SLAITS: The State and Local Area Integrated Telephone Survey

- Developed and conducted by CDC/NCHS
- Makes use of the sampling frame of the National Immunization Survey
- Surveys conducted using SLAITS mechanism
  - National Survey of CSHCN
  - National Survey of Children’s Health
  - National Survey of Early Childhood Health
  - Survey of Adult Transition and Health
  - National Survey of Adoptive Parents
  - National Asthma Survey
NS-CSHCN Sponsor

- Has primary responsibility for promoting and improving the health of U.S. women, children and families.
- Provides leadership to improve the physical and mental health, safety and well-being of the MCH population
- Administers block grants to state MCH agencies
The US federal government budgets more than $1 billion annually for MCH services.

In order to be entitled to Title V payments, states must use at least 30 percent of such payment amounts for services for children with special health care needs (CSHCN).

Why CSHCN?
- CSHCN account for 42% of total medical care costs (excluding dental costs).
## Indicators of Problems with Health Care and School

<table>
<thead>
<tr>
<th>Indicator</th>
<th>CSHCN</th>
<th>Non-CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fair or poor health status (parent report)</td>
<td>11.0%</td>
<td>1.7%</td>
</tr>
<tr>
<td>Miss 11+ school days due to illness, past year</td>
<td>13.5%</td>
<td>3.5%</td>
</tr>
<tr>
<td>3+ doctor visits for sick care, past year</td>
<td>43.4%</td>
<td>19.9%</td>
</tr>
<tr>
<td>2+ emergency dept visits, past year</td>
<td>13.1%</td>
<td>4.1%</td>
</tr>
<tr>
<td>Does not have a medical home</td>
<td>50.2%</td>
<td>40.6%</td>
</tr>
<tr>
<td>Problems accessing specialty care (among children needing such care)</td>
<td>27.0%</td>
<td>21.2%</td>
</tr>
<tr>
<td>4+ calls home from school due to problems</td>
<td>20.5%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Has repeated one or more grades</td>
<td>18.5%</td>
<td>8.2%</td>
</tr>
</tbody>
</table>

Data Source: NSCH, 2003 and 2007
### Indicators Related to Social Behaviors, Activities, and Family

<table>
<thead>
<tr>
<th></th>
<th>CSHCN</th>
<th>Non-CSHCN</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age 6-17:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has problematic social behaviors</td>
<td>17.9%</td>
<td>6.2%</td>
</tr>
<tr>
<td>Lacks consistent positive social skills</td>
<td>12.3%</td>
<td>4.6%</td>
</tr>
<tr>
<td>No vigorous physical activity</td>
<td>13.2%</td>
<td>9.5%</td>
</tr>
<tr>
<td>Does not get adequate sleep daily</td>
<td>41.1%</td>
<td>34.1%</td>
</tr>
<tr>
<td><strong>All ages:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother’s health less than very good</td>
<td>52.2%</td>
<td>41.0%</td>
</tr>
<tr>
<td>Father’s health less than very good</td>
<td>41.8%</td>
<td>36.3%</td>
</tr>
<tr>
<td>Does not share ideas or talk to parents about things that matter</td>
<td>37.4%</td>
<td>28.1%</td>
</tr>
<tr>
<td>Parents usually/always stressed</td>
<td>20.0%</td>
<td>7.9%</td>
</tr>
</tbody>
</table>

Data Source: NSCH, 2007
Purpose of the NS-CSHCN

- Measures and tracks prevalence of CSHCN
  - Nationally and by state
- Describes demographic characteristics
- Describes impact of special health care needs
  - Functional limitations
  - Health care access
  - Needs and satisfaction with care
  - Burden and impact on family
Uses of the NS-CSHCN Data

- Title V performance measures
- Measuring Healthy People objectives
- Planning and program development at the state level
- Inform organizations that work directly with CSHCN
- Scientific research
Definition of “Children with Special Health Care Needs”

- “Children with special health care needs 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.” (McPherson, Arango, Fox, et al., 1998)
Defining Special Health Care Needs

Special Health Needs Continuum

GROUP A
- No special health care needs
- At risk for developing a special health care need

GROUP B
- On going health conditions; above average service use needs; few to moderate functional limitations

GROUP C
- On going health conditions; high or complex service use needs; moderate to severe functional limitations

MOST INCLUSIVE DEFINITIONS
- Include “at risk” groups
  \( A + B + C \)

BROADER DEFINITIONS
- Include those with wider array of conditions, levels of severity and service use needs
  \( B + C \)

NARROWER DEFINITIONS
- Include only those with very severe conditions or highly complex needs
  \( C \) only

Inclusion of Groups:

\[ A + B + C \]
What is the CSHCN Screener?

- A non-condition-specific, consequences-based method for identifying CSHCN, targeting Categories B and C
- Designed in 1998-2000 by the Child and Adolescent Health Measurement Initiative (now at OHSU)
- Developed through a national process involving physicians, state leaders, families, methods experts, and policymakers
- Tested with parents of 36,000+ children during development phase
- Several versions tested, leading to final version, which takes 1 minute for parents to complete
- NCHS has collected Screener data for more than 1 million children since 2000
The CSHCN Screener

- Asks about five “common” consequences
  1. Limitation of activities
  2. Need for or use of prescription medication
  3. Need for or use of specialized therapies
  4. Above routine need or use of medical, mental health, or education services
  5. Need for or receipt of treatment or counseling for an emotional, behavioral, or developmental problem

(Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002)
The CSHCN Screener

- **Two follow-up questions**
  1. Is this due to a medical, behavioral, or other health condition?
  2. Is this a condition that has lasted or is expected to last 12 months or longer?

(Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002)
Key Features of CSHCN Screener

- Based on parent report
  - Most amenable to uniform data collection

- Short (1 minute to complete)
  - Costs per item are usually high in government surveys
  - Longer surveys threaten participation rates

- Based on consequences rather than conditions
  - Condition checklists tend to be very long
  - Condition checklists are hard to analyze and interpret
  - Focus on consequences helps capture children with conditions not yet diagnosed or poorly recalled
“Triangulate” to Validate

- **SURVEY PARENTS**
  - Ask about specific health services children need or use
  - Ask about child health status & impact of any health problems

- **SURVEY PARENTS**
  - Ask to name any specific diagnoses or health conditions children have

- **MEDICAL RECORDS**
  - Examine encounter & claims data for diagnoses listed in children’s records

- **CLINICAL EVALUATION**
  - Review of children’s medical charts by pediatric clinicians

- **COMPARE to:**
  - CYSHCN identified by other methods or definitions such as program eligibility
  - Children not identified

Group id’d by CSHCN Screener
Who is Identified by the Screener?

- All or nearly all children with complex health conditions such as:
  - Cerebral palsy; cystic fibrosis; muscular dystrophy
  - Rare metabolic or genetic disorders
  - Mental retardation; developmental delay; autism
  - Sickle cell anemia; Down Syndrome; diabetes

- Only those children whose asthma, ADHD, allergies, or other conditions result in:
  - Elevated service use,
  - Long-term use of prescription medicine, or
  - Limitations in functioning
Who is Missed by the Screener?

- The CSHCN Screener is likely to miss children who have only:
  - Food or environmental allergies
  - Special diet (e.g., lactose intolerance)
  - Vision problems (e.g., amblyopia, colorblindness)
  - Developmental delays early in life

- Some parents of children with speech problems, learning disabilities, developmental delay, and conduct problems report consequences but then say they are not due to “health conditions”
The CSHCN Screener is Not a Measure of Child Disability

- Reliably identifies children requiring ongoing medical and other health-related services
  - Broadly inclusive of children with health care consequences due to ongoing conditions
  - Over 98% of identified CSHCN had some type of functional difficulty, as defined by the International Classification of Functioning (ICF)
The CSHCN Screener is Not a Measure of Child Disability

- Does ask whether child has functional limitations

  *Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?*

  - 99% of children with functional limitations also qualify as CSHCN based on other CSHCN Screener criteria
  - Including functional limitations in the Screener permits stratification of children into meaningful subgroups related to condition complexity (Bramlett et al., 2009)
Survey-Based Uses of the CSHCN Screener in the U.S.

- National Survey of CSHCN (NS-CSHCN)
- National Survey of Children’s Health (NSCH)
- Medical Expenditure Panel Survey (MEPS)
- Consumer Assessment of Health Plans Survey (CAHPS)
Random-digit-dial telephone survey with independent random samples for all 50 states plus D.C.

Screened households for children under 18 years of age

Screened all children in household to identify children with special health care needs using the CSHCN Screener
NS-C SHCN 2009-2010: Locating and Identifying CSHCN

- Sample of landline numbers was supplemented with an independent random-digit-dial sample of cell-phone numbers
- Households contacted by cell phone were eligible if:
  - Households do not have a landline telephone, or
  - Respondents said they were unlikely to be reached through the landline if they had one
NS-CSHCN 2009-2010: Interview Process

- Detailed questionnaire for CSHCN
- One CSHCN randomly selected from households with multiple CSHCN
- Target was 750 CSHCN per state
- Calling and screening of households continued until we met the target in all states
- Data were collected from July 7, 2009 until March 2, 2011
NS-CﺸH�试 2009-2010: Interview Process

- Respondent was a parent or guardian knowledgeable about the health of the child
  - 75% mother, 17% father, 6% grandparent
- Interview lasted about 33 minutes (mean)
- Interviews conducted in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean
- Monetary incentives were offered when households with age-eligible children had not completed screener or interview
NS-C SHCN 2009-2010:
Sample Size

- 372,698 children screened for special health care needs
  - Minimum: 5,911 in Kentucky
  - Maximum: 10,290 in California

- 40,242 completed interviews for CSHCN
  - Minimum: 751 in District of Columbia
  - Maximum: 878 in Texas
  - Includes 2,991 interviews with cell-phone sample
NS-CSHCN Questionnaire

- Health and functional status
- Chronic conditions and functional difficulties
- Access to care, utilization, unmet need
- Medical home
- Satisfaction with care
- Health insurance and adequacy
- Transition to adulthood
- Impact on the family
Speech and Language Content

- Compared to other children the same age, would you say [he/she] experiences a lot, a little, or no difficulty speaking, communicating, or being understood?
- During the past 12 months, was there any time when [child] needed:
  - Physical, occupational, or speech therapy?
  - Hearing aids or hearing care?
  - Communication aids or devices, such as communication boards?
- Did [child] receive all the ____ [he/she] needed?
### Speech and Language Subgroups for Analysis

<table>
<thead>
<tr>
<th>Subgroups</th>
<th>Prevalence among all CSHCN age 1-17</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN age 1-17 with <strong>any</strong> speech/language difficulty</td>
<td>32.9%</td>
</tr>
<tr>
<td>CSHCN age 1-17 with <strong>a lot of</strong> speech/language difficulty</td>
<td>12.3%</td>
</tr>
<tr>
<td><strong>Poor</strong> CSHCN age 1-17 with <strong>a lot of</strong> speech/language difficulty</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
# Demographic Distributions

<table>
<thead>
<tr>
<th></th>
<th>All CSHCN</th>
<th>Any difficulty</th>
<th>A lot of difficulty</th>
<th>Poor and a lot of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5 years</td>
<td>19.7</td>
<td>25.5</td>
<td>33.6</td>
<td>36.8</td>
</tr>
<tr>
<td>6-11 years</td>
<td>39.2</td>
<td>40.1</td>
<td>36.7</td>
<td>34.4</td>
</tr>
<tr>
<td>12-17 years</td>
<td>41.1</td>
<td>34.4</td>
<td>29.7</td>
<td>28.8</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>59.4</td>
<td>66.9</td>
<td>67.3</td>
<td>61.6</td>
</tr>
<tr>
<td>Female</td>
<td>40.6</td>
<td>33.1</td>
<td>32.7</td>
<td>38.4</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
Demographic Distributions

<table>
<thead>
<tr>
<th></th>
<th>All CSHCN</th>
<th>Any difficulty</th>
<th>A lot of difficulty</th>
<th>Poor and a lot of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>16.8</td>
<td>20.4</td>
<td>23.6</td>
<td>30.7</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>59.3</td>
<td>53.5</td>
<td>50.4</td>
<td>34.2</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>16.1</td>
<td>17.1</td>
<td>16.0</td>
<td>26.8</td>
</tr>
<tr>
<td>Other, non-Hispanic</td>
<td>7.8</td>
<td>8.9</td>
<td>9.9</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>Poverty status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 100% FPL</td>
<td>22.2</td>
<td>30.8</td>
<td>33.4</td>
<td>100.0</td>
</tr>
<tr>
<td>100-199%</td>
<td>21.8</td>
<td>24.0</td>
<td>23.0</td>
<td>-</td>
</tr>
<tr>
<td>200-399%</td>
<td>28.5</td>
<td>25.7</td>
<td>25.3</td>
<td>-</td>
</tr>
<tr>
<td>400% or above</td>
<td>27.5</td>
<td>19.5</td>
<td>18.3</td>
<td>-</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
## Health Care Needs

<table>
<thead>
<tr>
<th>Need for Services</th>
<th>All CSHCN</th>
<th>Any difficulty</th>
<th>A lot of difficulty</th>
<th>Poor and a lot of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>PT/OT/speech therapy</td>
<td>26.5</td>
<td>57.4</td>
<td>77.4</td>
<td>70.5</td>
</tr>
<tr>
<td>Hearing aids/care</td>
<td>5.1</td>
<td>9.9</td>
<td>14.3</td>
<td>14.5</td>
</tr>
<tr>
<td>Communication aids</td>
<td>2.5</td>
<td>6.7</td>
<td>14.2</td>
<td>11.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unmet Needs</th>
<th>Any of 14 services</th>
<th>PT/OT/speech therapy</th>
<th>Hearing aids/care</th>
<th>Communication aids</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>23.7</td>
<td>4.7</td>
<td>0.5</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td>35.2</td>
<td>11.7</td>
<td>1.2</td>
<td>1.6</td>
</tr>
<tr>
<td></td>
<td>40.8</td>
<td>18.0</td>
<td>1.6</td>
<td>3.4</td>
</tr>
<tr>
<td></td>
<td>40.0</td>
<td>13.8</td>
<td>2.2</td>
<td>3.8</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
# Health Care Quality

<table>
<thead>
<tr>
<th>Quality indicators</th>
<th>All CSHCN</th>
<th>Any difficulty</th>
<th>A lot of difficulty</th>
<th>Poor and a lot of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty getting referral, among those needing one</td>
<td>23.7</td>
<td>29.0</td>
<td>33.5</td>
<td>39.7</td>
</tr>
<tr>
<td>No usual place of care</td>
<td>9.4</td>
<td>10.6</td>
<td>11.3</td>
<td>16.1</td>
</tr>
<tr>
<td>No personal doctor/nurse</td>
<td>6.9</td>
<td>7.8</td>
<td>8.2</td>
<td>12.1</td>
</tr>
<tr>
<td>Care not family centered</td>
<td>35.5</td>
<td>47.4</td>
<td>51.1</td>
<td>55.2</td>
</tr>
<tr>
<td>Care coordination not effective, among those needing coordination</td>
<td>44.1</td>
<td>44.5</td>
<td>40.6</td>
<td>43.7</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
## Health Care System Performance

<table>
<thead>
<tr>
<th>Performance measures</th>
<th>All CSHCN</th>
<th>Any difficulty</th>
<th>A lot of difficulty</th>
<th>Poor and a lot of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Receives coordinated, ongoing, comprehensive care within a medical home</td>
<td>42.8</td>
<td>28.2</td>
<td>23.3</td>
<td>22.2</td>
</tr>
<tr>
<td>• Can easily access community-based services</td>
<td>65.0</td>
<td>51.7</td>
<td>45.6</td>
<td>49.0</td>
</tr>
</tbody>
</table>

Data Source: NS-CSHCN, 2009-2010
For Data Files and More Information

- The NS-CSHCN home page is located at http://www.cdc.gov/nchs/slaits/cshcn.htm
  - Data files
  - Questionnaire
  - Codebooks
  - Sample SAS programs
  - Instructions for formatting SAS data files

- Please read the “Frequently Asked Questions” online before analyzing data

- Includes important information about sampling weights, estimating variance, and using the cell-phone sample
Challenges and Limitations

- Growing prevalence of cell-only households
- Declining response rates
- Expanding data needs
- Need for more frequent estimates
Percent of Children in Wireless-Only Households

Figure. Percentages of adults and children living in households with only wireless telephone service: United States, 2003–2014

<table>
<thead>
<tr>
<th>Year</th>
<th>Adults with wireless service only</th>
<th>Children with wireless service only</th>
</tr>
</thead>
<tbody>
<tr>
<td>2003</td>
<td>52.1</td>
<td>43.1</td>
</tr>
</tbody>
</table>

NOTE: Adults are aged 18 and over; children are under age 18.
DATA SOURCE: CDC/NCCHS, National Health Interview Survey.
## NS-CSHCN 2009-2010 Outcome Rates

<table>
<thead>
<tr>
<th>Outcome Rate</th>
<th>Landline Sample</th>
<th>Cell-Phone Sample</th>
<th>Combined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolution Rate</td>
<td>81.2%</td>
<td>46.6%</td>
<td>61.4%</td>
</tr>
<tr>
<td>Age Screener Completion Rate</td>
<td>88.7%</td>
<td>75.4%</td>
<td>80.1%</td>
</tr>
<tr>
<td>CSHCN Screener Completion Rate</td>
<td>72.6%</td>
<td>56.5%</td>
<td>64.3%</td>
</tr>
<tr>
<td>Interview Completion Rate</td>
<td>83.6%</td>
<td>76.6%</td>
<td>80.8%</td>
</tr>
<tr>
<td>Response Rate</td>
<td>43.7%</td>
<td>15.2%</td>
<td>25.5%</td>
</tr>
</tbody>
</table>
### Changing Performance Measures for Title V Funding Applications

<table>
<thead>
<tr>
<th>Previously</th>
<th>Currently (MCH 3.0)</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Performance Measures (NPM) for CSHCN:</td>
<td>National Performance Measures:</td>
</tr>
<tr>
<td></td>
<td>• Medical home, adequate insurance, transition planning</td>
</tr>
<tr>
<td></td>
<td>• Oral health, developmental screening, well visits</td>
</tr>
<tr>
<td></td>
<td>• Household tobacco exposure, physical activity, bullying</td>
</tr>
<tr>
<td></td>
<td>National Outcome Measures:</td>
</tr>
<tr>
<td></td>
<td>• Health status</td>
</tr>
<tr>
<td></td>
<td>• Overweight / obesity</td>
</tr>
<tr>
<td></td>
<td>• Cavities</td>
</tr>
<tr>
<td></td>
<td>• Mental health (ASD, ADHD, other)</td>
</tr>
<tr>
<td></td>
<td>• Systems of care</td>
</tr>
<tr>
<td></td>
<td>• Healthy and ready to learn</td>
</tr>
</tbody>
</table>

- NPM 2: Family-provider partnerships
- NPM 3: Medical home access
- NPM 4: Adequate insurance
- NPM 5: Community-based service systems
- NPM 6: Transition planning
Survey Periodicity

- National Survey of CSHCN
  - 2001
  - 2005 – 2006
  - 2009 – 2010

- National Survey of Children’s Health
  - 2003
  - 2007
  - 2011 – 2012
Redesigning the National Survey

- Shift the sampling frame from landline and cell phone numbers to household addresses
  - Address-based sampling frame should improve response rates and will support improved nonresponse bias analyses

- Shift the majority of interviews from an interviewer-administered mode to a self-directed response mode (mail or web)
  - Telephone follow-up only as necessary
  - Data collection conducted by US Census Bureau
Redesigning the National Survey

- Combine the NS-CSHCN and the National Survey of Children’s Health into a single instrument
  - The single combined survey will be fielded annually
  - State-level estimates should be available after the first two years, with three-year rolling averages after that
Redesigned Survey Content

General Health
- General health status
- General oral health
- Flourishing
- School readiness (0-5)
- Activity limitations
- Condition lists
- ASD & ADHD content
- Height & weight

Infant Health
- Pre-term birth
- Low birth weight

Health Care Services
- Preventive care
- Usual place for sick/well care
- Receipt of specialist care
- Unmet needs
- Developmental screening

Experience with Health Care Providers
- Medical home
- Shared decision-making
- Preparation for transition (12-17)

Health Insurance
- Status
- Type
- Adequacy

Providing for Your Child’s Health
- Expenses & problems paying
- Employment & care-giving burden
  - Screen time, physical activity, & sleep

About Your Family and Household
- Extracurricular & family activities
- Child care
- Parenting stress
- Family resilience
- Adverse family experiences

About Your Neighborhood & Community
- Amenities
- Social support
Redesign Timeline

- Expert consultation on sampling, mode, and other methods issues: 2012 – 2013
- Meetings with expert panel and stakeholders regarding content: 2013 – 2014
- Cognitive interviews and mode effects experiments: Fall 2014 – Winter 2015
- Revise instruments: Spring 2015
- Survey pretest: Summer – Fall 2015
- Full survey fielded: Summer – Fall 2016
- Public data release: Spring 2017
Contact Info

- Stephen J. Blumberg, Ph.D.
  National Center for Health Statistics
  Centers for Disease Control and Prevention
  3311 Toledo Road
  Hyattsville, Maryland 20782
  SBlumberg@cdc.gov

- General e-mail: slaits@cdc.gov