

# When Complex Care Goes Complementary: Closing the Loop on Integrated Care for Children With Special Health Care Needs

Presented by:

**Susan Carson, MPH**

The Child and Adolescent Health Measurement Initiative  
Oregon Health & Science University

Authors: Christina Bethell, PhD, MBA, MPH,  
Narangerel Gombojav, PhD, Adam Carle, PhD, John Neff, MD,  
Paul Newacheck, DrPH, Thomas K. Koch, MD



# **Pediatric Academic Societies and Asian Society For Pediatric Research**

JOINT MEETING • MAY 3 – MAY 6, 2014 • VANCOUVER

**The presenter and authors**  
document that they have no  
financial relationships to disclose  
or Conflicts of Interest to resolve.

# Overall NIH/NCCAM R2I Study

## *Use and Impact of CAM and Conventional Care Among US Children (2011-2014) (PI: Bethell)*

### **Study Components**

- **Methods:** Survey development and meta-data analysis on existing NCCAM NHIS supplement for children and linkages with MEPS
- **Framework/Agenda:** Health services research framework and methods and data gap analysis
- **New Knowledge:** Baseline epidemiologic profile of CAM use among US children in context of conventional care use, access and quality
  - *Examination of CAM use for children with special health care needs (our focus today)*

### **Additional Study Focus: Data and Research Resources**

Interactive online data query tool; quick-guides to learn about the NHIS NCCAM survey; constructed data sets and codebooks, etc. ([www.nhiscamdata.org](http://www.nhiscamdata.org))

About the Data Resource Center

Learn About the Surveys

Browse the Data

Put Data into Action

Get Help



▶▶ Survey Fast Facts

▶▶ Quick Data Search

▶▶ Get Region Snapshots

▶▶ How to Use This Site

Keyword Search




Go

## Data at a Glance

At your fingertips—easy-to-read data snapshots for each region



Region Nationwide

Browse Region Snapshots

## Connect with the DRC

Sign up for email updates

email address

Submit

Join our conversation!



## The National Health Interview Survey (NHIS) Child Complementary and Alternative Medicine (CAM) Supplement

The **Child CAM Supplement** is one of the NHIS Supplements and collects information about non-conventional health services, products, and practices commonly used in the United States. NHIS is the principal source of information on the health of the civilian non-institutionalized household population of the United States. One child age 0-17 years from each family was randomly selected for the **Sample Child Core** questionnaire. Additional information about this "sample child" and other family members is collected with the **Family Core** questionnaire.

The Data Resource Center takes the results from the NHIS Child CAM Supplement, Sample Child and Family Cores and makes them easily accessible to parents, researchers, community health providers and anyone interested in child health and child CAM use data. Estimates on this site are nationally representative. National data can be further refined to assess differences by the US region, race/ethnicity, income, child's health and condition status and a variety of other important demographic and health status characteristics. ▶▶[Read more about the NHIS and Child CAM Supplement](#)

### NHIS CAM Highlights

▶▶ Survey development

### Learn about the NHIS Child CAM Supplement

• Interested in an overview of the NHIS Child CAM

# Today's Paper

## **Objective:**

To report national data on the use of CAM and conventional care **among children with special health care needs (CSHCN)**

## **Research Question Focus**

- 1. Overall Prevalence:** CAM use prevalence for CSHCN vs. Non-CSHCN
- 2. Use Variations:** Within CSHCN CAM Prevalence
  - By complexity of conventional care service needs & use
  - By qualification on CMS Primary Care Medical Home Demonstrations provider payment incentive code list (CMS/ACA-qualifying conditions list)
- 3. Parent Reported Reasons and Communication With Providers:**
  - Characterize primary reason for CAM use among CSHCN
  - Report on parental report of CAM use to conventional care providers
- 4. Quality of Conventional Care:**
  - Associations with whether CSHCN experience care meeting medical home criteria (as assessed using the MEPS variables)

# Key Variables: CSHCN

**Definition of CSHCN:** Children who have any type of chronic condition(s) that require an above routine type or amount of health and related services

**Identification of CSHCN:** Used the standardized and validated CSHCN Screener is used to define CSHCN. This is included in MEPS (since 1999).

Required linkage of NHIS files to MEPS



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

## Who Are Children with Special Health Care Needs?

### Definition of Children with Special Health Care Needs

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:

*"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"*<sup>1</sup>

This definition is used to guide the development of family-centered, coordinated systems of care for children with special needs and their families served by the state Title V block grants administered by the Maternal and Child Health Bureau.

The National Survey of CSHCN (NS-CSHCN) and the National Survey of Children's Health (NSCH) both use a validated, non-condition specific, consequences-based screening tool to identify children meeting the Maternal and Child Health definition of CSHCN, with the exception that the "at risk" component is not

### Health Issues and Functional Difficulties that CSHCN

Experience: **All CSHCN** experience at least one type of ongoing health condition that results in an above routine need for health and related services. Across the list of 18 specific health issues asked about in the **2011/12 NSCH**, 78.4% of CSHCN were reported to experience at least one of the conditions that was asked about; 41.1% experienced two or more from the limited list. Of the 18 health issues asked about, CSHCN most commonly were reported to experience ADD/ADHD (32.2%). Among those with ADHD, 71.8% also experienced at least one other health issue from the list of 18 asked about.

Health Issue Asked About*	% Among CSHCN	Health Issue Asked About	% Among CSHCN
Learning Disability	27.2	Speech Problems	15.6
ADD/ADHD	32.2	Tourette Syndrome	0.2
Depression	8.5	Asthma	30.2
Anxiety Problems	13.4	Diabetes	1.4
Autism, Asperger's, ASD	8.0	Epilepsy	3.1
Behavioral Problems	13.6	Hearing Problems	4.2

Learn more at  
[www.childhealthdata.org](http://www.childhealthdata.org)

# Key Variables: 39 CAM Modalities

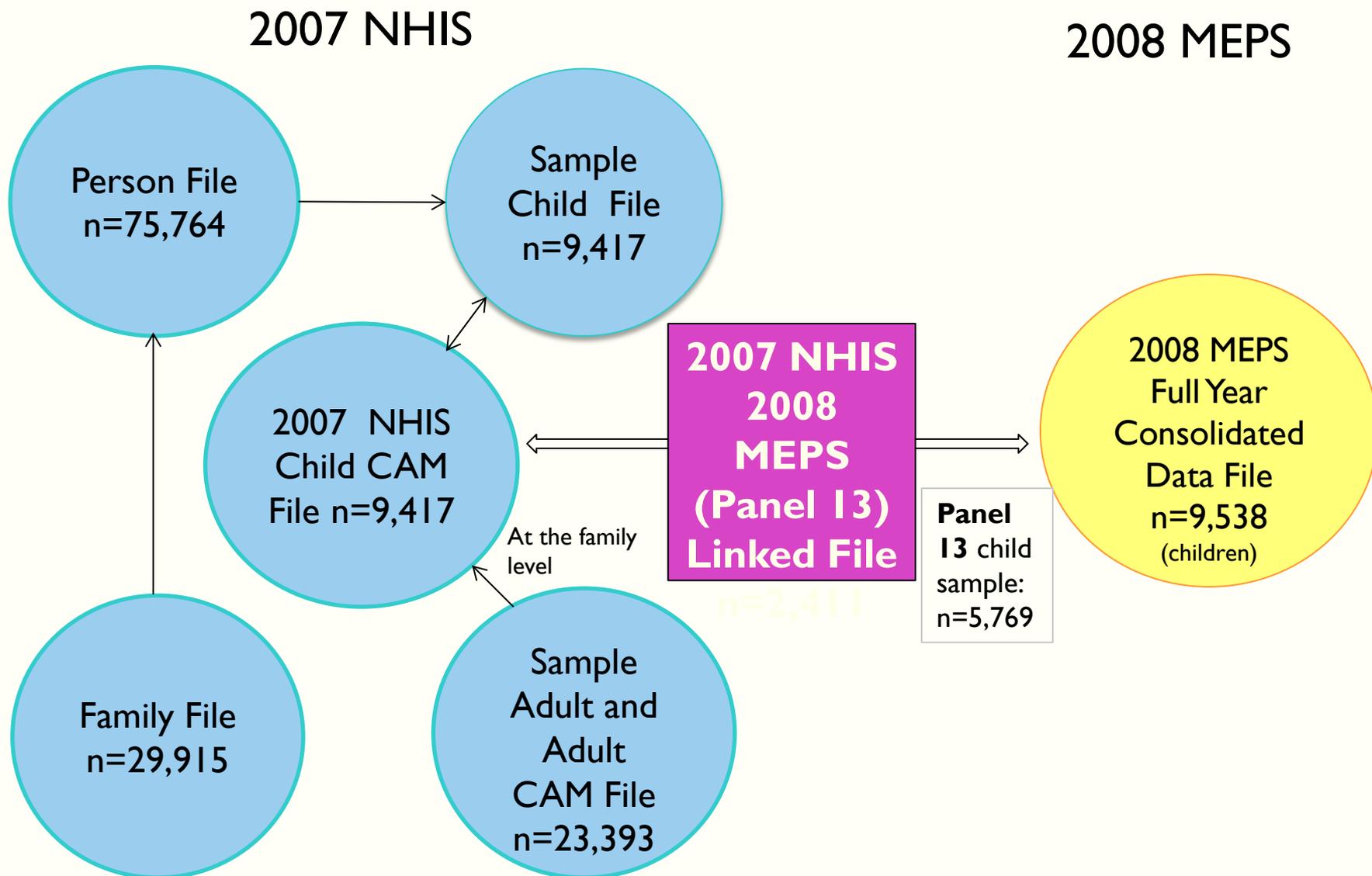
## **Grouping A:**

- Alternative Medical Systems  
(e.g., acupuncture, homeopathy)
- Biologically Based therapies  
(e.g., herbs, special diets, vitamin supplements)
- Manipulative and Body-Based Therapies  
(e.g., chiropractic, craniosacral)
- Mind-Body Therapies  
(e.g., meditation, yoga, biofeedback)

## **Grouping B (not shown today)**

- CAM Services
- CAM Practices
- CAM Products

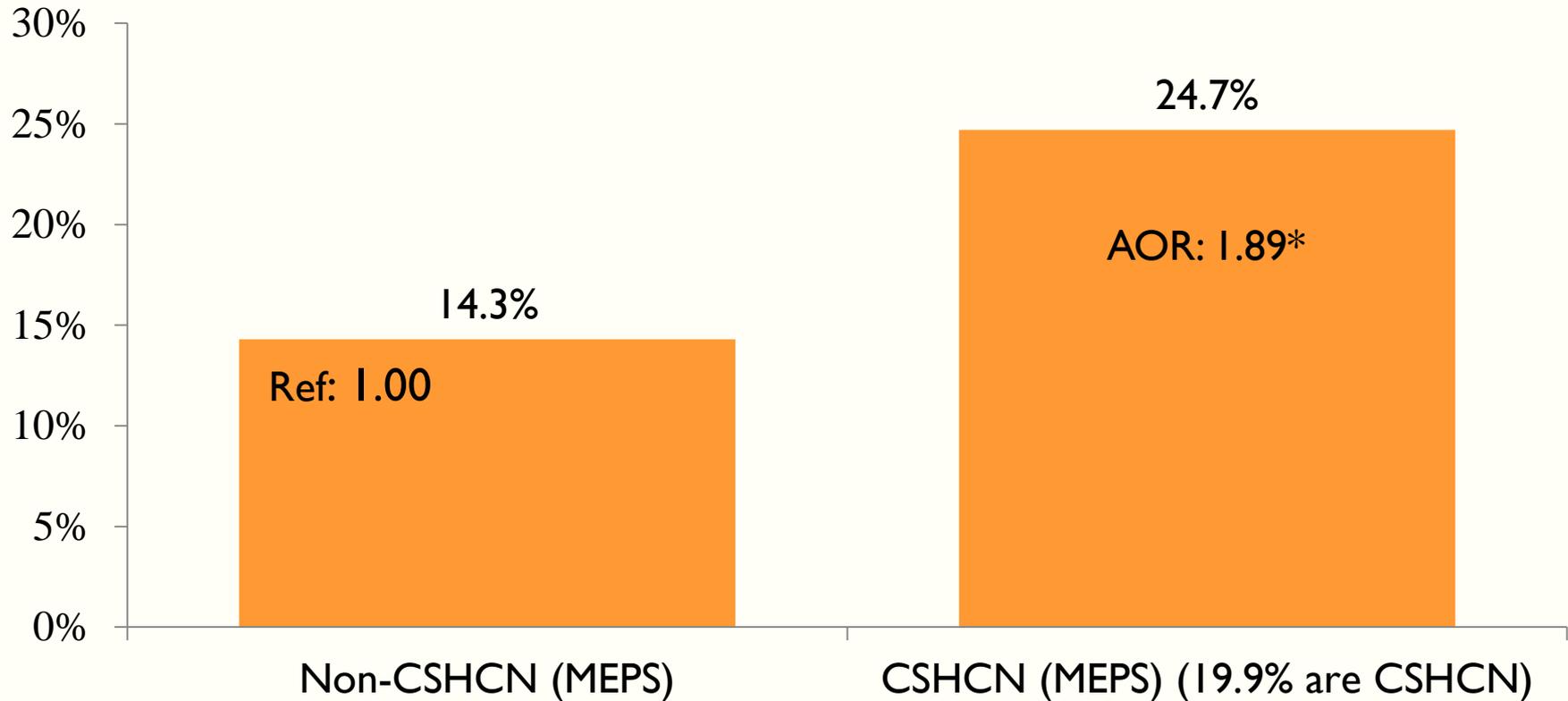
# Data Sources and Linkage: NHIS + MEPS



# Statistical Methods

- *Uni- and bivariate analyses*
- *Multivariate analyses to calculate adjusted odds ratios (AOR), controlling for*
  - CSHCN complexity
  - demographic characteristics
- *Standard two-part regression model analyses for MEPS expenditures data*

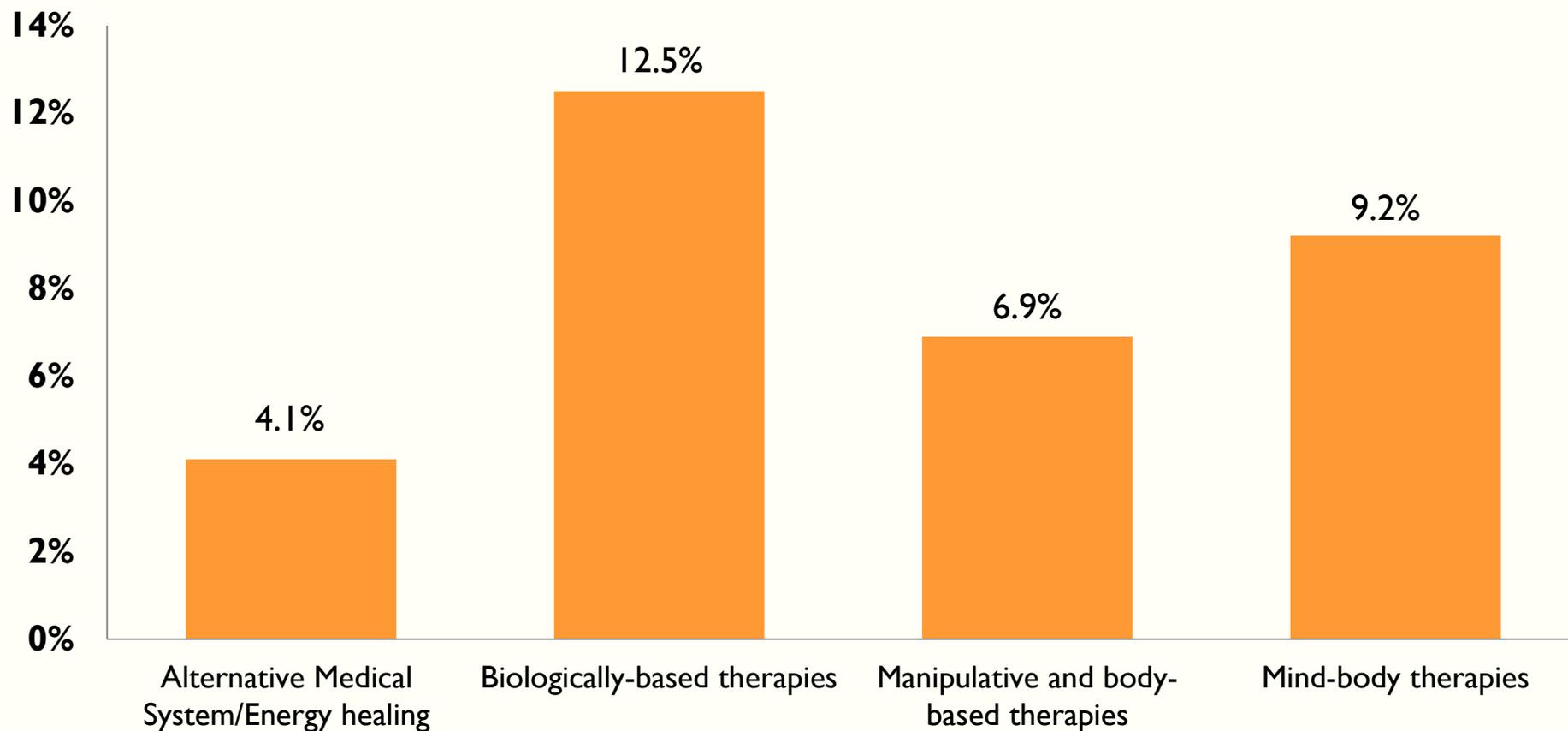
# Prevalence of CAM Use: CSHCN are more likely to use CAM



Data source:  
NHIS/MEPS linked file

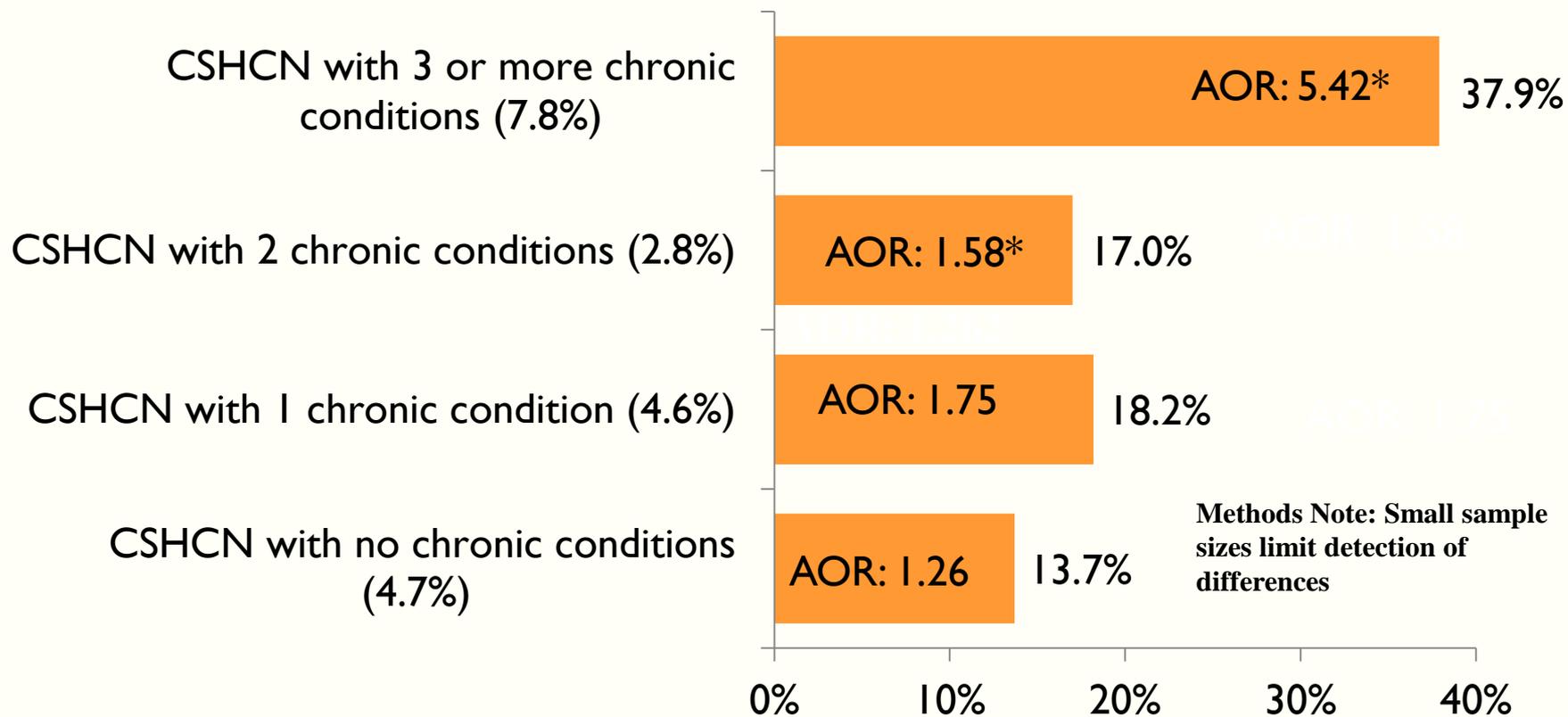
AOR controlling for age, sex, race/ethnicity, region and income

# Prevalence of CAM Use Among CSHCN by Type of CAM



Data source: NHIS/MEPS linked data

# CAM use by Complexity: Number of Chronic Conditions (based on NHIS list of conditions)

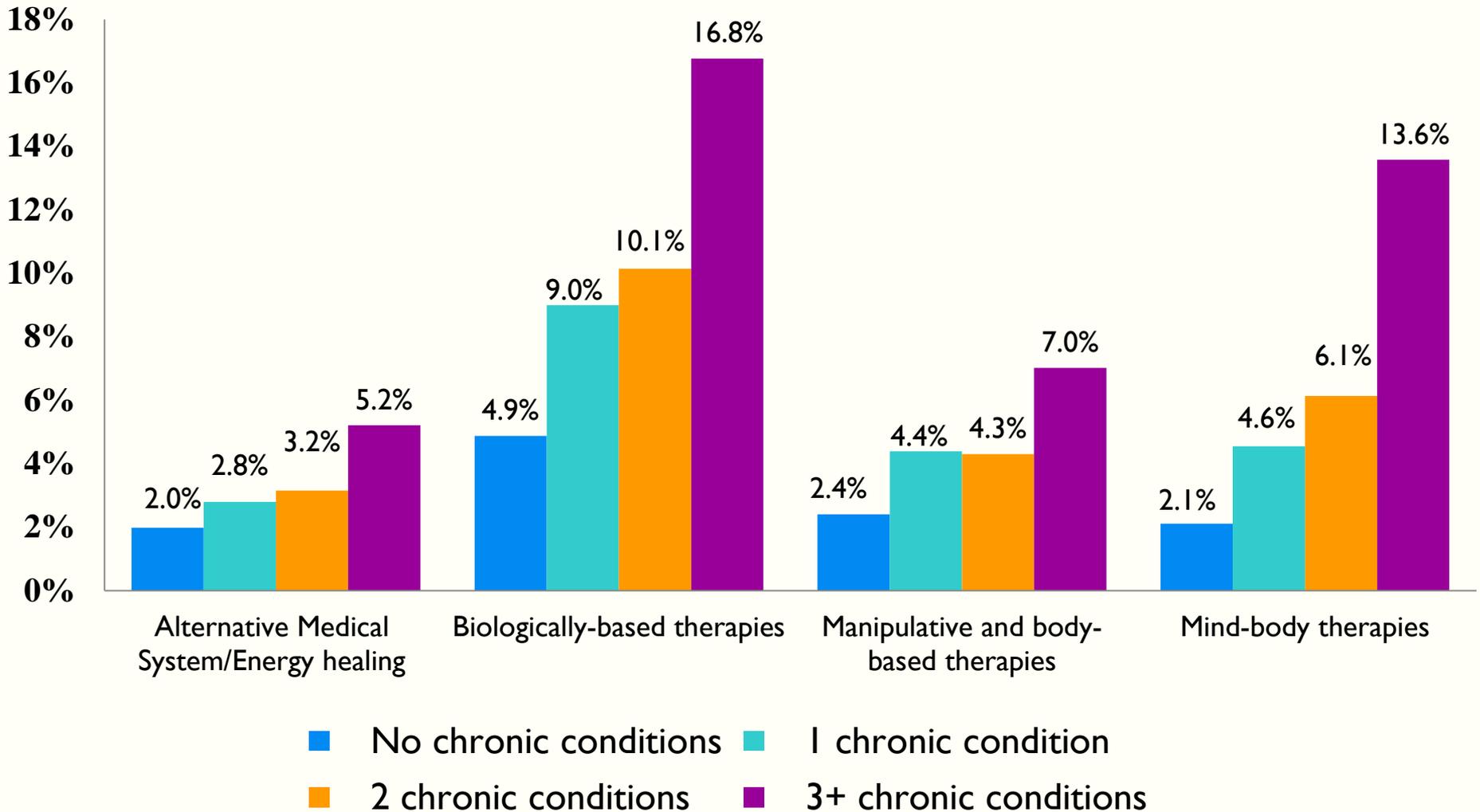


Data source: NHIS/MEPS linked file

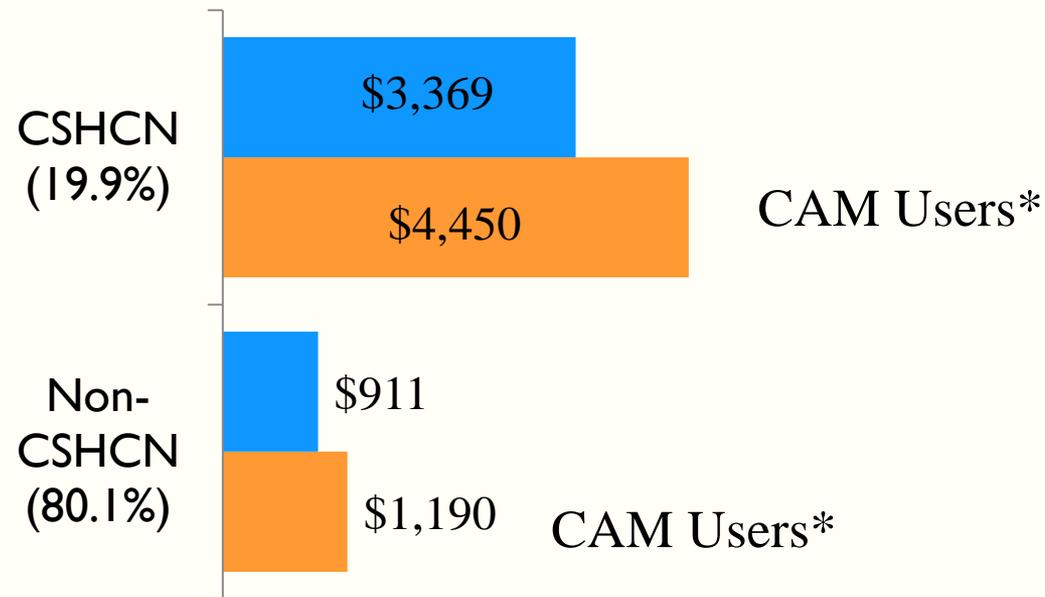
Reference: Non-CSHCN; No Chronic Conditions

<sup>ss</sup>**AOR** is statistically significant compared to the **reference group - No chronic condition and Non-CSHCN** after controlling age, sex, race/ethnicity, region and income

# This relationship is seen within all CAM modality groups

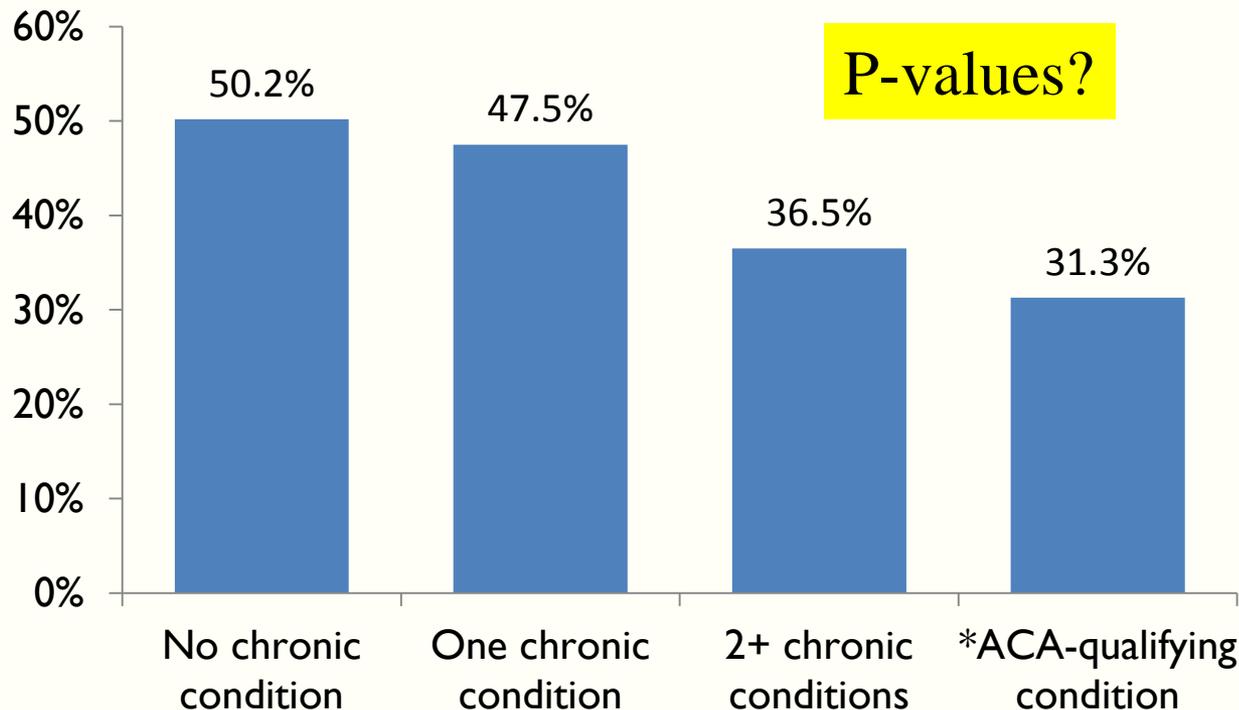


# Conventional medical care expenditures are higher among CSHCN who use CAM



# CSHCN use CAM for health problems and needs— not simply for overall wellness and prevention

## Children whose parents cite “wellness and disease prevention” as the most important reason they use CAM

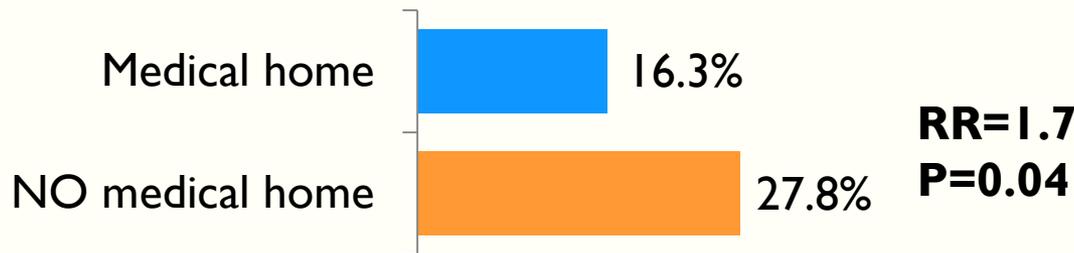


\*Child has at least one: depression, ADD/ADHD, or autism  
and/or  
two of: asthma, diabetes, overweight

CSHCN, especially those with more complex service needs, do not use CAM primarily for general health and wellness. Rather, they seek help beyond conventional medical care for health problems.

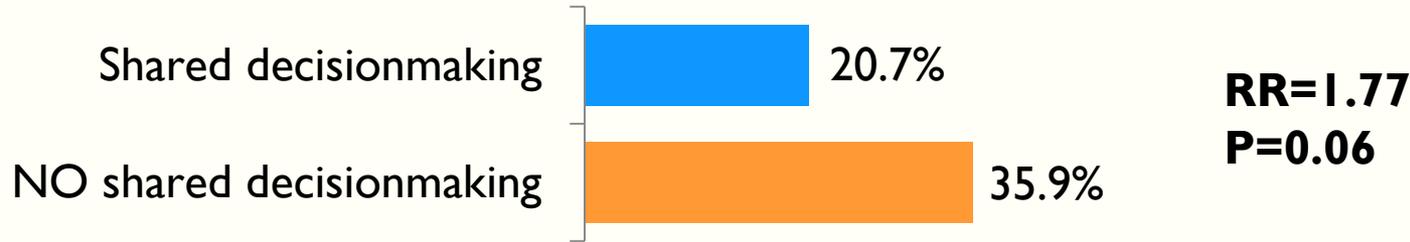
# CSHCN who do NOT meet medical home criteria are 1.7 times more likely to use CAM

Prevalence of CAM use medical home



# Patient-Provider Partnership and CAM Use: CSHCN who do NOT experience shared decision-making in their health care encounters are much more likely to use CAM

Prevalence of CAM use among CSHCN



Data source: NHIS/MEPS linked file

## Patient-Provider Communication:

The majority of children with chronic conditions who use CAM have parents who do not communicate this use to

- **45.8%** of children with chronic conditions have parents who did not tell the child's providers about their child's use of CAM
- **WHY?** Most common reasons for not disclosing CAM use:
  - The provider did not ask (**55.7%**)
  - Parents did not think the provider needed to know (**42.2%**)

Source: 2012 NHIS CAM Supplement (Based on chronic conditions list from NHIS—can not link 2012 NHIS to MEPS until 2014)

# Question

Are parents of CSHCN seeking out CAM providers for reasons related to poor patient engagement and communication ?

# Conclusion

- **We need to close the loop on integrating care for CSHCN**
  - CAM use is associated with the **complexity** and **intensity** of children's health service needs and **poorer quality of conventional medical care**.
  - Children with complex health problems receive multiple forms of conventional, complementary and alternative care, emphasizing the **need for well integrated and coordinated pediatric care systems** within the context of a **medical home**.

# Study Limitations

- **CAM use may be underestimated** because some CAM modalities (e.g. prayer, music therapies) are not included in the 2007 and 2012 NHIS CAM Supplement.
- **Sample size in linked NHIS/MEPS File**
  - Prevents further subgroup analysis and likely Type 2 errors
- **Question inconsistencies** between surveys limited ability to assess the impact of CAM use on children's health and health outcomes
- **Methods for NHIS CAM Supplement Regarding “condition/reason for using CAM**