Impact of Special Needs on Children/Families

What It Is
Children with special health care needs (CSHCN) are defined as those 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. On kidsdata.org, indicators on the impact of special health care needs include difficulties faced by CSHCN, effects on their school, and impacts on parental stress, time, finances, and employment.

See kidsdata.org's CSHCN category for the full list of indicators related to CSHCN, including data on demographics, access to care, quality of care, and health insurance coverage. These data come from the National Survey of Children with Special Health Care Needs and the National Survey of Children’s Health, which are conducted through telephone interviews with parents. Depending on the indicator, data are available for California, the U.S., all states other than California (including the District of Columbia), and/or geographies with at least 70,000 residents (as local area synthetic estimates based on American Community Survey data from the U.S. Census Bureau).

Why This Topic Is Important
In California there are more than one million children and youth whose needs for health care services are greater or more complex than children generally. Their ongoing health problems—physical, behavioral, or developmental—can affect their ability to function and participate in important educational and social activities (1). In some cases their health problems can shorten their lives (1). Medical care for children with special health care needs (CSHCN) is often complicated by the co-occurrence of social, emotional, and academic problems (1, 2).

Because of the higher caregiving burdens, families of CSHCN tend to experience more stress and difficulties with employment and finances than other families (1, 2). For example, the demands on families of CSHCN may require that parents cut down their work hours or give up a job, at the same time that they face higher than average out-of-pocket health care costs (1). Having a child with special needs also is a significant time commitment. Families of CSHCN may spend large amounts of time providing care, learning about their child’s condition and available services, and/or coordinating their child’s care.
CSHCN account for more than 40% of all health care costs among children nationwide, despite making up less than 20% of the U.S. child population (1). Though 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. More than four in five CSHCN do not receive one or more basic aspects of quality health care, in California and nationally (1).

How Children Are Faring

Nearly 30% of children with special health care needs (CSHCN) in California have conditions that impact their daily lives, according to 2009-2010 data. In addition, in 2011-2012, a larger proportion of CSHCN had parents who experienced stress from parenting compared with other children in California and compared with children with and without special health care needs in the U.S.

In 2009-2010, almost one-quarter of California's CSHCN (24%) had conditions that caused family financial problems. About 16% of CSHCN had families that spent 11+ hours per week providing and/or coordinating care for the child, an increase from 9% in 2005-2006.

Some data show disparities by complexity of health needs, poverty level, insurance type, and race/ethnicity. For example, 29% of CSHCN in California have conditions that cause their families to cut back or stop working, according to 2009-2010 estimates. However, among CSHCN who have conditions that require more than just prescription medication, 41% have families that cut back or stop working. Furthermore, 46% of CSHCN in families at the lowest poverty level (0-99%) and 45% of CSHCN using public insurance have families that cut back or stop working. These rates also differ by race/ethnicity—20% of white, 26% of African American/black, and 36% of Hispanic/Latino CSHCN have conditions that cause their families to cut back or stop working.*

Definition: Percentage of children ages 0-17 with special health care needs, by effect of child’s health needs on parental employment (e.g., 29.4% of California children with special health care needs had parents who cut back or stopped working to care for their child in 2009-10).


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