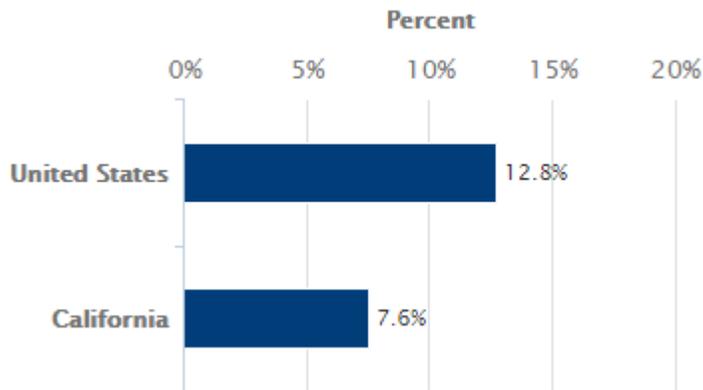


Children with Special Needs: Quality of Care

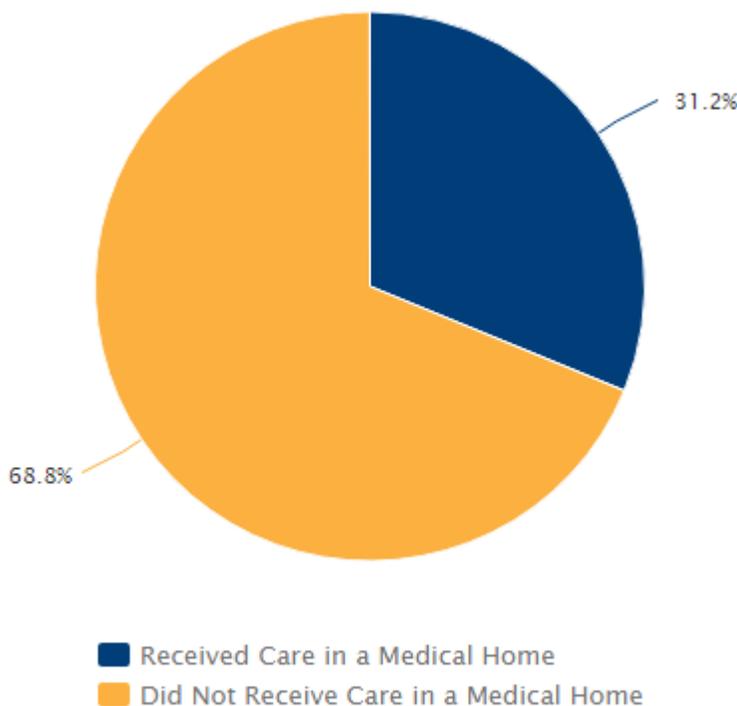
Children Ages 0-17 with Special Health Care Needs (CSHCN) Who Receive Care in a Well-Functioning Health System: 2022



Definition: Estimated percentage of children ages 0-17 who receive and do not receive health care in a well-functioning system of services, by special health care needs status (e.g., in 2022, 7.6% of California children with special health care needs (CSHCN) received care in a well-functioning health system).

Data Source: U.S. Dept. of Health and Human Services, [National Survey of Children's Health](#) (May 2024).

CSHCN Who Receive Care Within a Medical Home: 2022 California



What It Is

Kidsdata.org provides the following indicators related to quality of care for children with special health care needs (CSHCN):

- Children who receive care in a well-functioning health system—an indicator built from six component measures including:
 - Children with adequate and consistent health insurance coverage
 - Children whose families feel like partners in shared decision-making with providers
 - Children who receive care within a medical home—a measure built from five components including:
 - Children who receive family-centered care
 - Children who receive needed care coordination

Why This Topic Is Important

Nearly 1.4 million California children, and more than 15 million children nationwide, have or are at increased risk for a chronic health condition—physical, developmental, mental, or behavioral—and require care and related services of a type or amount beyond that required by children generally. As advances in technology and medicine continue to improve and extend the lives of children with special health care needs (CSHCN), these numbers are expected to grow. Over the next decade, for instance, it is estimated that the number of children with medically complex conditions will double.

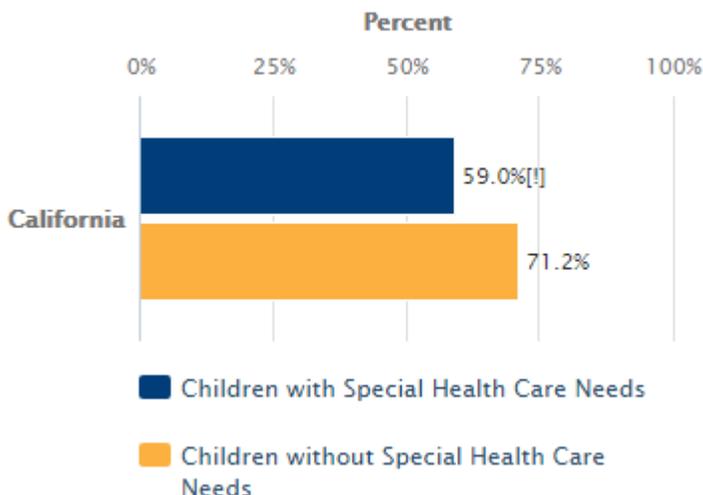
Obtaining timely, appropriate, and affordable care is a major problem for many CSHCN families. Statewide and nationally, around 9 in 10 CSHCN do not receive care in a well-functioning system—one meeting federal standards for accessibility of services, adequacy of health insurance coverage, shared decision-making with families, and receipt of care within a medical home. Having a medical home itself requires—among other benchmarks for comprehensive, high-quality primary care—that children receive family-centered care and effective care coordination when needed.

Major barriers to care, especially in California, include a fragmented system of services and an

Definition: Estimated percentage of children ages 0-17 who receive coordinated, ongoing, comprehensive health care that meets American Academy of Pediatrics 'medical home' standards, by special health care needs status (e.g., in 2022, 31.2% of California children with special health care needs (CSHCN) received care within a medical home).

Data Source: U.S. Dept. of Health and Human Services, [National Survey of Children's Health](#) (Jun. 2024).

Children with Adequate Health Insurance Coverage, by Special Health Care Needs Status: 2022



Definition: Estimated percentage of children ages 0-17 with and without health insurance coverage that usually or always (i) meets their needs, (ii) allows them to see needed providers, and (iii) has reasonable or no out-of-pocket costs (e.g., in 2022, among California children with special health care needs (CSHCN), both insured and uninsured, 59% had adequate health insurance coverage).

Data Source: U.S. Dept. of Health and Human Services, [National Survey of Children's Health](#) (Jun. 2024).

CSHCN Whose Families Feel Like Partners in Shared Decision-Making with Providers: 2022

Locations	Percent
United States	83.2%
California	87.4%

Definition: Estimated percentage of children ages 0-17 with and without special health care needs whose families felt like partners in shared decision-making with providers in the previous 12 months, among those with a health care visit who needed decisions to be made regarding their care (e.g., in 2022, among California children with special health care needs (CSHCN) who needed decisions to be made regarding their health care in the previous year, 87.4% had families who were partners in shared decision-making with providers).

Data Source: U.S. Dept. of Health and Human Services, [National Survey of Children's Health](#) (Jun. 2024).

inadequate, shrinking workforce of pediatric subspecialists. Beyond service system barriers, social factors and practices—such as poverty and discrimination (e.g., on the basis of race/ethnicity or ability)—influence access to care, and, as a result, health outcomes. For example, CSHCN of color and those in low-income families are more likely to have unmet health needs and limited access to high-quality care when compared with their more affluent and white peers.

How Children Are Faring

In 2022, fewer than 1 in 13 California children with special health care needs (CSHCN) received care in a well-functioning health system. Among California children without special health care needs, the share receiving care in a well-functioning system was twice as high as for CSHCN, but still lower than 1 in 6.

Although a vast majority of California CSHCN (96%) in 2022 had consistent health insurance coverage over the previous year, only 59% had adequate coverage at the time of survey—meaning their current benefits met their needs, allowed them to see needed providers, and had reasonable or no out-of-pocket costs. By comparison, 71% of non-CSHCN statewide had adequate health insurance.

According to 2022 estimates, 31% CSHCN in California, and 38% nationwide, received health care meeting American Academy of Pediatrics standards for a medical home—accessible, continuous, coordinated, compassionate, comprehensive, culturally effective, family-centered primary care.

Access to a medical home varies by demographic and socioeconomic factors. CSHCN in households with incomes below their federal poverty threshold (\$27,479 for a family of two adults and two children in 2022) are generally less likely to have a medical home than their peers living at or above 400% of their poverty threshold—16% vs. 40%, according to the latest California estimates. Nationwide, fewer than a third of African American/black and Hispanic/Latino CSHCN received care in a medical home in 2022, compared with almost half (44%) of white CSHCN.

View references for this text and additional research on this topic:

<https://www.kidsdata.org/topic/17/quality-of-care-for-children-with-special-health-care-needs/summary>



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