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California Ranks Last in Nation on Index Measuring System of Care for Children with Special Health Care Needs, Study Finds

PALO ALTO – An estimated one in seven children in California has a special health care need, yet the state ranked worst in the nation on a composite index that measures whether these children have adequate health insurance, receive basic preventive care, and receive medical care that is comprehensive, ongoing and family-centered, according to a study released today.

Children with special health care needs are those who have a chronic condition that requires health care beyond what is needed by most children. Conditions may range from mild, manageable asthma to highly complex conditions such as cerebral palsy or heart disease. Most of these children have multiple health conditions.

“These children are one of the most vulnerable segments of our society, and in many senses the system in California is not doing well for them,” said David Alexander, a

pediatrician who is president and CEO of the Lucile Packard Foundation for Children's Health, which commissioned the study. "Most of us know a child with a special health care need – they are our friends, families and neighbors. This study makes it clear that we need to develop better ways to ensure that they get the care they need in a timely fashion."

Nearly all children with special health care needs in California experience some limitations in their daily lives. However, about one in four of the 1.4 million special needs children in California experiences difficulties severe enough that they are unable to do things other children their age can do. These children and their families usually have the most difficulty in finding medical and dental care, child care, transportation, educational assistance, medical equipment, consistent health insurance, and a range of other services.

"This is particularly concerning because advances in medical care mean that many children are surviving who previously would not have, and it will become increasingly difficult for our already overburdened system to care for them adequately," Alexander said.

The composite index noted in the study does not evaluate the quality of the medical treatment that individual children receive, which is often excellent, Alexander said. Rather, it assesses adequacy of insurance, access to care, and other measures of how well the system functions, such as whether families are involved in the care. "We must make significant improvements in these areas," he said.

The study, *Children with Special Health Care Needs: A Profile of Key Issues in California*, analyzes the most recently available data from two surveys of parents sponsored in every state by the U.S. Maternal and Child Health Bureau: the 2007 National Survey of Children's Health and the 2006 National Survey of Children with Special Health Care Needs.

"Children with special health care needs in California have exceptionally complex conditions, and there is no question that many families are struggling to meet their basic requirements," said lead study author Christina Bethell, professor in the Department of Pediatrics at Oregon Health and Science University and director of the Child and Adolescent Health Measurement Initiative, where the study was conducted. "One of our significant findings was that nearly one in four of these children has parents who cut back or stopped working due to their child's health. This has a tremendous impact not only on families but also on employers."

The study describes the demographics of California's children with special needs; their physical, mental and social functioning; the impact of the special need on the lives of the children and their families; and the accessibility and quality of health care services and health insurance.

In other key findings:

- Ethnic/racial and economic disparities in California are stark among children with special needs. Children of color and publicly insured children are much more likely to have poorer health status and sub-optimal health care.
- Children with special needs are much more likely to repeat a grade and to miss more days of school than children without special needs.
- In all other states, 23.5 percent of children with special needs ages 0-3 receive early intervention services, but only 12.1 percent in California do so.
- California ranked 45th among states in addressing the transition from pediatric to adult care. Among children whose conditions most affect their daily lives, only 26 percent received assistance in moving to the adult care system, which often is not prepared to meet their medical needs.
- California had the nation’s highest percentage of children whose parents reported stress from parenting their special needs child.

The barriers to creating a higher quality system are longstanding and complex, with no single solution, Alexander said. “All parts of the community that have an interest in special needs children need to come together to advocate for change,” he said.

Ensuring that all children have adequate health insurance, and streamlining the way care is financed are two important steps, he said. Improving physician education about special needs children is key. Advocates and policymakers also need to press for treating children in an environment where their multiple health and social needs can be coordinated, and families can be involved in decision making, Alexander said.

Although California ranks poorly on many indicators, the state is not alone, Alexander said. “Throughout the country, children with special needs receive care in a system that is poorly designed to meet their specific requirements. As health reform is implemented, we must be sure that the needs of this growing population finally are addressed.”

Children with Special Health Care Needs (CSHCN) in California vs. Nation	California Ranking (1=best, 51=worst)
CSHCN whose health care meets a minimum quality index ^{1b}	51
CSHCN whose parents experience stress ^b	51
CSHCN whose parents feel like partners in their child's care ^a	51
CSHCN who receive family-centered care ^a	50
CSHCN who have difficulty accessing community-based services ^a	49
CSHCN who needed a referral and had problems getting one ^a	49
CSHCN who receive effective care coordination ^a	48
CSHCN with inadequate insurance coverage ^b	46
CSHCN who receive needed transition services to adulthood ^a	45

CSHCN who receive coordinated care within a medical home ^a	44
CSHCN who do not have a usual source of sick and well care ^a	44
CSHCN who receive needed mental health care ^b	43
CSHCN who are uninsured ^b	40

Note: Rankings are based on all states and the District of Columbia. National percentages include all states and the District of Columbia without California calculated into the estimate.

¹ Minimum quality index = CSHCN who have a medical home, have adequate health insurance coverage, and had at least one preventive visit in the past 12 months.

Data sources:

^a 2005-06 *National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. www.cshcndata.org

^b 2007 *National Survey of Children's Health*, Data Resource Center for Child and Adolescent Health website. www.nschdata.org

ABOUT THE FOUNDATION: The Lucile Packard Foundation for Children’s Health, a non-profit public charity, works to improve children’s health by bringing public attention to key issues, particularly those related to children with special health care needs.

ABOUT CAHMI: The Child and Adolescent Health Measurement Initiative 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.