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

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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
Why?

- **Optimize health and wellbeing of California’s children**

How can we optimize early and life-long health of children, youth and families in California?

What can we learn to inform efforts to leverage, modify or renew the current system of care in California?
Who Are Children With Special Health Care Needs (CSHCN)

“CSHCN are 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”

- **Current CSHCN** — existing condition resulting in above routine need or type of health care and related services (5 item screener)
- **At risk (examples)**
  - diagnosis, but no above routine need or use
  - unclear chronicity, above routine need or use
  - meets criteria for being “at risk” of developmental problems
  - born premature or low birth weight but not yet CSHCN
  - psychosocial risks strongly associated with health (e.g. Adverse Childhood Experiences, etc.)
Who Are Children With Special Health Care Needs (CSHCN)

Why No Current CSHCN – existing condition resulting in above routine need or type of health care and related services (5 item screener)

Define by Diagnoses?

- Common DX errors, misses and miscoding
- Significant within DX variation in needs
- Significant across DX similarities
- Multiple conditions is the norm
- Needs naturally vary across time within any DX
- Supposedly “non-serious” DX can be very serious depending on co-morbidities and psychosocial context
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
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 miles

=174 miles
Overall Prevalence and Variation by Race/Ethnicity

Data Source: 2011/12 National Survey of Children’s Health

NATIONWIDE

% CSHCN

Children 0-17 years

19.8

80.2

CALIFORNIA (1.4 Million)

% CSHCN

Children age 0-17 years

15.0

85.0

Prevalence of CSHCN by Race/Ethnicity in California

Overall

Hispanic

White, NH

Black, NH

Other, NH

10.6

13.2

18.3

31.9

10.6

Data Source: 2011/12 National Survey of Children’s Health
Demographic Characteristics of California’s CSHCN

<table>
<thead>
<tr>
<th></th>
<th>Non-CSHCN</th>
<th>CSHCN</th>
<th>CSHCN with Complex Health Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-5 years</td>
<td>36.2%</td>
<td>18.8%</td>
<td>18.1%</td>
</tr>
<tr>
<td>6-11 years</td>
<td>32.0%</td>
<td>38.0%</td>
<td>38.8%</td>
</tr>
<tr>
<td>12-17 years</td>
<td>31.8%</td>
<td>43.2%</td>
<td>43.1%</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>49.4%</td>
<td>58.1%</td>
<td>60.4%</td>
</tr>
<tr>
<td>Female</td>
<td>50.6%</td>
<td>41.9%</td>
<td>39.6%</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>25.2%</td>
<td>17.4%</td>
<td>18.9%</td>
</tr>
<tr>
<td>White, NH</td>
<td>51.5%</td>
<td>56.8%</td>
<td>55.9%</td>
</tr>
<tr>
<td>Black, NH</td>
<td>12.8%</td>
<td>16.4%</td>
<td>16.0%</td>
</tr>
<tr>
<td>Other, NH</td>
<td>10.5%</td>
<td>9.3%</td>
<td>9.2%</td>
</tr>
<tr>
<td><strong>Household Income Level</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-99% FPL</td>
<td>22.2%</td>
<td>23.6%</td>
<td>27.5%</td>
</tr>
<tr>
<td>100-199% FPL</td>
<td>21.5%</td>
<td>21.6%</td>
<td>22.4%</td>
</tr>
<tr>
<td>200-399% FPL</td>
<td>28.3%</td>
<td>27.9%</td>
<td>26.7%</td>
</tr>
<tr>
<td>400% or more</td>
<td>28.0%</td>
<td>26.9%</td>
<td>23.4%</td>
</tr>
</tbody>
</table>

DATA SOURCE: 2011/12 National Survey of Children’s Health
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)**

<table>
<thead>
<tr>
<th></th>
<th>CSHCN</th>
<th>Non-CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent of children with inadequate insurance</td>
<td>34.70%</td>
<td>23.10%</td>
</tr>
<tr>
<td>Percent of children with adequate insurance</td>
<td>65.30%</td>
<td>76.90%</td>
</tr>
</tbody>
</table>
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

![Graph showing 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 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

Appendix 18
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Health Care Quality Summary Measure (All Children)

DATA SOURCE: 2011/12 National Survey of Children’s Health

Nationwide: 39.0%

California: 31.7%
(Ranks Lower 5)

Health Care Quality:
• Adequate Health Insurance
• Preventive Medical Visit in Past Year
• Has a Medical Home

Statistical significance: p<.05
Within State Comparisons
Public vs. Private Insurance

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

Four or More Functional Difficulties

<table>
<thead>
<tr>
<th></th>
<th>Public Insurance</th>
<th>Private Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>33.9</td>
<td></td>
<td>20.2</td>
</tr>
</tbody>
</table>
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

Appendix 18
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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
Prevalence and Medical Expenditures for CSHCN: By Complexity

Prevalence Data: 2011/12 National Survey of Children’s Health; Expenditures Data: 2008 MEPS

(For reference: Non-CSHCN average expenditures: $856).

Prevalence Data: 2011/12 National Survey of Children’s Health; Expenditures Data: 2008 MEPS
Expanding Our Reach: Importance of a Broad View

<table>
<thead>
<tr>
<th><strong>Children with Current Chronic Conditions and Special Health Care Needs (CSHC)</strong></th>
<th>Nation</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>19.8%</td>
<td>15.0%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Non-CSHCN Who May Be At Risk for Special Health Care Needs</strong></th>
<th>Nation</th>
<th>California</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Conditions (1+ of 18 conditions assessed) -but not CSHCN</td>
<td>8.1%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Met 1+ CSHCN Consequences (but not condition/duration CSHC criteria)</td>
<td>10.3%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Risk of Developmental Delay: Moderate or Severe (PEDS) (&lt; age 6)</td>
<td>20.2%</td>
<td>20.2%</td>
</tr>
<tr>
<td>Adverse Child and Family Experiences (2+ of 9 assessed)</td>
<td>15.5%</td>
<td>15.5%</td>
</tr>
<tr>
<td>Born Premature</td>
<td>8.1%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Overweight/Obese: (age 10-17)</td>
<td>22.3%</td>
<td>23.3%</td>
</tr>
<tr>
<td>Non-CSHCN: 1+ risk factors</td>
<td>39.0%</td>
<td>39.7%</td>
</tr>
<tr>
<td><strong>CSHCN + Non-CSHCN With 1+ Risk Factors</strong></td>
<td>58.8%</td>
<td>54.7%</td>
</tr>
</tbody>
</table>

*Number of conditions is based upon the list of 18 conditions included in the 2011/12 National Survey of Children’s Health, including ADD/ADHD, anxiety problems, asthma, autism/ASD, behavioral problems, brain injury or concussion, depression, developmental delay, diabetes, hearing problems, intellectual disability, bone/joint/muscle problems, learning disability, epilepsy or seizure disorder, Tourette Syndrome, vision problems.
**Almost half of children (47.9%) nationally have 1 or more Adverse Child/Family Experiences, with 44.3% of children in California.
Nine Adverse Child/Family Experiences were included in the survey: (1) socioeconomic hardship, (2) divorce/separation of parent, (3) death of parent, (4) parent served time in jail, (5) witness to domestic violence, (6) victim of neighborhood violence, (7) lived with someone who was mentally ill or suicidal, (8) lived with someone with alcohol/drug problem, (9) treated or judged unfairly due to race/ethnicity.*
### Positive and Protective Health Indicators: By CSHCN Status

<table>
<thead>
<tr>
<th>Indicator</th>
<th>California Non-CSHCN</th>
<th>California CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protective Home Environment (no smoking in home; share meals; limit TV...)</td>
<td>28.7%</td>
<td>19.5%</td>
</tr>
<tr>
<td>Neighborhood Safety &amp; Support</td>
<td>56.8%</td>
<td>53.9%</td>
</tr>
<tr>
<td>Factors that Promote School Success</td>
<td>63.3%</td>
<td>53.0%</td>
</tr>
<tr>
<td>Resilience: Age 10 months-5 years</td>
<td>81.5%</td>
<td>63.0%</td>
</tr>
<tr>
<td>Resilience: Age 6-17 years</td>
<td>68.0%</td>
<td>62.7%</td>
</tr>
<tr>
<td>Met All Flourishing Components: (6-17)</td>
<td>51.7%</td>
<td>43.2%</td>
</tr>
<tr>
<td>11+ Missed School Days (6-17)</td>
<td>3.0%</td>
<td>20.8%</td>
</tr>
<tr>
<td>High Levels of Parenting Aggravation w/Child</td>
<td>12.0%</td>
<td>27.8%</td>
</tr>
</tbody>
</table>

DATA SOURCE: 2011/12 National Survey of Children’s Health
Health of the Family: Parental Health

Parental Overall Health Status (Physical & Mental/Emotional) by CSHCN Status

CSHCN with More Complex Needs are noted with dark blue dotted line.

DATA SOURCE: 2011/12 National Survey of Children’s Health

<table>
<thead>
<tr>
<th>Health Status</th>
<th>Non-CSHCN</th>
<th>CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother's Overall Health is Excellent/Very Good</td>
<td>55.3%</td>
<td>49.0%</td>
</tr>
<tr>
<td>Father's Overall Health is Excellent/Very Good</td>
<td>59.5%</td>
<td>57.9%</td>
</tr>
</tbody>
</table>

California
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
Prevalence of Meeting Minimum Quality Index Among Children in California, by CSHCN Status

- All Children: 31.7%
- Non-CSHCN: 32.6%
- CSHCN: 26.4%

Data Source: 2011/12 National Survey of Children’s Health

Prevalence of Meeting Minimum Quality Index Among CSHCN in California, by Insurance Type

- CSHCN with Private Insurance: 34.2%
- CSHCN with Public Insurance: 18.2%

Data Source: 2011/12 National Survey of Children’s Health
Developmental screening refers to a child (age 10 months-5 years) being screened for being at risk for developmental, behavioral and social delays using a parent-reported standardized screening tool during a health care visit.

DATA SOURCE: 2011/12 National Survey of Children’s Health
Consistent and Adequate Health Insurance

COMPONENTS OF CONSISTENT AND ADEQUATE HEALTH INSURANCE

1. CSHCN who are currently insured  
   - Nationwide: 60.6%  
   - Texas: 57.9%  
   - California: 59.1%

2. CSHCN who have consistently had insurance for past year
   - 91.7%

3. CSHCN with adequate health insurance
   - 62.8%

3a. CSHCN’s health insurance offer benefits or cover services that meet his/her needs
   - 83.0%

3b. CSHCN’s health insurance allow him/her to see the health care providers he/she needs
   - 86.4%

3c. CSHCN’s health insurance premiums or costs reasonable
   - 71.2%

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs
The American Academy of Pediatrics' (AAP) description of a "medical home" lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.
The American Academy of Pediatrics' (AAP) description of a "medical home" lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective.
Receipt of Effective Care Coordination when Needed, California and Nation, by Complexity of Health Needs and Insurance Type

<table>
<thead>
<tr>
<th>CSHCN Receiving Care Coordination</th>
<th>More Complex CSHCN</th>
<th>Less Complex CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>% CSHCN 2+ services (qualify for CC items)</td>
<td>83.7%</td>
<td>59.5%</td>
</tr>
<tr>
<td>% 2+ getting any CC help</td>
<td>22.2%</td>
<td>19.5%</td>
</tr>
<tr>
<td>% very satisfied with doctor-doctor communication</td>
<td>44.8%</td>
<td>33.1%</td>
</tr>
<tr>
<td>% very satisfied with doctor-school communication</td>
<td>52.8%</td>
<td>21.8%</td>
</tr>
<tr>
<td><strong>Summary Measure: % who received effective care coordination, when needed</strong></td>
<td>45.8%</td>
<td>70.1%</td>
</tr>
</tbody>
</table>

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs
CSHCN whose families are partners in shared decision-making: California ranks last (51\textsuperscript{st}) in the nation

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence -- CSHCN age 12-17 years only

**Components of Youth Transition in California:**

**Anticipatory Guidance:** Over half of adolescents (58.4%) did not get all needed anticipatory guidance
- Discuss shift to adult health care providers
- Discuss changing health needs as youth becomes an adult
- Discuss health insurance as youth becomes an adult

**Self-Management Skills:** Almost ¾ of adolescents have doctors who encourage self management skills (73.7%)
- Older youth are more likely to be encouraged (12-14: 65.4%; 15-17: 81.2%)

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs
**CSHCN whose conditions cause family members to cut back or stop working**

- California ranks last (51st) in the nation

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**Prevalence of CSHCN whose conditions cause family members to cut back and/or stop working in CALIFORNIA, by Household Income and Complexity of Health Needs**

<table>
<thead>
<tr>
<th>Household Income Level</th>
<th>Less Complex Health Needs</th>
<th>More Complex Health Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-99% FPL</td>
<td>29.4%</td>
<td>45.6%</td>
</tr>
<tr>
<td>100-199% FPL</td>
<td>37.7%</td>
<td></td>
</tr>
<tr>
<td>200-399% FPL</td>
<td>28.3%</td>
<td></td>
</tr>
<tr>
<td>400% FPL or more</td>
<td>19.4%</td>
<td>7.4%</td>
</tr>
<tr>
<td>California Overall</td>
<td></td>
<td>41.4%</td>
</tr>
</tbody>
</table>

FPL refers to Federal Poverty Level, as defined by the Federal Register issued by the Department of Health and Human Services.

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs

Appendix 18
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CSHCN whose family member(s) avoided changing jobs in order to maintain health insurance for child

California ranks 46th in the nation on this measure

DATA SOURCE: 2009/10 National Survey of Children with Special Health Care Needs
Comparing Prevalence and Utilization of Children who Qualify on CSHCN Screener, compared to Affordable Care Act (ACA) Medical Home Section 2703 Condition List*. Average total healthcare expenditures and average number of office-based healthcare visits in past year.

Data Source: 2008 Medical Expenditures Panel Survey (2008 MEPS)

*ACA Medical Home Section 2703 outlined diagnosis-based criteria for eligibility. This included having (1) One serious mental illness, and/or (2) Two conditions on the list (asthma, diabetes, heart disease, and being overweight). HIV/AIDS is optional upon CMS approval at state-level. (Public Law 111-148, Section 2703. March 23, 2010. Available at http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf)
The Importance of Selecting Incentives Carefully: Medical Home

*ACA Medical Home Section 2703 outlined diagnosis-based criteria for eligibility. This included having (1) One serious mental illness, and/or (2) Two conditions on the list (asthma, diabetes, heart disease, and being overweight). HIV/AIDS is optional upon CMS approval at state-level. (Public Law 111-148, Section 2703. March 23, 2010. Available at http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf)
If you have any questions, feel free to contact us:

The Child and Adolescent Health Measurement Initiative

www.cahmi.org
Email: cahmi@ohsu.edu

For more data on Children with Special Health Care Needs, visit:

National Data Resource Center (DRC) for Child and Adolescent Health

www.childhealthdata.org
Like us on Facebook:
Follow us on Twitter: @childhealthdata
California Children’s Services offers assistance to children who have a health problem covered by CCS (and meet additional criteria related to household income):

- Infectious Diseases
- Neoplasms
- Endocrine, Nutritional, and Metabolic Diseases, and Immune Disorders
- Diseases of Blood and Blood-Forming Organs
- Mental Disorders and Mental Retardation
- Diseases of the Nervous System
- Diseases of the Eye
- Diseases of the Ear and Mastoid
- Diseases of the Circulatory System
- Diseases of the Respiratory System
- Diseases of the Digestive System
- Diseases of the Genitourinary System
- Diseases of the Skin and Subcutaneous Tissues
- Diseases of the Musculoskeletal System and Connective Tissue
- Congenital Anomalies
- Perinatal Morbidity and Mortality
- Accidents, Poisonings, Violence, and Immunization Reactions

It is important to consider whether the diagnostic-based approach is capturing the children that could benefit most from services.

- Capturing children with less complex health care needs
- Missing children with more complex health needs without the specific diagnoses