



Report

Children with Special Health Care Needs in California

A Profile of Key Issues

Prepared by



The Child and Adolescent Health Measure Initiative



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ABOUT CAHMI: The Child and Adolescent Health Measurement Initiative (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. The CAHMI is committed to advancing patient-centered innovations by putting children, youth and families at the center of quality measurement and improvement.

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ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children's Health works in alignment with Lucile Packard Children's Hospital and the child health programs of Stanford University. The mission of the Foundation is to elevate the priority of children's health, and to increase the quality and accessibility of children's health care through leadership and direct investment. The Foundation is a public charity, founded in 1997.



Foreword

In 2010, the Lucile Packard Foundation for Children’s Health published *Children with Special Health Care Needs: A Report on Key Issues in California*. That [report](#) concluded that California’s health care system was falling short in many respects on meeting the needs of children with special health care needs and their families. Unfortunately, this 2012 update to the report shows little improvement on many measures. Compared to children in other states, California’s children continue to receive care that is less coordinated, less family-centered, and fails to meet many of the key quality indicators prescribed by the Federal Maternal and Child Health Bureau. For example, our state ranks 50th in the nation on the percentage of children with special health care needs who are able to obtain needed referrals for specialty care.

The state’s current system of care unquestionably provides many valuable services and supports for these children and their families. However, the problems noted in 2010 remain: little or no support for care coordination; a lack of family-centered care; economic and social burdens on families; complicated and inefficient funding mechanisms; a shortage of pediatric subspecialists; and many others.

These new findings are based on data from the 2009/10 National Survey of Children with Special Health Care Needs, the most recent version of the survey, which is conducted in every state by the federal government. Our foundation commissioned this special analysis of California’s results to allow us to assess how the state is faring, and also to compare our performance with other states. The results show California’s system at or near the bottom among states on many key measures. Clearly, there is much to be done.

In the two years since the first report, our Foundation has continued to work with other stakeholders to encourage improvements in California’s system of care. We have expanded our investments in system improvement through grants that support, among other topics, care coordination, discharge planning, parent advocacy training, young medical investigators, and quality standards.

We also established the **California Advocacy Network for Children with Special Health Care Needs**, which brings together individuals and organizations to press for policy changes to improve the system. More than 450 individuals are Network members, representing families, young adults, care providers, insurers, advocates, researchers, and more.

Our hope is that these efforts, along with the findings in this report, will encourage action toward an effective, cost-efficient system that truly meets the needs of children and families. For information on the Foundation’s work, or to join the Advocacy Network, [please visit our new website](#).

We are grateful to the Child and Adolescent Health Measurement Initiative for its thorough and thoughtful report.

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



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.¹ 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.

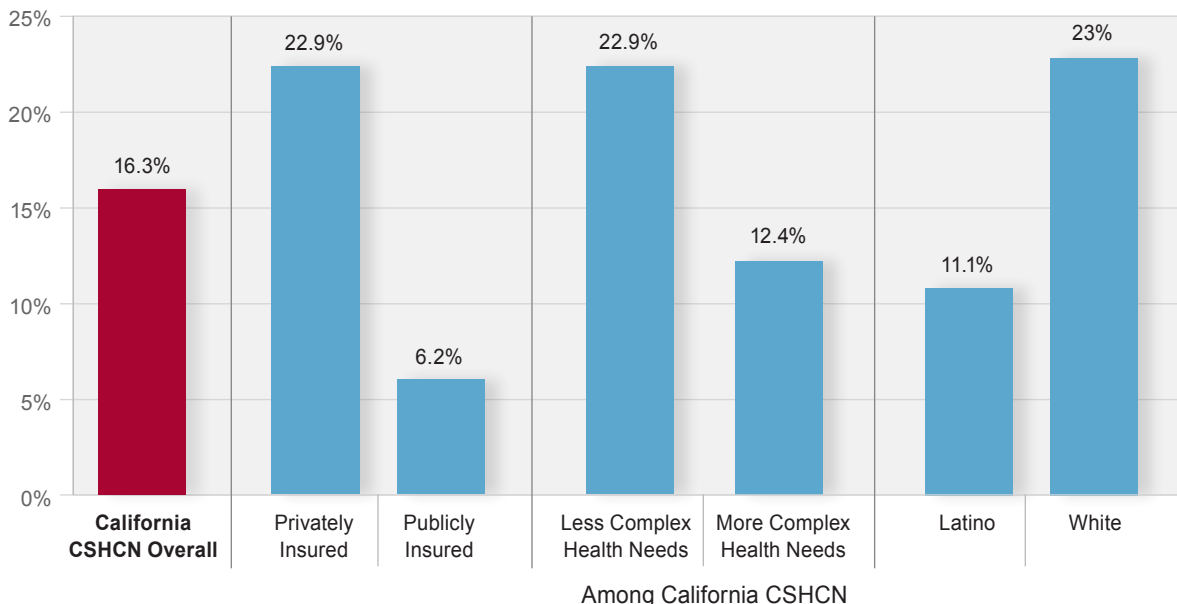
Nearly half of California children with special health care needs do not receive effective care coordination.

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).²
- 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,³ 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 ¹ 1=first, 51=last
Prevalence of children with special health care needs [†]	10.6%	15.7%	*
CSHCN of color (Latino, African American, Asian, and Multiracial/Other) [†]	63.9%	38.0%	*
CSHCN who have more complex health needs [†]	63.9%	59.9%	42
CSHCN who are uninsured	3.5%	3.5%	31
CSHCN who have public insurance only [†]	28.1%	36.6%	*
CSHCN who have private insurance only [†]	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 [†]	87.6%	90.6%	35
Receive care within a comprehensive medical home [†]	38.3%	43.4%	44
Receive family-centered care	61.2%	64.9%	44
Had no difficulty getting needed referrals [†]	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 [†]	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 & 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 [†]	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 [†]	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

¹ 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.

[†] 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. 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 ²	% Latino	% White
Percent of children with special health care needs (CSHCN) [†]	9.2%	12.8%
CSHCN who have difficulty getting needed referrals [†]	43.8%	22.0%
CSHCN who receive needed transition services to adulthood (for ages 12-17) [†]	22.1%	50.4%
CSHCN with one or more overnight hospital stays [†]	11.0%	5.4%
CSHCN whose families spend 11 or more hours on care per week [†]	20.4%	8.6%
CSHCN whose family member(s) had to cut back or stop working due to the child's condition [†]	35.8%	20.3%
CSHCN who receive care that meets federal minimum quality standards ^{**†}	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 [†]	20.3%	39.1%
Who can easily access community-based services [†]	72.1%	56.7%
Who receive care within a comprehensive medical home [†]	47.0%	25.4%
Who receive family-centered care	68.4%	49.8%
Whose families feel engaged in shared decision making with providers [†]	65.3%	51.5%
Whose family member(s) had to cut back or stop working due to the child's condition [†]	17.7%	44.5%
Whose families spend 11 or more hours on care per week [†]	8.8%	24.9%
Whose family member(s) avoided changing jobs due to health insurance coverage [†]	27.0%	9.2%
Who receive care that meets federal minimum quality standards ^{**†}	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 [†]	29.2%	54.2%
Receive family-centered care [†]	56.2%	70.2%
Have difficulty getting needed referrals [†]	40.0%	18.9%
Receive effective care coordination, when needed [†]	45.8%	70.1%
Can easily access community-based services [†]	56.0%	80.6%
Have families that feel engaged in shared decision making with providers [†]	57.3%	69.9%
Receive needed transition services to adulthood (for ages 12-17) [†]	30.2%	49.3%
Receive care that meets federal minimum quality standards ^{**†}	12.4%	22.9%

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

[†] 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.



Introduction

This report offers policymakers, families, advocates, health care professionals and other child health stakeholders a summary of the most recent data available about California's approximately 1 million children with special health care needs (CSHCN).

Unfortunately, California's health system is not meeting the needs of many CSHCN, and the state is performing worse than other states across multiple measures. Though assuring a high performing system of care for CSHCN is a problem throughout the country, data show that the problem is particularly acute in California.

The data largely come from the latest National Survey of Children with Special Health Care Needsⁱ. This report is a follow-up to an earlier report, *Children with Special Health Care Needs: A Profile of Key Issues in California*, and highlights key updates on the characteristics, health status, health service needs, and system performance for California's CSHCN. This information is intended to help inform efforts to improve the state's system of care and, ultimately, the health outcomes for CSHCN and the quality of life for these children and their families.

ⁱ 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.



Section 1

Who Are Children with Special Health Care Needs in California?

About 1 million children in California have ongoing physical, behavioral, mental, or emotional conditions that can affect their ability to function and participate in activities important to their development and, in some cases, can shorten their lives. These children with special health care needs (CSHCN), as a group, use more health care services than other children and account for more than 40 percent of all health care costs among children nationwide, despite making up only 16 percent of the U.S. child population.¹⁻² Though advances in medical care have extended and improved the lives of millions of children, more than four in five CSHCN still fail to receive one or more basic aspects of quality health care, statewide and nationally.

The Federal Maternal and Child Health Bureau defines children with special health care needs as:

About 1 in 10 California children under age 18 is estimated to have a special health care need—equivalent to approximately 1 million children.

“[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.”³

This definition is used in numerous surveys of the U.S. population, including the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), which is the primary source for this brief (see the Methodological Appendix for more information). The “CSHCN Screener” is used in this survey to identify children with special health care needs, based on those who experience one or more of the following health-related consequences due to an ongoing (lasted or expected to last at least 12 months) medical, behavioral or other type of health condition:⁴

- The need for or use of prescription medication
- 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)
- Need for or use of 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 are able to do
- An ongoing emotional, behavioral, or developmental problem that requires treatment or counselingⁱⁱ

ii See the Methodological Appendix that accompanies this report for more information on the CSHCN Screener and the 2009/10 National Survey of Children with Special Health Care Needs.

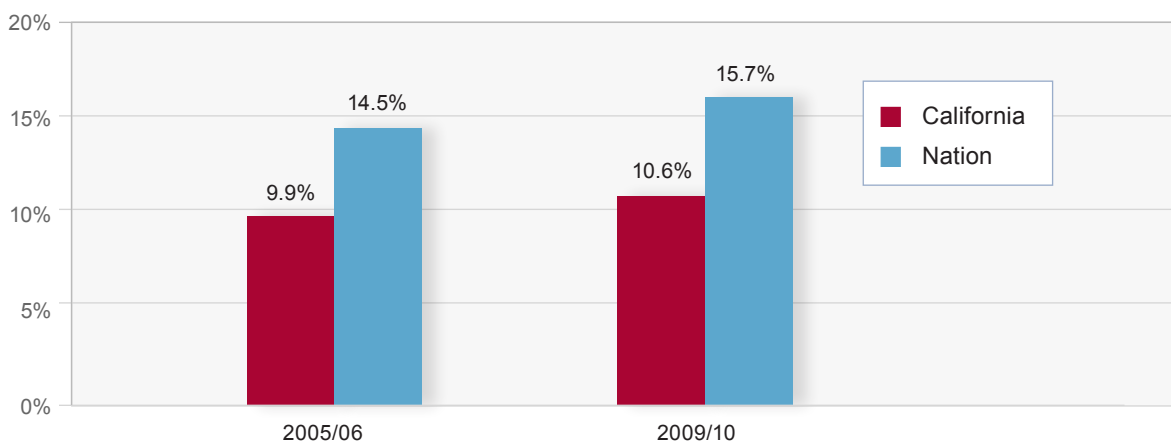
Numerous hurdles exist in both identifying children with ongoing conditions and supporting them with services, and the gaps in care for this population are well documented.⁵⁻⁷ Advancing understanding of this population in California is an important step toward identifying effective policy and program solutions to meet these children's needs.

In California, 10.6 percent of children ages 0-17 are estimated to have a special health care need.ⁱⁱⁱ This means that at least 1 million children and youth in California experience one or multiple chronic health conditions. Though their health problems vary in type and severity, all CSHCN require a greater variety of health care services and systems than children without special health care needs.

Why Is the Prevalence of Children with Special Health Care Needs Lower in California than the Nation?

Fewer children are identified with special health care needs by the standardized CSHCN Screener in California than in the rest of the nation.^{iv} According to the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN), California's estimate of 10.6 percent is significantly different from the national rate. While the prevalence of CSHCN in the rest of the nation increased between the 2005/06 and 2009/10 NS-CSHCN surveys, it did not change significantly in California (Figure 1).

Figure 1: Percentage of Children with Special Health Care Needs Among All Children Ages 0-17



Data Source: 2005/06 and 2009/10 National Surveys of Children with Special Health Care Needs Screener files. Note: Even after controlling for age, sex, race, household language and income, California's prevalence rate in 2009/10 is lower than the rest of the United States (Adjusted Odds Ratio {AOR}: 0.75 [0.68-0.81]). Differences between 2005/06 and 2009/10 were significant nationally (AOR: 1.13 [1.11-1.15]), but not in California.

iii The estimated prevalence and population estimate of CSHCN in California in 2009/2010 was lower than reported in the 2007 National Survey of Children's Health. There are expected differences based on the sampling methodology used in that survey compared with the National Survey of Children with Special Health Care Needs.* For additional information, please see the Methodological Appendix that accompanies this report.

iv Nation or "rest of the nation" is defined throughout this report as the 49 states (excluding California) plus the District of Columbia.

The data indicate two primary reasons for the lower prevalence rate in California. First, California's overall child population is ethnically and linguistically diverse, which is associated with different prevalence rates for CSHCN. For instance, children of color represent more than 70 percent of the state's child population versus 41 percent in the rest of the nation. More than half of the parents of Latino and Asian children in California were born outside of the U.S. Further, nearly one in three California children lives in a household where English is not the primary language, compared with only about one in 10 such children in the rest of the nation (32.6% vs. 12.1%). CSHCN prevalence rates among two of the largest non-white populations in California are particularly low: 9.2 percent among Latinos and 6.6 percent among Asian Americans, compared with 12.8 percent among white children. Research has shown that parents of Latino and Asian children, especially parents born outside the U.S. or with a primary language other than English, are less likely to report their child's health concerns as outside of typical development. Latino families, in particular, may accept a wide variety of health care experiences as "normal" before they identify health issues as problems, according to recent analyses.⁹⁻¹⁰ In addition, identifying a child as having a special need may be more stigmatizing among some communities of color.¹¹

California's lower CSHCN prevalence rate—consistent across all racial/ethnic groups, but especially low among Latinos and Asian Americans—does not indicate a lesser problem in the state.

However, the prevalence rate among *all* groups, including white CSHCN in California, is lower than the rest of the nation. Therefore, a second possible reason for the low overall prevalence rate in California is that a much lower percentage of children meet the CSHCN criteria based on prescription medication need or usage, compared to the rest of the nation (67.8% vs. 76.9%). This generally is the most common way of meeting the criteria, and the lower prevalence holds true across all racial and ethnic groups in California.

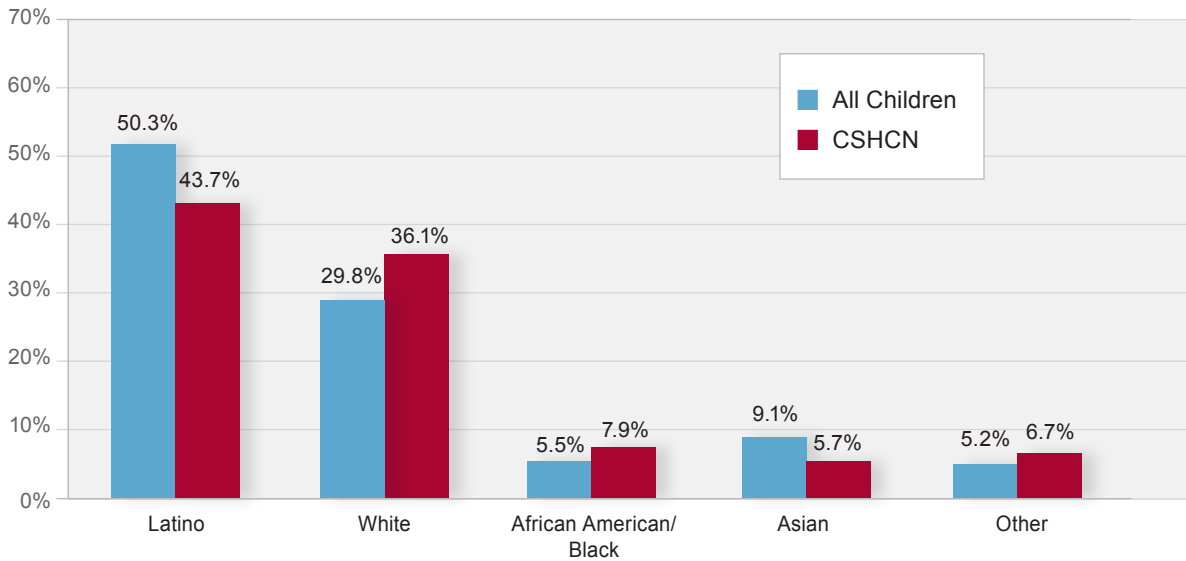
Lower prescription medication use across California may stem from a statewide cultural preference that favors alternatives to traditional prescription medications. Within state differences between Latino and white CSHCN also may be based upon cultural preferences around medication. Though access to care in California may be an issue (e.g. under-prescription or difficulty accessing or paying for medication), further research is needed to explain why California children—especially Latino CSHCN—are much less likely to need or use prescription medications than in the rest of the nation.

California's Children with Special Health Care Needs: Diverse and Complex

Similar to the general child population in California, the state's CSHCN population is highly diverse. The CSHCN population in California comprises 63.9 percent children of color, compared to 38 percent nationally (Figures 2A and 2B). Therefore, any improvements in the system of care must be prepared to meet the challenges associated with CSHCN who come from a variety of backgrounds and whose needs are wide-ranging.

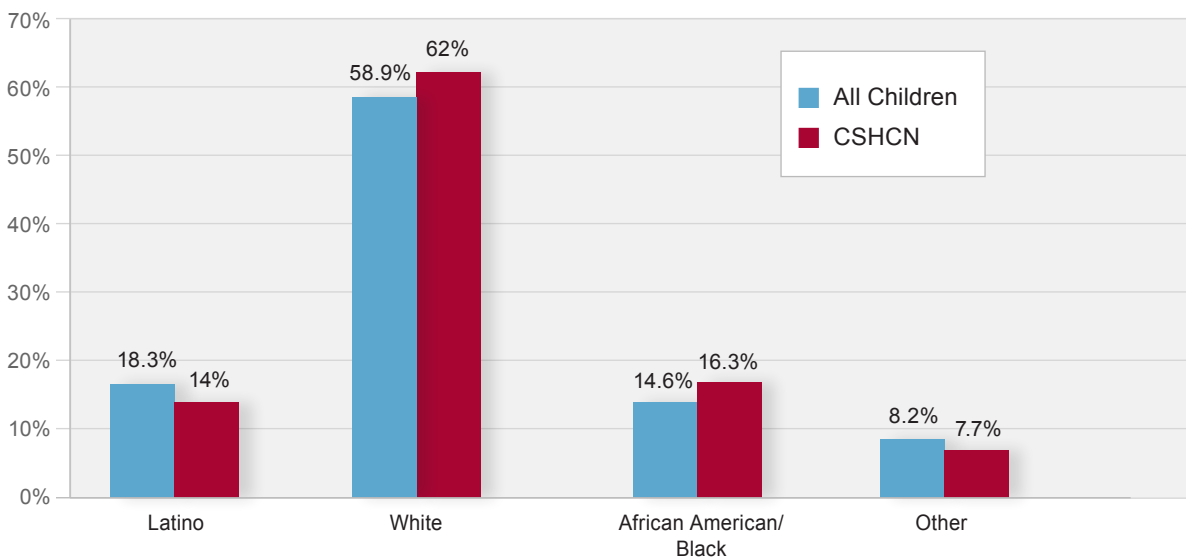
As noted, fewer CSHCN in California use prescription medications than in the rest of the nation. CSHCN whose conditions are primarily managed by prescription medications might include those with less complex chronic conditions such as asthma, allergies, and attention deficit and hyperactivity disorder (ADHD). Data indicate that most California CSHCN, however, have *greater health care needs* and *more complex conditions*, such as limitations in functioning and the need for complex educational

Figure 2A: Percentages of Overall Child Population and CSHCN in California, by Race/Ethnicity



Data Source: 2009/10 National Survey of Children with Special Health Care Needs Screener File, which provides data for all children in the population and serves as the source of the estimate of CSHCN. Note: Asian data are available in California only. In order to protect confidentiality, “other” race includes all groups for which there is not a minimum of 5% in the population: American Indian, Alaskan Native, Native Hawaiian, Other Pacific Islander or multiracial children (two or more races).

Figure 2B: Percentages of Overall Child Population and CSHCN in Nation, by Race/Ethnicity



Data Source: 2009/10 National Survey of Children with Special Health Care Needs Screener File, which provides data for all children in the population and serves as the source of the estimate of CSHCN. Note: Asian data are available in California only. In order to protect confidentiality, “other” race includes all groups for which there is not a minimum of 5% in the population: Asian, American Indian, Alaskan Native, Native Hawaiian, Other Pacific Islander or multiracial children (two or more races).

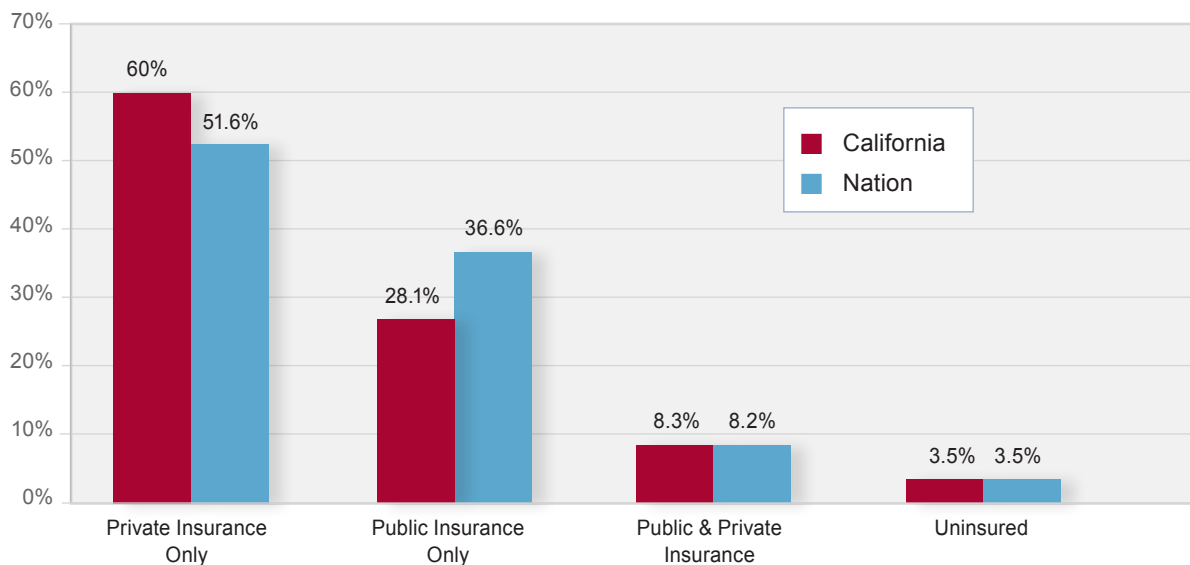
and health services such as speech and occupational therapies.^v Among children identified with special health care needs, the national rate for those who have more complex needs is 59.9 percent, compared to 63.9 percent in California. Though the difference is not large, it is statistically significant.

It also is rare for CSHCN to have only one condition or to have difficulty with only one area of functioning; multiple conditions and functional difficulties are quite common. In California, 45.3 percent of CSHCN have four or more functional difficulties and 25.8 percent have three or more of the health conditions that are asked about in the survey. These rates do not differ significantly from the rest of the nation. Though chronic allergies (41.4%) and asthma (34.9%) are the most common conditions (almost always occurring with other conditions), the next most prevalent conditions among CSHCN in California are: ADHD (23.1%); developmental delays (18.5%); anxiety problems (14.5%); behavioral/conduct problems (11.5%); and autism spectrum disorder (9.9%). This list of most common conditions does not differ between California and the nation.

Insurance Coverage Among CSHCN in California: More Reliance on Private Coverage

Most Californians, as others in the nation, access the health care system through some form of health insurance coverage. California and the nation have the same rate of uninsured CSHCN (3.5%), according to the 2009/10 NS-CSHCN. However, California CSHCN are more likely to have private insurance versus public insurance compared to rest of the nation (Figure 3). Publicly insured CSHCN often face particularly acute problems in accessing care, as further outlined later in this report.

Figure 3. Type of Insurance Coverage Among Children with Special Health Care Needs



Note: The comparison of California vs. the nation for both private insurance and public insurance is significant at the $p < 0.001$ level.

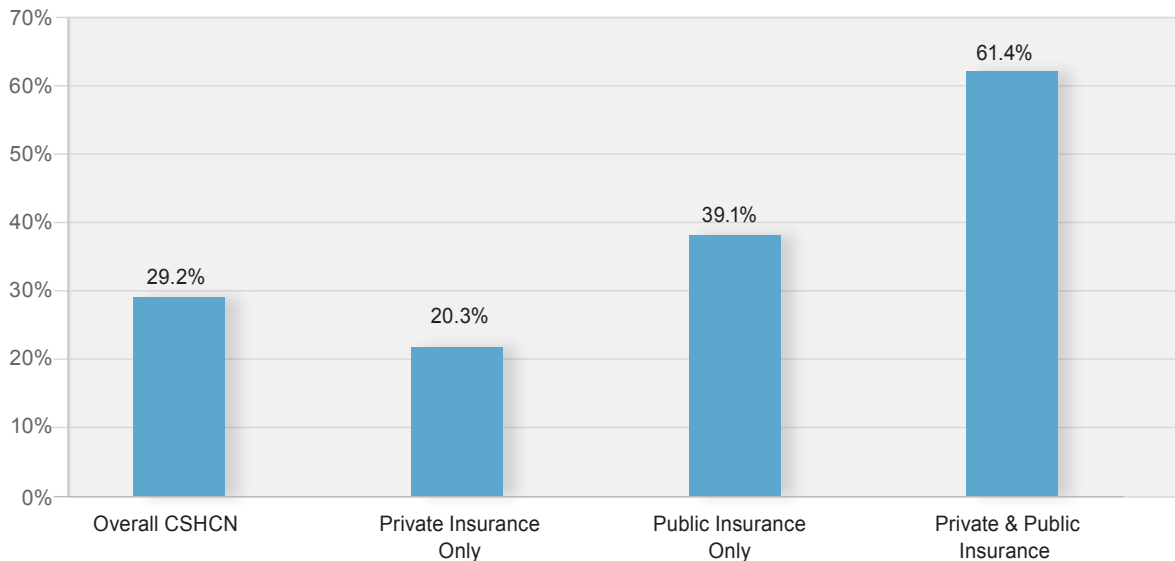
^v Throughout the remainder of this report, those CSHCN who require anything beyond just prescription medications to treat their health conditions will be described as “CSHCN with more complex health needs.” “Less complex health needs” describes those CSHCN who primarily require prescription medications for their health conditions as defined in the CSHCN Screener.¹² See the Methodological Appendix that accompanies this report for additional information.

Impact of Conditions on Daily Lives of Children with Special Health Care Needs

Chronic health conditions fundamentally affect how children live and experience their daily lives. Given the wide variation in complexity, severity, and number of health conditions, their health care needs may range from an intermittent concern to a pervasive influence on all activities.

In the 2009/10 NS-CSHCN, parents of CSHCN were asked both how often and how greatly their child's health condition affected their daily activities. Nearly 30 percent of CSHCN in California have conditions that impact daily life greatly and/or consistently; this is similar to other states (26.9%). CSHCN in California with public insurance, similar to those in the rest of the nation, are substantially more likely to experience conditions that affect their daily lives compared to privately insured CSHCN (Figure 4). This may suggest that public insurance is not meeting the health needs required to improve functioning among CSHCN, or that children with public insurance tend to be those with more severe conditions. Further research is needed to ascertain why those CSHCN with public insurance experience greater health impacts. Those with both public *and* private insurance report experiencing even greater impacts; this may be because children with more severe health conditions are more likely to qualify for public insurance in addition to private insurance.

Figure 4: Percentage of CSHCN in California Whose Conditions Greatly and/or Consistently Impact Their Daily Lives, by Insurance Type



Note: The comparison of public insurance and private insurance is significant at the $p < 0.001$ level. Statistical comparisons were not made for private & public insurance data due to small sample size.

Implications: Complex Health and System Needs for a Vulnerable Group of California Children

California’s 1 million children with special health care needs, like all young people, need consistent access to a high-quality health care system. CSHCN, in particular, must depend on health care and related services to function well in everyday life and to minimize the impacts of their health conditions. California policymakers and child health advocates should continue to find ways to address

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Since a substantial number of CSHCN experience multiple, chronic health problems and functional difficulties, policymakers and others interested in reforming the health care system should move beyond condition-specific approaches. While improving quality for common chronic conditions such as asthma or ADHD is important, CSHCN in California need programs and policies that take a “whole child” approach, focusing on ways to improve overall functioning and well being regardless of the health condition.

Such an approach would involve increased efforts to improve the coordination of services among a child’s multiple health care and educational providers, as well as among the many state and community agencies that typically are involved in caring for CSHCN and their families. Solutions that focus on single-conditions can miss opportunities for intervention, and neglect those who do not yet have named diagnoses.

California policymakers also can take advantage of fiscal incentives built into the new Patient Protection and Affordable Care Act (ACA, 2010) that provide enhanced Medicaid payments for states that offer care coordination, health promotion, patient and family support, and referrals to community and social services for children with chronic conditions.¹³

To address the complex and varying needs of CSHCN in California, policy and program development also must account for the diversity of the state’s children, with particular focus on cultural and linguistic barriers to the early identification and treatment of chronic conditions. Providers, the educational infrastructure, and community-based services may need to customize services and materials for families with limited English proficiency, lower health literacy, or different cultural expectations about child health. The myriad components of the health care system need to further collaborate and enhance existing collaborations in order to improve the financial and systemic support for California’s most valuable resource—its children.



Section 2

The Potential for Care Coordination to Provide a Solid Foundation of Quality Care

Pediatric “care coordination” is a patient- and family-centered, team-based approach built around an individualized care plan designed to meet the needs of children and youth. High quality care coordination also involves working to enhance the care-giving capabilities of families. Care coordination for children with special health care needs often is complex, as these children have more needs than other children and typically are involved in multiple systems of care such as schools, hospitals, community-based organizations, therapists, and government agencies, without a single point of entry. As a result, family members frequently become their child’s primary care coordinators.

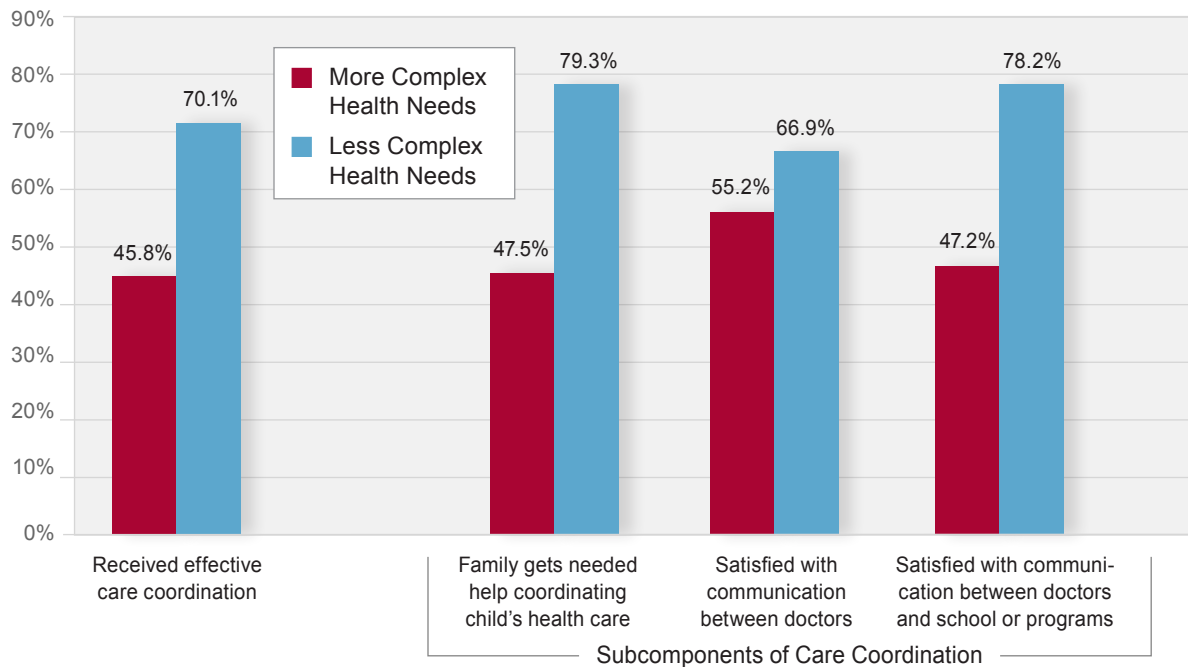
Among CSHCN in California who need care coordination services, nearly half (47.3%) do not receive effective care coordination, putting California at 46th in the nation. As depicted in Figure 5, CSHCN with more complex needs are significantly less likely to get those services (see the Methodological Appendix that accompanies this report for additional information on the measurement of care coordination).

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.

Data show a clear link between the receipt of care coordination and positive health outcomes. For example, care coordination is associated with a reduced impact of conditions on the daily lives of CSHCN; among those who receive sufficient care coordination, only 25 percent are greatly affected, compared with 44.7 percent who do not receive coordination services. Effective care coordination also is associated with reduced school absences among CSHCN; only 8.6 percent who receive coordination services miss 11 or more days of school in a year, compared with 19 percent who are not receiving care coordination. These data and other evidence suggest that effective coordination of services can make a significant difference in the lives of CSHCN and their families.¹⁴

In the 2009/10 NS-CSHCN, the Lucile Packard Foundation for Children’s Health asked an additional question about whether California families would use a care coordination website, should one be available. Nearly 40 percent of parents indicated that they would be *very likely* to use a web-based care coordination site, while almost 30 percent reported that they would be *somewhat likely* to use a site. Notably, 20 percent did respond that they were *very unlikely* to use such a site, perhaps requiring further study on the potential barriers to using a website to coordinate care and how to overcome those barriers.

Figure 5: Percentage of CSHCN in California Who Needed and Received Effective Care Coordination and Its Subcomponents, by Complexity of Health Needs



Note: The differences between CSHCN with more complex needs vs. less complex needs are significant as follows: overall (composite) measure of care coordination, $p < 0.001$; family gets needed help, $p < 0.001$; communication between doctors, $p = 0.07$; communication between doctors and schools/programs, $p = 0.009$.

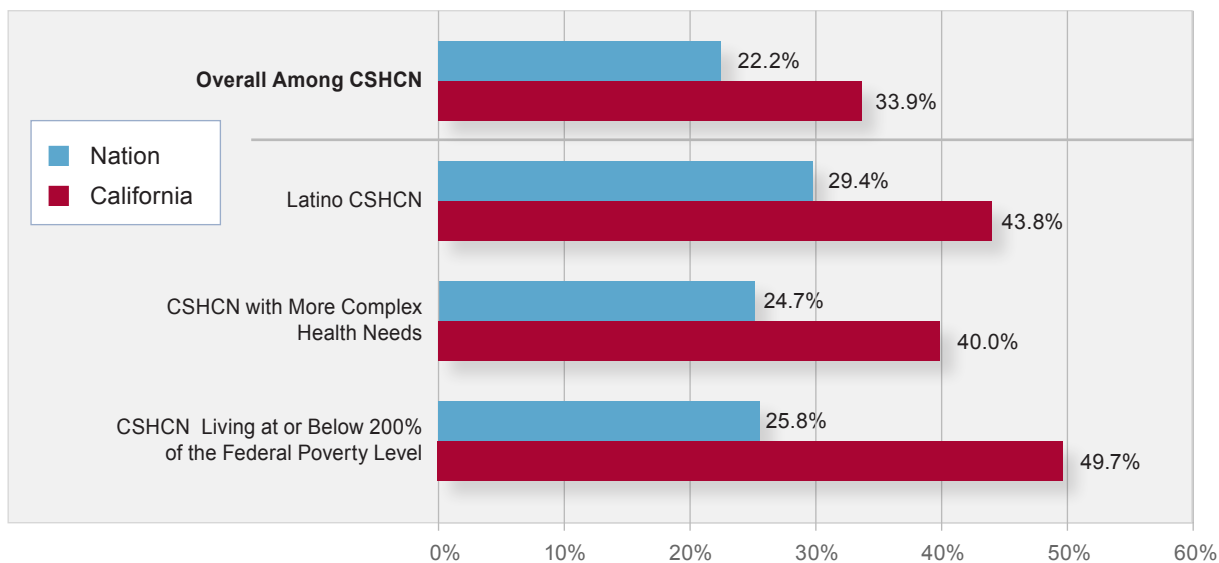
The interest in web-based coordination of care is greatest among those who are not receiving care coordination. That is, about half (51.2%) of those who are not currently receiving care coordination indicate a very high likelihood of using a website, compared with 34.5 percent among current recipients of care coordination.

Problems Obtaining Health Care Referrals When Needed

CSHCN frequently require care from many types of health care providers, including pediatric subspecialists, which typically involves referrals.¹⁵ Access to appropriate referrals, when needed, is an important measure of health care quality. The percentage of CSHCN in California who experience problems accessing specialist care is much higher than in the rest of the U.S. (33.9% vs. 22.2%); California ranks 50th in the nation on this measure. Some demographic subgroups in California have even greater problems obtaining referrals: CSHCN in California who are Latino, have more complex health care needs, or live below 200 percent of the federal poverty level fare worse (Figure 6).

Not surprisingly, CSHCN who experience difficulties obtaining needed referrals are more likely to have unmet health care needs: 57.5 percent of those with problems obtaining referrals had some gap or unmet need in care, compared with 17.2 percent for those who had no problems with referrals.

Figure 6: Percentage of CSHCN Who Experience Problems Obtaining Needed Referrals, by Key Demographic Subgroups



Note: In 2010, the Federal Poverty Level (FPL) was \$22,050 for a family of four in the 48 contiguous states and the District of Columbia. Currently (in 2012), the FPL is \$23,050 for a family of four. For Latino CSHCN, the Adjusted Odds Ratio (AOR) controlling for age, sex, household language, and household income is 2.07 (1.25-3.43). For CSHCN with more complex needs, the AOR controlling for age, sex, race/ethnicity, household language, and household income is 2.00 (1.38-2.89). For CSHCN living at or below 200% of the FPL, the AOR controlling for age, sex, race/ethnicity, and household language is 2.11 (1.24-3.59).

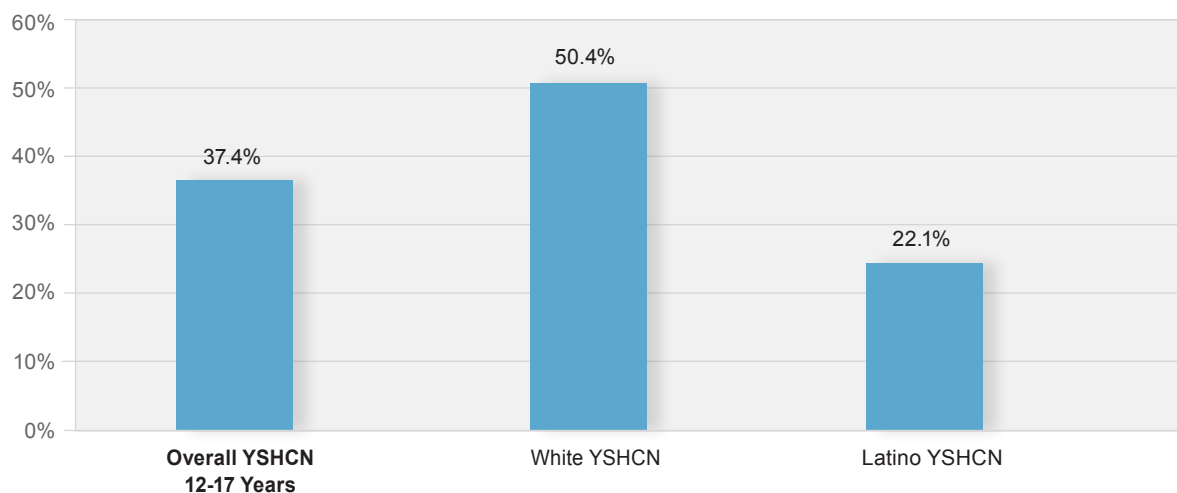
Transition to Adulthood: A Critical Moment

Youth with special health care needs (YSHCN) ages 12 to 17 require care coordination and planning to help them transition to adult health care. According to the American Academy of Pediatrics, transition planning should begin around age 11, and all adolescents with special health care needs should have a written health care transition plan by 14 years of age.¹⁶

Unfortunately, many YSHCN do not receive such transition services. In fact, only a little more than one-third (37.4%) of YSHCN in California receive all components of the transition services assessed (see Methodological Appendix). This is similar to rates found in the rest of the nation (40.3%). Planning for youth to transition to adult care is less likely to occur among YSHCN with more complex health needs compared to those with less complex needs (30.2% vs. 49.3%). Rates are even lower for California's Latino youth: only 22.1 percent of Latino youth with special health care needs receive transition services, compared to 50.4 percent of white youth (Figure 7).

As might be expected, youth who receive other care coordination services are more than twice as likely to get transition support, compared to youth who do not receive care coordination services (47.7% vs. 21.1%).

Figure 7: Percentage of California Youth with Special Health Care Needs (YSHCN) Receiving Transition Services to Adult Health Care



Note: The comparison between white and Latino YSHCN in California is significant at the $p < 0.001$ level. Data on other racial/ethnic categories are not reported due to insufficient sample size.

Implications: Care Coordination Eases Access Across Critical Services

The coordination of health care services—including the coordination of referrals offering access to specialty care—is a critical component of a quality health care delivery system and may enhance the health and well being of CSHCN. Furthermore, the provision of transition services beginning in early adolescence is essential to ensuring that YSHCN do not fall through the cracks of the health care system as they enter adulthood. By bridging the gap between pediatric and adult health care among YSHCN, they may experience more positive outcomes. As the available data indicate, it also is critically important to develop and implement culturally and linguistically competent practices for Latino CSHCN and their families. Further research is needed to provide data for all youth of color in the state.

As California works to improve health system performance for CSHCN, it may be helpful to look to other states that have developed innovative care delivery models for CSHCN, as described in a [2009 report](#) prepared by the Association of Maternal and Child Health Programs.¹⁷ For example, Florida created the Children’s Medical Services Network through its State Title V program to ensure that Medicaid-eligible children who meet clinical screening criteria receive care coordination services. A web-based application is used to track child health assessments, care plans, and notes as part of their care coordination services. Other state-driven medical home^{vi} initiatives incorporating care coordination as a fundamental feature similarly have been launched to enhance health care system performance for CSHCN. Pennsylvania has implemented one such initiative, Educating Practices in Community Integrated Care (EPIC-IC). The EPIC-IC program educates providers about how to embed effective care coordination services in their practices. Increased access to coordination of services, along with other quality of care improvements outlined in Section 3 below, is critical to advancing the health outcomes of CSHCN in California.

^{vi} According to the American Academy of Pediatrics, a “medical home” is a model of delivering primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. This is further discussed in section 3 of this report and in the Methodological Appendix.



Section 3

California's Health Care System Performs Poorly in Comparison to Other States

All children would benefit from having access to an integrated system of care that efficiently provides high-quality services and that has the capacity to adapt to diverse and changing needs. As children with special health care needs (CSHCN) depend more on the health care system than other children, the system's performance has a greater impact on their health and well being, their development, and their families' experiences. California's system of care, however, often falls short of meeting the needs of CSHCN, and by some measures it is the last in the nation. The following section reviews California's performance in several critical areas—including providing CSHCN with a stable source of comprehensive health insurance, adequate preventive care, and a medical home—all of which are important components in a comprehensive system of care.^{vii}

Consistent and Adequate Insurance: A Necessary Foundation for Quality Care

Consistent and adequate health insurance is a key measure of system performance for CSHCN,^{viii} as it helps remove barriers to accessing needed services. About three out of five CSHCN in California have consistent and adequate insurance coverage to meet their health needs, which means that nearly 40 percent of CSHCN have coverage that is insufficient to meet their needs. California ranks 34th in the nation on this measure (see Methodological Appendix for the full definition).

Preventive Care: Essential to Identifying Emerging Health Issues and Reducing Hospital Stays

Comprehensive, preventive health care may reduce unnecessary hospitalizations and provide early identification of emerging health issues or conditions. Though many CSHCN already visit their health care provider and specialists on a regular basis, it still is critical that they receive annual preventive check-ups with deliberate screening, rather than relying solely on visits related to current

vii According to the American Academy of Pediatrics, a “medical home” is a model of delivering primary care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. This is further discussed in section 3 of this report and in the Methodological Appendix.

viii The Maternal and Child Health Bureau conducts the National Survey of Children with Special Health Care Needs in part to measure key indicators for Title V Block Grant state-level reporting. In collecting data, a national expert panel helps determine key outcomes and indicator measures and how to score them. They are published in a Chartbook on CSHCN found at: <http://mchb.hrsa.gov/cshcn05/>. The 2009/10 Chartbook has not yet been published (as of October 2012). Many of the quality measures developed through this national process are used in this report.

conditions. This is only achieved for 87.6 percent of California CSHCN, a rate similar to the rest of the nation. Latino CSHCN and those with public insurance fare slightly worse than the California average (84.1% and 83.5%, respectively), with about 16 percent missing annual preventive care.

Research shows that CSHCN have up to five times the number of hospitalizations as the general child population.^{1,2} In the 2009/10 NS-CSHCN, California data were collected for the first time on overnight hospital stays among children with special needs (national data were not collected). Data showed that nearly one in 10 (8.6%) CSHCN in California was admitted to a hospital overnight in

More than 40% of CSHCN in California with complex health needs have difficulty accessing community-based services, compared to 20% with less complex needs.

the preceding year. Overnight hospital stays are more common among California's Latino CSHCN than white CSHCN (11.0% vs. 5.4%), publicly insured than privately insured (11.8% vs. 5.4%), and those living below 200 percent of the federal poverty level (FPL) than those living at or above 200 percent FPL (12.8% vs. 6.5%). These disparities indicate that the health care system may not be performing as well for certain demographic subgroups, as higher quality, well-coordinated outpatient care has been found to reduce hospitalizations.^{1,18} The disparities also may be attributed, in part, to the fact that California's low-income and Latino CSHCN may present with greater health care

needs and face more health consequences than other CSHCN once they are identified, especially if that identification is delayed.

Ease of Access to Community-Based Services: California Needs to Reduce the Burden on Families

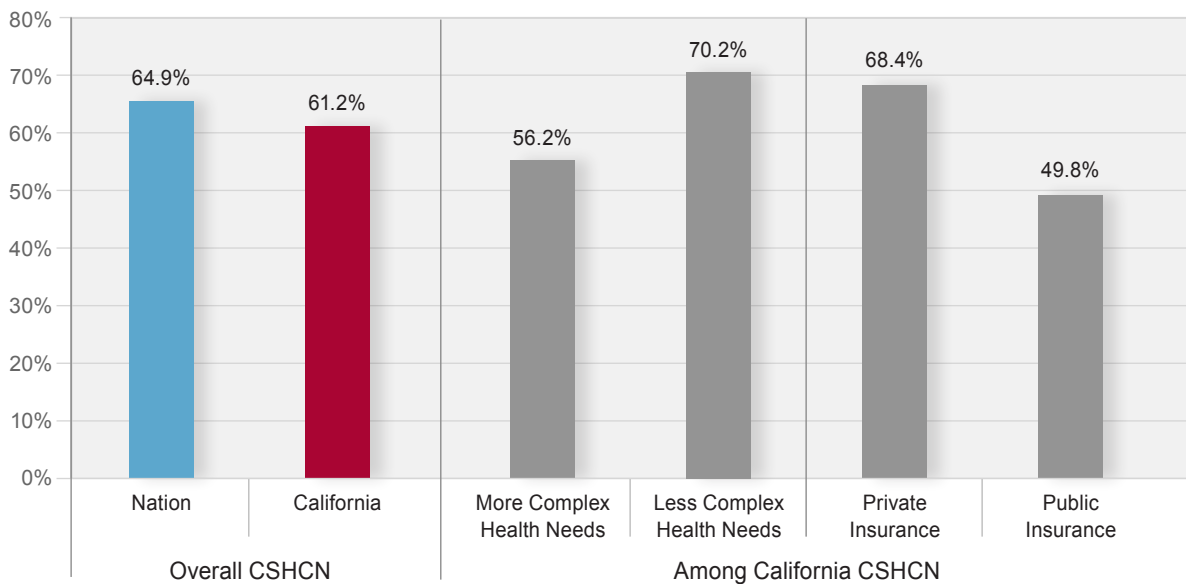
Easy access to community-based services is another core measure of system performance for CSHCN. Being able to access community services includes meeting eligibility requirements, being able to find providers, and scheduling and receiving services in local hospitals, clinics, and doctor's offices. These services often are fragmented and complex to navigate, and include barriers such as multiple or confusing eligibility requirements, policies, procedures, and service sites. In the 2009/10 NS-CSHCN, this was measured by asking if families experience difficulties or delays accessing services for their children and how often they are frustrated in their efforts to obtain services (see Methodological Appendix).

California performs about the same on ease of access to community-based services as the national average, at about 65 percent of CSHCN with good access to services. However, disparities exist within the state, and the nation, by the complexity of children's conditions as well as by insurance type. Only 56 percent of CSHCN with more complex needs can easily access community-based services, compared to more than 80 percent of CSHCN with less complex needs. In addition, more privately insured CSHCN are able to easily access community services than those with public insurance (72.1% vs. 56.7%). Current data show no disparities by race/ethnicity or household language within California on this measure, though differences by insurance type remain, even after controlling for income.

California Is Lagging Behind on Family-Centered Care

“Family-centered care” involves actively supporting the family’s relationship with the child’s health care providers and recognizing the importance of the family’s customs and values in the child’s care. This approach should be reflected in the planning, delivery, and evaluation of the child’s health care. Family-centered care is a critical component of culturally effective and compassionate care within a medical home. However, in California, only 61.2 percent of all CSHCN, and about half of those who are publicly insured, receive such care. California is ranked 44th in the nation on this measure. As demonstrated in Figure 8, disparities in family-centered care also exist by the complexity of children’s health care needs.

Figure 8: Percentage of CSHCN Who Receive Family-Centered Care, by Complexity of Child’s Needs and Insurance Type



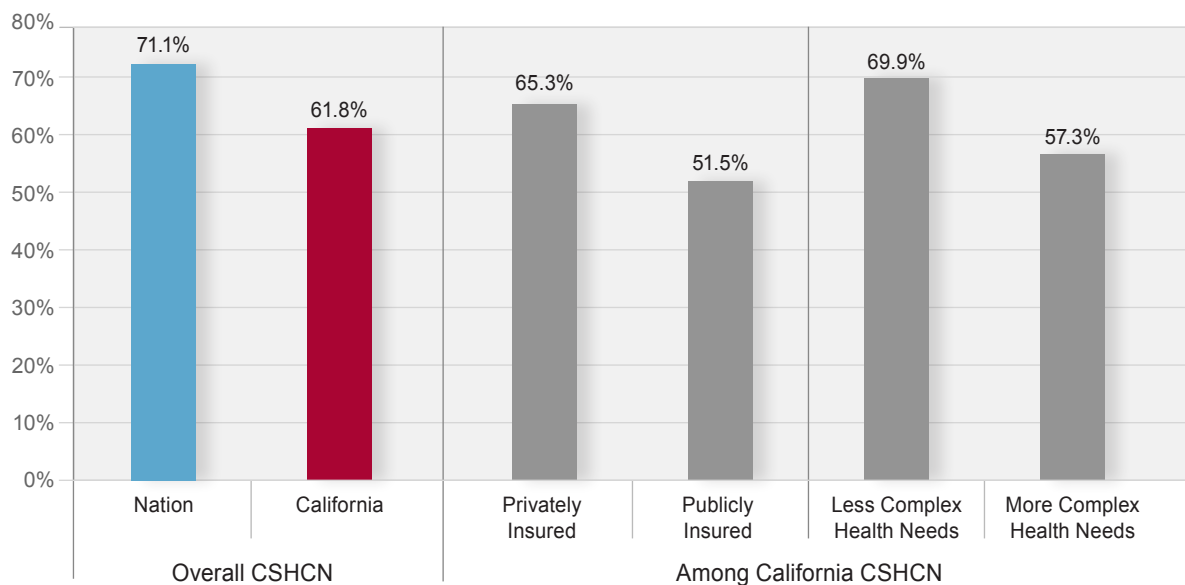
Note: The comparison of California vs. the nation is not significant. The comparison of more vs. less complex health needs in California is significant at the $p=0.002$ level; and the comparison for private vs. public insurance in California is significant at the $p=0.001$ level.

Shared Decision Making: California Should Improve Partnerships Between Providers and Families

Shared decision making between families and providers is an integral component of quality family-centered care and sets the stage for open and intentional discussions about each child’s unique health needs. Shared decision making refers to the extent to which parents feel health professionals do the following: engage them in decisions about their child’s health care, such as discussing treatment options; encourage them to ask questions; and respect their choices about health care (see the Methodological Appendix for a complete description of this measure). Shared decision making is positively associated with receiving care coordination, access to referrals, and access to needed services.

California is ranked last in the U.S. on this measure and is one of only two states that perform significantly worse than the national average (61.8% vs. 71.1%). As shown in Figure 9, this measure varies by insurance type and condition complexity. Only about half (51.5%) of publicly insured CSHCN in California receive health care that meets the shared decision making criteria, significantly lower than those with private insurance (65.3%). Further, 69.9 percent of CSHCN with less complex needs have families that participate in shared decision making versus 57.3 percent of CSHCN with more complex needs. Notably, even the subgroups of CSHCN in California that are performing better still are below the national average.

Figure 9: Percentage of CSHCN Whose Health Care Includes Shared Decision Making, by Insurance Type and Complexity of Needs



Note: The comparison for California vs. the nation is significant at the $p < 0.05$ level. Within California, p values are $p = 0.011$ for the private vs. public insurance comparison and $p = 0.007$ for the less vs. more complex health needs comparisons.

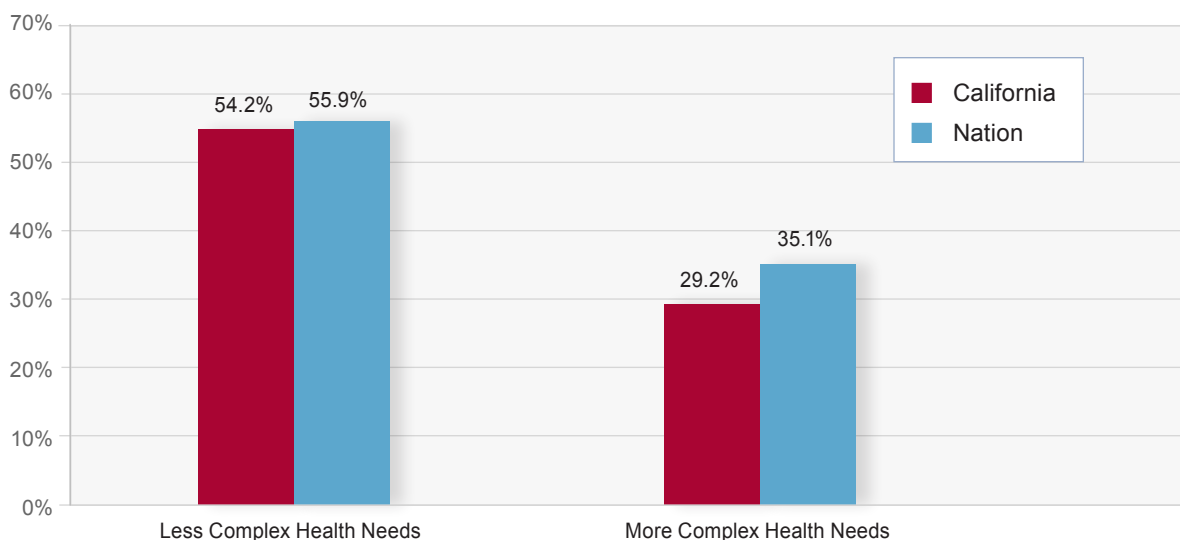
A Highly Effective System Offers Coordinated Care Through a Medical Home

A “medical home” is not a specific place for care, but rather a comprehensive and coordinated set of services that provide optimal health care for children with special health care needs. The American Academy of Pediatrics describes the desirable characteristics of a medical home for children with special health care needs as being accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.¹⁹⁻²⁰ These characteristics of a medical home have been shown to be especially important for children with special health care needs, given their need for stable and coordinated care. The parent and patient experience of receiving care within a medical home is critical to achieving patient-centered care. (See the Methodological Appendix for information on how this concept was measured in the NS-CSHCN.)

Fewer than four in 10 CSHCN in California meet the criteria for having a medical home (38.3%), which is significantly worse than the national average of 43.4 percent. California ranks 44th in the nation on this measure. Among publicly insured CSHCN, the state ranks even lower—49th—with only 25.4 percent receiving care within a medical home.

Figure 10 shows that California also fares worse than the nation in providing medical homes for CSHCN with more complex health needs, with less than one-third receiving care within a medical home. An estimated 430,000 California CSHCN with more complex needs are not receiving comprehensive, family-centered care within a medical home, which puts California at 46th in the nation.

Figure 10: Percentage of CSHCN Receiving Care within a Medical Home, by Complexity of Health Needs



Note: The comparison of more complex CSHCN in California vs. the nation is significant at the $p = 0.033$ level. The comparison of less complex CSHCN in California vs. the nation is not statistically significant.

California's Overall Health System Performance: Much Room for Improvement, Especially for Publicly Insured CSHCN

The Federal Maternal and Child Health Bureau collects data on children with special health care needs to provide national and state-level assessments of the performance of the health care system for CSHCN. They examine system performance in six areas: (1) shared decision making for optimal care; (2) care within a medical home; (3) current, consistent, and adequate health insurance coverage; (4) annual screening through preventive medical and dental visits; (5) ease of access to community-based health services; and (6) youth transition planning for ages 12-17. An overall system performance measure is calculated based on the number of CSHCN in the nation and in each state who meet all age-relevant performance measures.

More than four in five CSHCN in California do not receive care meeting these six minimal standards. The state is not significantly different from the nation on this measure; 16.3 percent of California's CSHCN experience care that meets these standards versus 17.7 percent nationally. Among publicly insured CSHCN in California, only 6.2 percent experience care meeting these standards, compared with 22.9 percent of privately insured CSHCN in the state and 12.7 percent of publicly insured CSHCN nationally. Similar disparities exist between children with more versus less complex health needs (12.4% and 22.9%), and Latino versus white children (11.1% and 23.0%).

Implications: How Can California Support a Well-Performing System?

Despite an increasing emphasis by the state of California on adopting health care quality components, such as care coordination and medical home, the rate of California CSHCN who receive quality health care has not improved since 2005/06, according to the 2009/10 National Survey of Children with Special Health Care Needs. While broad-based improvements undeniably are needed,

Only 6% of publicly insured children with special health care needs in California experience care that meets a set of minimum quality standards. The state ranks last in the nation on this measure.

more targeted efforts also may be necessary to remedy persistent disparities in the quality of care received by key subgroups of CSHCN—those who are Latino, have more complex health needs, are publicly insured, or who live below 200 percent of the Federal Poverty Level.

How can California improve the health and functioning of CSHCN throughout the life course? Comprehensive and adequate insurance coverage for all CSHCN is essential. Quality preventive care and chronic condition management must become integrated throughout the pediatric primary care delivery system. Access to core primary prevention services—immunizations, well-child visits, preventive dental care, weight assessment, and developmental screening—is paramount to promoting the healthy development of *all* children, including CSHCN.

As part of these broader efforts to enhance health care quality for CSHCN, California could expand efforts to implement evidence-based strategies to address cultural and linguistic barriers, which can preclude some racial and ethnic groups from accessing requisite health care.¹⁷ One Utah clinic, for example, collaborated with Utah State University to conduct formative research to better understand why Spanish-speaking families encounter difficulties accessing care for CSHCN. In addressing some of the challenges, the use of Spanish-speaking clinic coordinators and parent advocates to triage patients was adopted as part of the clinic's participation in a statewide medical home initiative. The use of community health workers (*promotores*) who connect families of CSHCN with needed resources was successful in improving access among Spanish-speaking clients at this clinic. California should continue to pursue systemic efforts to address the linguistic and cultural disparities in accessing high quality care for Spanish-speaking CSHCN.



Section 4

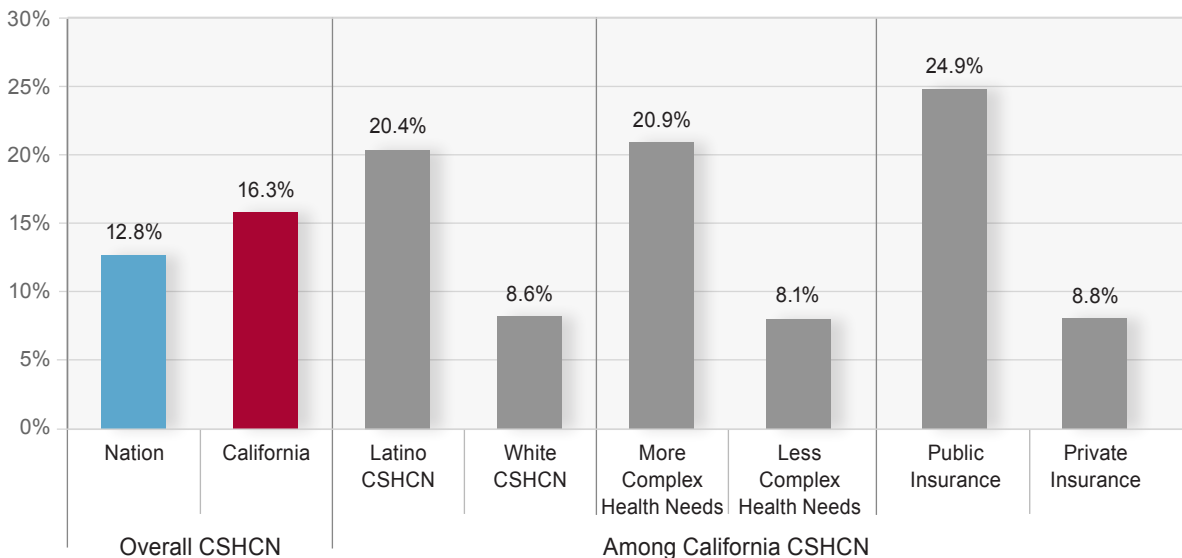
Impact on Family Life and Economics

Time Spent Providing, Arranging, or Coordinating Care: Real Impacts on California Families

Having a child with special health care needs alters the lives of families, creating a “new normal” in terms of family experiences, responsibilities, and relationships. Initially, and most apparent, are changes in how family members spend their time. Families often spend many hours providing, arranging, or coordinating the child’s health care. About 16 percent of California’s children with special health care needs (CSHCN) have families that spend 11 or more hours per week providing and/or coordinating care for the child, compared to 12.8 percent nationally. The state ranks 48th on this measure. In California, this percentage has increased significantly since 2005/06, when only 9.1 percent spent 11 or more hours per week caring for their child’s medical needs.

Figure 11 shows significant disparities in the amount of care provided by families of Latino CSHCN compared to families of white CSHCN (20.4% vs. 8.6%) and between those with complex needs versus less complex needs (20.9% vs. 8.1%). Health insurance type also is associated with the

Figure 11: Percentage of CSHCN Whose Families Spend 11+ Hours/Week Providing or Coordinating the Child’s Health Care, by Key Subgroups



Note: These comparisons are significant at the following levels: California vs. the nation, $p < 0.057$; Latino vs. white CSHCN in California, $p = 0.002$; more vs. less complex needs in California, $p = 0.001$; public vs. private insurance in California, $p < 0.001$.

amount of time families spend providing care; California CSHCN with public insurance are much more likely to have families that spend 11 or more hours per week providing, arranging, or coordinating health care than CSHCN with private insurance (24.9% vs. 8.8%).

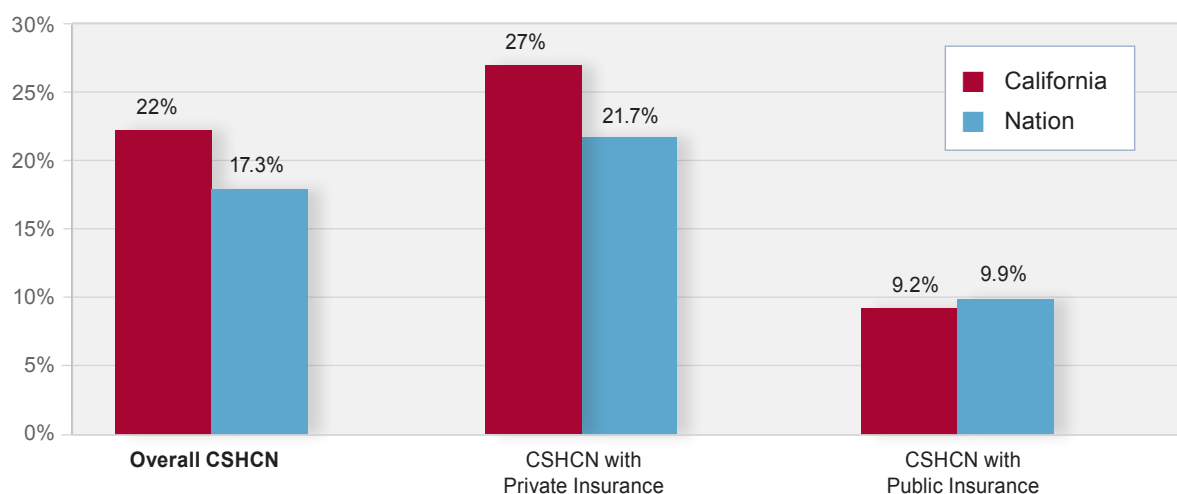
The Impact of CSHCN on Parental Employment and Finances Is Not Improving in California

The challenge of caring for CSHCN can cause family members to cut back or stop working. Nationally, almost one in four (24.6%) CSHCN have conditions that cause their families to cut back and/or stop working, according to 2009/10 data. In California, 29.4 percent (an estimated 290,000 CSHCN) experience this consequence. While the California figure is not significantly different from the nation, it does represent an increase from 23.7 percent in 2005/06 and it is the highest percentage in the nation. The recent economic problems in California and the U.S. likely have exacerbated the financial circumstances and the stress of families who must provide care for their children.

Disparities by income and race/ethnicity also exist among California families on this measure. For example, a significantly higher percentage of publicly insured CSHCN have families who cut back or stop working due to their children's conditions (44.5%) compared to privately insured CSHCN (17.7%). In addition, families of Latino CSHCN are more likely to experience this effect on their employment (35.8%) relative to white CSHCN (20.3%).^{ix} This difference also is pronounced between California CSHCN with more complex needs (41.4%) versus less complex needs (7.4%).

Family members of CSHCN also may avoid changing jobs in order to simply maintain health insurance coverage for CSHCN. This occurs for a higher percentage of CSHCN in California than in the rest of the nation (22.0% vs. 17.3%). In California and nationwide, this happens more often for CSHCN with private health insurance (27.0%) than public insurance (9.2%). As private insurance is directly tied to employment status, this highlights the need for portability and continuity of coverage (Figure 12).

Figure 12: Percentage of CSHCN Whose Families Avoid Changing Jobs to Maintain Their Health Insurance, by Type of Insurance



Note: Overall comparison of California vs. the nation, $p < 0.01$; the comparison of private vs. public insurance in California is significant at the $p < 0.001$ level.

^{ix} Comparisons among other groups were not possible due to small sample size.

Both receipt of care coordination services and ease of access to community-based health services may lessen the employment impacts experienced by families of CSHCN. Those who receive care coordination are less likely to avoid changing jobs due to concerns about health insurance (20.8% vs. 30.7% without care coordination). Similarly, California CSHCN whose families can easily access community-based health services also are less likely to cut back or stop working (19.6% vs. 46.0% without good access) or avoid changing jobs due to concerns about health insurance (17.9% vs. 29.5%). This highlights, again, the importance of care coordination programs and easy access to care, which can help in ameliorating the impact of conditions on California families.

The percentage of California children with special health care needs whose conditions cause their families financial problems significantly increased from 15.5% in 2005/06 to 24.2% in 2009/10.

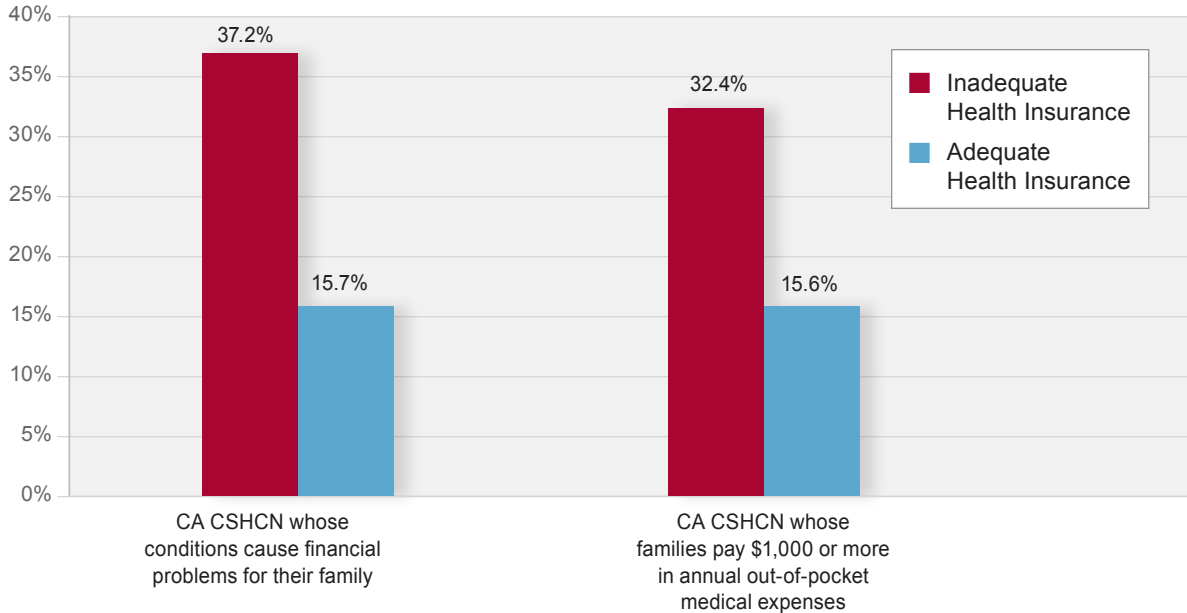
Along with effects on parental employment, special health care needs can cause serious financial hardship for families. Nearly one-quarter (24.2%) of California CSHCN have conditions that cause financial problems for their families, a significant increase from 15.5 percent in 2005/06. California ranks 41st in the nation on this measure.

Not surprisingly, adequate health insurance coverage significantly lessens the financial burden on families (Figure 13). California CSHCN with adequate insurance are less likely to have families who experience financial problems than those with inadequate coverage (15.7% vs. 37.2%).

Another measure of financial hardship is how much families pay out of pocket for medical expenses. In California, 21.8 percent of CSHCN have families who pay \$1,000 or more in out-of-pocket medical expenses annually. Nearly one-third (32.4%) of CSHCN with inadequate health insurance have families who pay \$1,000 or more in out-of-pocket medical expenses, compared to 15.6 percent of CSHCN with adequate health insurance in California (Figure 13).

The complexity of children's needs also affects out-of-pocket expenditures for families. Among California CSHCN, those with more complex needs are more likely to have families who pay \$1,000+ in out-of-pocket medical expenses (25.6%) than CSHCN whose conditions are less complex (15.1%). It is important to consider that out-of-pocket expenses of less than \$1,000 per year may still cause financial problems among families with lower household incomes.

Figure 13: Percentage of California CSHCN Who Experience Financial Problems or Pay Annual Out-of-Pocket Medical Expenditures of \$1,000 or More, by Adequacy of Health Insurance



Note: The comparison of financial problems by inadequate vs. adequate insurance is significant at the $p < 0.01$ level; the comparison of out-of-pocket expenses by inadequate vs. adequate insurance is significant at the $p < 0.001$ level.

Implications: Families of CSHCN in California Require More Support Than They Currently Receive

A high functioning health system can mitigate adverse impacts on families caring for children with special health care needs. For example, ease of access to community-based health services is associated with a reduced likelihood of financial or employment problems for family members of California CSHCN. Striking disparities exist in family impacts for CSHCN who are poor, Latino, who have complex health conditions, and who have inadequate insurance. These inequities suggest that targeted policies and programs intended to enhance care coordination services, along with improved access to community-based health services, are imperative to an overall reduction in the financial and employment impacts, and the amount of time spent providing care, for families of California CSHCN. Further, trends based on 2005/06 and 2009/10 data indicate that the employment and financial effects experienced by families of California CSHCN have not improved—remaining the same or even worsening over time. Further research might help identify factors—both within and beyond the health care arena—that shape these trends, to determine ways in which California’s system of care may be strengthened to improve the health and well being of children with special health care needs and their families.



Conclusions

California has more than 1 million children with special health care needs (CSHCN), most of whom 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 CSHCN, and the state is performing worse than other states across multiple measures. Though assuring a high performing system of care for CSHCN is a problem throughout the country, data show that the problem is particularly acute in California.

California's difficulty in meeting the needs of its diverse population of CSHCN relates partially to the composition of the state's CSHCN population. California's CSHCN are diverse and parents of color may be more reluctant to identify their child as having a special health care need when the health issue is relatively mild or results in few health consequences. As a result, CSHCN of color in California, by the time they are identified, may present with needs that are generally quite substantial. For instance, compared to white CSHCN, Latino CSHCN are more likely to have an overnight hospital stay, and more likely to have parents who are spending extended periods of time providing, arranging and coordinating their care. Encouraging families of color to take early action on their child's health needs may be one way to improve long-term outcomes among CSHCN and their families. For example, culturally sensitive efforts to increase developmental screening, or improve the early identification and treatment of common conditions such as asthma or ADHD, could lead to improved health outcomes and quality of life among California's CSHCN. Such efforts have improved quality of care and reduced health care disparities in other states.²¹

California's poor overall performance also is demonstrated by the low quality of health care services provided to CSHCN with more complex conditions in the state. For instance, children with complex conditions are less likely to experience family-centered care or shared decision making between families and providers. These 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.

Findings suggest that California needs to do more to make care comprehensive, affordable, and easy to access for CSHCN with more complex needs and their families. Improving care coordination may be an important way to advance this agenda. This report found broad acceptability of web-based care coordination services, which might be part of the solution to reduce health care barriers.

In addition, California could expand efforts that co-locate or integrate administrative and care services across the various agencies that serve CSHCN, thereby reducing access and coordination burdens on families.

The data also show that CSHCN who are poor and who lack consistent and adequate insurance have more difficulty accessing care and have worse health outcomes than other CSHCN. California's Medicaid Program (MediCal) is a critical safety net for low-income CSHCN, and it plays a vital role in mitigating costs for CSHCN with high needs. Continuing to protect this program from budget cuts is an important way to ensure that CSHCN's health care access does not deteriorate further. The Patient Protection and Affordable Care Act (ACA, 2010) also may be a promising step toward improved health care access for CSHCN; new provisions that prevent lifetime caps on insurance coverage, prohibit insurance denials or limits due to pre-existing conditions, and allow coverage of youth on their parents' plans up to age 26, may make comprehensive coverage more attainable for CSHCN. In addition, the law assures that California's public sector insurance will continue at existing levels until 2019, and makes a number of administrative changes designed to make Medicaid enrollment and maintenance of coverage easier for families.¹³ Additional research is needed to determine how these changes may affect health outcomes, access, and utilization for children with special health care needs.

Policymakers, advocates, and other child health stakeholders must work together in new and expanded ways to improve health care for California's 1 million children experiencing special health care needs.

The data shown here make a powerful argument for California stakeholders and policymakers: special health care needs are common among California's children, and these children will be future participants in California's complex system of care for adults. Unfortunately, many of their medical needs—and for that matter, their emotional and educational needs—are currently unmet. Improving availability, comprehensiveness, and affordability of insurance, making services easier to access, and promoting family-centered care and care coordination, are important ways for California's health care system to ameliorate both short- and long-term outcomes for CSHCN. Policymakers, advocates, and other child health stakeholders must work together in new and expanded ways to make these goals a reality for California's 1 million children experiencing special health care needs.

This report and its Methodological Appendix are available at <http://lpfch-cshcn.org/publications/research-reports/children-with-special-health-care-needs-in-california-a-profile-of-key-issues>.

References

1. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics* 2004;114:79-85.
2. Newacheck PW, Kim SE. A national profile of health care utilization and expenditures for children with special health care needs. *Archives of Pediatric & Adolescent Medicine* 2005;159:10-7.
3. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics* 1998;102:137-40.
4. Bethell CD, Read D, Stein RE, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambulatory Pediatrics* 2002;2:38-48.
5. Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Pediatric & Adolescent Medicine* 2011;165:1020-6.
6. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. Children with Special Health Care Needs in Context: A Portrait of States and the Nation. Rockville, Maryland: U.S. Department of Health and Human Services, 2011.
7. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The National Survey of Children with Special Health Care Needs Chartbook 2005–2006. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.
8. 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 & Child Health Journal* 2008;12:1-14.
9. Blumberg SJ, Read D, Avila RM, Bethell CD. Hispanic children with special health care needs from Spanish-language households. *Pediatrics* 2010;126 Suppl 3:S120-8.
10. 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 & Child Health Journal* 2007;11:568-85.
11. Richardson LA. Seeking and obtaining mental health services: What do parents expect? *Archives Psychiatric Nursing*. 2001;15:223-231.
12. 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 & Child Health Journal* 2009;13:151-63.
13. Catalyst Center. The Affordable Care Act: A side-by-side comparison of major provisions and the implications for children and youth with special health care needs. <http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf>
14. Homer CJ, Klatka K, Romm D, Kuhlthau K, Bloom S, Newacheck P, Van Cleave J, Perrin JM. A review of the evidence for the medical home for children with special health care needs. *Pediatrics*. 2008 Oct;122(4):e922-37.
15. Harrold LR, Field TS, Gurwitz JH. Knowledge, patterns of care, and outcomes of care for generalists and specialists. *Journal of General Internal Medicine* 1999;14: 499-511.
16. American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, Transitions Clinical Report Authoring Group, Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2011;128:182-200.
17. Association of Maternal and Child Health Programs. Models of care for children and youth with special health care needs: promising models for transforming California's system of care. November 2009. <http://www.lpfch.org/nationalmodels/>.
18. Raphael JL, Mei M, Brousseau DC, Giordano TP. Associations between quality of primary care and health care use among children with special health care needs. *Archives of Pediatric & Adolescent Medicine* 2011;165:399-404.
19. Medical Home Initiatives for Children With Special Needs Project Advisory Committee, American Academy of Pediatrics. The medical home. *Pediatrics* 2002;110:184-6
20. 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;113:1529-37.
21. Earls MF, Hay SS. Setting the stage for success: implementation of developmental and behavioral screening and surveillance in primary care practice—the North Carolina Assuring Better Child Health and Development (ABCD) Project. *Pediatrics*. 2006;118:e183-8.