

# Comparing Health and Health Outcomes for CSHCN and Non-CSHCN: Findings from 3 National Surveys



[www.childhealthdata.org](http://www.childhealthdata.org)

CAHMI – Child & Adolescent Health Measurement Initiative

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Family Voices

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# Agenda

- 5 mins: Welcome / Introduction**
- 20 mins: CSHCN vs. Non-CSHCN comparison**
- 20 mins: Within CSHCN groups comparison**
- 20 mins: MCHB core outcomes for different grps of CSHCN and Across state variations**
- 20 mins: Resources for accessing NSCH & NS-CSHCN data**
- Questions/discussion**



**Once upon a time in a  
galaxy far, far away ....**

**There was great need to  
learn more about children's  
health and well-being .....**



# 2001 National Survey of CSHCN



372,174 children, 0 - 17 yrs, in  
the household

CSHCN Screener --  
asked for all children in  
household

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

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



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

**38,866 CSHCN interviews**  
completed

# 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

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*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

# NS-CSHCN interview collects in-depth information for CSHCN group only:

- CSHCN health and functional status
- CSHCN 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 CSHCN and
- Key indicators of CSHCN health & system performance

# GOOD START:

MUCH was learned in-depth about  
CSHCN  
in general

BUT . . .







# National Survey of Children's Health

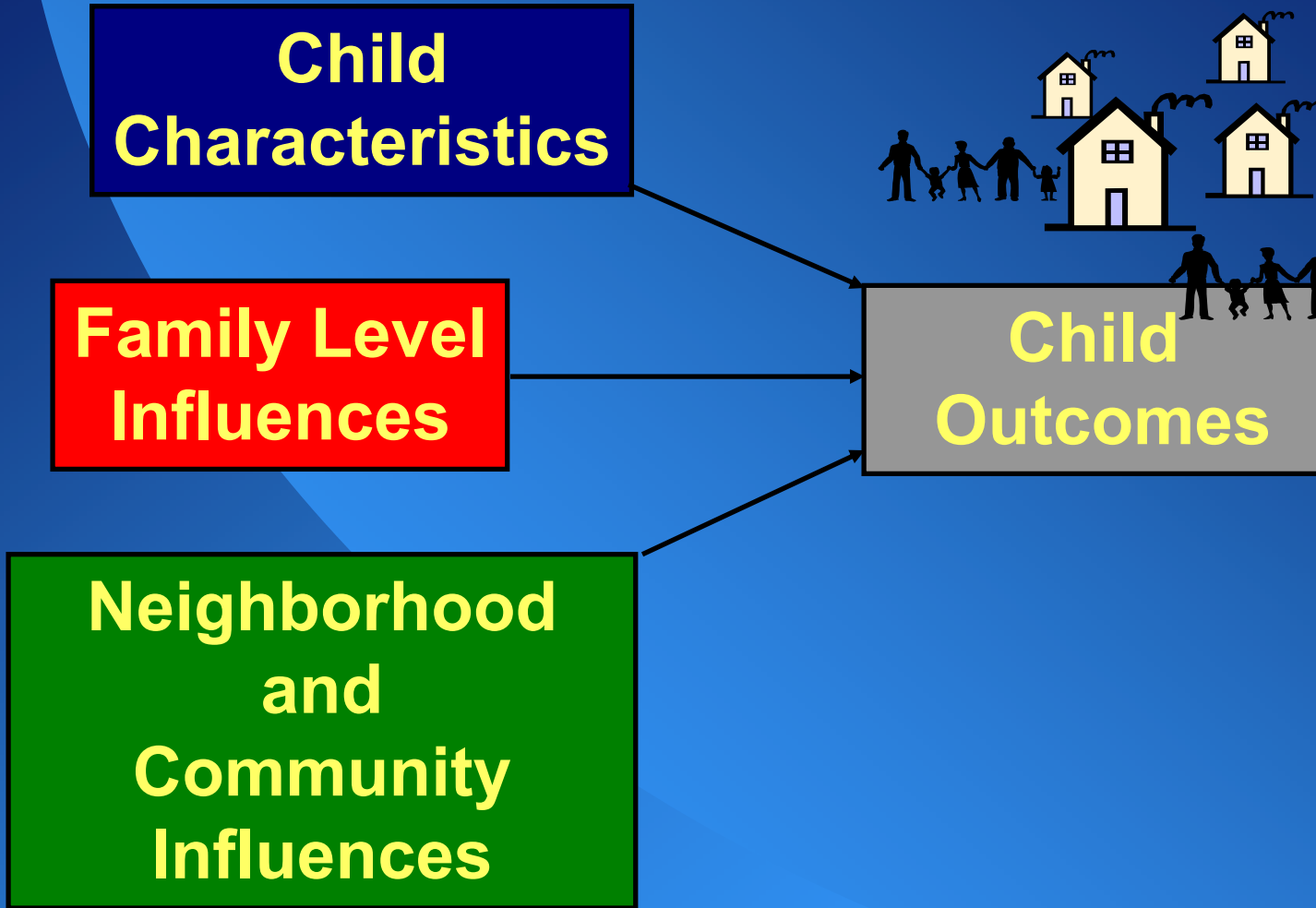
**Child  
Characteristics**

**Family Level  
Influences**

**Neighborhood  
and  
Community  
Influences**



**Child  
Outcomes**



# National Survey of Children's Health



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



CSHCN Screener --  
asked only for target  
child (1 per HH)

**102,353**

Children ages 0-17

randomly selected, 1 per HH

**Early Childhood**

questions (Sections 1-5)

asked  
children

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



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

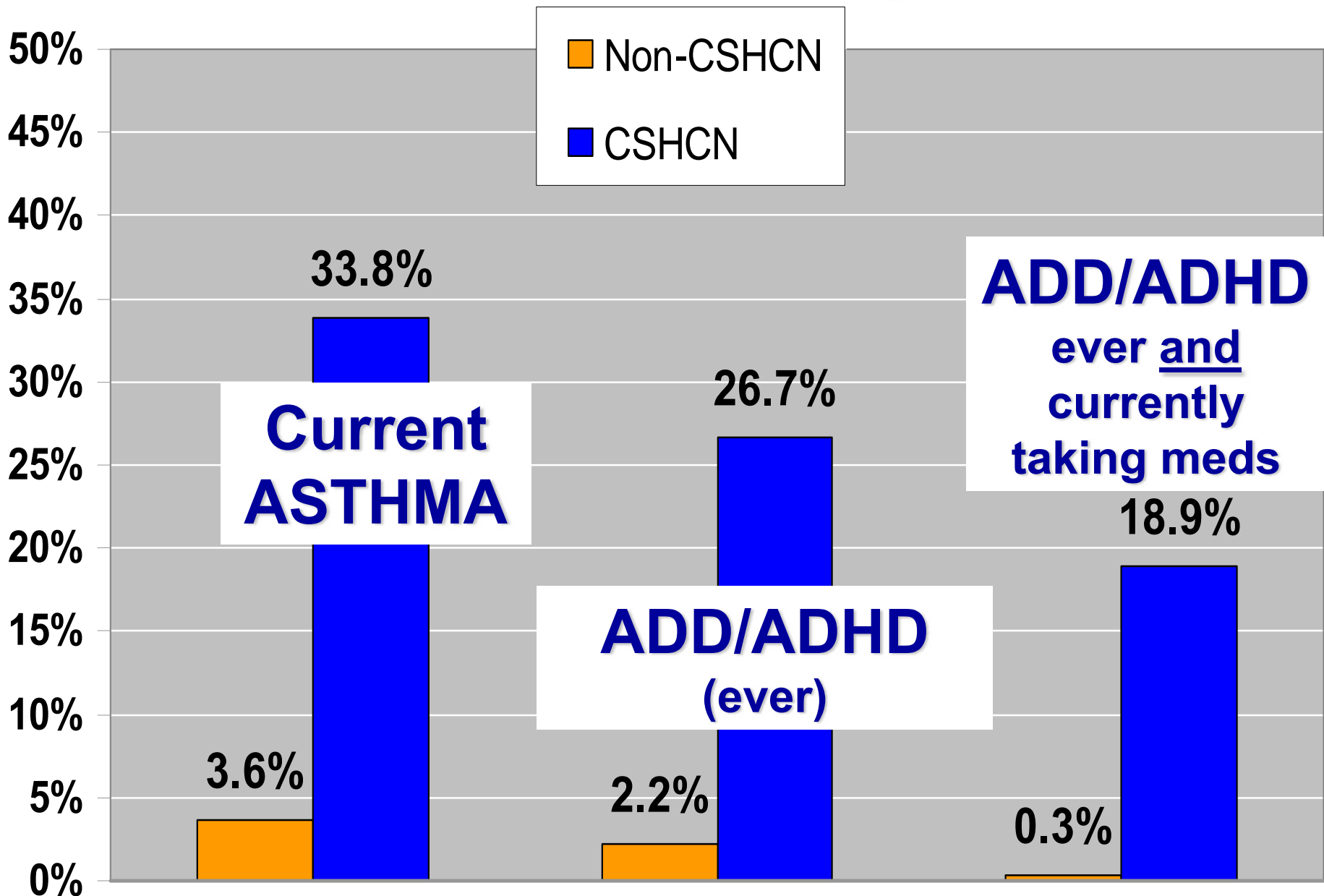
- Child's health status: physical, emotional, dental
- Child's health care – including medical home
- Child's school & activities
- Child's family & neighborhood -- including maternal health status
- Early childhood (ages 0-5)
- School-age (ages 6-17)



## NSCH offers first time ever opportunity to:

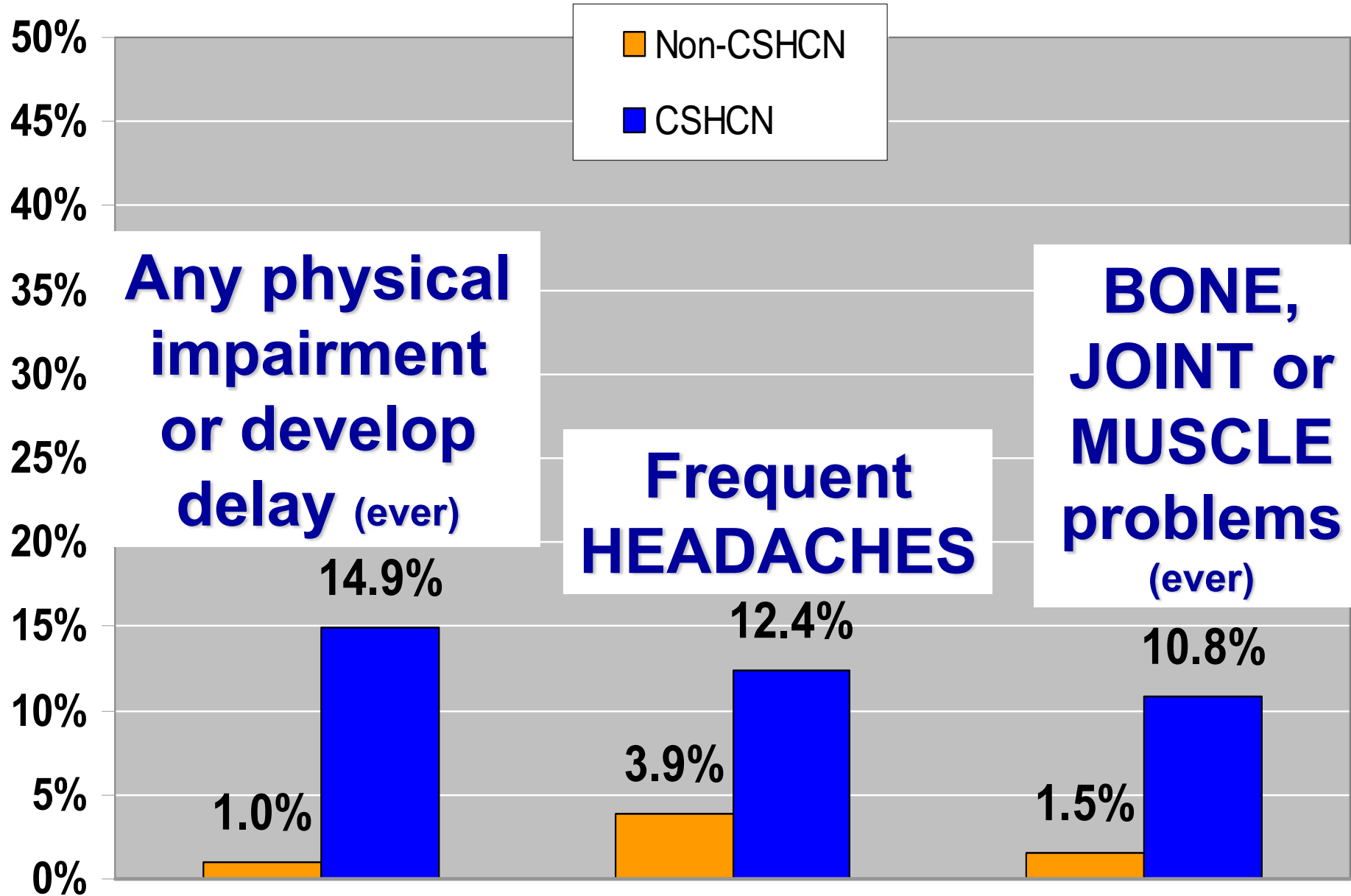
- Examine health status & outcomes for CSHCN and non-CSHCN populations using standardized methods
- Further characterize the group of CSHCN identified by the MCHB definition
  - **HEALTH CONDITIONS** profile
  - **HEALTH STATUS** profile
  - **FAMILY and SCHOOL** profile

# Health conditions profile



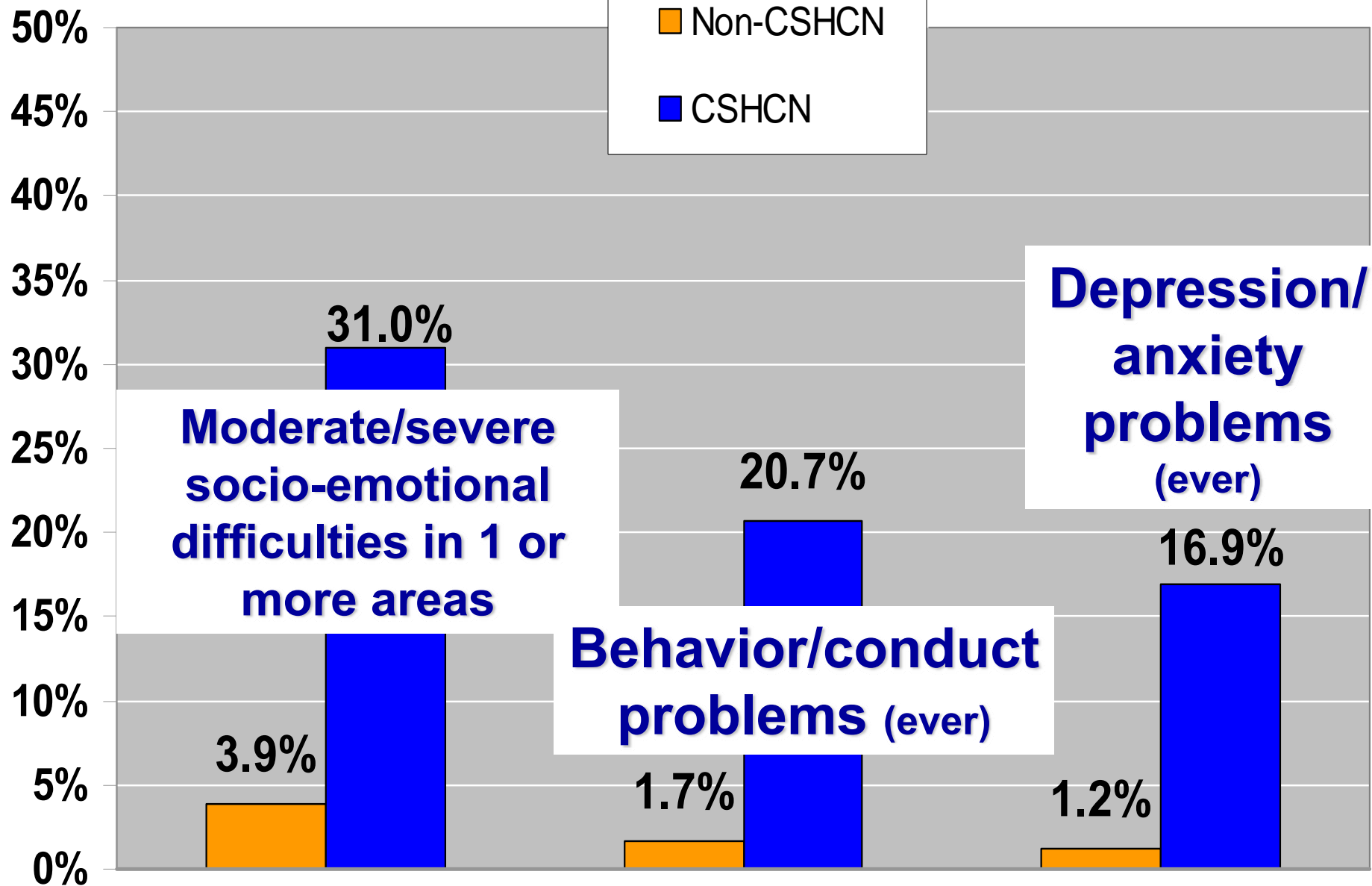
NSCH 2003 (n = 102,353)

# Health conditions profile



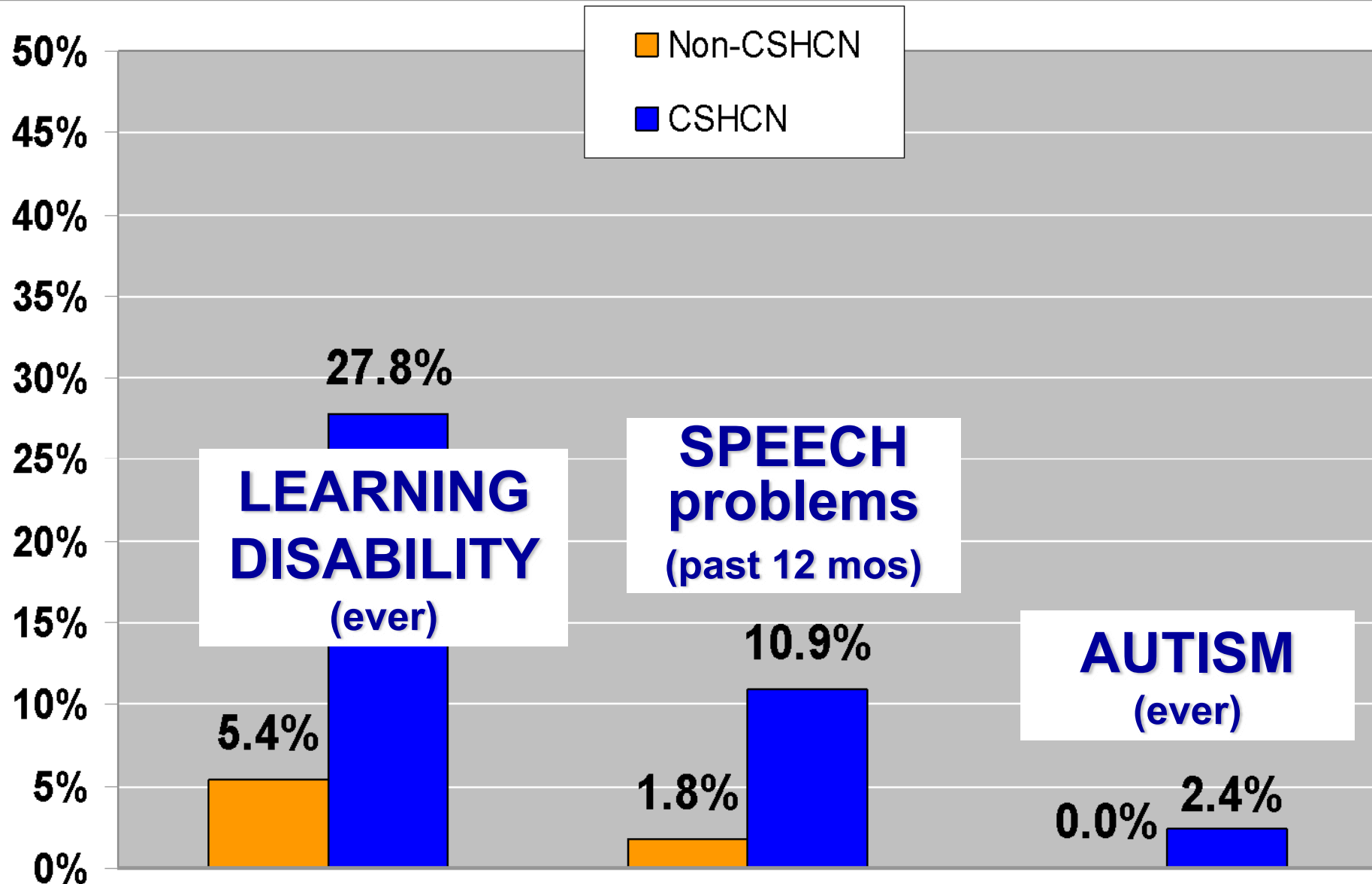
NSCH 2003 (n = 102,353)

# Health conditions profile



NSCH 2003 (n = 102,353)

# Health conditions profile

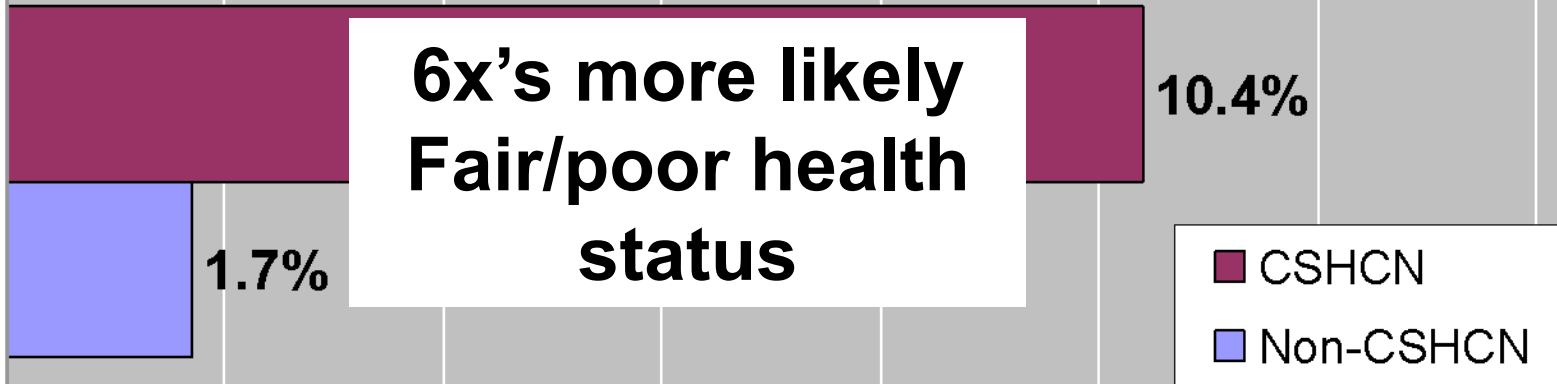


NSCH 2003 (n = 102,353)

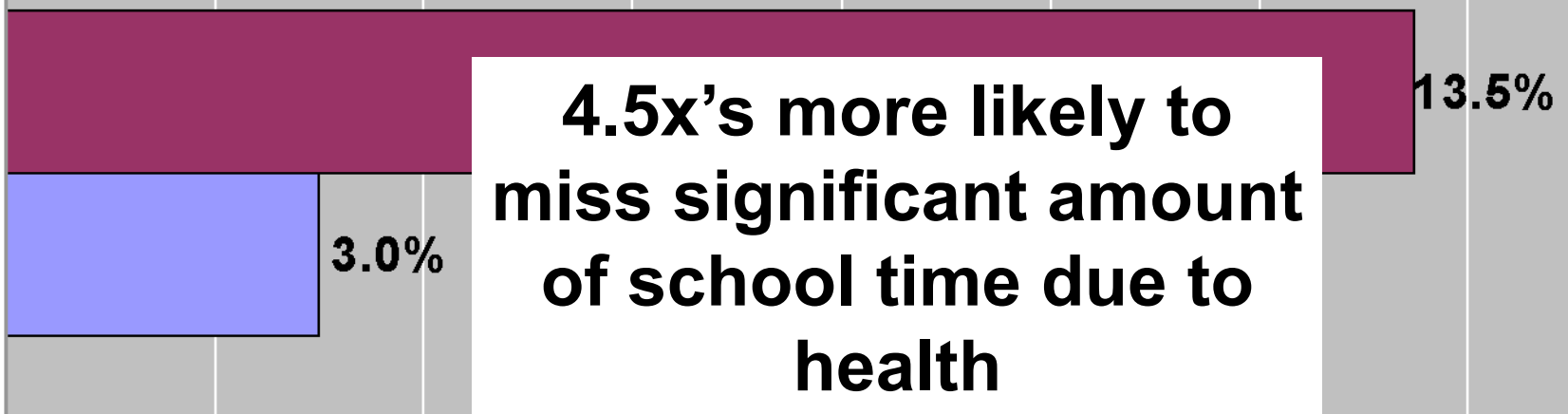


# Health status profile

Overall health status rated FAIR or POOR



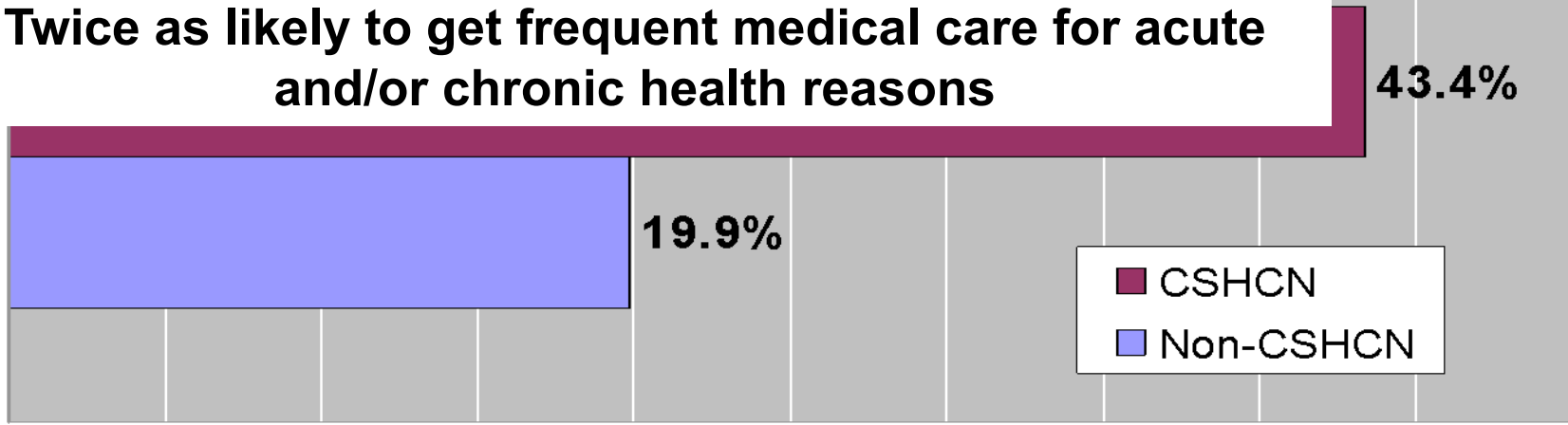
Missed 2 + weeks of school due to illness



# Health status profile

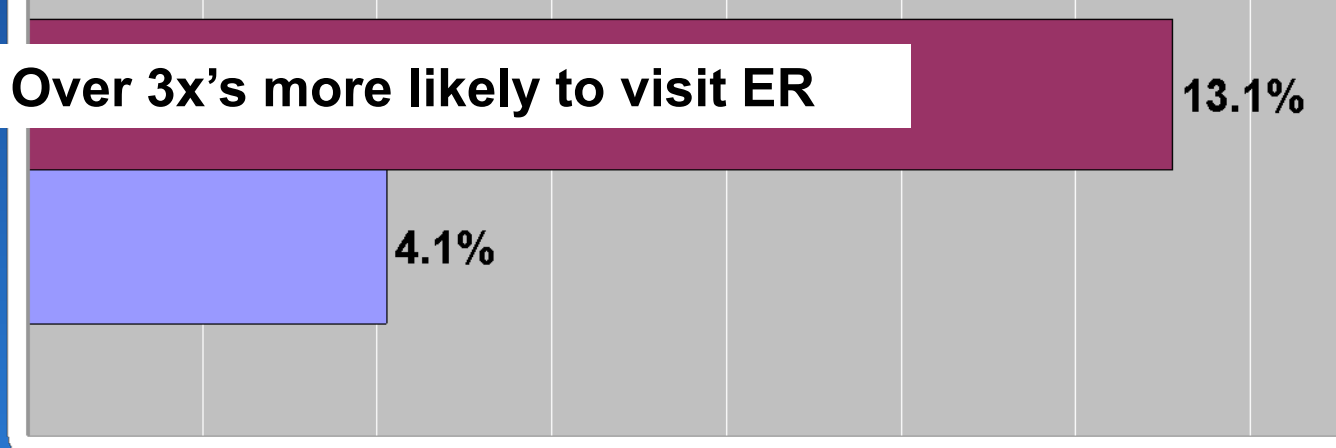
3+ doctor visits for sick care, past 12 mos.

Twice as likely to get frequent medical care for acute and/or chronic health reasons

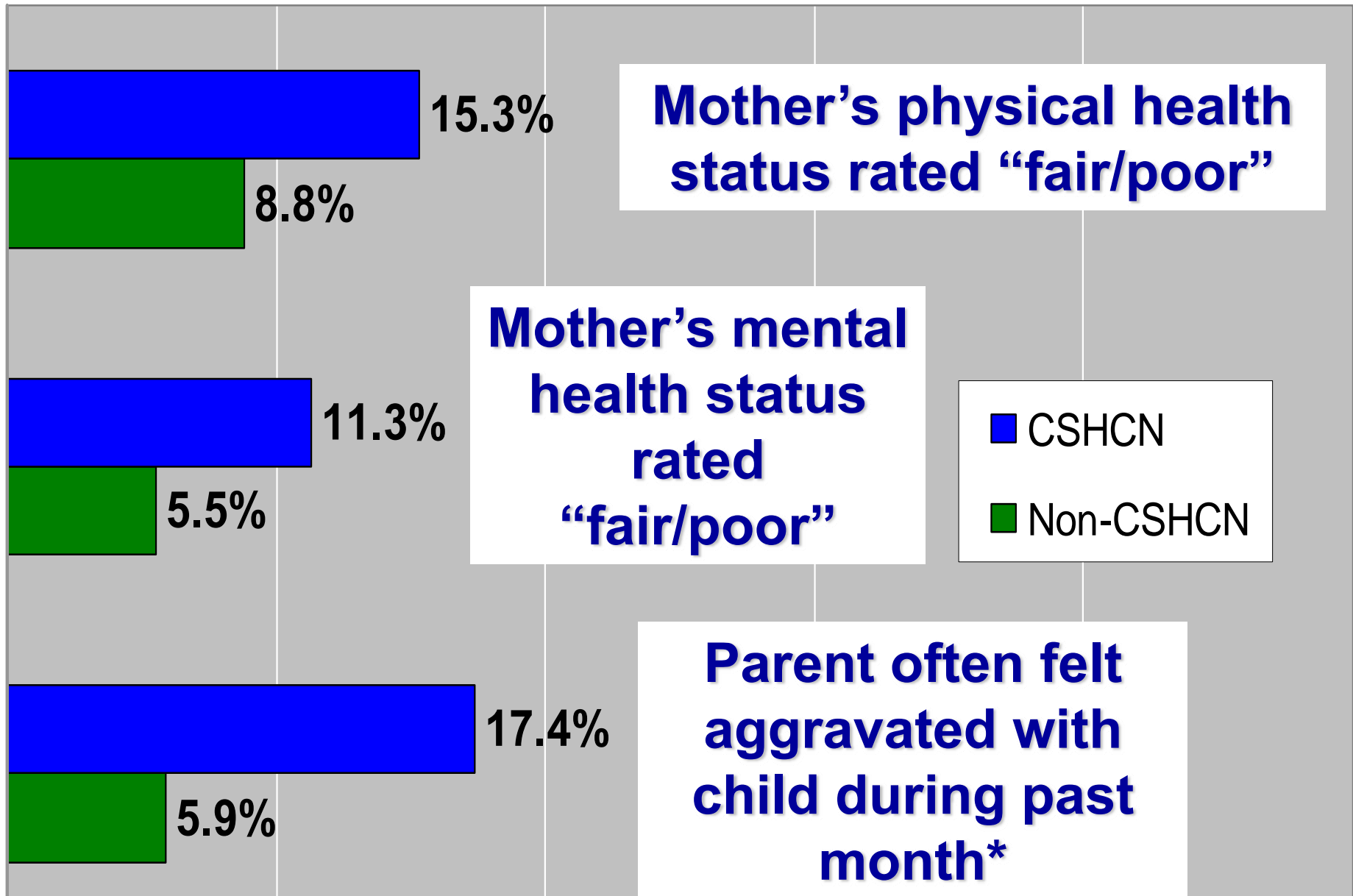


2 or more ER visits, past 12 mos.

Over 3x's more likely to visit ER



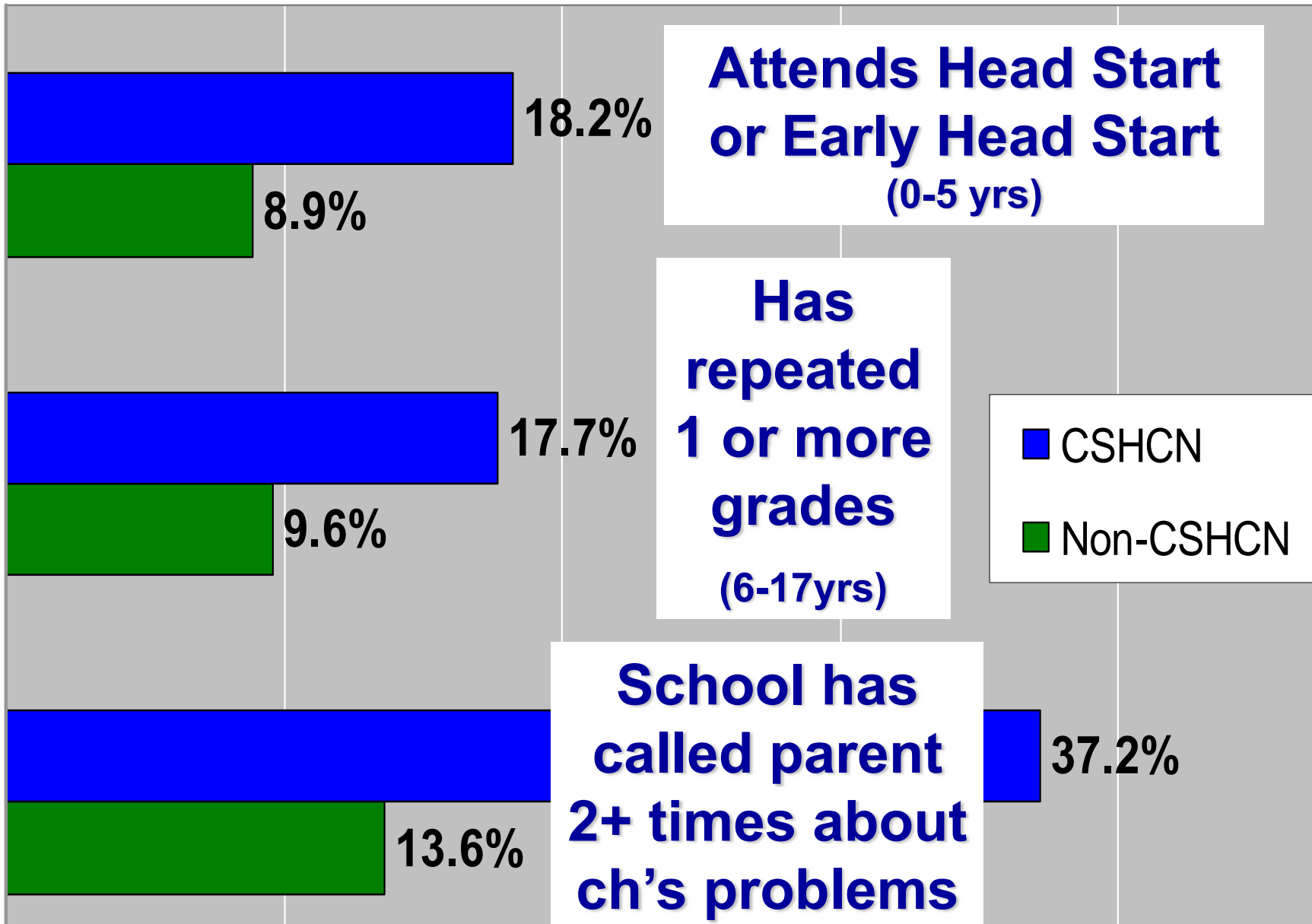
# Home & School profile



**\* During the past month, how often have you felt:**

- . . . (ch's name) is much harder to care for than most children his/her same age? (S8Q07)
- . . . He/she does things that really bother you a lot? (S8Q08)
- . . . Angry with him/her? (S8Q10)

# Home & School profile



**Comparing health and  
health outcomes for  
different groups of**

**CSHCN**

# 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**

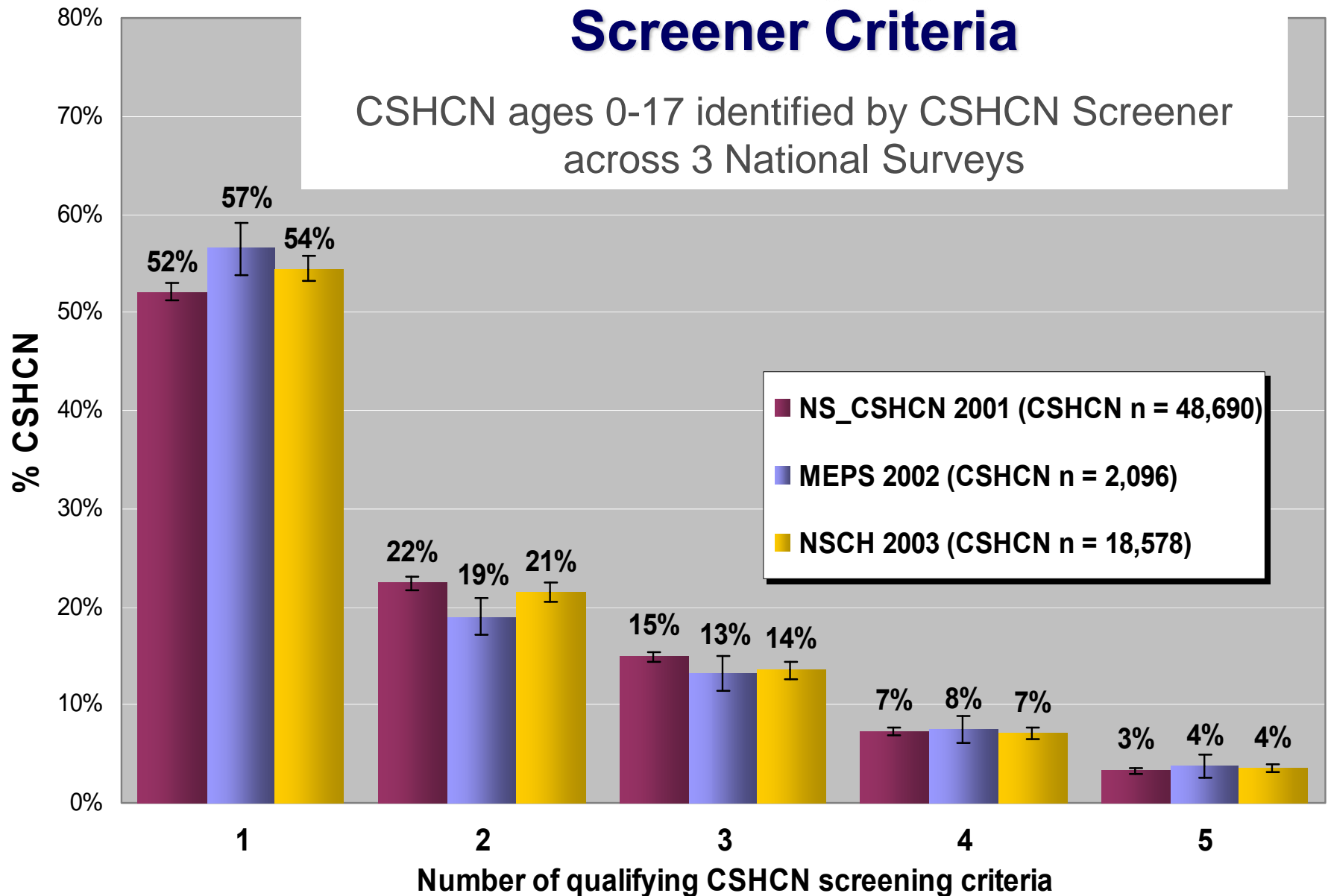
**Q5:**  
**MENTAL  
HEALTH**





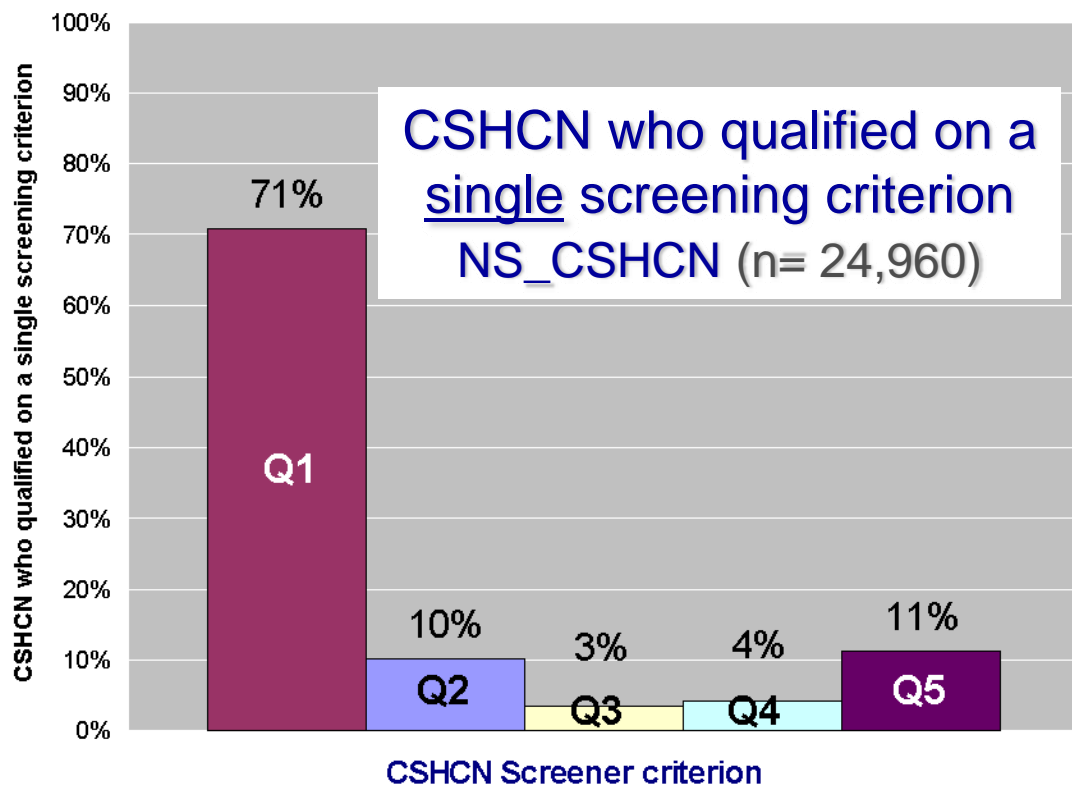
# Number Qualifying CSHCN Screener Criteria

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



Statewide sample of children  
ages 0 -12 receiving SSI  
disability benefits (n=1,493)

**88%** Qualified on Functional  
Limitations (Q3) in addition to 1 or  
more other criteria



**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)**

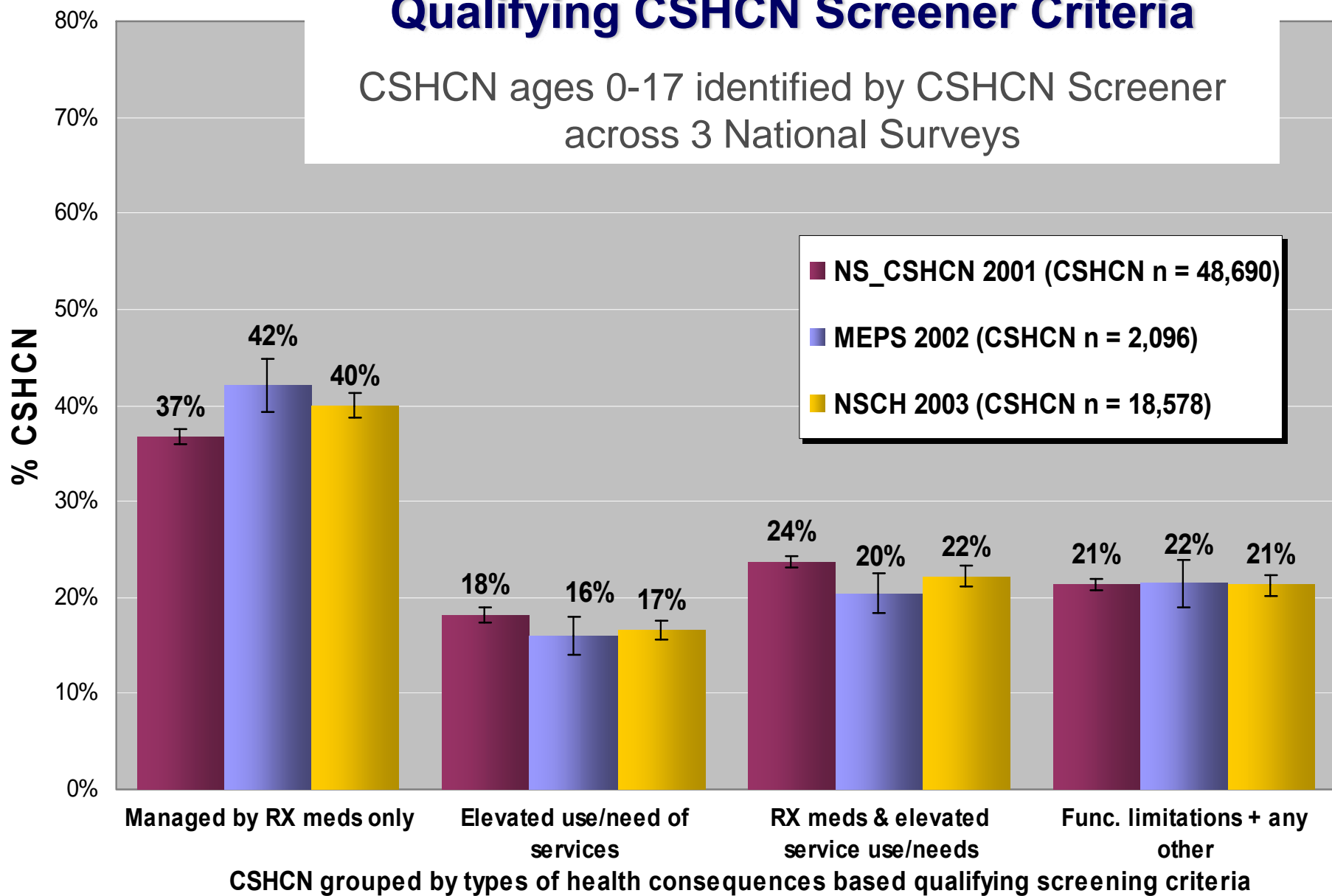
**Service Use ONLY**  
**(Q2, Q4, and/or Q5)**

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

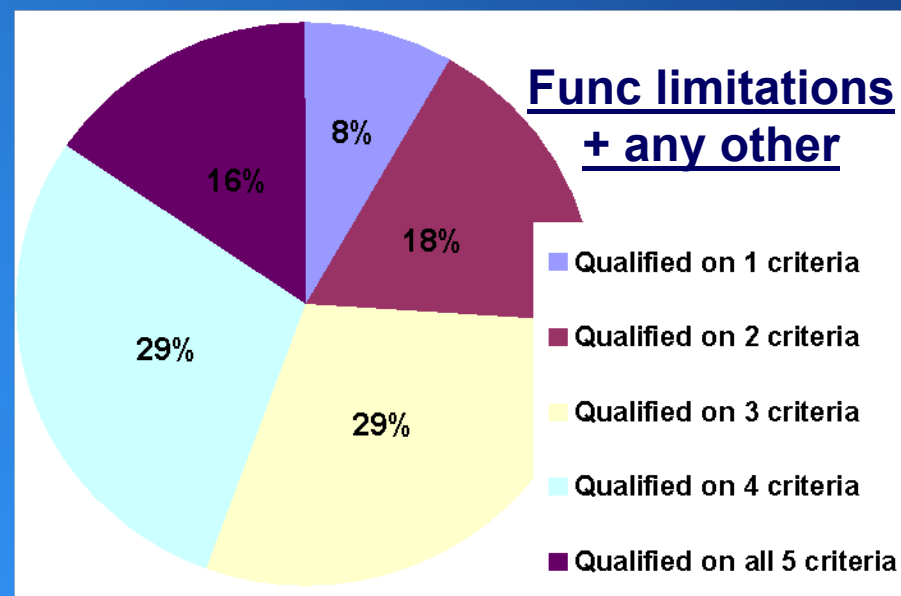
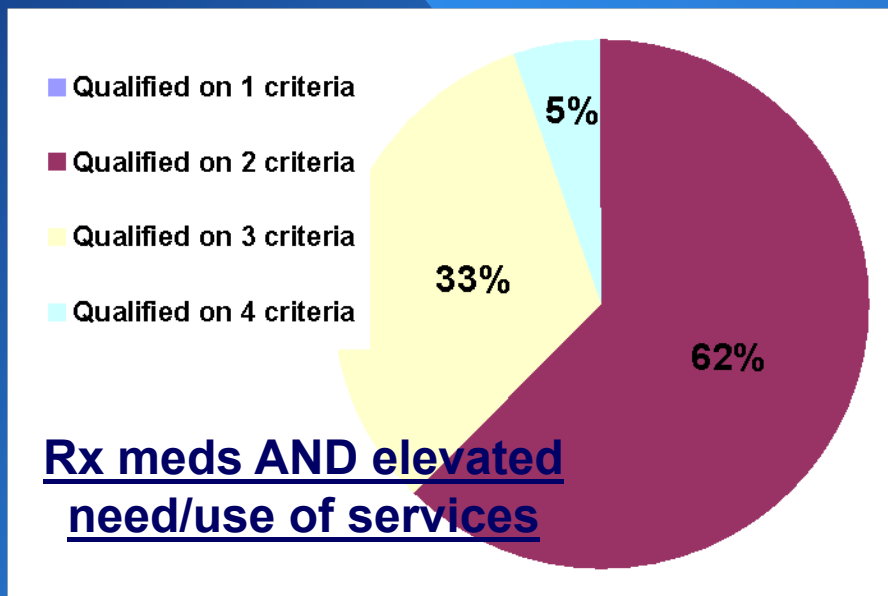
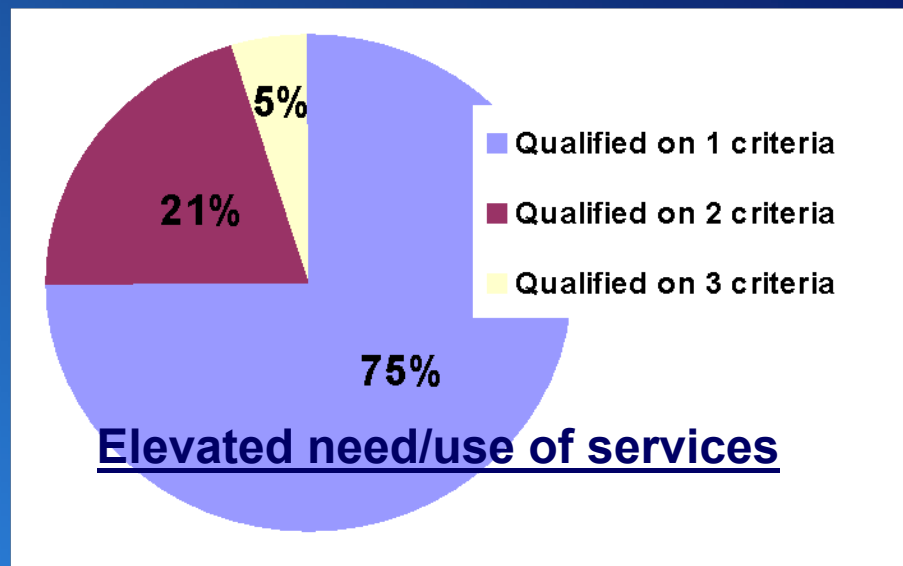
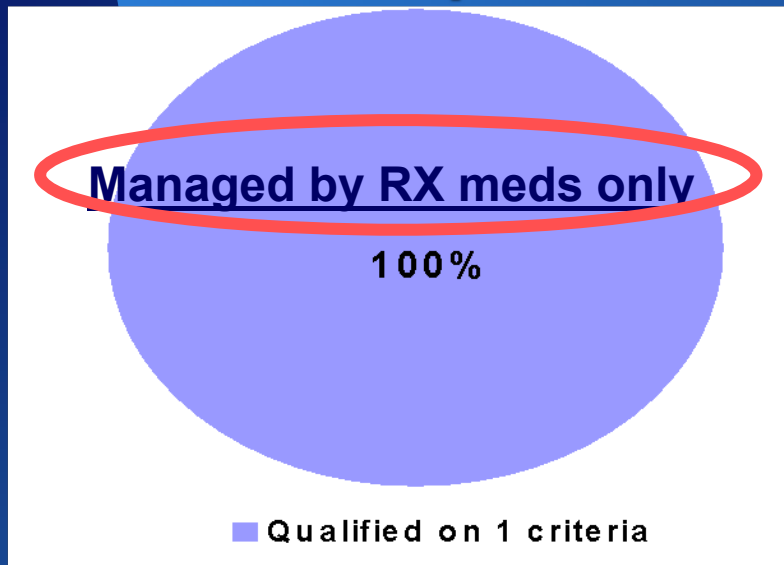
**Functional  
Limitations**  
**Q3 only or w/any other  
Q, Q, Q, Q's**

# Type of Health Consequences based on Qualifying CSHCN Screener Criteria

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

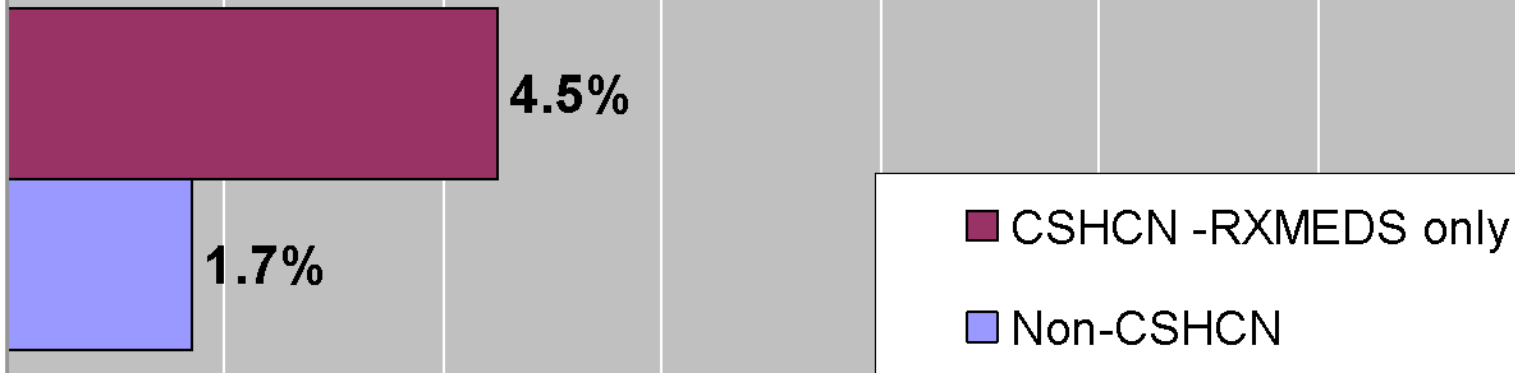


# Number of Qualifying Screener Criteria per Specific Health Consequences Group -- NS\_CSHCN 2001 (n = 48, 690)

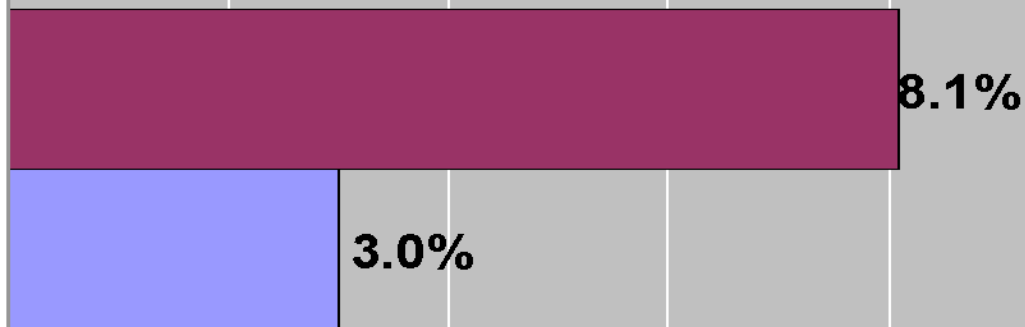


# Non-CSHCN vs. CSHCN Rxmeds only

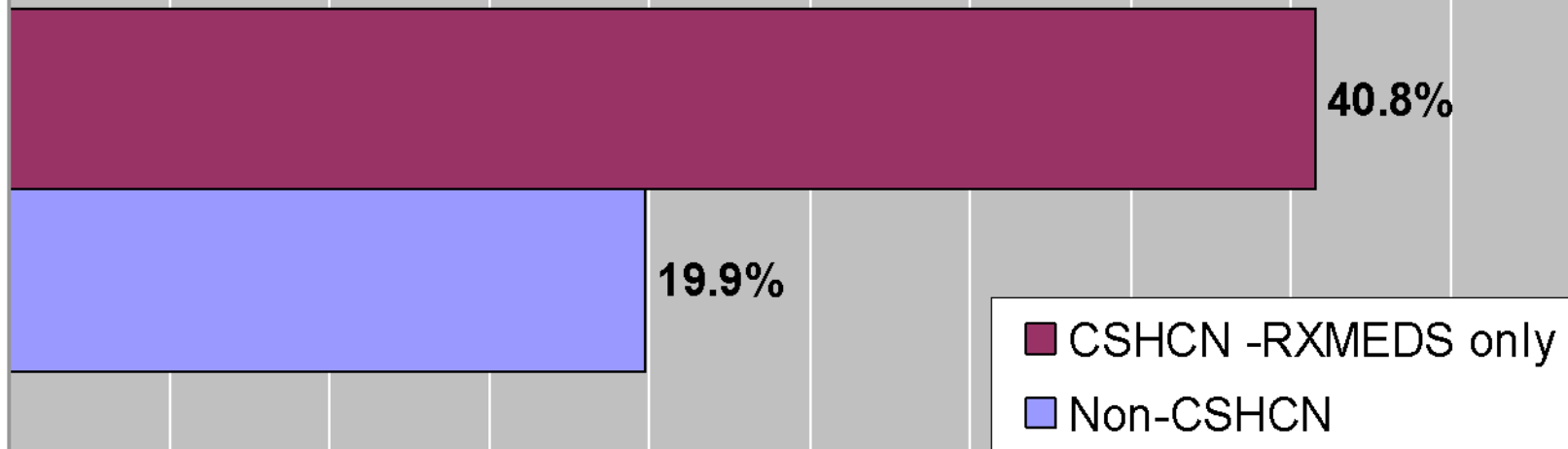
## Overall health status rated FAIR or POOR



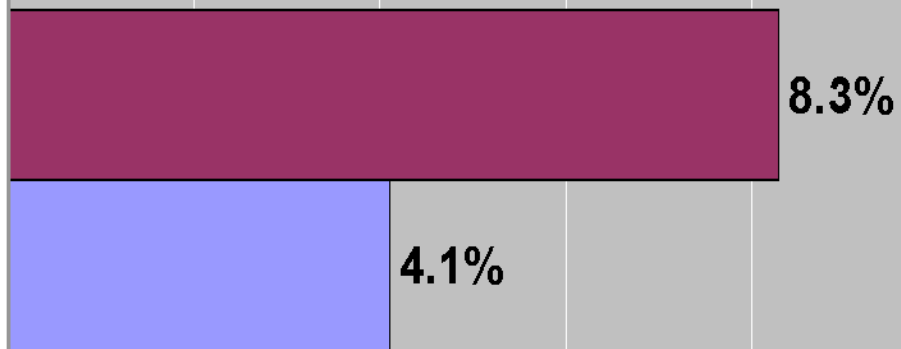
## Missed 2 + weeks of school due to illness



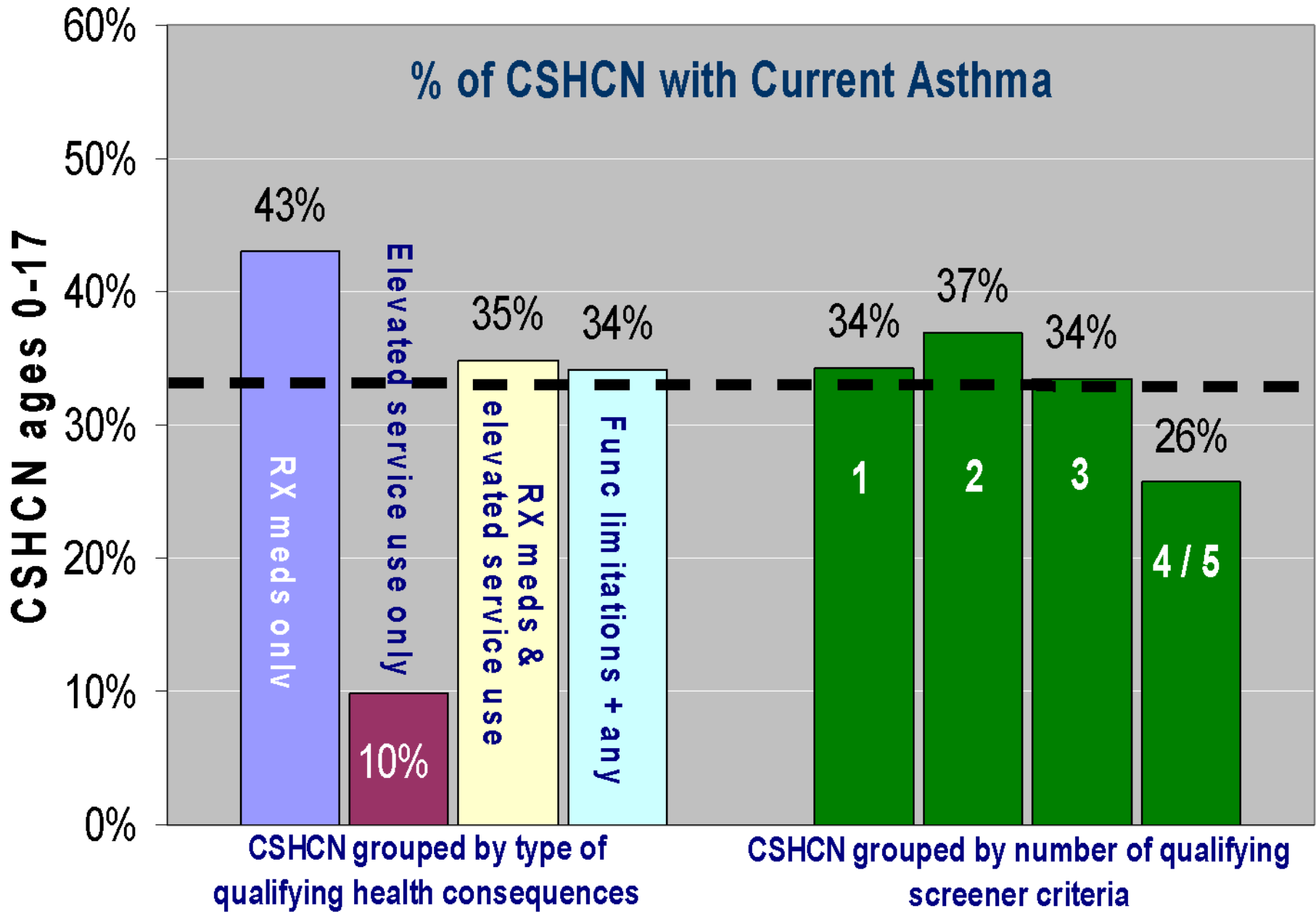
### 3+ doctor visits for sick care, past 12 mos.



### 2 or more ER visits, past 12 mos.

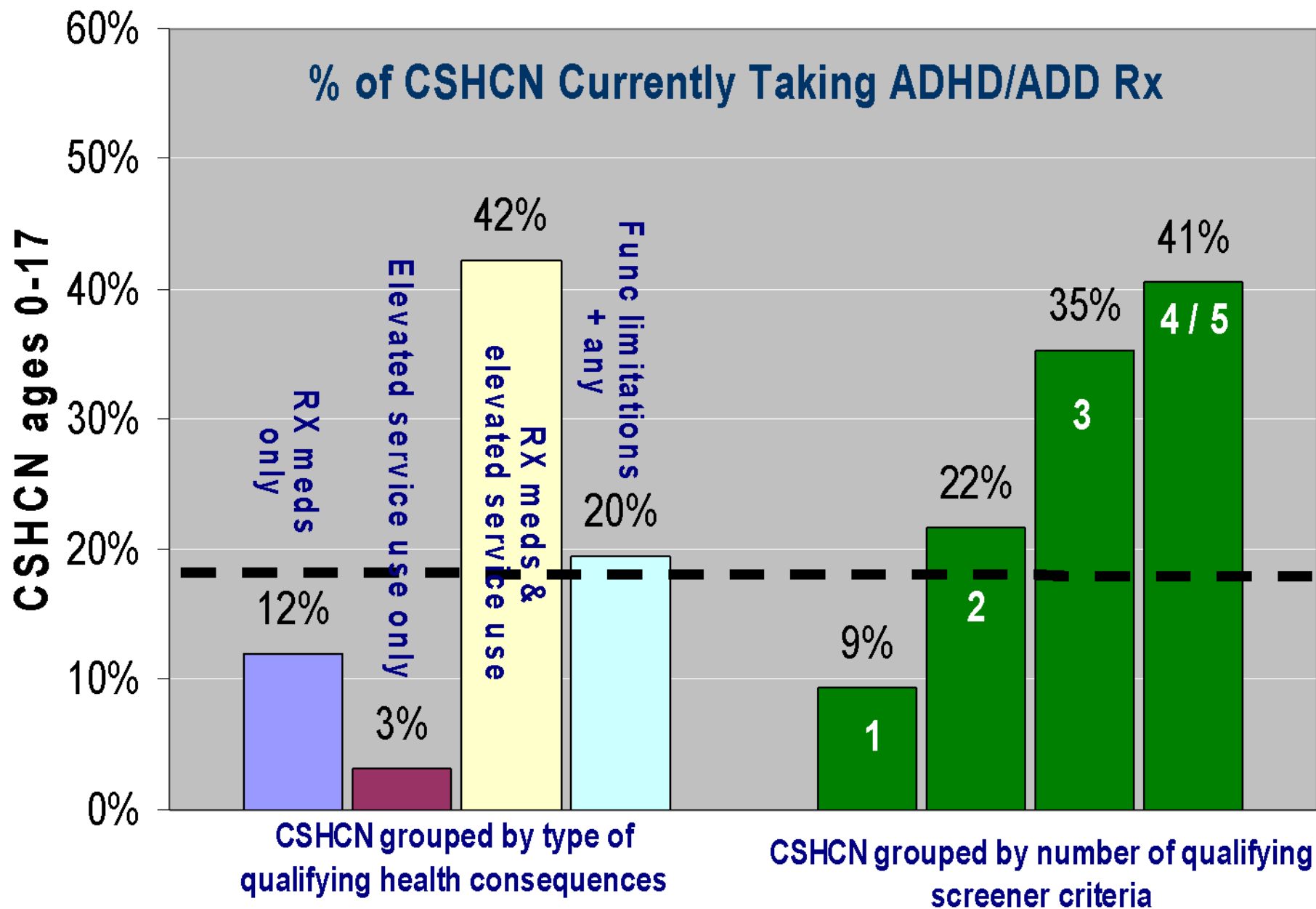


## % of CSHCN with Current Asthma

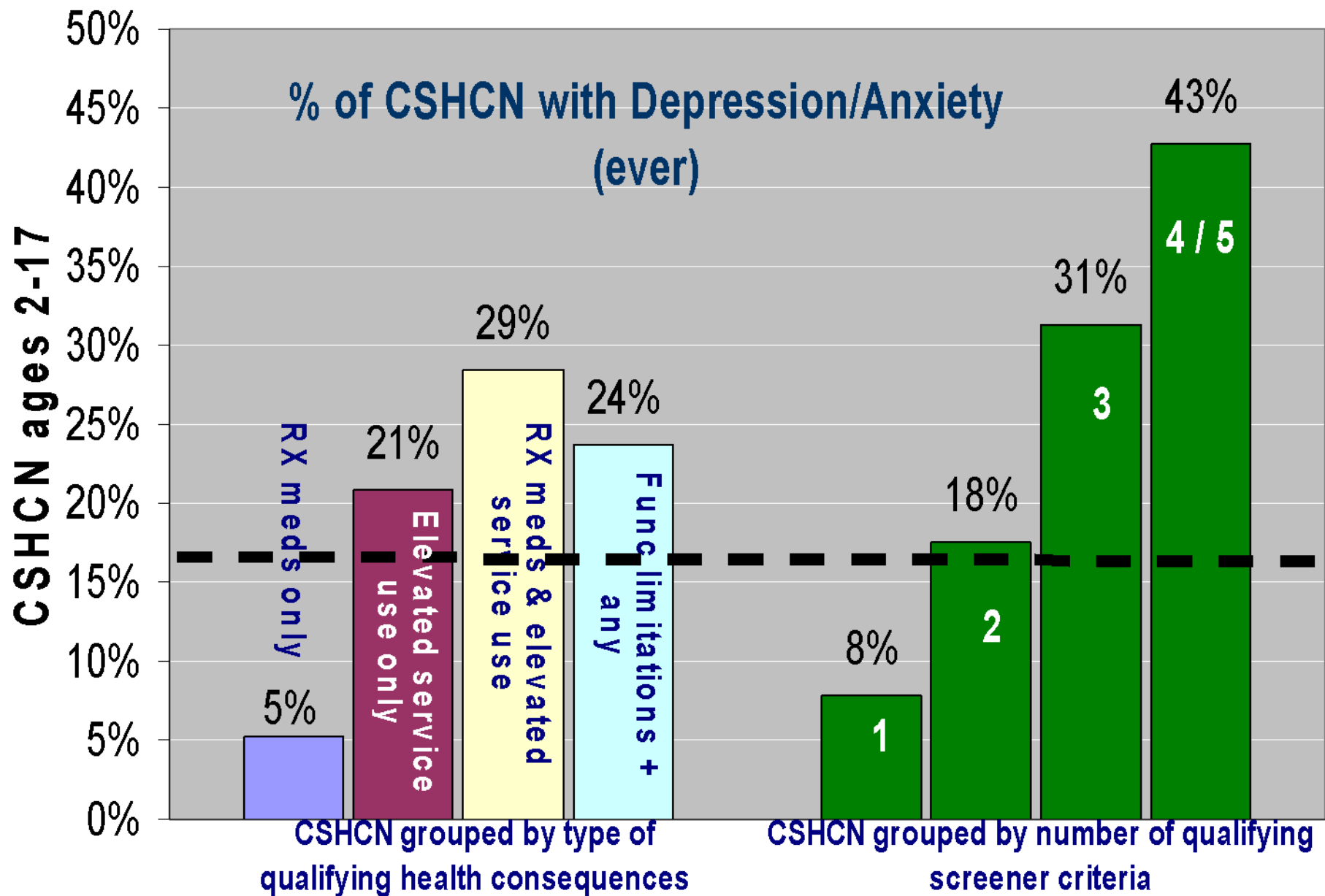


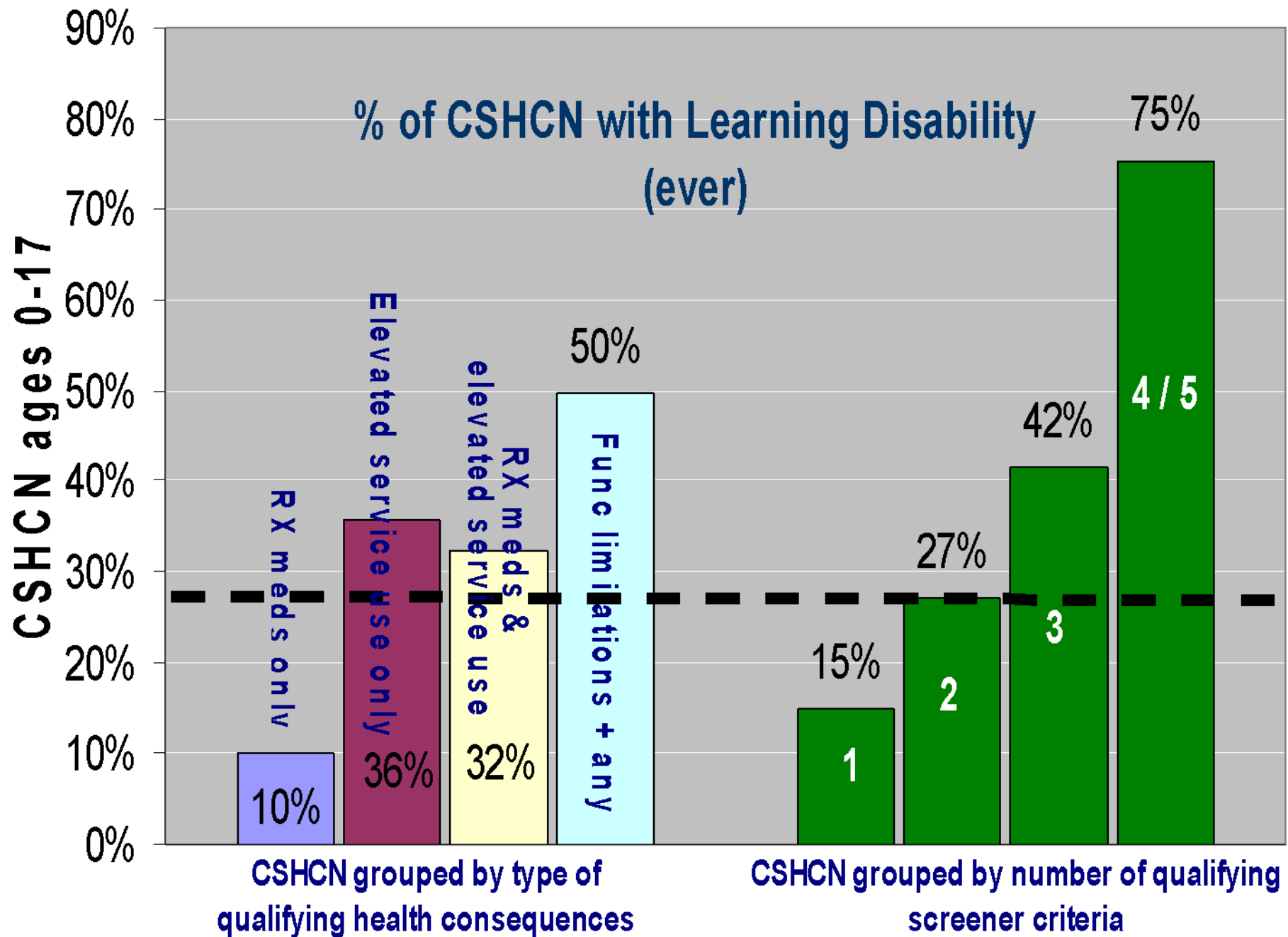


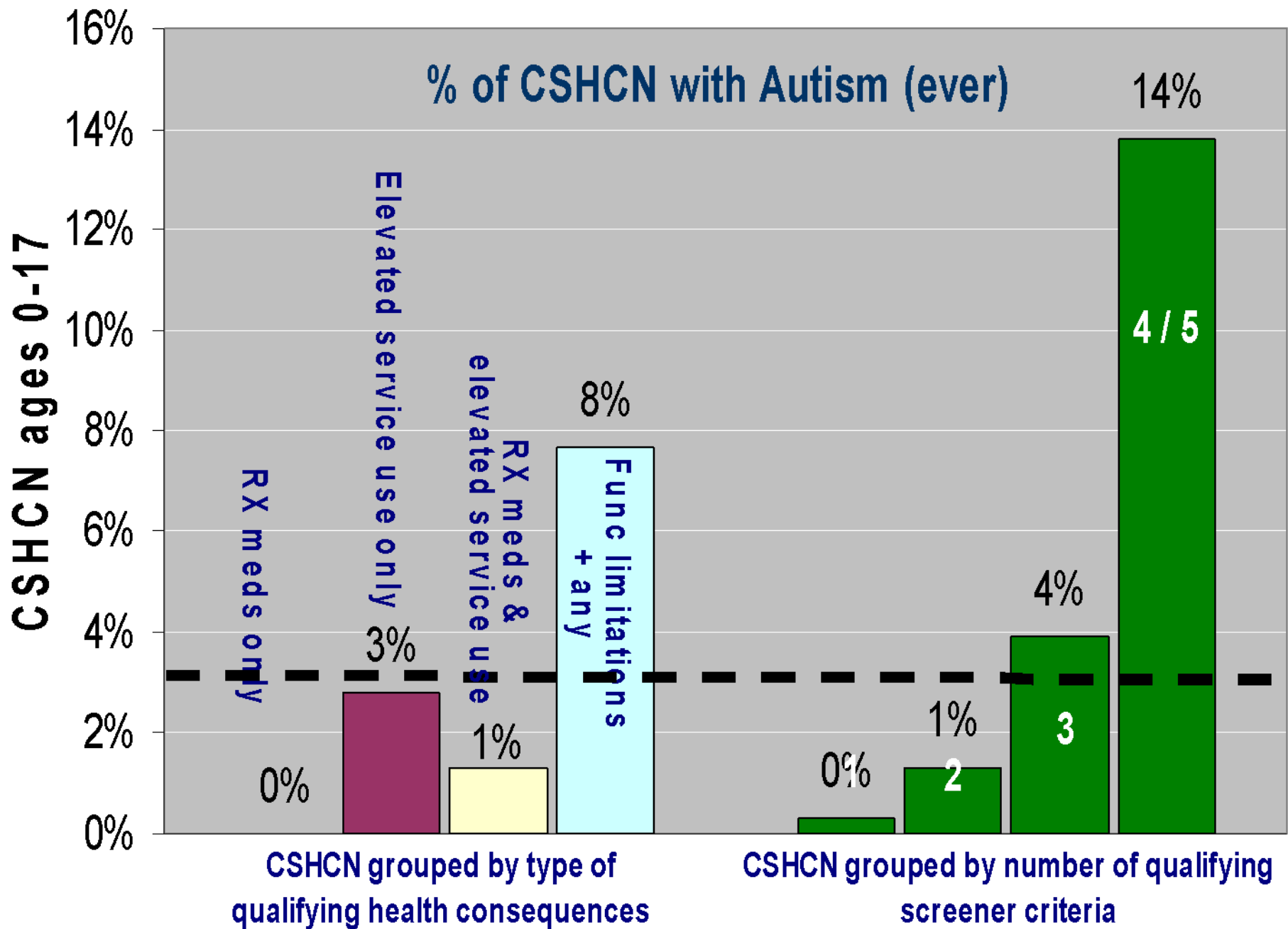
## % of CSHCN Currently Taking ADHD/ADD Rx



## % of CSHCN with Depression/Anxiety (ever)

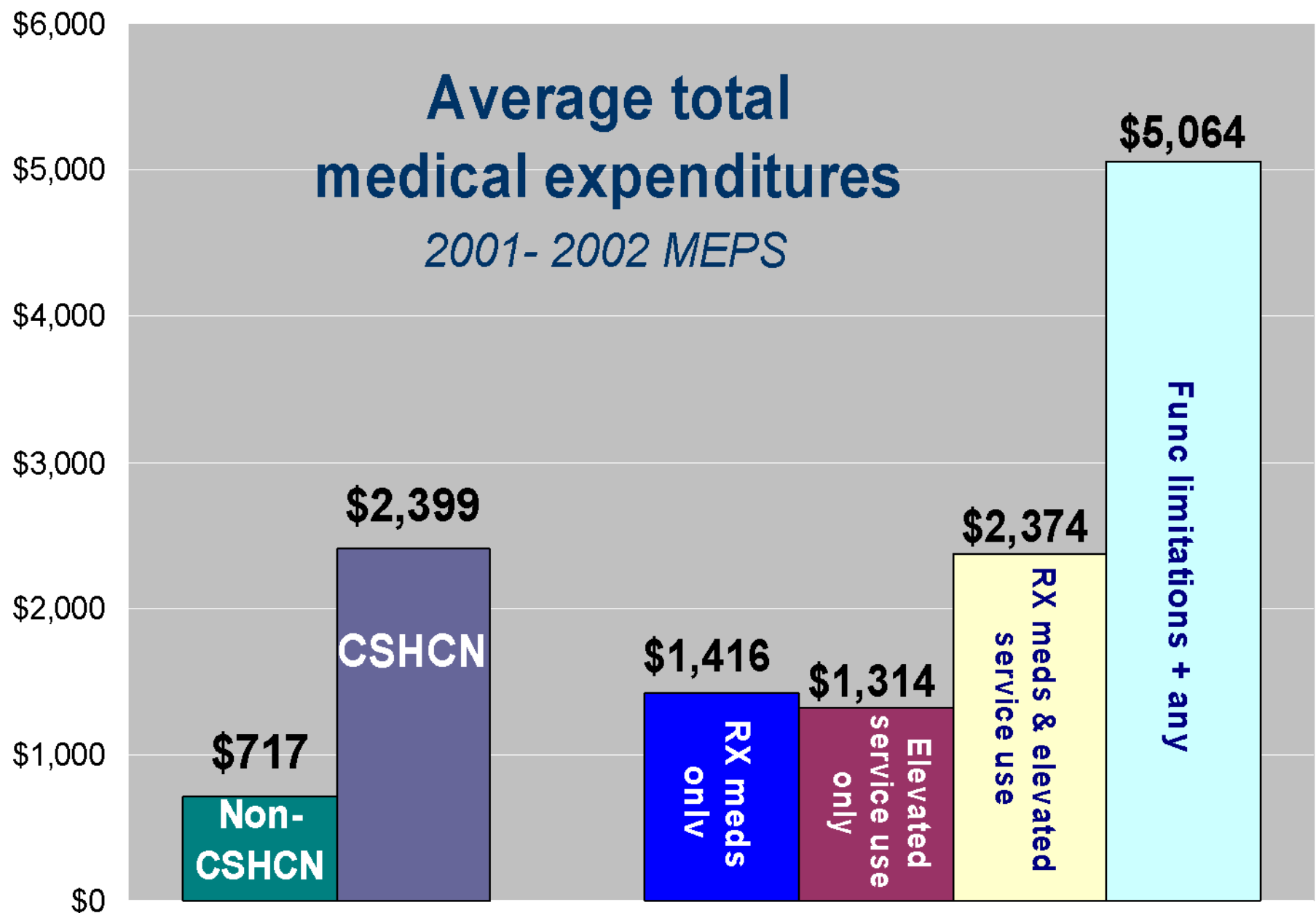






# Average total medical expenditures

2001-2002 MEPS



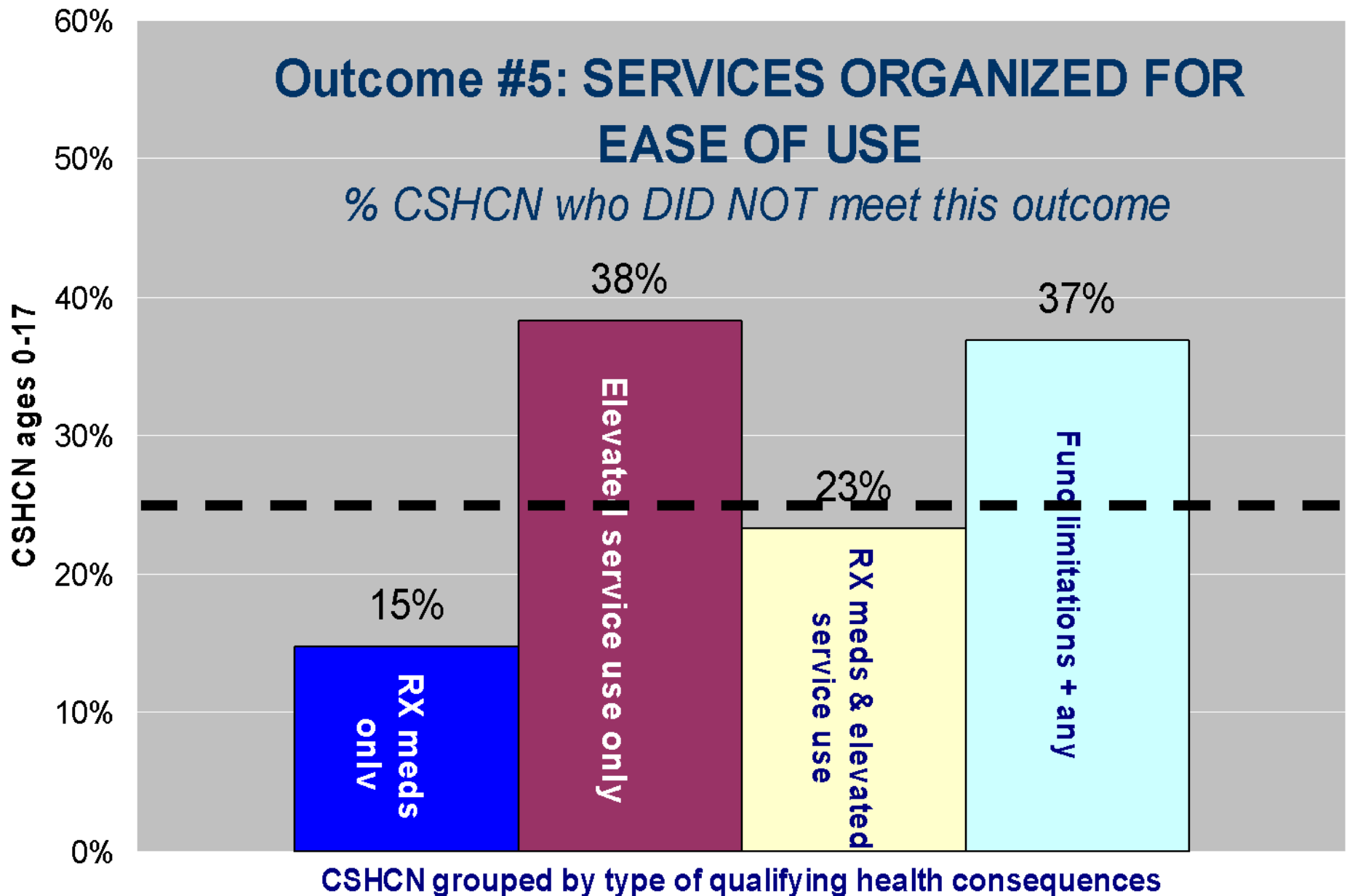
CSHCN grouped by type of qualifying health consequences

# Using Qualitative Groupings to Stratify MCHB Outcomes for CSHCN

- Outcome #5:** Community services organized for ease of use
- Outcome #1:** Families partner in decision making and satisfied w/ services
- Outcome #3:** Adequate public or private insurance to pay for needed services
- Outcome #2:** Coordinated, comprehensive, ongoing care in Medical Home

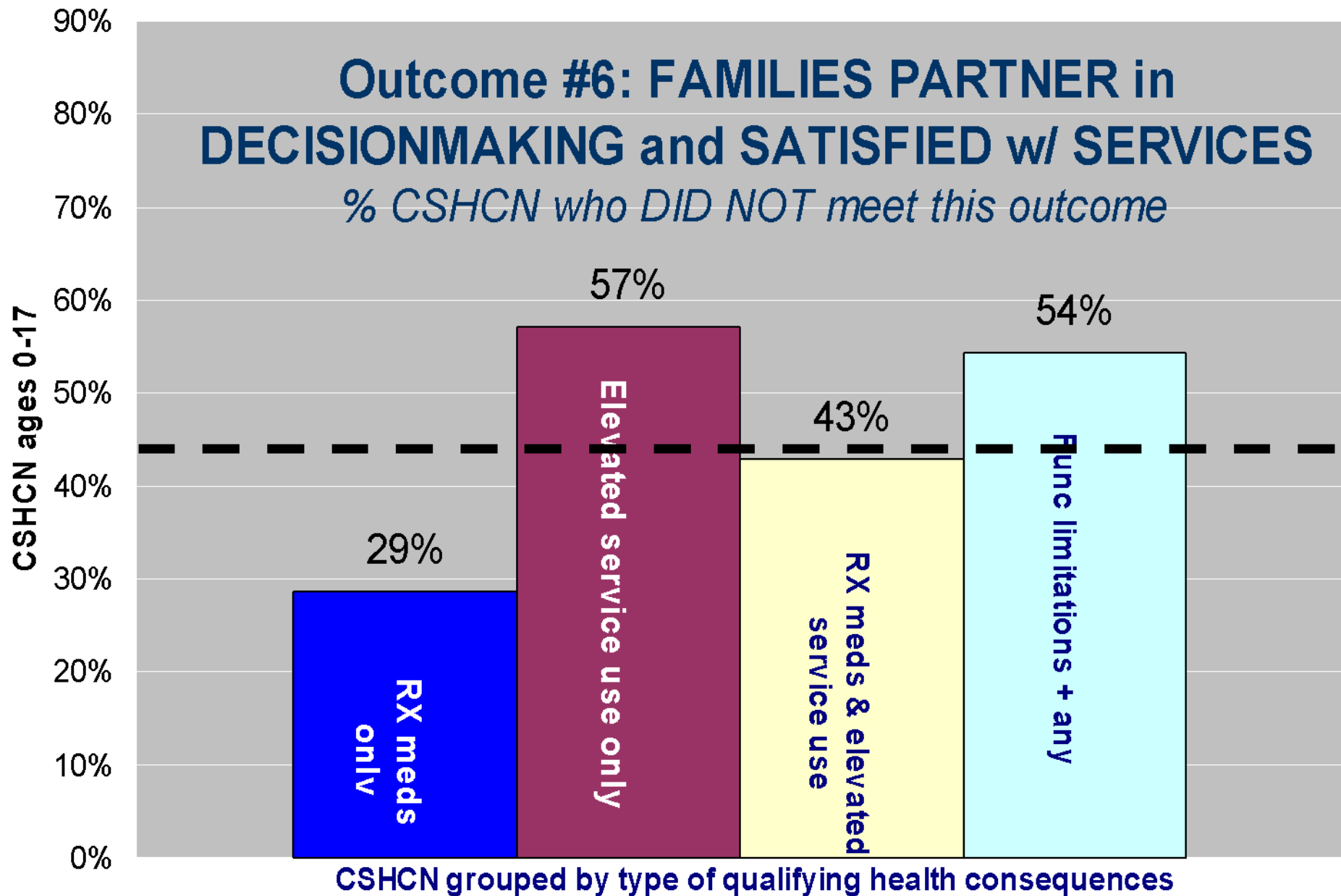
# Outcome #5: SERVICES ORGANIZED FOR EASE OF USE

*% CSHCN who DID NOT meet this outcome*



# Outcome #6: FAMILIES PARTNER in DECISIONMAKING and SATISFIED w/ SERVICES

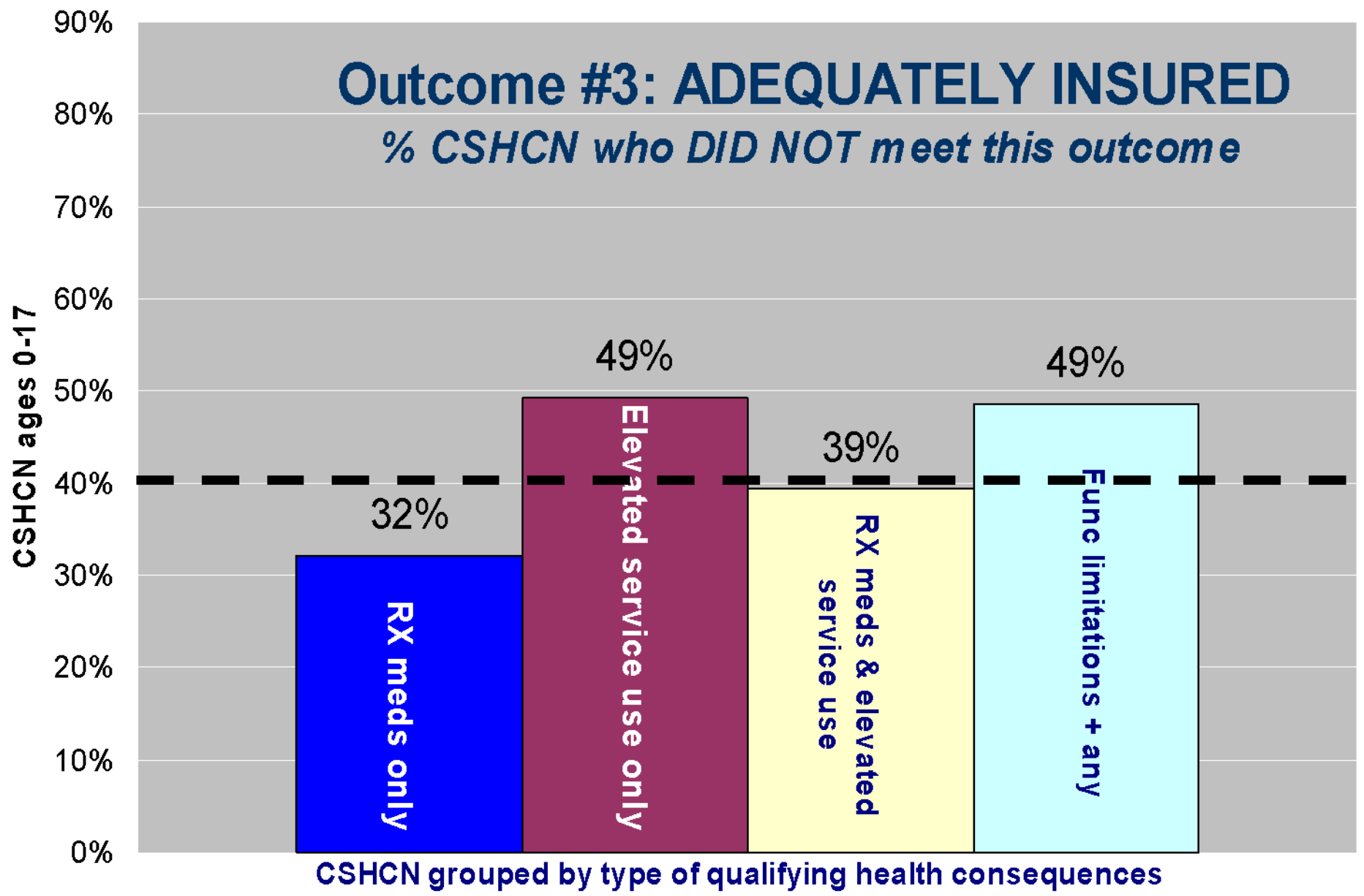
*% CSHCN who DID NOT meet this outcome*





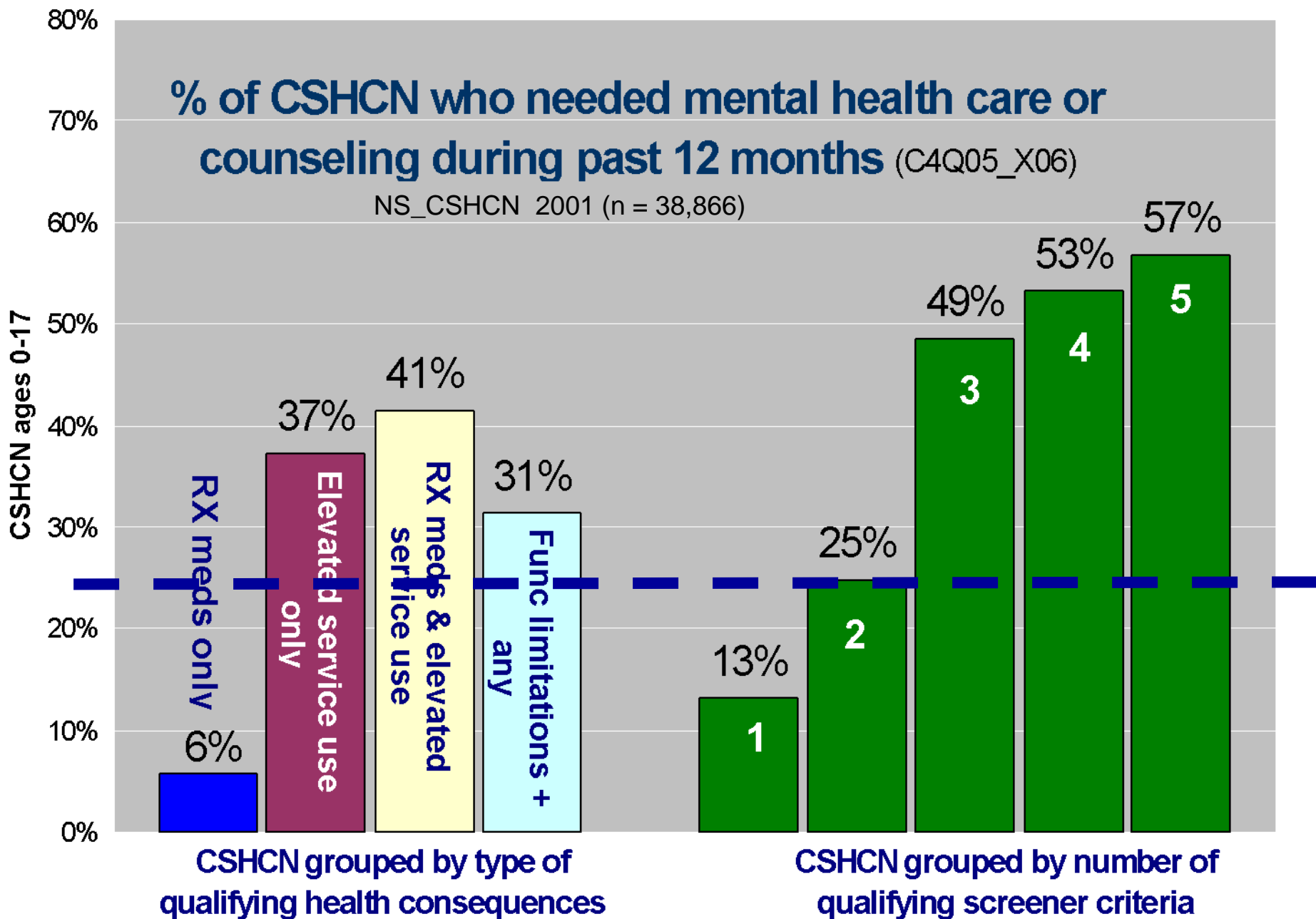
# Outcome #3: ADEQUATELY INSURED

*% CSHCN who DID NOT meet this outcome*



# % of CSHCN who needed mental health care or counseling during past 12 months (C4Q05\_X06)

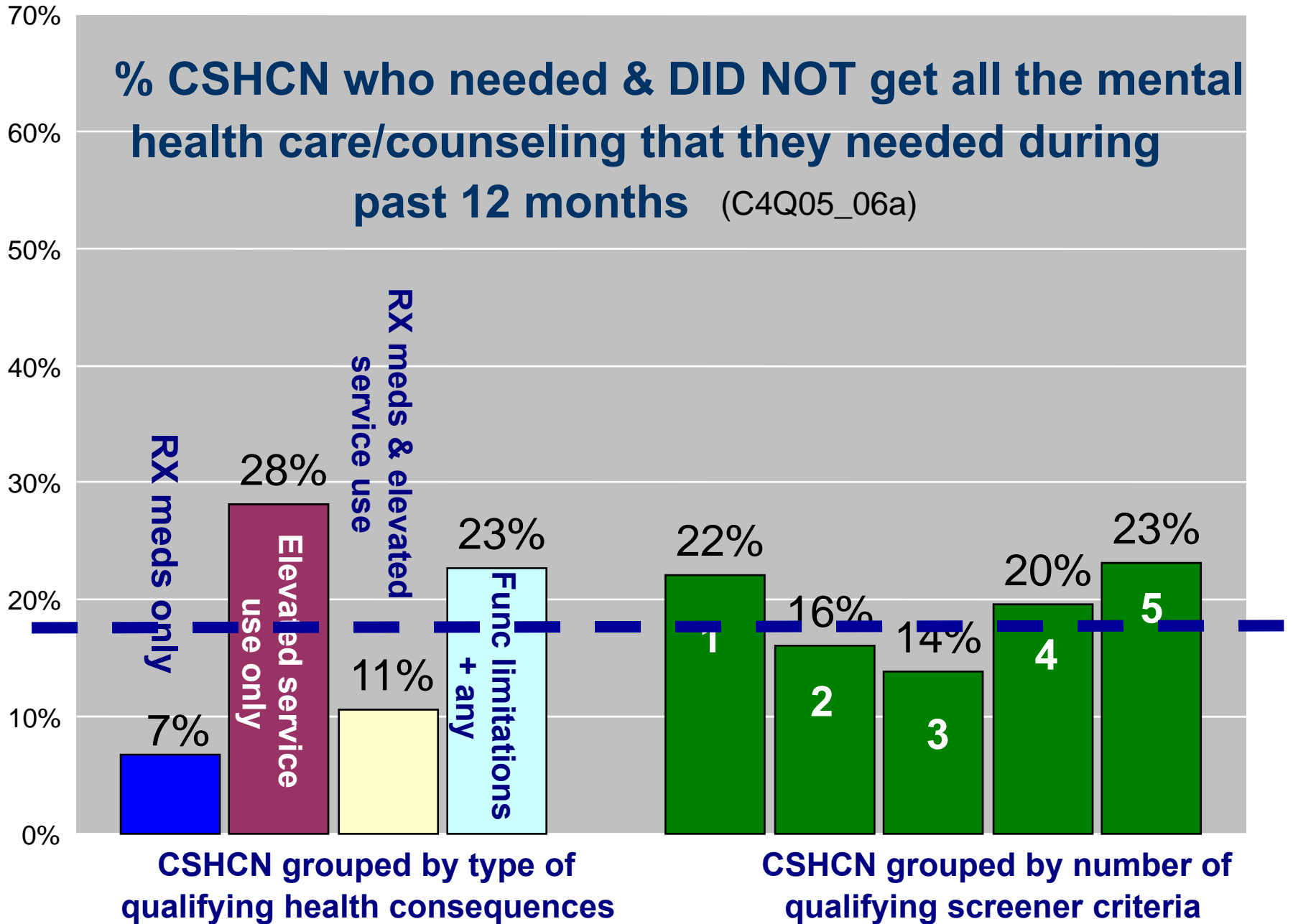
NS\_CSHCN 2001 (n = 38,866)



NS\_CSHCN 2001 (n = 38,866)

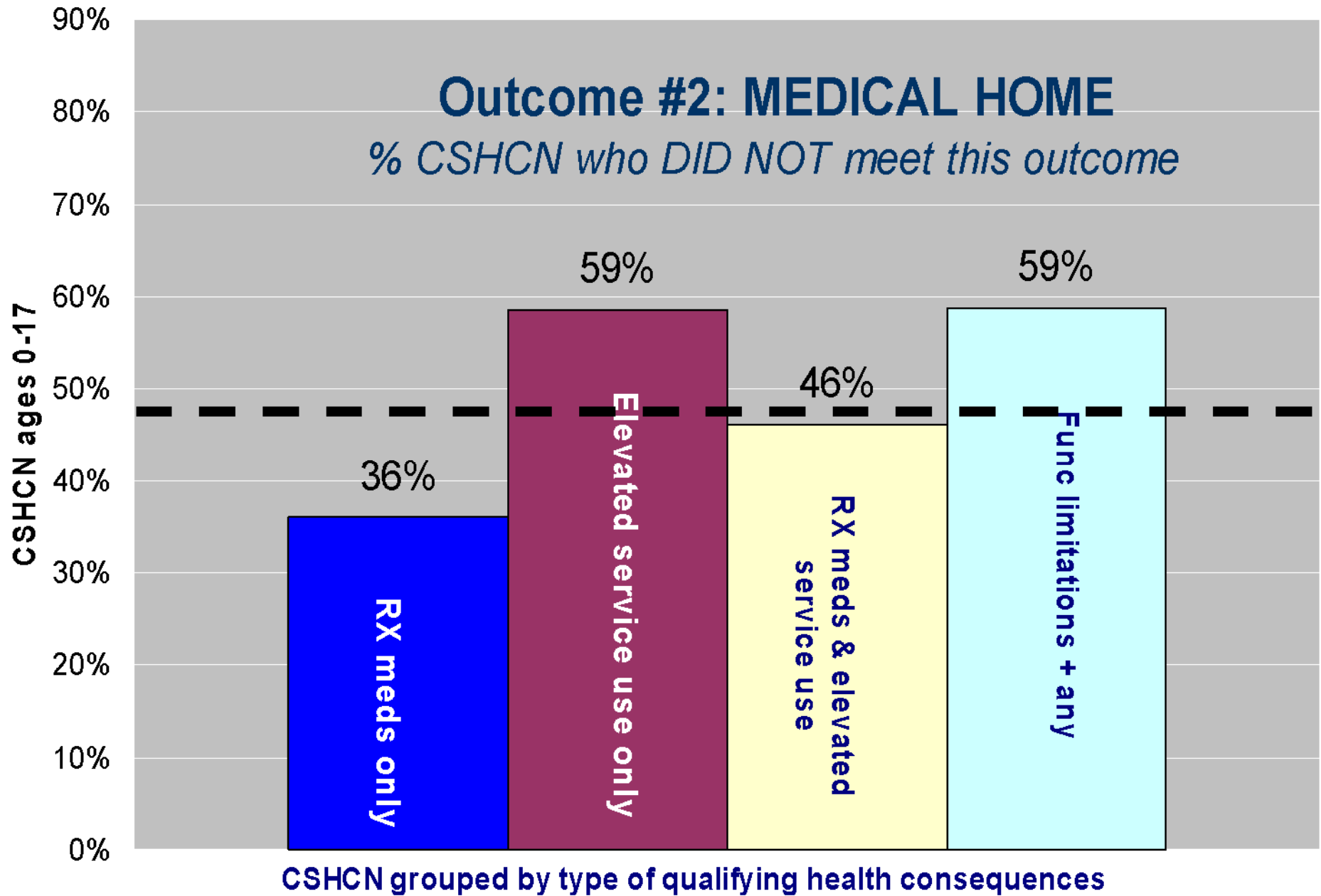
# % CSHCN who needed & DID NOT get all the mental health care/counseling that they needed during past 12 months (C4Q05\_06a)

CSHCN ages 0-17



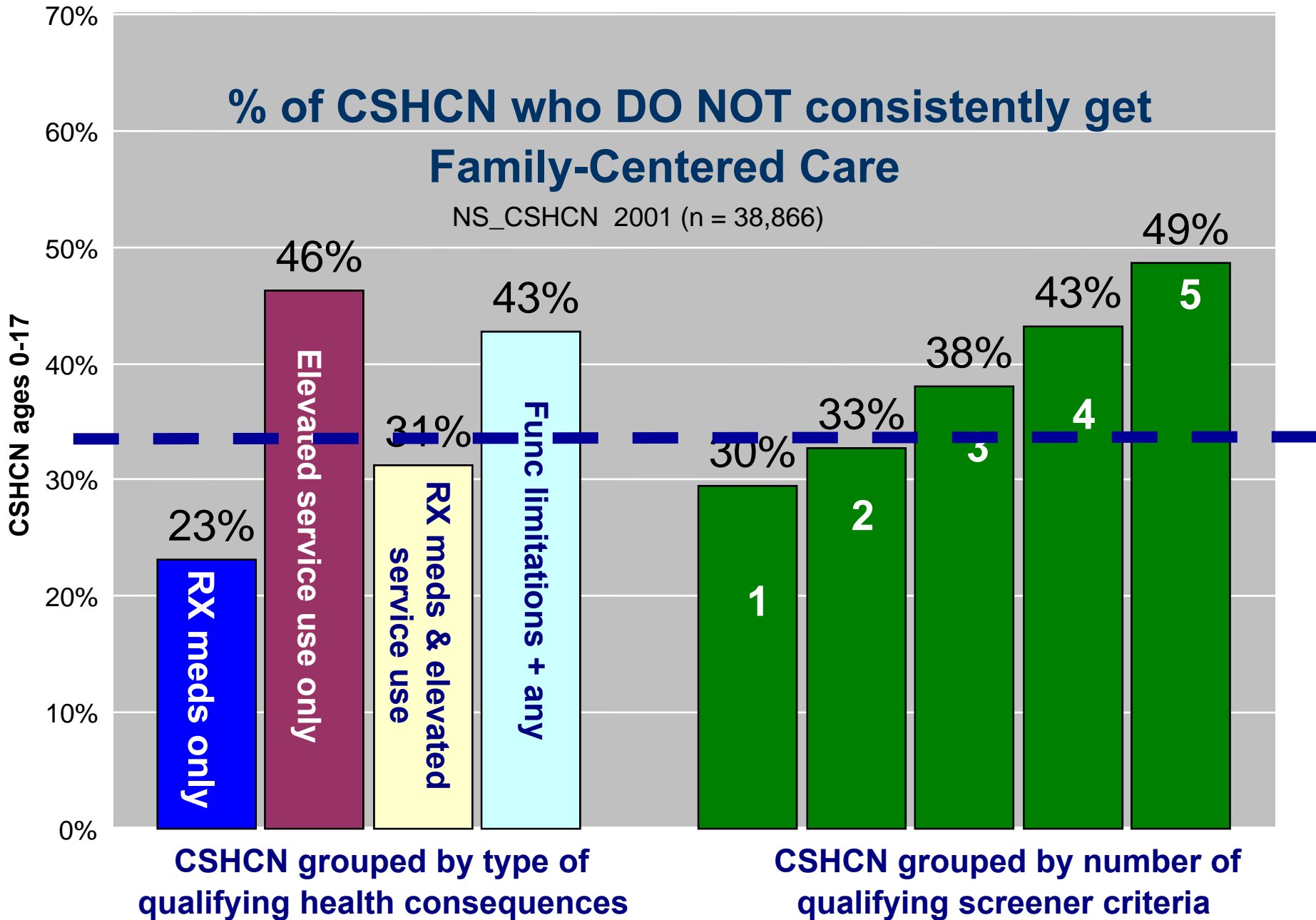
## Outcome #2: MEDICAL HOME

*% CSHCN who DID NOT meet this outcome*



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

NS\_CSHCN 2001 (n = 38,866)



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

- Do you need an ordinal vs. categorical variable?
- 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 (*see MMWR Vol.54:39, October 7, 2005*)

# **Across States Variation for CSHCN vs. non-CSHCN**

**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 for children ages 0-5:**  
**5.2% - 9.9%**

**Indicator 3.2:** How many children/youth (ages 0-17) had consistent health insurance coverage during the past 12 months?  
(derived)

**RANGE across states for children ages 0-17:**  
**7.0% - 24.8%**

*% 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

*% children with inconsistent insurance coverage or currently uninsured, by Special Health Care Needs*

<u>Region</u>	<u>NO special health care needs %</u>	<u>Special health care needs %</u>
<u>Missouri</u>	10.9	5.0
<u>District of Columbia</u>	10.2	5.7
<u>Vermont</u>	7.2	6.0
<u>Washington</u>	12.6	7.0
<u>Connecticut</u>	8.1	7.3
<u>Virginia</u>	13.1	7.8
<u>Rhode Island</u>	10.7	8.2
<u>Minnesota</u>	11.8	8.6

<u>Idaho</u>	17.7	14.0
<u>Wisconsin</u>	10.4	14.6
<u>New Mexico</u>	16.8	17.0
<u>Oklahoma</u>	21.2	17.5
<u>Nevada</u>	25.7	17.9
<u>Alaska</u>	18.0	18.0
<u>Florida</u>	20.7	18.0
<u>Texas</u>	26.3	18.2
<u>Arizona</u>	24.2	18.4
<u>Mississippi</u>	13.8	20.2
<u>Montana</u>	19.3	20.5

# **Resources for using the NSCH and the NS-CSHCN**



# Data Resource Center for Child & Adolescent Health

Your Data... Your story

- [DRC Home](#)
- [Link to Us](#)
- [Glossary](#)
- [Search](#)
- [Contact Us](#)


- [Ask a Question](#)
- [Tell a Friend](#)
- [E-Updates](#)
- [Answer Our Brief User Poll](#)

National, state, and regional survey data right at your fingertips!

**To go to the NSCH homepage, CLICK here**

- [NSCH Survey](#)
- [NS-CSHCN Survey](#)
- [AWSTATS](#)

**N**ational 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.


Want to view your state's data profile?



[CLICK HERE](#)

**OR**

**N**ational Survey of Children with Special Health Care Needs (NS-CSHCN), 2001



- 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.

Want to view your state's data profile?



[CLICK HERE](#)





# National Survey of Children's Health

Data Resource Center — Your Data... Your story

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## Start HERE!



1. Learn about the survey



2. Search the data



3. Report your results

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1. Learn about the survey    2. Start data query— Search the data    3. Report your results

## STEP 2: Start data query— Search the data

### ○ Child Health Measures

Over 60 indicators of child health and well-being derived from the survey

### ○ State Profile

Compare results from the State Profile pages for children of different ages, race/ethnicity groups, and more

### ○ Healthy People 2010

Query the survey content and child health indicators pertaining to Healthy People 2010

### ○ Survey Sections

Search and compare results for the questions asked in each section of the survey





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- [FAST FACTS about the National Survey of Children's Health \(PDF\)](#)  
Who sponsors the survey? What areas of child health and well-being are addressed? How many surveys were collected? Quick answers to these and other questions.
- [Sampling and Administration Process \(PDF\)](#)  
One-page diagram summarizing the sampling and administration steps for the National Survey of Children's Health.
- [Guide to Topics and Questions Asked \(PDF\)](#)  
Summary of the questions asked in each section of the National Survey of Children's Health - very helpful for navigating the full-length survey instrument.
- [National Survey of Children's Health - Full Length Instrument \(PDF\)](#)  
Download the 65-page Computer Assisted Telephone Interview (CATI) version of the National Survey of Children's Health.
- [Design and Operation of the National Survey of Children's Health, 2003 \(PDF\)](#)  
Technical report authored by CDC staff describes the methodological details of the survey's sampling and data collection procedures.
- [National Center for Health Statistics \(NCHS\)](#)  
NCHS conducted the National Survey of Children's Health. This link takes users to the NCHS website for additional information about the survey, including downloadable SAS input files of the survey data.

# National Survey of Children Health: Guide to Topics & Questions Asked

(PDF printable version)

NOTE: Telephones are dialed at random to identify households with one or more children under 18 years old. The interviewer asks to speak to the parent or guardian who knows the most about the child's or children's health and health care. If he or she is not available, multiple call back attempts are made to reach them.

CLICK on the question numbers in green text below to view the full text of the question and its response options.

- ▼ SECTION 1: Initial Demographics
  - ▼ SECTION 2: Child's Health and Functioning Status
  - ▼ SECTION 3: Health Insurance Coverage
  - ▼ SECTION 4: Health Care Access and Utilization
  - ▼ SECTION 5: Medical Home
  - ▼ SECTION 6: Early Childhood (0-5 years)
  - ▼ SECTION 7: Middle Childhood and Adolescence (6-17 years)
  - ▼ SECTION 8: Family Functioning
  - ▼ SECTION 9: Parental Health
  - ▼ SECTION 10: Neighborhood Characteristics
  - ▼ SECTION 11: Additional Demographics
- 

## SECTION 1: Initial Demographics [↑TOP](#)

1. Child's sex ([S1Q01](#))
2. Respondent's relationship to the child ([S1Q02](#))

## 2003 National Survey of Children's Health



### Survey Section 3: Health Insurance Coverage

**INTRODUCTION:** The next questions are about health insurance.

**S3Q01:** Does [CHILD] have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicaid?

- (0) NO [SKIP TO S3Q05]
- (1) YES
- (6) DON'T KNOW
- (7) REFUSED

**HELP SCREEN (S3Q01):** Medicaid refers to a medical assistance program that provides health care coverage to low-income and disabled persons. The Medicaid program is a joint federal-state program that is administered by the states. Private health insurance refers to any type of health insurance, including Health Maintenance Organizations (HMOs), other than public programs. These plans may be provided in part or fully by the person's employer or union, or purchased directly by the individual.

# OTHER RESOURCES

- **DRC indicator datasets available at no cost from CAHMI**
  - **SAS and SPSS formats**
  - **All DRC child health Indicator variables included in data set**
  - **Request data use agreement: [cahmi@ohsu.edu](mailto:cahmi@ohsu.edu)**
- **SAS and SPSS codebooks with programming code used to construct child health indicators**
- **Download raw datasets and methods reports at: [www.cdc.gov/nchs](http://www.cdc.gov/nchs)**

# 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**

# More information

- [www.childhealthdata.org](http://www.childhealthdata.org)
- [www.cahmi.org](http://www.cahmi.org)

