



Children with Special Health Care Needs: A Profile of Key Issues in California

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LPFCH CSHCN Report: A unique synthesis of nationally comparable data

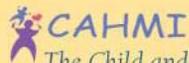


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A Profile of Key Issues in California

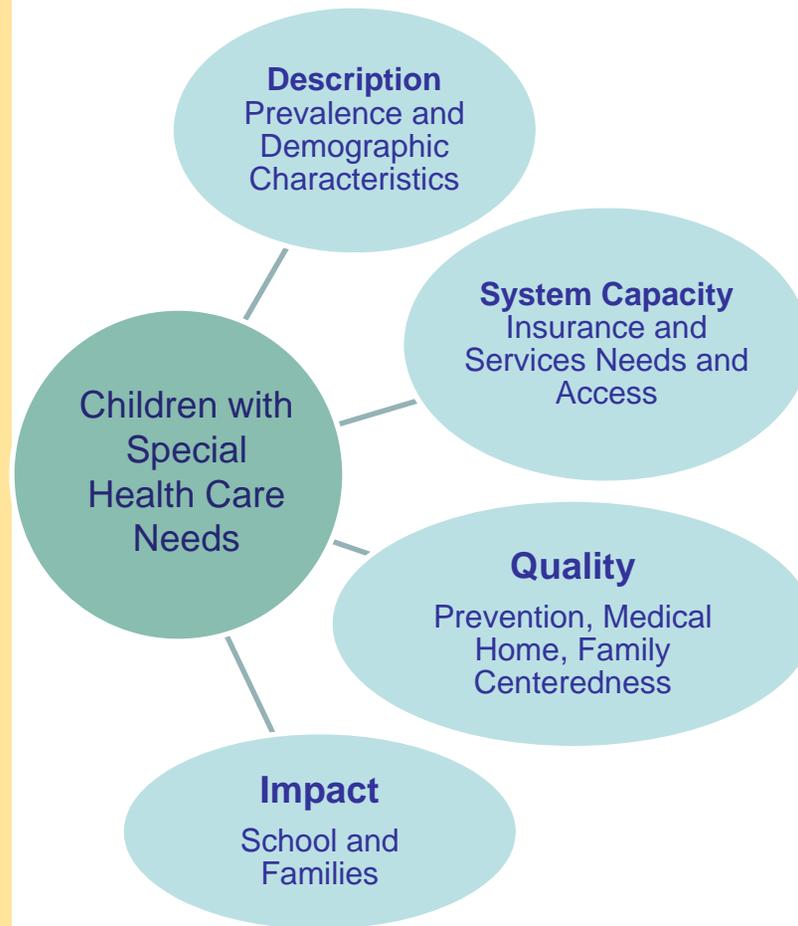


Prepared by



The Child and Adolescent Health Measurement Initiative

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Report Goals

1. Build on existing understanding and commitment to California's CSHCN
2. Offer new insights into improving policy and practice
3. Motivate and inform the formulation of new ideas for how to make a difference in improving system performance and health outcomes for California's children



Data and Methods Highlights

- Most recent national data
- Standardized and accepted measures
- Some analyses limited by sample size
- Methods adjusted for California's unique demography



How Many CSHCN In California

- Approximately 14.5% of all children age 0-17—about 1 in 7 children
- Equals an estimated 1.4 million CSHCN living in California



All of the CSHCN living in California would fill 25,454 school buses and stretch 174 miles



How far would the buses span if they were filled with subgroups of California CSHCN?

- Publicly Insured: 49 miles
- Privately Insured: 111 miles
- Uninsured: 14 miles (CA 40th)
- White: 83 miles
- Non-white: 91 miles



Highlights of CSHCN in California



How far would the buses span if they were filled with subgroups of California CSHCN?

- Asthma: 73 miles
- 2+ of 16 more common conditions: 103 miles
- CSHCN who are also overweight or obese: 68 miles
- Complex needs: 73 miles
- Functional difficulties: 152



In Perspective

573,000 CSHCN in CA have asthma,
which is the equivalent of enough
children to fill 30 Staples Centers!

- 29 for CSHCN with 2+ conditions
- 20 for CSHCN with emotional,
developmental or behavioral health issues
- 17 for ADHD
- 3.35 for Autism/ASD
- 1.88 for Cerebral Palsy
- 1.52 for Epilepsy
- .78 for Diabetes
- .57 for Down Syndrome





Health Insurance

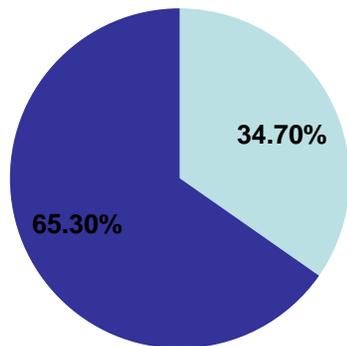
- **Gaps in coverage:** Nearly one in nine CSHCN is currently uninsured or lacked coverage for at least part of the year



Health Insurance

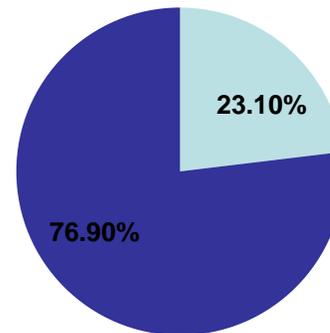
- Even having consistent insurance isn't always enough... **More than 1 in 3 CA CSHCN** has insurance that is inadequate to meet his or her health care needs (46th in nation)

CSHCN



■ Percent of children with inadequate insurance
■ Percent of children with adequate insurance

Non-CSHCN



■ Percent of children with inadequate insurance
■ Percent of children with adequate insurance



Service Use

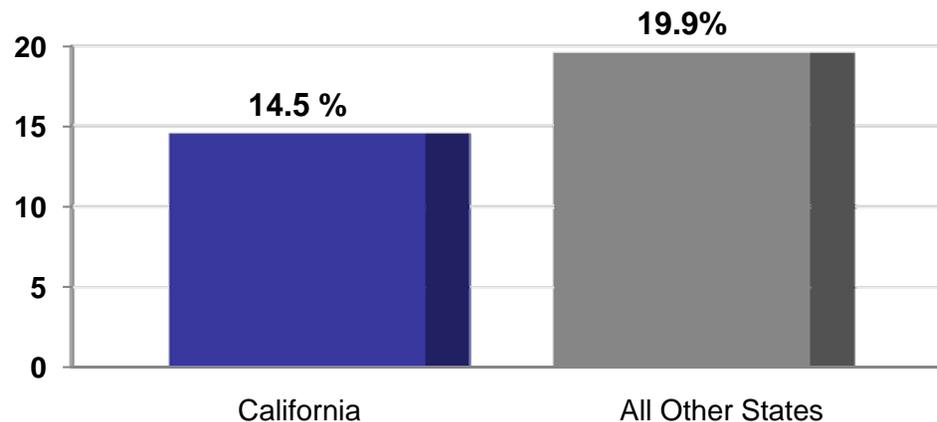
- **High need for service use:** In California, 42 percent of CSHCN need at least five types of health services
 - Most common examples include preventive dental care, prescription medication, routine preventive care, specialist care, etc.
- About **2 in 5** CSHCN in California did not receive needed mental health care



Highlights of National Comparisons

- Lower prevalence, higher complexity, higher diversity than the rest of the nation

**CSHCN as percent of all children
age 0-17**



- Higher rates of Functional Limitations among CSHCN (28.4%)
- Lower prevalence and higher functional limitations consistent with high proportion of Latino children in CA



National Comparison

- California rates in the bottom third of all states on many **Quality of Care** Measures for CSHCN, with several Measures falling in the bottom 8 states
 - Ranked 49th in nation for ease of accessing community based services
 - Ranked 46th in nation for inadequate insurance
 - Ranked 48th in nation for care coordination
 - Ranked 45th in nation for transition to adulthood
 - Ranked 44th in nation for meeting baseline criteria for having a Medical Home
 - Ranked 43rd in receiving needed mental health services

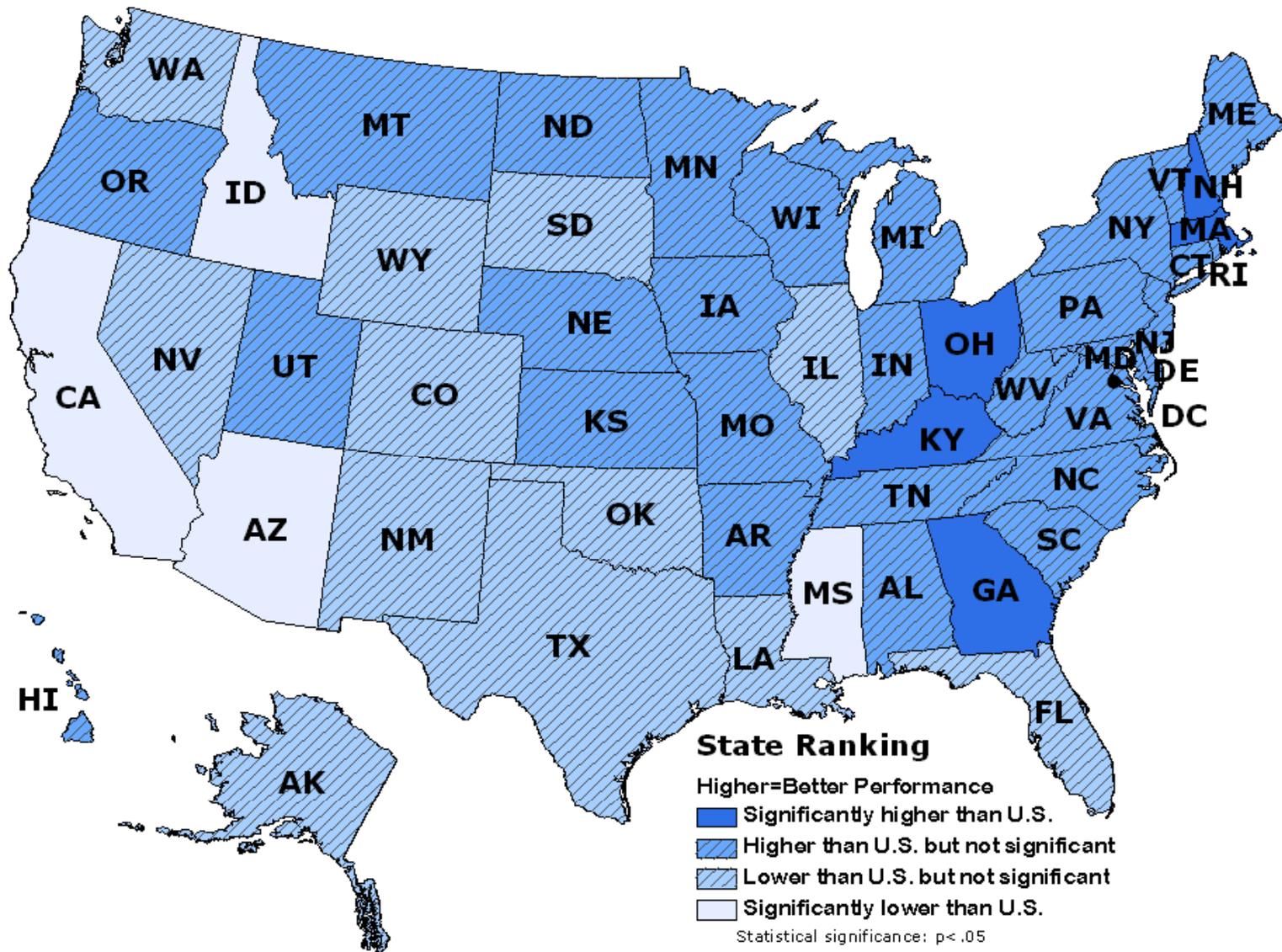


National Comparison

- California rated as the worst or second to worst state in nation among CSHCN for:
 - Quality Index (17% met minimal index for adequate insurance, preventive care visit and medical home)
 - Receiving family-centered care
 - Above average stress among parents of CSHCN
 - Parents who feel engaged in decision-making and like partners in care for their child with special health care needs



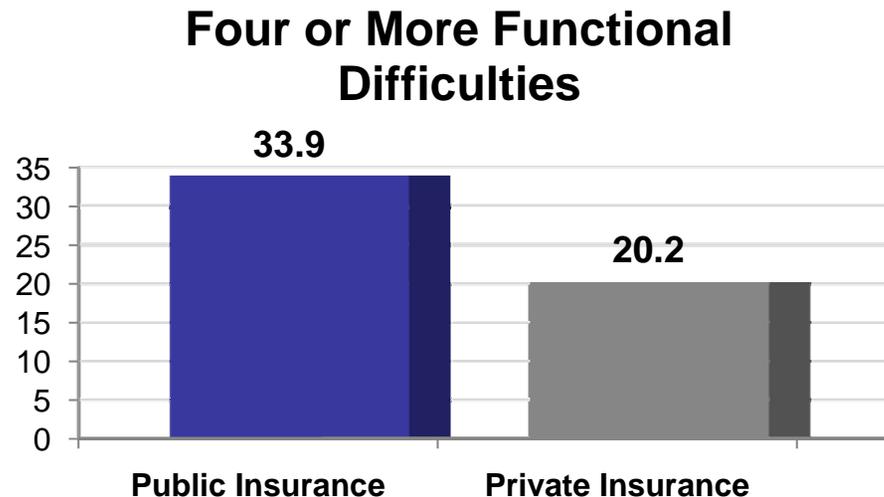
Standardized Measures Allow Comparison: Quality Composite Index among CSHCN in Nation California 17%; All other states 40%





Within State Comparisons Public vs. Private Insurance

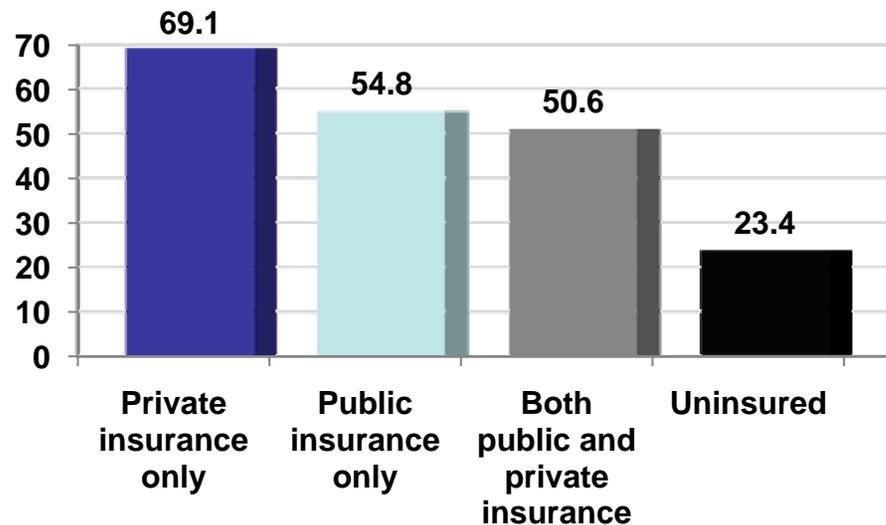
- CA CSHCN with public insurance are **more likely** to experience 4+ functional difficulties





Within-State Comparisons Public vs. Privately Insured CSHCN

- Privately insured CSHCN more likely than publicly insured CSHCN to receive routine preventive medical and dental care visits (69.1% vs. 54.8%)

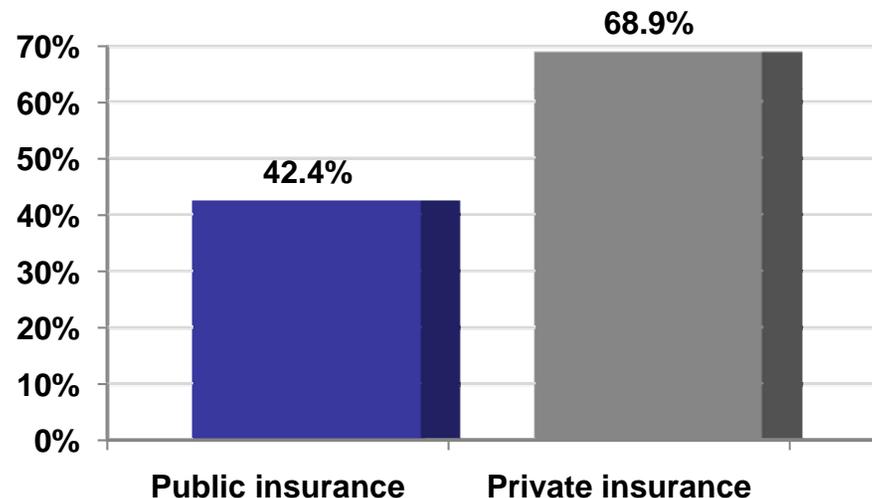


- 94.3% of privately insured and only 87.6% of publicly insured CSHCN in California have a usual source of sick and well care



Public vs. Private Insurance

- Privately insured CSHCN are more likely than publicly insured CSHCN to receive all components of family-centered care

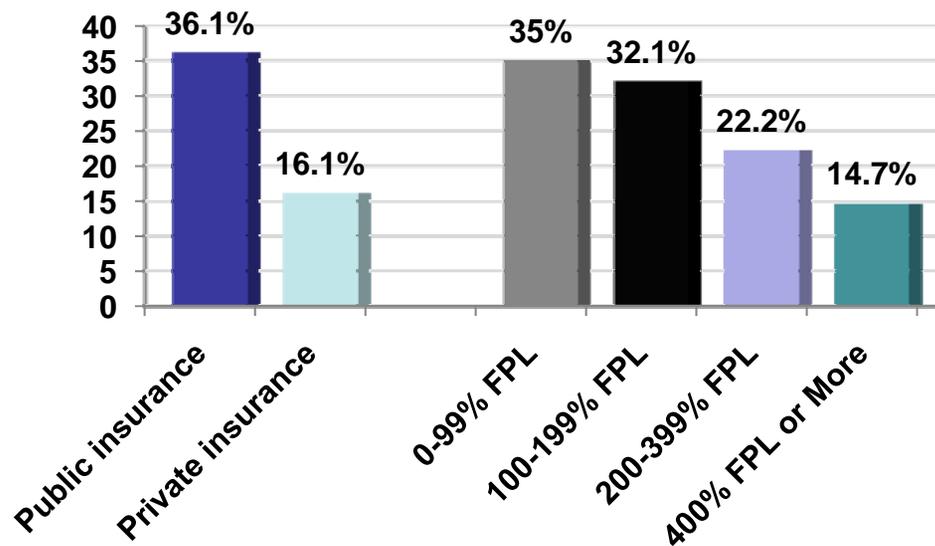


- Additionally, 49.9% of privately insured and only 29.7% of publicly insured CSHCN receive coordinated, ongoing, comprehensive care within a medical home



Public vs. Private Insurance

- More than twice as many CSHCN with public vs. private insurance have parents who had to stop or cut back on work to care for their child (36.1% vs. 16.1%)

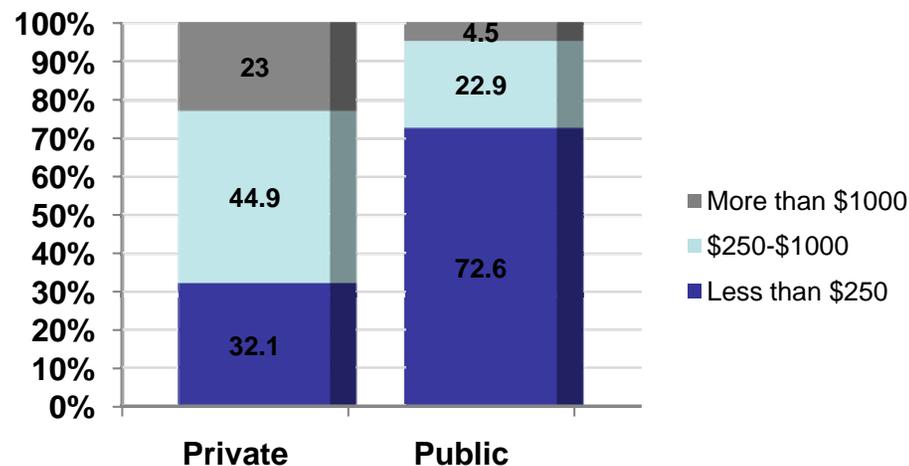


Percentage of California CSHCN Whose Parents Stopped or Cut Back on Work to Care for Their Child, by Income and Type of Insurance



Public vs. Private Insurance

- Parents of CSHCN who have private insurance pay more out-of-pocket expenses than those with public insurance.
 - 23% of those with private insurance vs. 4.5% of those with public insurance pay at least \$1,000 a year out of pocket



Percentage of California CSHCN Families with Each Amount of Annual Out-of-Pocket Expenditures, by Type of Insurance



Impact on School and Readiness for Life and Work

- 15.4% of CA CSHCN Missed 11 or More Days of School in the past year
- 35% have an individualized education plan (IEP)
- 21% CSHCN repeated a grade in school (vs. 7.8 for non-CSHCN)





Impact on Families

- Families spend 3,780,000 hours per week coordinating their child's care, which is equivalent to 94,500 full time employees in CA
- Approximately 330,000 families cut back or stopped working to care for CSHCN—almost 3X the size of Humboldt County





The Good News

- California is in good company with priority areas for improvement
- Even the best performing states have tremendous room for improvement
- Everyone is in the same boat—public and privately insured CSHCN face similar needs, challenges...
- Many efforts underway and the dialogue is far along in California



Systemic Change Needed

- **Upstream**

- Proactive and long term vision
- Scope and flexibility of coverage
- Services integration (real mechanisms to enable on the ground patient, provider and community coordination)
- Integration with public health and primary prevention
- Financing and aligned incentives
- Work force and capacity
- Accountability, transparency and continuous improvement



Systemic Change Needed

- Downstream
 - Infrastructure—facilities, information technology, etc.
 - Family-centered, cross-provider integration—capacity, training, incentives, mechanisms
 - Will, capacity and rewards for improvement
 - Family and community engagement