

Issues to Consider when Analyzing Data from the SLAITS Child Health Surveys

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Topic 1: Different Surveys / Different Prevalence Rates

Topic 2: Stratifying survey results by child health status

Topic 3: Hispanic children and language of interview

Strong focus on the CSHCN

- New NS_CSHCN data coming Fall 2007
- NSCH first opportunity to examine differences for + and – grps
- CSHCN important policy group – as much as 80% of child health costs due to this group
- Changes in the epidemiology of this grp effect many sectors – parental health, school system, health system, etc.



National Survey of CSHCN



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

National Survey of Children's Health



**Survey Sections
1 – 5 and 8 – 11
are asked for children
of all ages**



102,353
Children ages 0-17

randomly selected, 1 per HH

Early Childhood
questions (Sections 1-5)
asked for
children

**Middle childhood/Adolescence
questions (Section 7)
asked for children ages 6-17**



Two Surveys

What do they have in common?

- Sponsored by the federal **Maternal and Child Health Bureau**
- **National Center for Health Statistics/CDC** oversees sampling and administration
- Use **SLAITS** (State & Local Area Integrated Telephone Survey) sampling mechanism
- **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



Two Surveys

What do they have in common?

- Both surveys identify **Children with Special Health Care Needs (CSHCN)**

“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

- **5 multi-part questions**, each asking about a different health consequence
- **All parts of at least one question** must be answered “YES” for a child to qualify as having a special health care needs
- Parents/caregivers can answer by paper/pencil or telephone interview
- Takes about **1 minute** to complete

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

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




Both use the same method to identify CSHCN

- National Survey of CSHCN, 2001
 - Prevalence = 12.8%
- National Survey of Children's Health, 2003
 - Prevalence = 17.6%

TOPIC 1:

Different Surveys / Different Prevalence Rates

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
- 

Respondent & Recall Period

- **National Survey of CSHCN**
 - CSHCN Screener asks about **consequences currently experienced**
 - Respondent was **generally the mother (78.9%)** or father (17.2%)
- **National Survey of Children's Health**
 - CSHCN Screener asks **about consequences currently experienced**
 - Respondent was **generally the mother (78.6%)** or father (17.3%)

Question Wording

- **National Survey of CSHCN**
 - Family-level (all children)
 - Do any of your children currently need or use medicine prescribed by a doctor?
 - Who is that?
- **National Survey of Children's Health**
 - Child-level (one randomly selected child)
 - Does **(CHILD)** currently need or use medicine prescribed by a doctor?

Question Ordering

- **National Survey of CSHCN**

- Do any of your children need or use more medical care, mental health, or educational services than is usual for most children of the same age?

- Do any of your children currently need or use medicine prescribed by a doctor?

- **National Survey of Children's Health**

- Does (CHILD) currently need or use medicine prescribed by a doctor?

- Does (CHILD) need or use more medical care, mental health, or educational services than is usual for most children of the same age?

Question Context

- **National Survey of CSHCN**
 - CSHCN Screener questions are the **first health questions** asked
 - **Immediately preceded** by demographics
- **National Survey of Children's Health**
 - CSHCN Screener questions **not the first** health questions asked
 - **Immediately preceded** by demographics, overall health status, height, and weight

Survey Introduction

- **National Survey of CSHCN**

- “...the survey asks about the **health and health care of the child or children under 18...**”
- “Depending on the health characteristics of your children, these questions **take between 5 and 25 minutes**, but for most families, **it’s around 10 minutes.**”

- **National Survey of Children’s Health**

- “...the survey will be about the **health and health care of (CHILD).**”
- “The survey will take **about 25 minutes.**”

Question Introduction

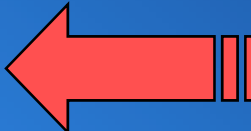
- **National Survey of CSHCN**

- “The next questions are about any kind of health problems, concerns, or conditions that may affect your children’s behavior, learning, growth, or physical development.”
- “Some of these health problems may affect your children’s abilities and activities at school or at play. Some of these problems affect the kind or amount of services your children may need or use.”

- **National Survey of Children’s Health**

- “The next questions are about any kind of health problems, concerns, or conditions that may affect your children’s behavior, learning, growth, or physical development.” **(Nothing more)**

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

- Dates of data collection
 - Method of data collection and estimation
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 - Sample size and sampling error
 - Method of identification
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 - Recall period
 - Question wording
 - Question ordering
 - Question context and introduction
- 

What other factors might contribute to increase in prevalence estimates?

- **2001 NS-CSHCN vs. 2003 NSCH**
 - **4.8 pt** increase in CSHCN prev. overall
 - **3.8 pt** increase in percentage of child population with qualifying responses the “rx meds” CSHCN Screener criteria
 - Rx meds criteria disproportionately “drives” increase in prevalence estimate relative to other screening criteria
- **Increased prescription medication use in child/adolescent population – especially psychotropic drugs – during this time period -- is reported in literature and other sources.**

What other factors might contribute to increase in prevalence estimates?

- **Medical Expenditure Panel Survey (MEPS)**
 - Btw 1999 & 2002: **5.8% increase** in % children using RX meds of any type/frequency
 - **17% increase** in % w/ 5 or more Rx meds orders filled responsible for this increase / in contrast, **no increase** observed for % reporting 1 – 4 Rx meds orders
 - Increase in 5+ Rx meds orders filled driven by **41.8% increase** in 12-17age grp vs. 4% - 6.5% increase for younger children

What other factors might contribute to increase in prevalence estimates?

Medical Expenditure Panel Survey (MEPS)

- Beginning in 2000, CSHCN Screener included in survey

From 2000 to 2002:

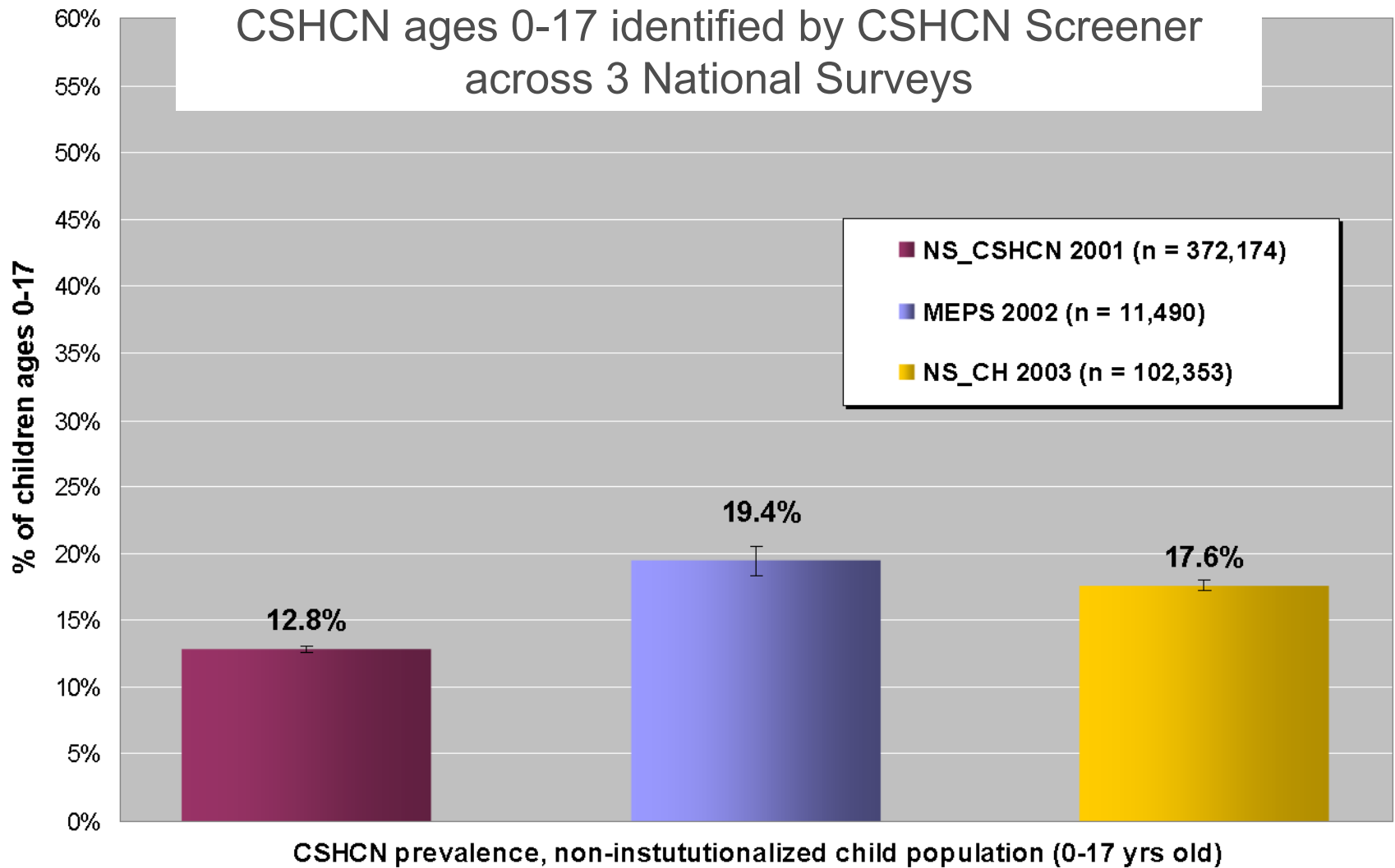
- **No increase** in % of non-CSHCN using Rx meds
- **7.6% increase** in % of CSHCN w/ 1 or more Rx meds orders filled
 - Driven by 10% increase in % w/ 5+ Rx meds orders filled
 - especially among CSHCN ages 12-17
 - Btw 2000 & 2002, 22% increase in % meeting RX meds screening criteria / 19% increase in CSHCN prevalence

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

- How much of increase is due to **methods?**
- How much is due to **changes in practice patterns?**
- Answering these questions:
 - 2005-06 NS_CSHCN design – preliminary data suggest that both contribute; support for both methods & practice pattern hypotheses
 - Further analysis of MEPS data on Rx med classes and frequency
 - Repeat administrations of same surveys over time

CSHCN prevalence

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys

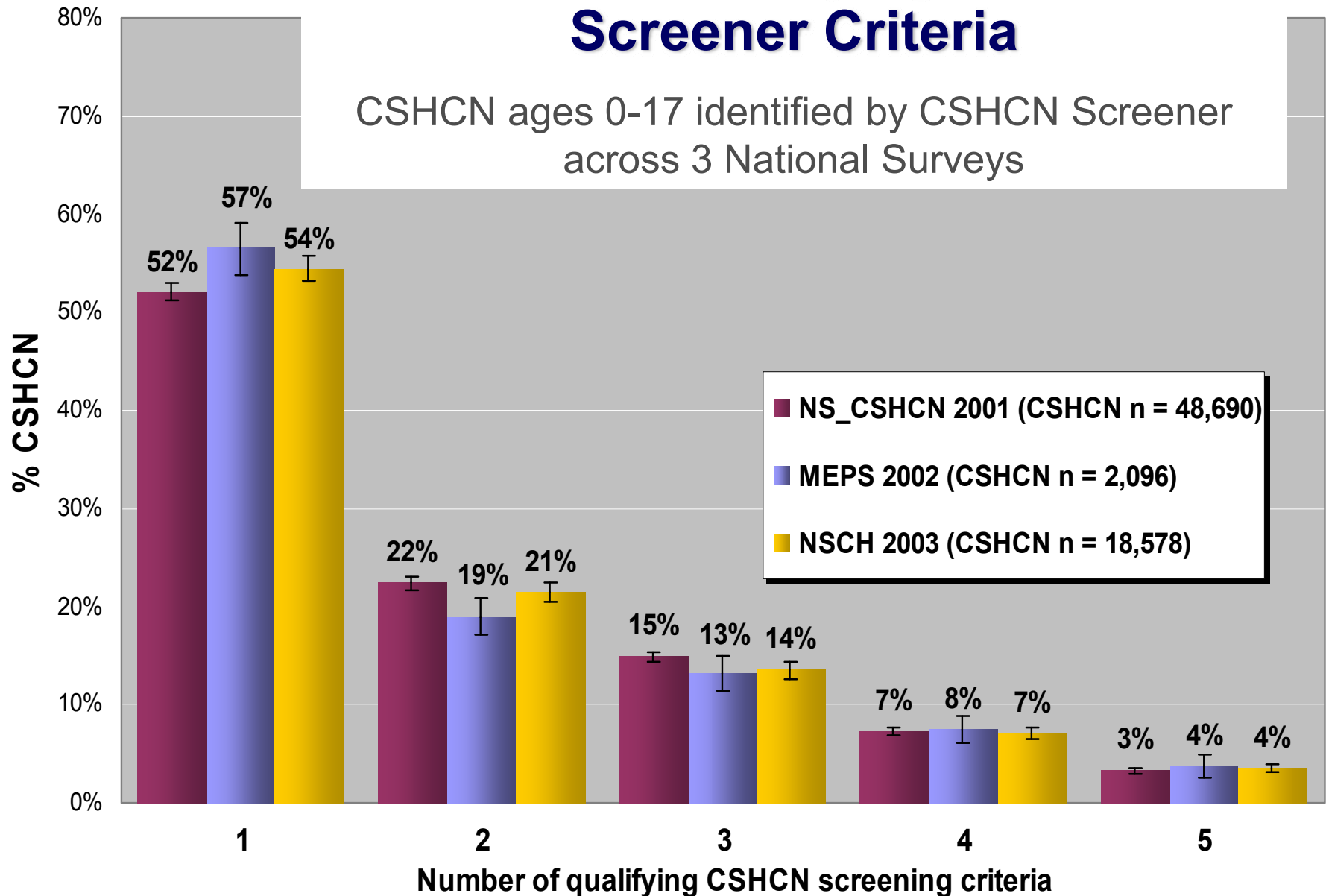


Implications for Researchers

- Why do we identify CSHCN?
 - To monitor prevalence or trends in the population
 - To identify children and families who need services or other assistance
 - To assess equalization of opportunity
- Differences in prevalence may not matter for researchers focusing on these last two reasons

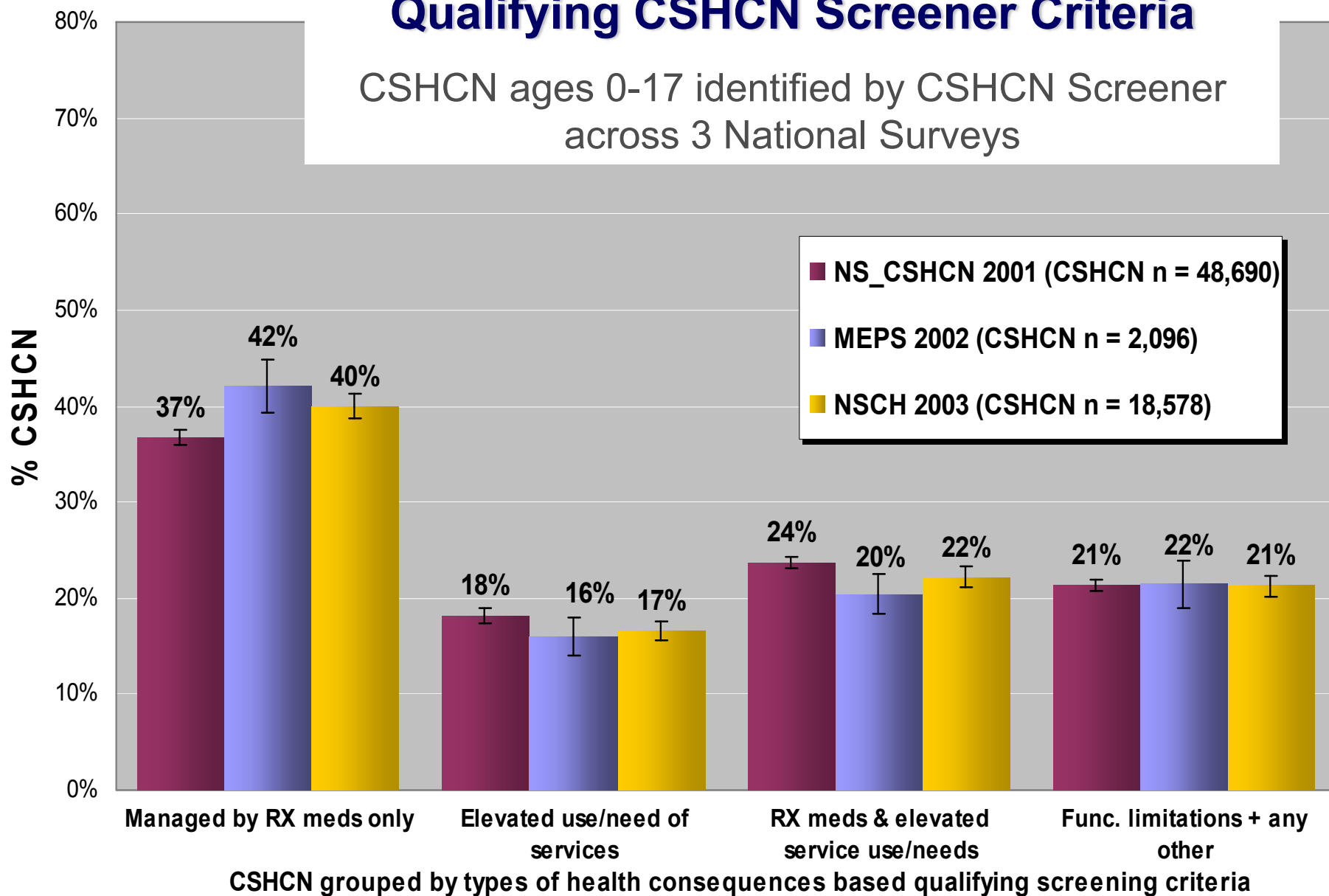
Number Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys



Type of Health Consequences based on Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys



TOPIC 2:

**Stratifying survey results by
child health status**

Stratifying survey results by child health status

Between Groups

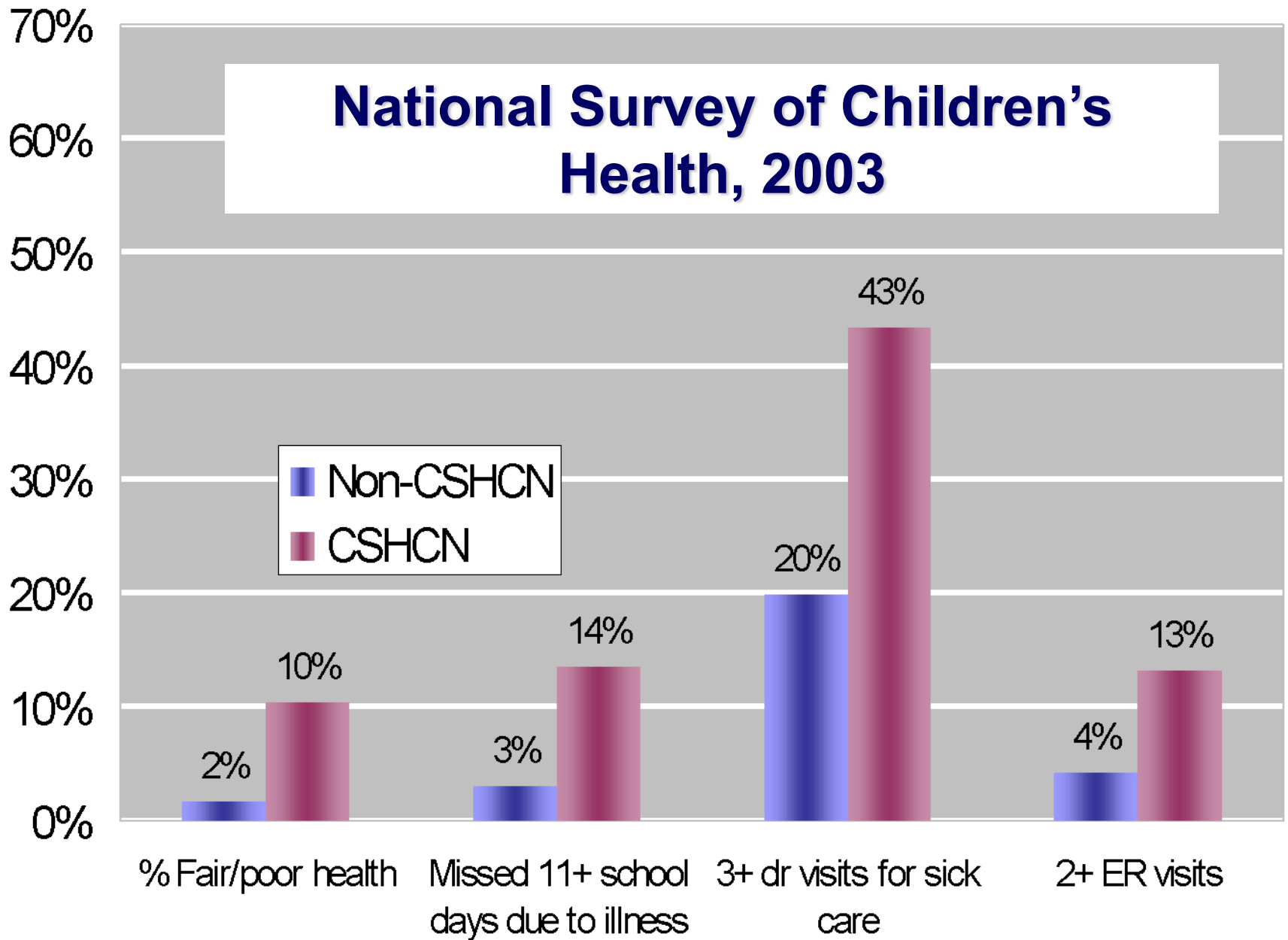
- Non-CSHCN vs. CSHCN

Within CSHCN Group

- CSHCN with different types of special health needs and/or different levels of complexity

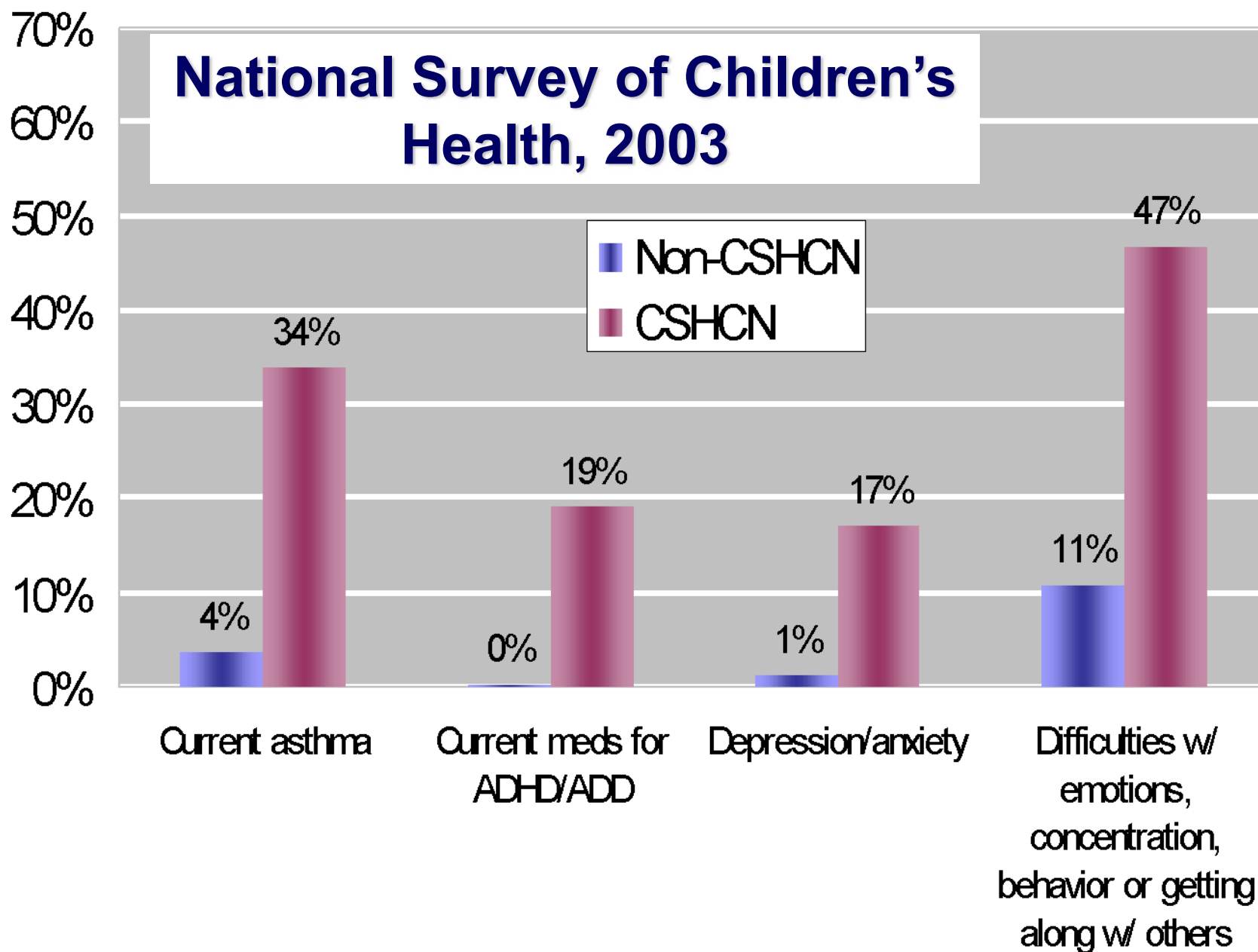
National Survey of Children's Health, 2003

Children ages 0-17



National Survey of Children's Health, 2003

Children ages 0-17



Stratifying group identified by CSHCN Screener

■ Makes sense logically & clinically:

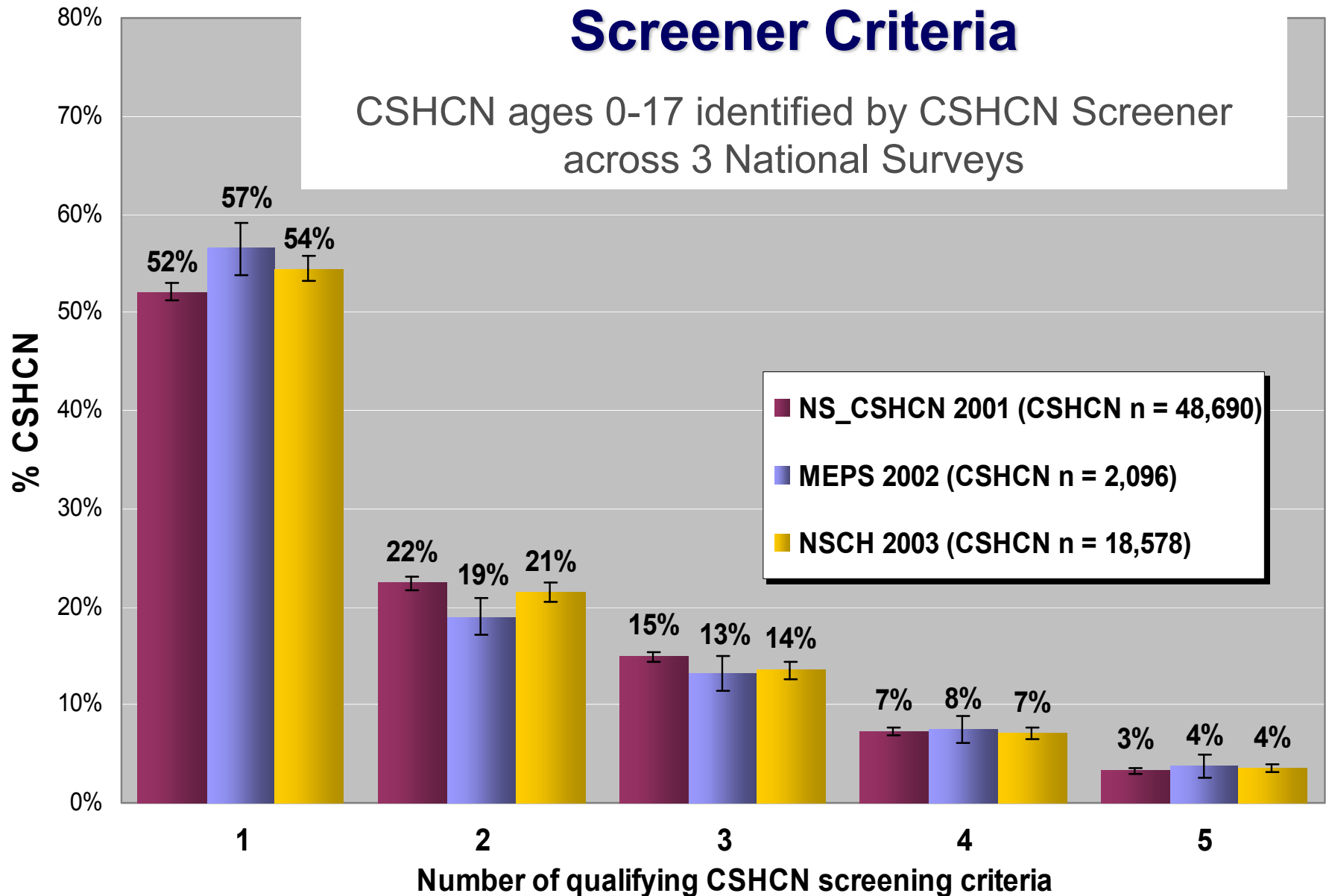
- Underlying epidemiology of childhood chronic conditions and disability
- Broader definition of CSHCN as starting point
- Wide variation in number and types of health services needed/used by CSHCN and by non-CSHCN vs. CSHCN

■ Options include:

- **Quantitative** – number of qualifying screening criteria
- **Qualitative** – type of qualifying health consequences
- **Other survey information** – alone or in combination w/ screening information

Number Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys



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)

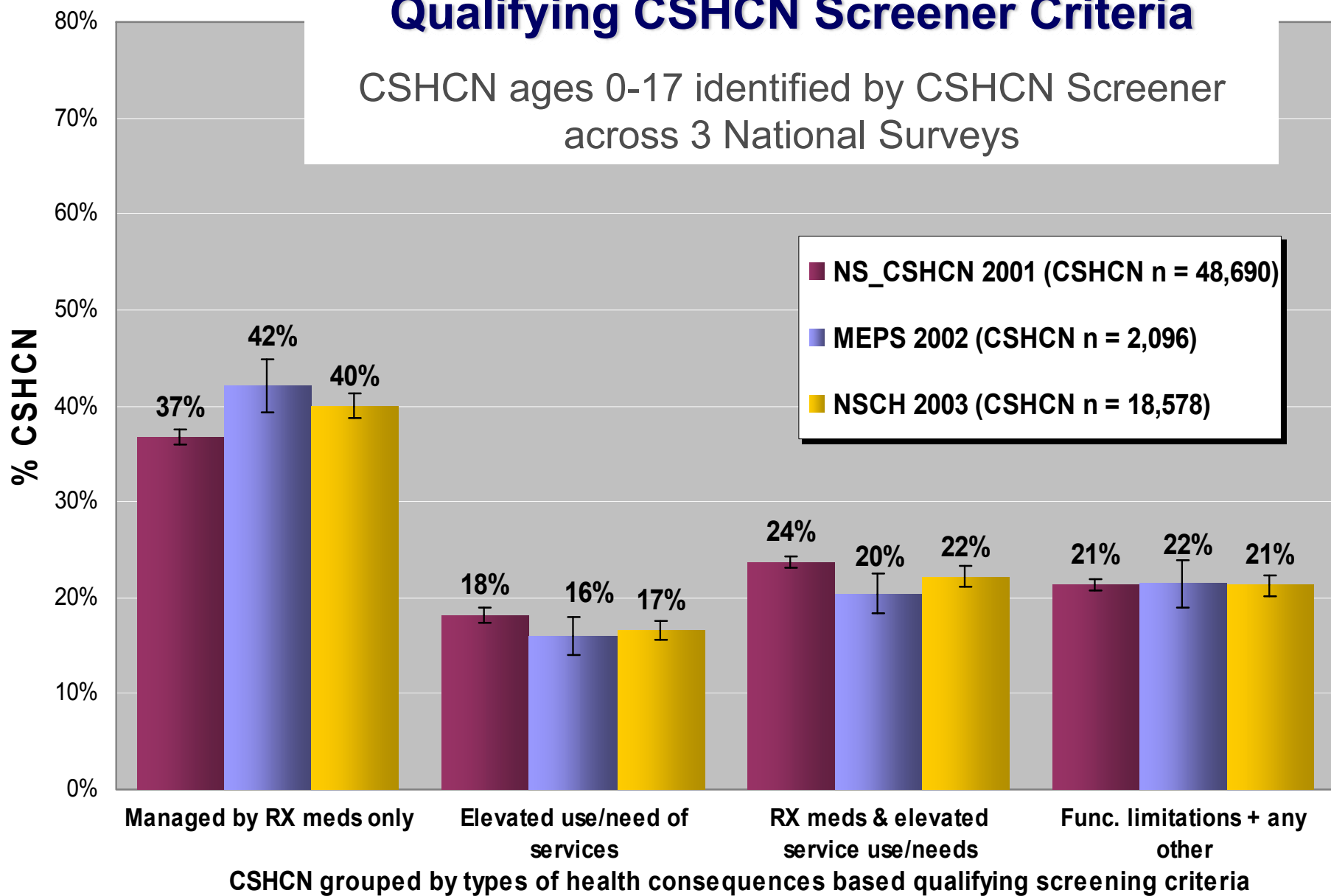
Service Use ONLY (Q2, Q4, or Q5)

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

Functional Limitations (Q3 only or w/ any other Q Q Q Q's)

Type of Health Consequences based on Qualifying CSHCN Screener Criteria

CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys

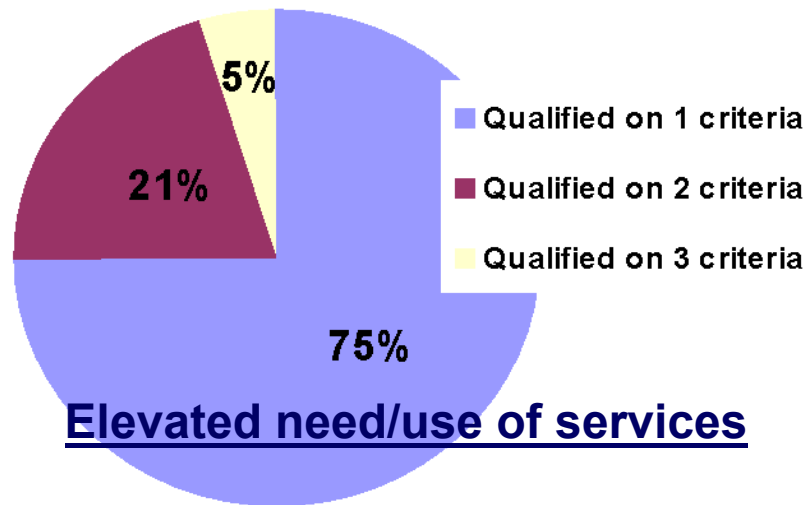


Number of Qualifying Screener Criteria per Specific Health Consequences Group -- NS_CSHCN 2001 (n = 48, 690)

Managed by RX meds only

100%

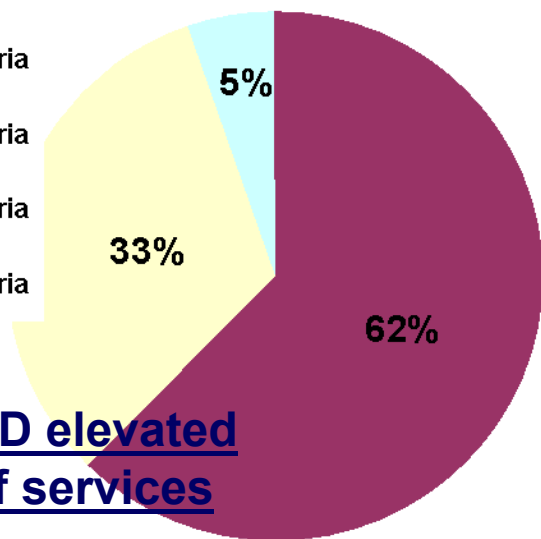
■ Qualified on 1 criteria



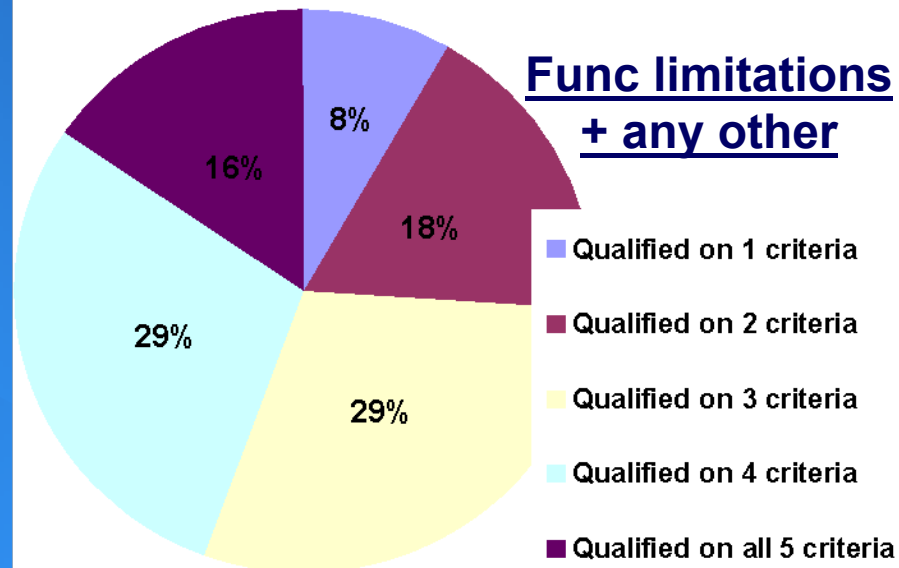
Elevated need/use of services

- Qualified on 1 criteria
- Qualified on 2 criteria
- Qualified on 3 criteria
- Qualified on 4 criteria

Rx meds AND elevated need/use of services



Func limitations + any other

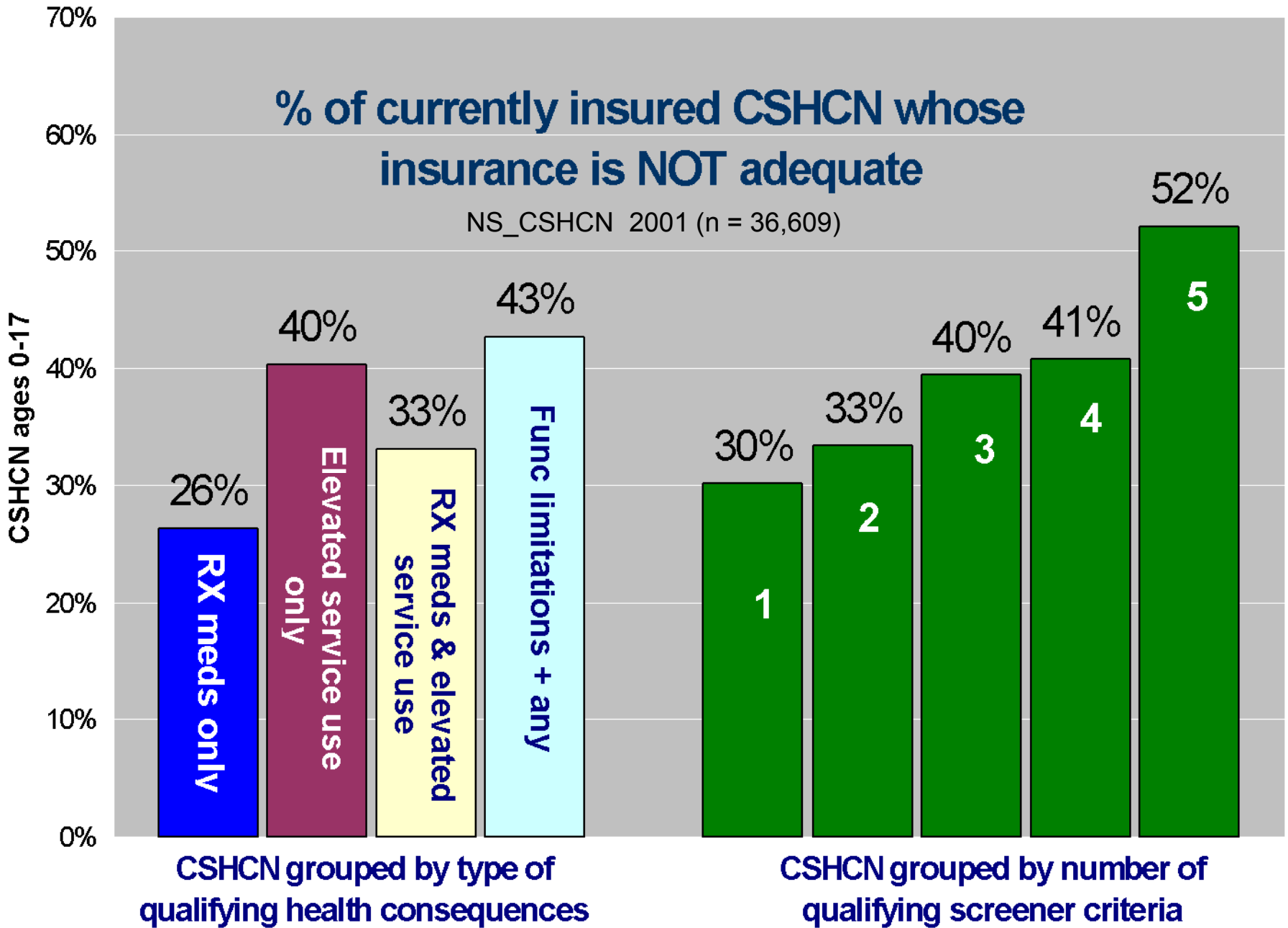


Differentiating CSHCN outcomes using Quantitative or Qualitative Classifications

- Adequacy of CSHCN current health insurance**
- Family-Centeredness of child's health care**
- Access to needed mental health care or counseling**

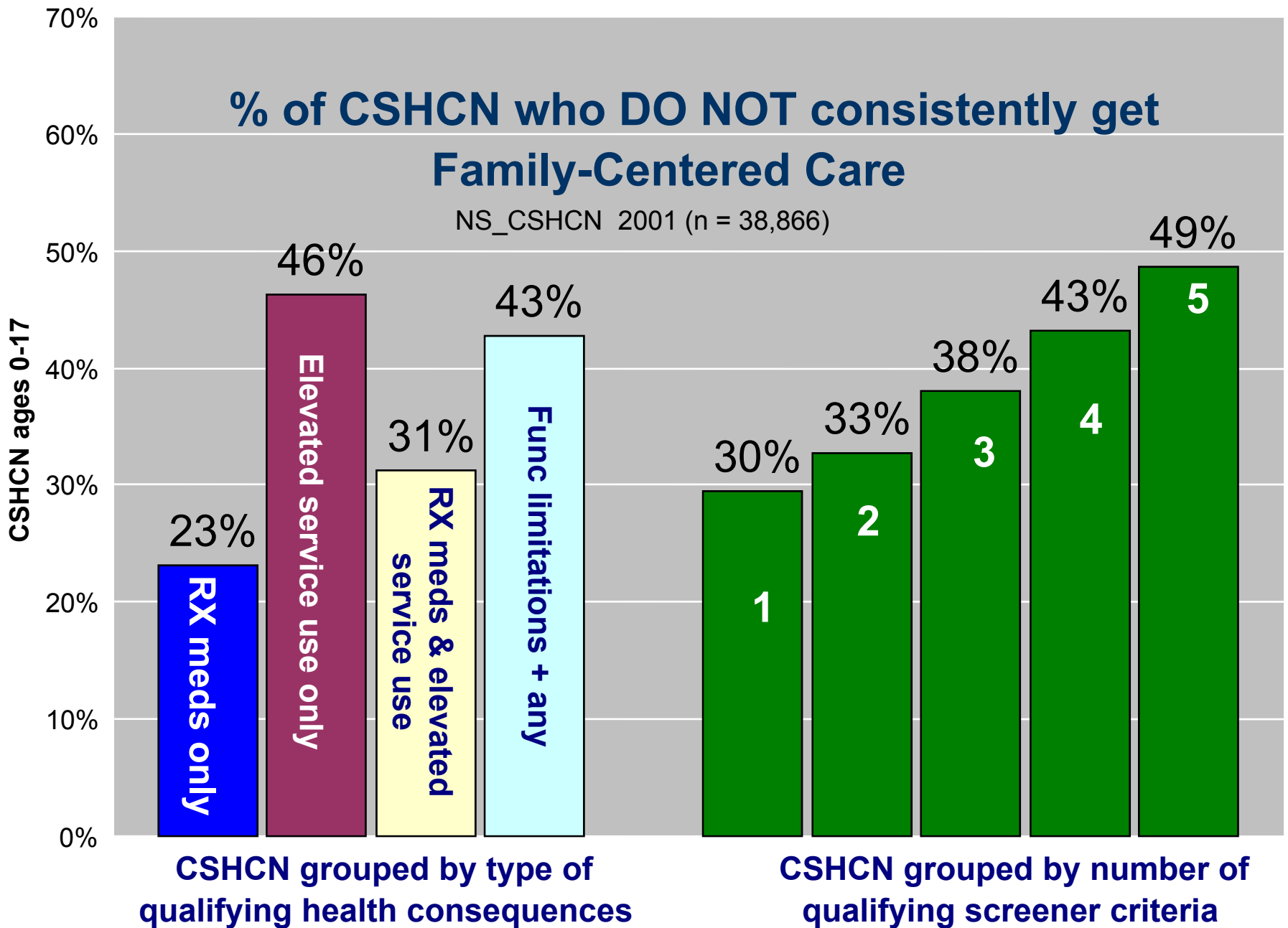
% of currently insured CSHCN whose insurance is NOT adequate

NS_CSHCN 2001 (n = 36,609)



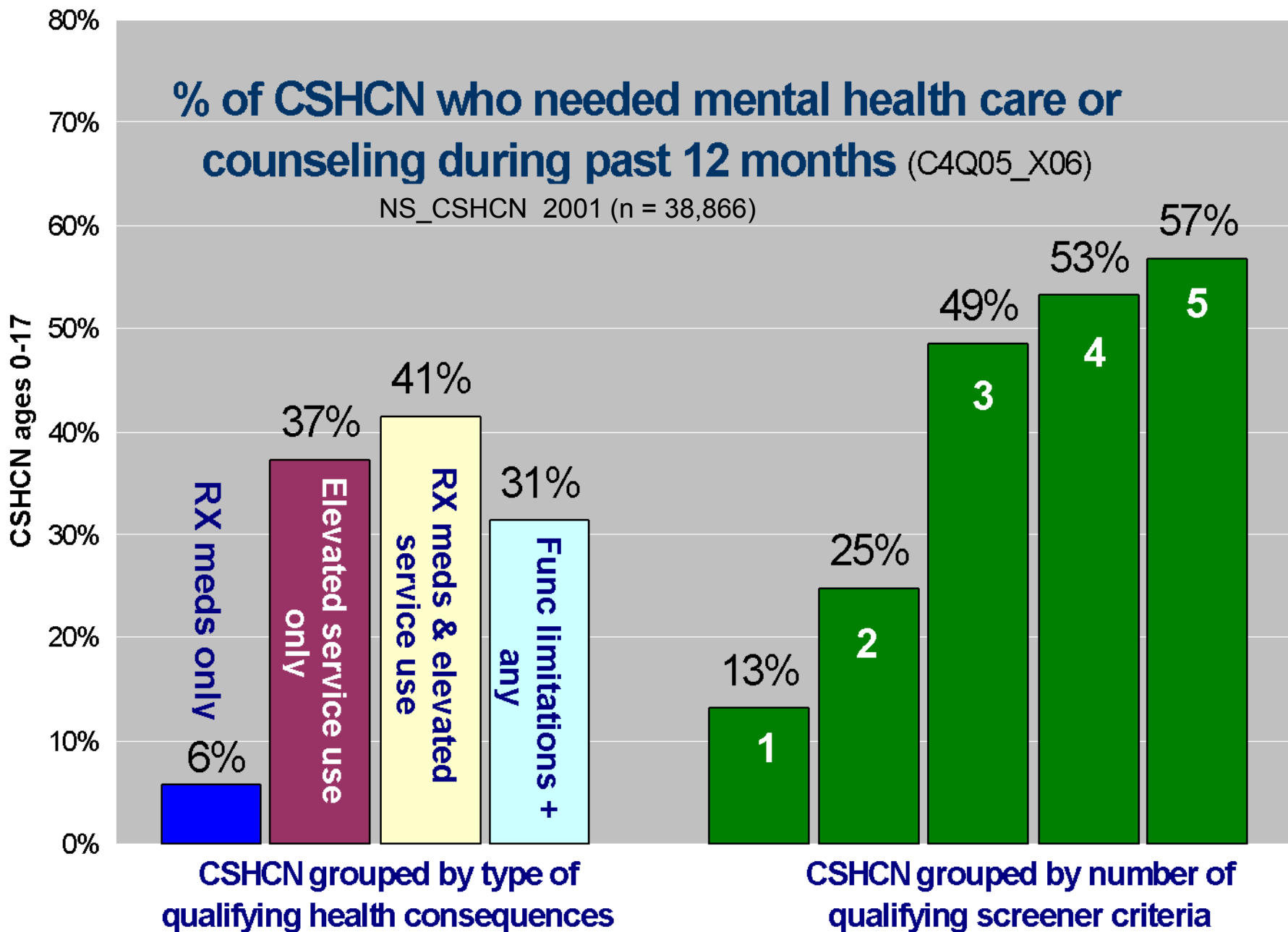
% of CSHCN who DO NOT consistently get Family-Centered Care

NS_CSHCN 2001 (n = 38,866)

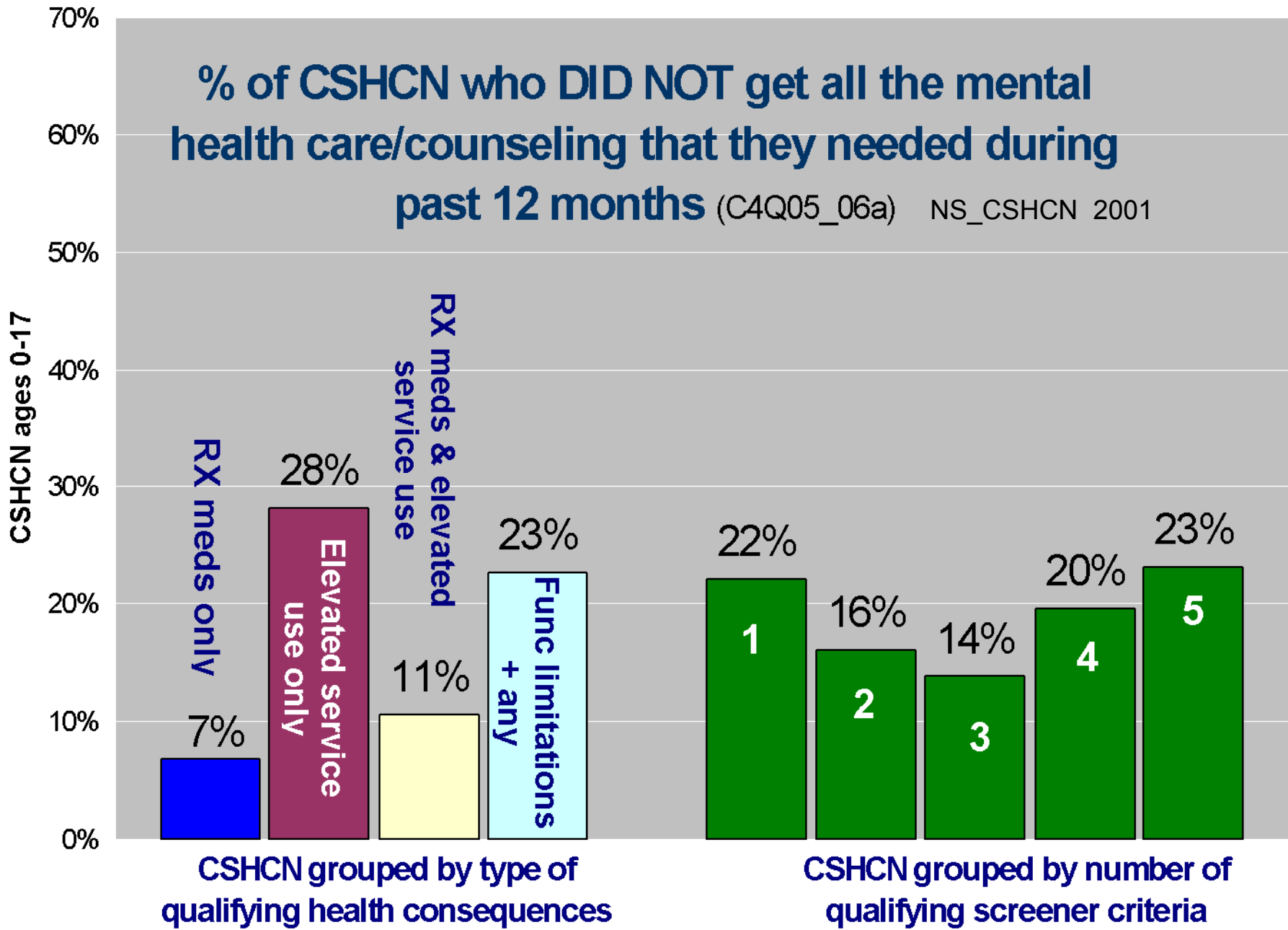


% of CSHCN who needed mental health care or counseling during past 12 months (C4Q05_X06)

NS_CSHCN 2001 (n = 38,866)



% of CSHCN who DID NOT get all the mental health care/counseling that they needed during past 12 months (C4Q05_06a) NS_CSHCN 2001

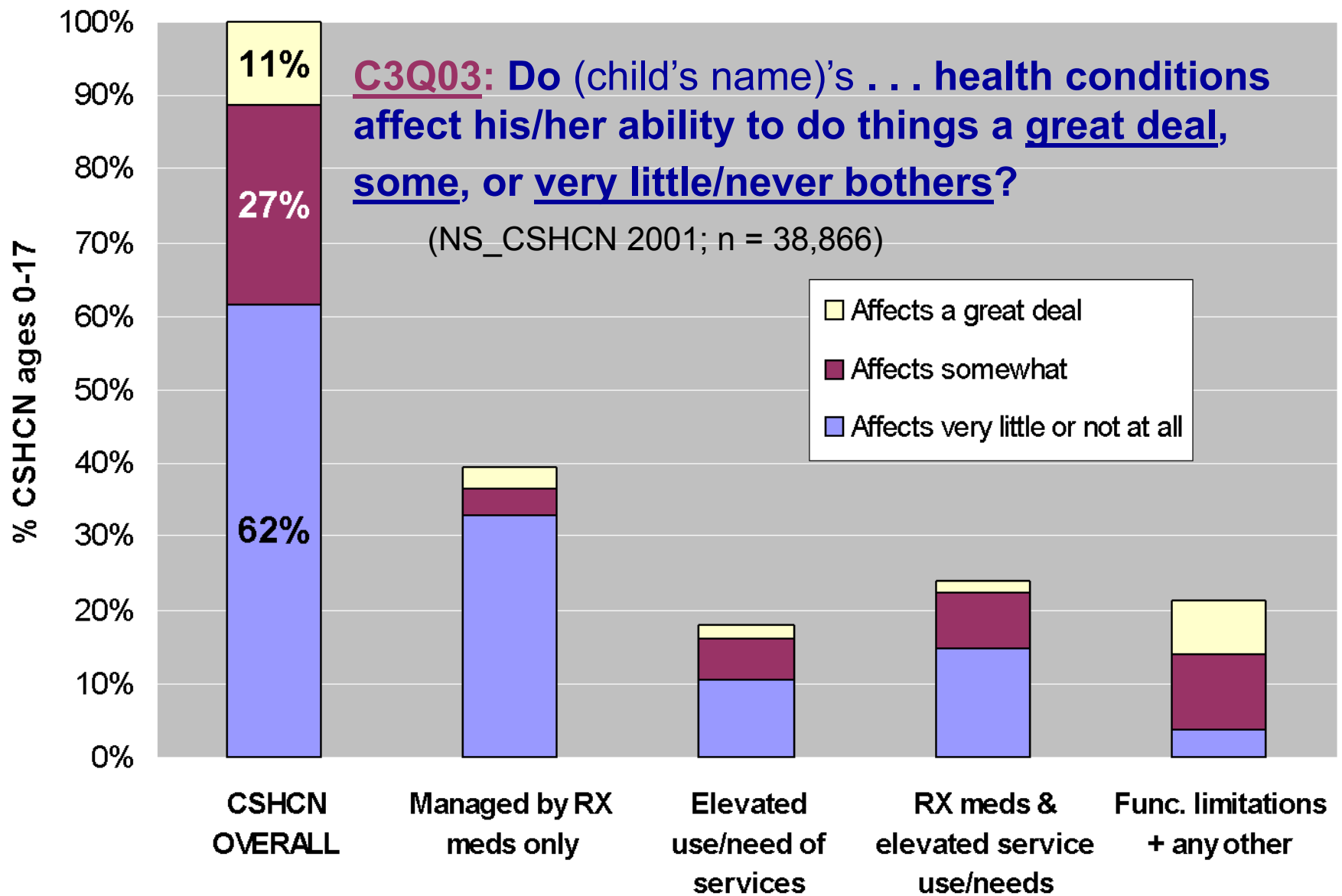


TIP # 1: When using other information in the survey to stratify results by child health status or complexity/severity keep in mind that:

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"

C3Q03: Do (child's name)'s . . . health conditions affect his/her ability to do things a great deal, some, or very little/never bothers?

(NS_CSHCN 2001; n = 38,866)



CSHCN grouped by types of health consequences based on qualifying screening criteria

TIP #2: Don't overlook or underestimate the effect of question design and/or format and its potential on "WHO" may be:

- **identified OR missed**
- **included / omitted**

NSCH Condition Checklist #1

Has a doctor or other health professional EVER told you that [child's name] has any of the following conditions? (NSCH 2003: S2Q19 – S2Q37)

- Hearing problems or vision problems
- ADD or ADHD
- Asthma
- Depression or anxiety problems
- Behavioral or conduct problems
- Bone, joint, or muscle problems
- Diabetes
- Autism
- Any developmental delay or physical impairment

NSCH Condition Checklist #2

During the past 12 months, have you been told by a doctor or other health professional that he/she had any of the following conditions?

(NSCH 2003: S2Q38 – S2Q42)

- Hay fever or any kind of respiratory allergy
- Any kind of food or digestive allergy
- Eczema or any kind of skin allergy
- Frequent or severe headaches
- Stuttering, stammering, or other speech problems

Children w/ YES
to 1 or more
conditions on
LIST #1

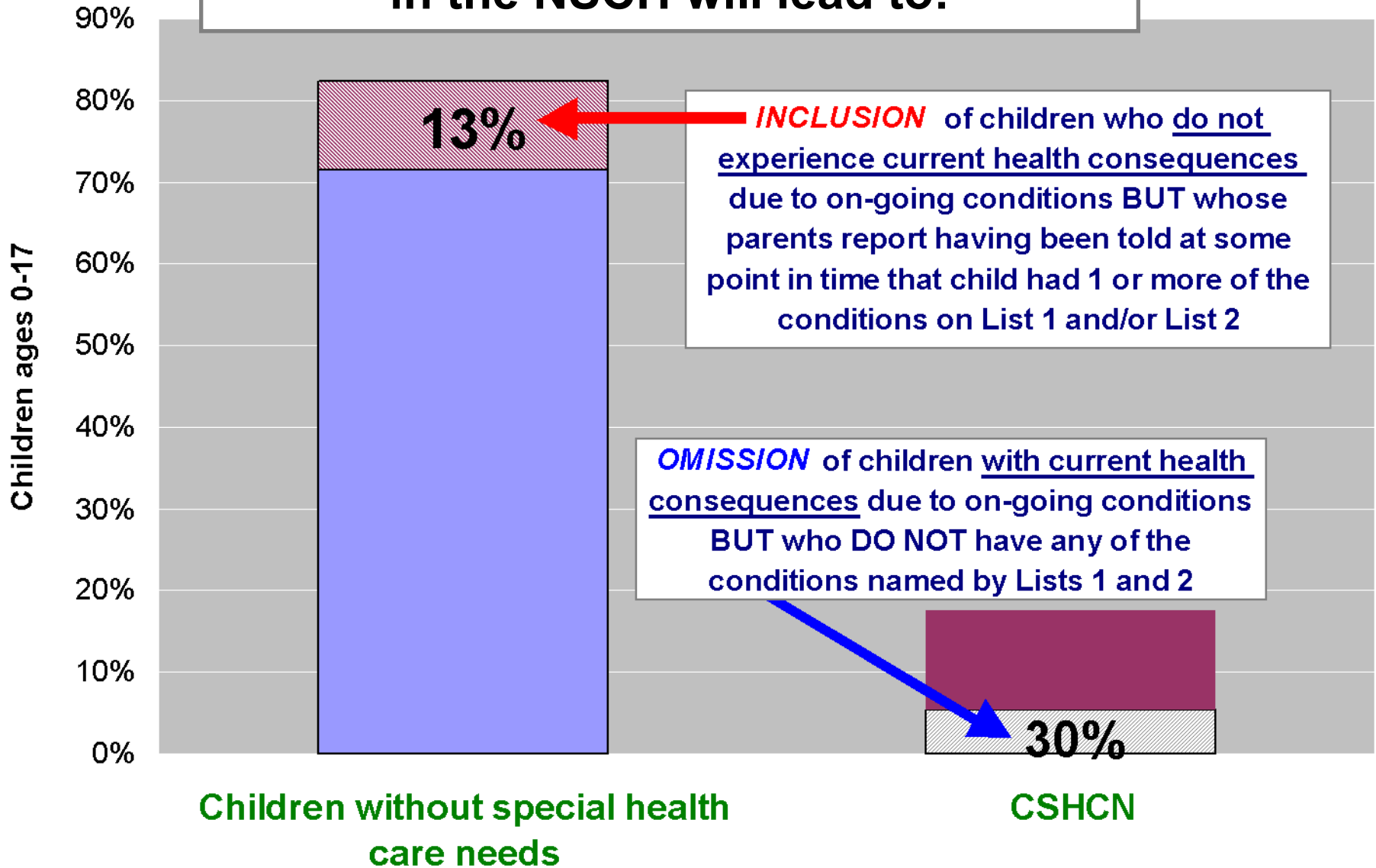
AND / OR

Children w/ YES
to 1 or more
conditions on
LIST #2

S2Q47: You said that [ch's name] **has / had / or has had** [names of conditions]. Would you describe his/her health condition(s) as minor, moderate, or severe?*

* Parent-rated severity question is not asked for children with health conditions not named by List #1 and/or #2 --

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



Anchor selection of stratification method to policy or research question, analytic purpose and requirements:

- Do you need an ordinal vs. categorical variable?
- Do you need variables included in all surveys in order to make across surveys comparisons?
- Keep purpose and end users in mind – How will results be used? By whom? For what purpose(s)?
- Consider the tradeoffs inherent in each method in terms of the characteristics of the groups, which CSHCN are likely to be included/excluded, and ability to interpret results
- Consider other combinations of screener results such as CSHCN with emotional, developmental, or behavioral issues (Q5) vs. CSHCN who did not meet these screening criteria

Upcoming 2005 NS-CSHCN:

- **Increased sample size: 850 CSHCN** interviews collected per state
- Added items asking about **current health conditions & specific functional difficulties**
- **Revised, improved questions** on care coordination & transition to adulthood
- **National referent sample of Non-CSHCN**
(n ≈ 5000)
- **Datasets publicly available** Fall 2007; **Data Resource Center website access** Winter 2007

TOPIC 3:

**Hispanic children and
language of interview**

Hispanic children / language of interview

NS-CSHCN:

- 5% HHs = Spanish interview
- >1% HHs = other than Eng or Spanish
- Parents of \approx 50% of Hisp children screened responded to interview in Spanish
- Across states, % children overall w/ Spanish interview ranges from >1% to nearly 25%

NSCH:

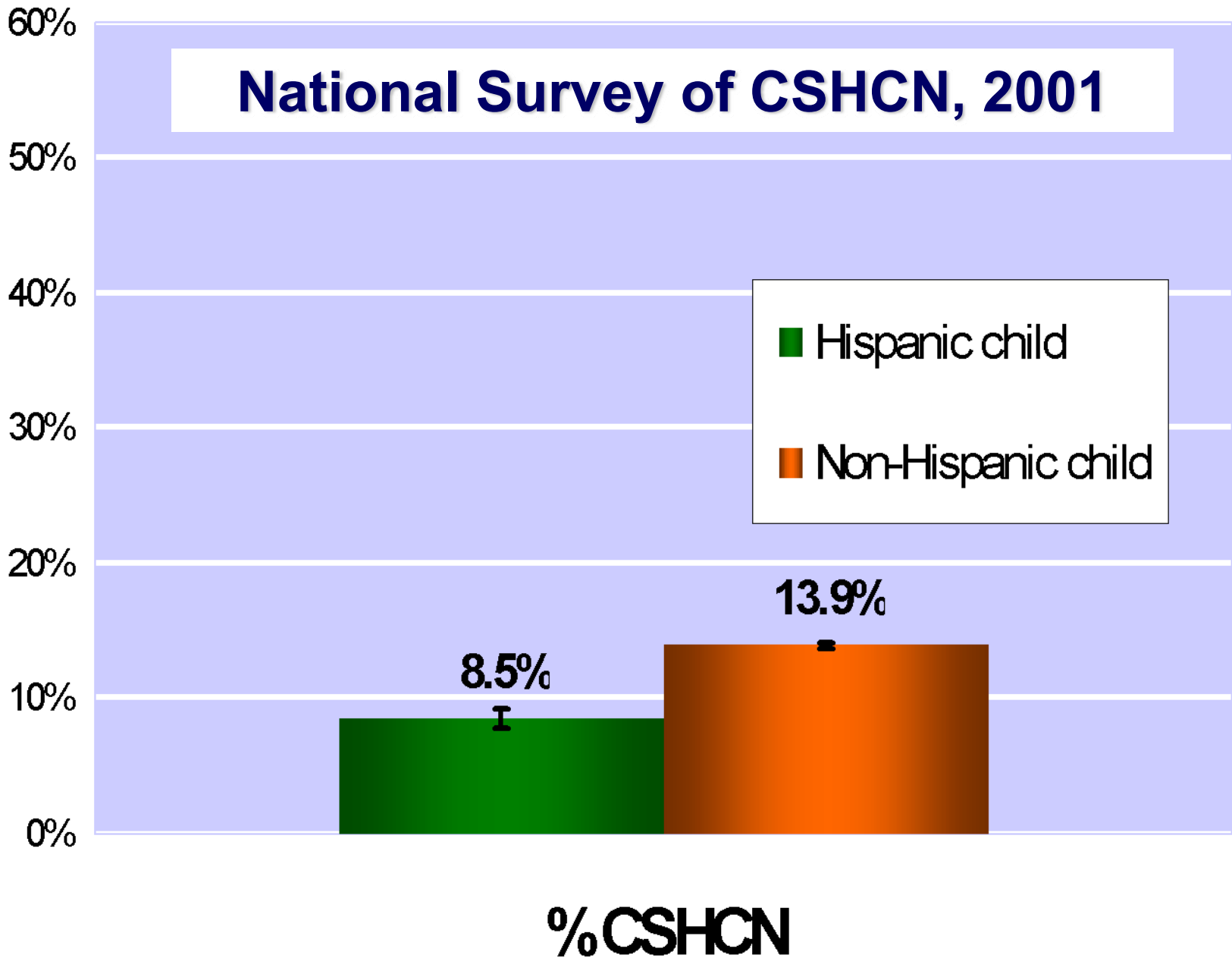
- 13% children from HH w/ primary lang other than English
(of this grp, 84% are Hispanic)
- 60% of Hispanic children from HH w/ primary lang other than English (\approx proxy for interview conducted in Spanish)

Hispanic children / language of interview

- Hispanic children **fastest growing** demographic grp in US child population
 - 1980 – 9%
 - 2003 – 19%
 - 2020** → Over 1 in 5 children of 80 million children in US population will be of Hispanic origin
- Disparities in access to insurance, health care, etc. well documented in literature -- as well as increasing Diabetes Type II and associated risks
- Developments in immigration policy may disproportionately effect on Hispanic children from limited English proficient families

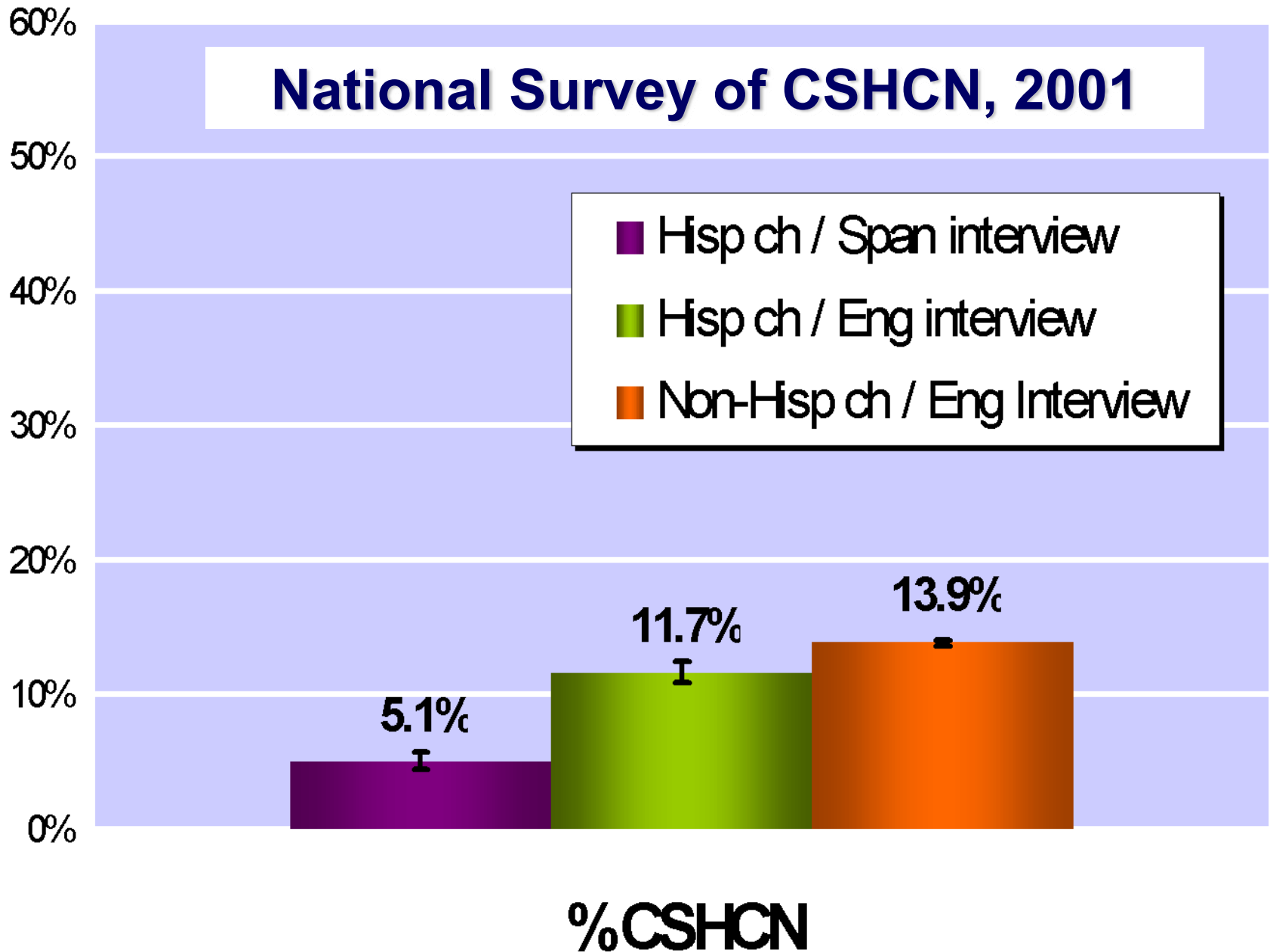
National Survey of CSHCN, 2001

Children ages 0-17



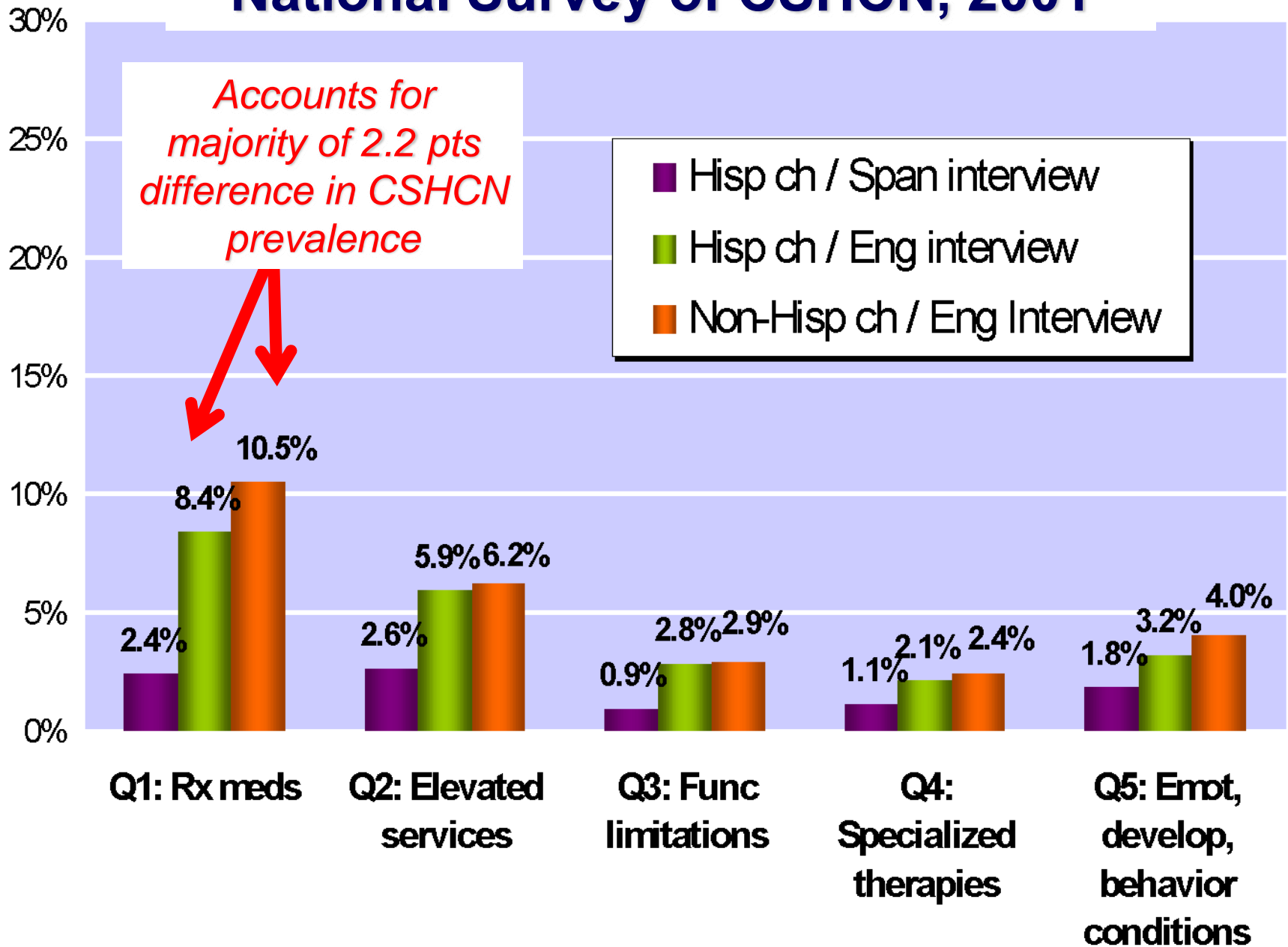
National Survey of CSHCN, 2001

Children ages 0-17



National Survey of CSHCN, 2001

Children ages 0-17



Hispanic children / language of interview

- 19 cognitive interviews w/ LEP parents of Hispanic children (8 in Ptd, OR 11 in Boston, MA)
- 37 children screened
- Did not identify any cultural or linguistic deficiencies in Spanish translation of CSHCN Screener
 - Parents expressed disinclination toward sharing details of ch. health in context of anonymous telephone interview
 - “This person does not know me – why would I tell them details about something as important as my child’s health?”

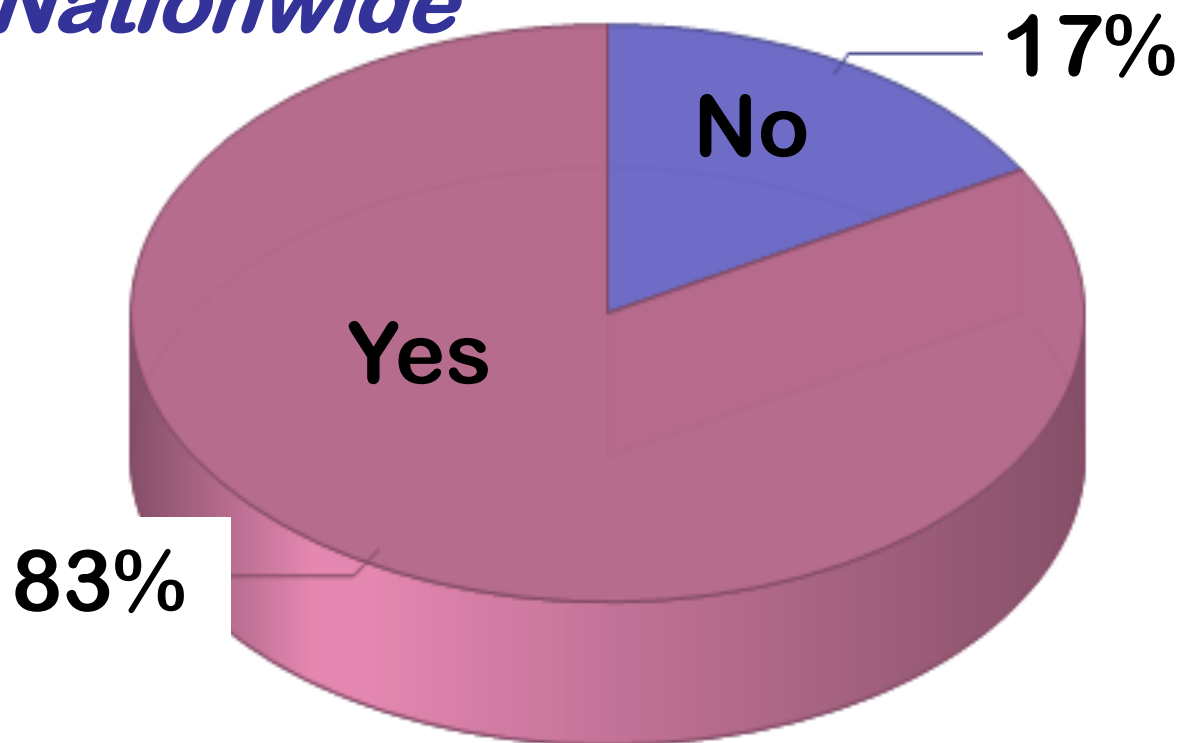
Hispanic children / language of interview

- NSCH collected parent-reported child height / weight
- BMI-for-age reliably calculated for ages 10-17 yr old group
- **6.4% 'unknown' values** overall – not randomly distributed
 - Hisp ch / Eng lang HH = 5% missing values
 - Hisp ch / Other than Eng HH = 41% missing values

*Other interesting things
to explore in the
2003 NSCH*

Indicator 4.9: A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. Do you have one or more person(s) you think of as (child's name)'s personal doctor or nurse? (S5Q01)

Nationwide

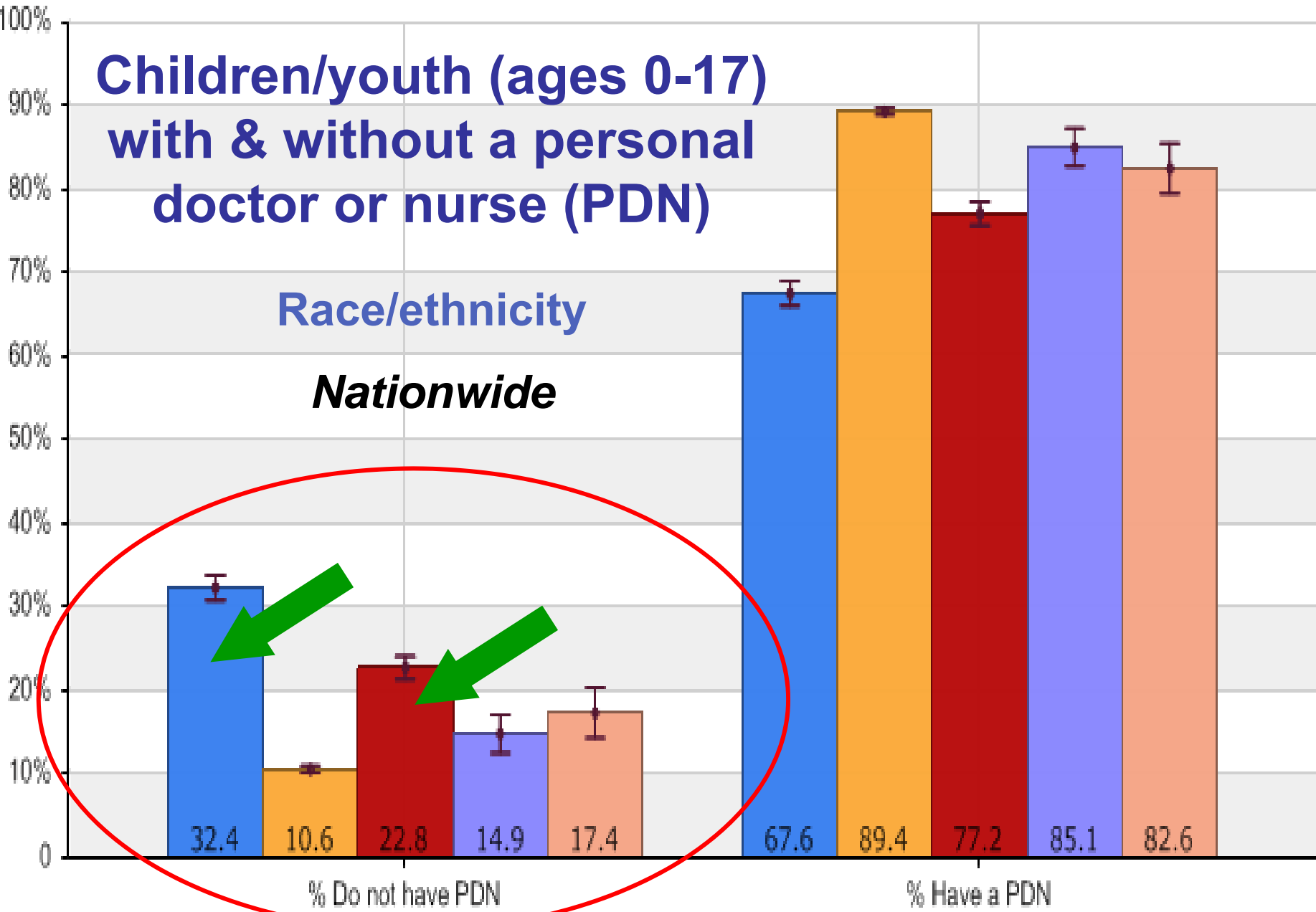


% Do not have PDN % Have a PDN

Children/youth (ages 0-17) with & without a personal doctor or nurse (PDN)

Race/ethnicity

Nationwide



Legend: Nationwide (Hispanic) Nationwide (White) Nationwide (Black) Nationwide (Multi-racial) Nationwide (Other)

Question: Indicator 5.2: Since starting kindergarten, has (child's name) repeated any grades? (S7Q09 -- ages 6-17 only)

<u>Region</u>	<u>No %</u>	<u>Yes %</u>	<u>Total %</u>
<u>Utah</u>	97.5	2.5	100.0
<u>Minnesota</u>	95.8	4.2	100.0
<u>Iowa</u>	95.3	4.7	100.0
<u>Wisconsin</u>	94.3	5.7	100.0
<u>Nebraska</u>	94.1	5.9	100.0
<u>Kansas</u>	93.7	6.3	100.0
<u>Idaho</u>	93.1	6.9	100.0
<u>Washington</u>	93.1	6.9	100.0

<u>Arkansas</u>	84.0	16.0	100.0
<u>South Carolina</u>	83.9	16.1	100.0
<u>Oklahoma</u>	83.8	16.2	100.0
<u>Florida</u>	83.5	16.5	100.0
<u>North Carolina</u>	83.4	16.6	100.0
<u>West Virginia</u>	83.4	16.6	100.0
<u>Alabama</u>	83.3	16.7	100.0
<u>District of Columbia</u>	81.1	18.9	100.0
<u>Louisiana</u>	77.4	22.6	100.0
<u>Mississippi</u>	75.4	24.6	100.0

Indicator 2.7: How many children/youth (ages 2-17) whose parents have ever been told child has ADD/ADHD currently take medication for this condition? (derived)

<u>Region</u>	<u>ADD/ADHD ever: child not taking medication now</u> %	<u>ADD/ADHD ever: child currently takes medication</u> %	<u>Never told child has ADD/ADHD</u> %	<u>Total %</u>
<u>California</u>	2.7	1.9	95.4	100.0
<u>Colorado</u>	1.9	2.4	95.7	100.0
<u>Hawaii</u>	3.1	2.4	94.4	100.0
<u>Utah</u>	2.1	2.6	95.3	100.0
<u>Arizona</u>	2.6	2.7	94.8	100.0
<u>New Jersey</u>	3.6	2.8	93.6	100.0
<u>Connecticut</u>	3.6	2.9	93.5	100.0
<u>Illinois</u>	2.6	2.9	94.4	100.0
<u>District of Columbia</u>	2.7	3.0	94.3	100.0
<u>Nevada</u>	3.5	3.0	93.6	100.0

<u>Virginia</u>	3.0	4.0	91.9	100.0
<u>Georgia</u>	3.5	4.9	91.6	100.0
<u>Iowa</u>	2.5	4.9	92.6	100.0
<u>New Hampshire</u>	3.1	5.2	91.7	100.0
<u>Rhode Island</u>	3.5	5.2	91.3	100.0
<u>Delaware</u>	3.4	5.3	91.3	100.0
<u>North Carolina</u>	3.1	5.3	91.6	100.0
<u>West Virginia</u>	3.8	5.3	90.9	100.0
<u>South Carolina</u>	3.3	5.4	91.3	100.0
<u>Louisiana</u>	3.5	5.6	90.9	100.0
<u>Alabama</u>	4.1	5.7	90.1	100.0
<u>Arkansas</u>	3.1	5.8	91.1	100.0

S6Q52: During the past month, did (child's name) regularly attend Head Start or Early Start program? (ages 0-5)

RANGE across states: 5.2% - 19.8%

% of children ages 0-5 attending Head Start or Early Start program during past month, by Special Health Care Needs

<u>Region</u>	<u>NO special health care needs</u> <u>%</u>	<u>Special health care needs %</u>
<u>Iowa</u>	5.3	6.3
<u>Indiana</u>	5.1	6.6
<u>North Dakota</u>	9.0	6.9
<u>Arizona</u>	6.7	7.9
<u>California</u>	8.3	9.6
<u>Texas</u>	8.6	11.6
<u>South Carolina</u>	13.8	12.1
<u>Hawaii</u>	9.9	12.2
<u>Utah</u>	5.0	12.2

<u>Mississippi</u>	19.1	23.1
<u>Wyoming</u>	8.6	23.9
<u>Kentucky</u>	9.1	25.1
<u>Louisiana</u>	14.8	25.3
<u>Missouri</u>	10.5	28.3
<u>Georgia</u>	11.1	30.9
<u>Illinois</u>	7.7	31.0
<u>Michigan</u>	8.2	31.7
<u>New Mexico</u>	9.9	39.6

More information

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