Demystifying Data!

An Overview of Three Child and Adolescent Parent Survey Health Datasets and Research Resources: MEPS, NSCH, NS-CSHCN

PAS Annual Conference
Honolulu, HI
May 3, 2008

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CAHMI
The Child and Adolescent
Health Measurement Initiative

AHRQ

Faculty Disclosure Information

We have no relevant financial relationships with the manufacture of any commercial product and/or provider of commercial services discussed in this CME activity:

We do intend to discuss an unapproved / investigative use of a commercial product / device in our presentation.

Agenda

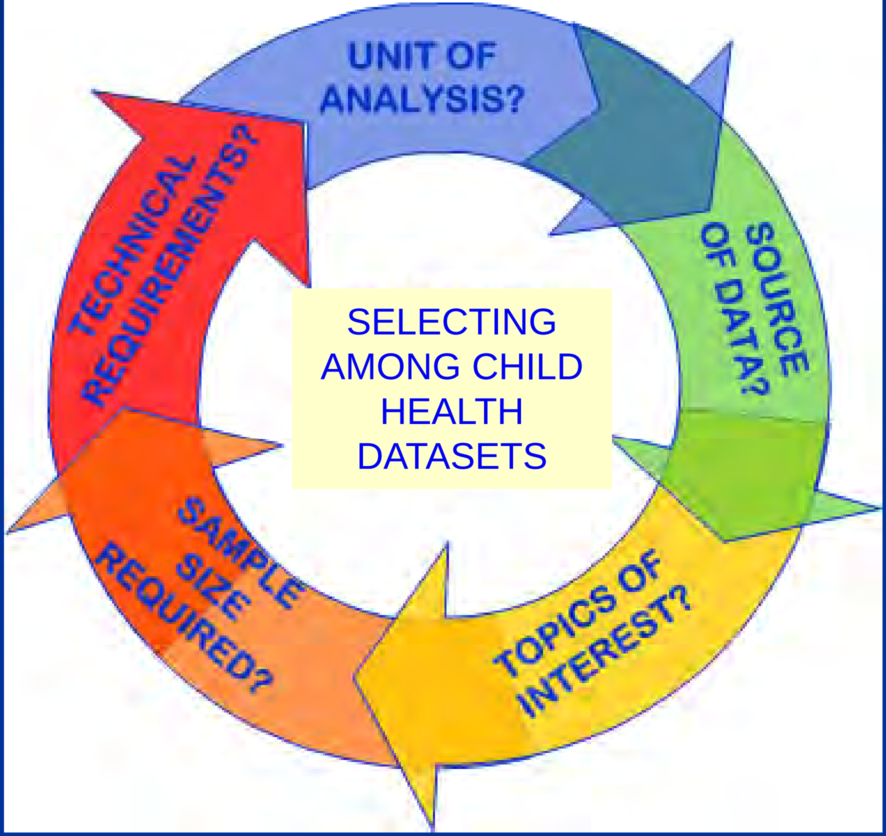
10:00-10:50	Meet and Greet: Introductions, Review Agenda and Round-Robin Participant Summary of Key Interests and Priorities for Workshop
10:50-11:30	Overview of datasets and key considerations for their use (Christina Bethell)
11:30-11:45	BREAK (have a snack—it's almost lunch time and 2 hours to go!)
11:45-12:30	Real –life llustrations of research applications and top tips and lessons learned
	11:45-12:05: Jun Ao 12:05-12:25 Katharine Zuckerman
12:30-12:50	Trivial Pursuit Game: Small group work
12:50-1:30	Review answers to key Trivial Pursuit questions and group discussion

Learning Objectives

You will be able to:

- Outline national and state level child health data available through the MEPS, NSCH and NS-CSHCN and consider their relevance to your research interests.
- Consider the inherent limitations and strengths of each dataset.
- You will know about and begin to use online resources to access findings from and learn about research applications of the MEPS, NSCH and NS-CSHCN
- Learn about top tips for using the MEPS, NSCH and NS-CSHCN for research purposes.

Overview of Datasets
5 Key Questions to Get Started



- What is the **unit of analysis** you are interested in?
- What **source of data** is most suitable to your research questions?
- What **key topics** are you interested in studying?
- What **sample size** is required to make your analysis possible and meaningful?
- Can you meet the **technical requirements** for using the dataset of interest?

Dataset Characteristics

- Description
  - Sponsor
  - Type of Data
  - Inclusion and Exclusion Criteria
  - Respondent
  - Geographic Units of Analysis
  - Scope of Content/Variables Included
- Periodicity and years of data available
- Data Collection Methods
  - Sampling Frame
  - Oversampling
  - Administration Mode
- Sample Size
- Data linkages options
- Limitations
- Technical requirements
- Availability/cost of data

Major Similarities and Differences to Know About

MAJOR SIMILARITIES

Source of Data
Survey-based data

Sampling Frame
US, non-institutionalized population

Topics Covered
Health status, access to care, insurance status, health care utilization, quality of care, etc.

Resources
Free datasets; web-based query and support

MAJOR DIFFERENCES

Sampling and Administration:
NIS/SLAITS RDD CATI vs. NHIS Respondent Subsample CAPI

Within Household Sampling:
All individual family members vs. target child vs. family unit plus target child

Sample Size
< 10K vs. 40-100K

Unit of Analysis
National/Regional Only vs. National/Regional & State

Why Might Findings On the Same Survey Items Differ from One Survey to the Next?

- Dates of data collection
- Method of data collection and estimation
  - Mode
  - Sampling frame
  - Interviewers
  - Weighting methods
- Sample size and sampling error
- Method of identification
  - Respondent
  - Recall period
  - Question wording
  - Question ordering
  - Question context and introduction

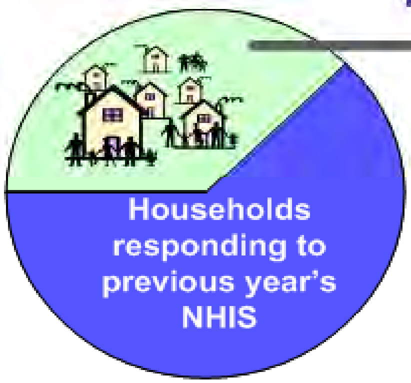
Medical Expenditure Panel Survey (MEPS)

- **Description:**
  - Sponsored by the **Agency for Healthcare Research and Quality** (AHRQ)
  - Nationally representative , **yearly cross-sectional and panel** data (over 2.5 years).
  - Collected **since 1996**
  - Includes a nationally representative sample of all U.S., **non-institutionalized civilians** of all ages based on a subsample of respondents to the prior year NHIS.
  - **Respondent** is any person living in the household over 16 years of age who rents or owns the home.
  - Produces **national and regional findings** (not state-level)

Medical Expenditure Panel Survey (MEPS)

- Description:
  - MEPS Interviews are conducted through a **Computer Assisted In- Person Interview** (CAPI). Some mail mode used at times.
  - **Five rounds** of in-person interviews are conducted with each panel at 4 to 5 month intervals **over a 2 ½ year period**
  - **Two 'follow back' surveys**, the Medical Provider Component and the Insurance Component are collected in addition to the information collected from the Household Component respondents
  - When the **full year MEPS survey** is complete, it consists of 1 Full Year Consolidated File, 8 Event Files, 1 Job File, and 1 Medical Conditions File and will enlist data from 2 panels

MEPS (Medical Expenditure Panel Survey)
Household Component Sampling and Administration



1) **SAMPLING FRAME:** A new MEPS panel is selected each year from a sampling frame representing about 3/8's of households responding to the previous year's National Health Interview Survey (NHIS).

NHIS is an ongoing cross-sectional survey based on a nationally representative sample of the U.S. non-institutionalized population, with an oversampling of Blacks and Hispanics.

2) Reporting Units (RUs) representing students living in student housing or consisting entirely of military personnel are removed from the new panel prior to the start of interviewing.

3) Five rounds of in-person Household Component interviews are conducted with each MEPS panel using computer-assisted personal interviewing (CAPI) at 4 to 5 months intervals over approximately a 2 ½ year period.*

Two "follow back" surveys, the Medical Provider Component and part of the Insurance Component collect additional data used to supplement the medical care events, expenditures and health insurance information obtained from Household Component respondents.

4) MEPS Full Year Public Use Data Releases for Each Calendar Year

All of the MEPS files for a specific calendar year are linkable to each other. Linking information is provided as part of the documentation for each public use data file.

Full Year Consolidated Data File:

- Each record represents one person
- Detailed person level information
- Oversampling of Black and Hispanics (carry over from NHIS)
- Asians and Low Income oversampled 2002 and beyond
- Weights to provide national estimates for individuals and family units
- 10,295 children ages 0-17 in 2004

Condition Level File:

Each record represents a unique condition reported for a particular person by the household respondent

8 Types of Event Level Files:

Each record represents a unique event:

- Hospital stays
- ER visits
- Out-patient dept visits
- Medical visits
- Home health
- Dental
- Prescribed medicines
- Other medical expenditures

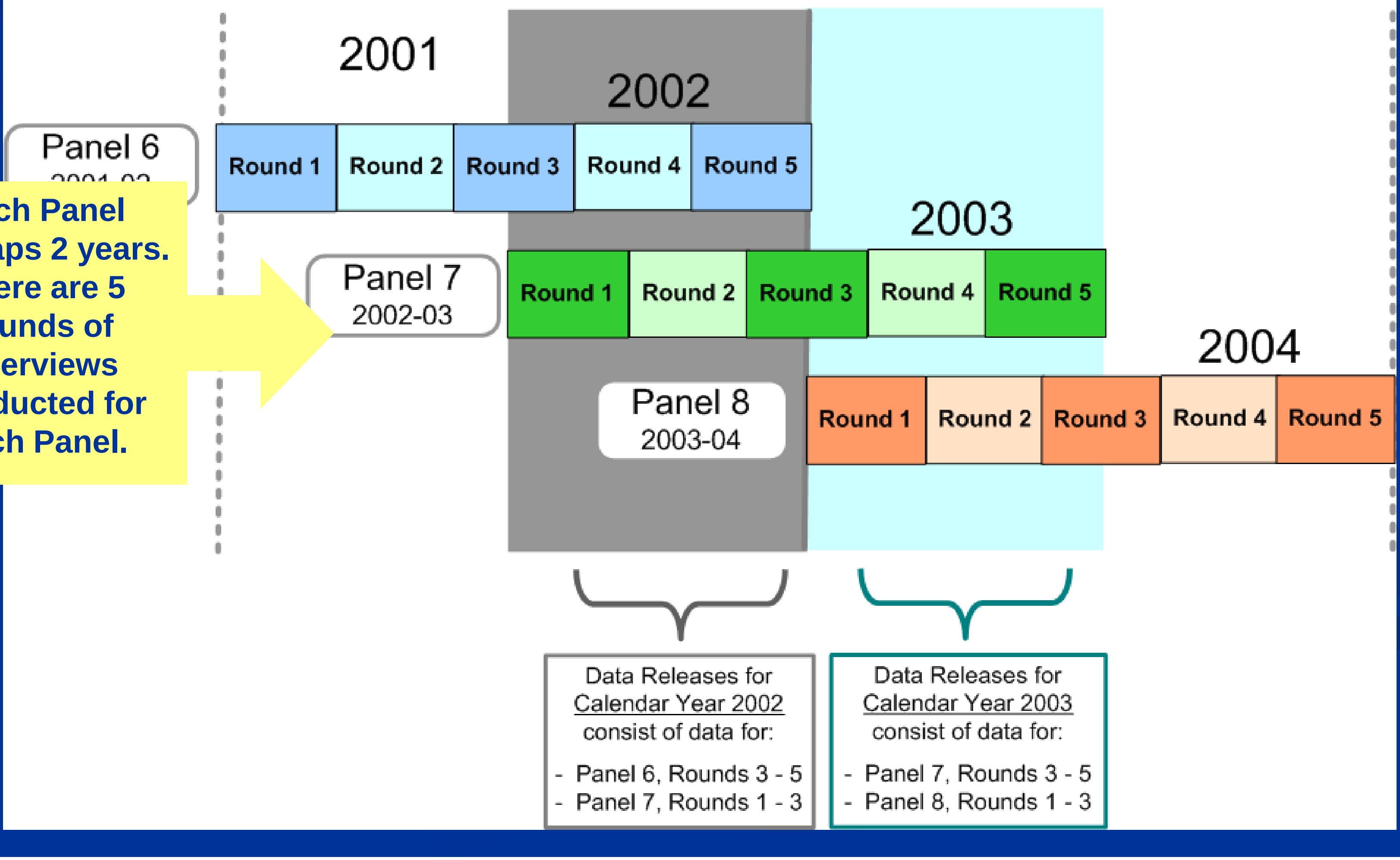
Job File:

Each record represents a unique job held by a household respondent 16 yrs and older; includes job characteristics such as wages, industry, and occupation

MEPS

Illustration of MEPS Overlapping Panel Design

A new MEPS panel is added each calendar year. Five rounds of in-person Household Component interviews are conducted with households in each MEPS panel at 4 to 5 months intervals over approximately a 2 ½ year period.



2001

2002

2003

2004

Panel 6
2001-02

Round 1 | Round 2 | Round 3 | Round 4 | Round 5

Panel 7
2002-03

Round 1 | Round 2 | Round 3 | Round 4 | Round 5

Panel 8
2003-04

Round 1 | Round 2 | Round 3 | Round 4 | Round 5

Data Releases for
Calendar Year 2002
consist of data for:

- Panel 6, Rounds 3 - 5
- Panel 7, Rounds 1 - 3

Data Releases for
Calendar Year 2003
consist of data for:

- Panel 7, Rounds 3 - 5
- Panel 8, Rounds 1 - 3

Each Panel overlaps 2 years. There are 5 rounds of interviews conducted for each Panel.

MEPS Data Files

PUF no.	Title	Data update	Year	File type
HC-077G	2003 Office-Based Medical Provider Visits File		2003	Household Event File
HC-077F	2003 Outpatient Department Visits		2003	Household Event File
HC-077E	2003 Emergency Room Visits File		2003	Household Event File
HC-077D	2003 Hospital Inpatient Stays File		2003	Household Event File
HC-077C	2003 Other Medical Expenses		2003	Household Event File
HC-077B	2003 Dental Visits		2003	Household Event File
HC-077A	2003 Prescribed Medicines File		2003	Household Event File
HC-076	2003 Person Round Plan Public Use File	X	2003	Household Full Year File
HC-074	2003 Jobs File		2003	Household Full Year File
HC-073	2003 Full Year Population Characteristics (HC-073 replaced by HC-079)		2003	Household Full Year File
HC-064	2003 P7R3/P8R1 Population Characteristics		2003	Household Point-in-Time File
HC-036BRR	MEPS 1996-2004 Replicates for Calculating Variances File		1996-2004	Pooled Linkage File
HC-036	MEPS 1996-2004 Pooled Estimation Linkage File		1996-2004	Pooled Linkage File

Medical Expenditure Panel Survey (MEPS)

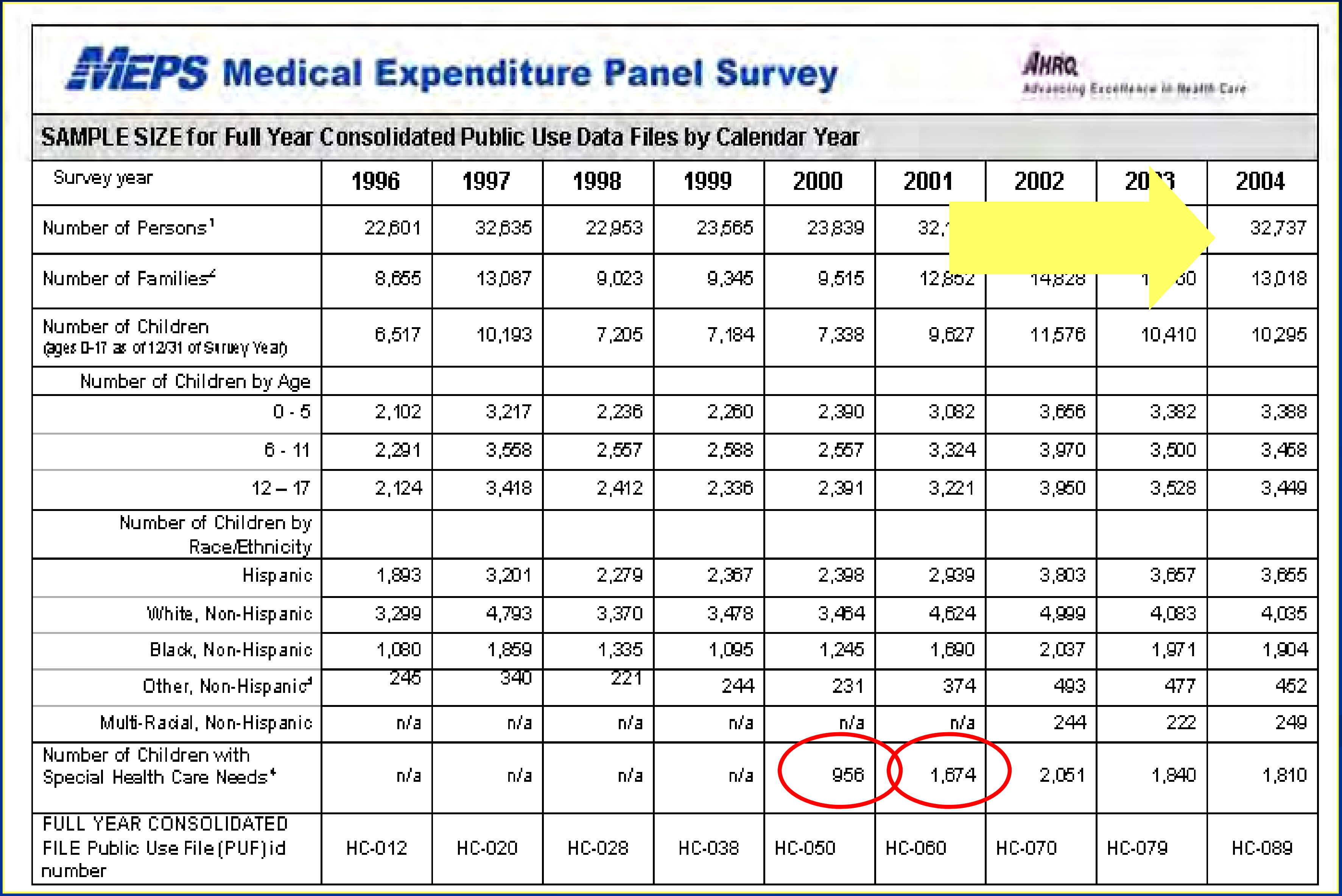
- **Description:**
  - **Key variables** include: medical expenditures, patterns of utilization, insured & uninsured populations, health status and health care quality.
  - Data collected for **all family members**;
  - Can be **examined for children only**.
  - Linkage of family members allows **family-level analysis** of child health & health care.
  - Capacity to **compare adult and child** health care utilization and expenditures. Children with Special Health Care Needs (CSHCN) Screener included since 2000.
- **Sample size:**
  - 12,000 households interviewed annually.
  - 2004: 32,737 overall.
  - 6,500-11,000 children annually

MEPS-HC Sample Sizes

Year	Families	Persons
1996	8,655	21,571
1997	13,087	32,636
1998	9,023	22,953
1999	9,354	23,565
2000	9,515	23,839
2001	12,852	32,122
2002	14,828	37,418
2003	12,860	32,681
2004	13,018	32,737
2005	12,810	32,320

http://www.meps.ahrq.gov/mepsweb/about_meps/workbook/522,8,MEPS-HC Sample Sizes

MEPS Sample Size



MEPS Medical Expenditure Panel Survey

AHRQ Advancing Excellence in Health Care

SAMPLE SIZE for Full Year Consolidated Public Use Data Files by Calendar Year

Survey year	1996	1997	1998	1999	2000	2001	2002	2003	2004
Number of Persons[1]	22,601	32,635	22,953	23,565	23,839	32,1[illegible]	[illegible]	[illegible]	32,737
Number of Families[2]	8,655	13,087	9,023	9,345	9,515	12,852	14,828	1[illegible]60	13,018
Number of Children (ages 0-17 as of 12/31 of Survey Year)	6,517	10,193	7,205	7,184	7,338	9,627	11,576	10,410	10,295
Number of Children by Age									
0 - 5	2,102	3,217	2,236	2,260	2,390	3,082	3,656	3,382	3,388
6 - 11	2,291	3,558	2,557	2,588	2,557	3,324	3,970	3,500	3,458
12 – 17	2,124	3,418	2,412	2,336	2,391	3,221	3,950	3,528	3,449
Number of Children by Race/Ethnicity									
Hispanic	1,893	3,201	2,279	2,367	2,398	2,939	3,803	3,657	3,655
White, Non-Hispanic	3,299	4,793	3,370	3,478	3,464	4,624	4,999	4,083	4,035
Black, Non-Hispanic	1,080	1,859	1,335	1,095	1,245	1,690	2,037	1,971	1,904
Other, Non-Hispanic[3]	245	340	221	244	231	374	493	477	452
Multi-Racial, Non-Hispanic	n/a	n/a	n/a	n/a	n/a	n/a	244	222	249
Number of Children with Special Health Care Needs[4]	n/a	n/a	n/a	n/a	956	1,674	2,051	1,840	1,810
FULL YEAR CONSOLIDATED FILE Public Use File (PUF) id number	HC-012	HC-020	HC-028	HC-038	HC-050	HC-060	HC-070	HC-079	HC-089

MEPS: Prevalence of CSHCN

	2001 MEPS	2002 MEPS	2003 MEPS	2004 MEPS
# of children in sample ages 0-17 on 12/31/XX	**9627**	**11576**	**10410**	**10295**
# of children in sample ages 0-17 on 12/31/XX with CSHCN Screener data	**9415**	**11298**	**10165**	**10045**
% CSHCN, all children	**18.9**	**19.3**	**19.3**	**18.8**

Medical Expenditure Panel Survey (MEPS) – cont.'d

- **Other Methods:**
  - Oversamples for Blacks and Hispanic persons
- **Data linkages:**
  - Previous year
  - Area Resource Files with AHRQ support to get geocodes
  - Census Bureau Information with AHRQ geocodes,
  - National Health Interview Survey
- **Technical requirements:** Statistical software
- **Availability/cost of data:** Most available within 24 hours, no cost. Dataset usually available 18-24 months from the end of the calendar year in which the data was collected.

Some Limitations to Consider for the MEPS

- Designed to yield **national estimates**
- **Limited to no capacity for State** or metropolitan statistical area level estimations for child population.
- Years must be **pooled to focus on small subpopulations** and rare events.
- Site of care, utilization, and medical condition information are **household identified**;
- **No condition check-list**; conditions asked about for utilization, etc.. Conditions not verified by clinical records.

The Medical Expenditure Panel Survey (MEPS) is a set of large-scale surveys of families and individuals, their medical providers, and employers across the United States. MEPS is the most complete source of data on the cost and use of health care and health insurance coverage. Learn more about MEPS.

New to MEPS?

Select a profile:
- General user
- Researcher
- Policymaker
- Survey participant
- Media

MEPS Topics

- Access to Health Care
- Children's Health
- Children's Insurance Coverage
- Chronic Conditions
- Dental
- Elderly
- Health Care Costs
- Health Care Disparities
- Health Insurance
- Medicare/Medicaid/SCHIP
- Mental Health
- Minority Health
- Obesity
- Prescription Drugs
- Projected Data
- Quality of Health Care
- State and Metro Area Estimates
- The Uninsured
- Women's Health

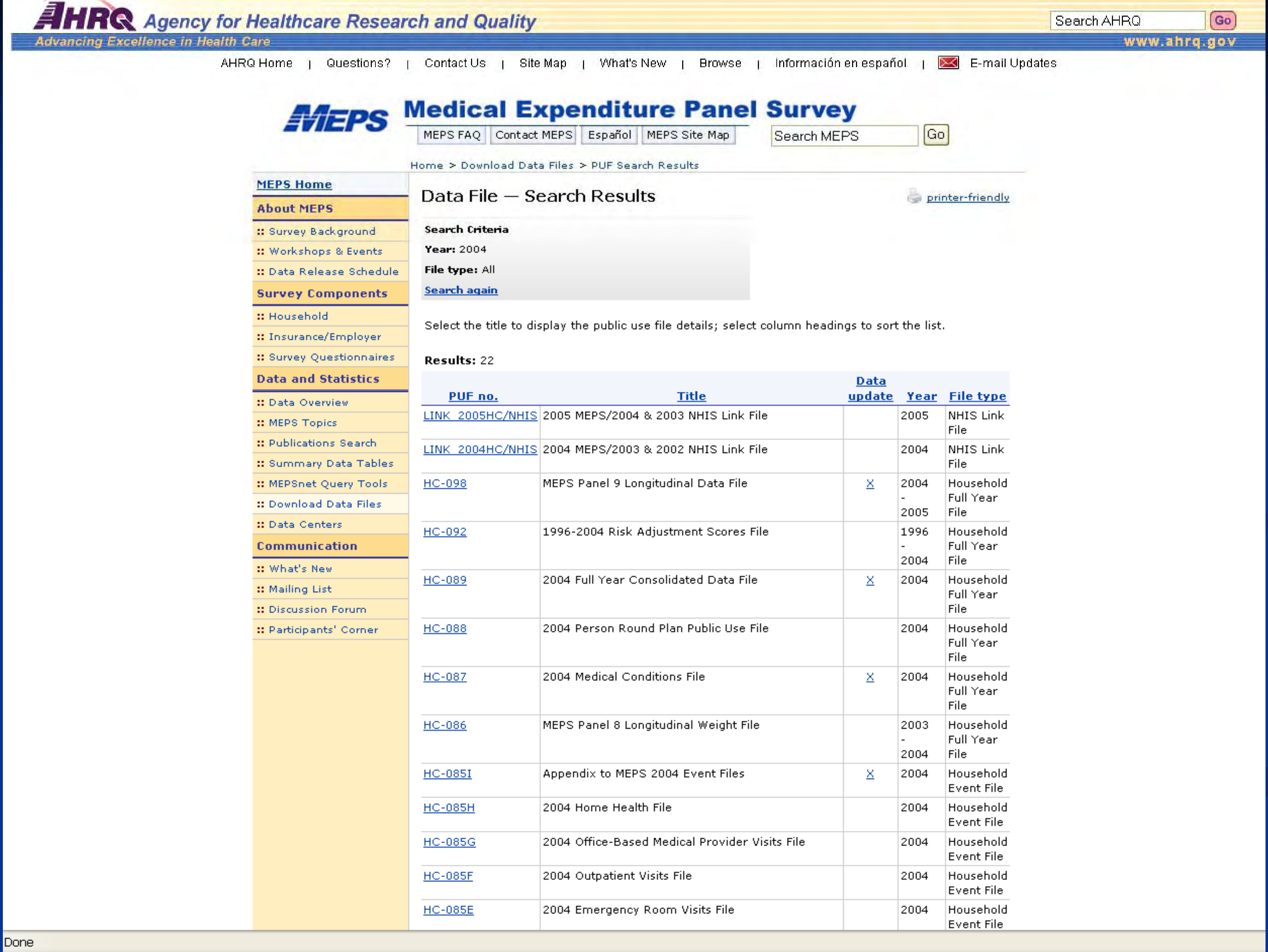
What's New Highlights

Upcoming Event

Registration is now open for a MEPS data users workshop featuring introductory lectures, programming exercises, and hands-on computer lab. The workshop will take place May 3–4, 2007, at the AHRQ Data Center, Rockville, MD. The registration period is March 15–April 16. Go to Workshops & Events to learn more details.

New Publications

While almost half of visits for office-based physician care were to doctors in general practice, family practice, internal medicine, or pediatrics, less than one-third of total expenditures were for visits to these types of physicians. — from Statistical Brief 166: Expenses for Office-Based Physician Visits by Specialty, 2004



Data File — Search Results

Search Criteria

Year: 2004

File type: All

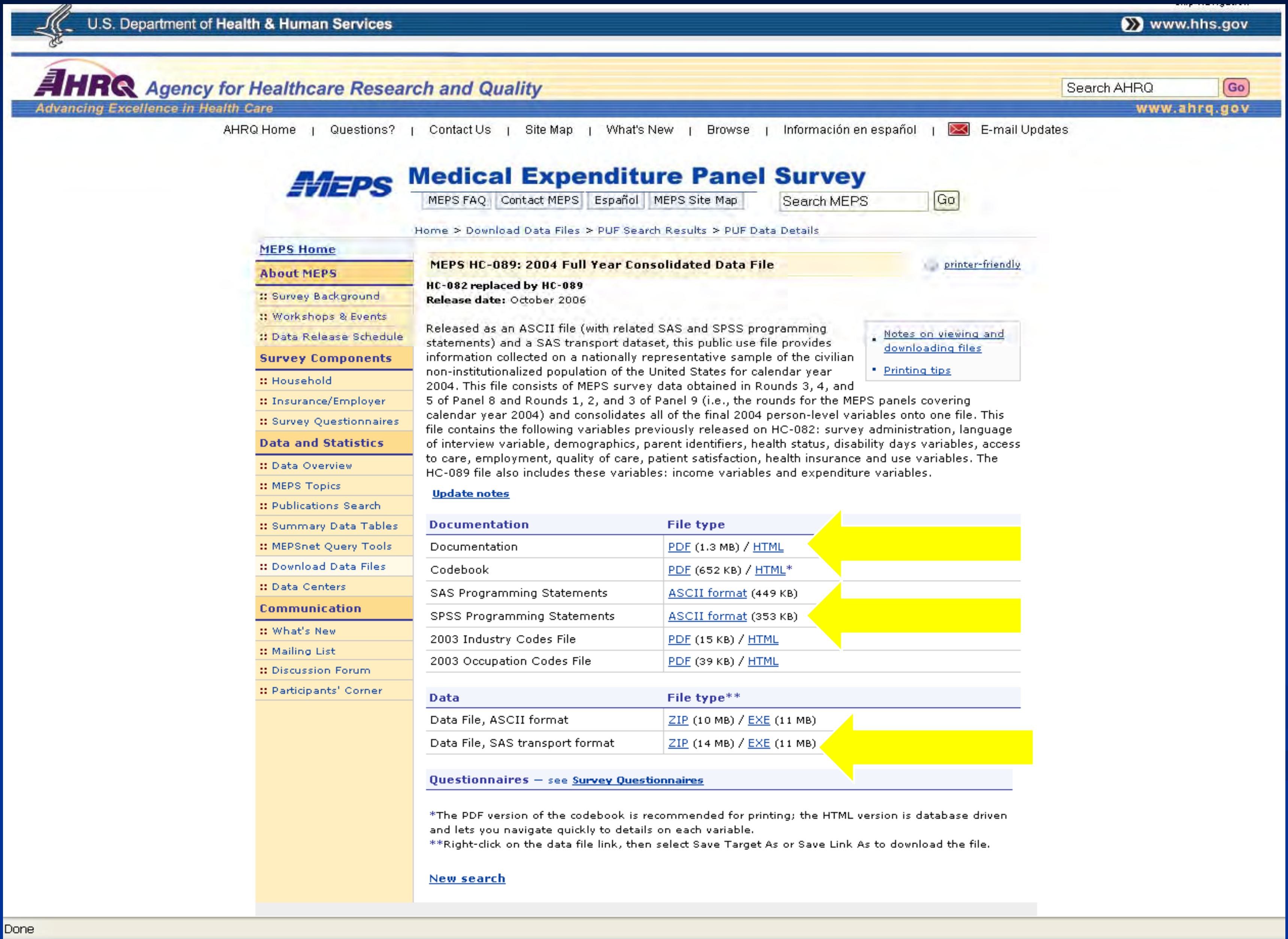
Search again

Select the title to display the public use file details; select column headings to sort the list.

Results: 22

PUF no.	Title	Data update	Year	File type
LINK_2005HC/NHIS	2005 MEPS/2004 & 2003 NHIS Link File		2005	NHIS Link File
LINK_2004HC/NHIS	2004 MEPS/2003 & 2002 NHIS Link File		2004	NHIS Link File
HC-098	MEPS Panel 9 Longitudinal Data File	X	2004 - 2005	Household Full Year File
HC-092	1996-2004 Risk Adjustment Scores File		1996 - 2004	Household Full Year File
HC-089	2004 Full Year Consolidated Data File	X	2004	Household Full Year File
HC-088	2004 Person Round Plan Public Use File		2004	Household Full Year File
HC-087	2004 Medical Conditions File	X	2004	Household Full Year File
HC-086	MEPS Panel 8 Longitudinal Weight File		2003 - 2004	Household Full Year File
HC-085I	Appendix to MEPS 2004 Event Files	X	2004	Household Event File
HC-085H	2004 Home Health File		2004	Household Event File
HC-085G	2004 Office-Based Medical Provider Visits File		2004	Household Event File
HC-085F	2004 Outpatient Visits File		2004	Household Event File
HC-085E	2004 Emergency Room Visits File		2004	Household Event File

Download MEPS data files



MEPS HC-089: 2004 Full Year Consolidated Data File

HC-082 replaced by HC-089
Release date: October 2006

Released as an ASCII file (with related SAS and SPSS programming statements) and a SAS transport dataset, this public use file provides information collected on a nationally representative sample of the civilian non-institutionalized population of the United States for calendar year 2004. This file consists of MEPS survey data obtained in Rounds 3, 4, and 5 of Panel 8 and Rounds 1, 2, and 3 of Panel 9 (i.e., the rounds for the MEPS panels covering calendar year 2004) and consolidates all of the final 2004 person-level variables onto one file. This file contains the following variables previously released on HC-082: survey administration, language of interview variable, demographics, parent identifiers, health status, disability days variables, access to care, employment, quality of care, patient satisfaction, health insurance and use variables. The HC-089 file also includes these variables: income variables and expenditure variables.

Update notes

Documentation	File type
Documentation	PDF (1.3 MB) / HTML
Codebook	PDF (652 KB) / HTML*
SAS Programming Statements	ASCII format (449 KB)
SPSS Programming Statements	ASCII format (353 KB)
2003 Industry Codes File	PDF (15 KB) / HTML
2003 Occupation Codes File	PDF (39 KB) / HTML

Data	File type**
Data File, ASCII format	ZIP (10 MB) / EXE (11 MB)
Data File, SAS transport format	ZIP (14 MB) / EXE (11 MB)

Questionnaires — see Survey Questionnaires

*The PDF version of the codebook is recommended for printing; the HTML version is database driven and lets you navigate quickly to details on each variable.
**Right-click on the data file link, then select Save Target As or Save Link As to download the file.

New search

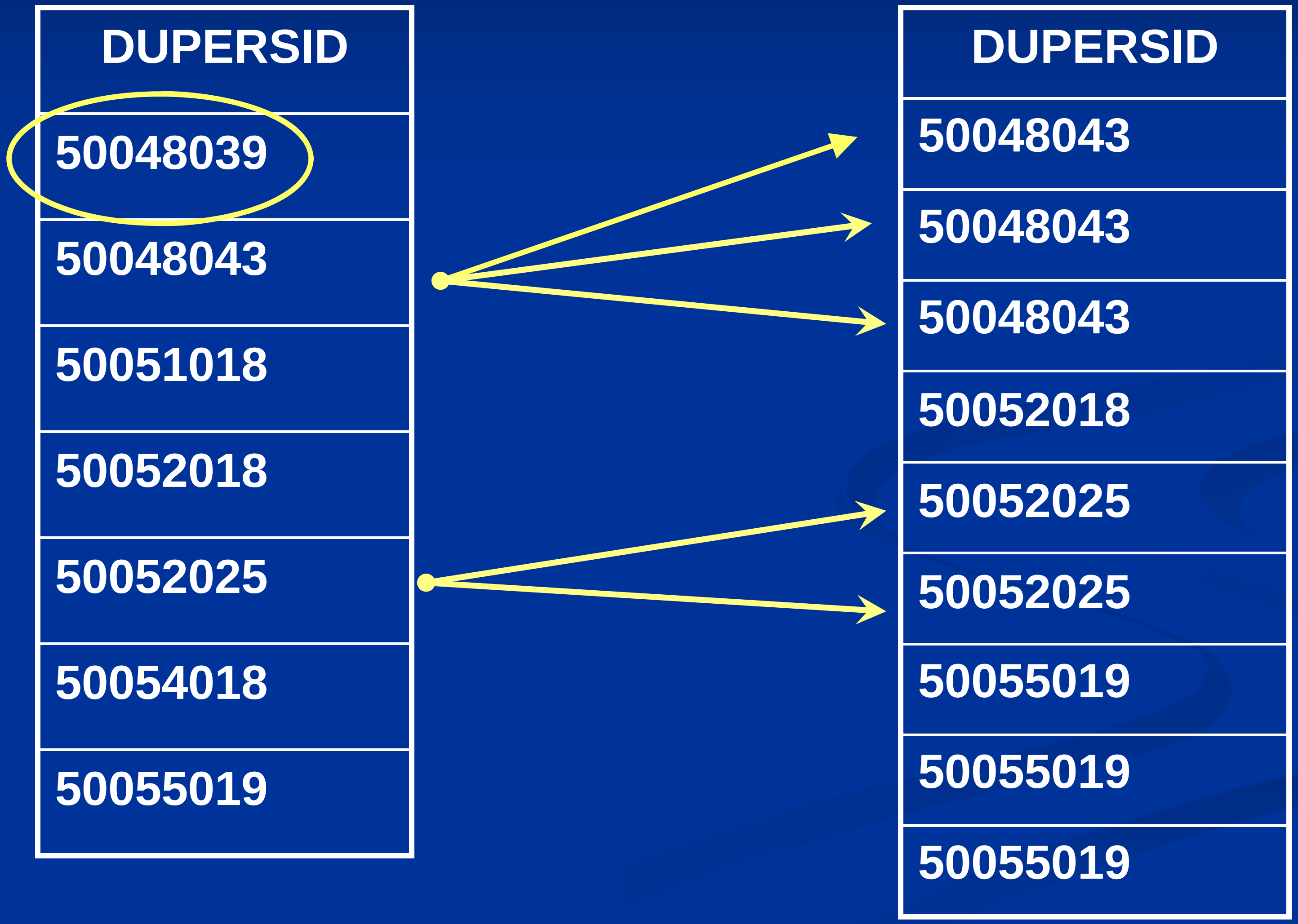
MEPS: Tips for using the data

- **Read the documentation.** There are many details in the documentation which serve as keys to using and understanding how the MEPS is collected and constructed.

- Pay close attention when **weighting the data in MEPS**. What number do you intend to report or reference? The unweighted n may be higher than the n to which weights are applied. Not all persons in the full year consolidated file receive a positive person-level weight. For example, in the 2005 MEPS Full Year Consolidate file, there are variables and frequency distributions for 33,961 persons. However, only 32,320 persons received a positive person-level weight.

- **Full year consolidated file is person level. Event files are EVENT level.** If you want to merge event files to the Full year consolidated file, you will have multiple rows of data per DUPERSID, i.e. per respondent for that event. AHRQ recommends linking files on person id and merging into the event file.

MEPS: HC File vs Event Level Files



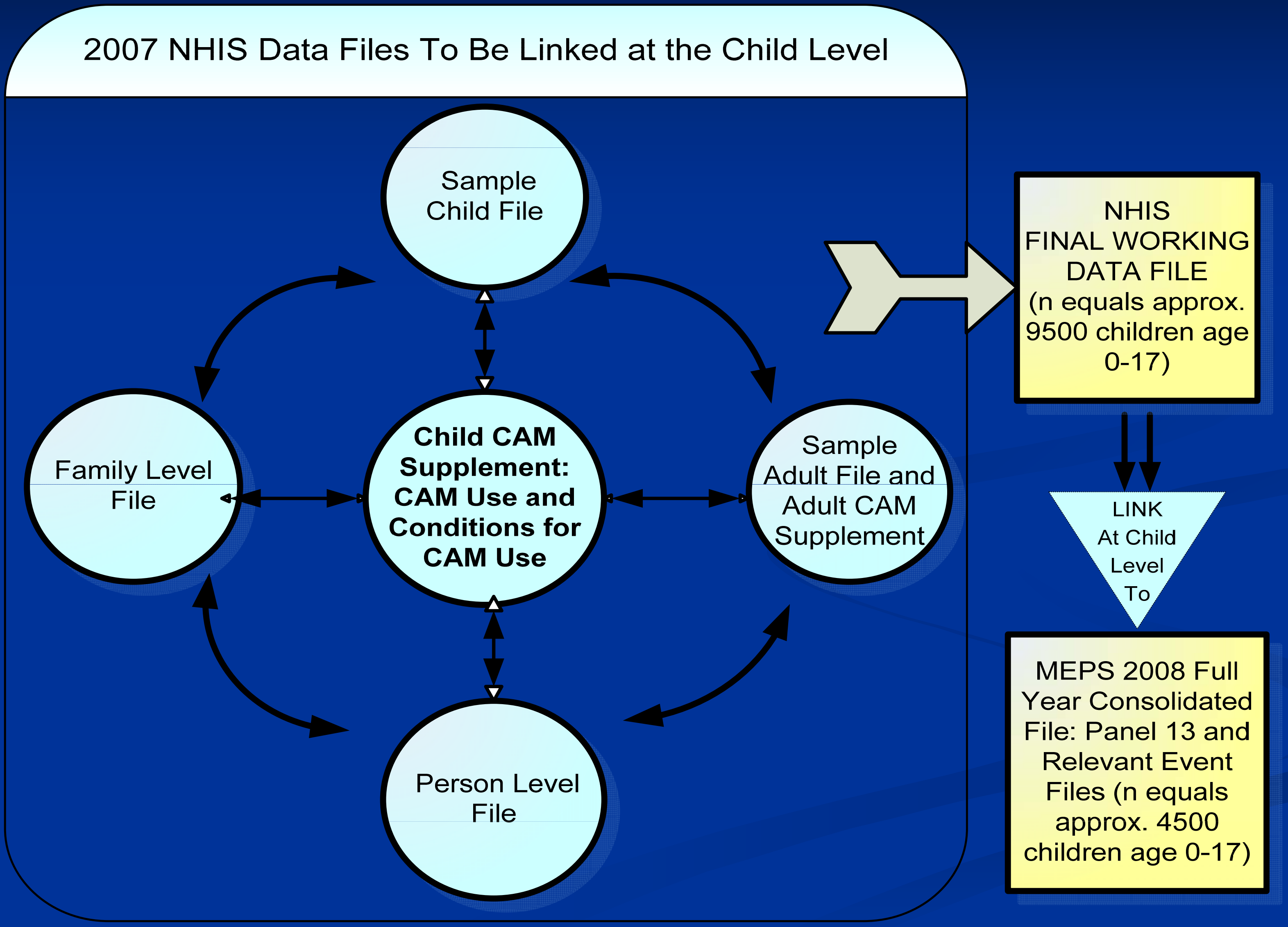
Full Year Consolidated File

DUPERSID
50048039
50048043
50051018
50052018
50052025
50054018
50055019

Prescription Meds File

DUPERSID
50048043
50048043
50048043
50052018
50052025
50052025
50055019
50055019
50055019

Figure 1: Illustration of the 2007 NHIS and 2008 MEPS Data Files to be Linked at the Child Level



2007 NHIS Data Files To Be Linked at the Child Level

Sample Child File

Family Level File

Child CAM Supplement: CAM Use and Conditions for CAM Use

Sample Adult File and Adult CAM Supplement

Person Level File

NHIS FINAL WORKING DATA FILE (n equals approx. 9500 children age 0-17)

LINK At Child Level To

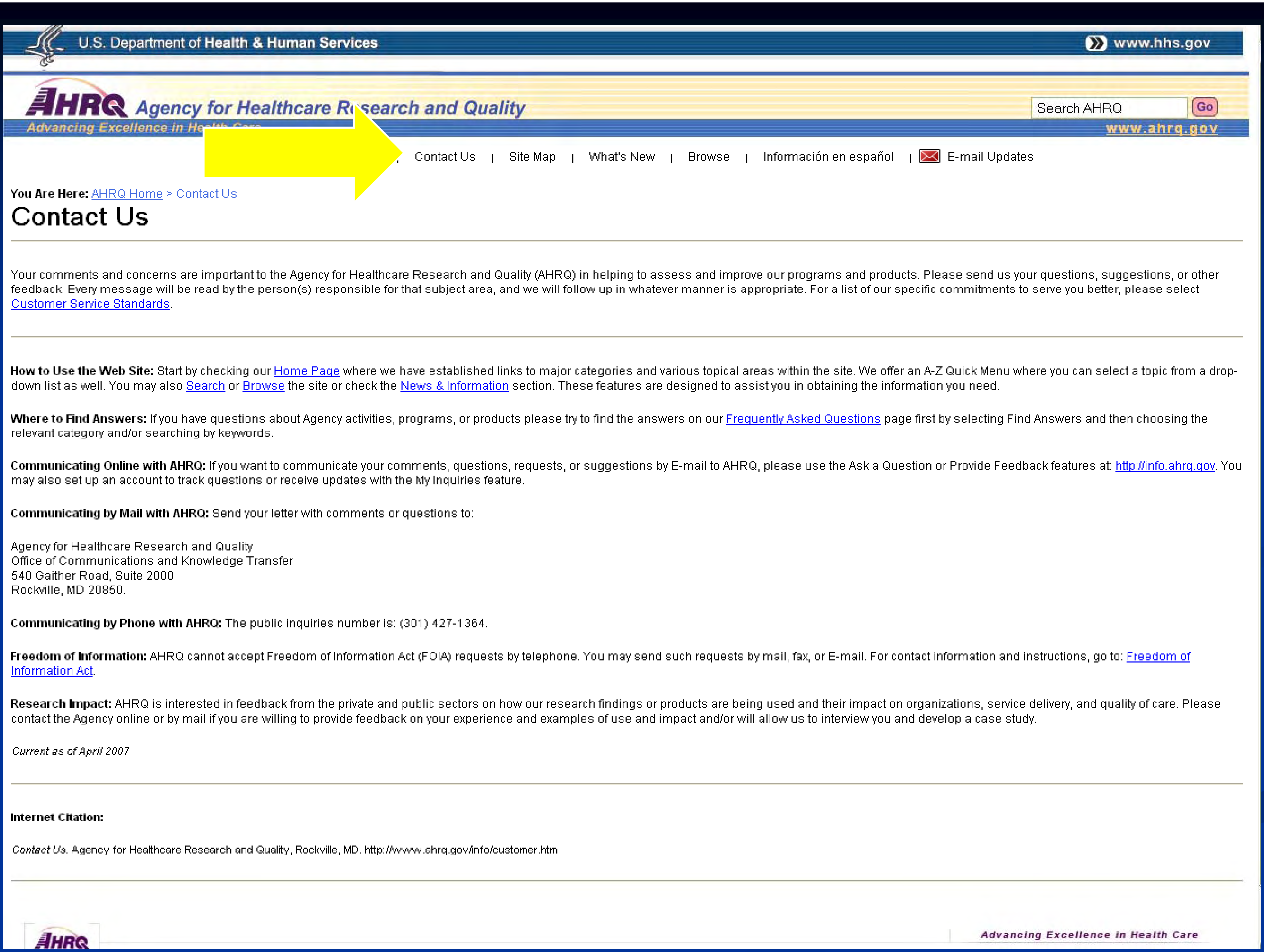
MEPS 2008 Full Year Consolidated File: Panel 13 and Relevant Event Files (n equals approx. 4500 children age 0-17)

MEPS: Tips for using the data (cont'd)

- **Join and utilize the MEPS listserv.** AHRQ provides a listserv for MEPS users when you have questions related to using the data. They are very helpful and respond in a timely manner.

http://www.meps.ahrq.gov/mepsweb/communication/listserv.jsp

- **Review the literature.** Many topics have been studied using MEPS, and so you may not have to reinvent the wheel. Looking at both the publications section of the MEPS website and on your favorite search engine (OVID, PubMed) for MEPS and your topic may provide good ideas for combining files and when to use variables from different time points.



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Overview of the National Survey of Children's Health (NSCH)

AND

National Survey of Children with Special Health Care Needs (NS-CSHCN)

The National Survey of Children's Health (NSCH)

- **Description:** State, national and regional representation of all non-institutionalized U.S. children ages 0-17. Broad range of information about children's health and well-being.
- **Data years:** 2003, 2007 (available early 2009)
- **Sample size:** 2003: 102,353 nationally. Between 1,483 and 2,241 per state.

The National Survey of Children with Special Health Care Needs (NS-CSHCN)

- **Description:** State, national and regional representation of all non-institutionalized U.S. children ages 0-17 who meet criteria for having a special health care need. Focus on health services need, use and performance.
- **Data years:** 2005/2006 and 2001
- **Sample size:** 2005/06: 40,804 nationally, approx. 800 per state

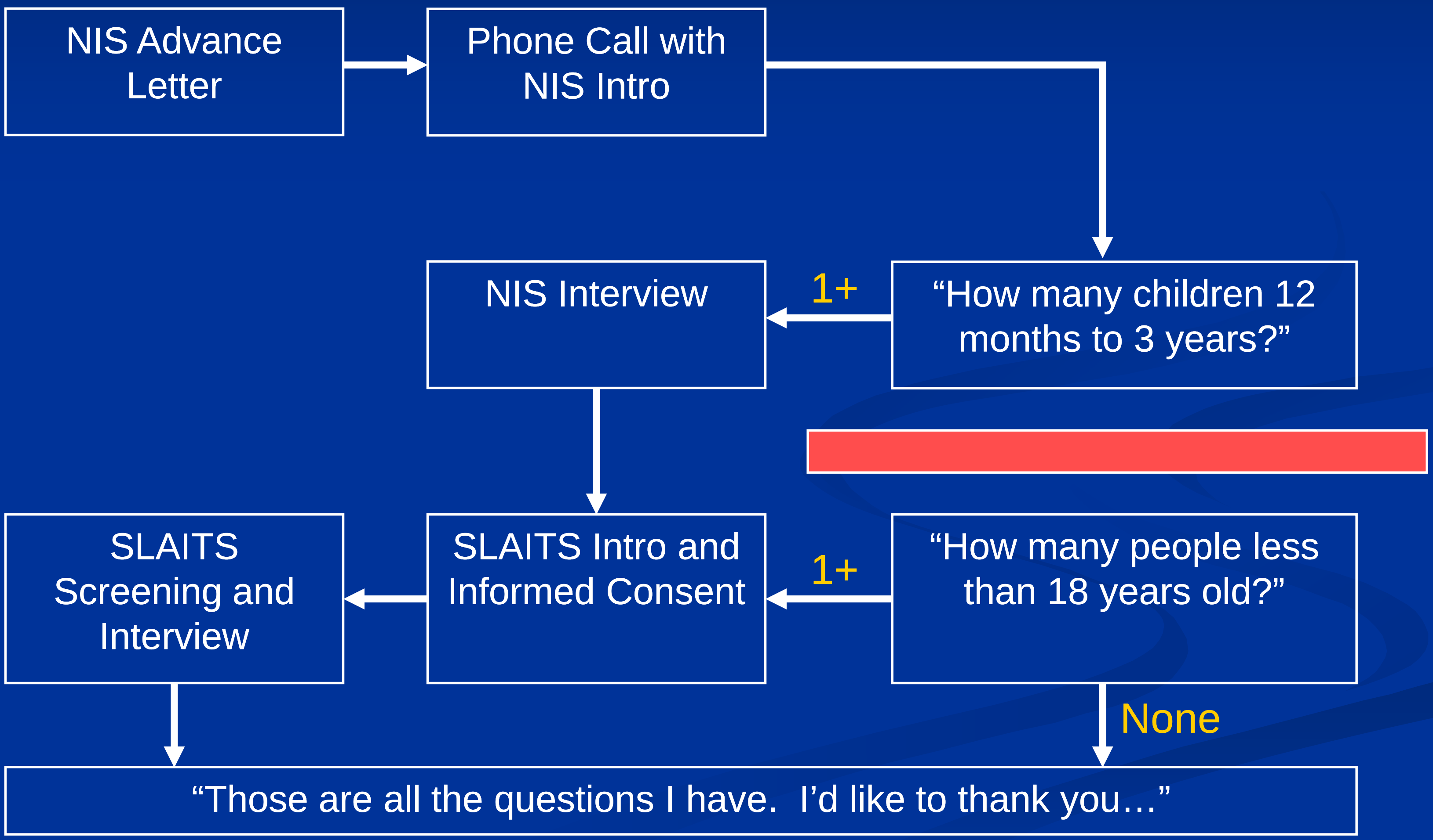
Two Surveys – what do they have in common?

- Sponsored by the Maternal and Child Health Bureau
- Use SLAITS (State & Local Area Integrated Telephone Survey) sampling mechanism
- National Center for Health Statistics/CDC oversees sampling and administration
- Designed and collected in a manner that allows valid state-to-state and national comparisons
- Weighted data yield prevalence estimates for non-institutionalized child population ages 0-17 in each state, and nationally

What is SLAITS?

- Uses National Immunization Survey sampling frame (which screens for households with children but only samples those w/ children ages 19-35 mos)
- Random Digit Dial telephone design
- Standardized questions produce comparative data across States & for the Nation
- Accommodates modules of customized questions and specific domains of interest
- Estimates are adjusted for non-coverage of HH’s without telephones

NSCH and NS-CSHCN Survey Design Flowchart



NIS Advance Letter

Phone Call with NIS Intro

"How many children 12 months to 3 years?"

1+

NIS Interview

"How many people less than 18 years old?"

1+

SLAITS Intro and Informed Consent

SLAITS Screening and Interview

None

"Those are all the questions I have. I'd like to thank you…"

NSCH and NS-CSHCN Overview

- **Data linkages:** To zipcode (not County) with NCHS RDC approval.
- **Technical requirements:** Statistical Software
- **Availability/cost of data:** Available on the Data Resource Center Web site and the NCHS Web site for no cost

How do the surveys differ?

- Population: CSHCN versus all children 0-17
- How subject of the interview is identified: Randomly selected a CSHCN after screening all children in household versus randomly selected one child in each household and then asked CSHCN screening questions

How do the surveys differ?

- Topic areas: CSHCN-specific versus inclusion of family, neighborhood, and wellness information
- CSHCN sample size: 750-800 per state for NS-CSHCN vs. about 300 per state for NSCH

National Survey of CSHCN: 2001

372,174 children, 0 - 17 yrs, in the 196,888 households contacted screened for having special health care needs

NO special health care needs
(323,484 children/youth)

YES special health care needs
(48,690 children/youth)

From this group, 750 CYSHCN selected in EACH state for the longer CSHCN interview

38,866 CSHCN interviews completed

Nat. Survey of CSHCN uses the MCHB definition as starting point for identification:

> *"Children with special health care needs . . . 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."*
>
> — Maternal and Child Health Bureau, July 1998

CSHCN Screener

Asks about 5 different health consequences:

1) Limited or prevented in ability to function
2) Prescription medication need/use
3) Specialized therapies (OT, PT, Speech)
4) Above routine use of medical care, mental health or other health services
5) Counseling or treatment for on-going emotional, behavioral or developmental problem

a) Due to medical, behavioral or other health condition

AND

b) Condition has lasted or is expected to last for at least 12 months

National Survey of CSHCN

<u>Denominator</u> #1
Households w/ children

372,174 children, 0 - 17 yrs, in
the 196,888 households

<u>Denominator</u> #2
Child population, ages 0-17

NO special health care needs
(323,484 children/youth)

YES special health care needs
(48,690 children/youth)

From this group, 750 CYSHCN selected in EACH state for the longer CSHCN interview

38,866 CSHCN interviews completed

<u>Denominator</u> #3
CSHCN population, ages 0-17

In-depth CSHCN interview collects information on:

- Child health and functional status
- Child health insurance status and adequacy of coverage
- Access to health care — needed services & unmet needs
- Care coordination
- Impact of child's health on family
- MCHB core outcomes for CYSHCN and
- Key indicators of CSHCN health & system performance

Conditions

Asthma; Allergies

ADHD/ADD

Depression, anxiety, etc.

Diabetes (w/ or w/o insulin use)

Migraine/freq headaches

Heart problem (including congenital heart disease)

Blood problems (including sickle cell or anemia)

Arthritis/other joint probs

Epilepsy or seizure

Cerebral palsy

Cystic fibrosis

Muscular dystrophy

Autism or ASD

Down Syndrome

Mental retardation or developmental delay

Functional Difficulties

Difficulty seeing even with glasses/contacts

Use hearing aids

Difficulty hearing even with aids

Respiratory problems

Swallowing, digesting etc.

Blood circulation

Chronic pain

Self care

Gross motor

Fine motor

Speaking; communicating

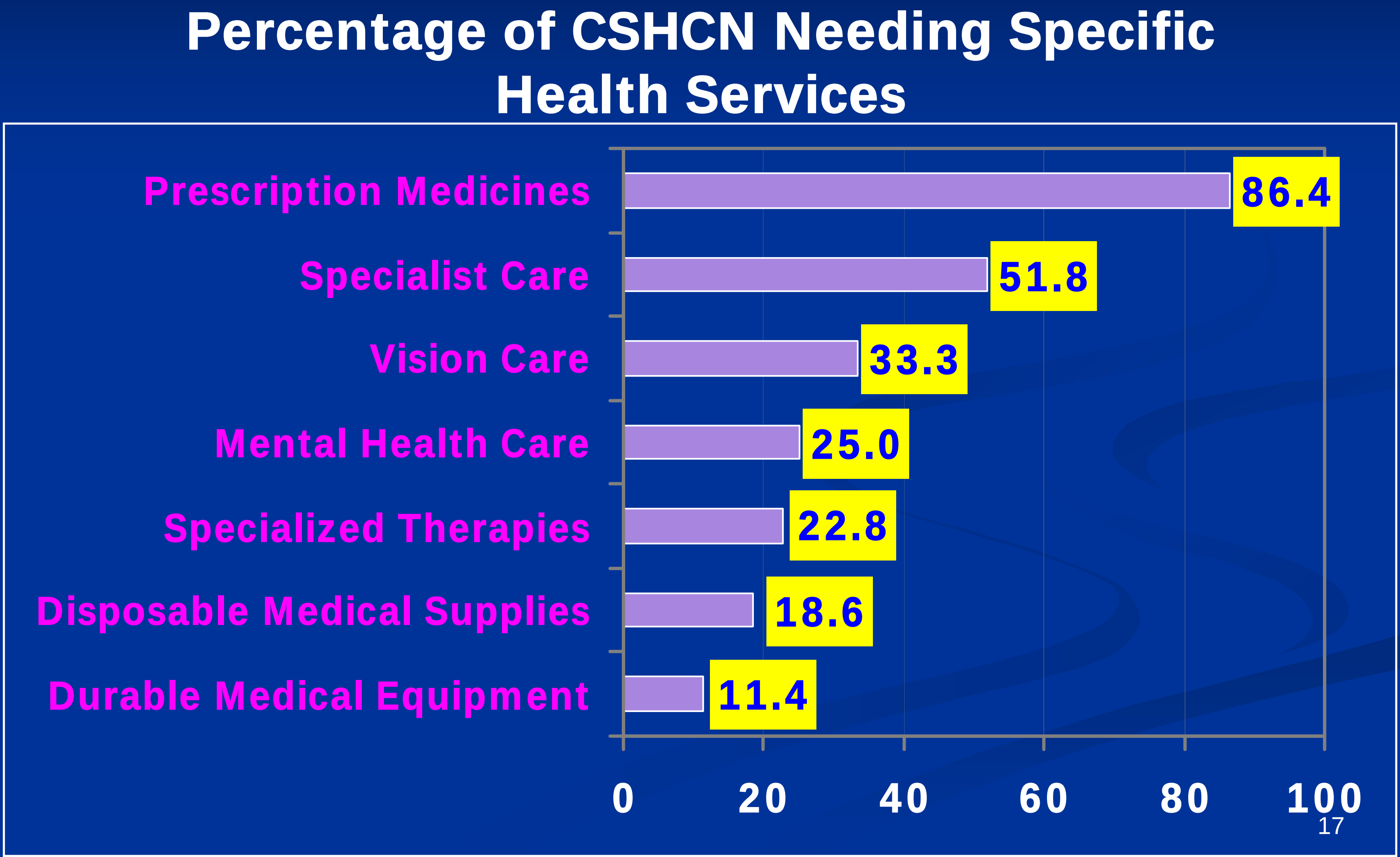
Learning, paying attention

Anxiety or depression

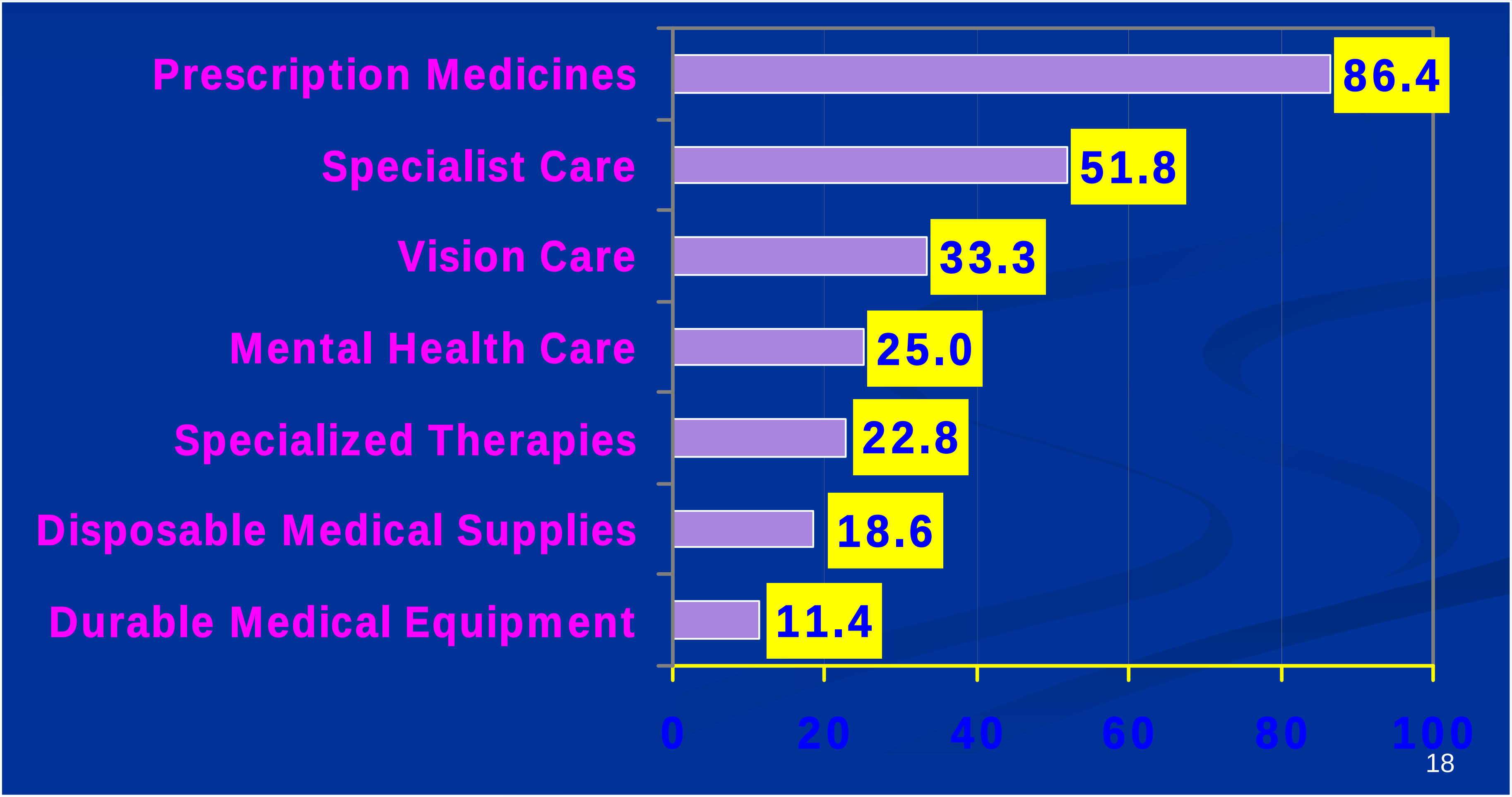
Behavior / conduct probs

Making & keeping friends

Common Service Needs



Common System Performance Improvement Needs



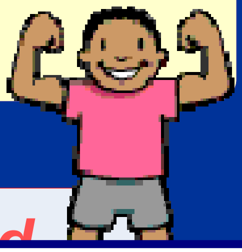
National Survey of Children's Health

- Conducted for the first time during 2003 – 2004
- One child randomly selected in each household subject of survey for a total of 102,353 interviews
- Same CSHCN screening method as NS-CSHCN
- Information on children's health and well-being collected in combination with data on child's family/neighborhood context
- First time such a broad range of info collected in manner that allow state-to-state and national comparisons

National Survey of Children's Health

Denominator #1
Children, ages 0-17

Survey Se tions
1 – 5 and 8 –11
are asked for children
of all ages



102,353
Children ages 0-17
d, 1 per HH

Early Childhood

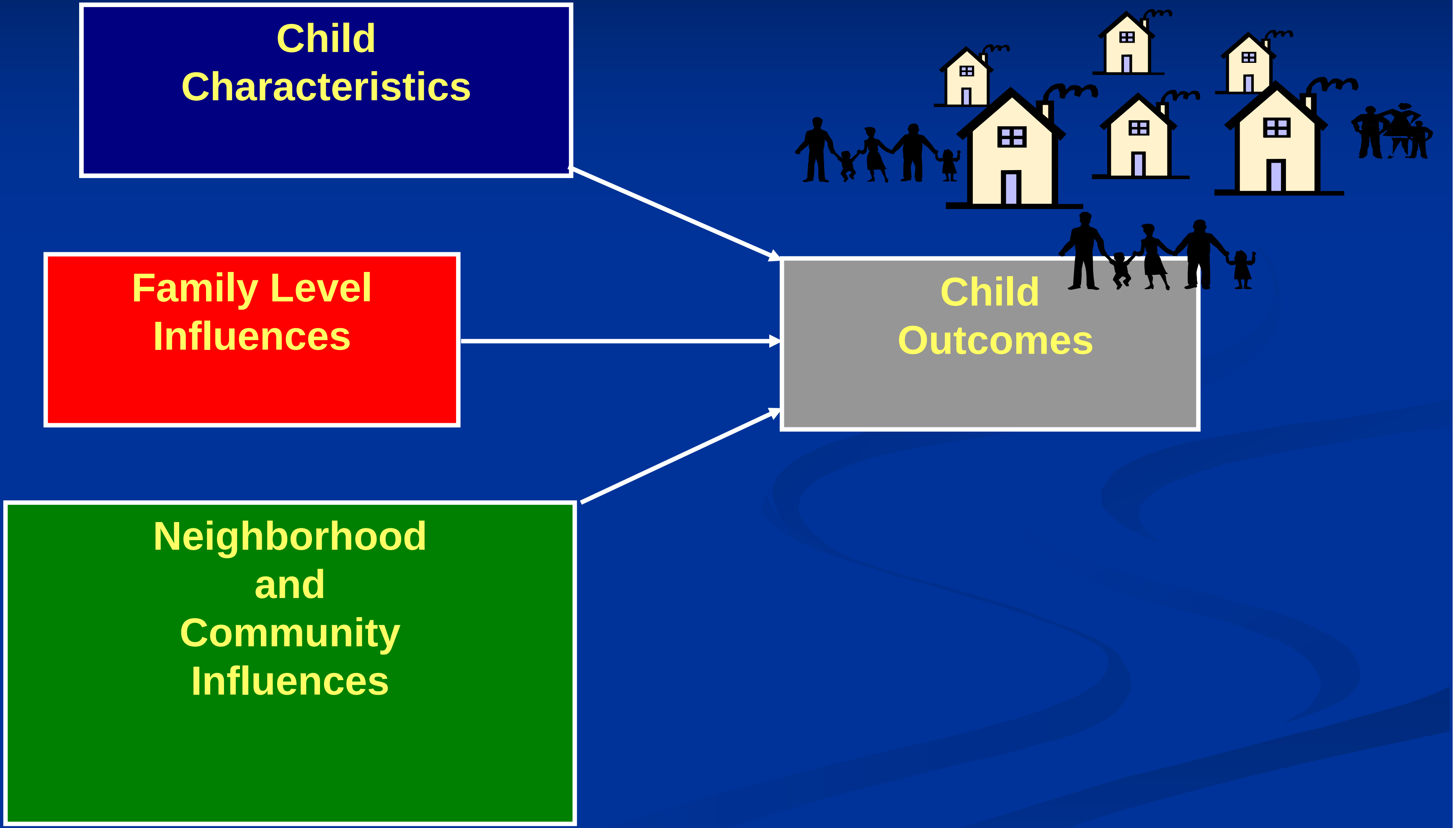
Denominator #2: Children, ages 0-5

asked for
children ages 0-5

Middle childhood/Adolescence
tions (Section 7)
children ages 6-17

Denominator #3
Children/youth,
ages 6-17

NSCH Survey Domains



Child Characteristics

Family Level Influences

Neighborhood and Community Influences

Child Outcomes

Survey yields over 100 indicators of child health & well-being in the following areas:

- Child’s health status: physical, emotional, dental
- Child’s health care – including medical home
- Child’s school & activities
- Child’s family & neighborhood -- including maternal health status
- Early childhood (ages 0-5)
- School-age (ages 6-17)

Some Limitations to Consider for the NS-CSHCN and NSCH

- Limited sub-state analytic capacity; no county level estimates
- Cross-sectional; point in time data every 4 years
- Parent report data; 12 months recall frame
- Telephone survey data subject to non-response, non-coverage, and related biases
- Revisions and changes to survey content prevent trending of some content across survey years

Other key considerations:

- The denominator for ALL results in both surveys is always CHILDREN -- never parents!
  - Correct -- % of children ages 0-17, or ages 0-5, or ages 6-17, etc.
  - Never % of parents, families, mothers . . . .
- To calculate prevalence, use correct weighting variable – esp. important detail for NS-CSHCN because there are the 3 different denominators each have their own weighting variable

Other key considerations:

- In order to make statistical comparisons, analysis software that adjusts variances for complex survey design must be used *(e.g. SUDAAN, STATA, SPSS complex samples)*
- *Each state's data can be analyzed separately – but do not subset data within a state or nationally unless using SUB POP options that account for complex survey design*
- The approaches to dealing with "unknown responses" (DON'T KNOW or REFUSE) vary ---- be sure to consider this issue when reporting estimates that involve population counts (% point estimates are generally not affected)

Using the Data Resource Center for Child and Adolescent Health to Access NSCH and NS-CSHCN Findings, Datasets and Resources

www.childhealthdata.org

www.childhealthdata.org

Data Resource Center

for Child & Adolescent Health

www.cshcndata.org

www.nschdata.org

National Survey of Children with Special Health Care Needs, 2001 & 2005/06

National Survey of Children's Health, 2003

NSCH 2007 *next Fall-Winter*

What are the Data Resource Center goals?

1) Provide **centralized, user-friendly interactive** access to standardized state & national child survey data

2) Build common **knowledge, capacity, and passion** for using data to stimulate system change

3) **Target user audience:** state health agency leaders and staff, family advocates and policy leaders

What features are available?

- **Learn** about the surveys
- **Search and compare** state & national results overall & for subgroups of children (age, race, sex, income, insurance and health status, etc.)
- **Access resources & examples** for reporting your findings in a valid and effective manner
- **Get expert help** – by e-mailing us your questions

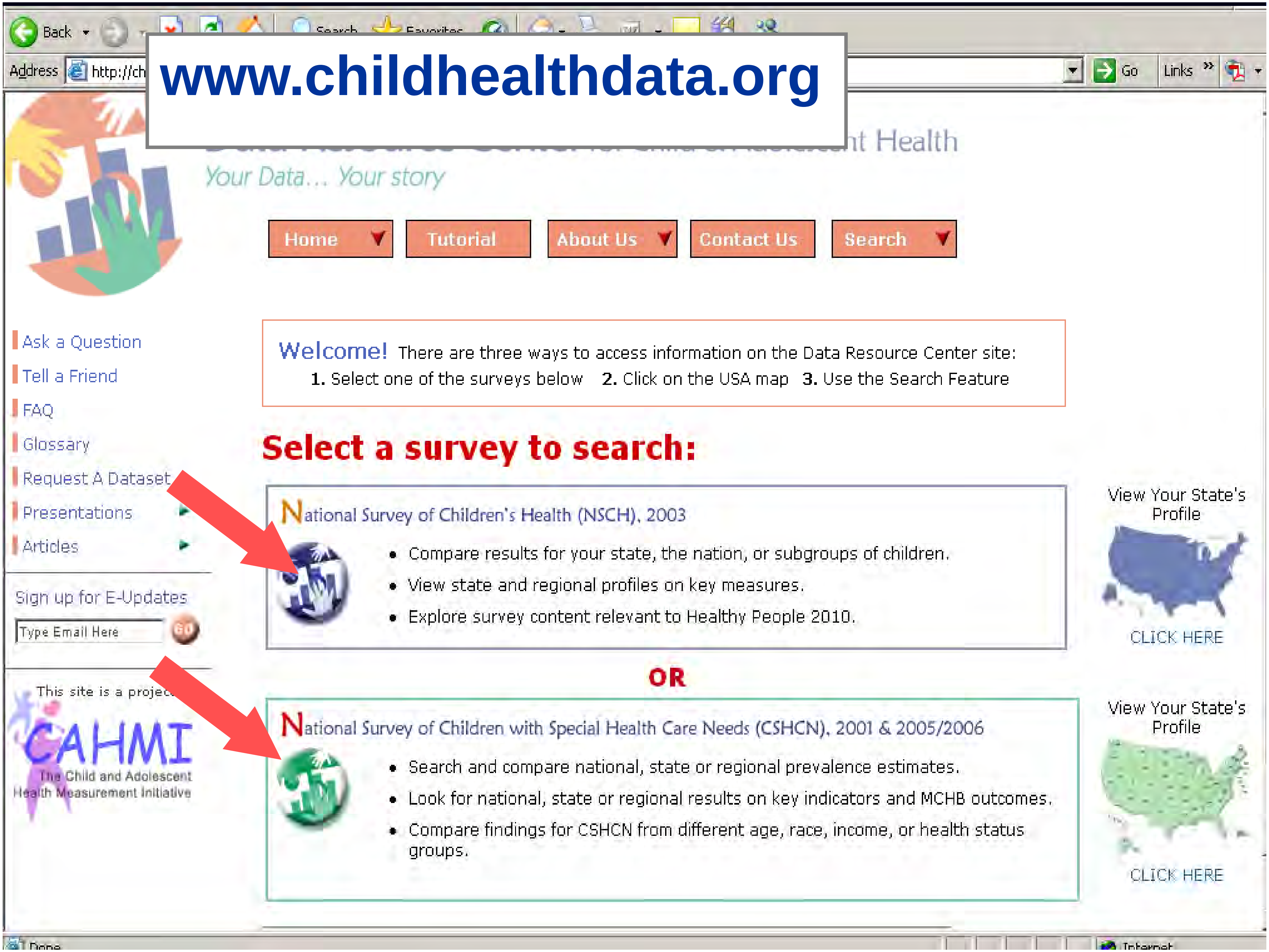
Interactive User-Generated Data Reports

1. **Tables & Graphs for Each Indicator or Survey Question**

2. **3 types of State Profile Summary Reports**

3. **“All States” Comparison & Ranking Tables**

www.childhealthdata.org



Welcome! There are three ways to access information on the Data Resource Center site:

1. Select one of the surveys below **2.** Click on the USA map **3.** Use the Search Feature

Select a survey to search:

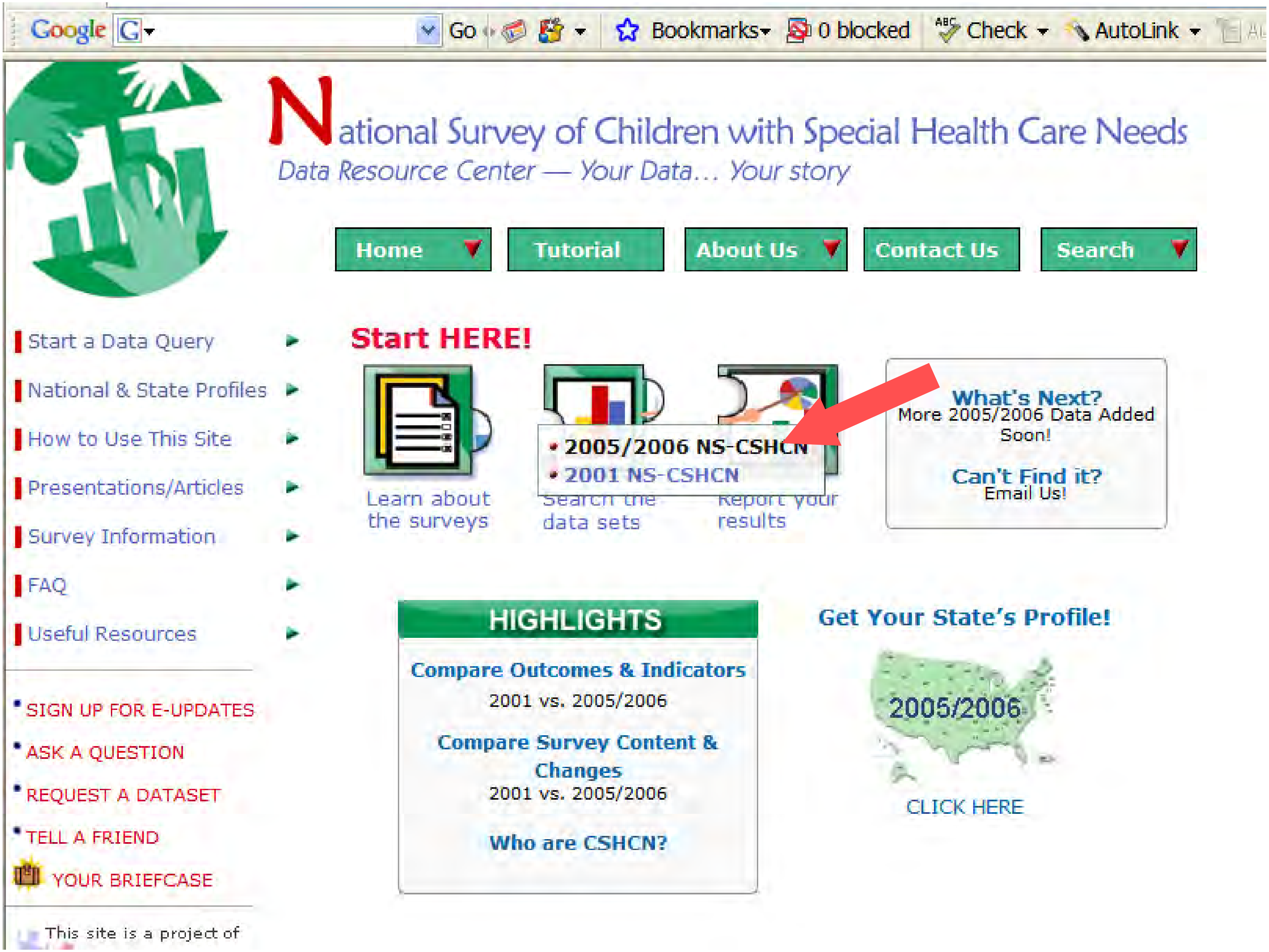
National Survey of Children's Health (NSCH), 2003

- Compare results for your state, the nation, or subgroups of children.
- View state and regional profiles on key measures.
- Explore survey content relevant to Healthy People 2010.

OR

National Survey of Children with Special Health Care Needs (CSHCN), 2001 & 2005/2006

- Search and compare national, state or regional prevalence estimates.
- Look for national, state or regional results on key indicators and MCHB outcomes.
- Compare findings for CSHCN from different age, race, income, or health status groups.



National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data… Your story

- Start a Data Query
- National & State Profiles
- How to Use This Site
- Presentations/Articles
- Survey Information
- FAQ
- Useful Resources

- SIGN UP FOR E-UPDATES
- ASK A QUESTION
- REQUEST A DATASET
- TELL A FRIEND
- YOUR BRIEFCASE

This site is a project of

Start HERE!

- 2005/2006 NS-CSHCN
- 2001 NS-CSHCN

Learn about the surveys

Search the data sets

Report your results

What's Next?
More 2005/2006 Data Added Soon!

Can't Find it?
Email Us!

HIGHLIGHTS

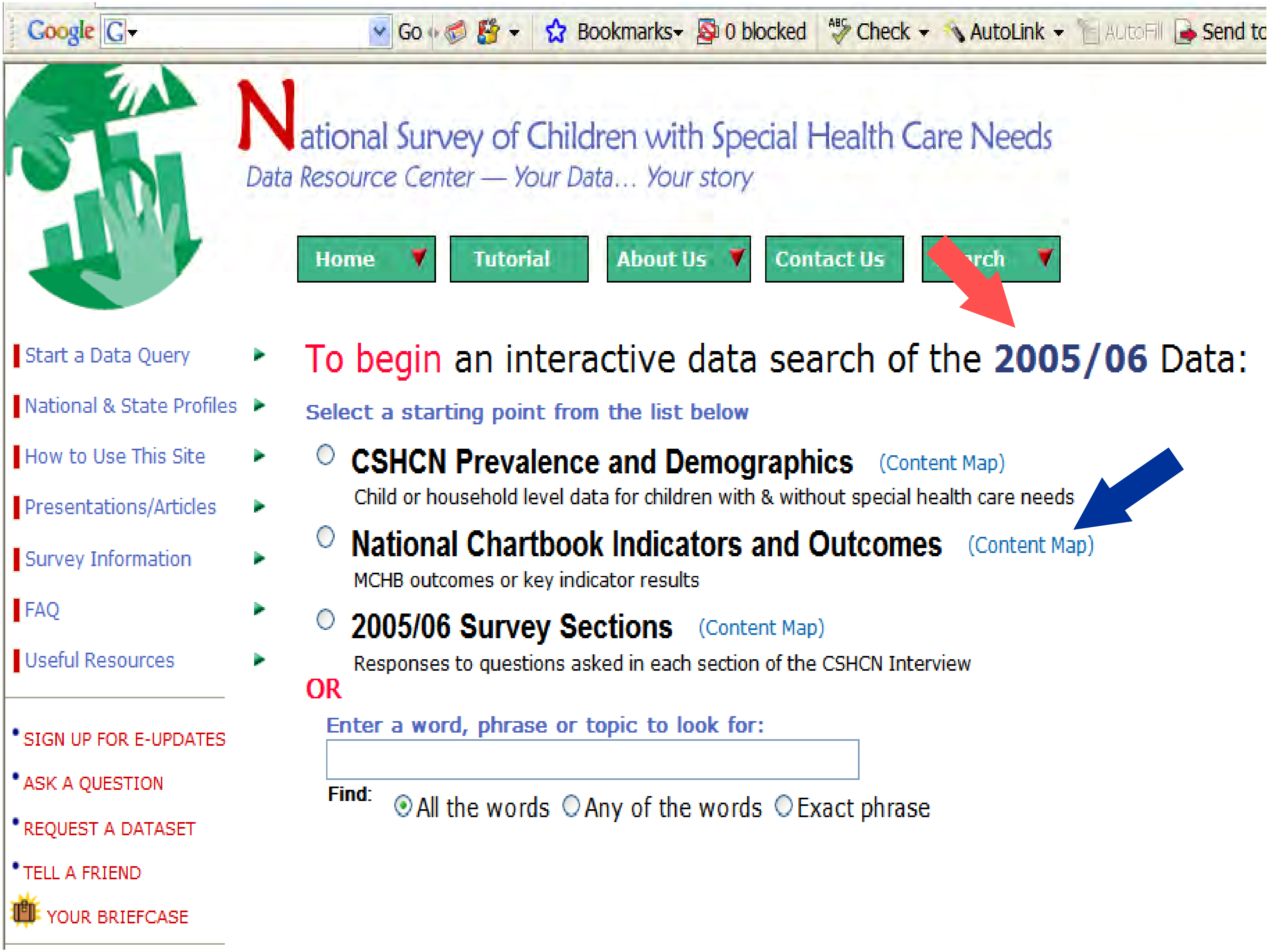
Compare Outcomes & Indicators
2001 vs. 2005/2006

Compare Survey Content & Changes
2001 vs. 2005/2006

Who are CSHCN?

Get Your State's Profile!

CLICK HERE



National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data… Your story

To begin an interactive data search of the **2005/06** Data:

Select a starting point from the list below

○ **CSHCN Prevalence and Demographics** (Content Map)

Child or household level data for children with & without special health care needs

○ **National Chartbook Indicators and Outcomes** (Content Map)

MCHB outcomes or key indicator results

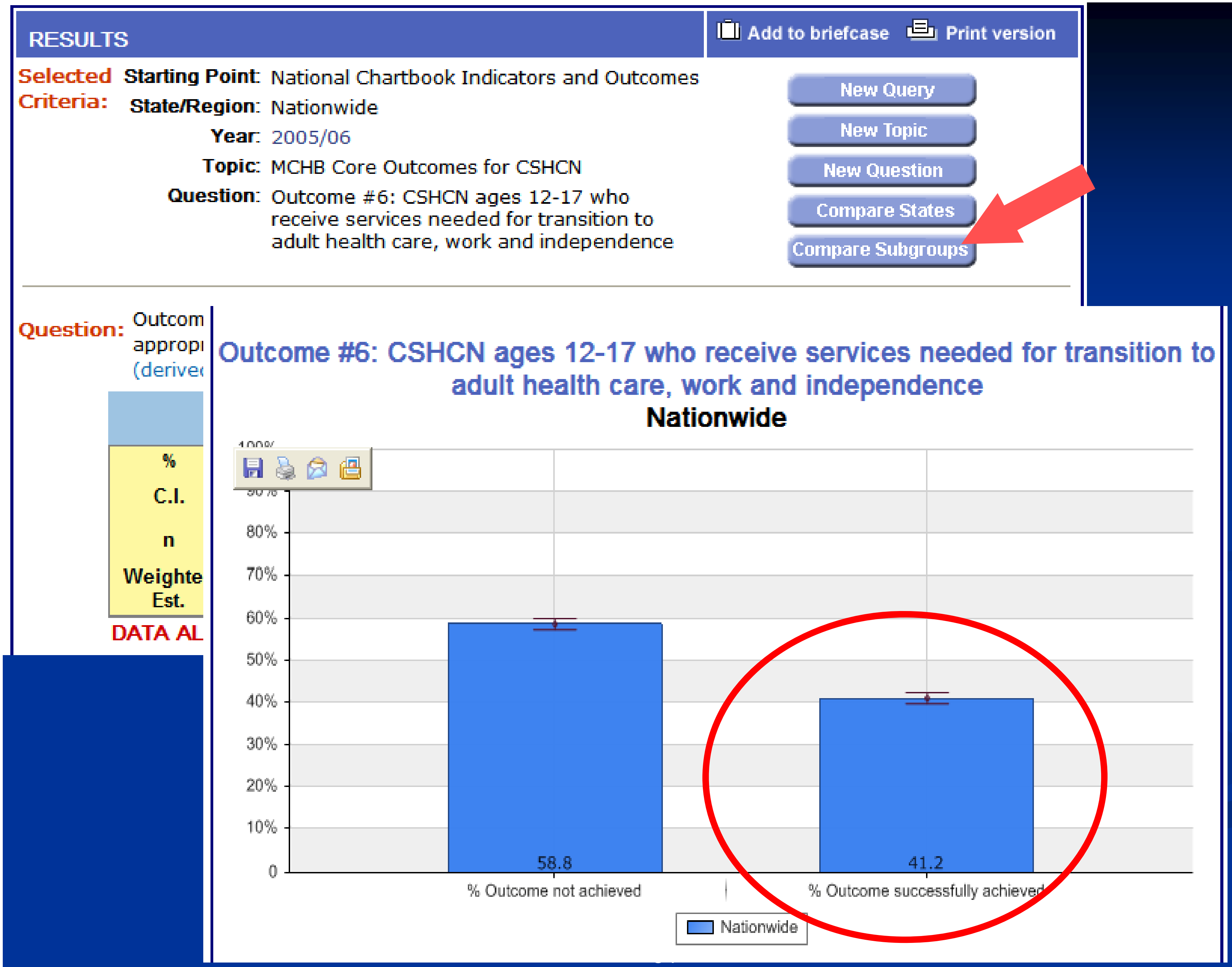
○ **2005/06 Survey Sections** (Content Map)

Responses to questions asked in each section of the CSHCN Interview

OR

Enter a word, phrase or topic to look for:

Find: ● All the words ○ Any of the words ○ Exact phrase



Selected Criteria:

Starting Point: National Chartbook Indicators and Outcomes

State/Region: Nationwide

Year: 2005/06

Topic: MCHB Core Outcomes for CSHCN

Question: Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work and independence

Question: Outcom
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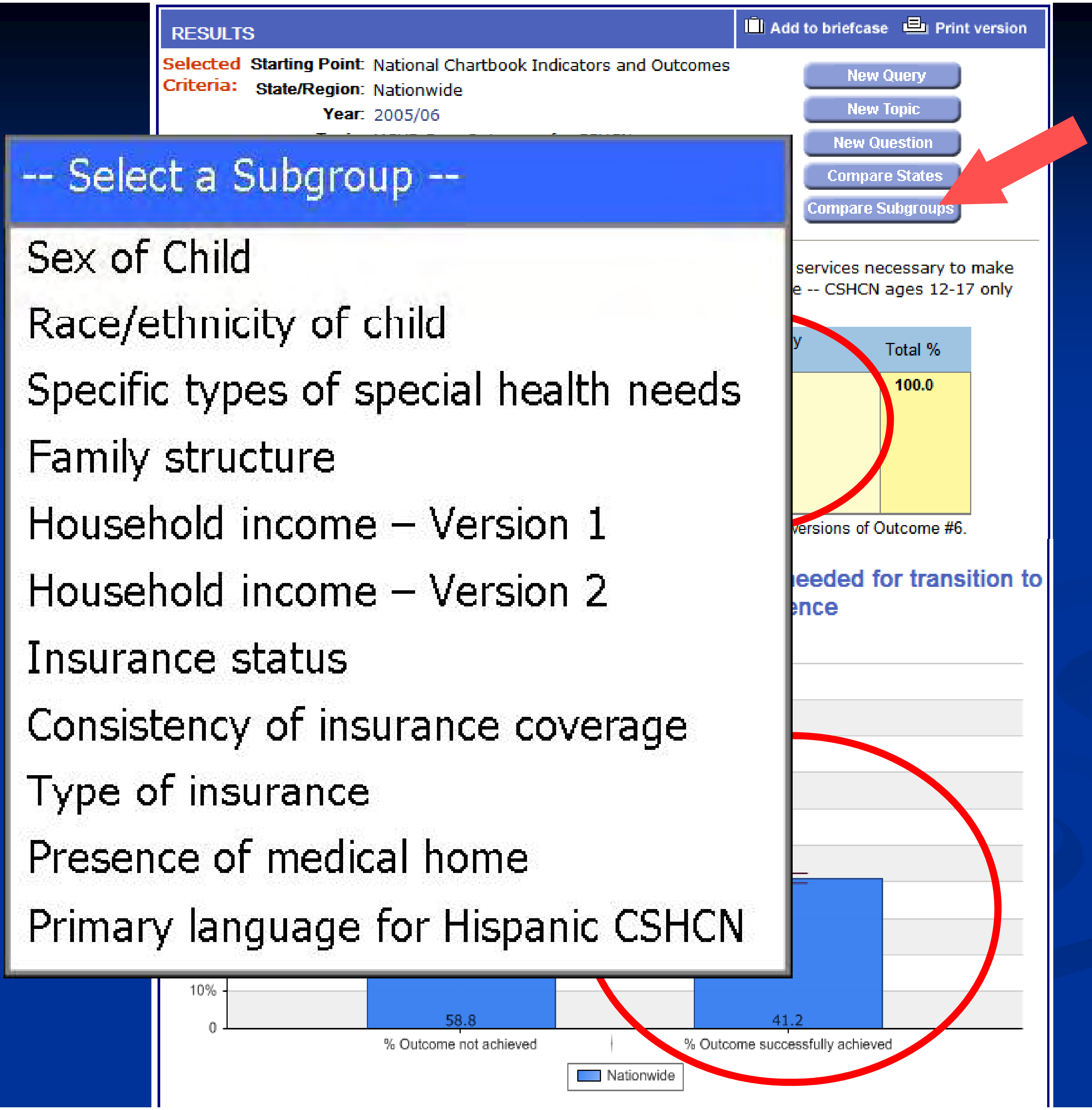
Outcome #6: CSHCN ages 12-17 who receive services needed for transition to adult health care, work and independence

Nationwide



Selected Criteria:
Starting Point: National Chartbook Indicators and Outcomes
State/Region: Nationwide
Year: 2005/06

services necessary to make
e -- CSHCN ages 12-17 only

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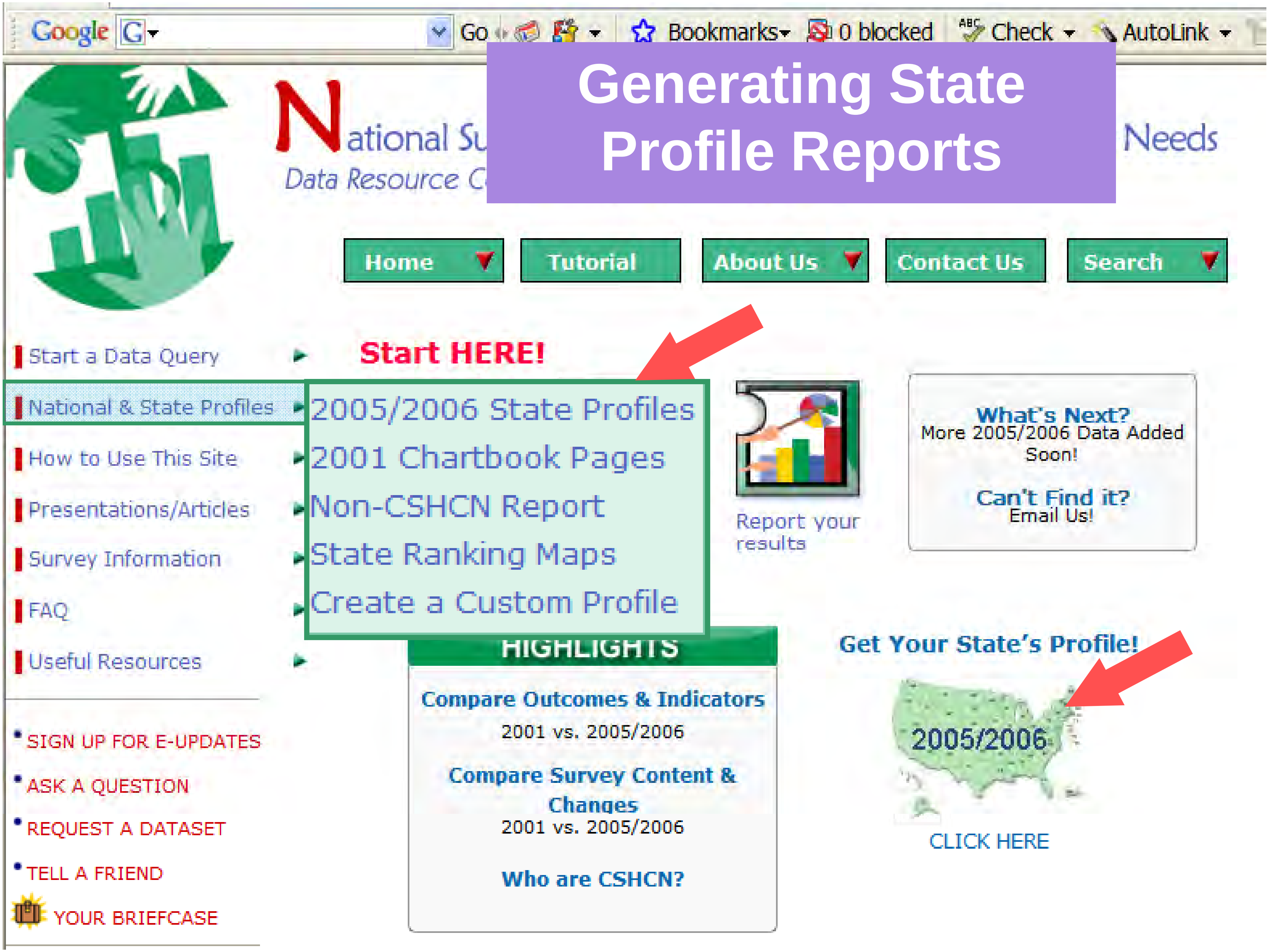
eeded for transition to
ence

Generating State Profile Reports



Start HERE!

- Start a Data Query
- National & State Profiles
- How to Use This Site
- Presentations/Articles
- Survey Information
- FAQ
- Useful Resources

- 2005/2006 State Profiles
- 2001 Chartbook Pages
- Non-CSHCN Report
- State Ranking Maps
- Create a Custom Profile

Report your results

What's Next?
More 2005/2006 Data Added Soon!

Can't Find it?
Email Us!

- SIGN UP FOR E-UPDATES
- ASK A QUESTION
- REQUEST A DATASET
- TELL A FRIEND
- YOUR BRIEFCASE

HIGHLIGHTS

Compare Outcomes & Indicators
2001 vs. 2005/2006

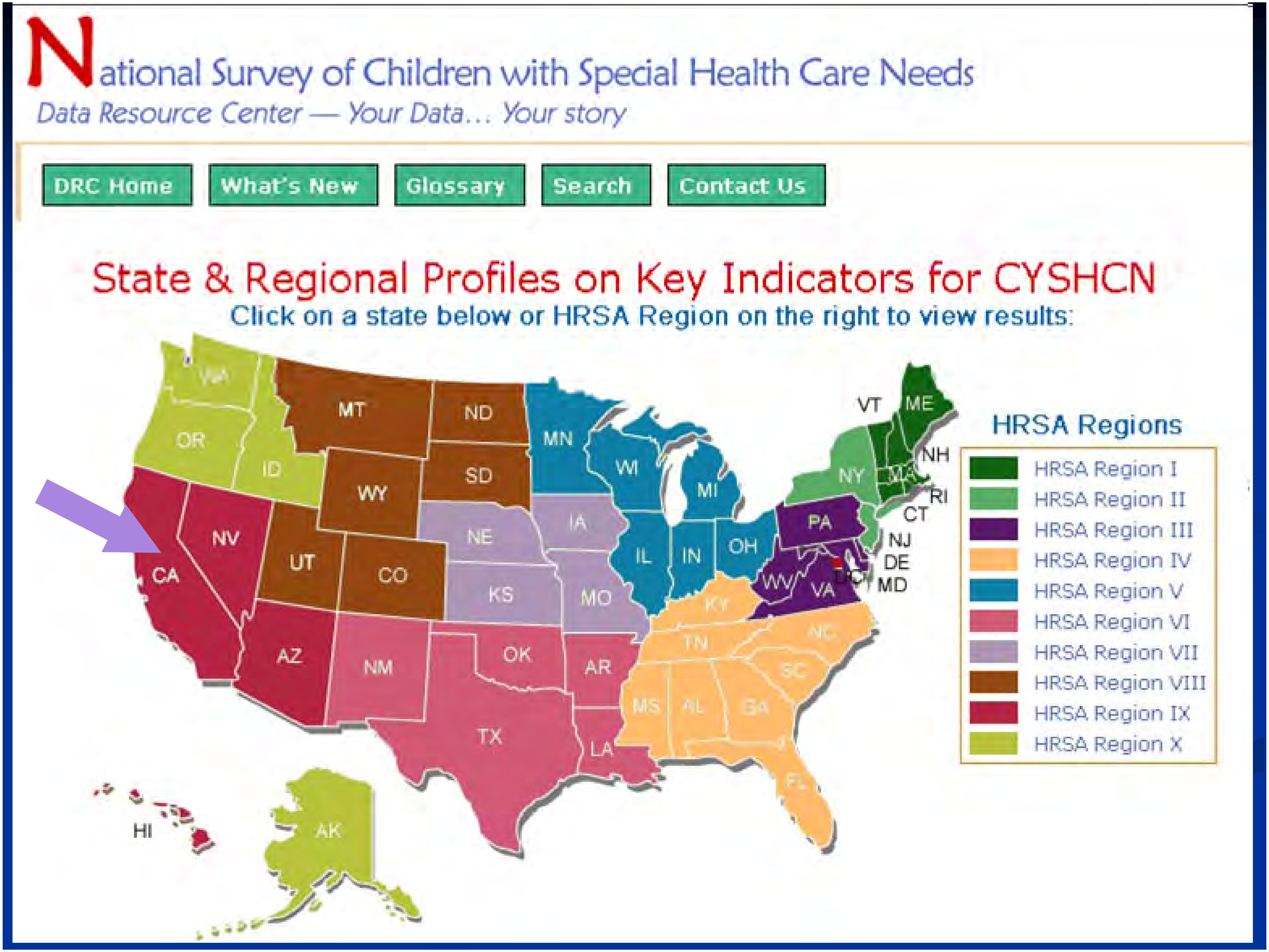
Compare Survey Content & Changes
2001 vs. 2005/2006

Who are CSHCN?

Get Your State's Profile!

2005/2006

CLICK HERE



National Survey of Children with Special Health Care Needs

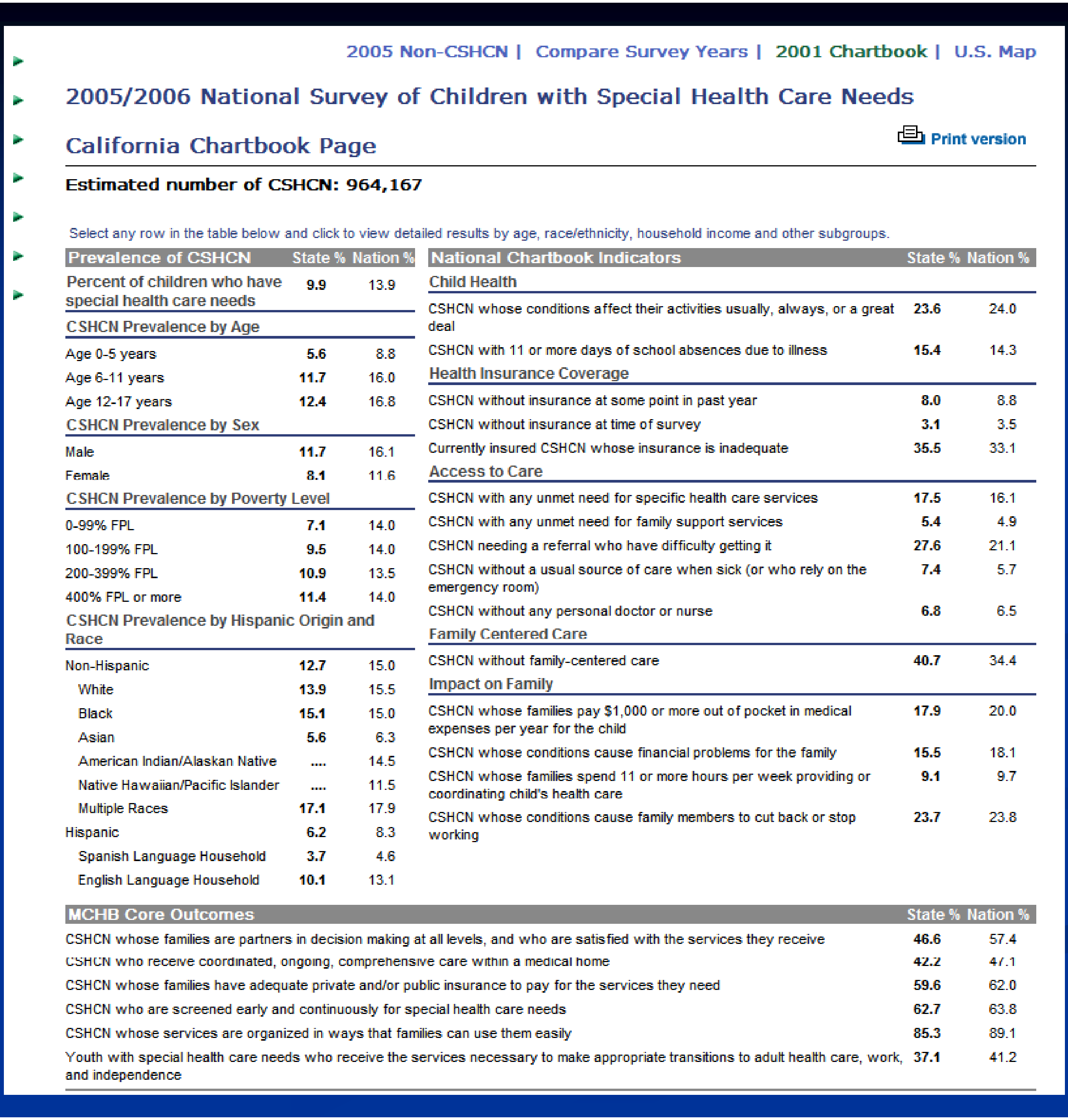
Data Resource Center — Your Data… Your story

State & Regional Profiles on Key Indicators for CYSHCN

Click on a state below or HRSA Region on the right to view results:

HRSA Regions

- 🟩 HRSA Region I
- 🟩 HRSA Region II
- 🟪 HRSA Region III
- 🟧 HRSA Region IV
- 🟦 HRSA Region V
- 🟥 HRSA Region VI
- 🟪 HRSA Region VII
- 🟫 HRSA Region VIII
- 🟥 HRSA Region IX
- 🟩 HRSA Region X



2005 Non-CSHCN | Compare Survey Years | 2001 Chartbook | U.S. Map

2005/2006 National Survey of Children with Special Health Care Needs

California Chartbook Page

Print version

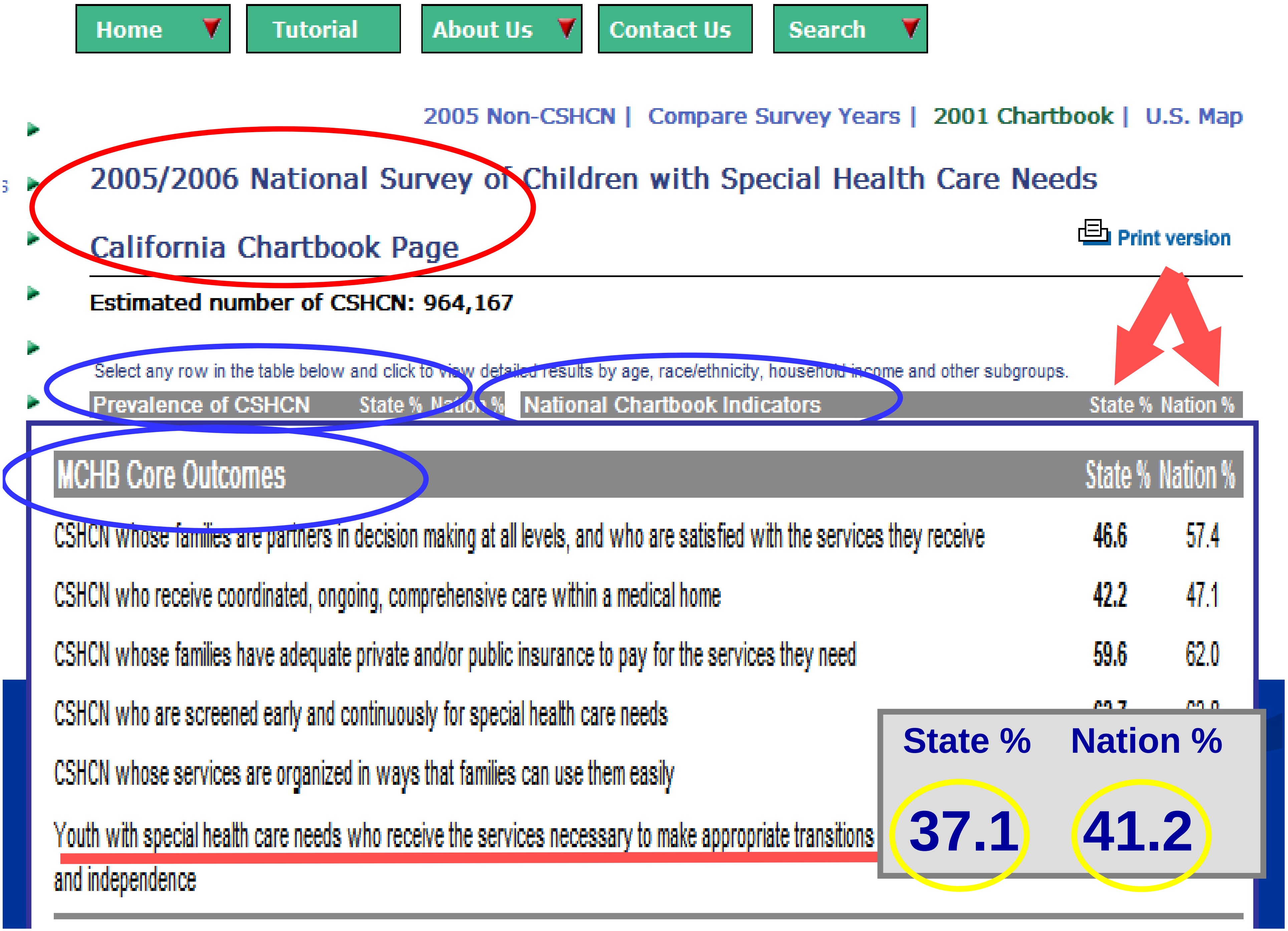
Estimated number of CSHCN: 964,167

Select any row in the table below and click to view detailed results by age, race/ethnicity, household income and other subgroups.

Prevalence of CSHCN	State %	Nation %
Percent of children who have special health care needs	**9.9**	13.9
CSHCN Prevalence by Age		
Age 0-5 years	**5.6**	8.8
Age 6-11 years	**11.7**	16.0
Age 12-17 years	**12.4**	16.8
CSHCN Prevalence by Sex		
Male	**11.7**	16.1
Female	**8.1**	11.6
CSHCN Prevalence by Poverty Level		
0-99% FPL	**7.1**	14.0
100-199% FPL	**9.5**	14.0
200-399% FPL	**10.9**	13.5
400% FPL or more	**11.4**	14.0
CSHCN Prevalence by Hispanic Origin and Race		
Non-Hispanic	**12.7**	15.0
White	**13.9**	15.5
Black	**15.1**	15.0
Asian	**5.6**	6.3
American Indian/Alaskan Native	**....**	14.5
Native Hawaiian/Pacific Islander	**....**	11.5
Multiple Races	**17.1**	17.9
Hispanic	**6.2**	8.3
Spanish Language Household	**3.7**	4.6
English Language Household	**10.1**	13.1

National Chartbook Indicators	State %	Nation %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	**23.6**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in past year	**8.0**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.5**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**17.5**	16.1
CSHCN with any unmet need for family support services	**5.4**	4.9
CSHCN needing a referral who have difficulty getting it	**27.6**	21.1
CSHCN without a usual source of care when sick (or who rely on the emergency room)	**7.4**	5.7
CSHCN without any personal doctor or nurse	**6.8**	6.5
Family Centered Care		
CSHCN without family-centered care	**40.7**	34.4
Impact on Family		
CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child	**17.9**	20.0
CSHCN whose conditions cause financial problems for the family	**15.5**	18.1
CSHCN whose families spend 11 or more hours per week providing or coordinating child's health care	**9.1**	9.7
CSHCN whose conditions cause family members to cut back or stop working	**23.7**	23.8

MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	**46.6**	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	**42.2**	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	**59.6**	62.0
CSHCN who are screened early and continuously for special health care needs	**62.7**	63.8
CSHCN whose services are organized in ways that families can use them easily	**85.3**	89.1
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	**37.1**	41.2



2005/2006 National Survey of Children with Special Health Care Needs

California Chartbook Page

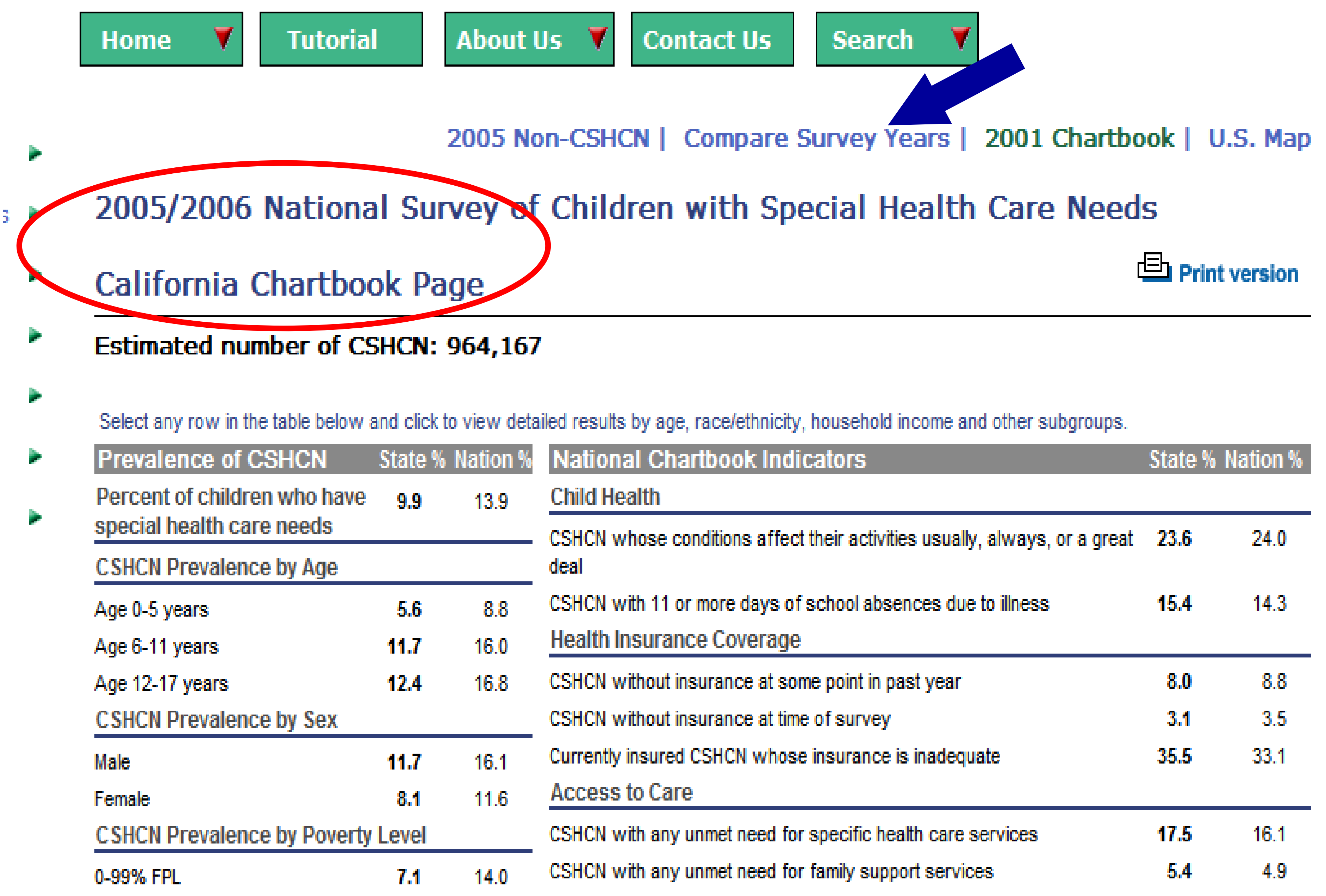
Estimated number of CSHCN: 964,167

Select any row in the table below and click to view detailed results by age, race/ethnicity, household income and other subgroups.

Prevalence of CSHCN	State %	Nation %	National Chartbook Indicators	State %	Nation %

MCHB Core Outcomes	State %	Nation %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	46.6	57.4
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	42.2	47.1
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	59.6	62.0
CSHCN who are screened early and continuously for special health care needs		
CSHCN whose services are organized in ways that families can use them easily		
Youth with special health care needs who receive the services necessary to make appropriate transitions and independence		

State %	Nation %
37.1	41.2



2005/2006 National Survey of Children with Special Health Care Needs

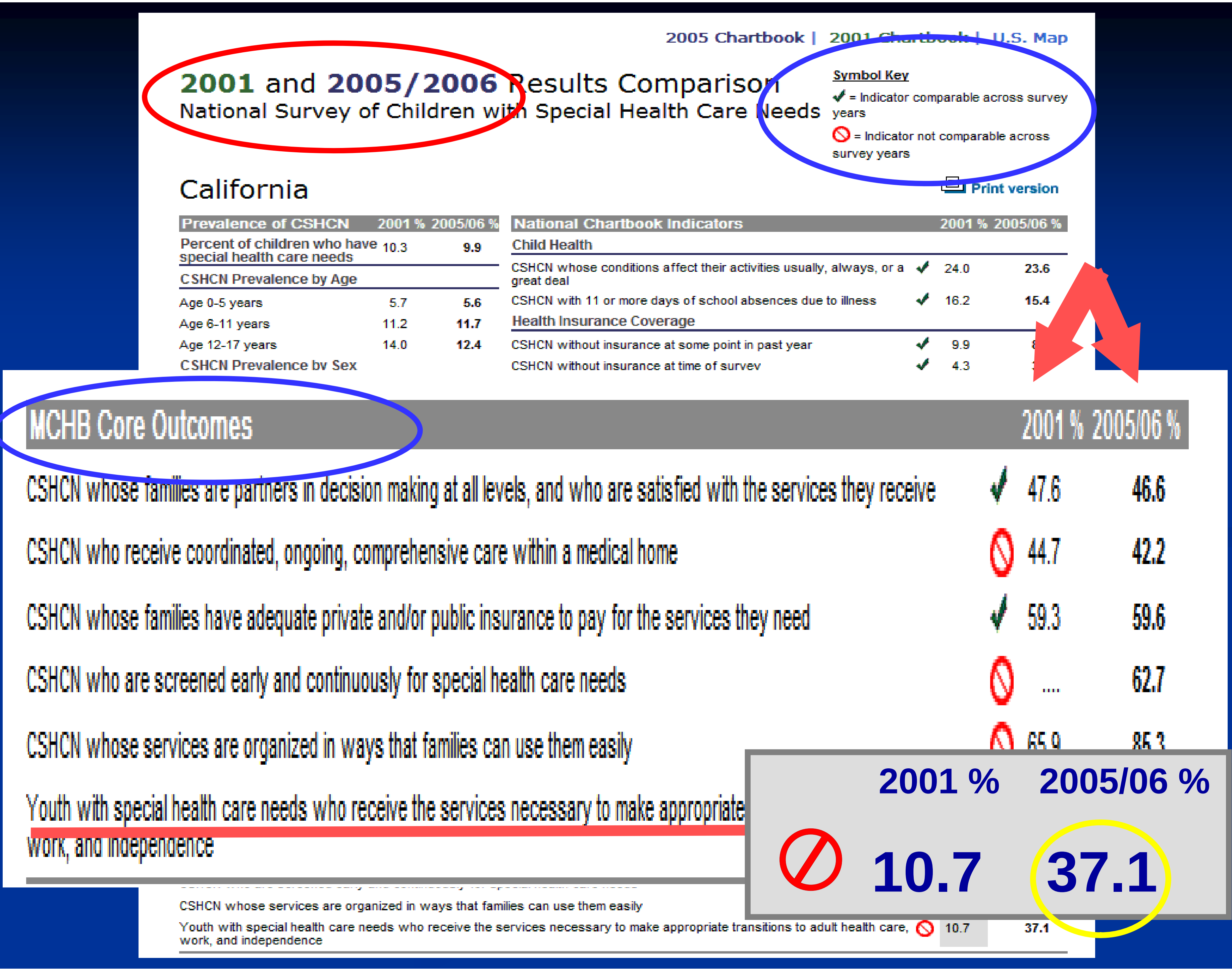
California Chartbook Page

Estimated number of CSHCN: 964,167

Select any row in the table below and click to view detailed results by age, race/ethnicity, household income and other subgroups.

Prevalence of CSHCN	State %	Nation %
Percent of children who have special health care needs	**9.9**	13.9
CSHCN Prevalence by Age		
Age 0-5 years	**5.6**	8.8
Age 6-11 years	**11.7**	16.0
Age 12-17 years	**12.4**	16.8
CSHCN Prevalence by Sex		
Male	**11.7**	16.1
Female	**8.1**	11.6
CSHCN Prevalence by Poverty Level		
0-99% FPL	**7.1**	14.0

National Chartbook Indicators	State %	Nation %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	**23.6**	24.0
CSHCN with 11 or more days of school absences due to illness	**15.4**	14.3
Health Insurance Coverage		
CSHCN without insurance at some point in past year	**8.0**	8.8
CSHCN without insurance at time of survey	**3.1**	3.5
Currently insured CSHCN whose insurance is inadequate	**35.5**	33.1
Access to Care		
CSHCN with any unmet need for specific health care services	**17.5**	16.1
CSHCN with any unmet need for family support services	**5.4**	4.9



2005 Chartbook | 2001 Chartbook | U.S. Map

2001 and 2005/2006 Results Comparison
National Survey of Children with Special Health Care Needs

Symbol Key
✓ = Indicator comparable across survey years
⃠ = Indicator not comparable across survey years

California

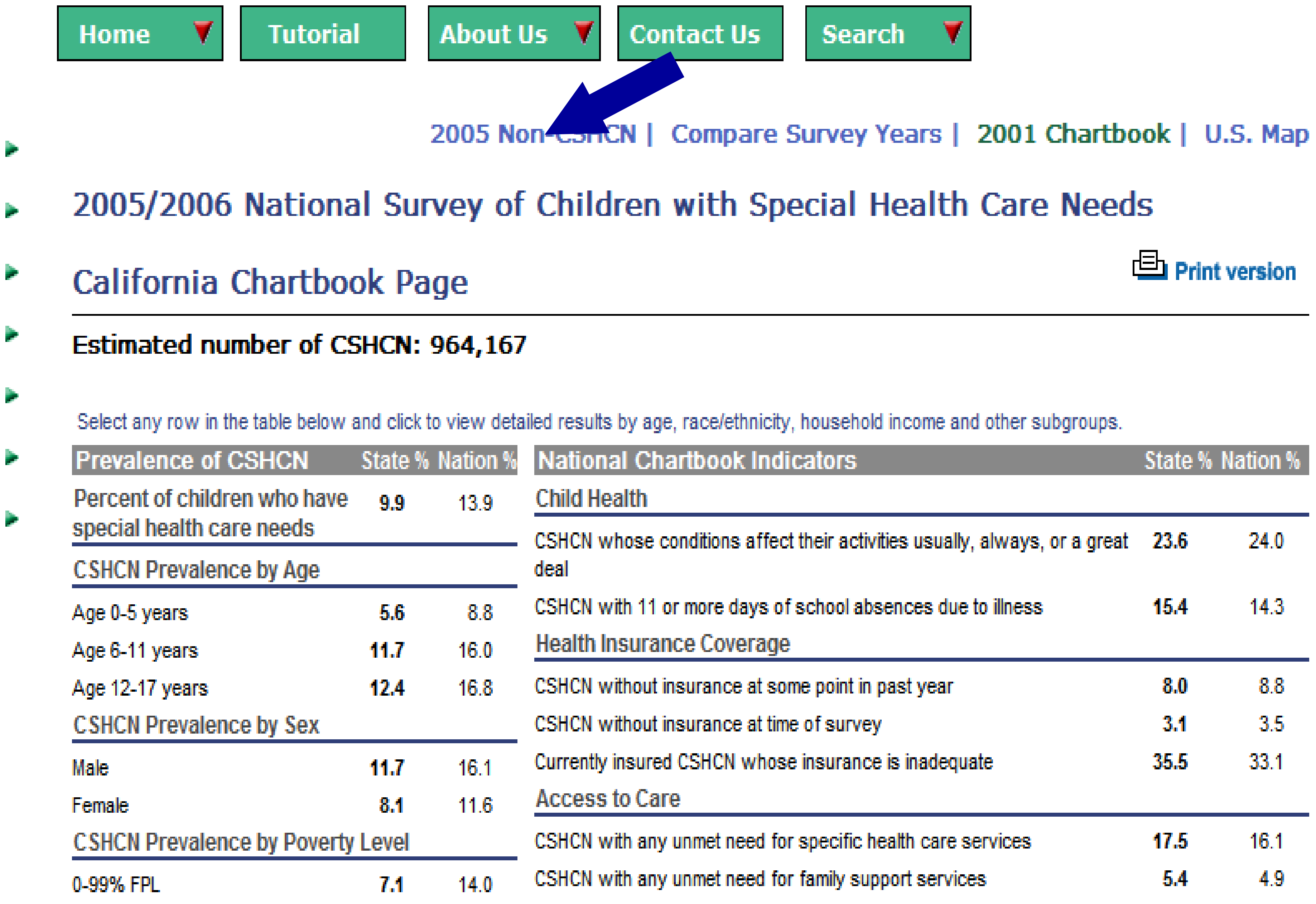
Print version

Prevalence of CSHCN	2001 %	2005/06 %
Percent of children who have special health care needs	10.3	**9.9**
CSHCN Prevalence by Age		
Age 0-5 years	5.7	**5.6**
Age 6-11 years	11.2	**11.7**
Age 12-17 years	14.0	**12.4**
CSHCN Prevalence by Sex		

National Chartbook Indicators		2001 %	2005/06 %
Child Health			
CSHCN whose conditions affect their activities usually, always, or a great deal	✓	24.0	**23.6**
CSHCN with 11 or more days of school absences due to illness	✓	16.2	**15.4**
Health Insurance Coverage			
CSHCN without insurance at some point in past year	✓	9.9	
CSHCN without insurance at time of survev	✓	4.3	

MCHB Core Outcomes		2001 %	2005/06 %
CSHCN whose families are partners in decision making at all levels, and who are satisfied with the services they receive	✓	47.6	46.6
CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	⃠	44.7	42.2
CSHCN whose families have adequate private and/or public insurance to pay for the services they need	✓	59.3	59.6
CSHCN who are screened early and continuously for special health care needs	⃠	....	62.7
CSHCN whose services are organized in ways that families can use them easily	⃠	65.9	85.3
Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence	⃠	10.7	37.1

	2001 %	2005/06 %
⃠	10.7	37.1



2005 Non-CSHCN | Compare Survey Years | 2001 Chartbook | U.S. Map

2005/2006 National Survey of Children with Special Health Care Needs

California Chartbook Page

Estimated number of CSHCN: 964,167

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CSHCN Prevalence by Sex		
Male	**11.7**	16.1
Female	**8.1**	11.6
CSHCN Prevalence by Poverty Level		
0-99% FPL	**7.1**	14.0

National Chartbook Indicators	State %	Nation %
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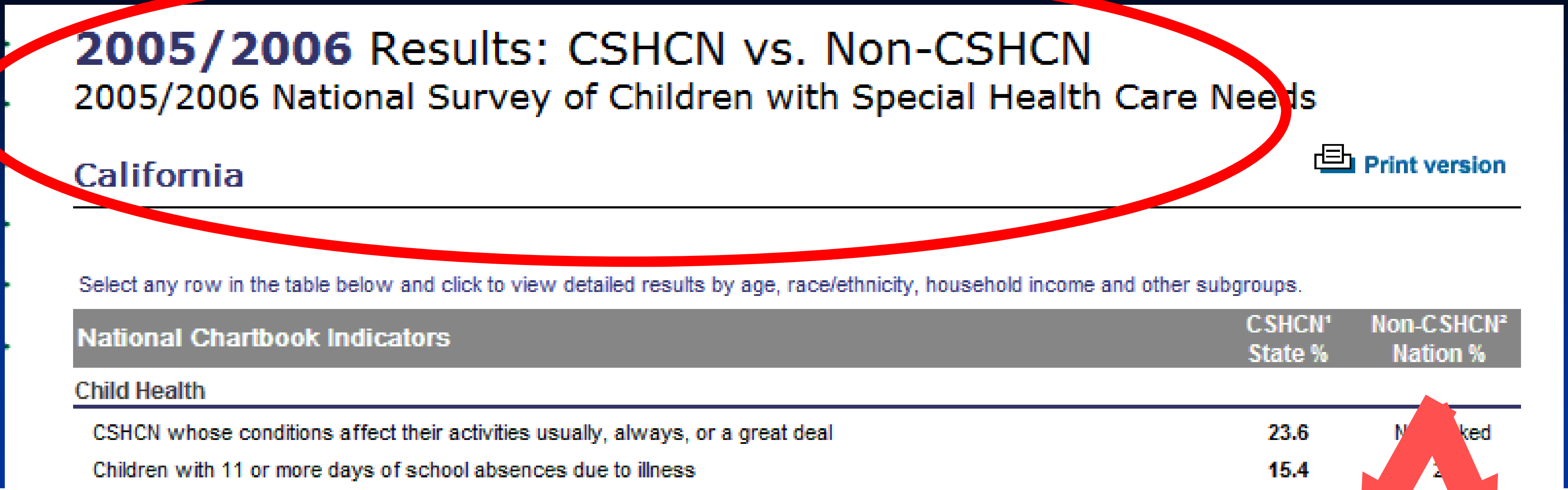
Access to Care		
CSHCN with any unmet need for specific health care services	**17.5**	16.1
CSHCN with any unmet need for family support services	**5.4**	4.9



2005/2006 Results: CSHCN vs. Non-CSHCN

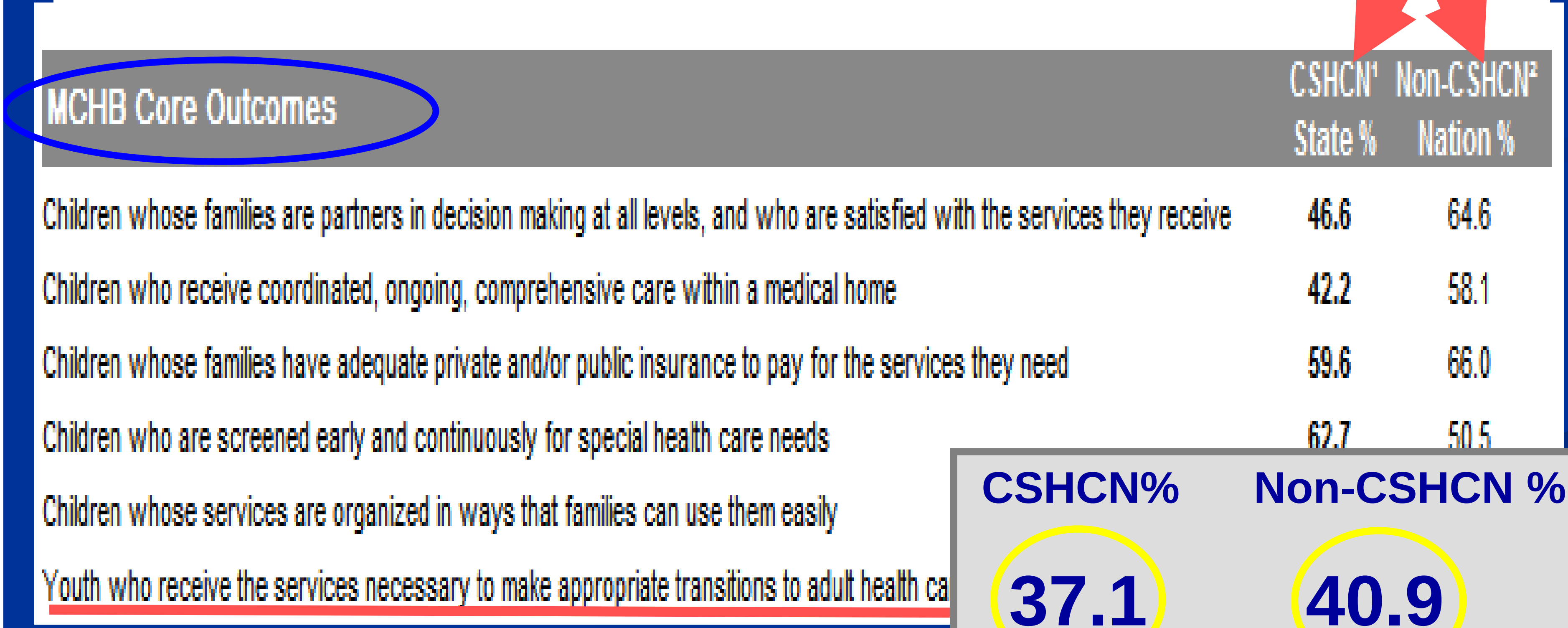
2005/2006 National Survey of Children with Special Health Care Needs

California

Print version

Select any row in the table below and click to view detailed results by age, race/ethnicity, household income and other subgroups.

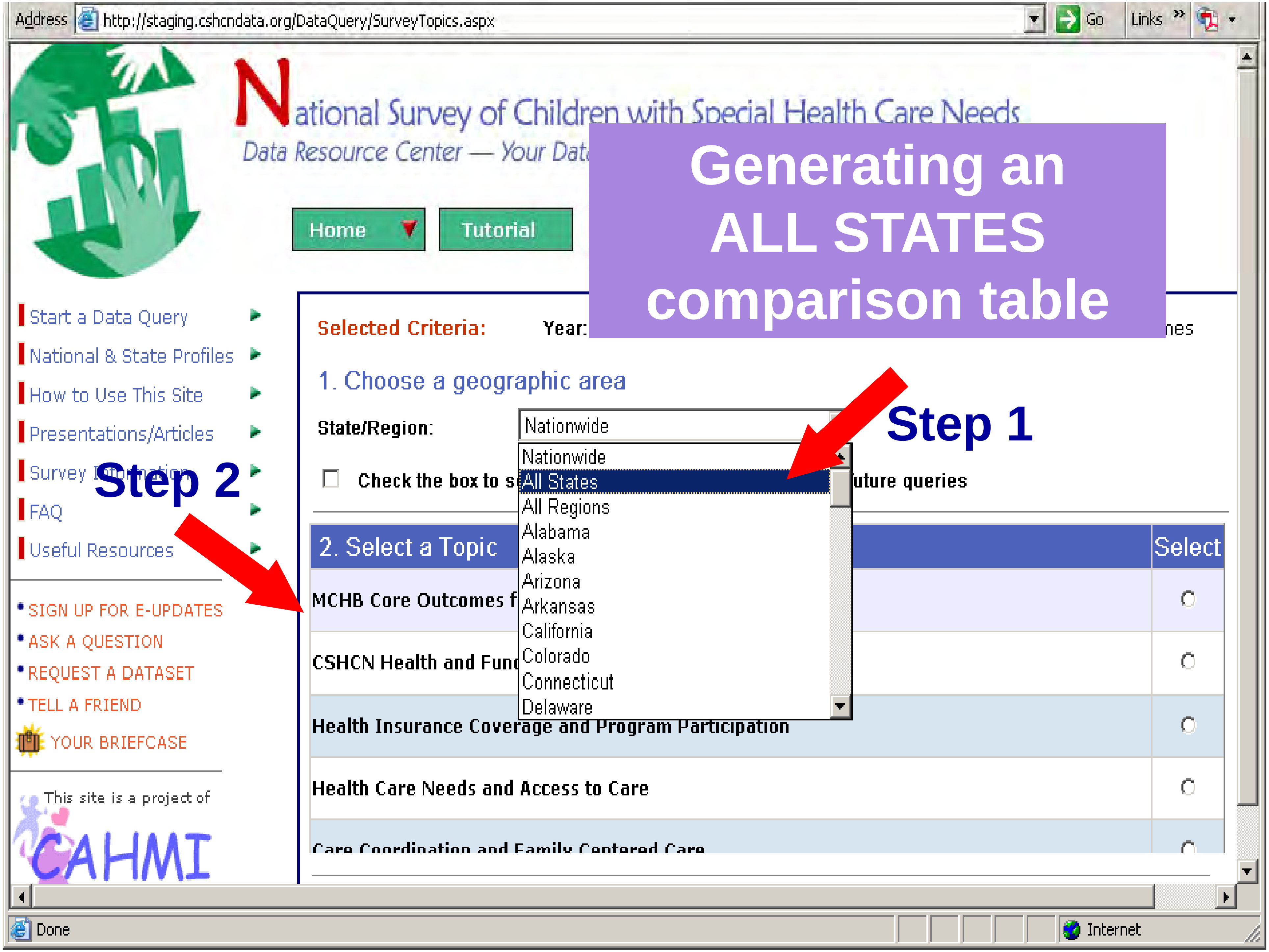
National Chartbook Indicators	CSHCN[1] State %	Non-CSHCN[2] Nation %
Child Health		
CSHCN whose conditions affect their activities usually, always, or a great deal	23.6	N ked
Children with 11 or more days of school absences due to illness	15.4	2



MCHB Core Outcomes	CSHCN[1] State %	Non-CSHCN[2] Nation %
Children whose families are partners in decision making at all levels, and who are satisfied with the services they receive	46.6	64.6
Children who receive coordinated, ongoing, comprehensive care within a medical home	42.2	58.1
Children whose families have adequate private and/or public insurance to pay for the services they need	59.6	66.0
Children who are screened early and continuously for special health care needs	62.7	50.5
Children whose services are organized in ways that families can use them easily		
Youth who receive the services necessary to make appropriate transitions to adult health ca		

CSHCN%	Non-CSHCN %
37.1	40.9

Generating an ALL STATES comparison table



Selected Criteria: Year:

1. Choose a geographic area

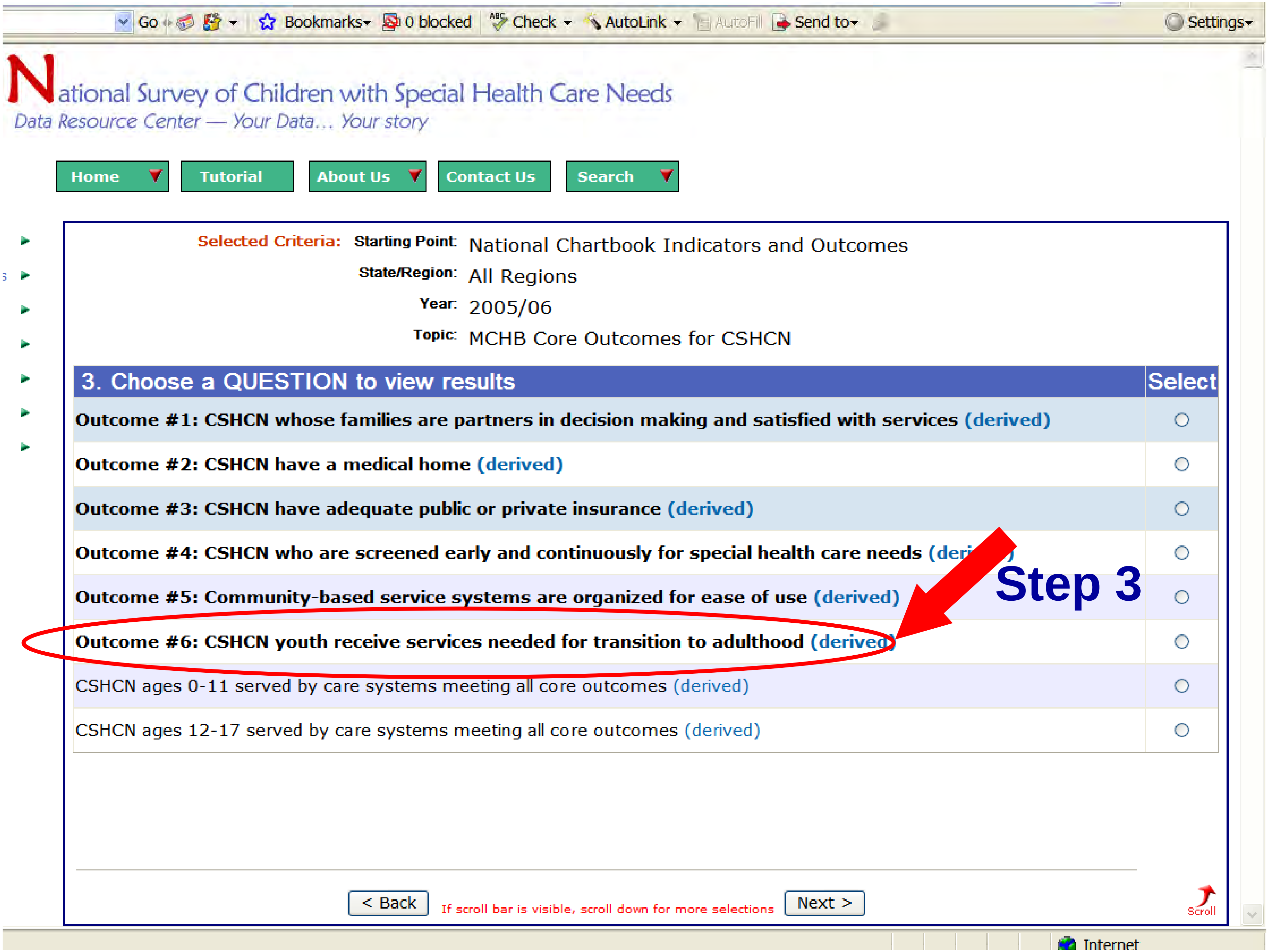
State/Region: Nationwide

☐ **Check the box to s… …uture queries**

2. Select a Topic	Select
MCHB Core Outcomes f…	○
CSHCN Health and Func…	○
Health Insurance Coverage and Program Participation	○
Health Care Needs and Access to Care	○
Care Coordination and Family Centered Care	○

Step 1

Step 2



Selected Criteria: **Starting Point:** National Chartbook Indicators and Outcomes
State/Region: All Regions
Year: 2005/06
Topic: MCHB Core Outcomes for CSHCN

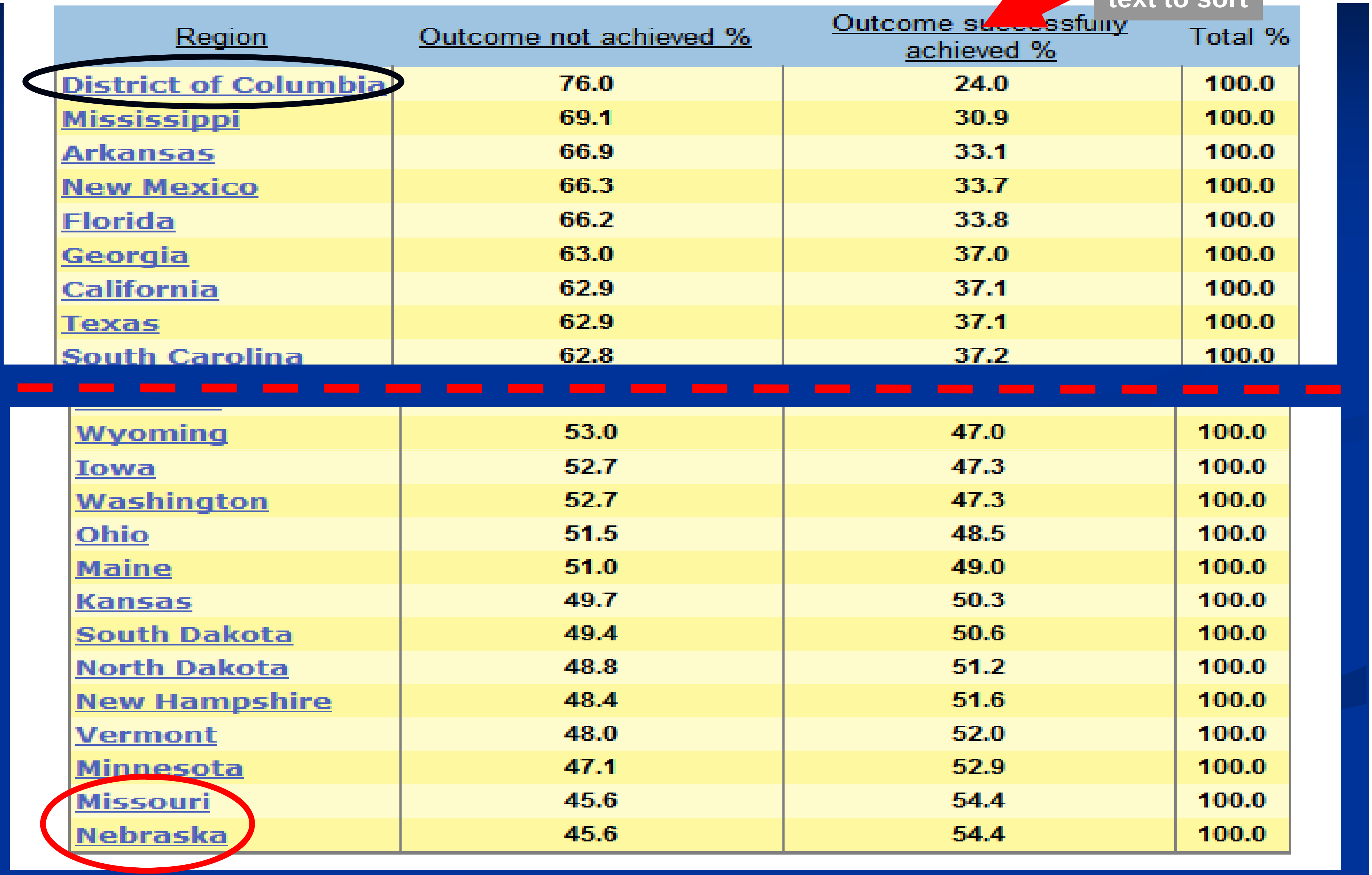
3. Choose a QUESTION to view results	Select
Outcome #1: CSHCN whose families are partners in decision making and satisfied with services (derived)	○
Outcome #2: CSHCN have a medical home (derived)	○
Outcome #3: CSHCN have adequate public or private insurance (derived)	○
Outcome #4: CSHCN who are screened early and continuously for special health care needs (derived)	○
Outcome #5: Community-based service systems are organized for ease of use (derived)	○
Outcome #6: CSHCN youth receive services needed for transition to adulthood (derived)	○
CSHCN ages 0-11 served by care systems meeting all core outcomes (derived)	○
CSHCN ages 12-17 served by care systems meeting all core outcomes (derived)	○

If scroll bar is visible, scroll down for more selections

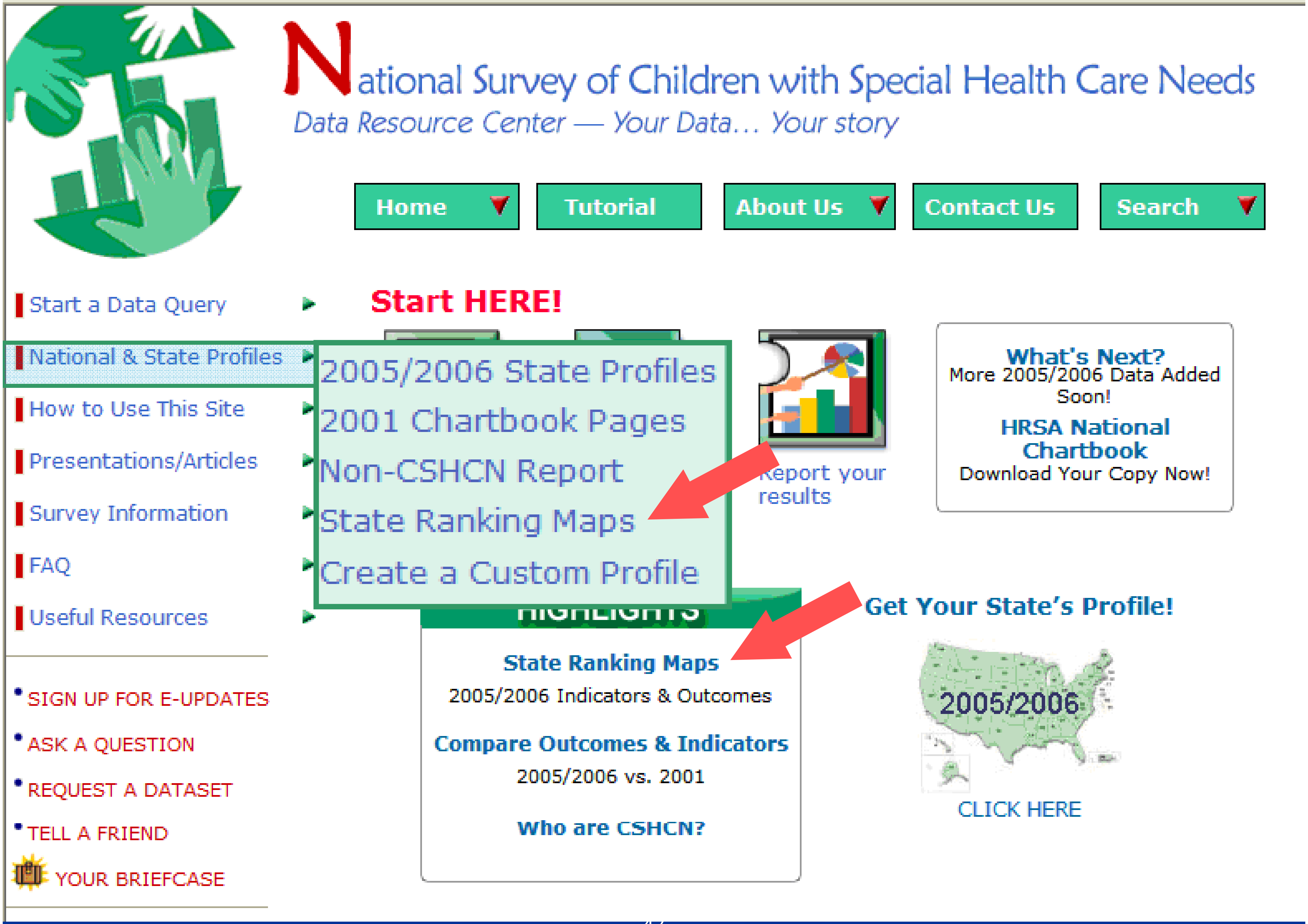
Step 3

Outcome #6: CSHCN ages 12-17 who receive servi eded for transition to adult health care, work and ind ce

Click on column heading text to sort



Region	Outcome not achieved %	Outcome successfully achieved %	Total %
District of Columbia	76.0	24.0	100.0
Mississippi	69.1	30.9	100.0
Arkansas	66.9	33.1	100.0
New Mexico	66.3	33.7	100.0
Florida	66.2	33.8	100.0
Georgia	63.0	37.0	100.0
California	62.9	37.1	100.0
Texas	62.9	37.1	100.0
South Carolina	62.8	37.2	100.0
Wyoming	53.0	47.0	100.0
Iowa	52.7	47.3	100.0
Washington	52.7	47.3	100.0
Ohio	51.5	48.5	100.0
Maine	51.0	49.0	100.0
Kansas	49.7	50.3	100.0
South Dakota	49.4	50.6	100.0
North Dakota	48.8	51.2	100.0
New Hampshire	48.4	51.6	100.0
Vermont	48.0	52.0	100.0
Minnesota	47.1	52.9	100.0
Missouri	45.6	54.4	100.0
Nebraska	45.6	54.4	100.0



National Survey of Children with Special Health Care Needs

Data Resource Center — Your Data… Your story

Start HERE!

Report your results

What's Next?
More 2005/2006 Data Added Soon!

HRSA National Chartbook
Download Your Copy Now!

Get Your State's Profile!

HIGHLIGHTS

State Ranking Maps
2005/2006 Indicators & Outcomes

Compare Outcomes & Indicators
2005/2006 vs. 2001

Who are CSHCN?

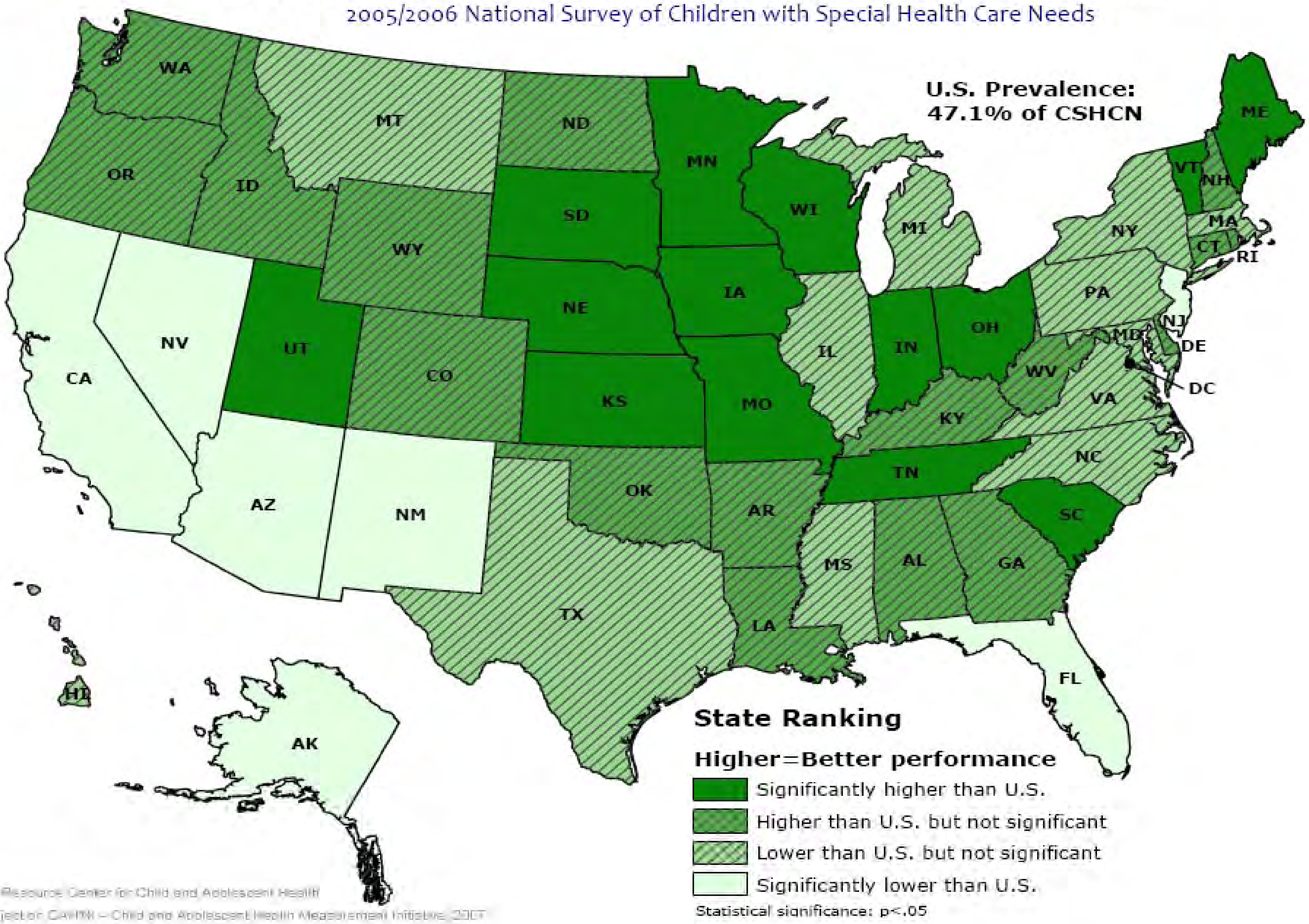
Data Resource Center for Child & Adolescent Health

Your Data… Your story

www.childhealthdata.org

MCHB Core Outcome #2: CSHCN have a Medical Home

2005/2006 National Survey of Children with Special Health Care Needs



Data Resource Center for Child and Adolescent Health

A project of CAHMI – Child and Adolescent Health Measurement Initiative, 2007

Coming May 2008!

New customizable report format allows users to:

- Choose a specific chronic condition from list asked in the survey
- Select performance measure, key indicators, demographics, etc. from menu
- Generate summary report profile for CSHCN with and without the specific condition

Additional features

- **Sign up** for regular e-updates and “e-facts”
- **Find out** about and access the latest publications, reports & abstracts using the national survey data
- **Order** NSCH & NS-CSHCN datasets with pre-constructed performance measures, indicators and additional variables (SAS & SPSS)

How the Data Resource Center Can Support Research and Policy Applications

Understand your population	User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help define your population of CSCHN and their health needs
Assess system performance	Immediate access to over 100 state-specific indicators of child health and well-being and system performance for children overall and children with special health care needs (CSHCN).
Examine research opportunities	"Point and click" menu allows users to explore disparities and gaps in access and services for different population subgroups of children and CSHCN.
Identify research priorities	User generated tables, bar and pie charts, and customizable reports supply prevalence estimates and population counts to help guide selection of priority needs.
Evaluate state variations	"All States" ranking maps and tables provide benchmark data to assist in identifying state-negotiated performance measure targets.
Identify promising improvement models	Information on national, within and across States variation using standardized indicators helps identify where quality is better and can help in cross-state learning for purposes of identifying promising models for improvement as well as identify key collaborators for improvement.
Monitor progress	Centralized resource for standardized, population-based survey questions to use in collecting child health and health care quality data locally.

Visit soon!

www.childhealthdata.org

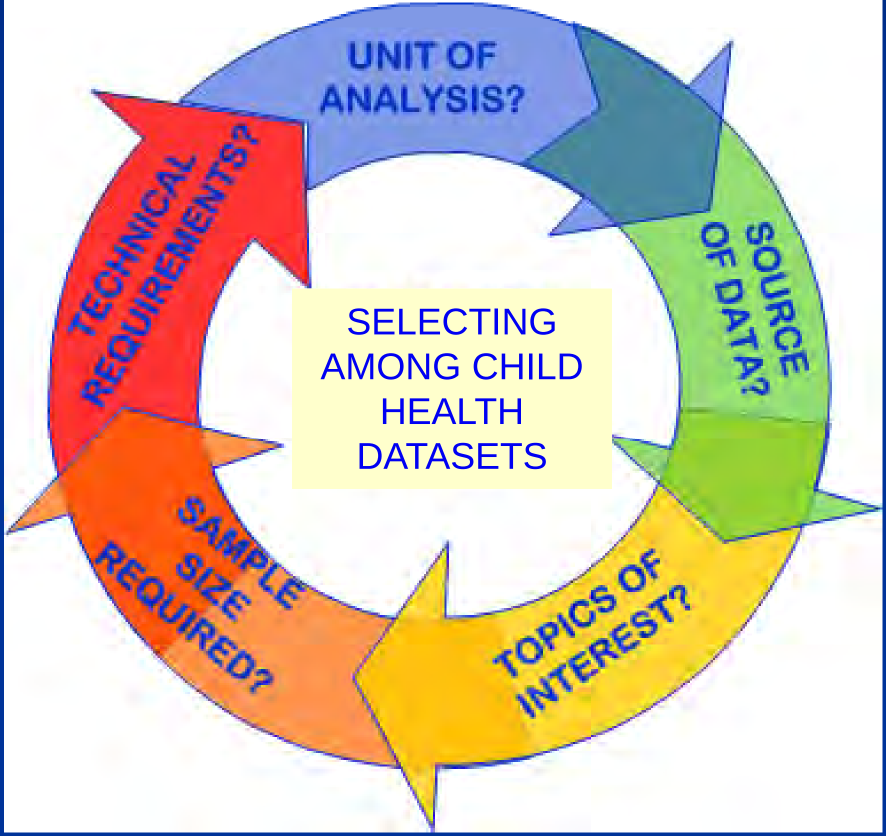
- National Survey of Children with Special Health Care Needs

www.cshcndata.org

- National Survey of Children's Health

www.nschdata.org

Overview of Datasets
5 Key Questions to Get Started



- What is the **unit of analysis** you are interested in?
- What **source of data** is most suitable to your research questions?
- What **key topics** are you interested in studying?
- What **sample size** is required to make your analysis possible and meaningful?
- Can you meet the **technical requirements** for using the dataset of interest?

Major Similarities and Differences to Know About

MAJOR SIMILARITIES

Source of Data
Survey-based data

Sampling Frame
US, non-institutionalized population

Topics Covered
Health status, access to care, insurance status, health care utilization, quality of care, etc.

Resources
Free datasets; web-based query and support

MAJOR DIFFERENCES

Sampling and Administration:
NIS/SLAITS RDD CATI vs. NHIS Respondent Subsample CAPI

Within Household Sampling:
All individual family members vs. target child vs. family unit plus target child

Sample Size
< 10K vs. 40-100K

Unit of Analysis
National/Regional Only vs. National/Regional & State

Why Might Prevalence Rates Differ from One Survey to the Next?

- Dates of data collection
- Method of data collection and estimation
  - Mode
  - Sampling frame
  - Interviewers
  - Weighting methods
- Sample size and sampling error
- Method of identification
  - Respondent
  - Recall period
  - Question wording
  - Question ordering
  - Question context and introduction

(Not So) Trivial Pursuit Questions for Research Applications of National and State Survey-Based Child Health Datasets

Got Data! Demystifying the Use of Three National and
State-Level Child and Adolescent Health Datasets

May 3, 2008
10:30 AM -1:30 PM
Hawaii Convention Center, Room 306B

A. DATA QUALITY

1A. What is an acceptable response rate for surveys such as the MEPS, NSCH and NS-CSHCN?

2A. What makes up a response rate calculation?

3A. All survey items included in MEPS, NSCH and NS-CSHCN have undergone some level of testing for reliability and validity. How can you learn more about variations in validity and reliability of survey items and scales and potential impact on your analyses? What are some things you can do to investigate this yourself using the data?

4A. What is a reasonable standard to use for deciding whether sample sizes for a subgroup analyses are too low to use or report findings?

B. VARIABLE CONSTRUCTION

1B. Which is more relevant: (a) proportion of children with unmet needs for specialty care; (b) proportion of children who require specialty care who have unmet needs for that care?

2B. Why might a composite score (e.g. Medical Home) be lower for a state than any of the sub-scores that make up that composite?

3B. True or False: If the binomial correlation between a dependent and independent variable is not significant, there is no need to proceed to include the independent variable in a multivariate regression model.

4B. Do you agree that a good standard is to always code “don’t know or unknown values” to missing? Why or why not?

5B. True or False?: AHRQ (MEPS) and NCHS (NSCH; NS-CSHCN) both agree that imputation of missing data is preferable and agree on one method for doing so?

C. OTHER COMMON ANALYTIC ISSUES

1C. True or False: Sampling weights are used to adjust frequency and prevalence estimates for potential sampling and response bias.

2C. SUDDAAN, SAS Complex Samples programs and similar programs are used to adjust standard errors of estimates derived from MEPS, NSCH and NS-CSHCN. What is the primary consequence of neglecting to do this?

3C. True or False: Rather than conduct analyses on unweighted data first and then compare to results using weighted data, to save time it is generally fine to just begin using weighted data.

4C. What are some common ways to of working with skewed data—for example, number of prescription medication orders fills, charges associated with care received, numbers of doctor visits, etc.

D. IDENTIFYING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

1D. Why do MEPS, the NSCH and NS-CSHCN use a non-condition specific method for identifying children with special health care needs? Why not just use a condition check-list? Where does a functional difficulties check list fit in?

2D. True or False? By definition, all children who meet criteria for having a special health care need will have some type of ongoing health condition.

3D. Looking at Table 2 in your packet, what proportion of CSHCN whose parents report they have asthma, ONLY have asthma as a named condition?

4D. True or False? The CSHCN Screener provide data on the proportion of parents who report that their children experience current health or health service need or use consequences due to an ongoing health condition.

5D. What's more meaningful?(a) the proportion of children age 12-17 who qualify as having a special health care need or (b) the proportion of those qualifying as having special health care needs who are age 12-17? What are the answers to (a) and (b) using the cross-tabulation print-out below?

metlwi Results for CSHCN screener * age_3 Derived. Age in years of selected child Crosstabulation

			age_3 Derived. Age in years of selected child			Total
			1 0-5 years	2 6-11 years	3 12-17 years	
metlwi Results for CSHCN screener	.00 No	Count	29816	24661	29298	83775
		% within metlwi Results for CSHCN screener	35.6%	29.4%	35.0%	100.0%
		% within age_3 Derived. Age in years of selected child	89.5%	79.3%	77.3%	81.8%
	1.00 Yes	Count	3506	6456	8616	18578
		% within metlwi Results for CSHCN screener	18.9%	34.8%	46.4%	100.0%
		% within age_3 Derived. Age in years of selected child	10.5%	20.7%	22.7%	18.2%
Total		Count	33322	31117	37914	102353
		% within metlwi Results for CSHCN screener	32.6%	30.4%	37.0%	100.0%
		% within age_3 Derived. Age in years of selected child	100.0%	100.0%	100.0%	100.0%

E. QUESTIONS REGARDING AVAILABLE RESOURCES

1E. What should you do if you want access to data findings that are not released in the Public Use File due to confidentiality concerns (e.g. data by zip code; data for the Native American population)?

2E: True or False?: The MEPS website is a great place to go to get state level estimates about child health care services utilization?

3E. True or False?: The CAHMI Data Resource Center provides for free already concatenated and coded datasets for the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health.

The (Not So)
Trivial Pursuit Game

Answers and Discussion

A. Data Quality

1A: All RDD Surveys Have Declining Response Rates

	Turn of the Century	Mid-Decade
National Household Education Surveys	60% (2001)	56% (2005)
Survey of Consumer Attitudes	60% (2001)	45% (2005)
National Survey of America's Families	62% (1999)	55% (2002)
Behavioral Risk Factor Surveillance System	51% (2001)	51% (2005)
NS-CSHCN	**61% (2001)**	**56% (2005/6)**

JAMA requires at least 60% response rate.

2A: Alternative Calculations

- Response Rate =

$$\frac{\text{(Completes)}}{\text{(Observed Eligibles)} + \text{(Unobserved Eligibles)}}$$

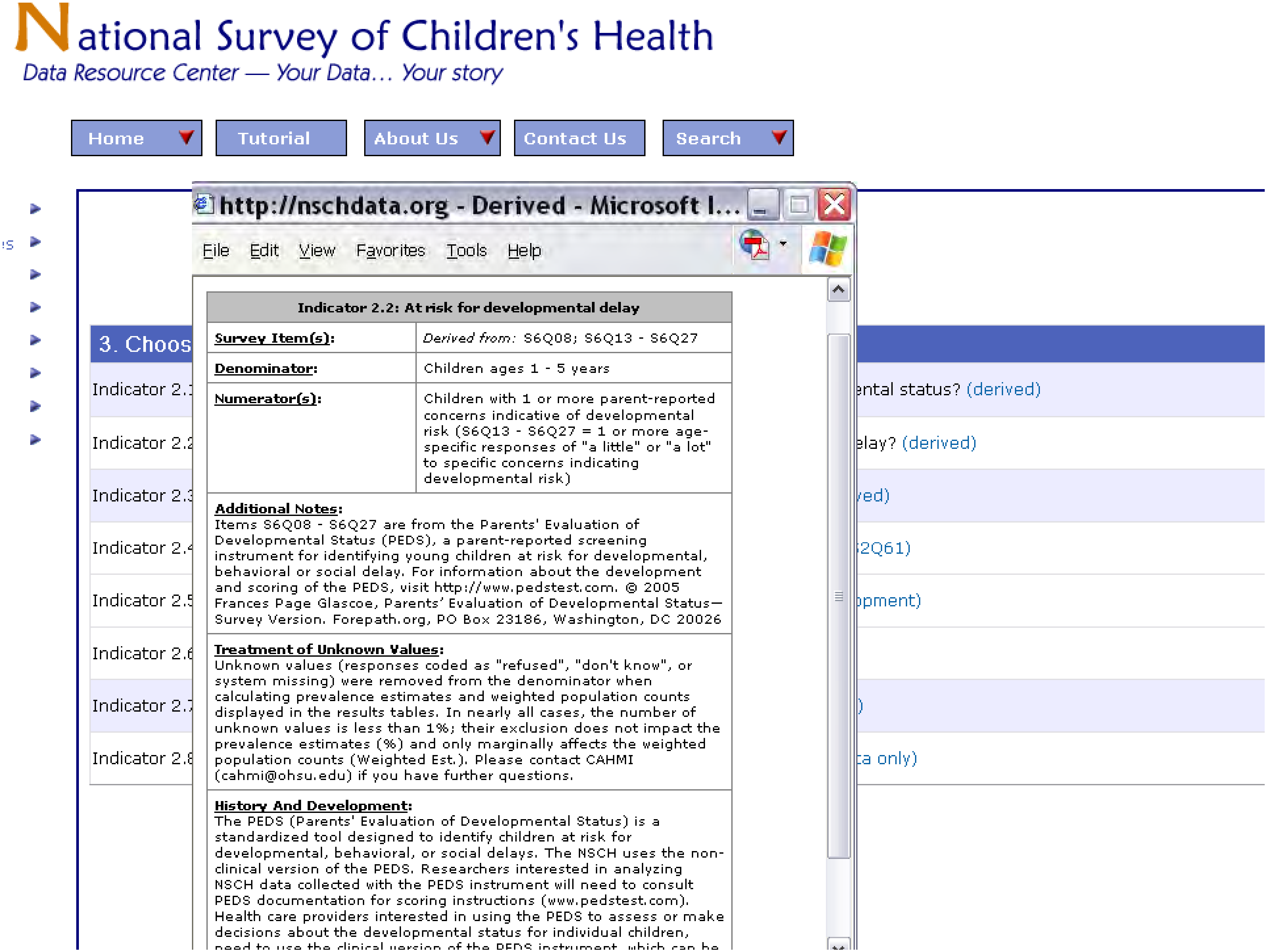
- CASRO (Council of American Survey Research Orgs) rates assume that the proportion of eligibles among unresolved or unscreened numbers is the same as the proportion of eligibles among all resolved and screened numbers
- Alternatively, we could assume that numbers that always ring with no answer or are always (or more often) busy, nonworking or ineligible
- 2005-06 NS-CSHCN: 56.1% vs. 61.2%

Response Rate: The Four Horsemen NS-CSHCN Example

	2001	05/06
Resolution rate	86.5	82.7
Age-screener rate	94.9	88.4
CSHCN Screener rate	76.2	79.7
Interview compl. rate	97.6	96.2
Overall CASRO rate	61.0	56.1

3A. Nonresponse Bias

- Two factors determine the degree of nonresponse bias:
  - The percentage of persons in the population of interest who do not respond to the survey
  - The magnitude of the difference between respondents and nonrespondents for the variables of interest



Indicator 2.2: At risk for developmental delay	
Survey Item(s):	*Derived from:* S6Q08; S6Q13 - S6Q27
Denominator:	Children ages 1 - 5 years
Numerator(s):	Children with 1 or more parent-reported concerns indicative of developmental risk (S6Q13 - S6Q27 = 1 or more age-specific responses of "a little" or "a lot" to specific concerns indicating developmental risk)

Additional Notes:
Items S6Q08 - S6Q27 are from the Parents' Evaluation of Developmental Status (PEDS), a parent-reported screening instrument for identifying young children at risk for developmental, behavioral or social delay. For information about the development and scoring of the PEDS, visit http://www.pedstest.com. © 2005 Frances Page Glascoe, Parents' Evaluation of Developmental Status—Survey Version. Forepath.org, PO Box 23186, Washington, DC 20026

Treatment of Unknown Values:
Unknown values (responses coded as "refused", "don't know", or system missing) were removed from the denominator when calculating prevalence estimates and weighted population counts displayed in the results tables. In nearly all cases, the number of unknown values is less than 1%; their exclusion does not impact the prevalence estimates (%) and only marginally affects the weighted population counts (Weighted Est.). Please contact CAHMI (cahmi@ohsu.edu) if you have further questions.

History And Development:
The PEDS (Parents' Evaluation of Developmental Status) is a standardized tool designed to identify children at risk for developmental, behavioral, or social delays. The NSCH uses the non-clinical version of the PEDS. Researchers interested in analyzing NSCH data collected with the PEDS instrument will need to consult PEDS documentation for scoring instructions (www.pedstest.com). Health care providers interested in using the PEDS to assess or make decisions about the developmental status for individual children, need to use the clinical version of the PEDS instrument, which can be

3A. The Quandry of Measuring Unmet Needs for Care: Examples from the NSCH

- **98.5%:** Indicator 4.6: During the past 12 months, did (child's name) receive all the medical care he/she needed? (S4Q07 -- asked only if children needed or used medical care during the past 12
- **79.9%:** When you have called (child's name)'s personal doctor or nurse (PDN) for help or advice over the phone, how often were you able to get the help or advice you needed for

When there is no "gold standard" for determining validity, triangulate to validate

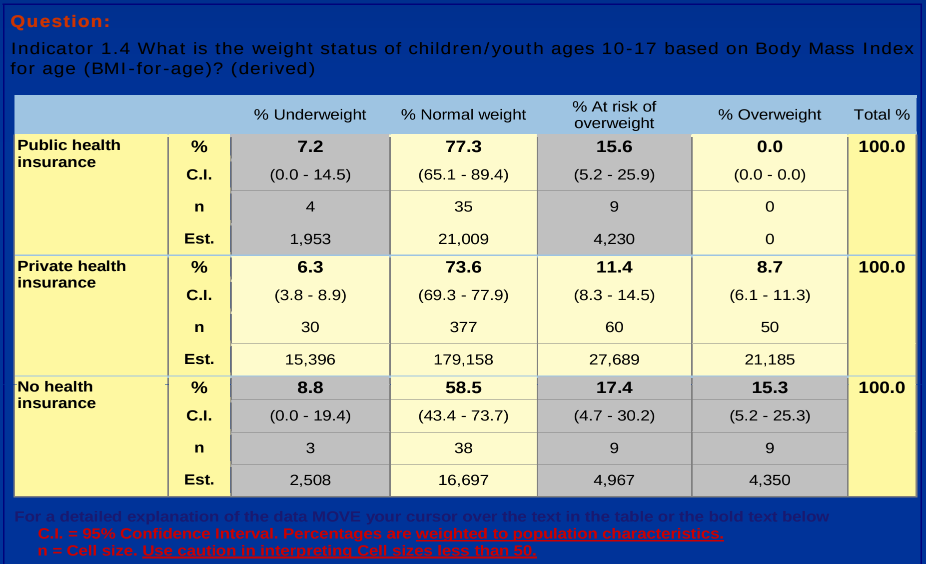
Convergent validity (things go together than should)

Divergent validity (things do not go together that should not)

External validity (finding gel with other high quality studies)

4A: Common Standard for Determining Unacceptably Poor Precision for Binomial Variables

Sample size is not the answer!
Example from www.childhealthdata.org



Question:

Indicator 1.4 What is the weight status of children/youth ages 10-17 based on Body Mass Index for age (BMI-for-age)? (derived)

		% Underweight	% Normal weight	% At risk of overweight	% Overweight	Total %
Public health insurance	**%**	**7.2**	**77.3**	**15.6**	**0.0**	**100.0**
	C.I.	(0.0 - 14.5)	(65.1 - 89.4)	(5.2 - 25.9)	(0.0 - 0.0)	
	n	4	35	9	0	
	Est.	1,953	21,009	4,230	0	
Private health insurance	**%**	**6.3**	**73.6**	**11.4**	**8.7**	**100.0**
	C.I.	(3.8 - 8.9)	(69.3 - 77.9)	(8.3 - 14.5)	(6.1 - 11.3)	
	n	30	377	60	50	
	Est.	15,396	179,158	27,689	21,185	
No health insurance	**%**	**8.8**	**58.5**	**17.4**	**15.3**	**100.0**
	C.I.	(0.0 - 19.4)	(43.4 - 73.7)	(4.7 - 30.2)	(5.2 - 25.3)	
	n	3	38	9	9	
	Est.	2,508	16,697	4,967	4,350	

For a detailed explanation of the data MOVE your cursor over the text in the table or the bold text below

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = Cell size. Use caution in interpreting Cell sizes less than 50.

Grey Cells: Estimates based on sample sizes too small to meet standards for reliability or precision.
The relative standard error is greater than 30%.

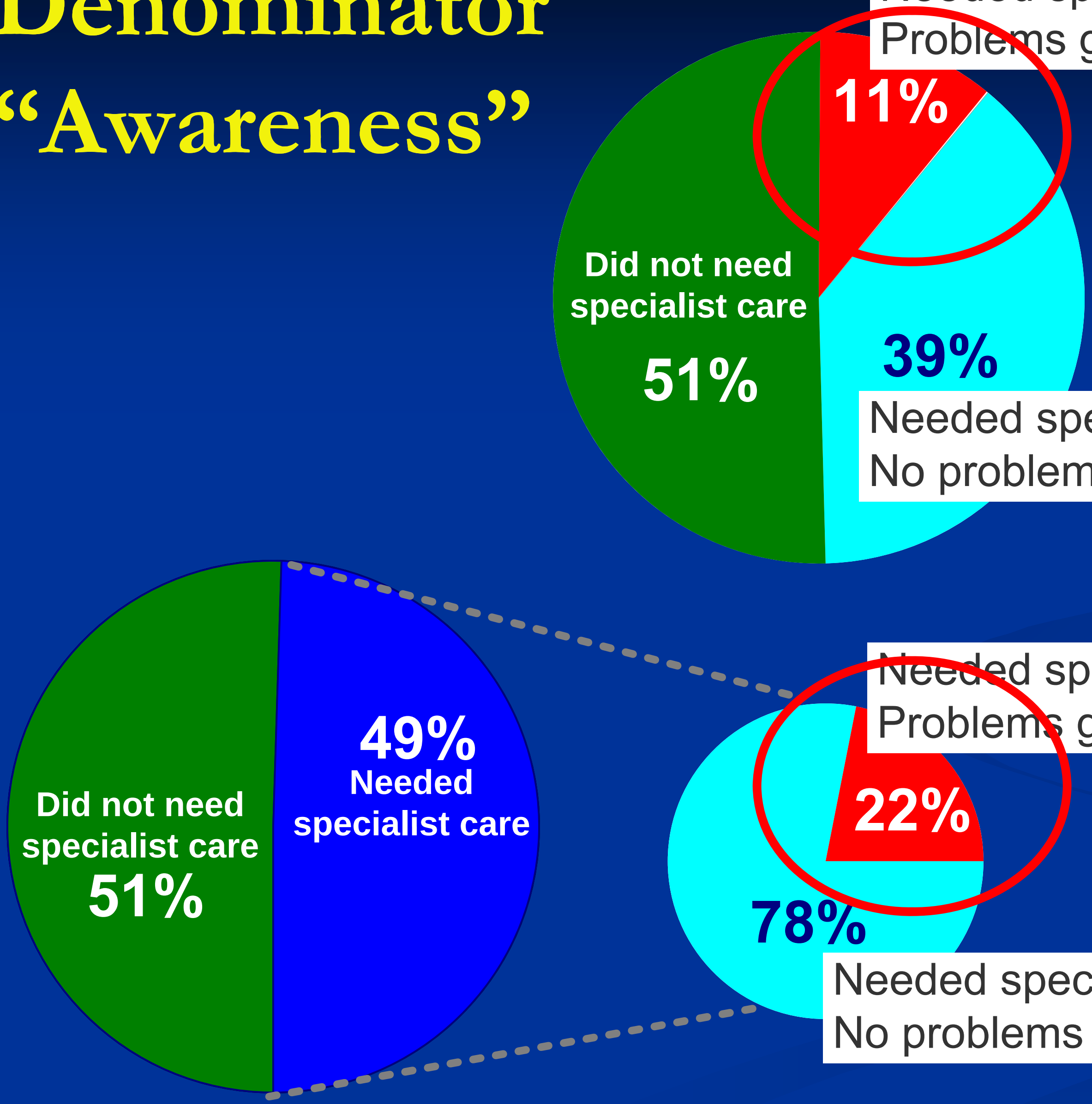
How the math works: The closer your estimate is to 0 or 100, the smaller the sample size needs to be to reach acceptable precision. A sample of 25 could be precise if 98% of cases meet criterion. A sample of 35 could be imprecise if only 50% do.

Relative Standard Error (RSE)

- This is the Standard Error expressed as a percentage of the estimate itself.
  - For example if the estimate is 0.5 and the standard error is 0.05, then the RSE will be 10%.
- RSE is often used in preference to standard error when comparing the variability of samples of different magnitudes.
- The RSE places the Standard Error in the context of the estimate.
  - For example, for an estimate of 0.01, a standard error of 0.1 would be of much greater issue than for an estimate of 0.5. In the first case, the RSE is 1000%, while in the second case it is much smaller (20%).

B. Variable Construction

Denominator “Awareness”



Needed specialist care AND
Problems getting referral

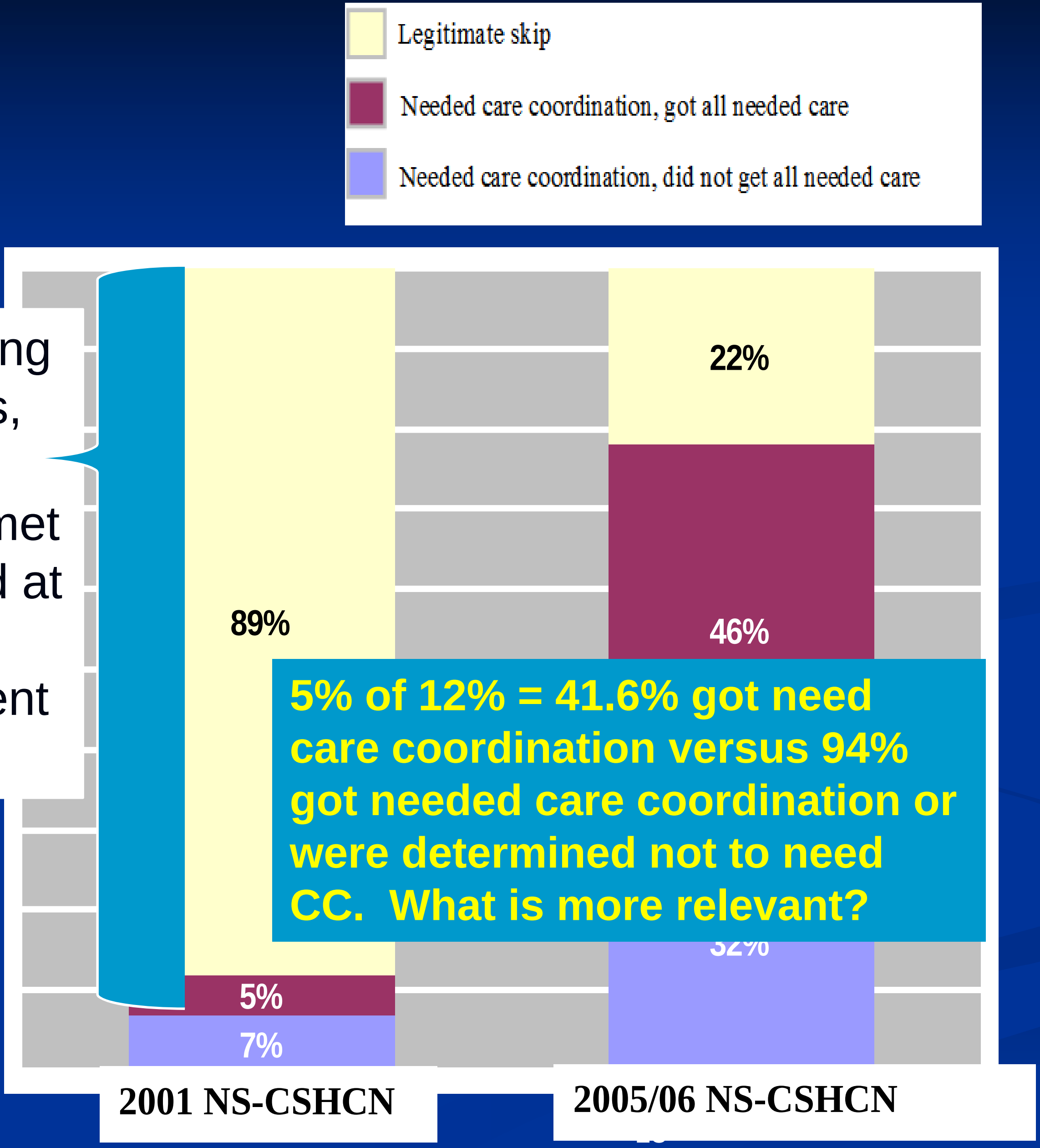
Needed specialist care AND
No problems getting referral

Needed specialist care AND
Problems getting referral

Needed specialist care AND
No problems getting referral

Counterintuitive Effects of Changing Inclusion Criteria

For scoring purposes, 94% of sample met threshold at the sub-component level



5% of 12% = 41.6% got need care coordination versus 94% got needed care coordination or were determined not to need CC. What is more relevant?

For scoring purposes, 68% of sample met threshold at the sub-component level

How can a composite score be lower than any of the subcomponents that make up that score?

MH score Equals:
.80(1) + .55(.50) +.65 (.40).

This Equals .80 + .275 + .26 = 1.335 divided by 3 subscores = 44.5%.

We are back to the issue of who is in the valid denominator! 100% for "partner", 50% for need specialty referral, 40% for needed care coord.

A

- made up of more than this)
  - Feel a partner in care- 80%
  - Get needed access to specialty referrals from PCP – 55%
  - Got all care coordination help wanted – 65%
- Overall MH score is 44.5%. WHY?

3B and 4B

- 3B: False
  - Binomial correlation is not a fool proof predictor of association in a multivariate context.
- 4B: Depends.
  - Could “don’t know” ever convey an answer? If a question is about, for example, parent receipt of information and parent answer is “don’t know”, might that be a “no”?

5B: False:

MEPS offers imputation on all variables; NCHS only on some and only recently AT ALL! No agreement on ideal method.

Example from the NS-CSHCN and NSCH: Imputed Poverty Status

- Approx. 18% of the 191,640 households in 2005/06 NS-CSHCN sample are missing data for "Poverty Status" variable (**POVLEVEL**)
- Similar levels for NSCH
- By contrast, nearly all other variables in survey have <1% missing data
- Consistent with other similar surveys (e.g. child sample for 2006 NHIS ≈ 24% missing poverty status data)

Imputed Poverty Status

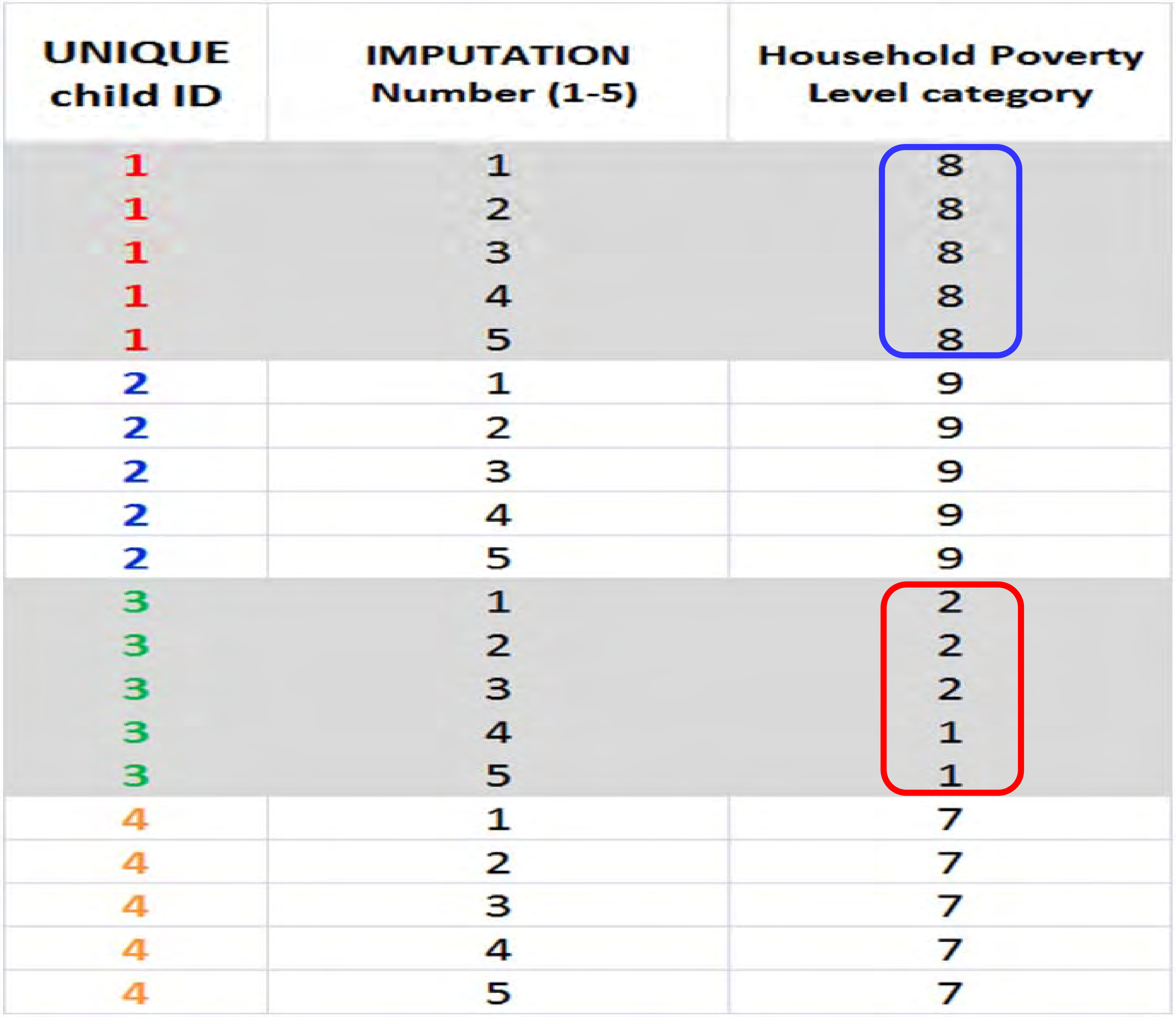
- Why do "missing data" matter?
  - Non-response on HH income status in NOT randomly distributed; rather – it is related to several child-level and HH level characteristics (e.g. lower or higher income, race/ethnicity, insurance status, primary HH lang)
- How does it affect your analysis?
  - LISTWISE DELETION is most common method for handing "missing data" in software packages
  - LISTWISE DELELTION deletes <u>all cases</u> with missing data on ANY of the variables used in a bivariate or multivariate analysis
  - Deletion of incomplete cases introduces bias and less precise interferences

Imputed Poverty Status

- Imputation "Solution"
  - Adjusts for observed differences btw respondents AND non-respondents
  - Estimates values for all missing data = completed dataset for analysis
- Various methods/lack of agreed upon standard
- NCHS selected "MULTIPLE IMPUTATION" method
  - Recently released MULTIPLE IMPUTED poverty status files for 2001 and 2005/06 NS-CSHCN and 2003 NSCH (download at no cost from: http://www.cdc.gov/nchs/about/major/slaits/imputed_data.htm)

Imputed Poverty Status

- Single Imputation
  - Model is run once to predict missing datum
  - Uncertainty of one "estimated guess" = SEs too small / / CIs too narrow / greater chance of Type I error
- Multiple Imputation
  - Model is run more than once (typically 5 times) to predict missing datum
  - Having several different "estimated guesses" allows more accurate variance estimation
  - All 5 "estimated" guesses are used during analysis and the results are combined in a way that more accurately reflects the uncertainty due to imputation



UNIQUE child ID	IMPUTATION Number (1-5)	Household Poverty Level category
1	1	8
1	2	8
1	3	8
1	4	8
1	5	8
2	1	9
2	2	9
2	3	9
2	4	9
2	5	9
3	1	2
3	2	2
3	3	2
3	4	1
3	5	1
4	1	7
4	2	7
4	3	7
4	4	7
4	5	7

Non-Imputed vs. Imputed Poverty Status

U.S. Population of CSHCN age 0-17 years (2005/06 NS-CSHCN)	Distribution of Household Poverty Status	
	Non-Imputed %	Imputed %
0% - 99% FPL	17.3	19.6
100% - 199% FPL	20.0	21.9
200% - 399% FPL	27.4	29.7
400% FPL and over	26.3	28.8
Income not reported	9.0	(100.0)
	(100.0)	

Using Single vs. Multiple Imputed Poverty Status

2005/06 NS-CSHCN	**% of CSHCN ever uninsured in past 12 mos. BY Household Poverty Status**	
	Using Multiple Imputation FPL	**Using Single Imputation FPL**
0% - 99% FPL	14.2	14.3
100% - 199% FPL	14.1	14.0
200% - 399% FPL	7.1	7.1
400% FPL and over	2.9	3.0

C. Other Common Analytic Issues

1C: True
NS-CSHCN Example

- Response rates were lower in:
  - Urban areas
  - Wealthier areas
  - Areas with larger non-White populations
  - Areas with a greater proportion of renters
- More calls were required to complete interviews in:
  - Urban areas
  - Wealthier areas
  - Areas with larger non-White populations
  - Areas with a greater proportion of renters

Comparisons Across Subgroups

- Response rates were lower in:
  - Urban areas
  - Wealthier areas
  - Areas with l
  - ers
- complete interviews in:
  - an areas
  - Wealthier areas
  - Areas with larger non-White populations
  - Areas with a greater proportion of renters

Sampling weights generally account for these differences

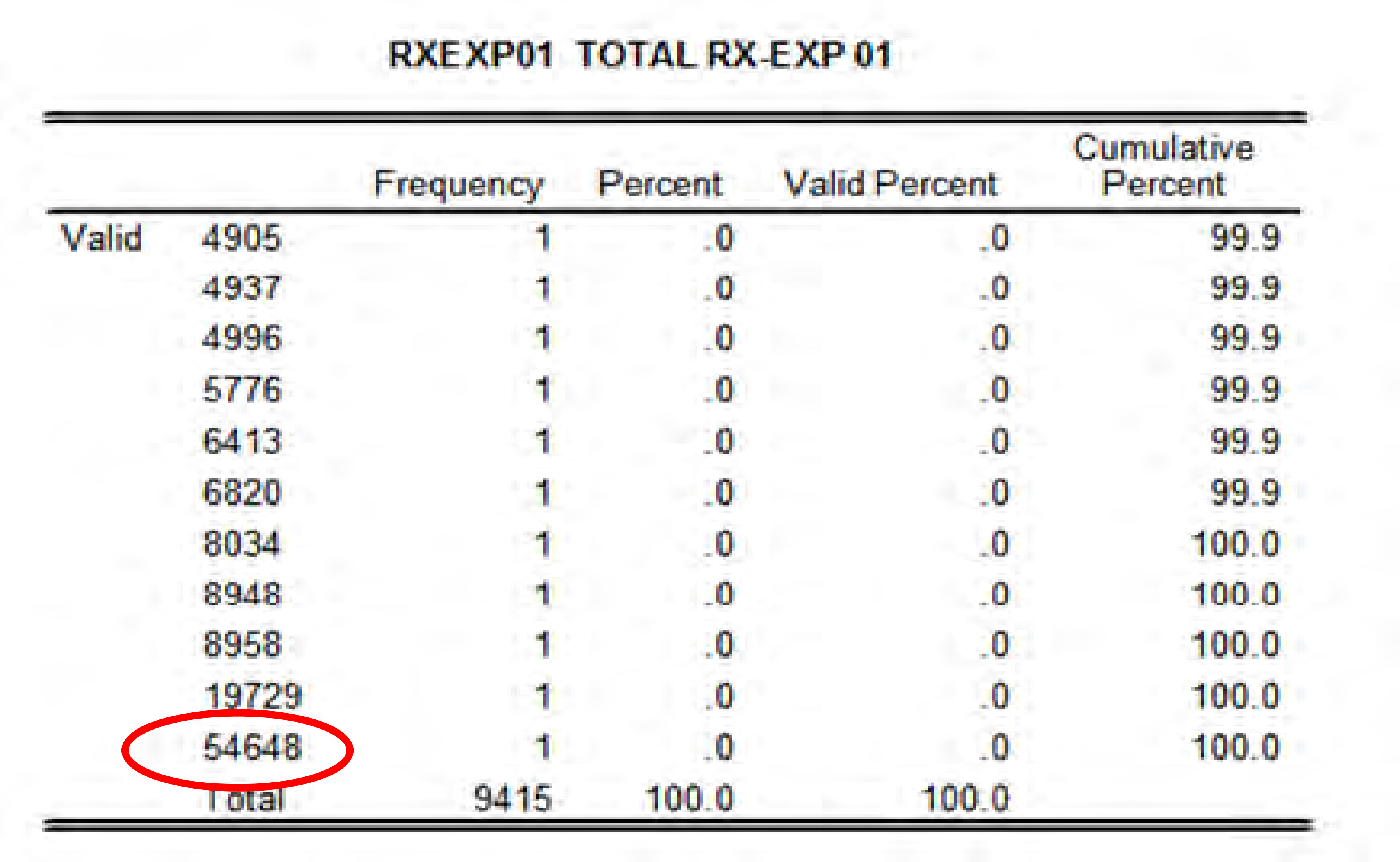
2C and 3C

- 2C: YOU MUST ADJUST Standard Errors!
  - See NCHS slideshow and example in packet and adjusting standard errors.
  - Not adjusting overestimates precision and biases all statistical tests.
- 3C: False.
  - Always looking at unweighted and weighted results help you understand the impact of weighting on results and forces you to track changes in sample size as you conduct your analysis.

4C: Handling skewed data
"Outliers" Matter

- Source = 2001 MEPS
- 9415 children age 0-17 as of 12/31/01
- 1617 CSHCN
- Variable = total expenditures for RX meds during calendar year (**RXEXP01**)

Tail of distribution for RXEXP01



RXEXP01 TOTAL RX-EXP 01

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	4905	1	.0	.0	99.9
	4937	1	.0	.0	99.9
	4996	1	.0	.0	99.9
	5776	1	.0	.0	99.9
	6413	1	.0	.0	99.9
	6820	1	.0	.0	99.9
	8034	1	.0	.0	100.0
	8948	1	.0	.0	100.0
	8958	1	.0	.0	100.0
	19729	1	.0	.0	100.0
	54648	1	.0	.0	100.0
	Total	9415	100.0	100.0	

“Outliers” Matter

- When $54,648 child is included:

  Mean RX expenditures

  for all CSHCN = **$493.97** (SE $120.56)

- When $54,648 child is NOT included:

  Mean RX expenditures

  for all CSHCN = **$371.19** (SE $20.24)

Regression and Skewed Data: Working with MEPS Expenditure Data

- MEPS expenditure data is skewed (many have no expenditures; huge outliers)
- A 2=part regression model was developed through the from Rand Health Insurance Experiment to analyze d highly skewed data such as health care expenditures data from MEPS
  - The model uses an initial separate multivariate logistic regression model to predict the probability of having ANY expenditure.
  - This probability is then multiplied by the predicted log-transformed expenditure of any individual with nonzero expenditures (as determined from separate multivariate linear regression models for children who have nonzero expenditures).

REFERENCES:

- Brook RH, Ware JE Jr, Rogers WH, et al. Does free care improve adults' health? Results from a randomized controlled trial. *N Engl J Med.* 1983;309:(23): 1426–1434.
- Monheit AC, Wilson R, Arnett RH. *Informing American Health Care Policy: The Dynamics of Medical Expenditure and Insurance Surveys, 1977–1996*. San Francisco, Calif: Jossey-Bass Publishers; 1999.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D. Once upon a time in a galaxy far, far away ….

There was great need to identify children with special health care needs ……..

The “Challenges”

- CSHCN vary widely:
  - Types & level of functional limitations
  - Type, intensity & scope of service use needs
  - Types of diagnoses (physical, emotional, developmental, behavioral, etc.)
- No perfect method for identifying CYSHCN
  - Diagnostic check lists, parent-report & administrative data records all have inherent limitations
- No “gold standard” for determining what constitutes a special health care need

Defining CSHCN

- Conceptual Approaches
  - Program-based
  - Diagnosis-based
  - Consequences-based
- Specific Criteria
  - Level and types of functional limitations
  - Level, frequency and types of services needed
  - Types of conditions
  - Diagnostic status
  - Duration of condition status

Defining Special Health Needs –
WHO do we want to identify?

NARROWER DEFINITIONS

include only those with
very severe conditions or highly
complex needs

(C only)

BROADER DEFINITIONS

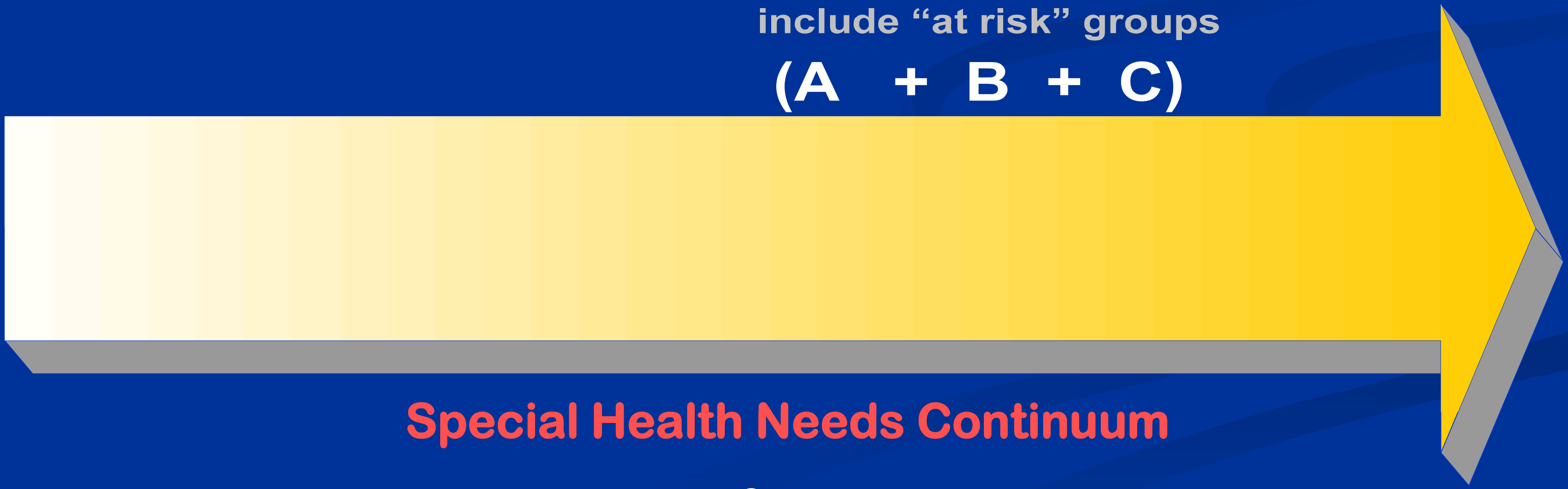
include those with wider array of
conditions, levels of severity
and service use needs

(B + C)

MOST INCLUSIVE DEFINITIONS

include “at risk” groups

(A + B + C)



Special Health Needs Continuum

How CSHCN are defined in MEPS, NS-CSHCN and NSCH

"Children with special health care needs are those who have…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."

— Maternal and Child Health Bureau, July 1998

What was the need for a non-condition specific, consequences-based tool?

- The epidemiology of children with chronic conditions makes condition by condition assessments impractical for comparison purposes.
- Single condition monitoring provides an inadequate view of overall quality of care for CSHCN, who share many common needs and often have more than one condition.
- Many children experience consequences long before they receive a diagnosis or the correct diagnosis, especially for children
  - with conditions for which clear diagnostic criteria do not exist are not routinely applied
  - with mental, behavioral or developmental problems.

What was the need for a short, parent-completed tool

- Parent-report most amendable to uniform data collection (vs. administrative records or medical chart data)
- Per survey item costs of national survey data collection high
- Longer surveys threaten participation rate.
- Limits of condition checklists, medical records and administrative, diagnostic data
    - Comprehensive condition check-lists need to be extraordinarily long
    - Verbatim responses to condition questions difficult to code and score
    - Condition check-list results difficult to interpret due small numbers for most conditions and high rates of co-morbidity
    - Parent report of conditions show many over and under-identification problems, especially when "EVER TOLD" method is used.
    - Reliable, "one stop shopping" medical record or administrative data not available in the US

CSHCN Screener

Asks about 5 different health consequences:

1) Limited or prevented in ability to function
2) Prescription medication need/use
3) Specialized therapies (OT, PT, Speech)
4) Above routine use of medical care, mental health or other health services
5) Counseling or treatment for on-going emotional, behavioral or developmental problem

---

a) Due to medical, behavioral or other health condition

AND

b) Condition has lasted or is expected to last for at least 12 months

Q1: PRESCRIPTION (RX) MEDS

Q2: ABOVE ROUTINE SERVICE USE

Q3: FUNCTIONAL LIMITATIONS

Q4: SPECIALIZED THERAPIES

Q5: MENTAL HEALTH

CYSHCN

Children meeting 1 or more of the above qualifying screening criteria

CSHCN Screener

Sample question:

Q3) Is **(child's name)** limited or prevented in any way in his/her ability to the things that most children of the same age can do?

IF YES:

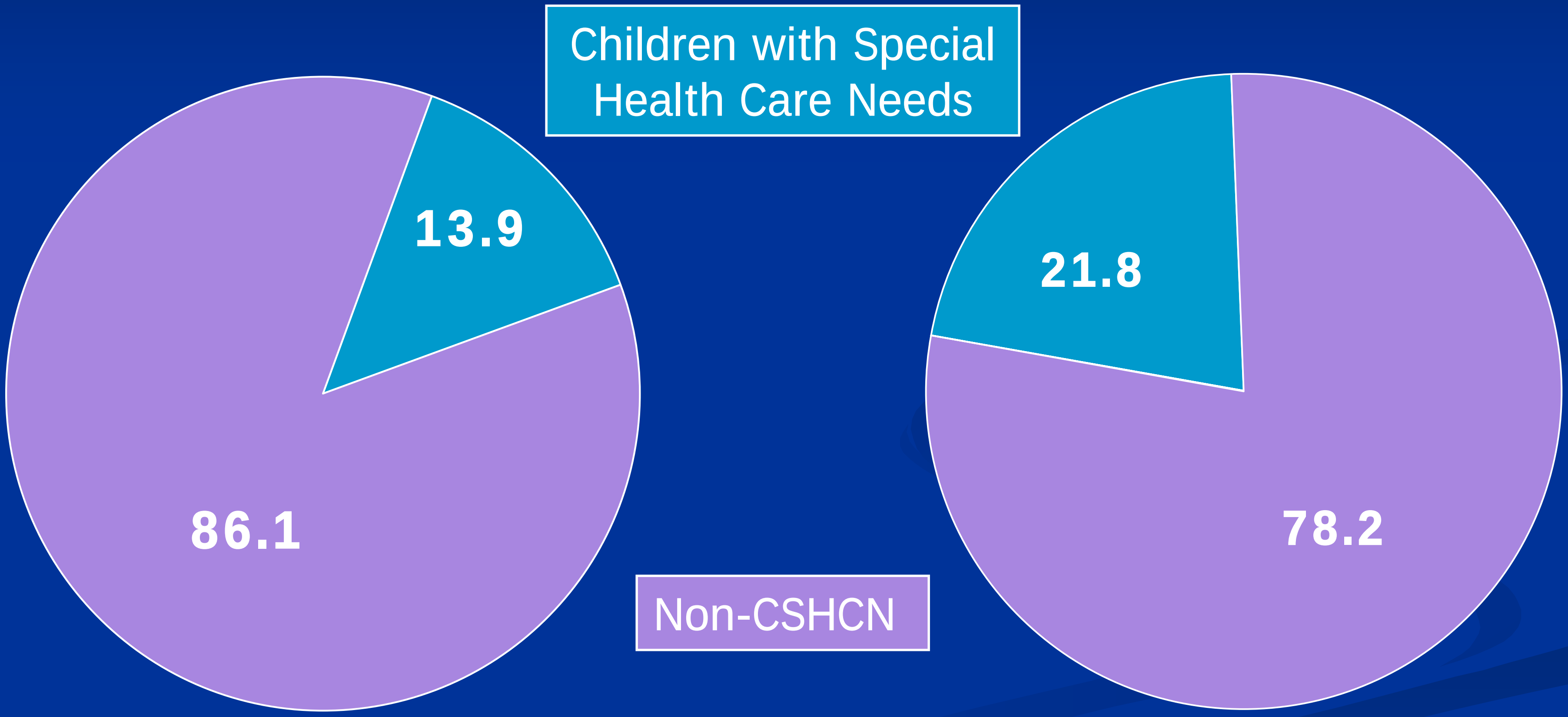
Q3a) Is **(child's name)** limitation in abilities because of ANY medical, behavioral or other health condition?

IF YES:

Q3b) Is **this a condition that has lasted or is expected to last for at least 12 months**?

All three parts of question 3 must be answered YES for a child to qualify on the functional limitations consequences criteria

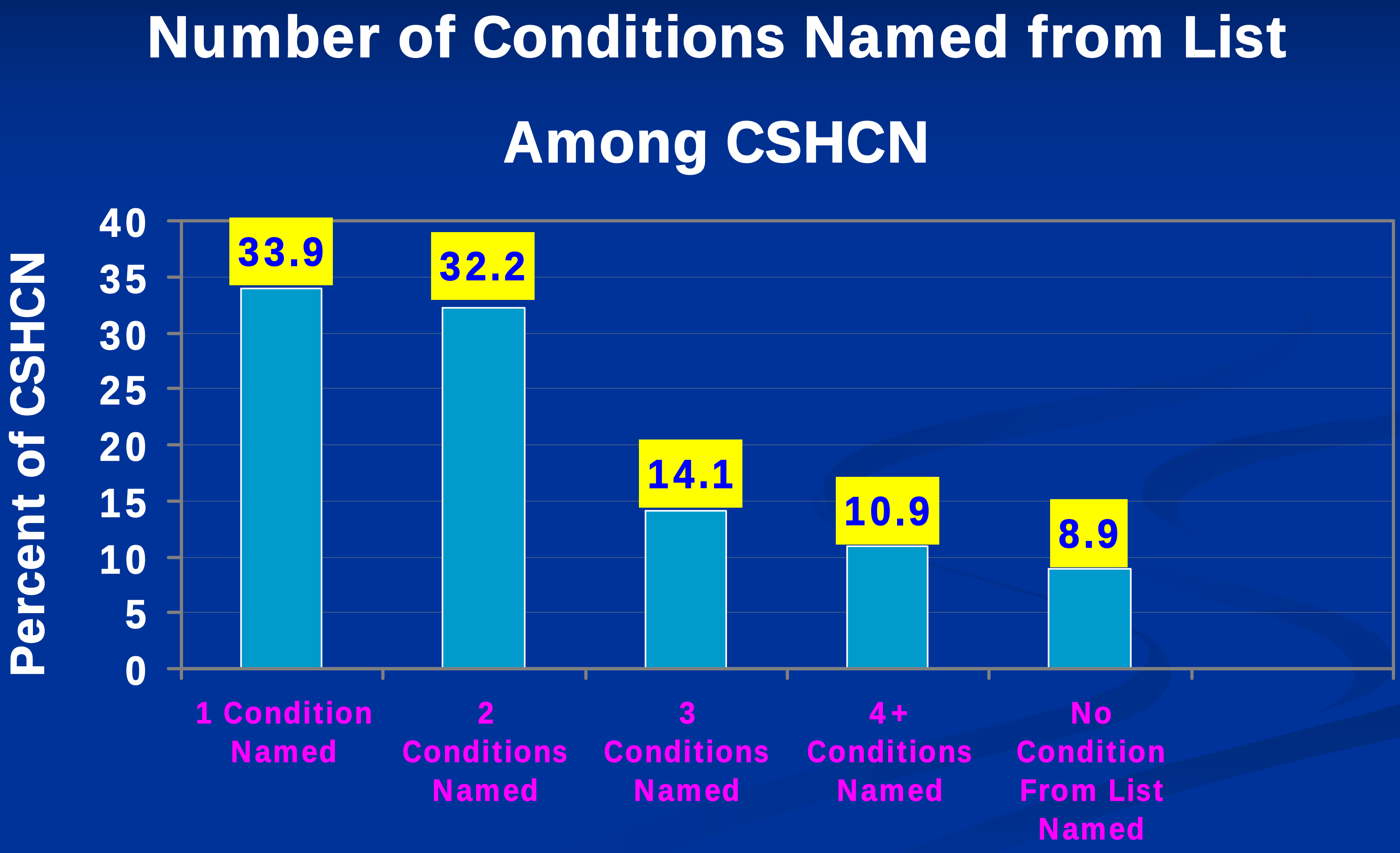
Prevalence of CSHCN Using CSHCN Screener



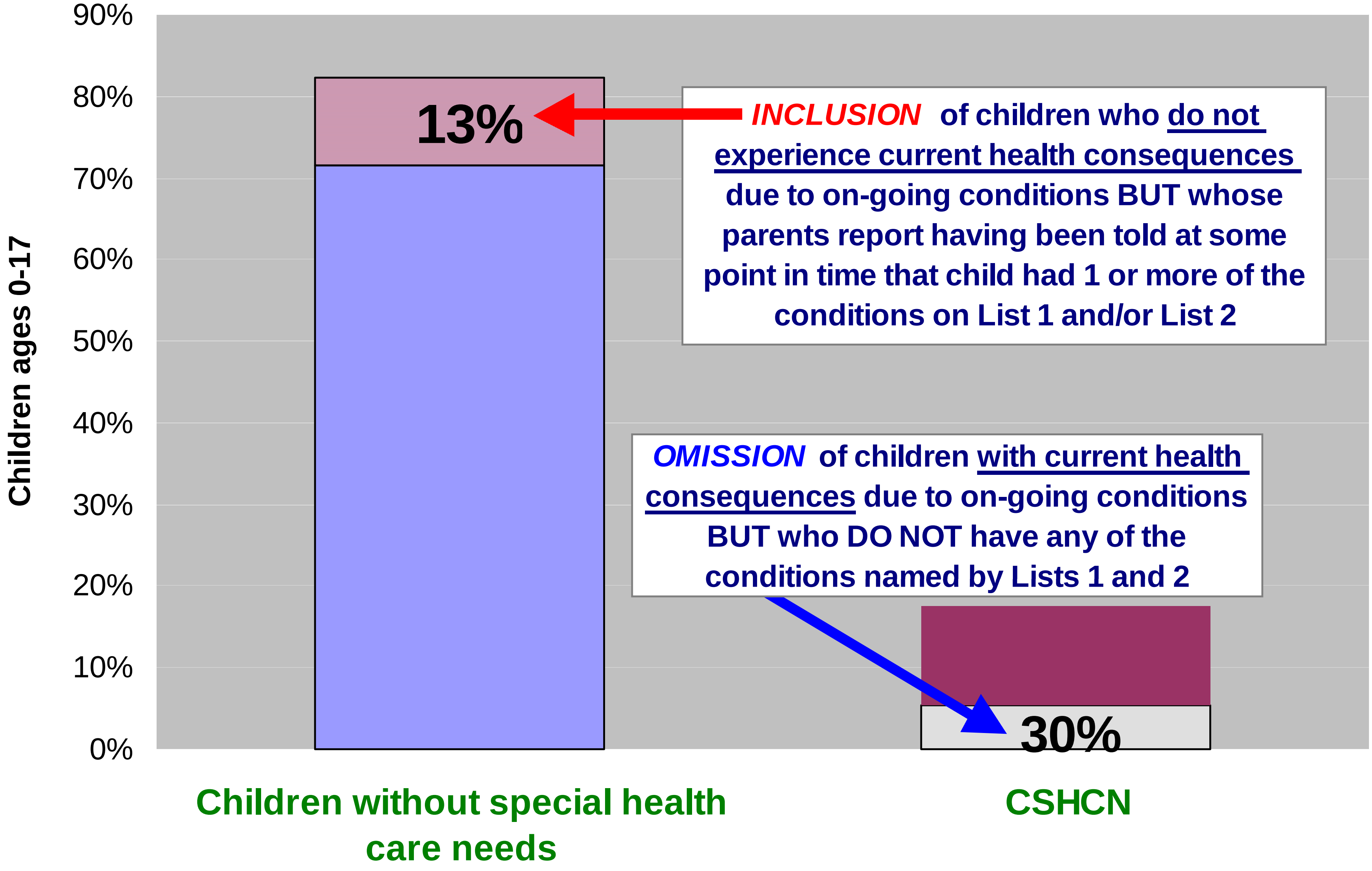
Individuals

Households

Conditions Among CSHCN



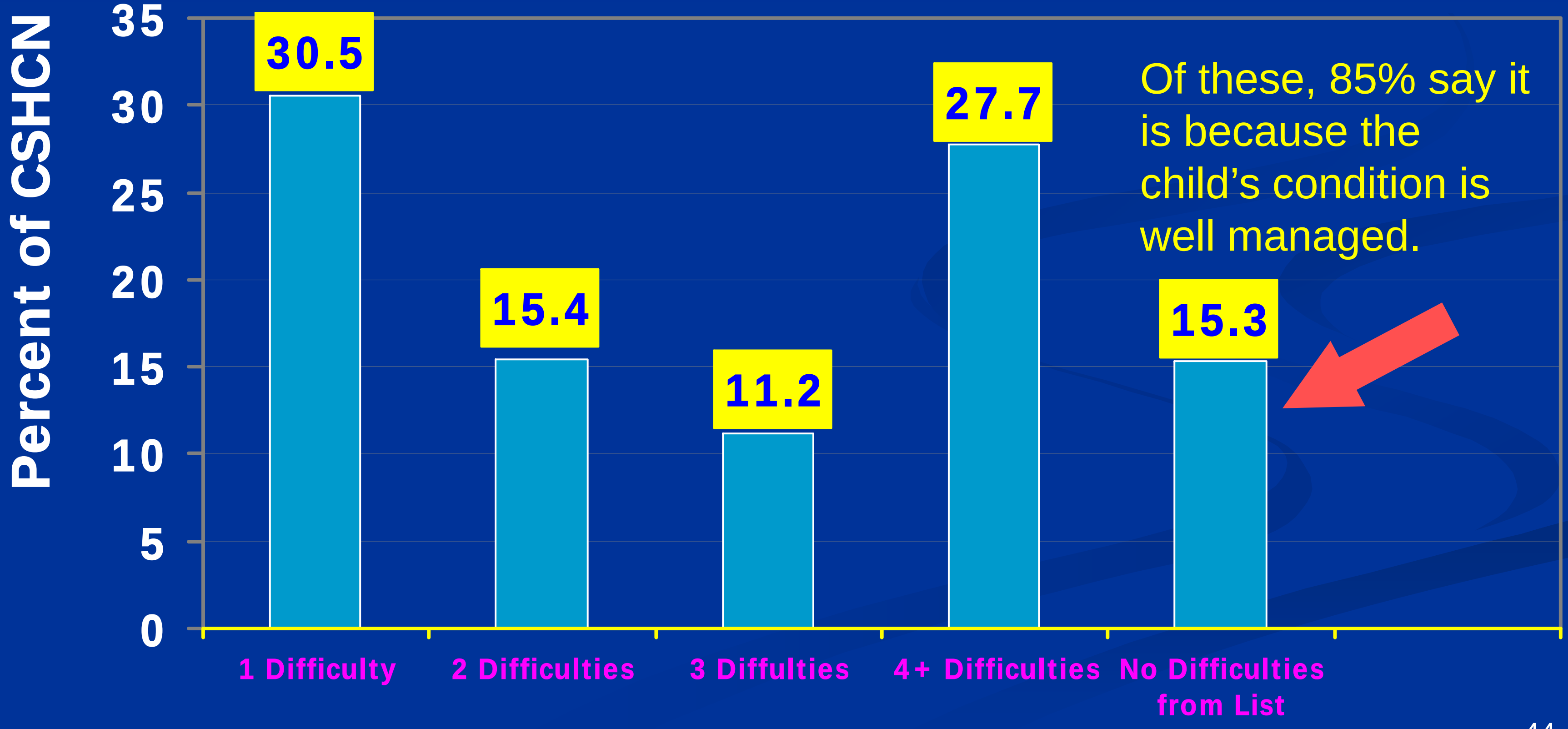
1D: Relying ONLY upon condition checklists and/or parent-rated severity in the NSCH would lead to:



INCLUSION **of children who do not experience current health consequences due to on-going conditions BUT whose parents report having been told at some point in time that child had 1 or more of the conditions on List 1 and/or List 2**

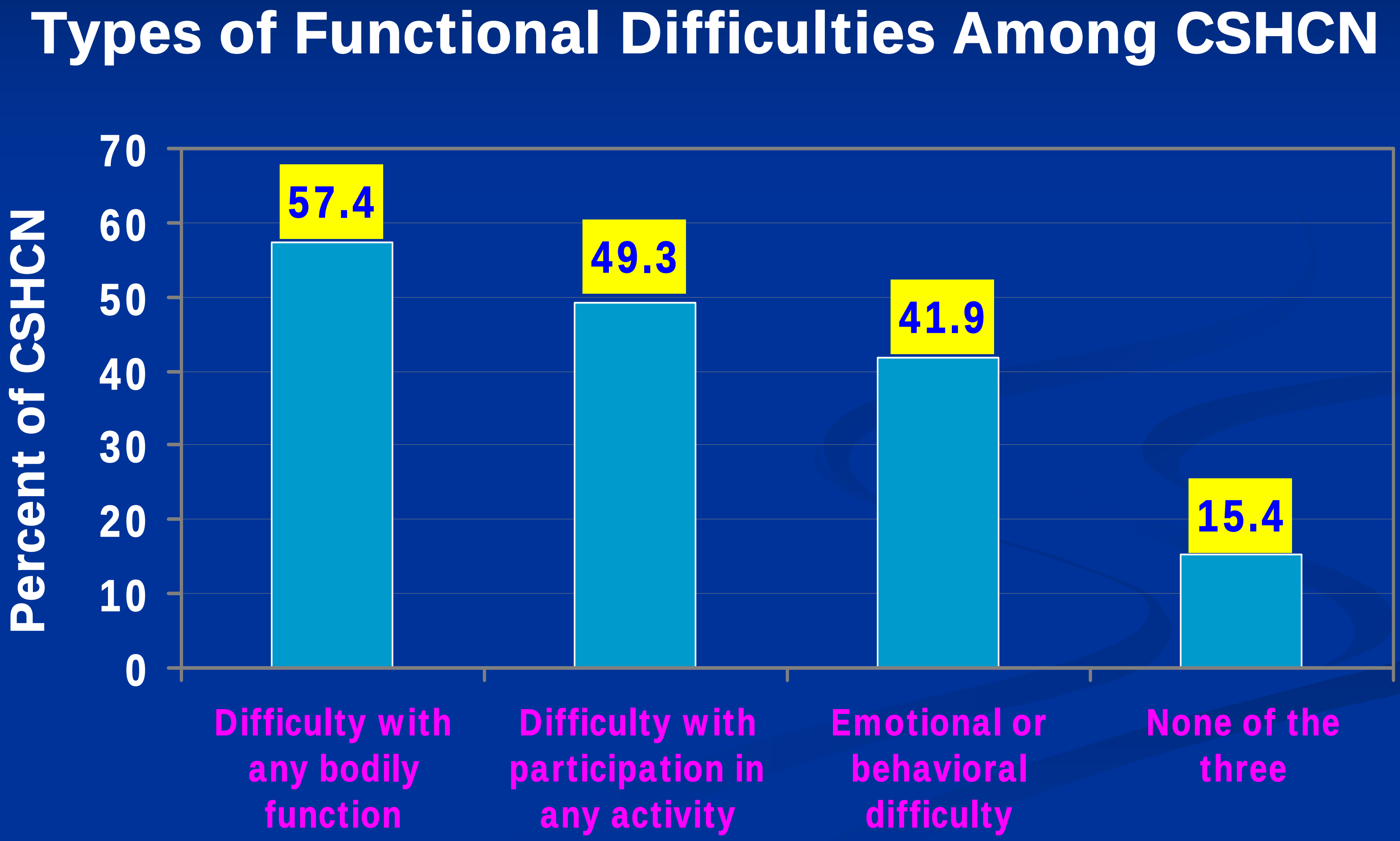
OMISSION **of children with current health consequences due to on-going conditions BUT who DO NOT have any of the conditions named by Lists 1 and 2**

Functional Difficulties Among CSHCN



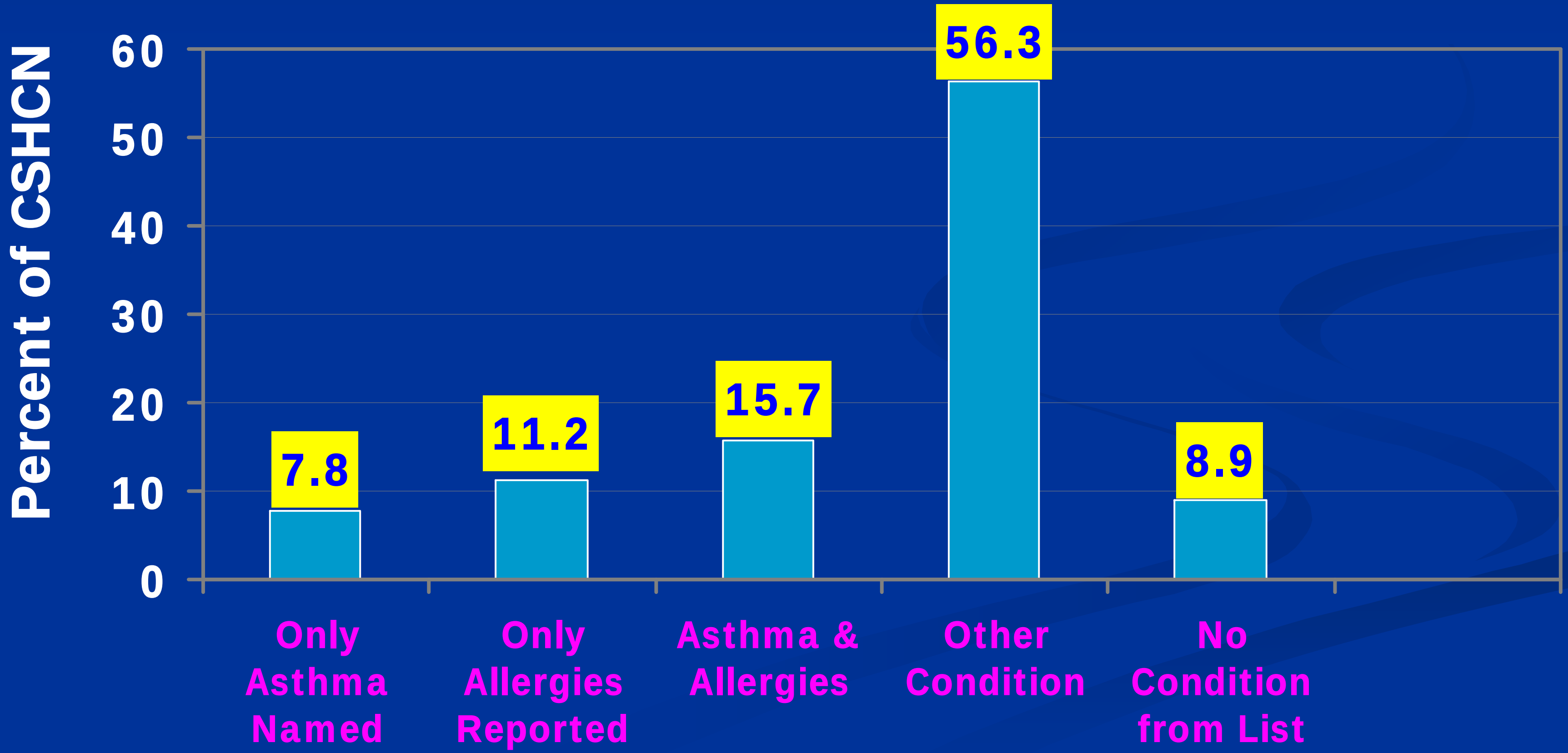
Of these, 85% say it is because the child’s condition is well managed.

Functional Difficulties



2D: True and False
3D: Conditions Among CSHCN

Type of Conditions Named from List Among CSHCN (defined as current health, health service need consequence for ongoing condition)



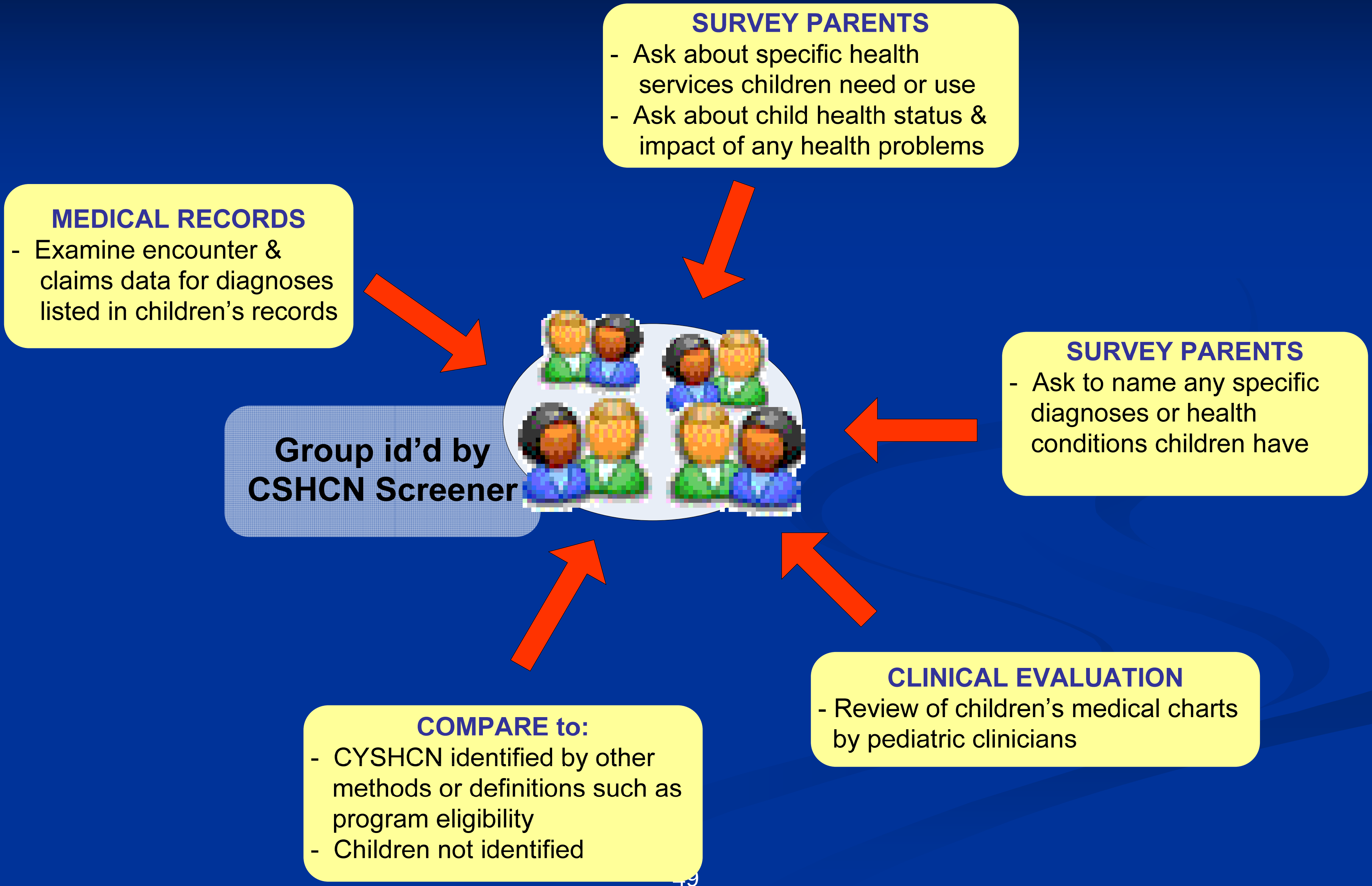
4D and 5D

- 4D: False.
  - Data is on proportion of CHILDREN whose parents report child experienced and needs, not the proportion of PARENTS (there are fewer parents than there are children)
- 5D: Depends.
  - A. 22.7% - % age 12-17 qualify as CYSHCN
  - B. 46.4% - % CYSHCN age 12-17

E. Available Resources

- 1E. Submit a research plan and request to NCHS Research Data Center. There is a cost.
- 2E. False.
  - MEPS provides National and Regional (and some MSA) findings ONLY!
- 3E: True.
  - www.childhealthdata.org
  - "Request a Data Set"
  - No cost as long as DRC is supported to provide this resource.
  - Requirement: Citation of data source and agreement to share research results when published or completed (so the DRC can continue to provide this resource).

NO GOLD STANDARD?
“Triangulate” to Validate



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

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

Group id’d by CSHCN Screener

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

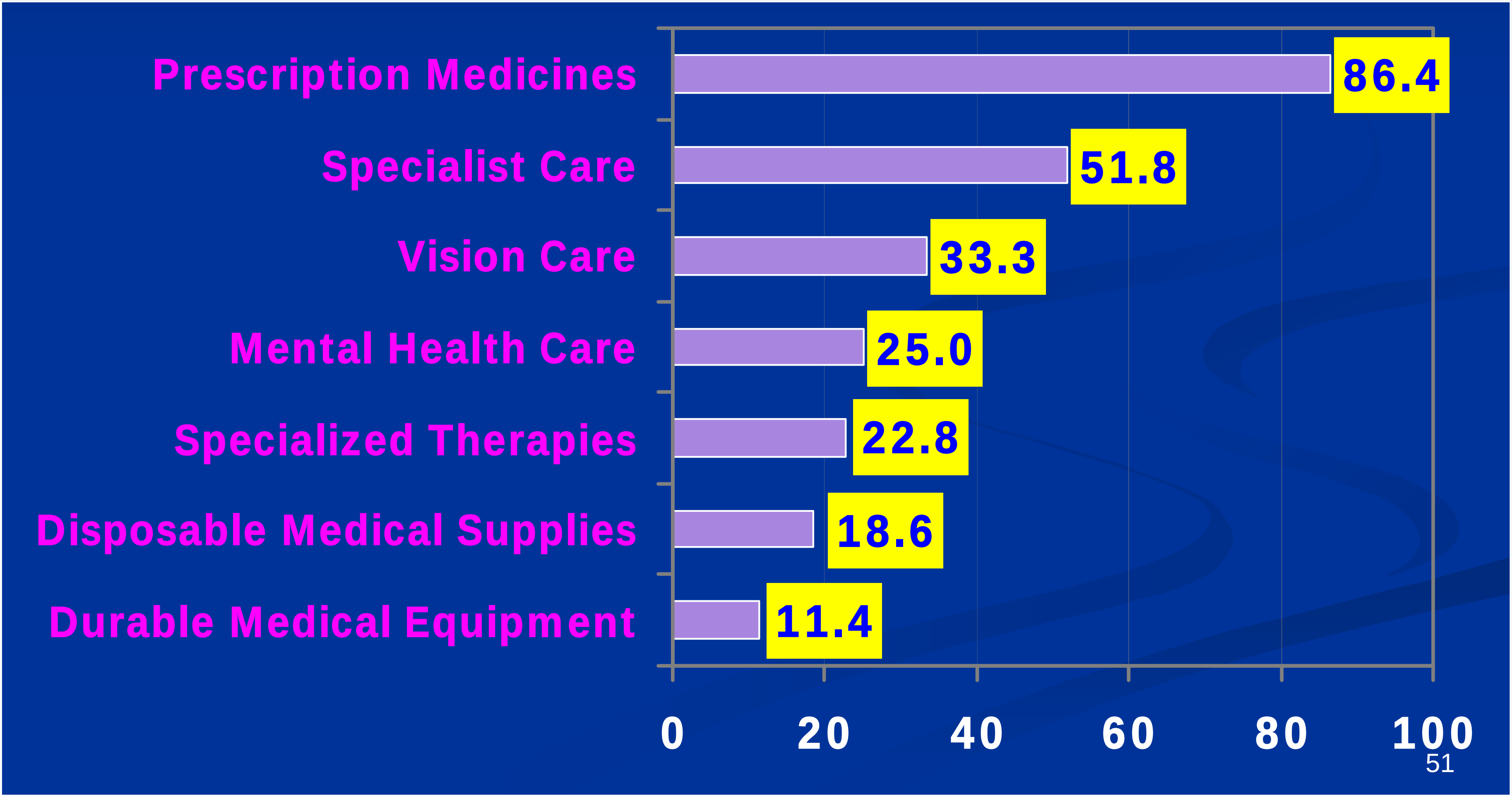
CLINICAL EVALUATION
- Review of children’s medical charts by pediatric clinicians

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

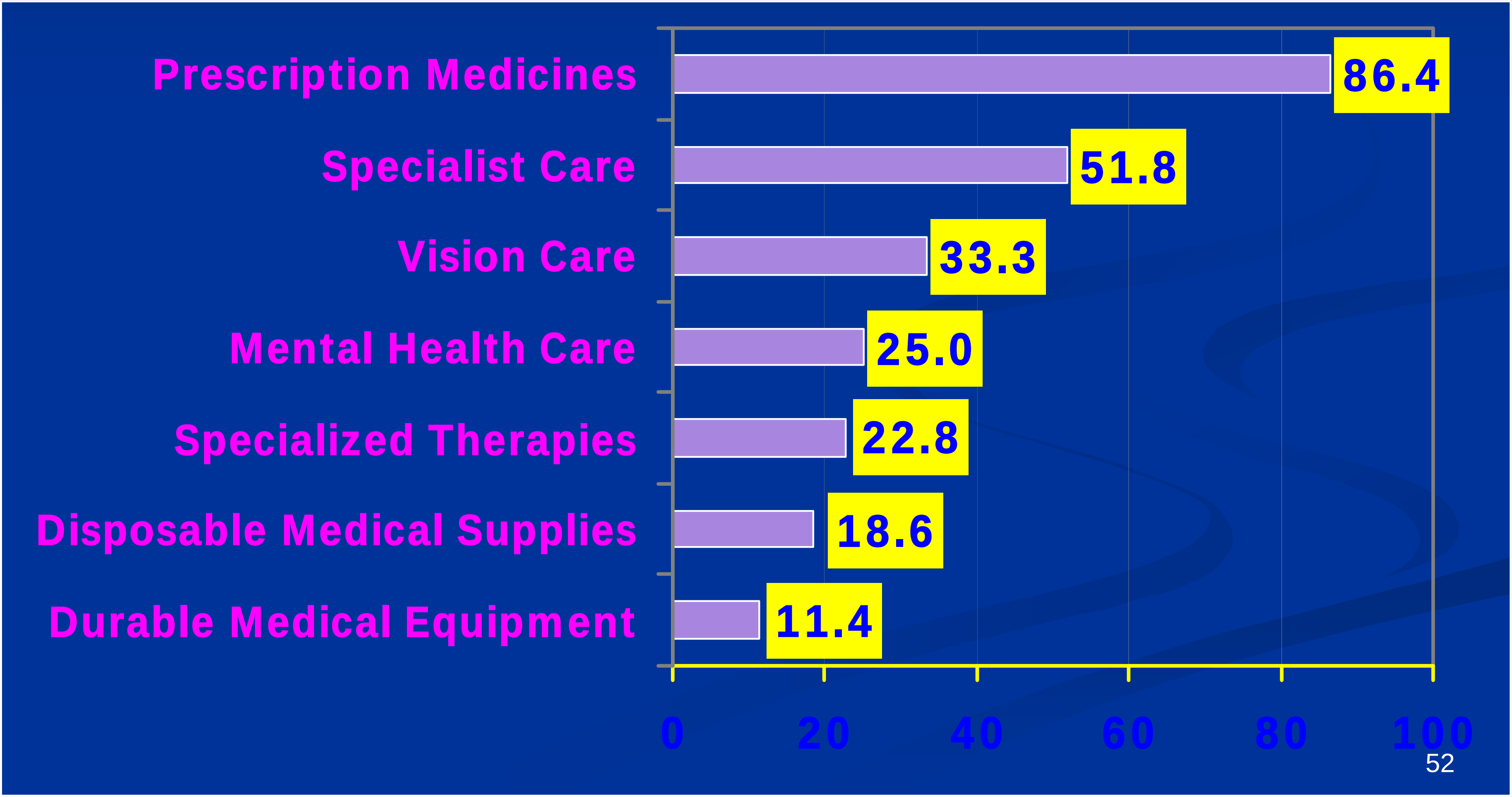
When using other information in the survey to stratify results by child health status or complexity/severity keep in mind that:

Parents tend to evaluate and report on their children’s current abilities from a “strength-based” perspective – especially in relation to other children or the “worst case scenario” . . . . .

Common Service Needs



Common System Performance Improvement Needs



Percentage of CSHCN Needing Specific Health Services

Stratifying groups identified by CSHCN Screener

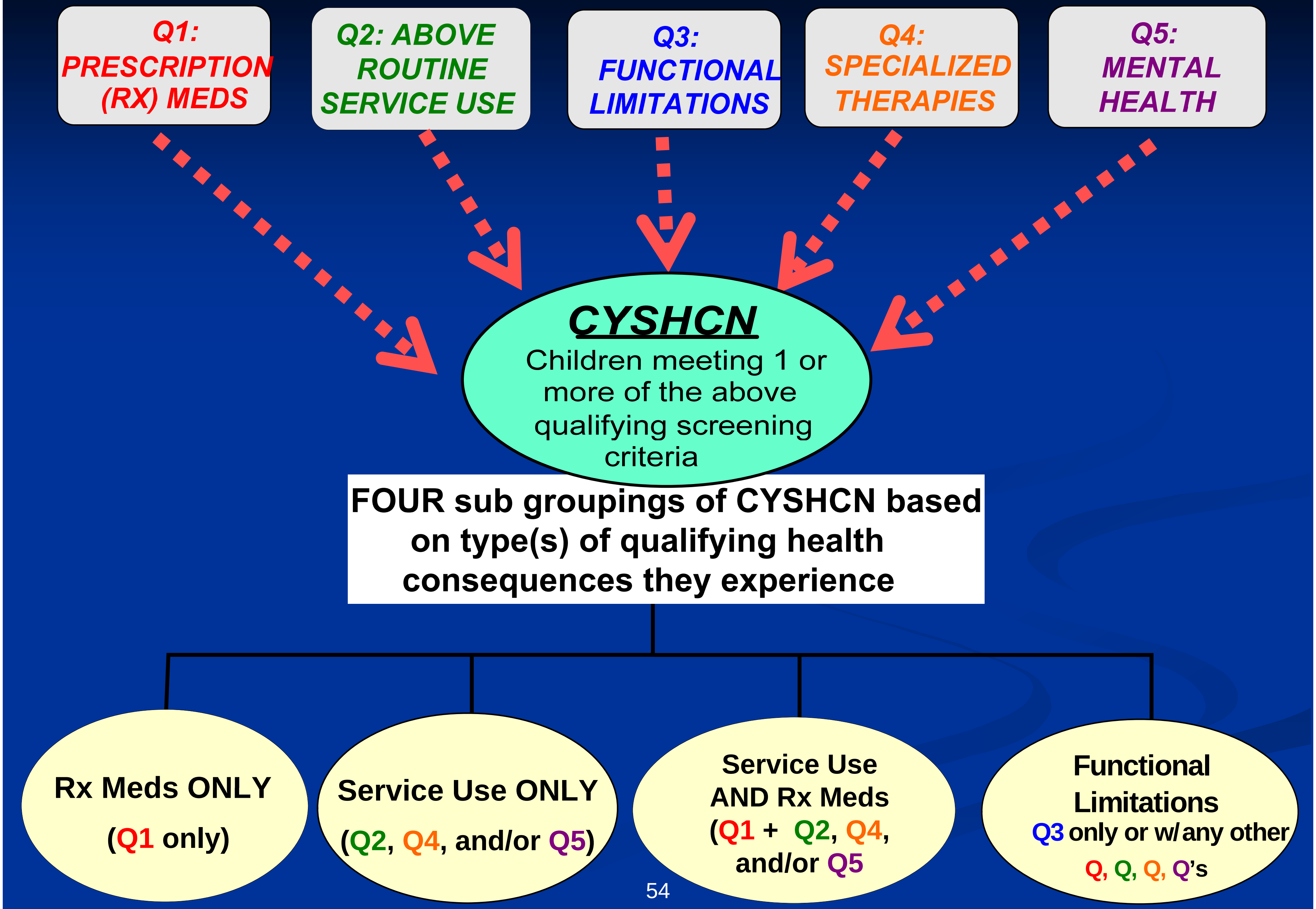
- Makes sense logically & clinically:
  - **Underlying epidemiology of childhood chronic conditions and disability**
  - **Broader definition of CSHCN as starting point**
  - **Wide variation in number and types of health services needed/used by CSHCN**

- Options include:

Quantitative – number of qualifying screening criteria

Qualitative – type of qualifying health consequences

Other survey information – alone or in combination w/ screening information



Q1: PRESCRIPTION (RX) MEDS

Q2: ABOVE ROUTINE SERVICE USE

Q3: FUNCTIONAL LIMITATIONS

Q4: SPECIALIZED THERAPIES

Q5: MENTAL HEALTH

CYSHCN

Children meeting 1 or more of the above qualifying screening criteria

FOUR sub groupings of CYSHCN based on type(s) of qualifying health consequences they experience

Rx Meds ONLY

(Q1 only)

Service Use ONLY

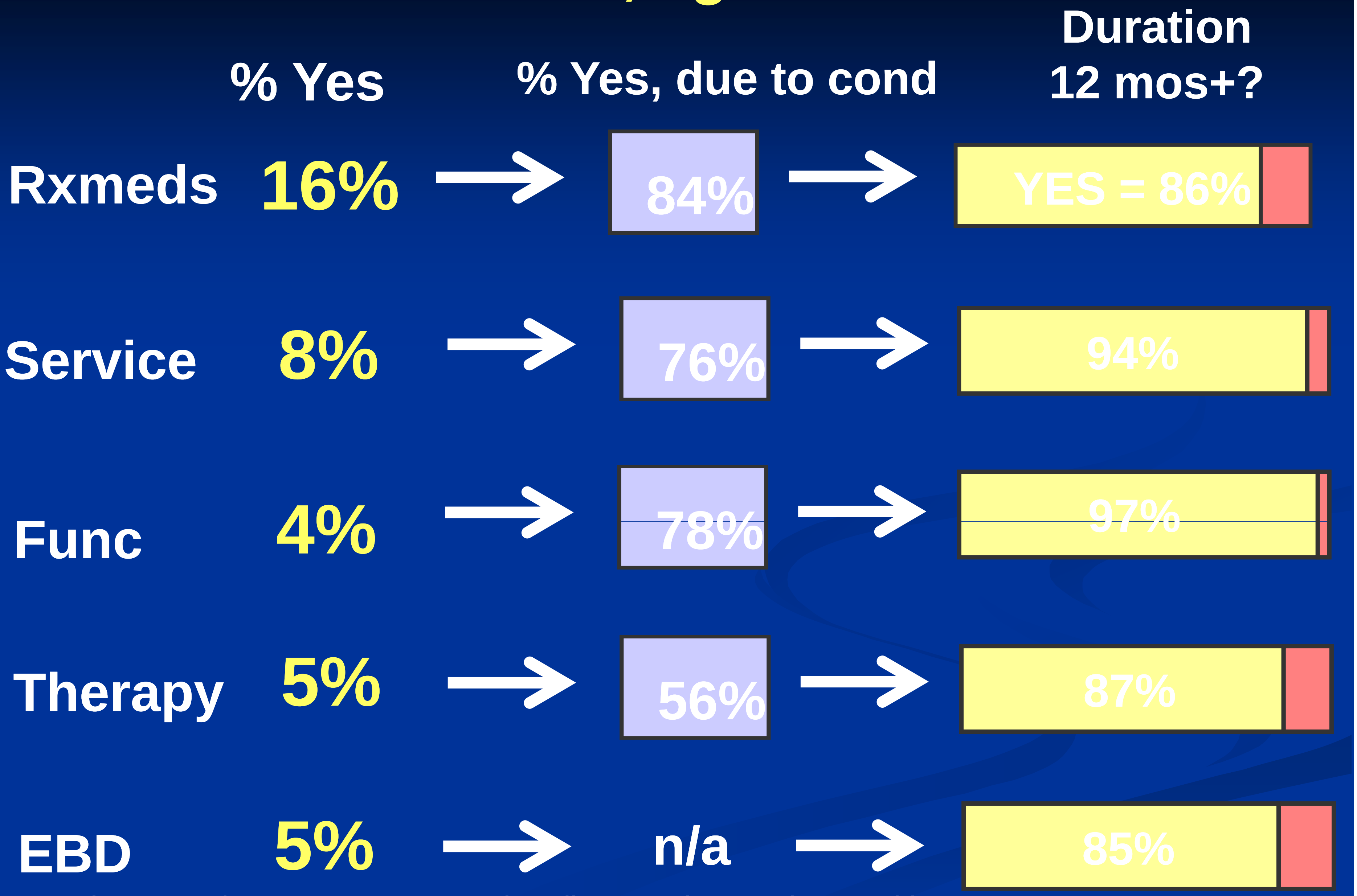
(Q2, Q4, and/or Q5)

Service Use AND Rx Meds (Q1 + Q2, Q4, and/or Q5

Functional Limitations

Q3 only or w/ any other Q, Q, Q, Q's

Children, ages 0-17



	% Yes	% Yes, due to cond	Duration 12 mos+?
Rxmeds	16%	84%	YES = 86%
Service	8%	76%	94%
Func	4%	78%	97%
Therapy	5%	56%	87%
EBD	5%	n/a	85%

Based on 2005/06 NS-CSHCN Interim File. Results consistent with 2001 NS-CSHCN, 2003 NSCH, 2004 MEPS.

Care Coordination (CC) Measures	CAHPS CCC	NS-CSHCN		NSCH	
		2001	2005	2003	2007
Got follow up from PDN after specialist or special care?				√	
Got help accessing specialist or special care by PDN?				√	
Got all needed professional CC?		√			
Overall satisfaction with professional CC.		√			
Satisfaction with communication among providers and/or with school?	√	√	√		√
Does anyone help with CC?	√		√		√
Got all/could not have used more help with CC?			√		√