



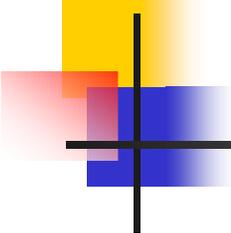
The National
Survey of Children with
Special Health Care Needs:
A Look Back and A Look Forward

Marcie Cynamon
Stephen Blumberg



Centers for Disease Control and Prevention
National Center for Health Statistics

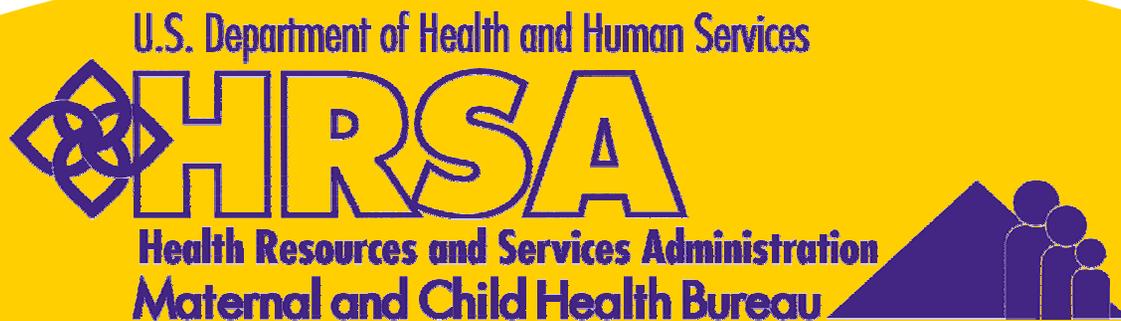
SAFER • HEALTHIER • PEOPLE™



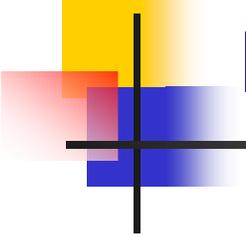
A Look Back and A Look Forward

- Today's agenda
 - Overview of 2001 survey
 - Plans and modifications for 2005-2006
 - How states can modify survey
- 1st round: Oct 2000 – Apr 2002
- 2nd round: Jan 2005 – Dec 2006

The 1st Round: 2001

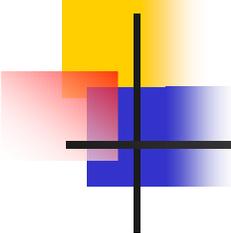


- Goal: National and state-based estimates on the prevalence and impact of children with special health care needs
- Dates: October 2000 – April 2002



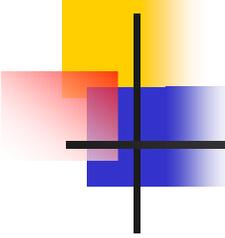
SLAITS: The State and Local Area Integrated Telephone Survey

- Developed by CDC/NCHS
- Addresses need for subnational data
- Uses sampling frame from the National Immunization Survey



National Immunization Survey Sampling Frame

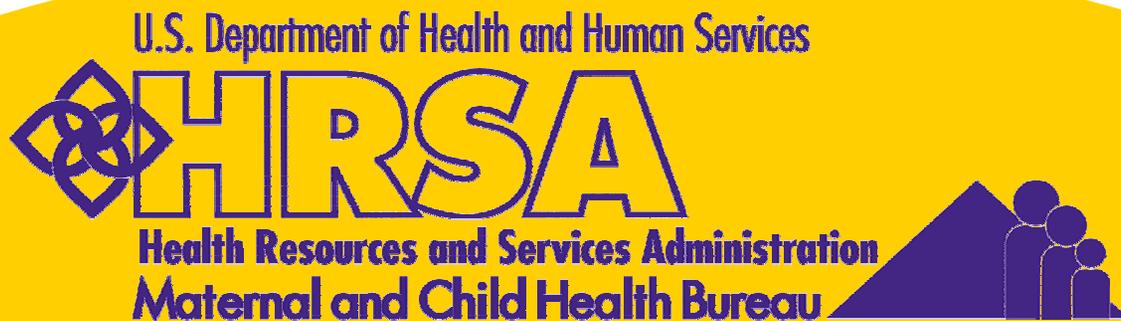
- Designed to produce immunization coverage estimates for 50 states and 28 metropolitan areas
- Random-digit-dial telephone survey
- Screens about 1 million households annually
- Target population: 19-35 months old



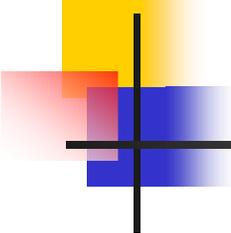
Key Features of SLAITS

- Expands on the National Immunization Survey
- Random-digit-dial telephone survey
- Computer assisted telephone interviewing (CATI)
- Customized content and sample

The 1st Round: 2001

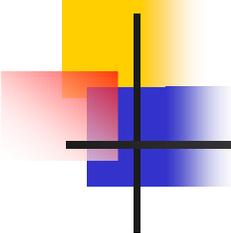


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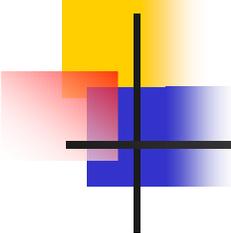
Interview Process

- Independent random-digit-dial samples for all 50 states plus D.C.
- Screened households for children under 18 years of age
- Respondent was the parent or guardian most knowledgeable about the health of the children in the household
- Screened all children to identify children with special health care needs



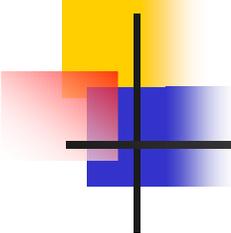
The CSHCN Screener

- Consequences-based screening tool
 - Prescription medication
 - Elevated service use
 - Functional limitations
 - Special therapy (e.g., PT, OT, Speech)
 - Treatment or counseling
- Must be due to medical, behavioral, or other health condition that has lasted or is expected to last at least 12 months



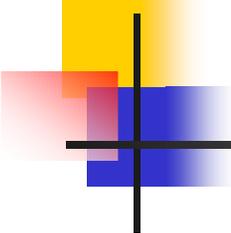
Interview Process

- One CSHCN randomly selected from households with multiple CSHCN
- Asked detailed questionnaire for children with special health care needs
 - Health and functional status
 - Access to care, utilization, unmet need
 - Health insurance and adequacy
 - Care coordination
 - Satisfaction with care
 - Impact on the family



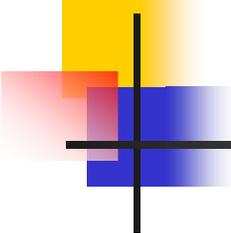
Interview Process

- Target was 750 CSHCN per state
- Calling and screening of households continued until we met the target in all states



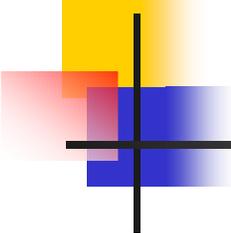
Sample Size

- 3,100 – 5,000 households with children screened in every state
- 5,600 – 9,700 children screened in every state
- 739 – 766 completed interviews in households with CSHCN in every state (except Missouri)



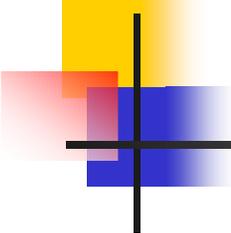
Features

- Interviews conducted in English and 11 other languages
- Response rate = 61%



Health Insurance Control Sample

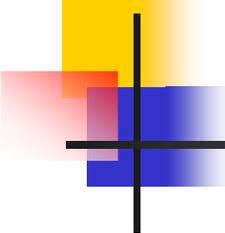
- One child without special health care needs was randomly selected for a brief health insurance interview
 - Presence of health insurance coverage at time of interview
 - Type of coverage
 - Gaps in coverage during past year
- 2,800 – 4,700 completed insurance interviews



Low-Income Uninsured Supplement

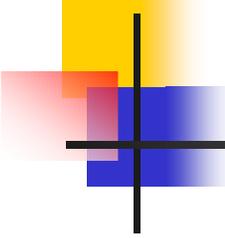
- When children were identified as uninsured and living in low-income households:
 - History of Medicaid and/or SCHIP coverage
 - Awareness of Medicaid and SCHIP
 - Attitudes toward Medicaid and SCHIP
 - Health status, utilization, and barriers to needed care (*for children without special needs*)

Sponsored by the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services



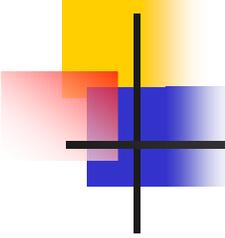
Weighting and Estimation

- Sampling weights to permit national and state-specific estimates of health characteristics
- Sampling weights are adjusted for potential non-response biases
- Sampling weights are adjusted to account for non-coverage of non-telephone households



Key Results from the 1st Round

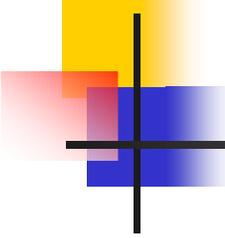
- 12.8% of children nationally have special health care needs
- A majority of CSHCN...
 - Receive care in a medical home
 - Receive all needed care
 - Are satisfied with care received
 - Are adequately insured



Key Results from the 1st Round

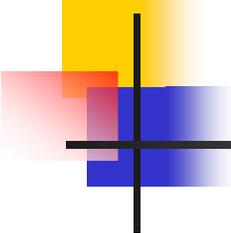
- 1 out of 3 are not adequately insured
- 1 out of 3 have a condition that required a family member to cut back on work or stop working in order to provide care
- 1 out of 5 have a condition that resulted in financial problems for the family
- 1 out of 6 have unmet care needs

Problems are concentrated among the most disadvantaged CSHCN and their families



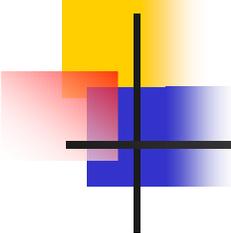
Goals for the 2nd Round

- National and state-based estimates on the prevalence and impact of children with special health care needs
- Assess changing needs of CSHCN over the past 4-5 years
- Continue to monitor MCHB's key performance measures and outcomes
- Address some of the survey limitations identified after the 1st round



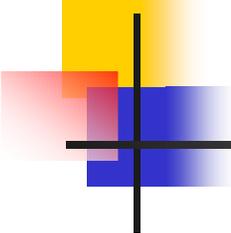
Limitations of the 1st Round of the National Survey of CSHCN

- Responses are subjective and are based only on families' experiences and perceptions
- No condition-specific information
- Limited ability to compare CSHCN to children without special health care needs
- Analyses of subpopulations at the state level may be limited due to sample size
- States were not permitted to customize survey to meet their specific needs for data



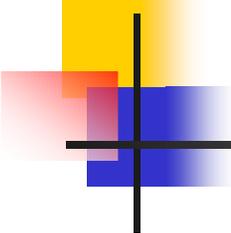
Obtaining Input for the 2nd Round

- Survey of data users sent to the SLAITS listserv in February 2004
- Convened a Technical Expert Panel in March 2004 to discuss data users' comments and recommend survey modifications



Technical Expert Panel

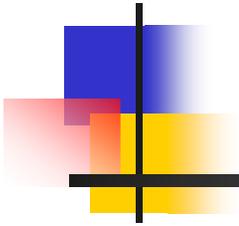
- Christina Bethell (CAHMI)
- Jeffrey Lobas (Iowa)
- Paul Newacheck (UC-San Francisco) – *Chair*
- Ginny Sharp (Washington)
- Phyllis Sloyer (Florida)
- Ruth Stein (Albert Einstein College of Medicine)
- Nora Wells (Family Voices)
- MCHB and NCHS/SLAITS Staff

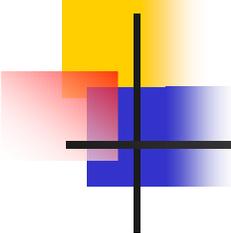


Obtaining Input for the 2nd Round

- Survey of data users sent to the SLAITS listserv in February 2004
- Convened a Technical Expert Panel in March 2004 to discuss data users' comments and recommend survey modifications
- TEP will continue to meet through the spring and summer to discuss comments that continue to be received
- MCHB makes the final decisions

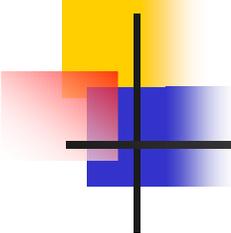
Section by Section Review of Questionnaire and Comments Received





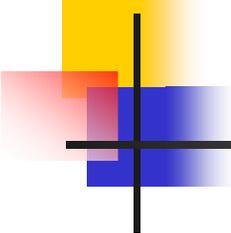
Section 2: Screening

- Content
 - CSHCN Screener
 - Demographics
- Examples of comments received
 - Is the CSHCN Screener valid for all subpopulations (e.g., Spanish-speaking parents of Hispanic children)?
 - Are there cultural differences that would affect reporting of consequences on the Screener?



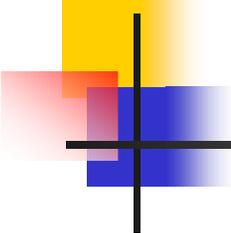
Section 2: Screening

- Content
 - CSHCN Screener
 - Demographics
- Examples of comments received
 - Please add race of parent, race and gender of personal doctor, language spoken at home, family composition/structure, employment status of adults, etc.



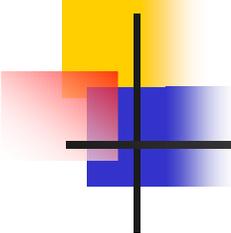
Section 2: Screening

- Content
 - CSHCN Screener
 - Demographics
- Examples of comments received
 - Please add more geographic variables for health care access analyses, such as RUCA codes, or time/distance to major medical center or doctor's office



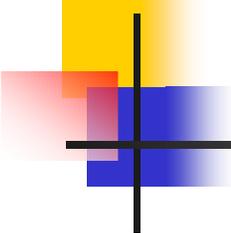
Section 3: Health & Functional Status

- Content
 - Frequency and magnitude of activity limitations
 - Rating of severity of conditions
 - Stability of health care needs
 - Early intervention/special ed services
 - Number of school days missed due to illness
- Examples of comments received
 - A better description of the population of CSHCN is needed



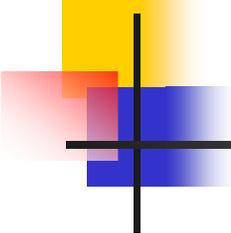
“A better description of the population of CSHCN is needed”

- Examples of comments received
 - Add condition checklists to permit identification of CSHCN with specific diagnosed problems
 - Add questions to permit classification of special needs by body systems or other domains
 - Add questions to understand why some parents report that the child is never affected by condition
 - Add questions to rate the severity of all difficulties experienced by CSHCN, not just the activity limitations



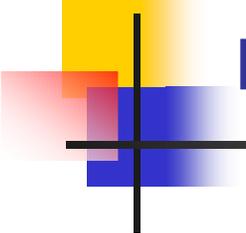
Section 4: Access to Care, Utilization, and Unmet Needs

- Content
 - Usual source of care and existence of personal doctor or nurse
 - Reasons for delayed care and unmet needs
 - Need for and receipt of 14 specific health care services and 3 family services
 - Problems obtaining needed referrals
- Examples of comments received
 - Add OB/GYN services for adolescent female CSHCN
 - Add questions on difficulties obtaining care



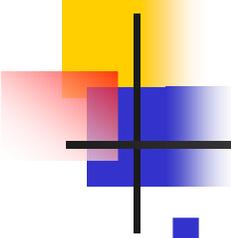
Section 5: Care Coordination

- Content
 - Need for, receipt of, and frequency of professional care coordination
 - Satisfaction with help received
 - Quality of doctors' communication with other doctors and other service providers
 - Use of services from Title V programs
- Examples of comments received
 - General sense that this section is not working as intended



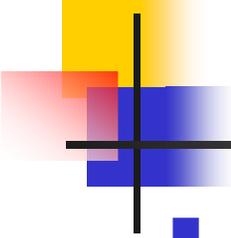
“General sense that this section is not working as intended”

- Examples of comments received
 - Section should focus on any assistance rather than just “professional” care coordination
 - Section should include all CSHCN with services received from different providers, rather than excluding parents who perceive no need for care coordination
 - Parents may know about “case management” but not “care coordination”
 - Parents may not know if doctors are communicating well with others
 - Parents may not know if a program is supported by Title V



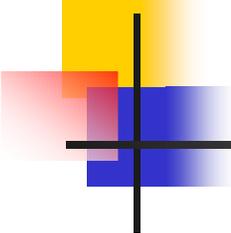
Section 6: Satisfaction with Care / Transition to Adult Care Providers

- Content
 - Number of doctor visits
 - Satisfaction with services received
 - Rating of whether services are organized for easy use
 - Whether care is family-centered
- Examples of comments received
 - One question may not be sufficient to assess whether services are organized for ease of use



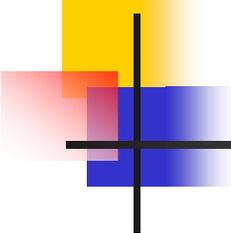
Section 6: Satisfaction with Care / Transition to Adult Care Providers

- Content
 - Whether doctors have talked about transition issues and changing health care needs, and developed a plan
 - Vocational or career training for an adult job
- Examples of comments received
 - The vocational training question behaves differently than the medical transition questions
 - General sense that the transition questions are too focused on medical services



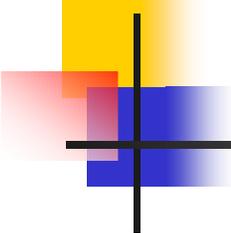
“General sense that the transition questions are too focused”

- Examples of comments received
 - No questions address whether children have the skills or knowledge to operate independently within the adult health care system
 - No questions address whether a health care payment source (e.g., insurance) is available when the child turns 18
 - No questions address the availability of adult service providers in the community



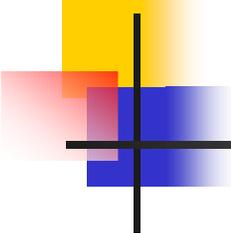
Sections 7 & 8: Health Insurance

- Content
 - Current coverage type and continuity of coverage over past 12 months
 - Adequacy of coverage (e.g., whether providers and services needed are covered, whether costs not covered are reasonable)
 - Satisfaction with health plan, desire to switch, and other ratings of whether plan is good for CSHCN
- Examples of comments received
 - Add questions on managed care
 - Verify state-specific program names



Section 9: Impact on the Family

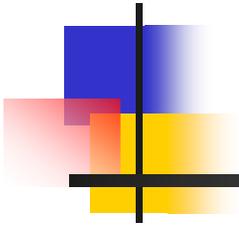
- Content
 - Out-of-pocket expenses for child's care
 - Hours providing or coordinating care
 - Financial problems due to child's care
 - Impact on employment of family members
- Examples of comments received
 - Desire for continuous measures of expenses and income to allow calculation of "expenses as a percent of income"

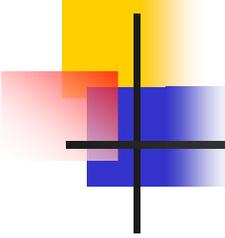


Section 11: Income

- Content
 - Income in past calendar year
 - Receipt of SSI
 - Receipt of cash assistance/welfare
- Examples of comments received
 - Add questions on use of faith-based or community resources for family needs

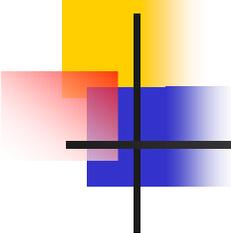
Tentative Plans for the 2nd Round of the National Survey of CSHCN





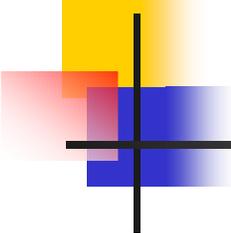
Goals for the 2nd Round

- National and state-based estimates on the prevalence and impact of children with special health care needs
- Assess changing needs of CSHCN over the past 4-5 years
- Continue to monitor MCHB's key performance measures and outcomes
- Address some of the survey limitations identified after the 1st round



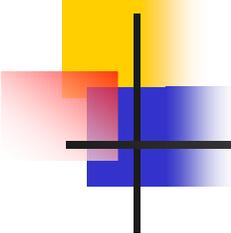
2nd Round Survey Design

- RDD telephone survey with equal-sized samples of CSHCN from every state and DC
- The same screener and selection criteria as in the 1st Round
- Slightly modified questionnaire based on comments received and TEP suggestions
- Health insurance control sample and low-income uninsured supplement will not be repeated
- Fielded from January 2005 to December 2006



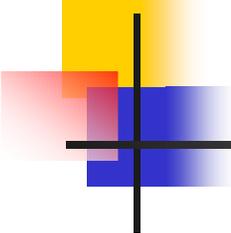
Addressing 1st Round Limitations

- Limited ability to compare CSHCN to children without special health care needs
 - **May add a sample of healthy children and administer an abbreviated version of questionnaire**
- Analyses of subpopulations at the state level may be limited due to sample size
- States were not permitted to customize survey to meet their specific needs for data



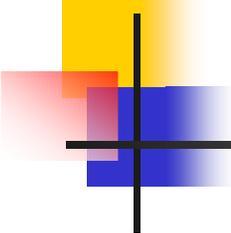
Addressing 1st Round Limitations

- Limited ability to compare CSHCN to children without special health care needs
- Analyses of subpopulations at the state level may be limited due to sample size
 - **May increase sample size to 1000 CSHCN per state**
 - **Will permit states to pay for further sample expansion**
- States were permitted to add sample but not questions to meet specific data needs



Addressing 1st Round Limitations

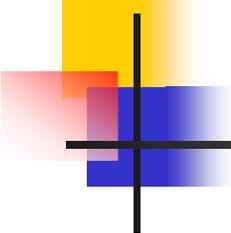
- Limited ability to compare CSHCN to children without special health care needs
- Analyses of subpopulations at the state level may be limited due to sample size
- States were not permitted to customize survey to meet their specific needs for data
 - **Will permit states to pay for up to 6 additional minutes of state-specific questions**



Cost for Adding Questions

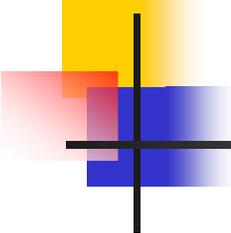
- 2 minutes = \$13,000 - \$15,000
- 4 minutes = \$25,000 - \$30,000
- 6 minutes = \$38,000 - \$45,000

(Costs above are "per state" assuming 1000 interviews per state. Costs are rough estimates. The data collection contract for the survey has not been awarded. Costs cannot be finalized until the contractor is selected in Fall 2004.)



Cost for Adding Sample

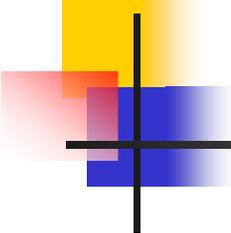
- Wide range occurs because some states have sufficient NIS sample to accommodate larger CSHCN sample sizes. Other states would be required to augment the NIS sample with “new” sample, which costs considerably more
- States expected to have the highest costs for adding sample:
 - AK, AR, CO, IA, ID, KS, KY, MN, MS, NE, NM, OR, SD, UT, WY



Cost for Adding Sample

- 500 interviews = \$38,000 - \$225,000
- 1000 interviews = \$75,000 - \$450,000

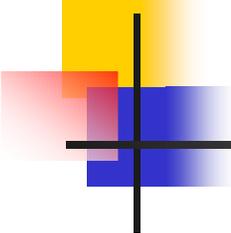
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We Would Like Your Help

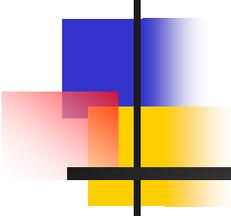
- Share your comments on the questionnaire
 - What questions should remain unchanged?
 - What concepts should remain, but with modified questions?
 - What new questions should be added?
 - What old questions should be removed?
- Send comments to
 - Marcie Cynamon (mcynamon)
 - Stephen Blumberg (sblumberg)

Both addresses
are "@ cdc.gov"



We Would Like Your Help

- Let us know if your state might be interested in adding questions or sample
- Let us know what concepts you are considering adding
 - The SLAITS team will work with you to develop the questions and, if necessary, will discuss options for testing those questions
 - If multiple states express interest in the same concepts, we may develop “modules” that permit direct comparisons between those states (if desired)



Questions?
