Children with Special Needs: Quality of Care

What It Is
Children with special health care needs (CSHCN) have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and require health and related services of a type or amount beyond that required by children generally. On kidsdata.org, indicators related to quality of care for CSHCN include:

- CSHCN who receive care within a medical home
- CSHCN who receive needed care coordination
- CSHCN who receive family-centered care
- CSHCN whose families feel like partners in their child’s care
- CSHCN who receive care meeting federal quality standards

Why This Topic Is Important
More than 1.25 million California children and youth, and nearly 14 million nationwide, have or are at increased risk for a chronic health condition and require care and related services of a type or amount beyond that required by children generally. Their ongoing health problems—physical, behavioral, or developmental—can affect their ability to function and participate in important educational and social activities, and, in some cases, can shorten their lives. Although advances in medical care have extended and improved the lives of millions of children, obtaining timely, appropriate, and affordable care remains a problem for many families. The vast majority of children with special health care needs (CSHCN) nationally (86%) do not receive care that meets federal standards for a well-functioning system. Improving access to quality care is critical to the health and well-being of CSHCN; as these children depend more on the health care system than children without special needs, the quality of services has a greater impact on their lives and their families’ experiences.

When compared with children who do not have special health care needs, CSHCN are more likely to experience social-emotional problems, academic challenges, and other types of adversity which can complicate their medical care. As a result, CSHCN often rely on a range of services from multiple sectors, and their parents and family members often face higher caregiving burdens and experience more stress and difficulties with employment and finances.
Definition: Estimated percentage of children ages 0-17 with special health care needs (CSHCN) who received and did not receive family-centered care, among those with a health care visit in the previous year (e.g., in 2016-2019, 80% of California CSHCN received family-centered care).


How Children Are Faring

In 2016-2019, among California children ages 0-17 with special health care needs (CSHCN), an estimated six in ten (61%) failed to receive care meeting American Academy of Pediatrics standards for a medical home (accessible, continuous, coordinated, compassionate, comprehensive, culturally effective, family-centered primary care). Among California CSHCN who saw a health care provider in the previous year, one in five (20%) did not receive family-centered care (in which the provider listens carefully to the family, shows sensitivity to the family's values and customs, provides the family needed information concerning the child, and helps the family feel like a partner in the child's care), and among CSHCN who saw two or more health care providers in the previous year, more than one in three (36%) did not receive effective care coordination between their providers and services.

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