on family finances—is more acute in California than in the rest of the nation as well.

This report provides a summary of the most recent data on the state's children with special health care needs. Most of the data come from the latest 2009/10 National Survey of Children with Special Health Care Needs.<sup>1</sup> This is an update of a prior report, *Children with Special Health Care Needs: A Profile of Key Issues in California*, and highlights the characteristics, health status, health service needs, and system performance for these children in California. This information is intended to inform efforts to improve the state's system of care, the health outcomes of these children, and the quality of life of their families.

1. Please see the Methodological Appendix that accompanies this report for further information on the 2009/10 National Survey of Children with Special Health Care Needs.

## Key Findings:

### California Has a Large, Diverse and Complex Population of Children with Special Health Care Needs

- An estimated 1 in 10—approximately 1 million—California children under age 18 has a special health care need.
- Children of color comprise 64% of California’s children with special health care needs, compared to 38% nationally.
- California has a lower prevalence rate of children with special health care needs than other states. However, these children in California generally have more complex health issues than those in the rest of the nation.

### Daily Life, Family Economics Strongly Affected in California

- Nearly 30 percent of children with special health care needs in California have conditions that impact daily life greatly and/or consistently; children with public insurance are substantially more likely to have their daily lives affected.
- Families of children with special health care needs in California are more likely than families in all other states to cut back or stop working due to their child’s condition.

### California Ranks at or Near the Bottom Compared to Other States on Providing Coordinated Care

- Nearly half of California children with special health care needs do not receive effective care coordination. The state ranks 46th in the nation on this measure. Effective coordination of health care services is a central component of quality health care.
- California children with more complex health needs, who arguably need the most help coordinating services, are significantly less likely to get help with care coordination than children with fewer needs. (In this report, “more complex needs” refer to those requiring more than just prescription medication to manage their conditions, while “less complex needs” refer to those primarily managed by prescription medications).
- California ranks 50th in the nation on the percentage of children with special health care needs who have problems getting needed referrals for specialty care.
- More than 40% of California’s children with complex health needs have a difficult time obtaining community-based services, such as finding doctors and scheduling appointments.

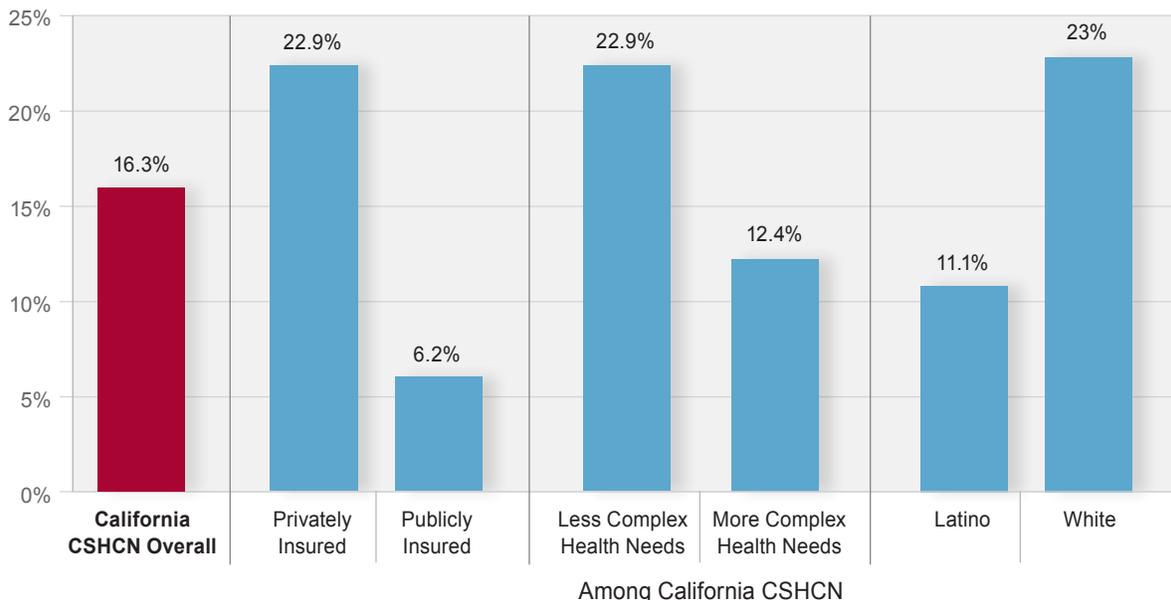
**Nearly half of California children with special health care needs do not receive effective care coordination.**

### California’s Health Care System Also Is Falling Short by Many Other Measures

- More than 4 in 5 children with special health care needs in California do not receive care that meets federal minimum quality standards (See Executive Summary Figure).<sup>2</sup>
- Among the estimated 270,000 children with special health care needs in California with public insurance coverage, only 6% receive health care that meets the federal quality standards. California ranks last in the nation on this measure, tied with Nevada.

2. A full description of the quality standards is included in Section 3 of this report.

**Executive Summary Figure: Percentage of California Children with Special Health Care Needs Receiving Care that Meets All Six Federal Quality Standards**



Note: Comparisons among other racial/ethnic groups were not possible due to small sample size.

- Although only 3.5% of California’s children with special health care needs are uninsured, just 59% of those who are insured have consistent and adequate health insurance coverage to meet their health needs.
- Only 61% of all children with special health care needs in California, and about half of those who are publicly insured, receive family-centered care. This refers to care that supports the family’s relationship with providers and recognizes the importance of the family’s customs and values. The state ranks 44th on this measure.
- Just 1 in 4 publicly insured children with special health care needs in California receives care within a comprehensive medical home,<sup>3</sup> making California 49th in the nation.
- Fewer than 1 in 3 of all children with complex special health care needs in California receives care within a medical home, which puts California 46th in the nation.
- California ranks last in the nation on the percentage of children with special health care needs whose families experience shared decision making with health care providers.

California’s poor overall performance is demonstrated by the low quality of health care services provided to children with special health care needs generally and the significant disparities in quality of care within this population. Children with complex health issues have the highest rates of health care needs, service utilization, and negative impacts on the child and family. In general, children with more complex health care needs are less likely to receive the services they need and less likely to experience high quality health care, including care coordination, family-centered care,

3. A “medical home” is a model of delivering primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.

and shared decision making between families and providers. Their parents are more likely to spend time arranging and coordinating the child's care, to have high out-of-pocket health care expenses, and to have adverse work consequences related to their child's health condition, compared to parents of children with less complex health needs.

California has an opportunity to make care comprehensive, affordable, and easy to access for the state's 1 million children with special health care needs and their families. To improve the quality of care, California must strengthen and expand care coordination efforts and facilitate access to community-based therapeutic and family support services. Improving availability, comprehensiveness, and affordability of insurance, making medical services easier to access, and promoting family-centered care are all important ways for California's health care system to enhance both short- and long-term outcomes for these children. Policymakers, advocates, and other child health stakeholders must work from a shared agenda to make these goals a reality.

## Executive Summary Data Tables

Children with Special Health Care Needs (CSHCN) in California vs. Nation	California	Nation	CA Ranking <sup>1</sup> 1=first, 51=last
Prevalence of children with special health care needs <sup>†</sup>	10.6%	15.7%	*
CSHCN of color (Latino, African American, Asian, and Multiracial/Other) <sup>†</sup>	63.9%	38.0%	*
CSHCN who have more complex health needs <sup>†</sup>	63.9%	59.9%	42
CSHCN who are uninsured	3.5%	3.5%	31
CSHCN who have public insurance only <sup>†</sup>	28.1%	36.6%	*
CSHCN who have private insurance only <sup>†</sup>	60.0%	51.6%	*
<i>Health System Performance: Percentage of Children with Special Health Care Needs Who...</i>			
Have consistent and adequate health insurance	59.1%	60.7%	34
Had a preventive medical visit in the last year <sup>†</sup>	87.6%	90.6%	35
Receive care within a comprehensive medical home <sup>†</sup>	38.3%	43.4%	44
Receive family-centered care	61.2%	64.9%	44
Had no difficulty getting needed referrals <sup>†</sup>	66.1%	77.8%	50
Receive effective care coordination, when needed	52.7%	56.3%	46
Have families that feel engaged in shared decision making with providers <sup>†</sup>	61.8%	71.1%	51
Can easily access community-based services	64.8%	65.1%	31
Receive needed transition services to adulthood (for ages 12-17)	37.4%	40.3%	36
Receive care that meets federal minimum quality standards**	16.3%	17.7%	36
<i>Impact on Children &amp; Families: Percentage of Children with Special Health Care Needs Whose...</i>			
Family member(s) had to cut back or stop working due to the child's condition <sup>†</sup>	29.4%	24.6%	51
Family member(s) spend 11 or more hours on care per week	16.3%	12.8%	48
Family member(s) avoided changing jobs due to health insurance coverage <sup>†</sup>	22.0%	17.3%	46
Parents report that the child's condition created a financial burden	24.2%	21.3%	41
Condition(s) impact the child's daily life greatly and/or consistently	29.2%	26.9%	40

<sup>1</sup> Rankings are based on all states and the District of Columbia. The national percentages are based on all states and the District of Columbia, not including California.

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

\* Indicator cannot be ranked.

\*\*Based on standards in six areas: 1) shared decision making between families and providers; 2) care within a medical home; 3) consistent and adequate insurance coverage; 4) annual screening through preventive medical/dental visits; 5) access to community-based services; and 6) transition planning for adulthood for ages 12-17.

Data source: 2009/10 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health, [www.childhealthdata.org](http://www.childhealthdata.org). All data in this table come from the Interview File except the following, which are from the Screener File: overall percent of CSHCN, CSHCN of color, and CSHCN with more complex health care needs.

Key Indicators for Latino and White Children with Special Health Care Needs in California <sup>2</sup>	% Latino	% White
Percent of children with special health care needs (CSHCN) <sup>†</sup>	9.2%	12.8%
CSHCN who have difficulty getting needed referrals <sup>†</sup>	43.8%	22.0%
CSHCN who receive needed transition services to adulthood (for ages 12-17) <sup>†</sup>	22.1%	50.4%
CSHCN with one or more overnight hospital stays <sup>†</sup>	11.0%	5.4%
CSHCN whose families spend 11 or more hours on care per week <sup>†</sup>	20.4%	8.6%
CSHCN whose family member(s) had to cut back or stop working due to the child's condition <sup>†</sup>	35.8%	20.3%
CSHCN who receive care that meets federal minimum quality standards <sup>***†</sup>	11.1%	23.0%

Key Indicators by Insurance Type in California: Percentage of Children with Special Health Care Needs...	Among Privately Insured	Among Publicly Insured
Whose condition(s) impact their daily life greatly and/or consistently <sup>†</sup>	20.3%	39.1%
Who can easily access community-based services <sup>†</sup>	72.1%	56.7%
Who receive care within a comprehensive medical home <sup>†</sup>	47.0%	25.4%
Who receive family-centered care	68.4%	49.8%
Whose families feel engaged in shared decision making with providers <sup>†</sup>	65.3%	51.5%
Whose family member(s) had to cut back or stop working due to the child's condition <sup>†</sup>	17.7%	44.5%
Whose families spend 11 or more hours on care per week <sup>†</sup>	8.8%	24.9%
Whose family member(s) avoided changing jobs due to health insurance coverage <sup>†</sup>	27.0%	9.2%
Who receive care that meets federal minimum quality standards <sup>***†</sup>	22.9%	6.2%

Key Indicators by Complexity of Health Care Needs in California: Percentage of Children with Special Health Care Needs Who...	Among CSHCN with More Complex Health Needs	Among CSHCN with Less Complex Health Needs
Receive care within a comprehensive medical home <sup>†</sup>	29.2%	54.2%
Receive family-centered care <sup>†</sup>	56.2%	70.2%
Have difficulty getting needed referrals <sup>†</sup>	40.0%	18.9%
Receive effective care coordination, when needed <sup>†</sup>	45.8%	70.1%
Can easily access community-based services <sup>†</sup>	56.0%	80.6%
Have families that feel engaged in shared decision making with providers <sup>†</sup>	57.3%	69.9%
Receive needed transition services to adulthood (for ages 12-17) <sup>†</sup>	30.2%	49.3%
Receive care that meets federal minimum quality standards <sup>***†</sup>	12.4%	22.9%

<sup>2</sup> Due to small sample sizes, other racial/ethnic groups are not displayed.

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

\*\*See definition on previous page.

Data source: 2009/10 National Survey of Children with Special Health Care Needs. Data Resource Center for Child and Adolescent Health. [www.childhealthdata.org](http://www.childhealthdata.org).