

Alternative Models for Stratifying CSHCN Identified through Three National Surveys

Debra Read, MPH

The Child and Adolescent Health Measurement Initiative
Oregon Health and Science University, School of Medicine

Co-Authors: Debra Read, MPH, Matthew Bramlett, Ph.D, Christina Bethell, PhD,
Stephen Blumberg, PhD

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Three national surveys use the MCHB definition as starting point for identification of CSHCN:

- **Nat. Survey of CSHCN (NS_CSHCN)**
- **Nat. Survey of Children's Health (NSCH)**
- **Medical Expenditure Panel Survey (MEPS)**

“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

CSHCN Screener

- **Designed to operationalize** MCHB definition of CSHCN
- **Developed through a national process** involving state leaders, families, experts, and policymakers
- **Over 36,000 children / youth screened** during development & testing phases
- **Several versions tested**, leading to final screener

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

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)

No special health care needs

GROUP A

At risk for developing a special health care need

GROUP B

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

GROUP C

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

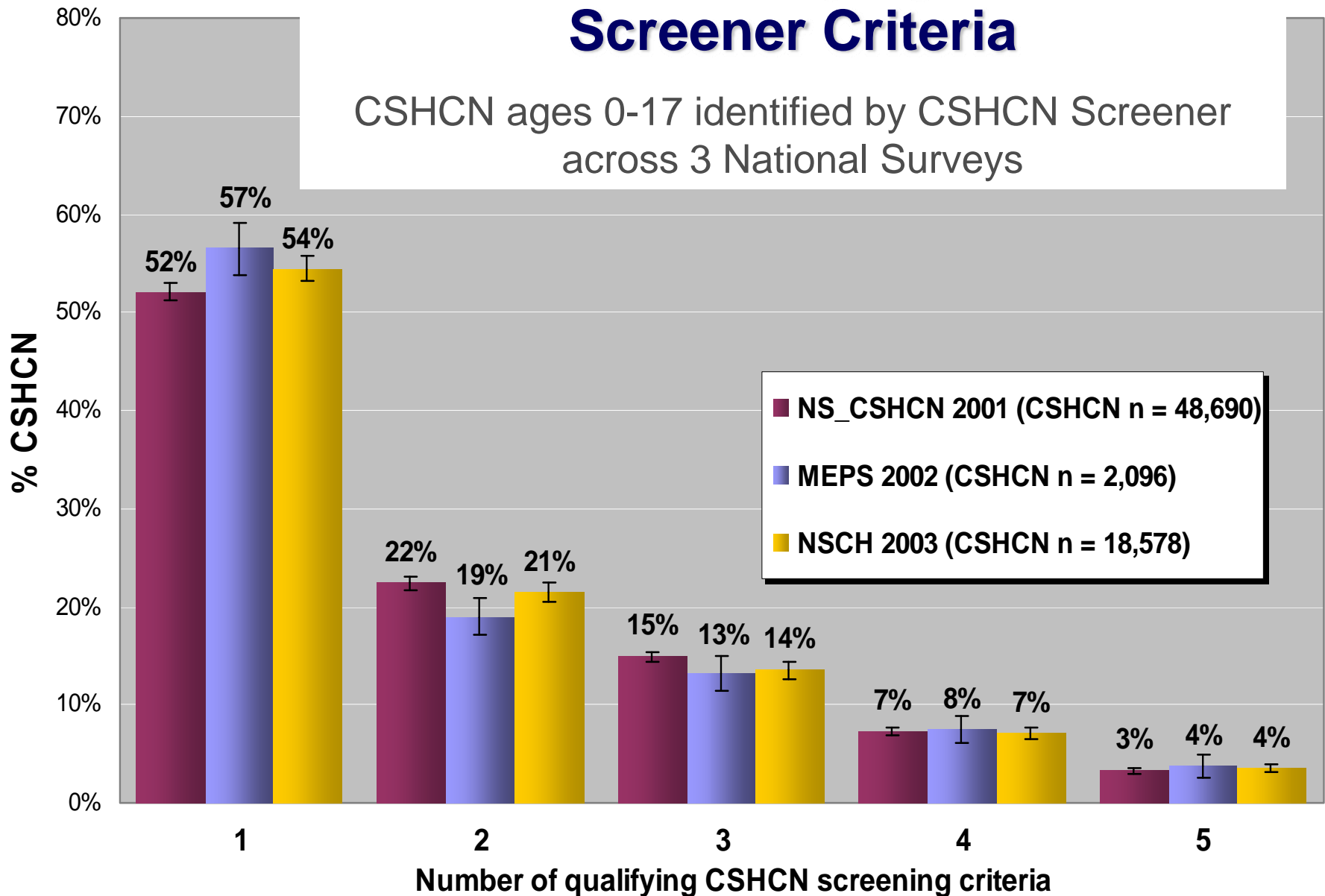
Special Health Needs Continuum

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

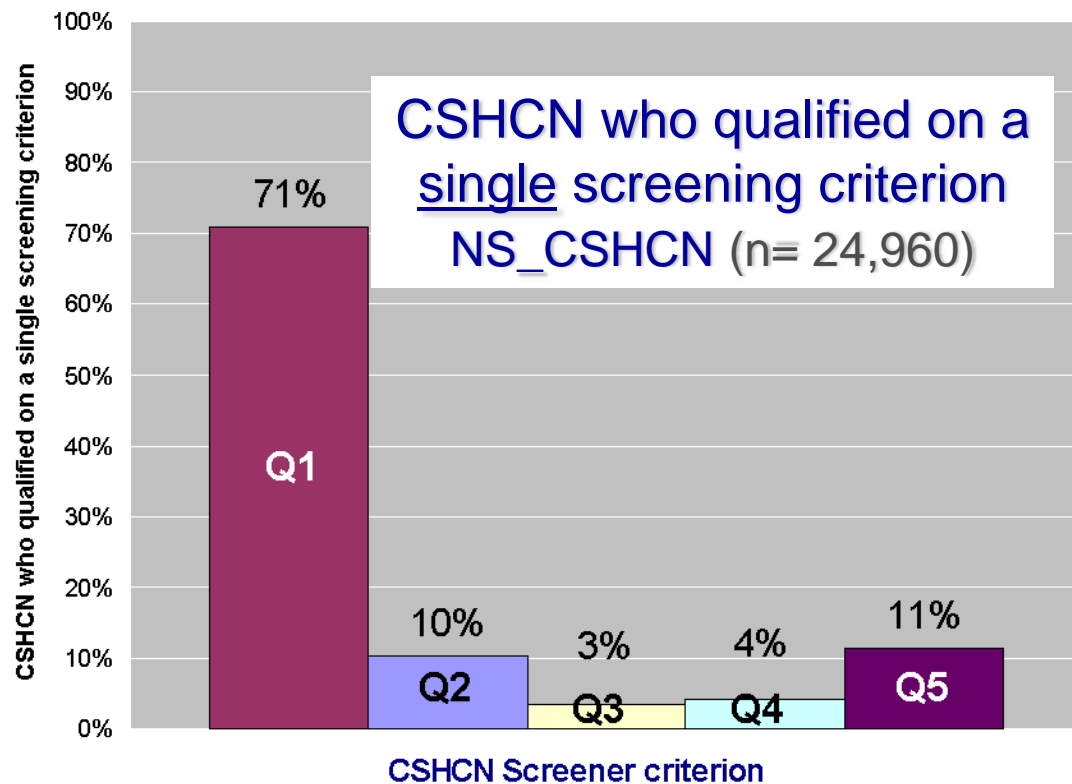
Number Qualifying CSHCN Screener Criteria

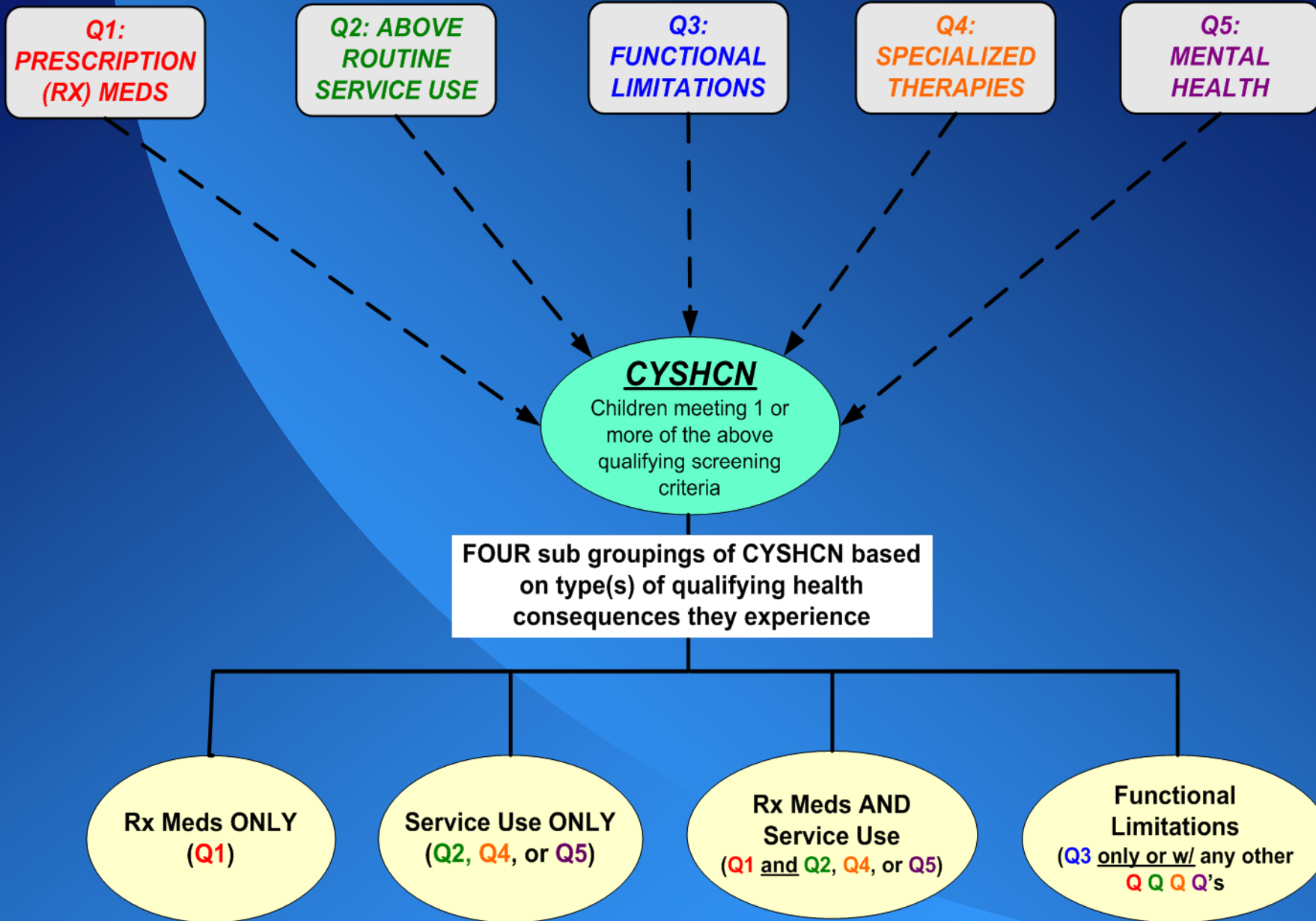
CSHCN ages 0-17 identified by CSHCN Screener across 3 National Surveys



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

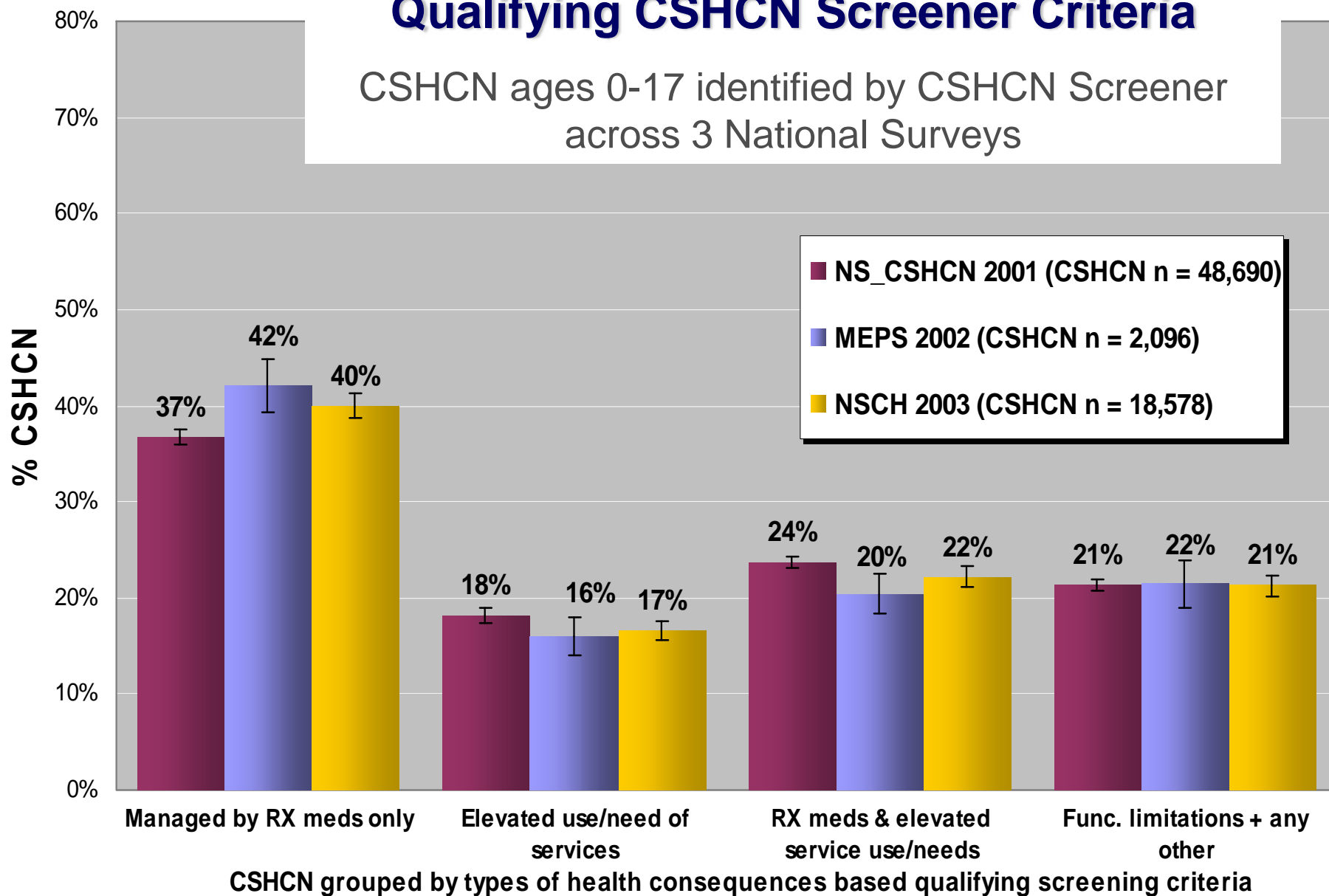
88% Qualified on Functional
Limitations (Q3) in addition to 1 or
more other criteria





Type of Health Consequences based on Qualifying CSHCN Screener Criteria

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



Rx Meds Only:

- Chronic conditions primarily managed by RX meds
- Conditions have little or no impact on daily activities because well-managed by RX meds
- Well-managed chronic conditions = “success story” dependent upon continued access to health care and medication

Elevated service need/use only:

- Conditions/disabilities not being primarily managed by RX meds
- 1 in 2 require more medical, mental health, or educational services than usual for most children
- 1 in 2 have on-going emotional, developmental or behavioral issues which require treatment of some type

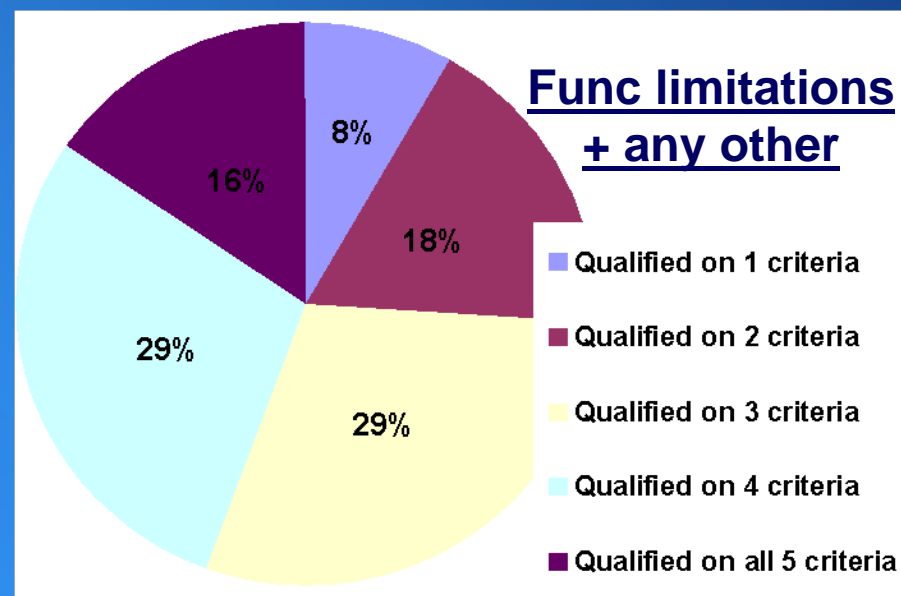
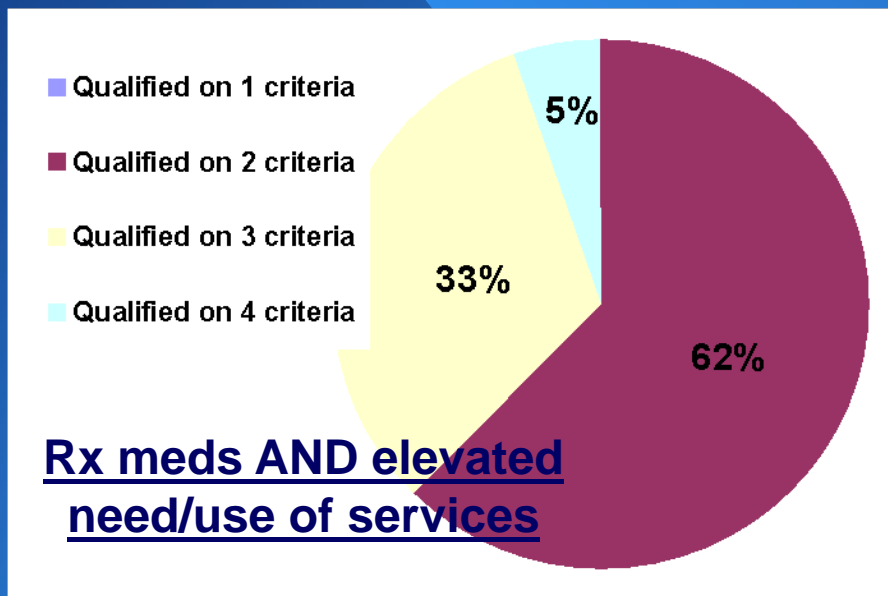
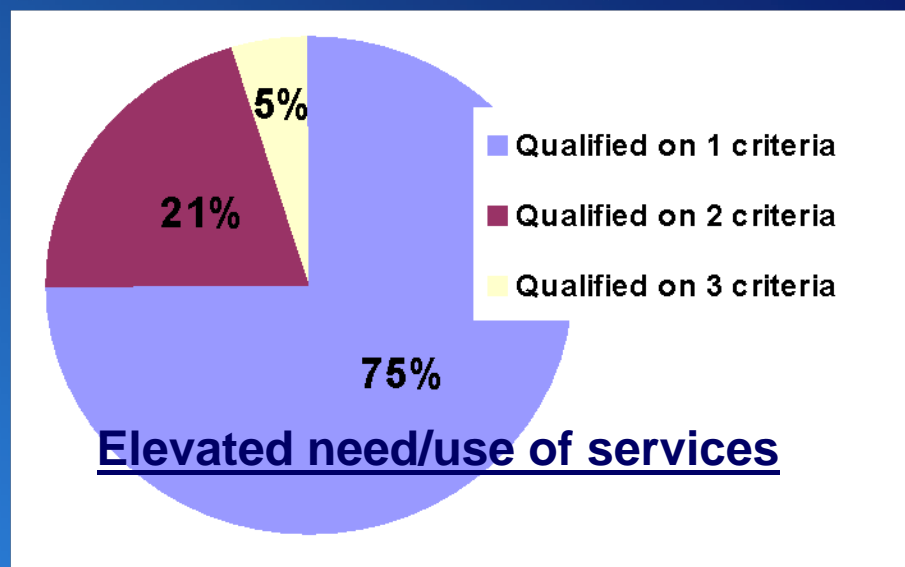
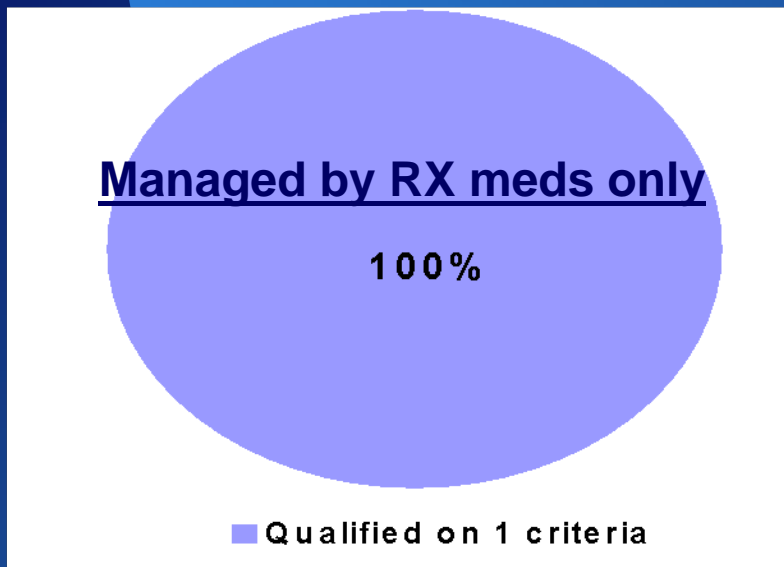
Rx Meds AND elevated service use:

- Managed by combination of RX meds AND other health services
- 85% require more health and/or educational services than usual for most children
- Nearly 50% report on-going emotional, developmental or behavioral issues which require treatment of some type

Functional limitations (alone or with other criteria):

- 75% require more health and/or educational services than most children
- 65% are using RX meds to manage condition(s)
- Nearly 1 in 2 require OT, PT or other specialized therapies
- About 45% have an on-going emotional, developmental or behavioral issue for which they need treatment or counseling

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

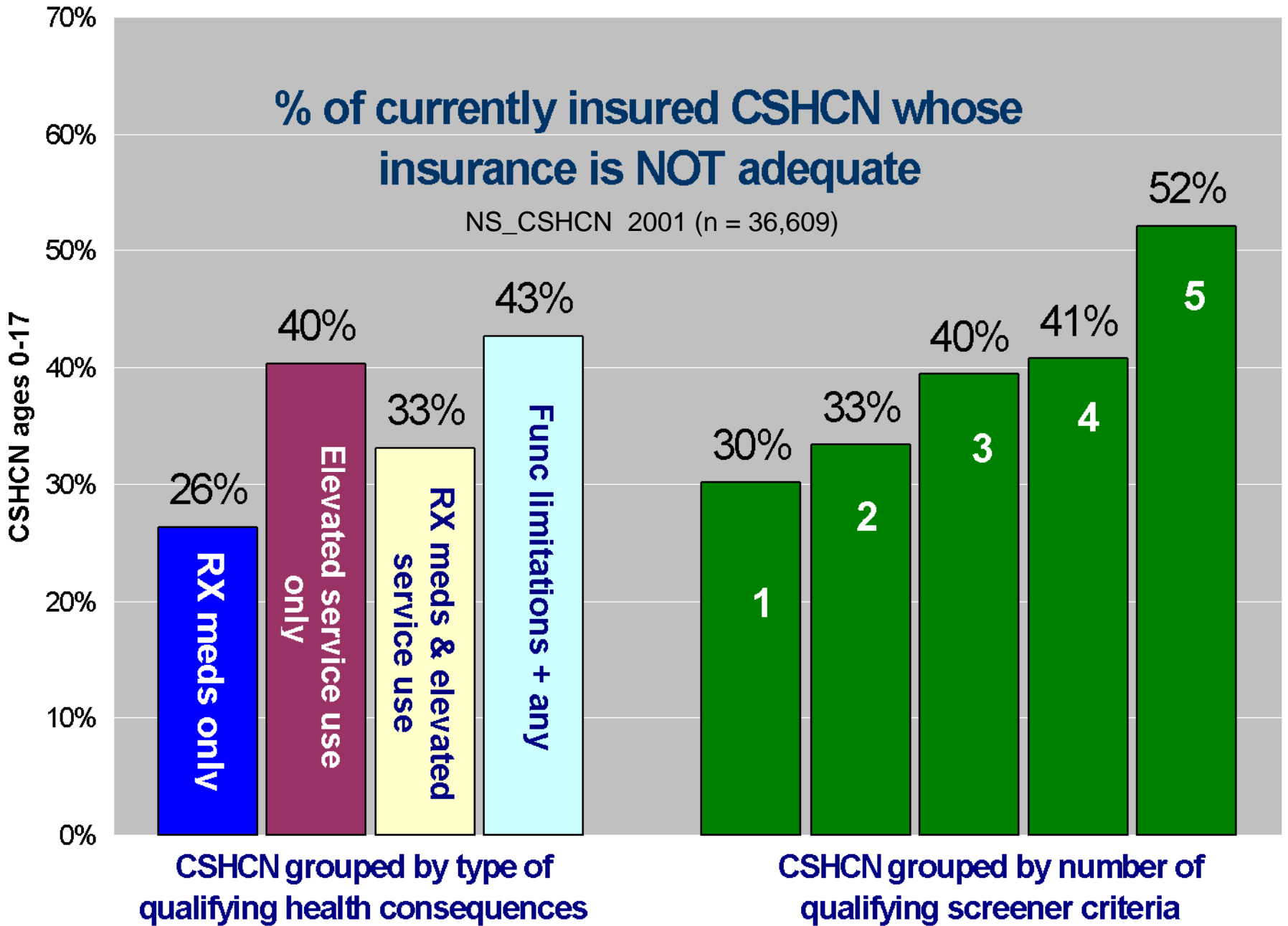


Using Quantitative and Qualitative Groupings to Stratify CSHCN Outcomes

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

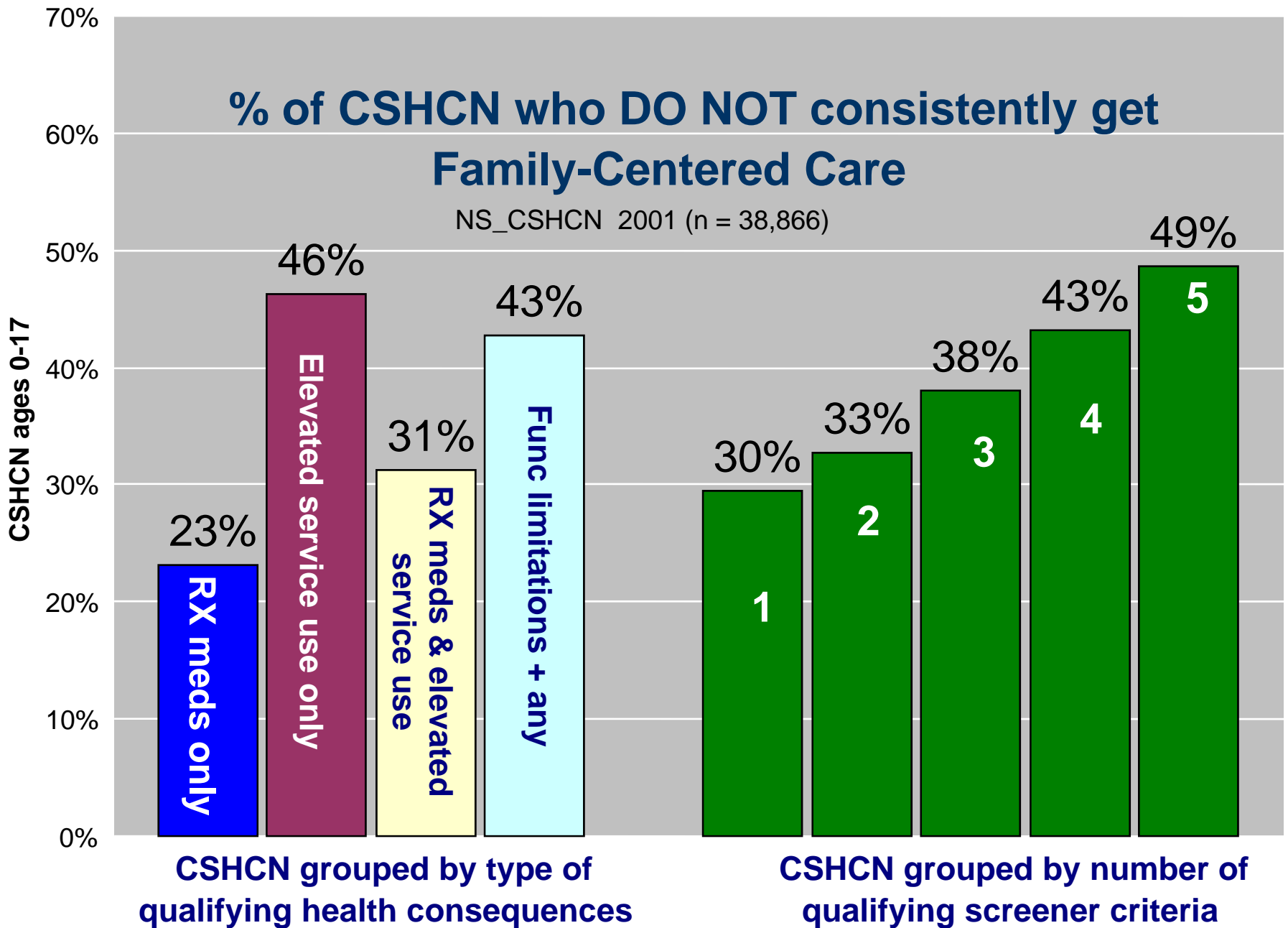
% of currently insured CSHCN whose insurance is NOT adequate

NS_CSHCN 2001 (n = 36,609)



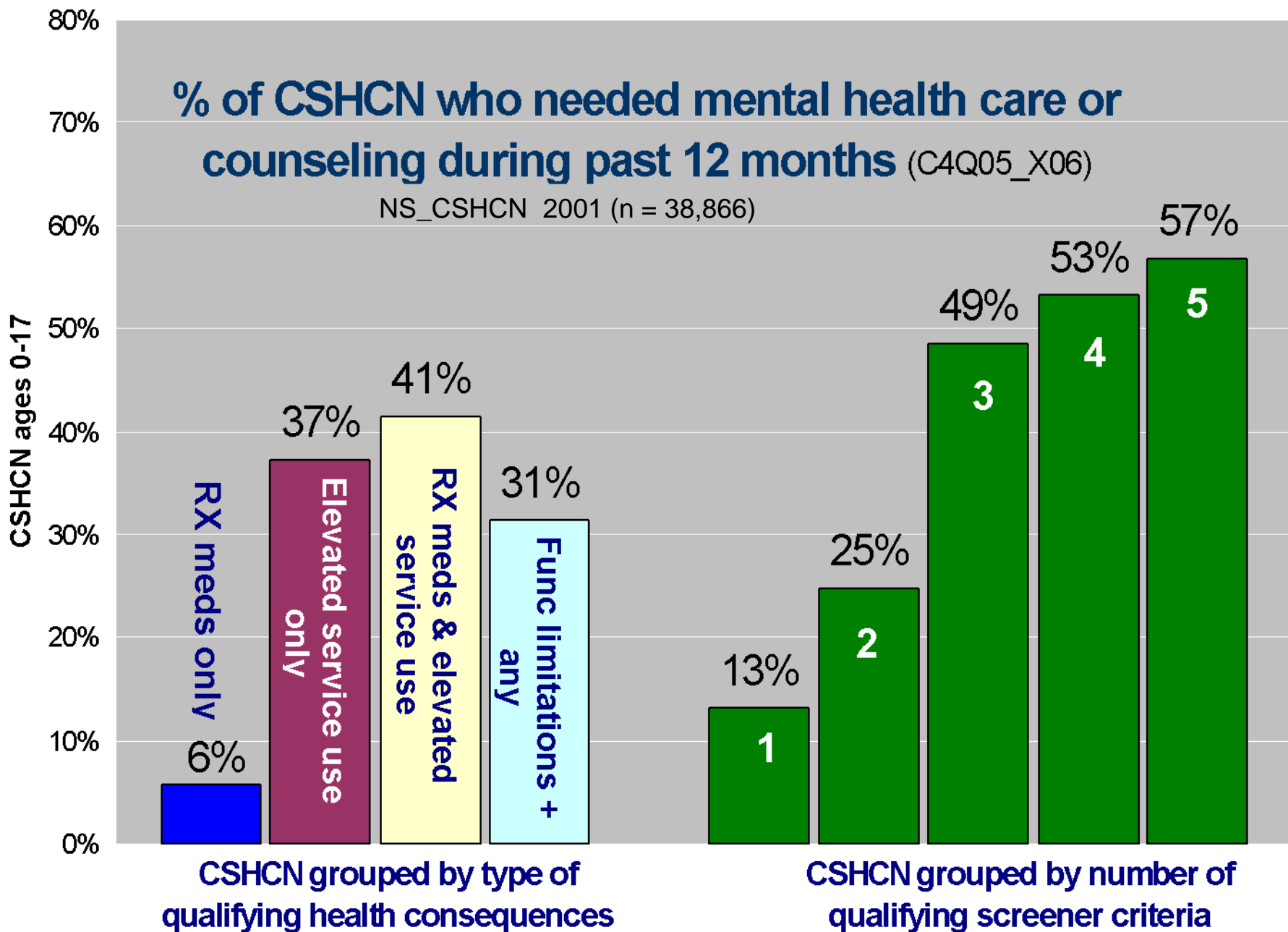
% of CSHCN who DO NOT consistently get Family-Centered Care

NS_CSHCN 2001 (n = 38,866)

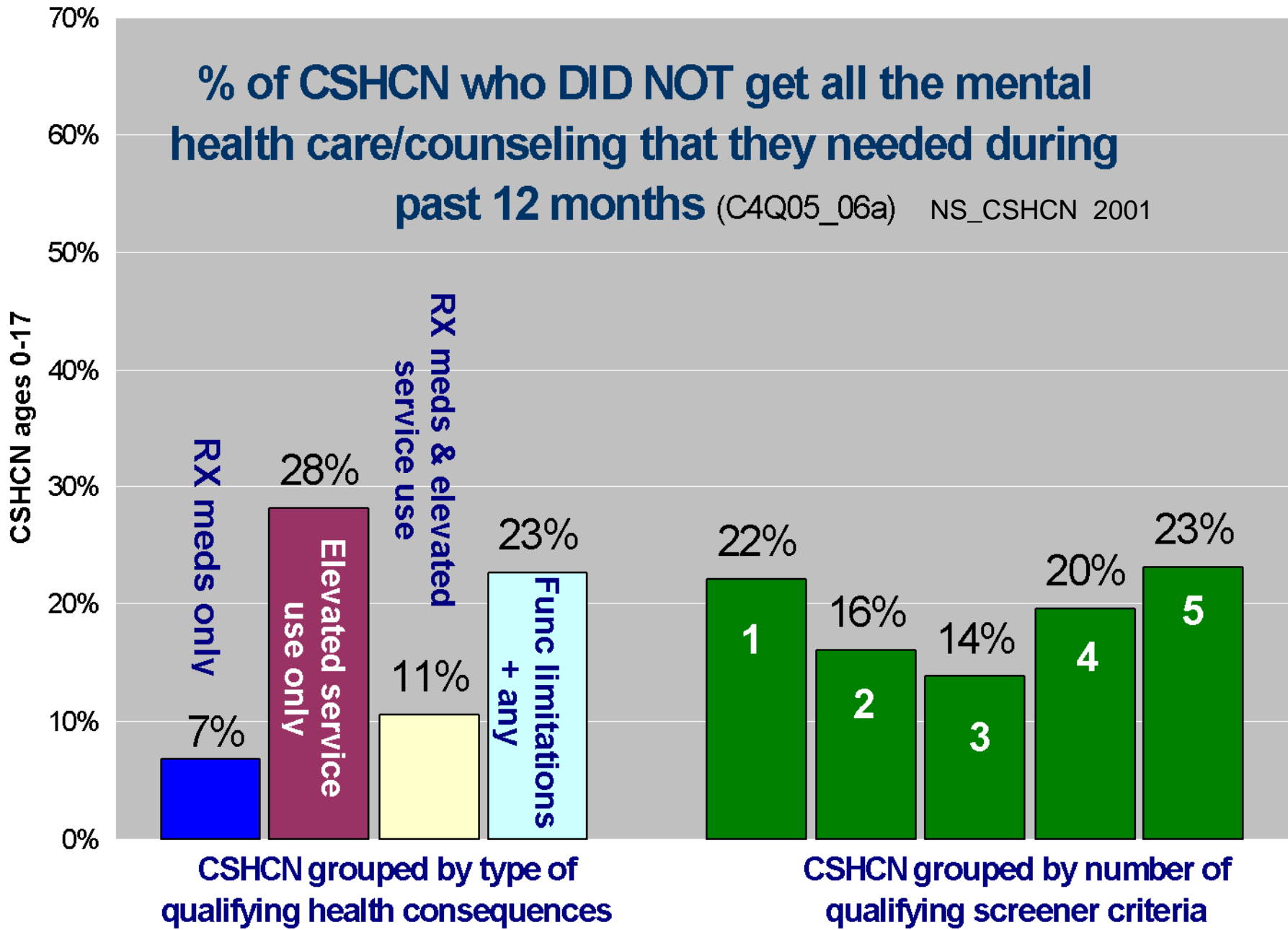


% of CSHCN who needed mental health care or counseling during past 12 months (C4Q05_X06)

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



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

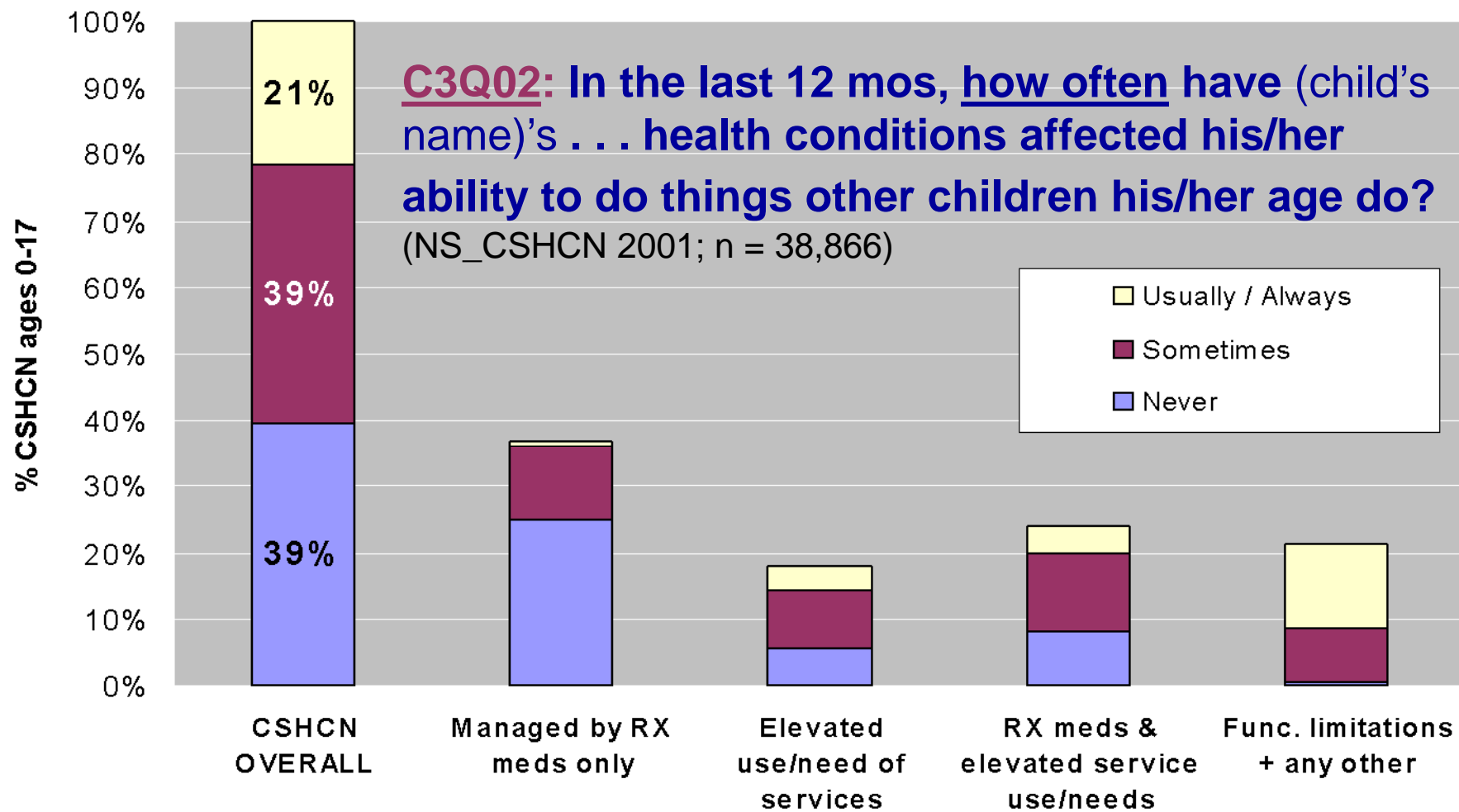
- Do you need an ordinal vs. categorical variable?
- Do you need variables included in all surveys in order to make across surveys comparisons?
- Keep purpose and end users in mind – How will results be used? By whom? For what purpose(s)?
- Consider the tradeoffs inherent in each method in terms of the 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

Using other survey information – either on its own or combined with screener information to stratify results by complexity, severity, or types of conditions

EXAMPLES:

- NS_CSHCN questions about how often and how much CSHCN's conditions affect their abilities and daily activities
- Condition checklists and/or parent-rated severity question included in NSCH

Parents evaluate and report on their children's abilities through a "strength-based" perspective – especially with relation to other children

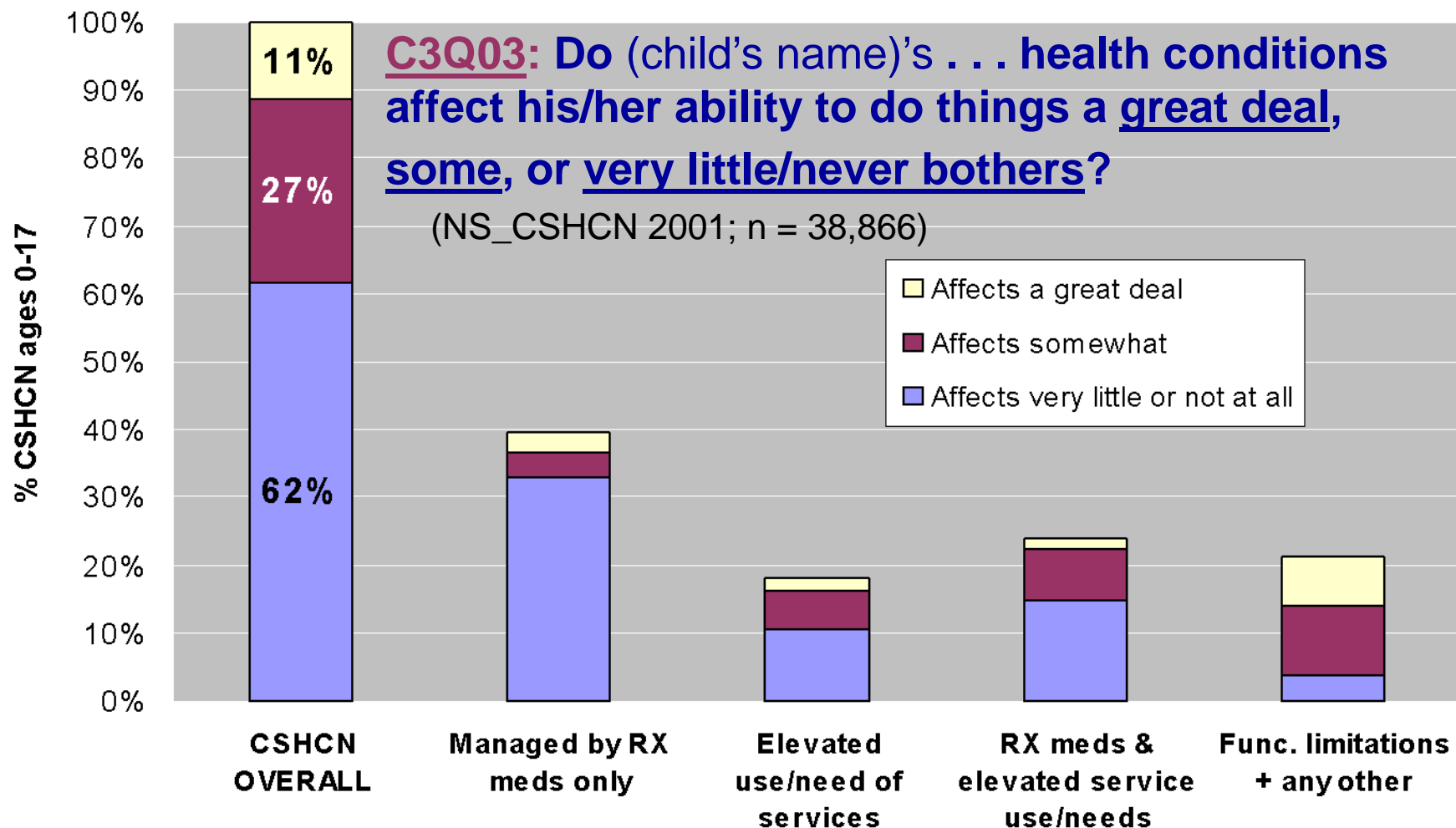


CSHCN grouped by types of health consequences based on qualifying screening criteria

..... take this into account when using parent-reports of children's abilities to stratify CSHCN by severity or complexity

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

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

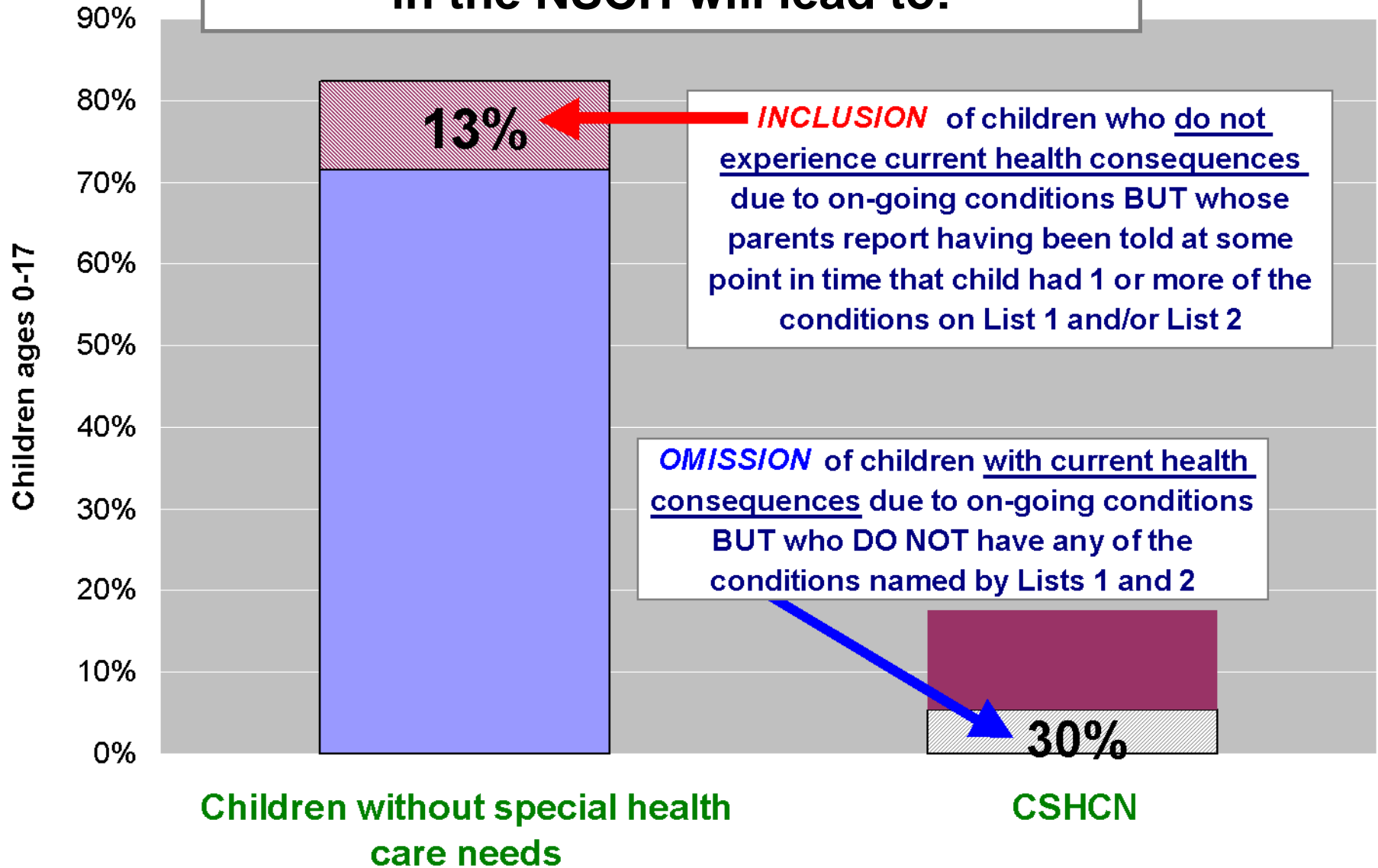
AND / OR

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

S2Q47: You said that [ch's name] has/had/has 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:



Development and testing of the CSHCN Screener

- Bethell CD, Read D, Neff J, Blumberg SJ, Stein REK, Sharp V, Newacheck P. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambulatory Pediatrics*. 2002;2:49-57.
- Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambulatory Pediatrics*. 2002;2:38-47.

More information

- readd@ohsu.edu
- bethellc@ohsu.edu
- www.cshcndata.org

