

# Identifying Children & Youth with Special Health Care Needs for the National Survey of CSHCN

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# **Part 1:**

## **Identifying Children & Youth**

**with Special Health Care  
Needs for the**

**National Survey of CSHCN**

# KEY questions:

- How are special health care needs defined?
- What method is used to identify children who meet this definition?
- Who is identified by the screening method used?

# The “Challenges”

- **CYSHCN 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**



# Implications

- **CYSHCN vary widely**
  - Have to be very specific about whom you want to identify and WHY.....
- **No perfect method**
  - All methods miss some children and mis-identify others (false negatives vs. false positives)
  - Always tradeoffs! (finding a robust group vs. not missing anyone)
- **No “gold standard”**
  - ‘Gray area’ group will always be a factor

# KEY questions:

- How are special health care needs defined?



# 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**

**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**

# KEY questions:

- What method is used to identify children/youth who meet the MCHB definition?



# *Finding children/youth who meet the MCHB definition – HOW?*

- **Ask parents if child has “special health care needs”?**
  - Not as simple or reliable as it sounds!
  - Misses or mis-identifies many children b/c too vague
  - Parents reluctant to “label” their children
- **Ask parents to name children’s diagnoses / conditions?**
  - Not as simple or reliable as it sounds!
  - Diagnostic checklists are too limited to cover vast numbers & types of childhood chronic conditions
  - Misses children are not yet diagnosed or whose parents do not know or recall specific dx’s



# *Finding children/youth who meet the MCH definition – HOW?*

## **CSHCN Screener**

- A set of **well-tested, standardized questions** used in the National Survey of CSHCN to identify children who meet the MCH definition
- **Non-categorical** approach --- uses **health consequences** currently experienced by child to identify special needs; not specific diagnoses or disabilities
- Focuses on the health consequences research shows are **MOST likely to indicate** special health care needs



# 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

## 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?

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

# 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*

# CSHCN Screener

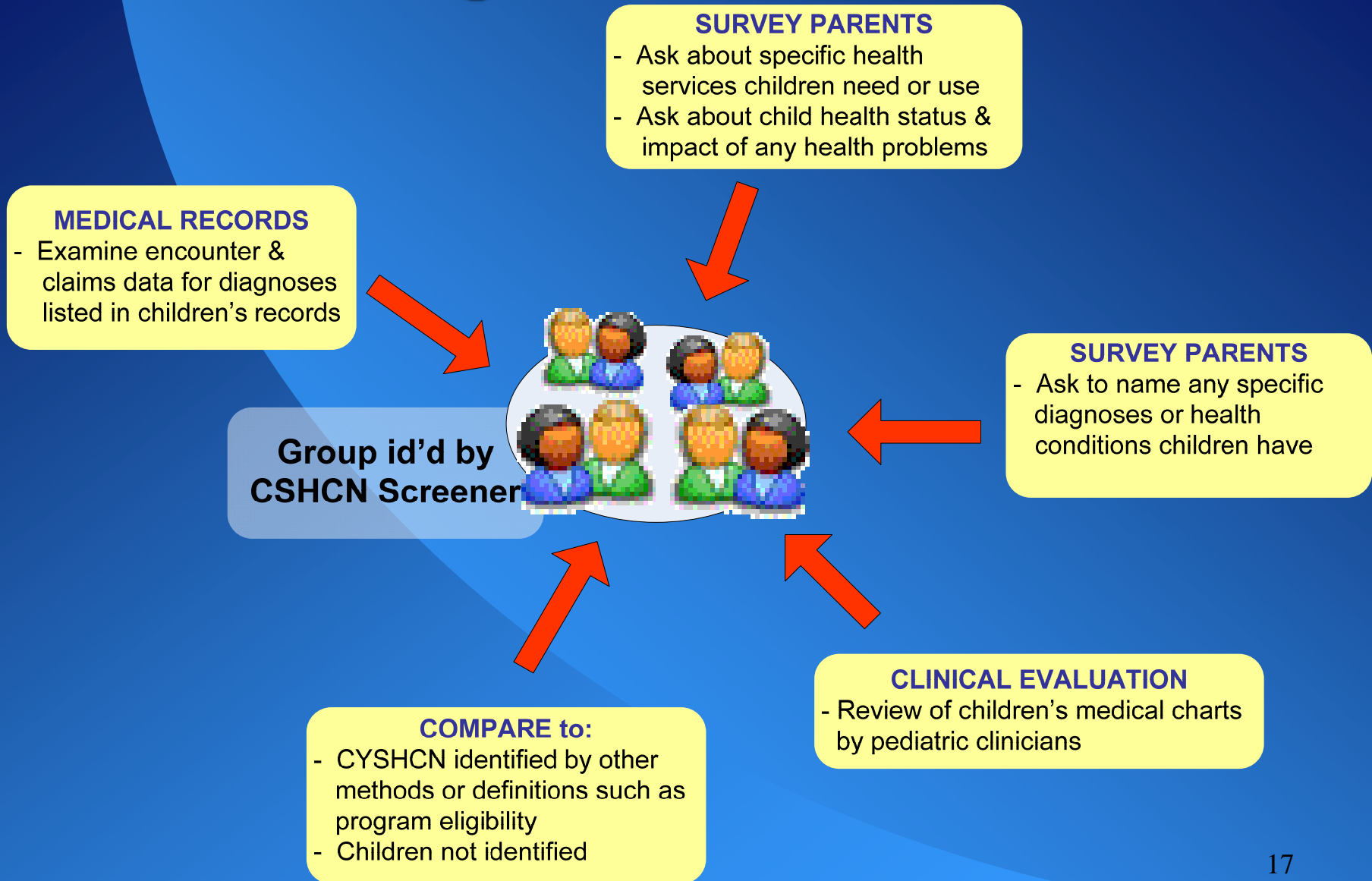
- **Developed through a national process** involving state leaders, families, experts, and policymakers
- **Over 36,000 children / youth screened** during development & testing phases
- **Several versions tested,** leading to final screener

# KEY questions:

- Who is **identified by the CSHCN Screener** ..... (how do we know we found the group we want to identify?)



# NO GOLD STANDARD? “Triangulate” to Validate



# Agreement with Other Definitions & Methods

Parent survey of children 0- 12 yrs old receiving SSI benefits (n = 1583)

**95%** identified by CSHCN Screener\*

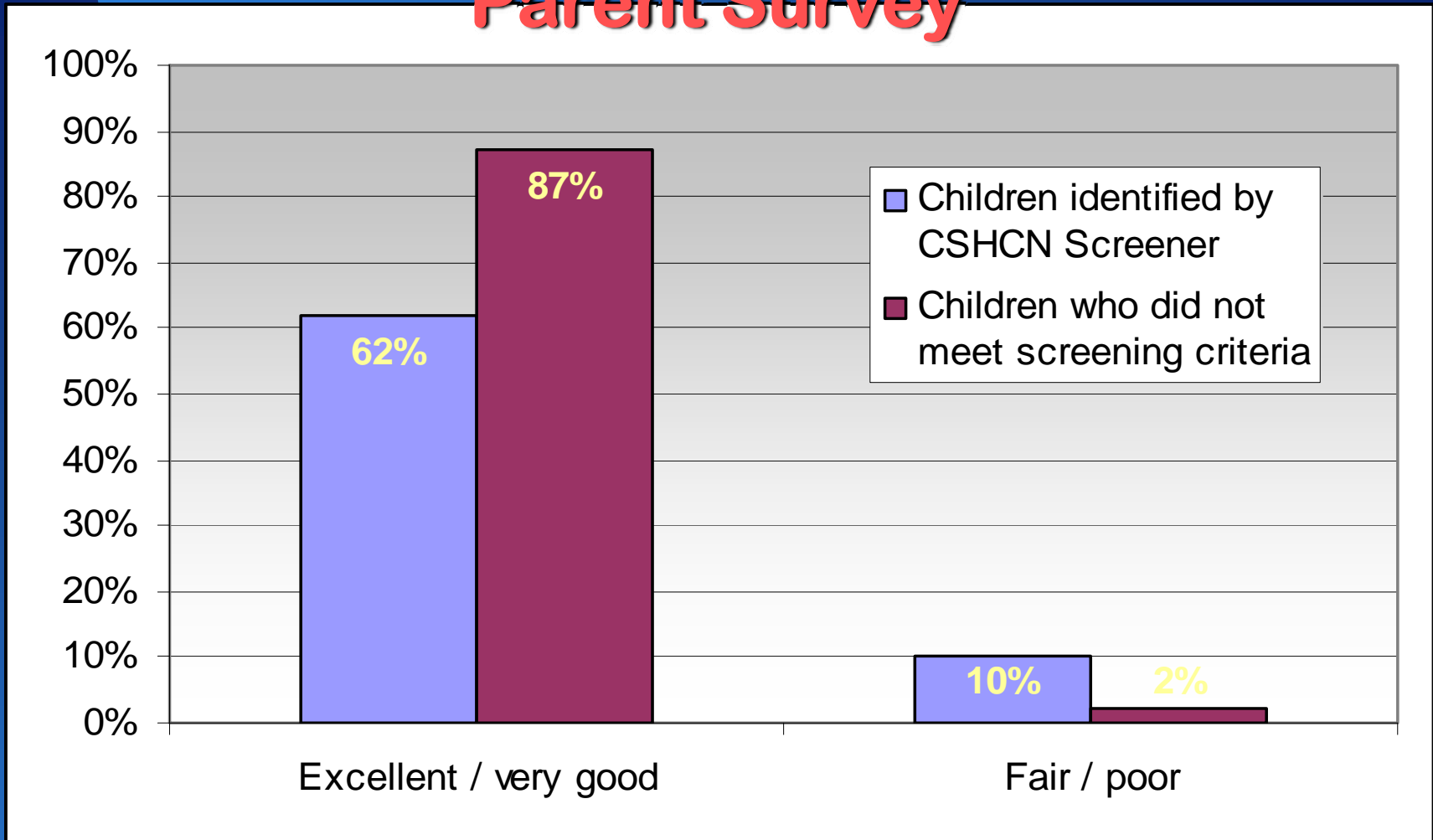
Other non-categorical or consequences-based methods:

**Agree with CSHCN Screener 9 out of 10 times<sup>\*/\*\*</sup>**

\* WA State Medicaid Pilot Study, CAHMI 2000 \*\* Nat.Sur.CSHCN / Pretest I 2000

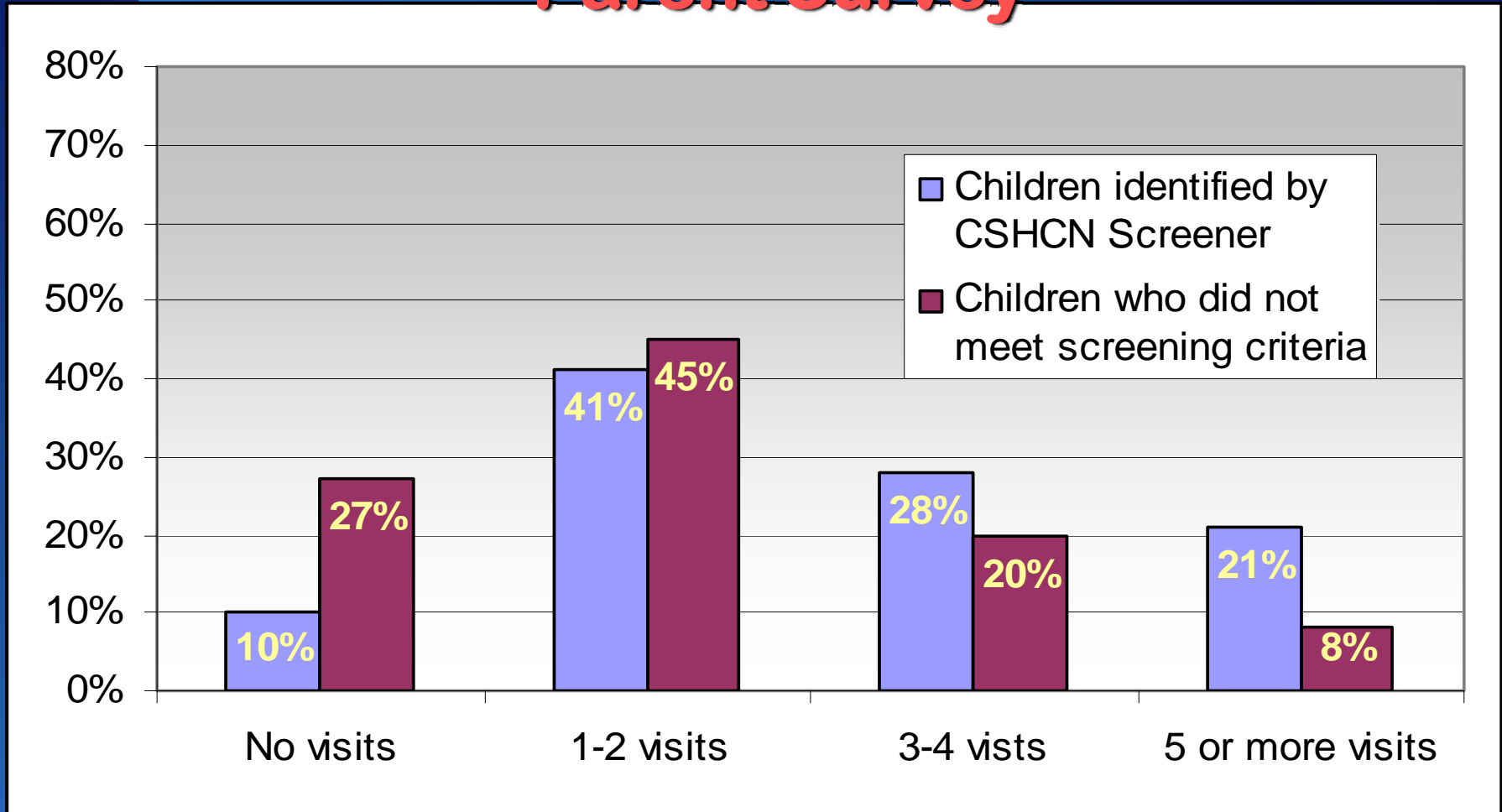


# Comparison with Group NOT Identified by CSHCN Screener – Parent Survey



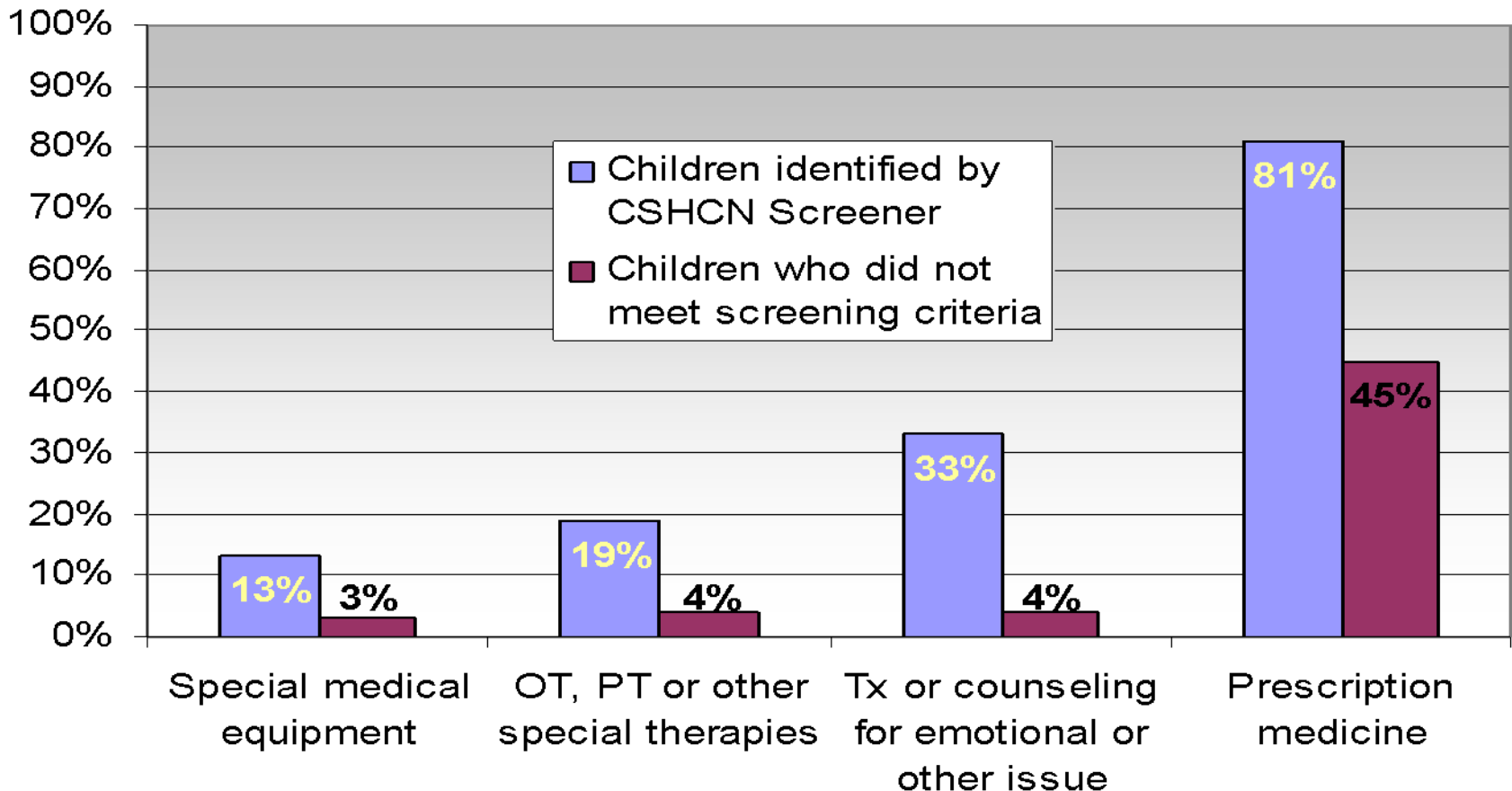
Parents'-rating of their children's overall health

# Comparison with Group NOT Identified by CSHCN Screener – Parent Survey



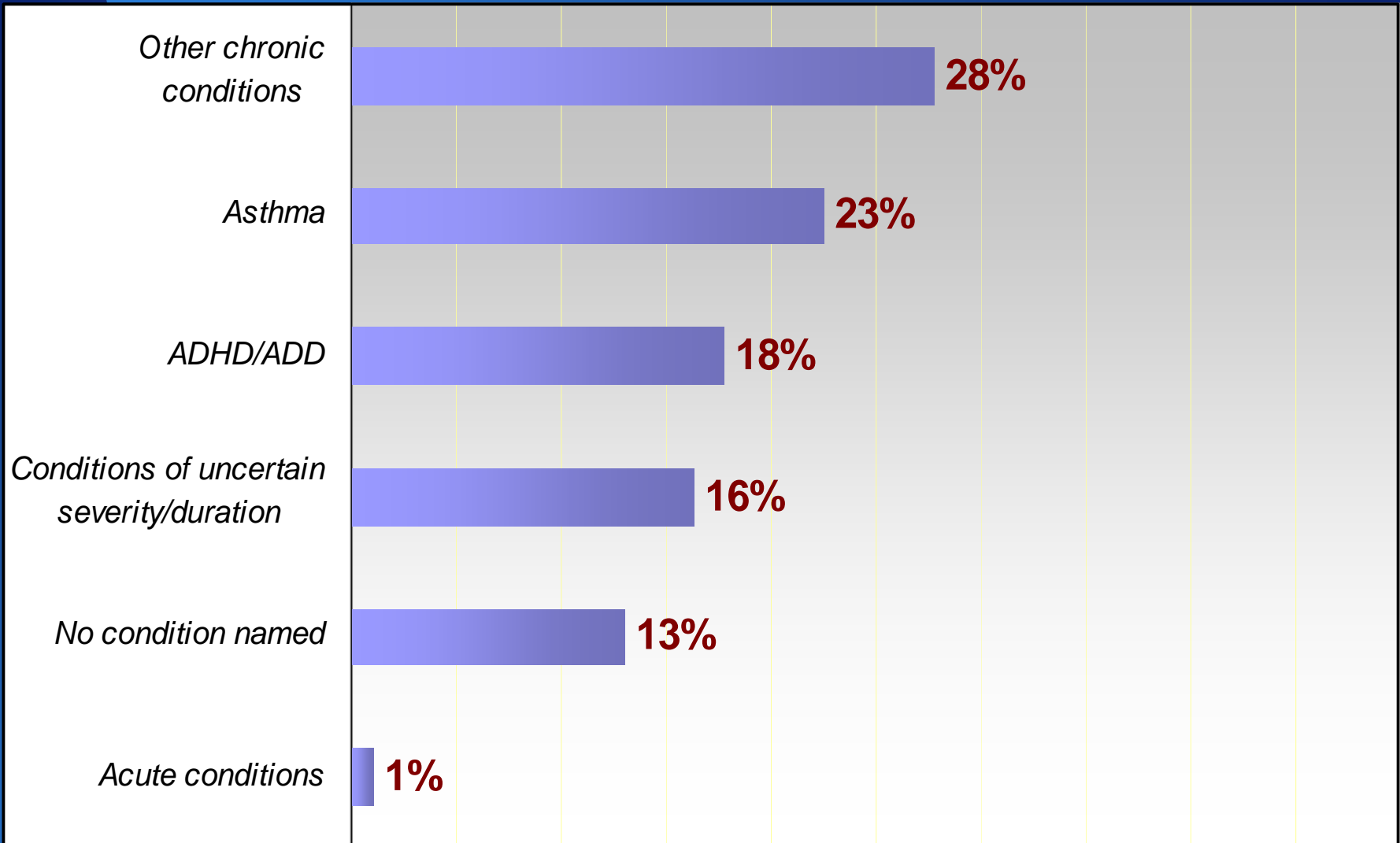
**Number of times children went to doctor's office or clinic during past 6 months**

# Comparison with Group NOT Identified by CSHCN Screener – Parent Survey



**Parent-report of health services needed or used by children during past 6 months**

# Parent-named conditions for group identified by CSHCN Screener



# Examples of Health Conditions Named by Parents

## ***“Other chronic conditions”***

- Spina bifida, autism, depression, seizure disorders, Down syndrome, limited hearing, eating disorder, PTSD, cerebral palsy, leukemia, diabetes, muscular dystrophy .....

## ***“Conditions of uncertain severity/duration”***

- Migraines, mental health issues, dyslexia, anger/behavioral problems, acne, allergies, “lazy eye”, ear infections, emotional problems, “unable to spell or pronounce problem” .....

# SUMMARY

**Based on parent survey data, children/youth identified by the CSHCN Screener are DIFFERENT in important ways from those not identified:**

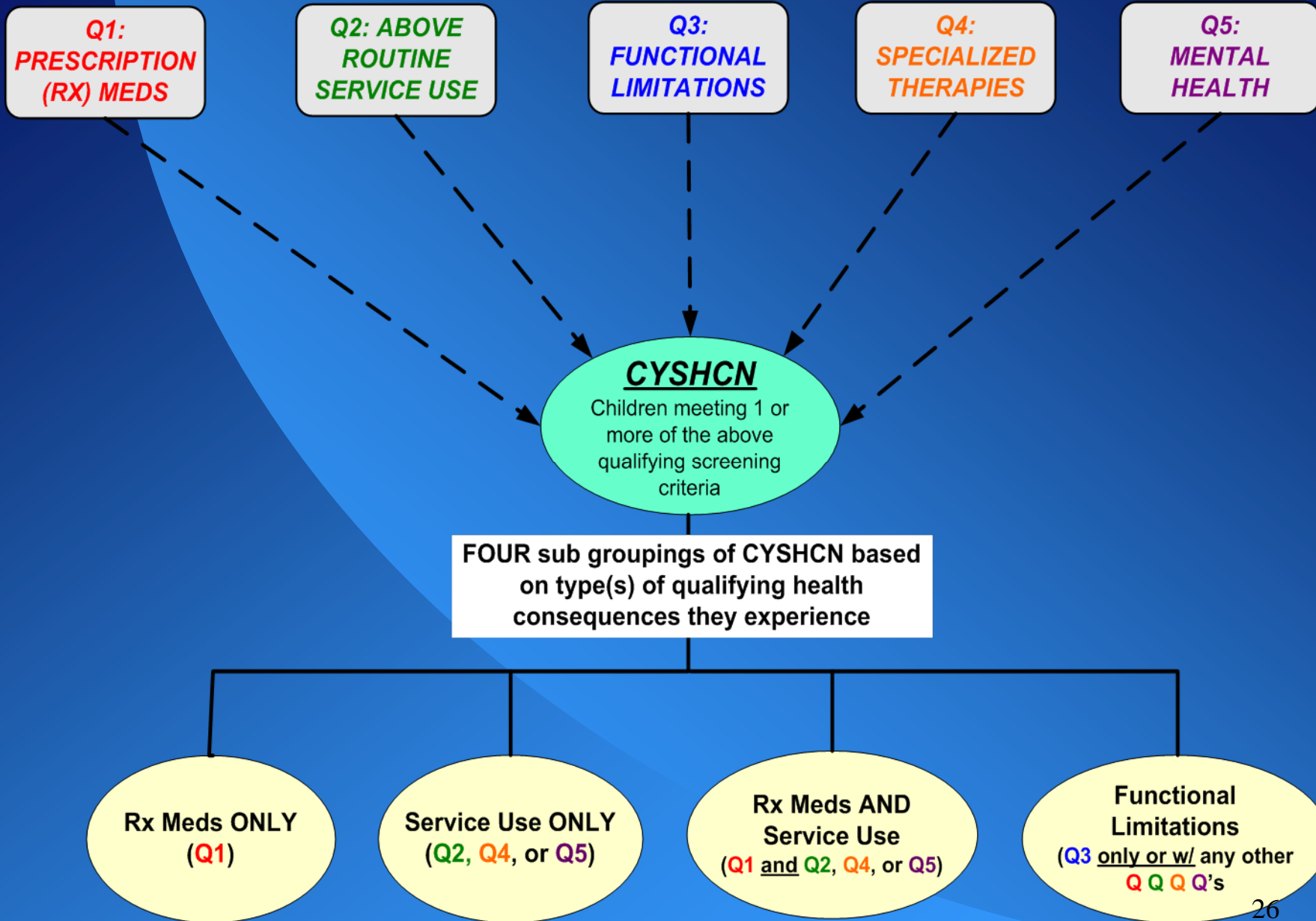
- **Poorer** overall health status
- **Much more likely** to both have gone to a doctor and to have visited more frequently
- Need/use **dramatically more** health-related services and/or prescription medicines
- Parents name **one or more childhood conditions** of the type, complexity and duration likely to produce the health consequences used as non-categorical screening criteria

# “Wait a MINUTE”! question

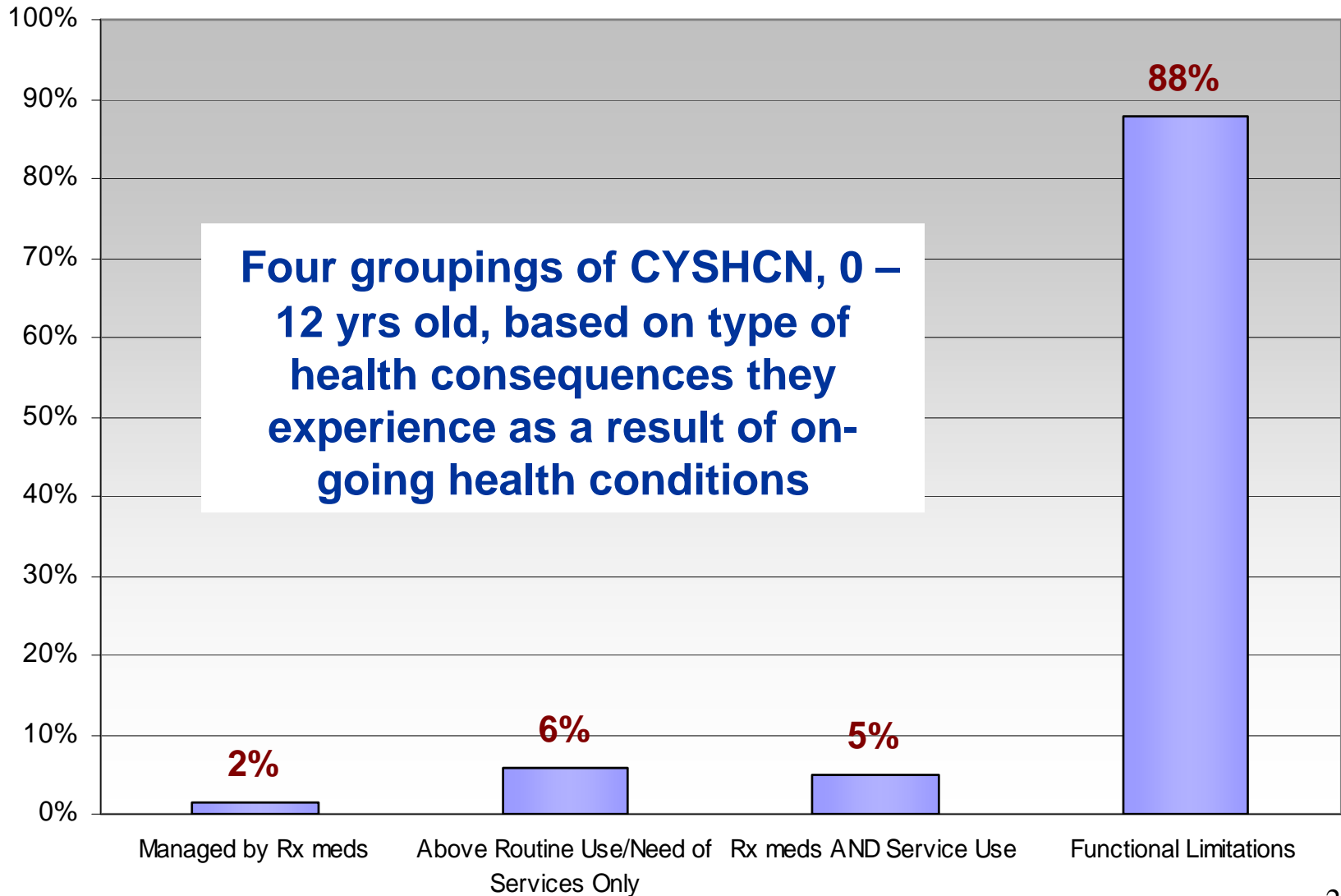


- Remember the **special needs continuum** -- CYSHCN are a varied group
- Can the CSHCN Screener results be used to identify subgroups of CYSHCN's whose **needs are more complex or extensive?**

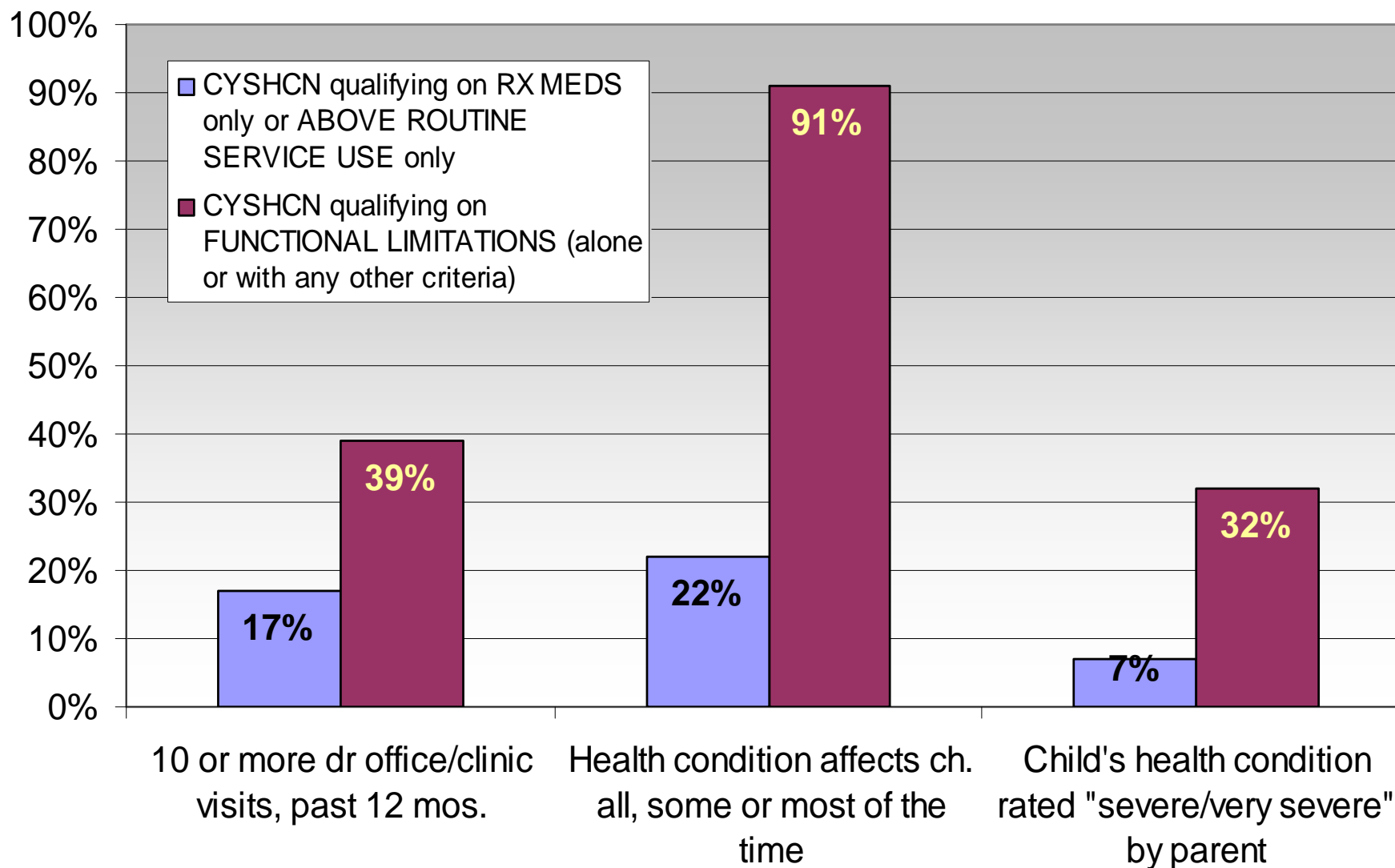




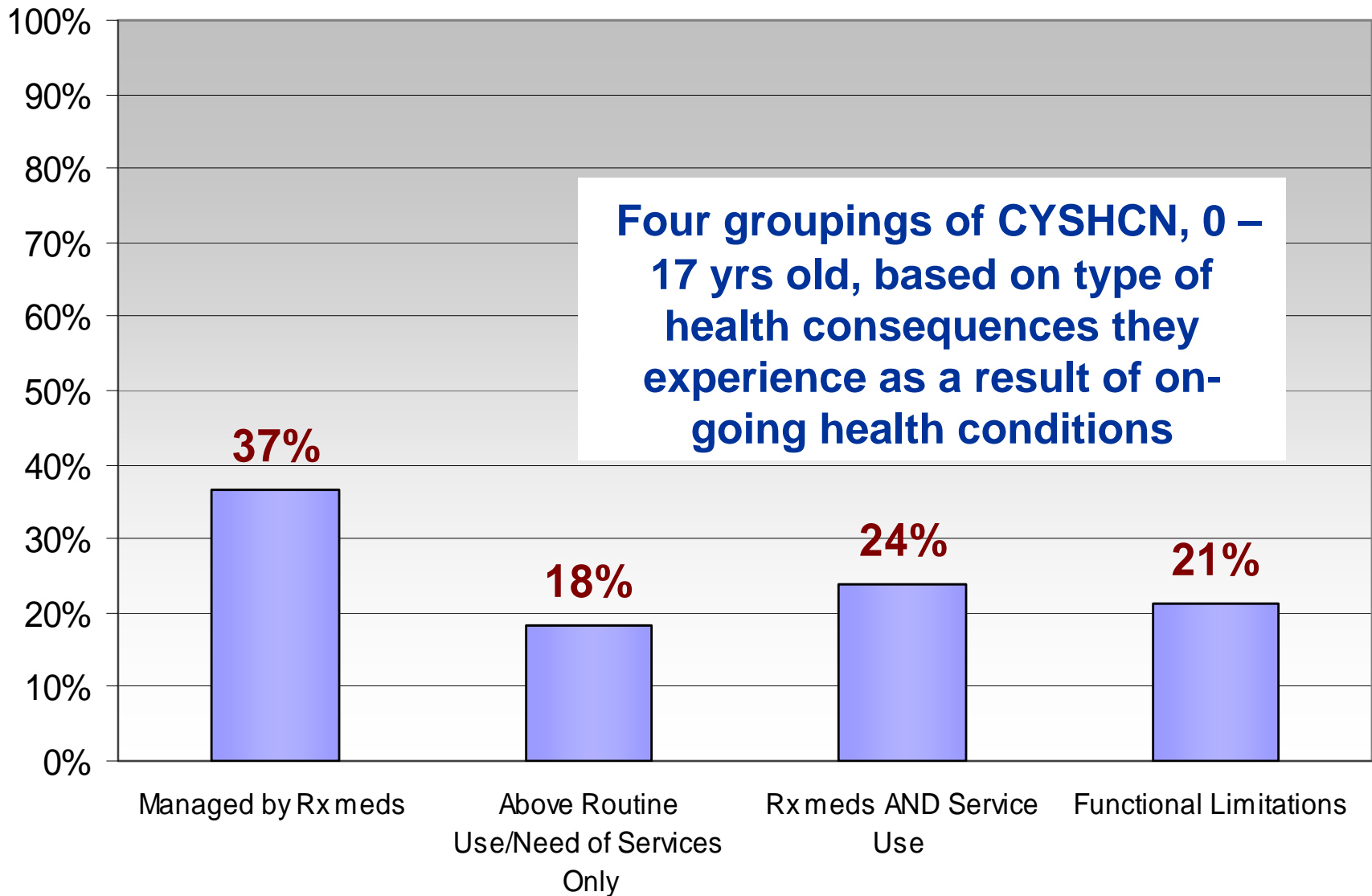
# CYSHCN Subgroups – Children (0-12yrs) receiving SSI disability benefits – Parent Survey (n = 1,493)



# CYSHCN Subgroups – Parent Survey



# CYSHCN Subgroups – National Survey of CSHCN (n = 48,690)



## Part 2:

Describing CYSHCN  
identified by the CSHCN  
 Screener Using Clinical  
Data

# Data Available for Clinical Review

- Health plan enrollment & encounter data, CY 1996, 1997, 1999
- Pharmacy claims for CY 1999
- Chart Reviews on child's PCP clinic charts for 391 children, conducted in 2000
- All available data for 897 sampled children merged into an Access database for easy review by physicians



# Physician Evaluation-1

Summary  
Category:

2

Attention Deficit Disorder

Child also on an inhaler for asthma and has eczema

Specific conditions identified:

Chronic?

2

ADD, ADHD



1

Asthma & related



16N

Other





# Physician Evaluation-2

## MCHB Definition Evaluation:

Dimension	present	at risk?	last 12+ months	requires services
Physical:	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Developmental:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral:	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Emotional:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

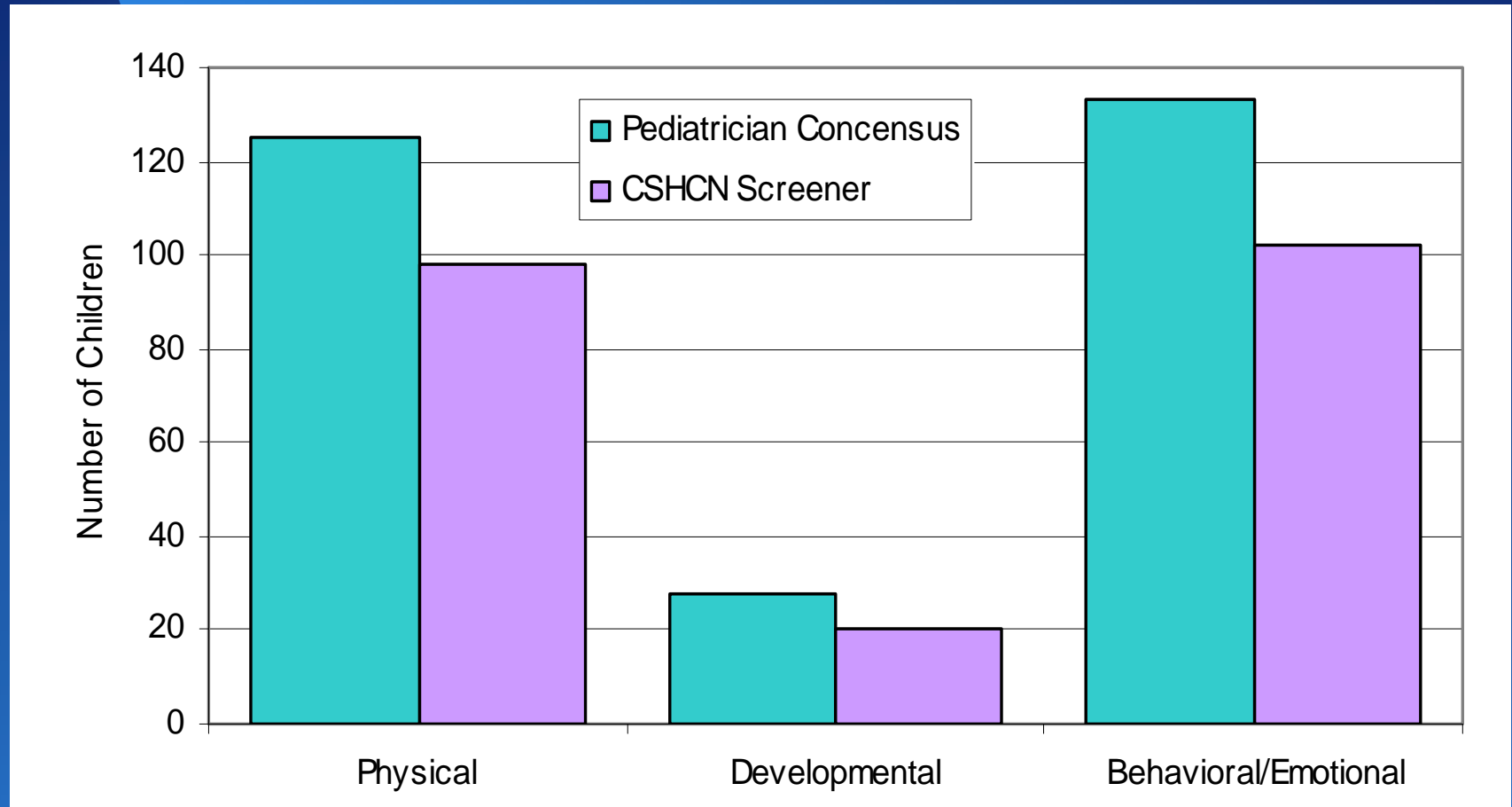
Does child meet MCHB definition, including "at risk"?



# Resultant Clinical Evaluations

- **MCHB Definition**
  - **Definitely/Possibly CYSHCN vs. At Risk vs. Not CYSHCN**
  - **Physical &/or Developmental &/or Behavioral/Emotional [combined]**
- **Condition-specific**
  - **Have only included PRIMARY condition identified**

# Clinical Evaluation vs. CSHCN Screener by MCHB Definition

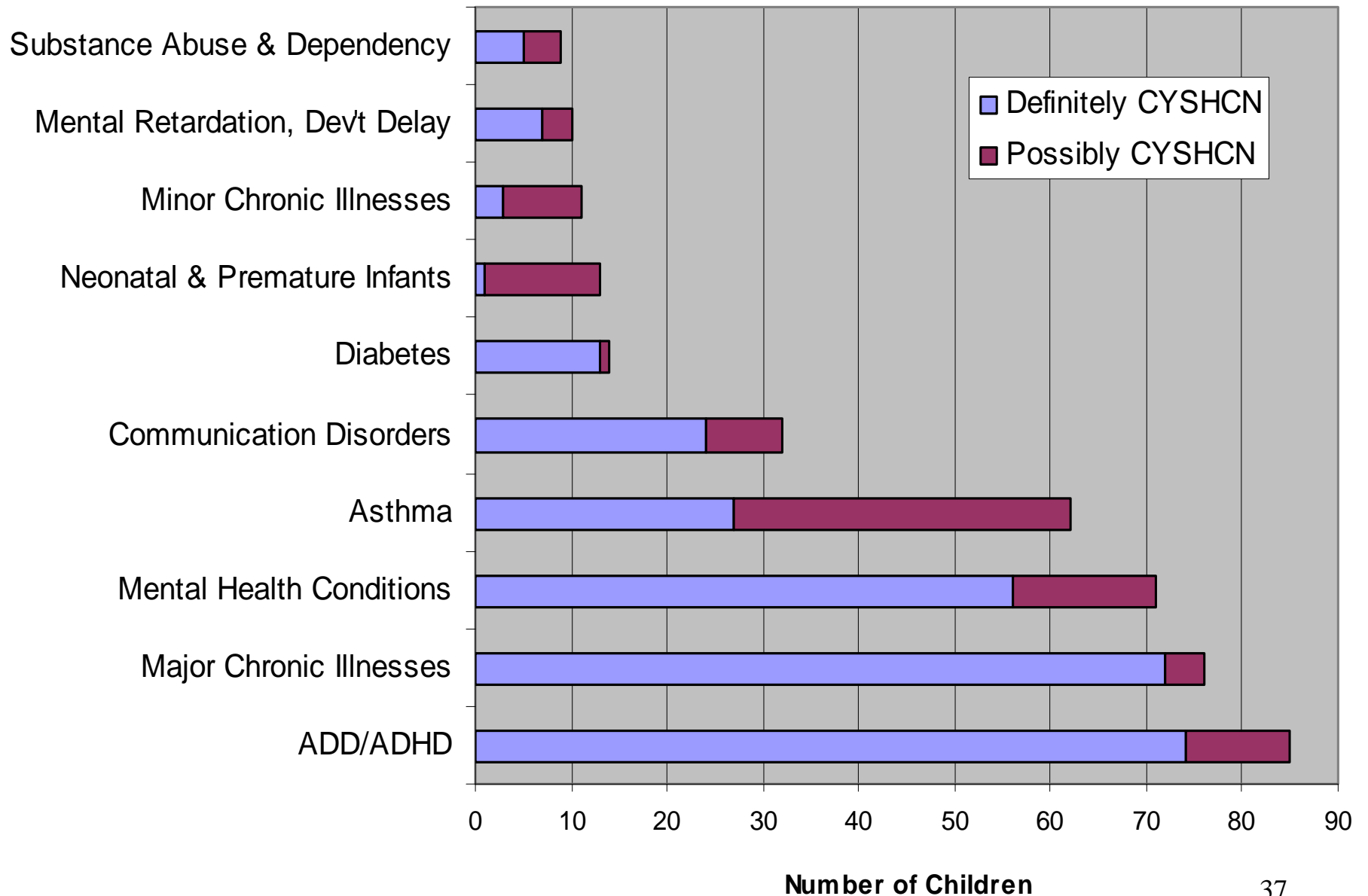


N = 897 convenience sample

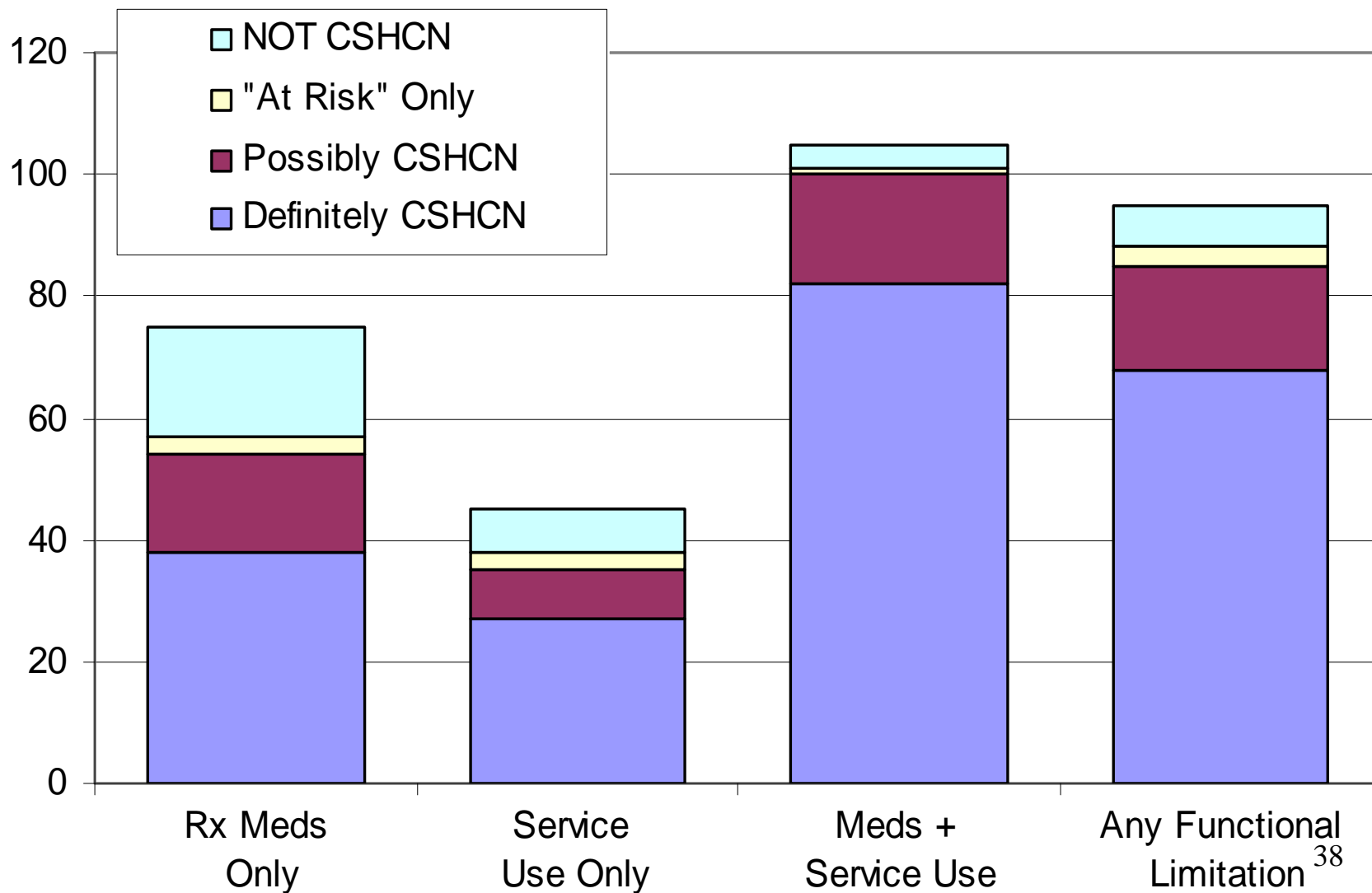
# Clinical CYSHCN Identification

- **No special need identified** **468**
- **Identified as “At Risk” by either or both doctors** **42**
- **One doctor identified as “special need” [Possibly CYSHCN]** **105**
- **Both doctors identified as “special need” [Definitely CYSHCN]** **282**

## Principal Diagnoses of CYSHCN, Physician Definition



# CSHCN Screener vs. Clinical Evaluations, by Screener Subgroup





# Clinically-Defined Conditions by CSHCN Screener Subgroup

- Rx Meds Only:
  - 41% Asthma
  - 16% ADHD
  - 16% Major Chronic
  - 9% Mental Health
- Service Use Only
  - 30% Major Chronic
  - 19% Commun. Dx
  - 19% Mental Health
  - 14% ADHD
- Rx Meds + Service Use
  - 45% ADHD
  - 15% Major Chronic
  - 12% Mental Health
  - 11 % Asthma
- Any Functional Limitation
  - 29% Major Chronic
  - 18% ADHD
  - 18% Mental Health
  - 14% Asthma



# CYSHCN Identified by Doctors but not by Parents (n=111)

- 28% Mental Health Conditions
- 15% Communication Disorders
- 14% Major Chronic Illness
  - 6 of 15 = Congenital Heart Disease
- 12% Asthma
- 9 of 11 Neonatal/Premature Infants

# Conclusions....

- **There is clearly no one “right” way to identify CYSHCN**
- **The CSHCN Screener identifies virtually all of the “sickest” kids, i.e. those using health services**
- **Stratifying the CSHCN Screener into the suggested Subgroups is clinically meaningful & provides an appropriate grouping related to condition complexity**

# More information

- [www.facct.org/cahmi.html](http://www.facct.org/cahmi.html)
- [debra.read@kpchr.org](mailto:debra.read@kpchr.org)
- [www.cshcndata.org](http://www.cshcndata.org)

