

**Identifying Children with Special Health Care Needs:
The Linguistic and Cultural
Validity of the CSHCN Screener**

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Acknowledgements

- **Debra Read** (Oregon Health and Science University)
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Changing Terminology

- Crippled children
- Handicapped children
- Disabled children
- Children with special health care needs
and youth

Definition of “Children with Special Health Care Needs”

- “Children with special health care needs are those who have or are at increased risk for 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.” (McPherson, Arango, Fox, et al., 1998)

Key Concepts in CSHCN Definition

- **Includes children “at risk”**
- **Goes beyond physical conditions**
- **Does not name specific conditions**
- **Limits definition to chronic conditions**
- **Identifies consequences of conditions**

Problems with Condition Lists

- **Inability to list every disorder**
- **Inconsistent application of diagnoses across clinicians and settings**
- **Bias toward identifying children with better access to health care**
- **Miss children with symptoms that emerge before diagnoses are made**
- **Lack information about extent of morbidity for any individual**

Benefits of Consequence-Based Measurement Approach

- **Increases the probability of identifying children with ongoing health conditions who:**
 - Are not yet formally diagnosed
 - Have conditions that are less likely to be recalled or acknowledged by name
- **Permits the identification of CSHCN in surveys of parents using a brief screening tool**

The CSHCN Screener

- **Five consequences**

1. Limitation of activities
2. Need for or use of prescription medication
3. Need for or use of specialized therapies
4. Above routine need or use of medical, mental health, or education services
5. Need for or receipt of treatment or counseling for an emotional, behavioral, or developmental problem

(Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002)

The CSHCN Screener

- **Two follow-up questions**
 1. Is this due to a medical, behavioral, or other health condition?
 2. Is this a condition that has lasted or is expected to last 12 months or longer?

(Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002)

Who is Identified by the CSHCN Screener?

- **All or nearly all children with complex health conditions such as:**
 - Cerebral palsy; muscular dystrophy; epilepsy
 - Rare metabolic or genetic disorders
 - Mental retardation; developmental delay; autism
 - Sickle cell anemia; Down Syndrome; diabetes
- **Only those children whose asthma, ADHD, allergies, or other conditions result in...**
 - Above routine need/use of services, long-term use of prescription medicine, or limitations in functioning

National Survey of Children with Special Health Care Needs, 2005-2006

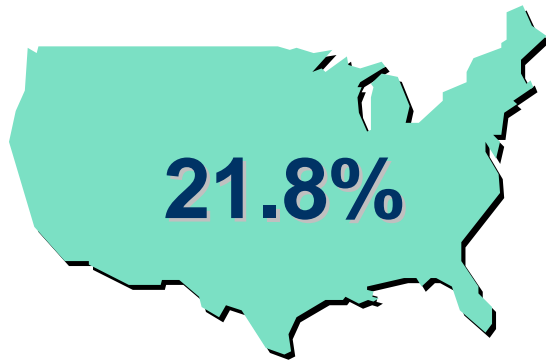
- **Sponsor:** The Maternal and Child Health Bureau
- **Purpose:** To produce national and State-based estimates of the prevalence and impact of special health care needs among children 0-17 years of age
- **Sample:** Independent random-digit-dial samples for all 50 States and the District of Columbia (DC)
- **Screening:** From 192,083 households with children, 364,841 children were screened for special needs
- **Interviews:** Completed interviews for approximately 800 CSHCN in each State (40,465 CSHCN nationally)
- **Languages:** Interviews completed in English, Spanish, Mandarin, Cantonese, Korean, and Vietnamese
- **Response Rate:** 56%

Who are Children with Special Health Care Needs?

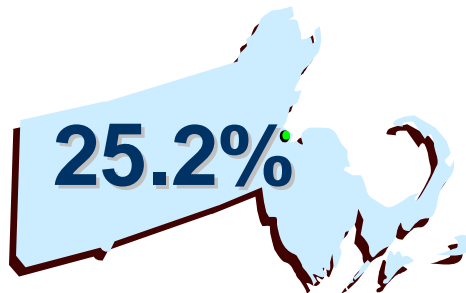
Population Prevalence Estimates

Prevalence Statistics

Proportion of households with children that include a child with special needs...



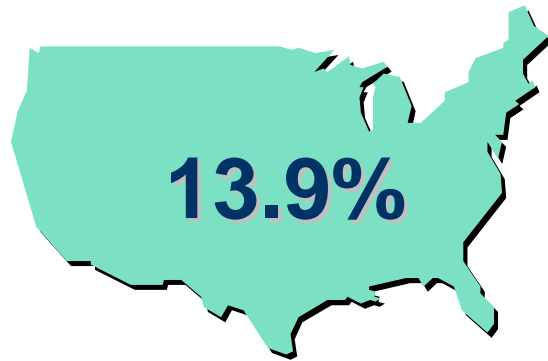
(Range: 16.5 – 26.7)



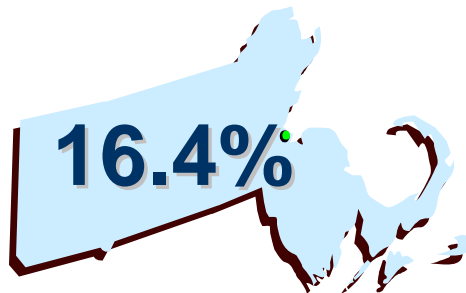
(Rank: Lower than 8 states)

Prevalence Statistics

Proportion of children who have special health care needs...

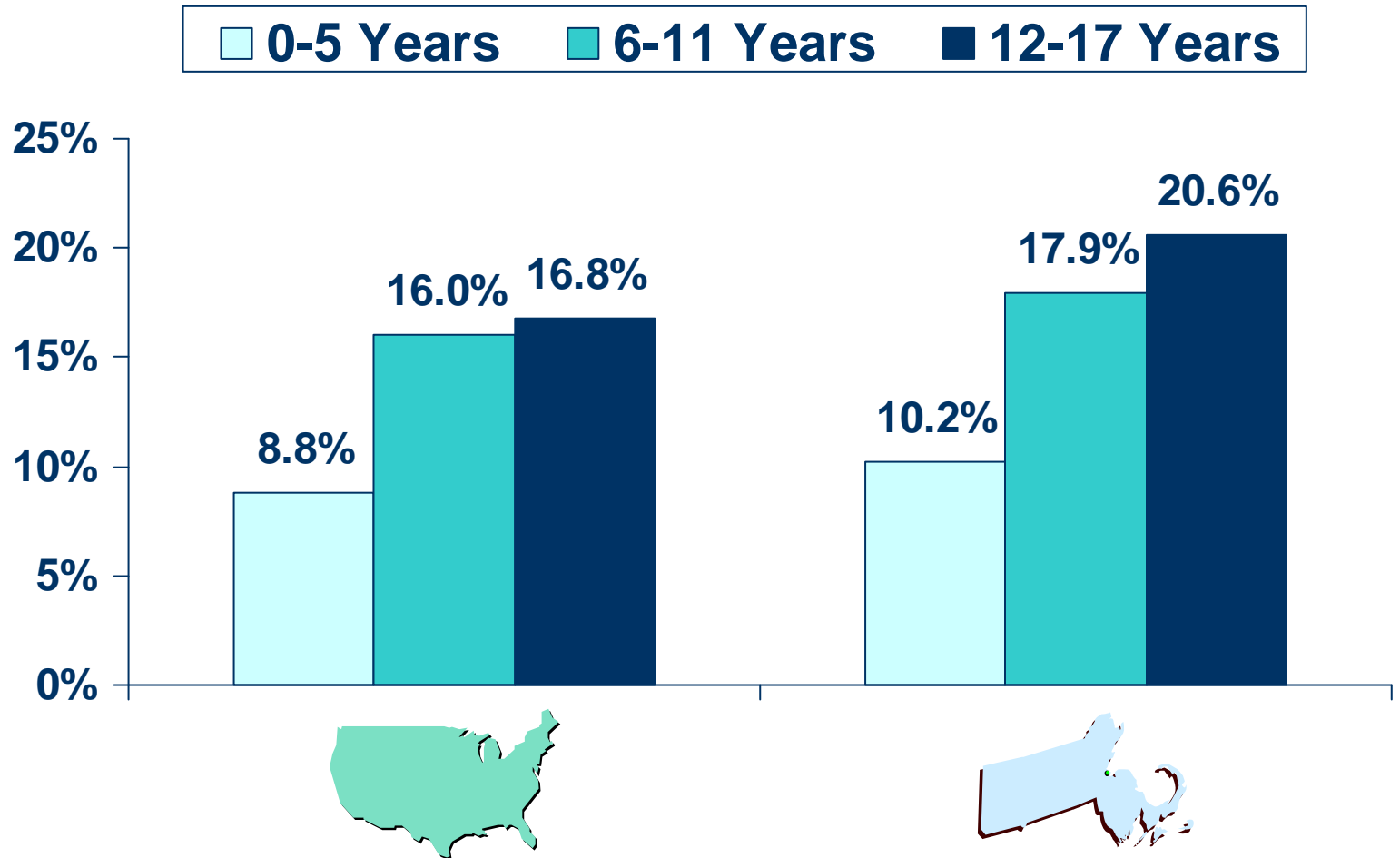


(Range: 9.9 - 18.5)

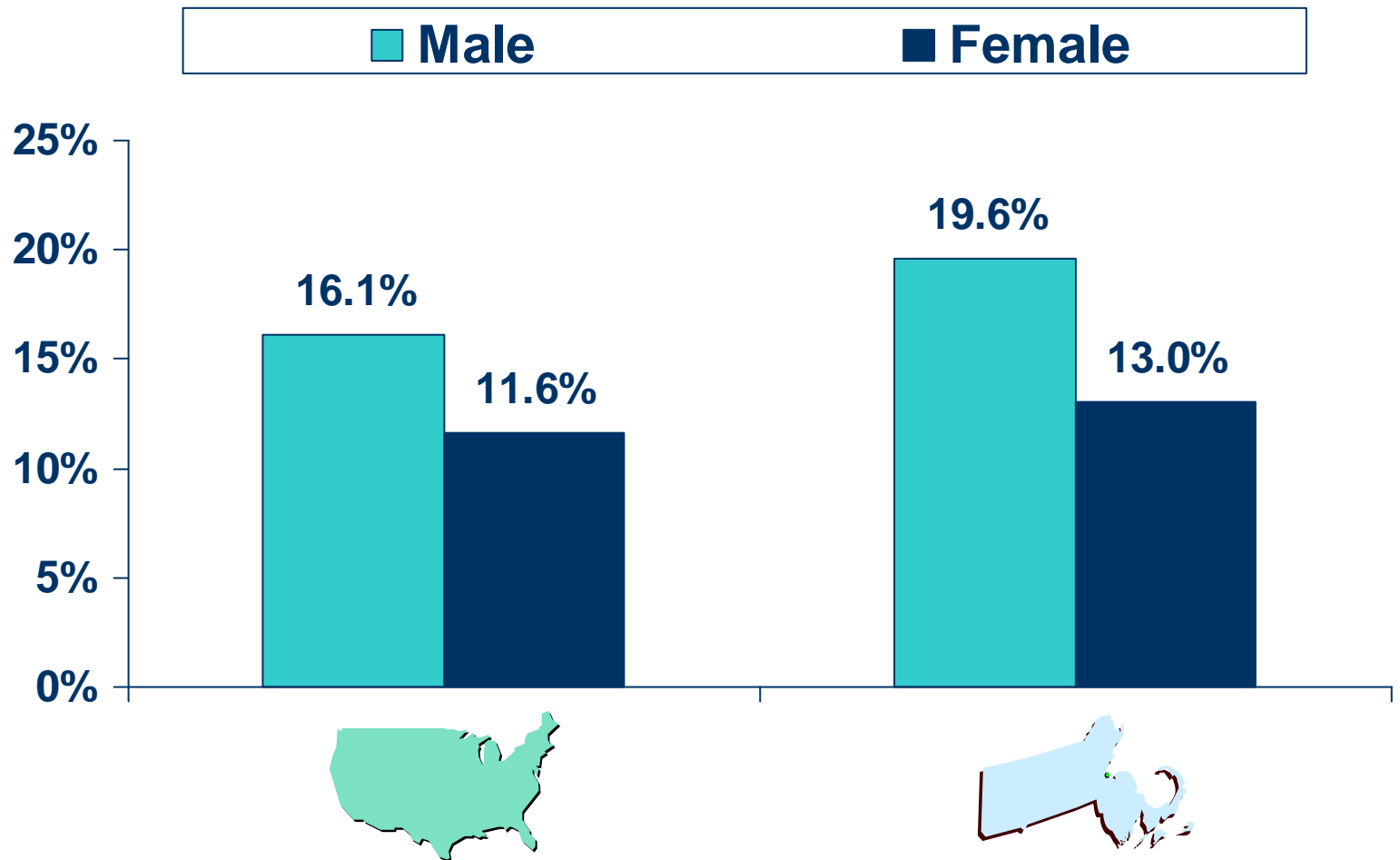


(Rank: Lower than 10 states)

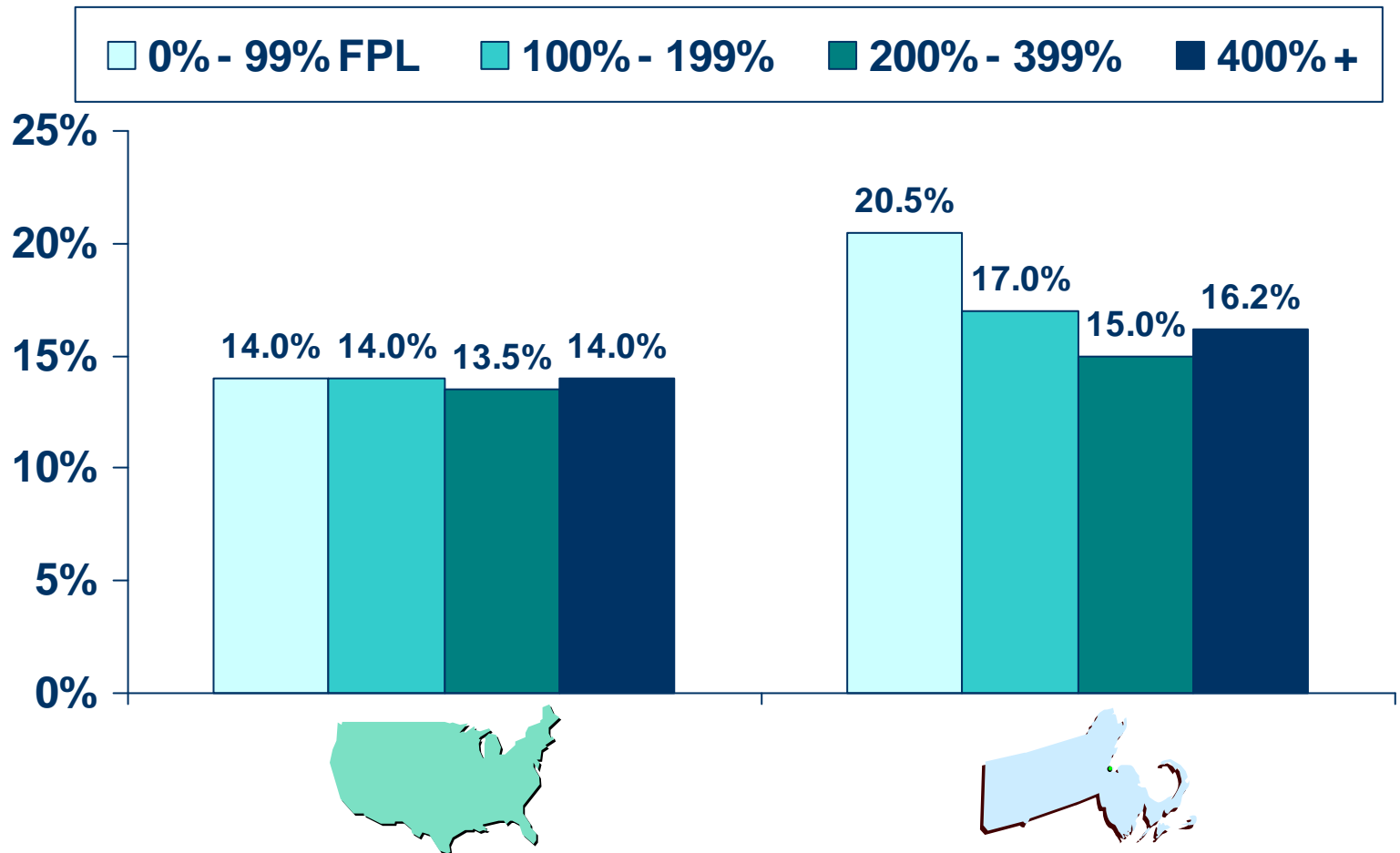
Prevalence by Age



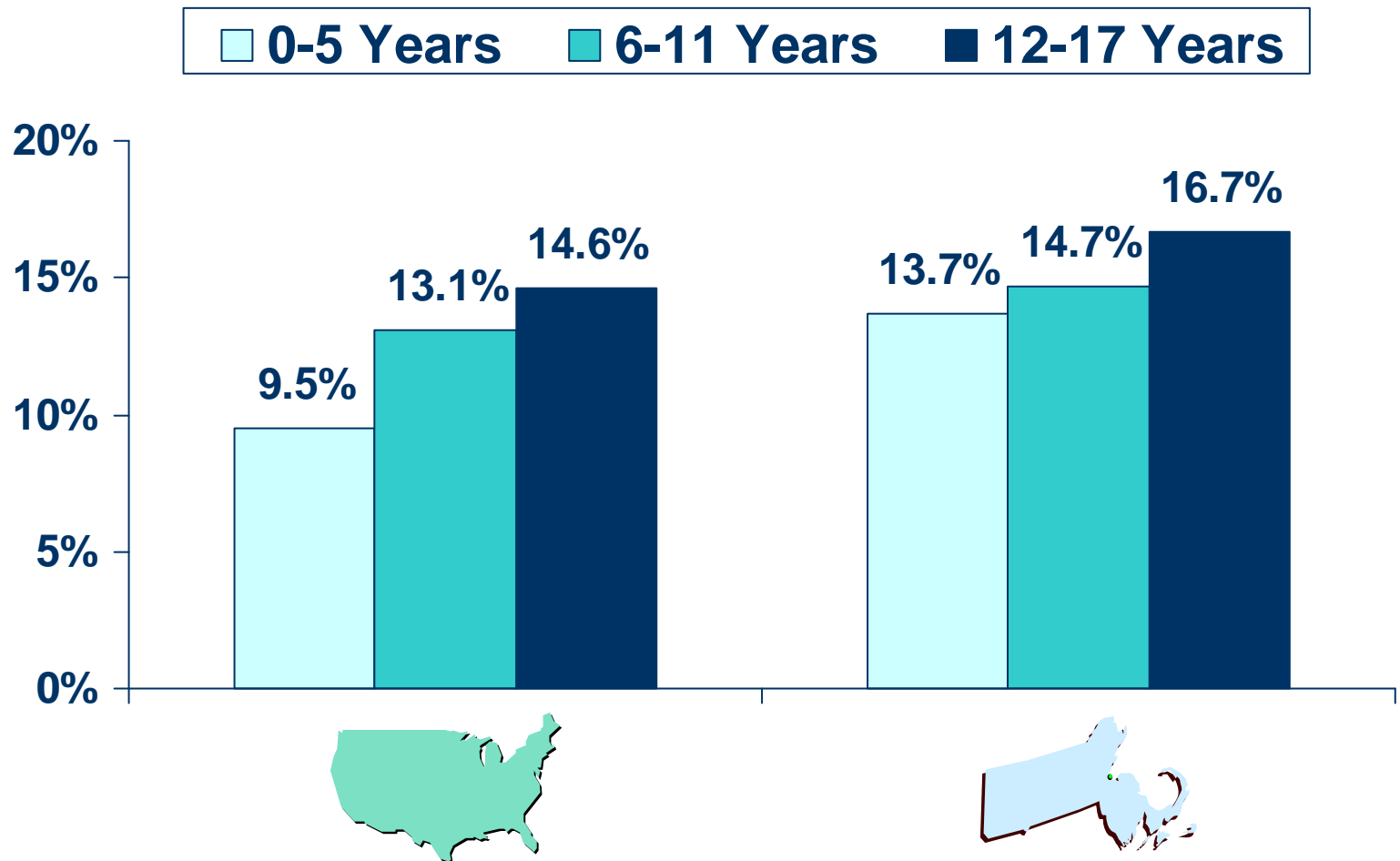
Prevalence by Sex



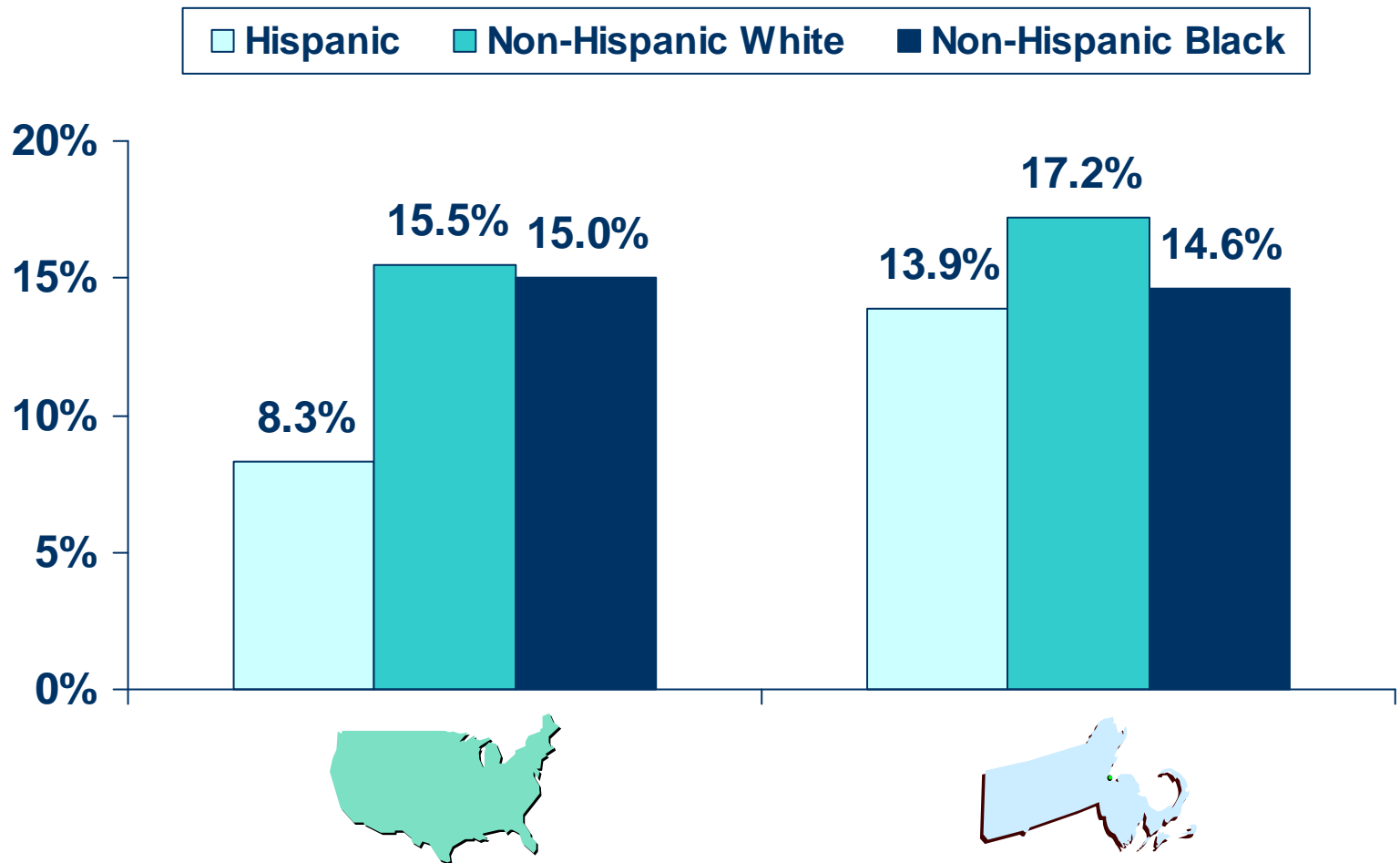
Prevalence by Poverty Level



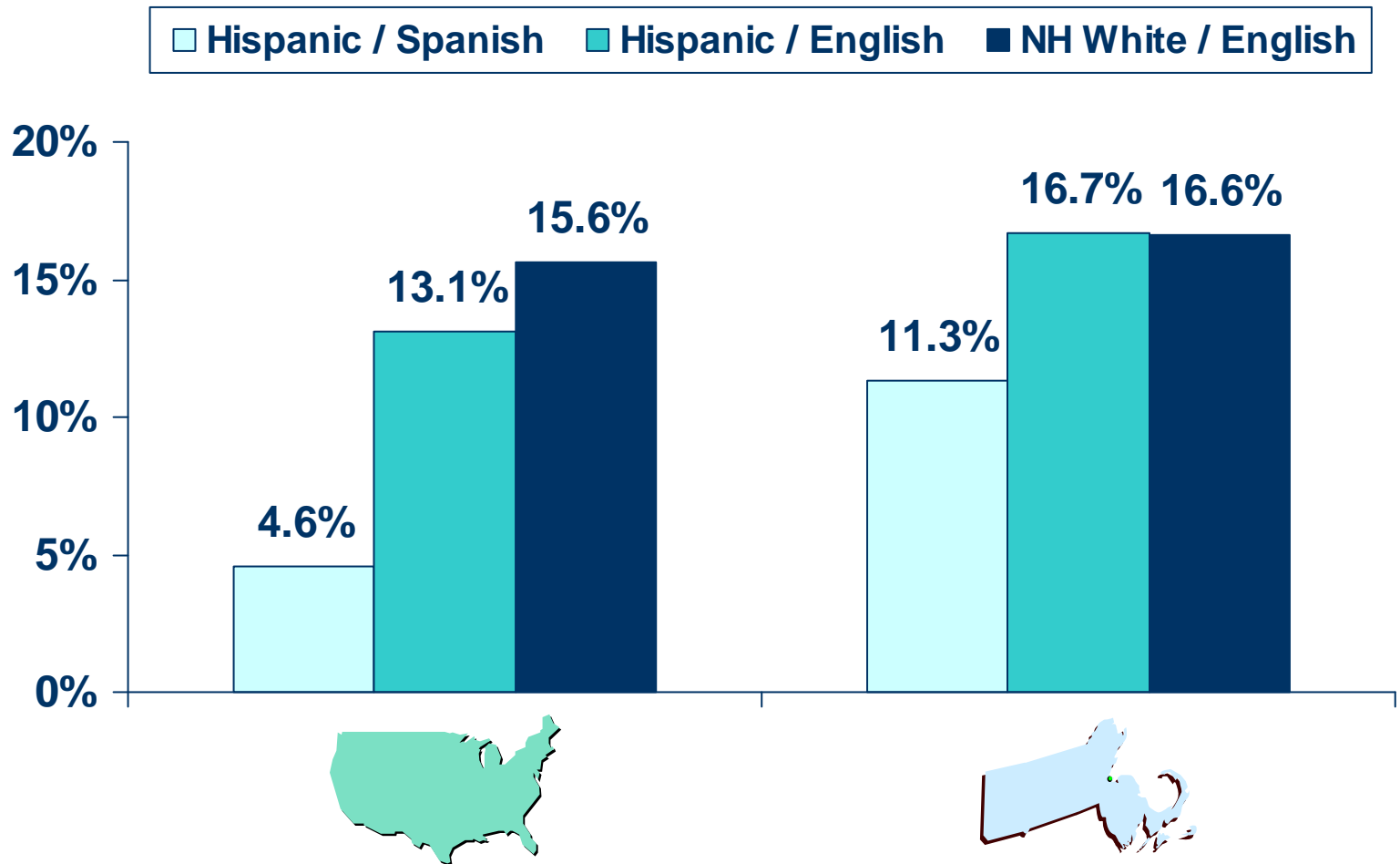
Prevalence by Highest Education in Household



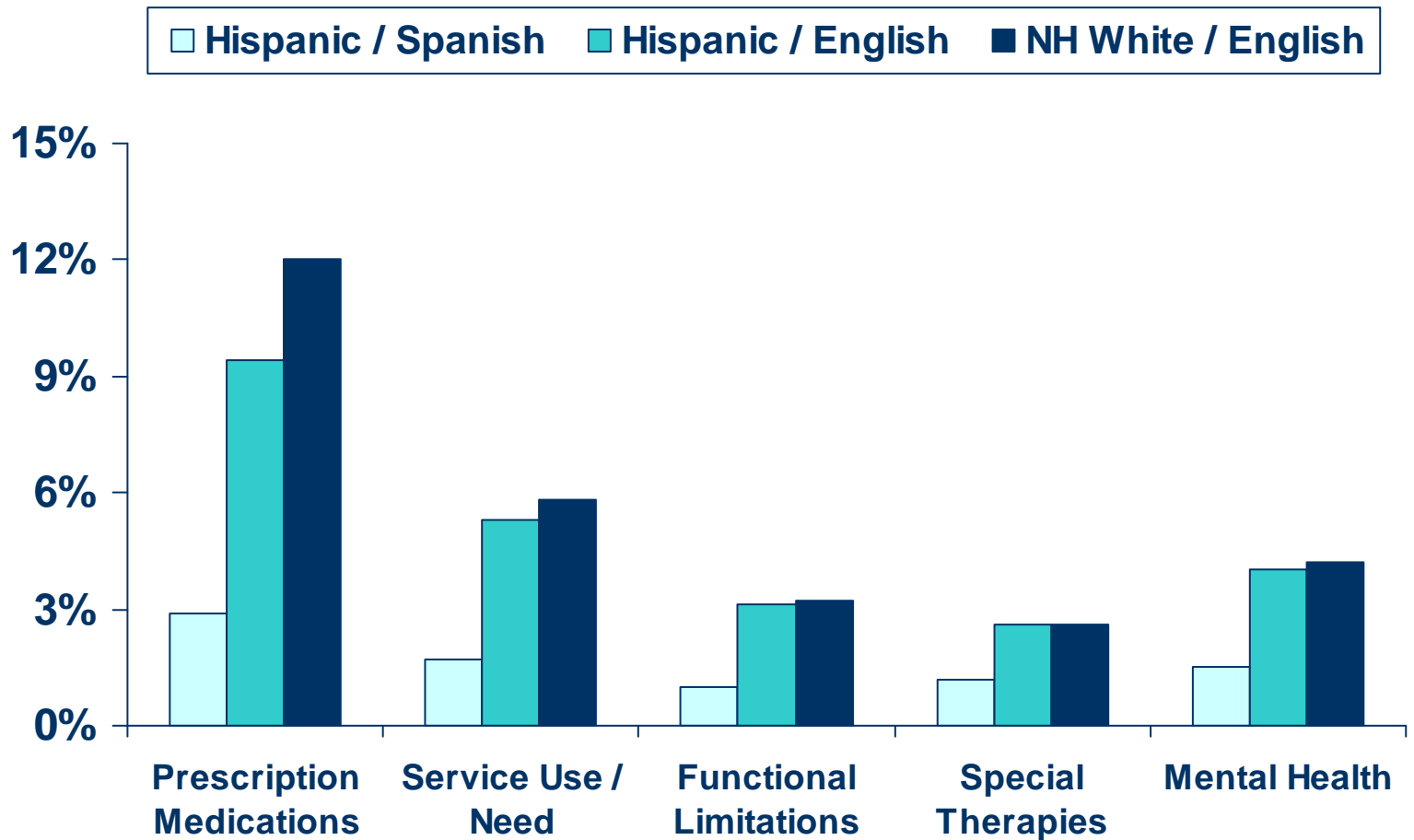
Prevalence by Race/Ethnicity



Prevalence by Race/Ethnicity and Primary Language at Home



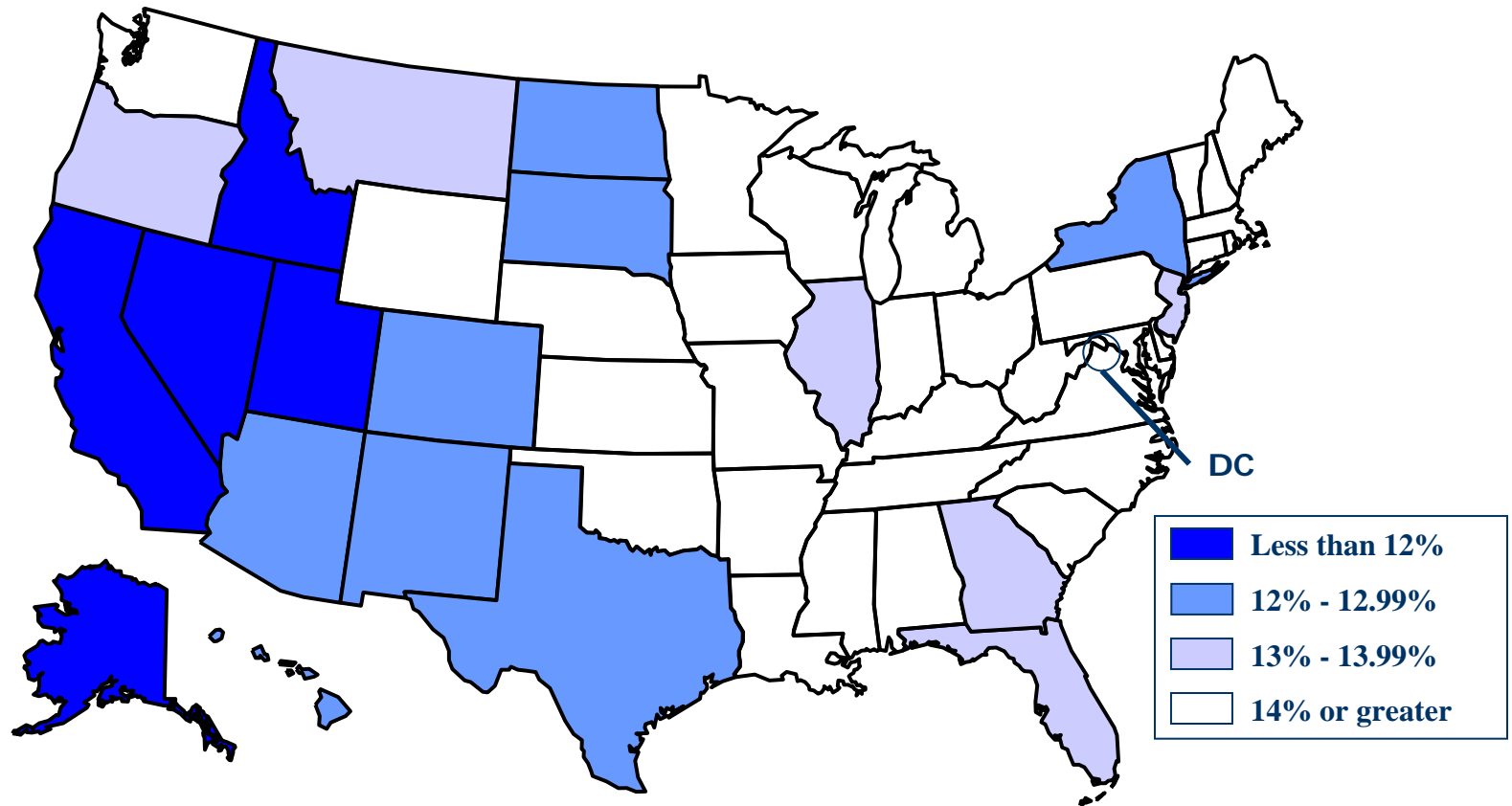
Prevalence by Race/Ethnicity and Primary Language at Home



Odds Ratios from Logistic Regression Predicting CSHCN Status

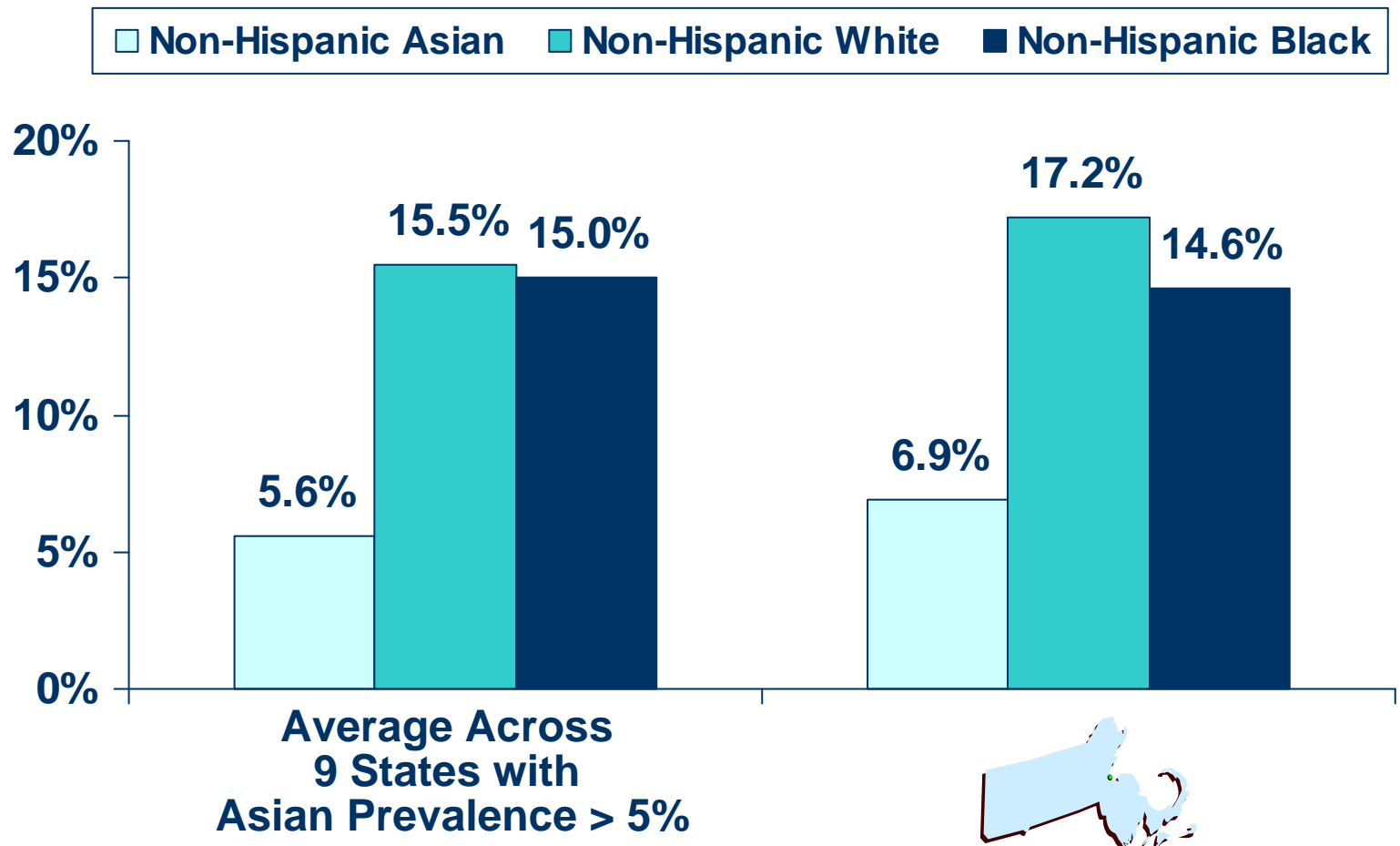
- Ethnicity/Language
 - Hisp / Spanish 0.23
 - Hisp / English 0.78
 - NH / English 1.00
- Age
 - 0-5 years 1.00
 - 6-11 years 1.96
 - 12-17 years 2.05
- Sex
 - Female 1.00
 - Male 1.48
- Income
 - Poor 1.60
 - Near poor 1.25
 - Not poor 1.00
- Highest education in household
 - Less than HS 1.00
 - High school 1.05
 - More than HS 1.25

Prevalence of Children with Special Health Care Needs, 2005-2006

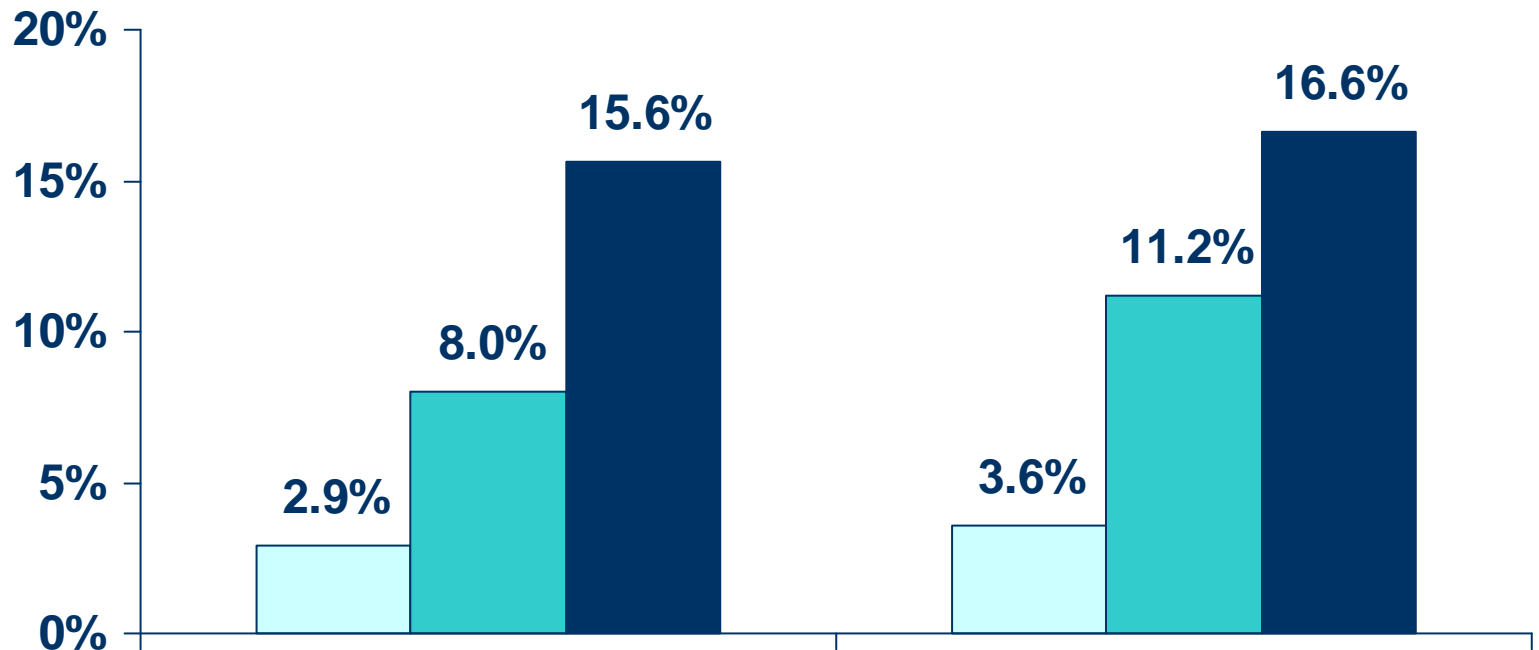


All 50 States and DC: 13.9%

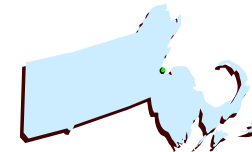
Prevalence by Race/Ethnicity



Prevalence by Race/Ethnicity and Primary Language at Home



Average Across
9 States with
Asian Prevalence > 5%



The Linguistic and Cultural Validity of the CSHCN Screener

A Closer Look at Hispanic Children from Spanish-Speaking Households

Spanish as a Primary Household Language

- **11.1% of children nationally are Hispanic and live in Spanish-language households**
 - Parents of 86.1% of these children completed the NS-CSHCN interview in Spanish
 - In total, parents of 52% of Hispanic children completed the NS-CSHCN interview in Spanish

Why is CSHCN Prevalence Lower for Hispanic Children from Spanish-Language Households?

- **Translation issues?**
- **Different understanding of CSHCN Screener concepts?**
- **Reluctance to report health problems?**
- **Differences in access to care?**
- **Differences in receipt of care?**

Cognitive Interviews

- **19 interviews with limited-English speaking parents of Hispanic children**
 - 37 total children screened
 - 8 interviews in Boston; 11 in Portland, OR
- **Goals of the interviews**
 - Test general reaction to Screener
 - Assess ability to answer questions
 - Examine concordance between researcher and parent interpretations of the Screener
 - Evaluate cultural validity of questions

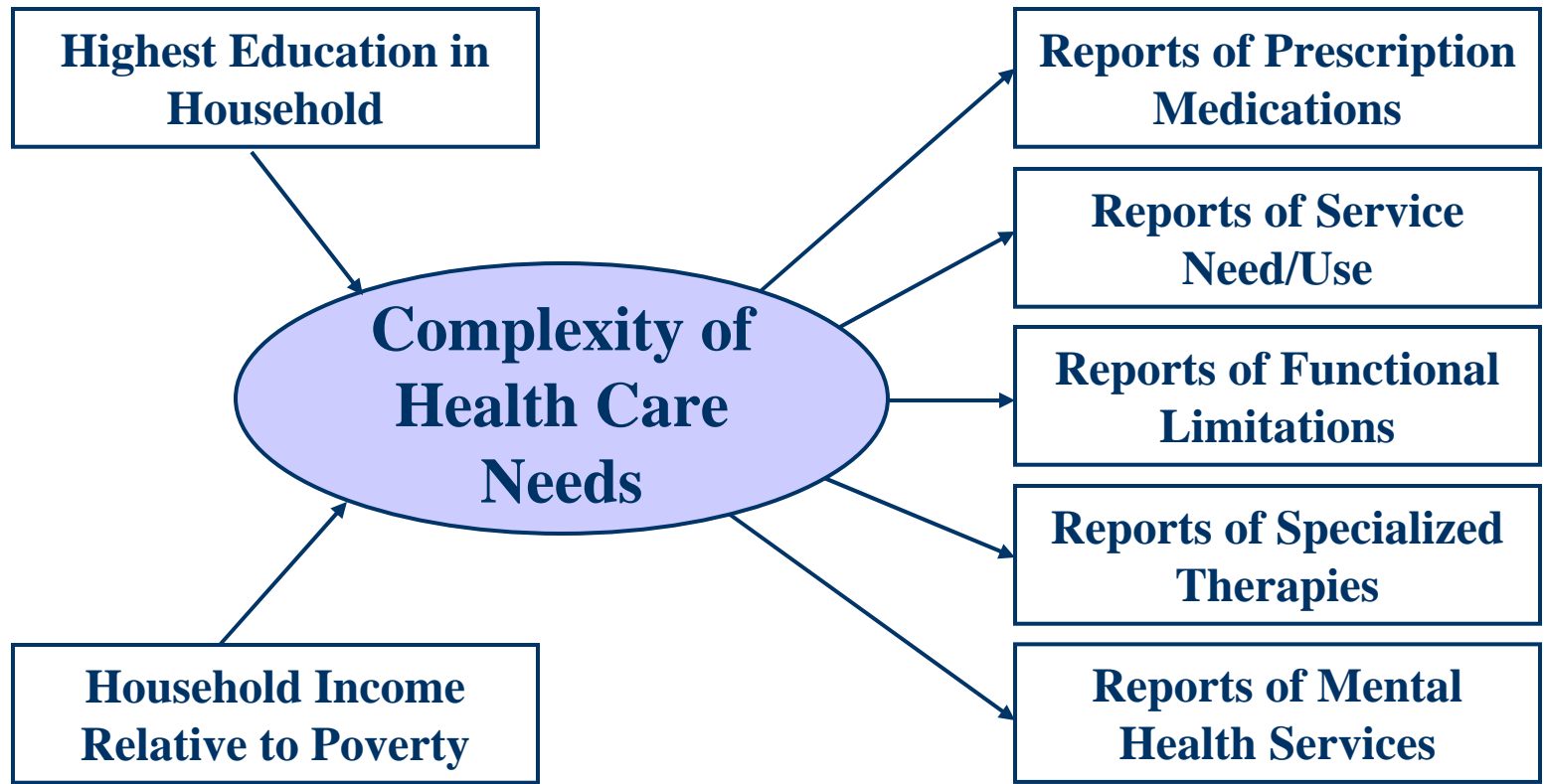
Results of Cognitive Interviews

- **No issues related to the translation emerged during the interviews**
- **Questions described as**
 - “Very clear”
 - “Easily answered”
 - “Things a mother of course knows about her children”
- **Concepts were familiar and perceived as relevant to their children’s health**

Results of Cognitive Interviews

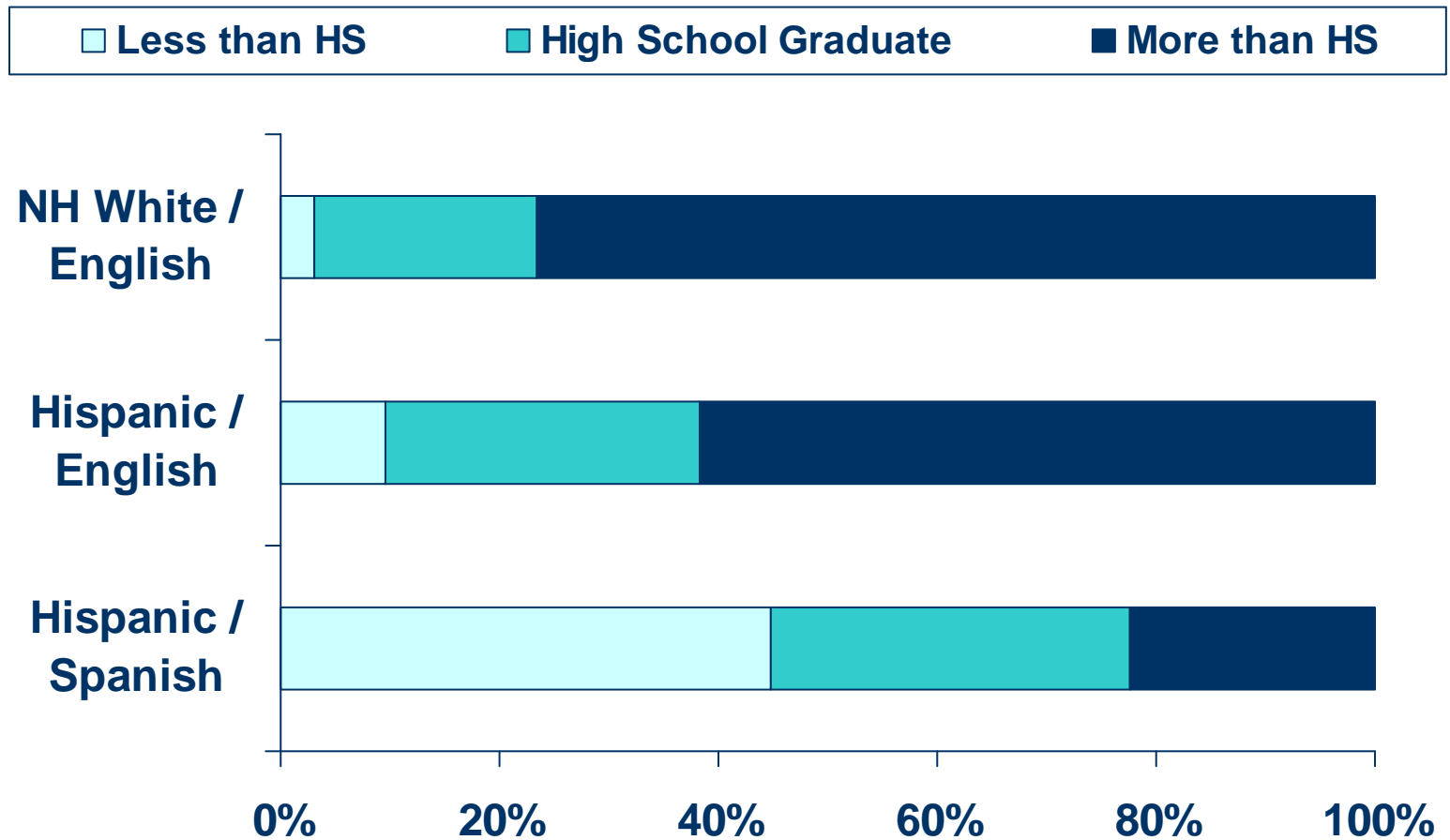
- **Parents accurately distinguished between medical, mental health, and educational services**
- **Parents accurately distinguished between prescription medications and traditional methods of healing**
- **Parents did not have any difficulty assessing whether their children needed or used these services**

Psychometric Analysis of Measurement Bias

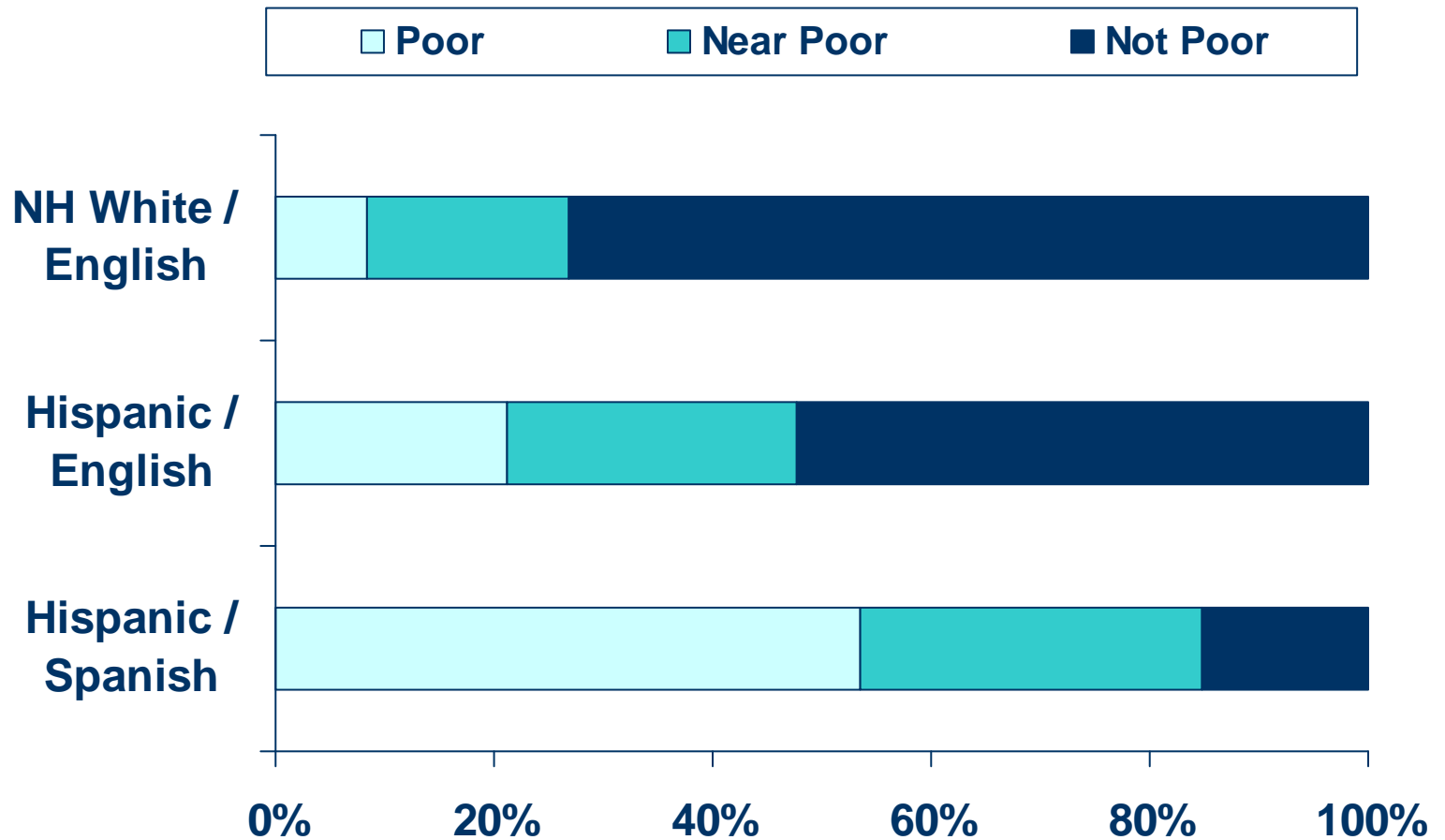


Thanks to Adam Carle, University of North Florida.

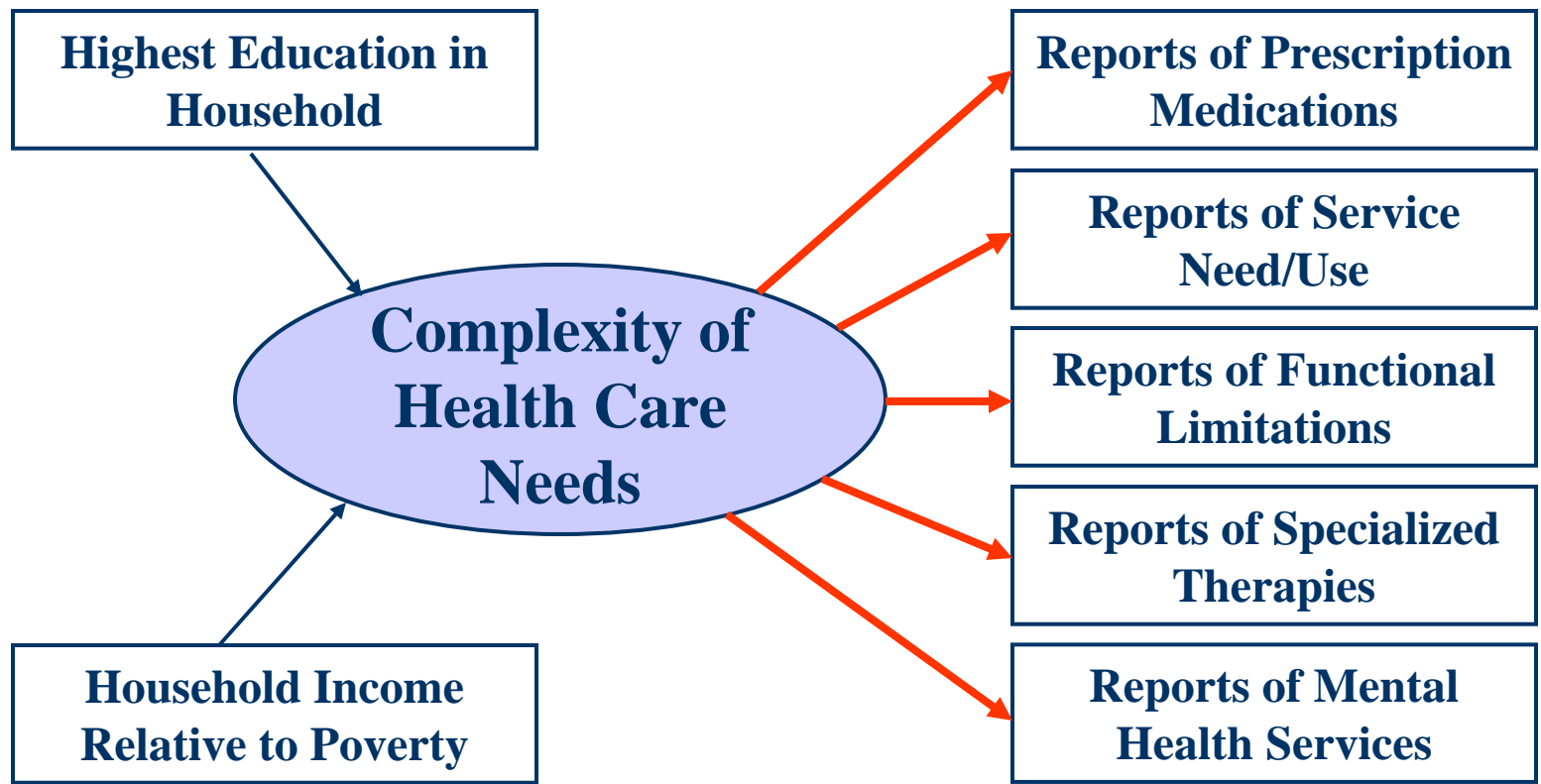
Highest Education in Household, by Ethnicity and Language of Interview



Household Income Relative to Poverty, by Ethnicity and Language of Interview

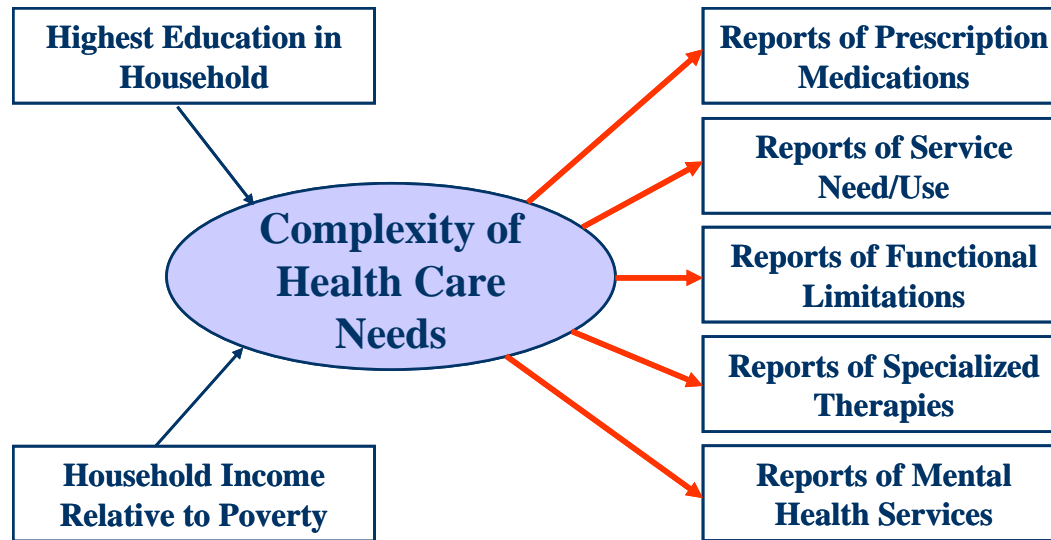


Psychometric Analysis of Measurement Bias



Thanks to Adam Carle, University of North Florida.

Psychometric Analysis of Measurement Bias



- **No measurement bias (differences in thresholds) by ethnicity or language**
- **No measurement bias when comparing Hispanic children from Spanish-speaking households to other groups of children**

Results of Cognitive Interviews

- **Nearly every parent interviewed expressed some degree of disinclination and reluctance related to speaking candidly about their children's health issues with anonymous telephone interviewers**
 - **Especially when facing barriers to getting care and services**
 - **Especially if there are concerns related to immigration status**

Functioning Difficulties

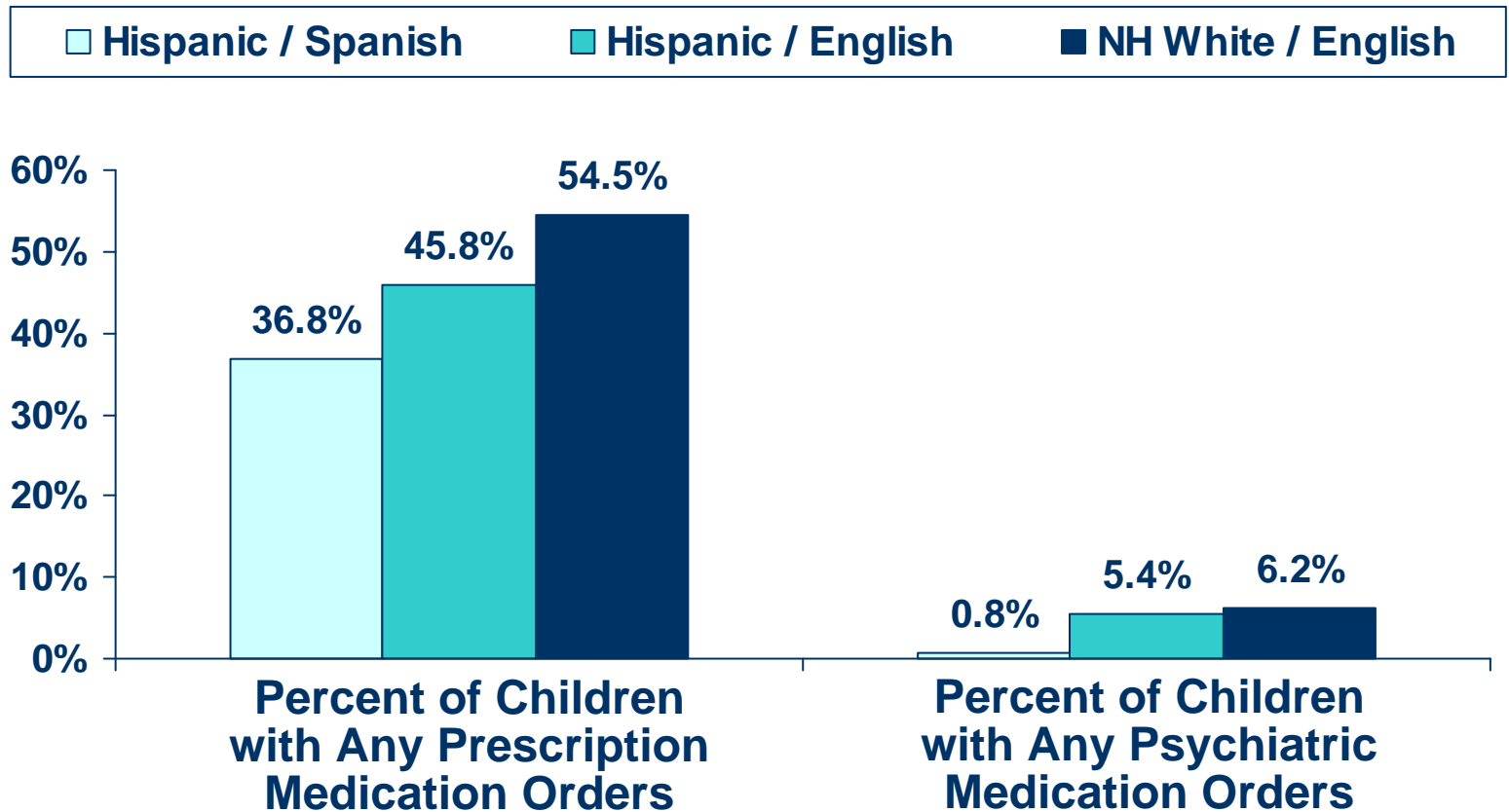
- **Hispanic CSHCN from Spanish-language households were more likely than other CSHCN to have difficulties with:**
 - Speaking, communicating, or being understood
 - Self-care
 - Coordination or moving around
 - Using hands or fingers
 - Blood circulation problems
- **And more likely to have conditions that affect activities usually, always, or a great deal**

Thanks to Rosa Avila, National Center for Health Statistics.

Why is CSHCN Prevalence Lower for Hispanic Children from Spanish-Language Households?

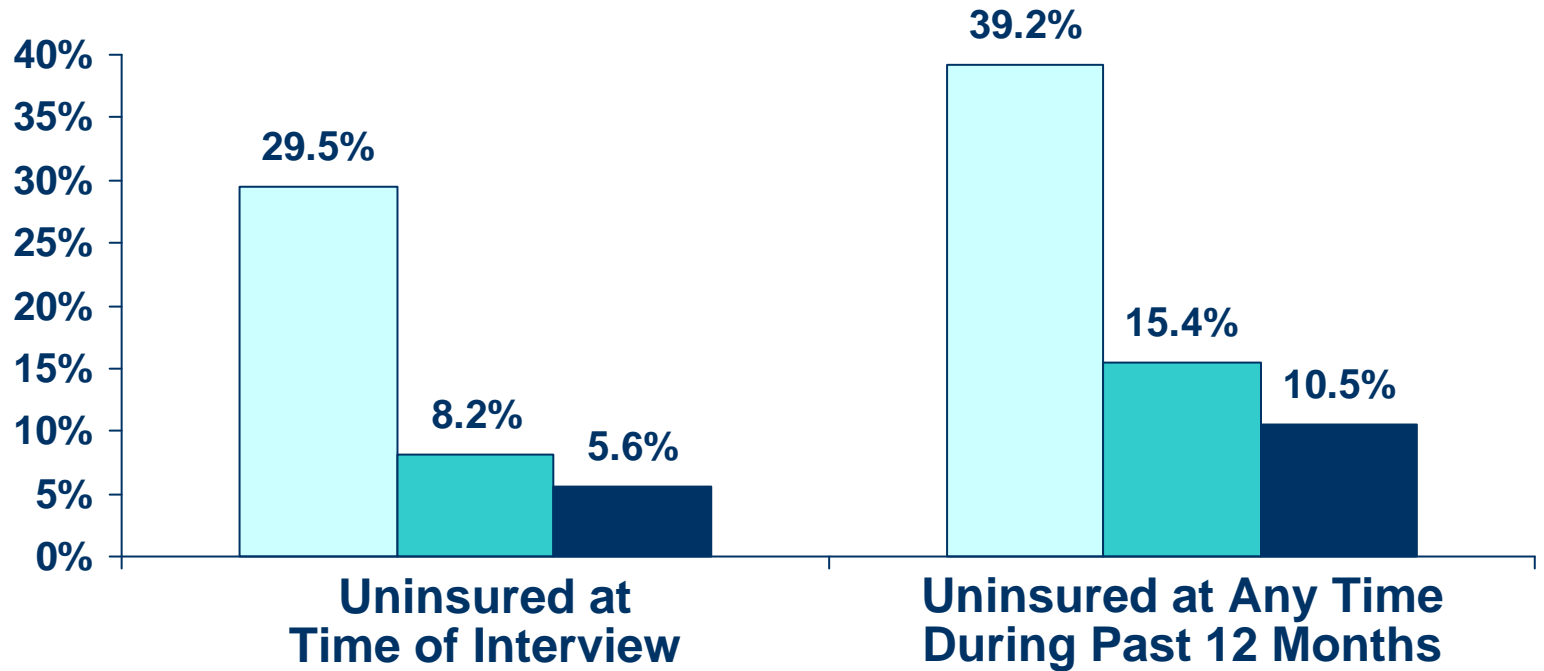
- **Translation issues?**
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Prescription Medication Orders Filled, by Ethnicity and Language of Interview

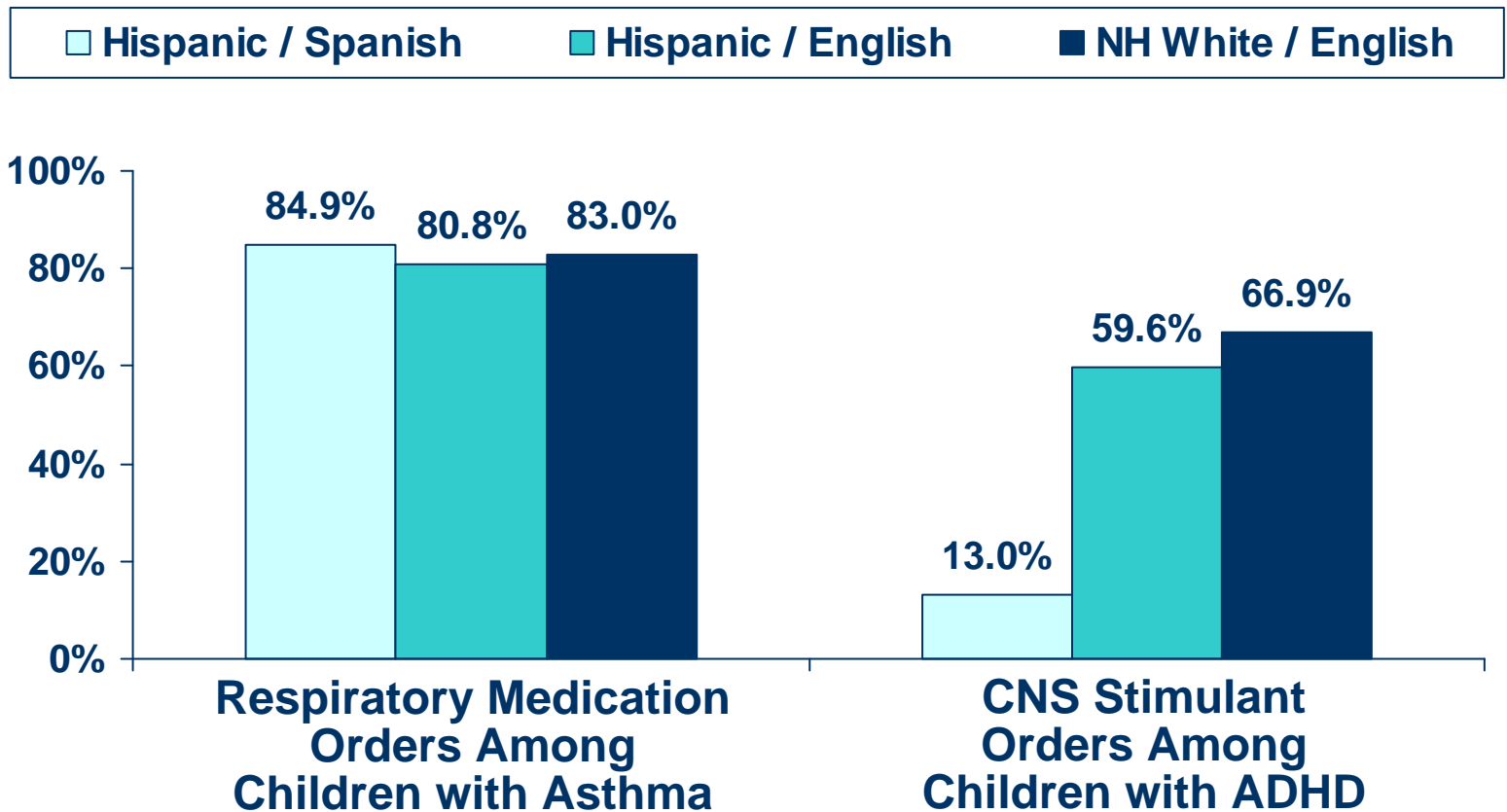


Thanks to Byron A. Foster, Oregon Health and Science University.

Health Insurance Coverage, by Ethnicity and Language of Interview



Prescription Medication Orders Filled, by Ethnicity and Language of Interview



Thanks to Byron A. Foster, Oregon Health and Science University.

Influence of Culture

- **Perceptions of need for treatment can be influenced by culturally-based perceptions**
 - “Maybe we Latinos just take better care of our children”
 - Family refused ADHD medication because they knew a child who took such meds and “he acted like a dummy”
- **Culturally biased provision of care?**

The Linguistic and Cultural Validity of the CSHCN Screener

Conclusions

Conclusions

- **“Special health care needs” is a social construct**
 - “Children with special health care needs are those who have or are at increased risk for 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.”

Conclusions

- **CSHCN Screener works very well identifying children who meet the definition of the construct, even Hispanic children from Spanish-language households**
- **But perhaps the construct doesn't fit well within this population**
 - Change definition?
 - Change experiences with care?
 - Change cultural beliefs?

For More Information...

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