

# CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN CALIFORNIA

CCS STAKEHOLDER MEETING OCT. 3, 2018

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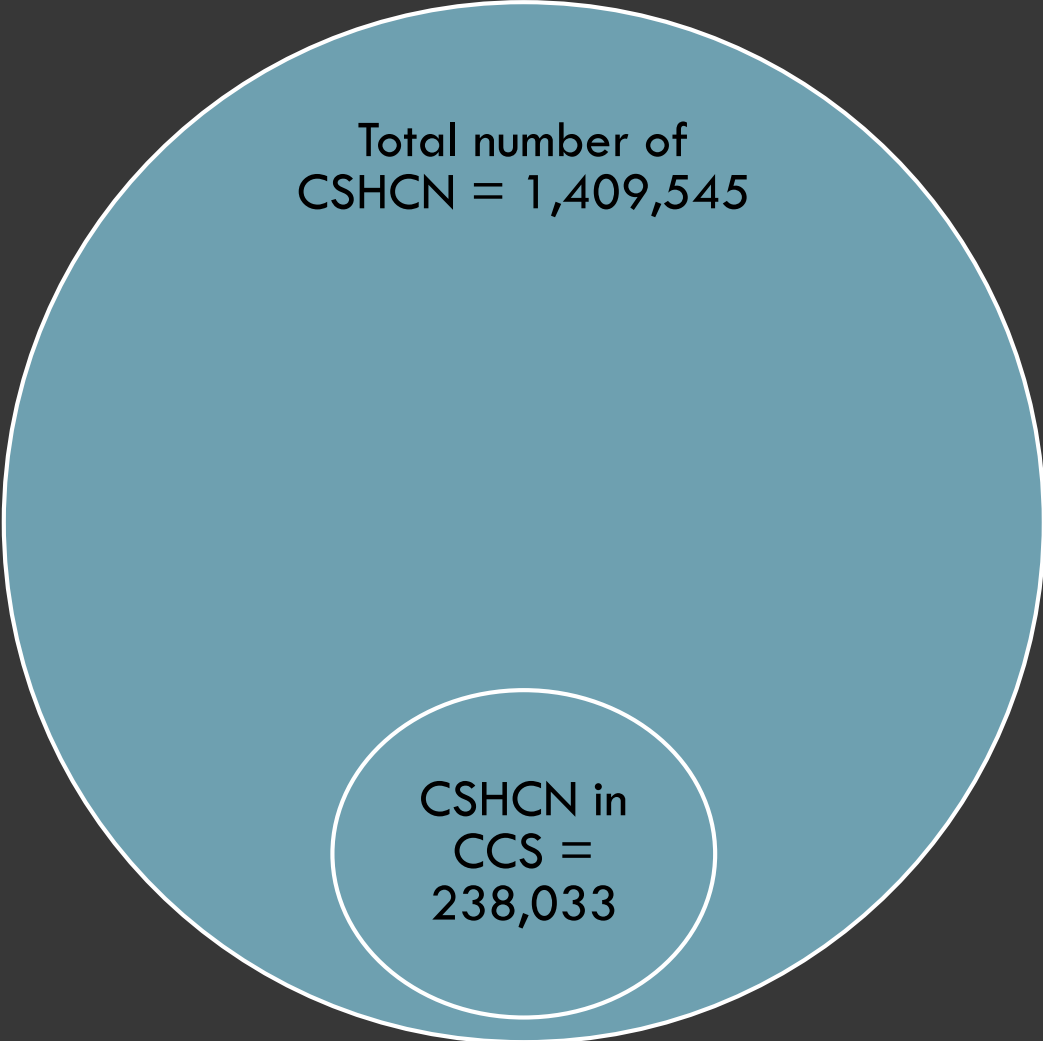
# Background

- The Family Health Outcomes Project (FHOP), at UCSF
- Conduct CCS Title V Needs Assessments every 5 years
- Funded by Integrated Systems of Care (ISCD)-DHCS

# Background continued

- California Children's Services:
  - ▣ Most CCS-eligible children are low-income, Medi-Cal eligible as well
  - ▣ Diagnosis and Treatment services, medical case management, and physical and occupational therapy services to children under age 21 with CCS-eligible medical conditions; Medical therapy services delivered in public schools
    - County, State General and Federally funded
    - Administered as a partnership between county health departments and DHCS

# CSHCN with CCS Enrollment in CA



Total number of  
CSHCN = 1,409,545

CSHCN in  
CCS =  
238,033

# NATIONAL SURVEY ON CHILDREN'S HEALTH – RESULTS IN CYSHCN

NSCH - 2016

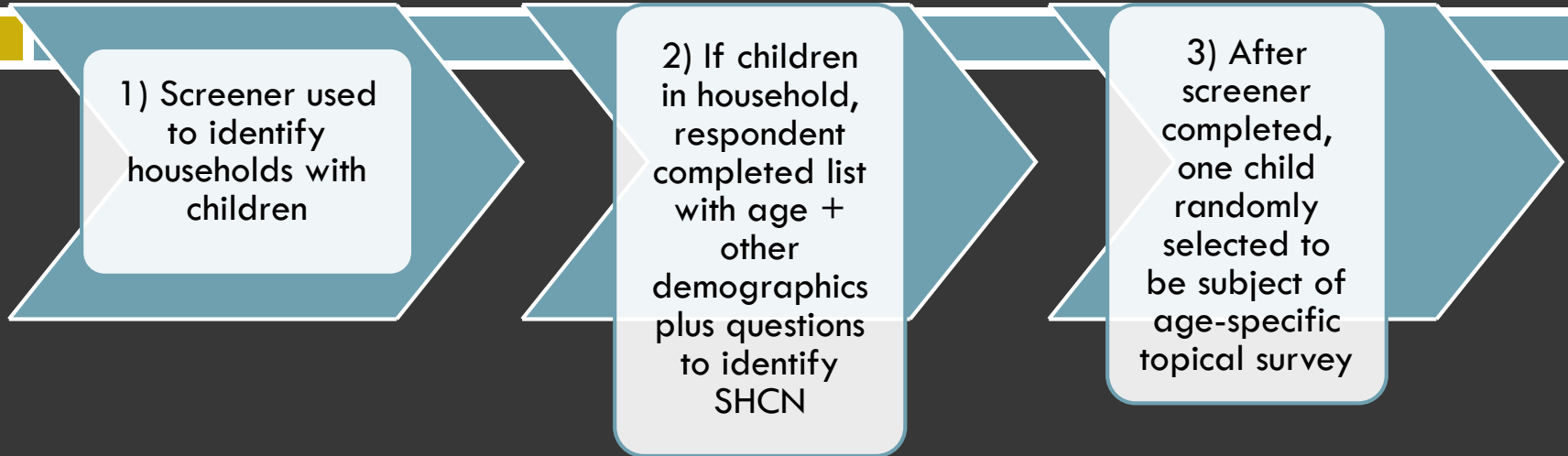
# National Survey on Children's Health (NSCH) 2016

- Sponsored by United States Department of Health and Human Services (HHS), Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB)
  - Conducted by the US Census Bureau on behalf of the above
  - designed to provide national and state-level estimates on key indicators of the health and well-being of children, their families and their communities, as well as information about the prevalence and impact of special health care needs.

# NSCH 2016: Methods

- Sample = 364,150 households in the US
- stratified by state and a child-presence indicator (to survey homes more likely to have children)
- Screener questionnaires, respondent = a parent or guardian who knew about the child's health and health care needs.
- NOTE: Between 2012 and 2015, HRSA MCHB redesigned the surveys, combining content into a single survey, and shifting from a periodic interviewer-assisted telephone survey to an annual self-administered web/paper-based survey utilizing an address-based sampling frame.

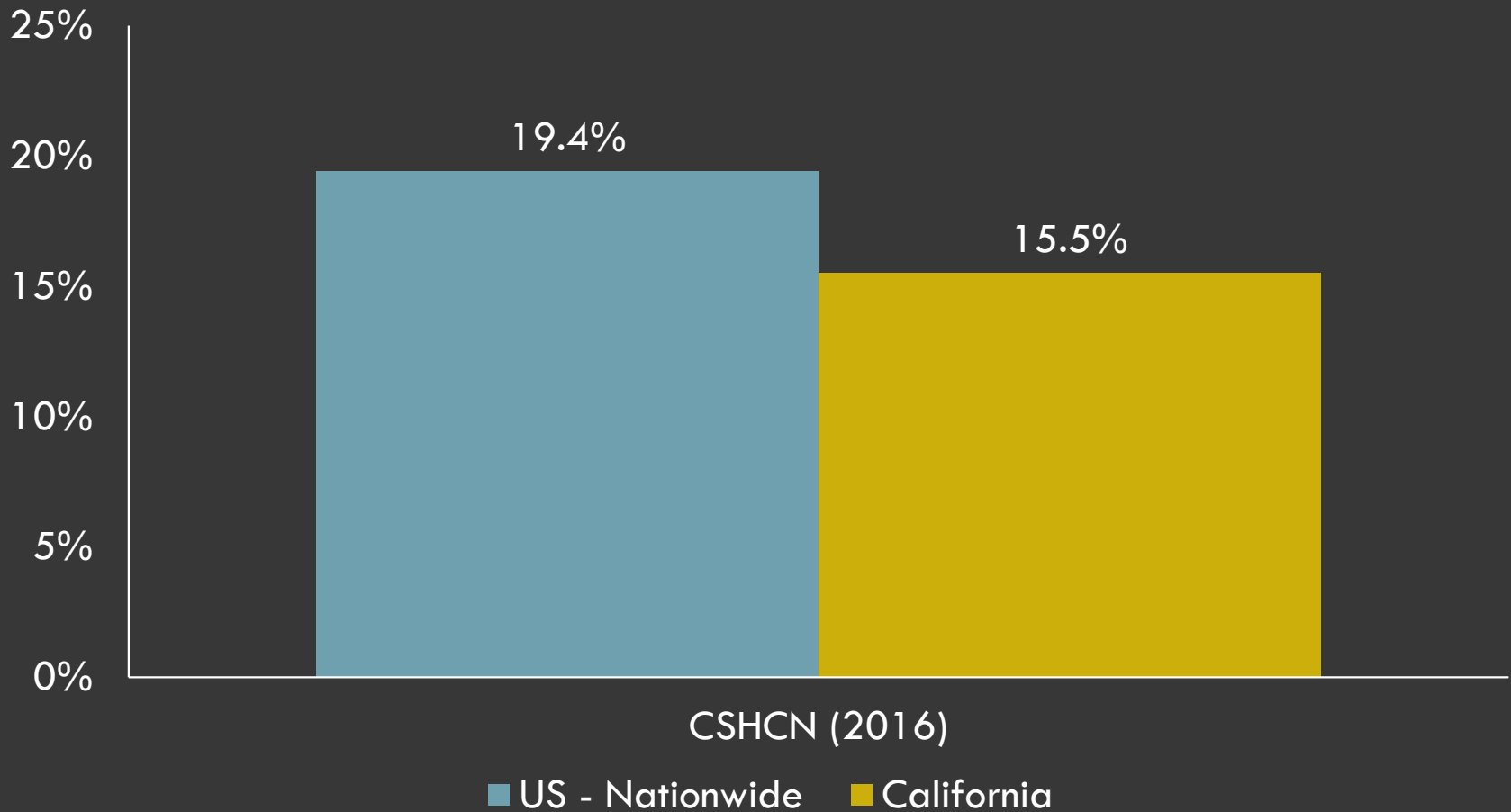
# NSCH 2016: Methods



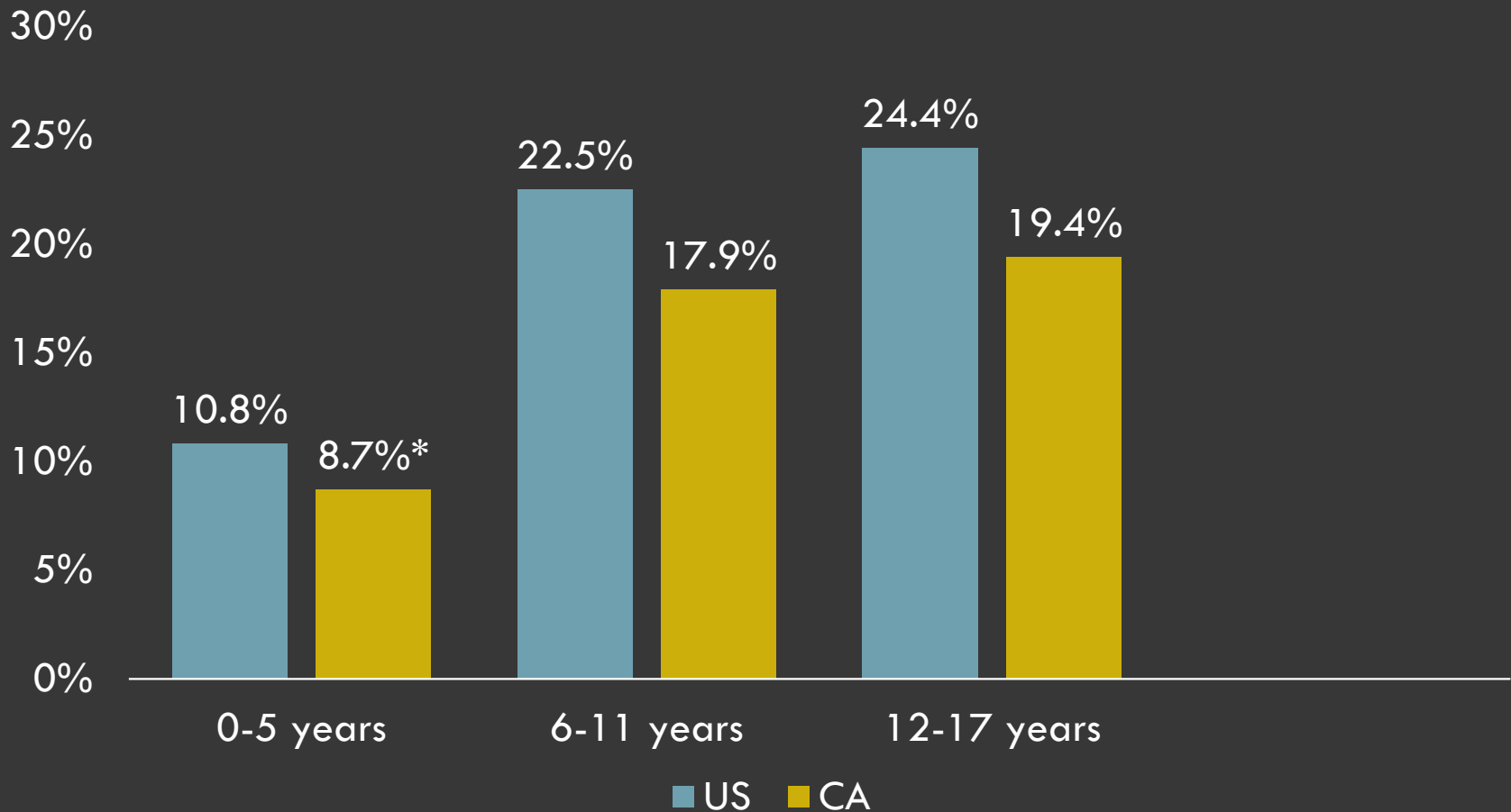
- *Web-survey invitations mailed – cannot be compared to previous year data because methods have changed*
- 138,009 Screener questionnaires completed
- 67,047 topical-eligible
  - ❖ **50, 212 completed the topical questionnaire**



# CSHCN ages 0-17: CA vs. Nation (2016)

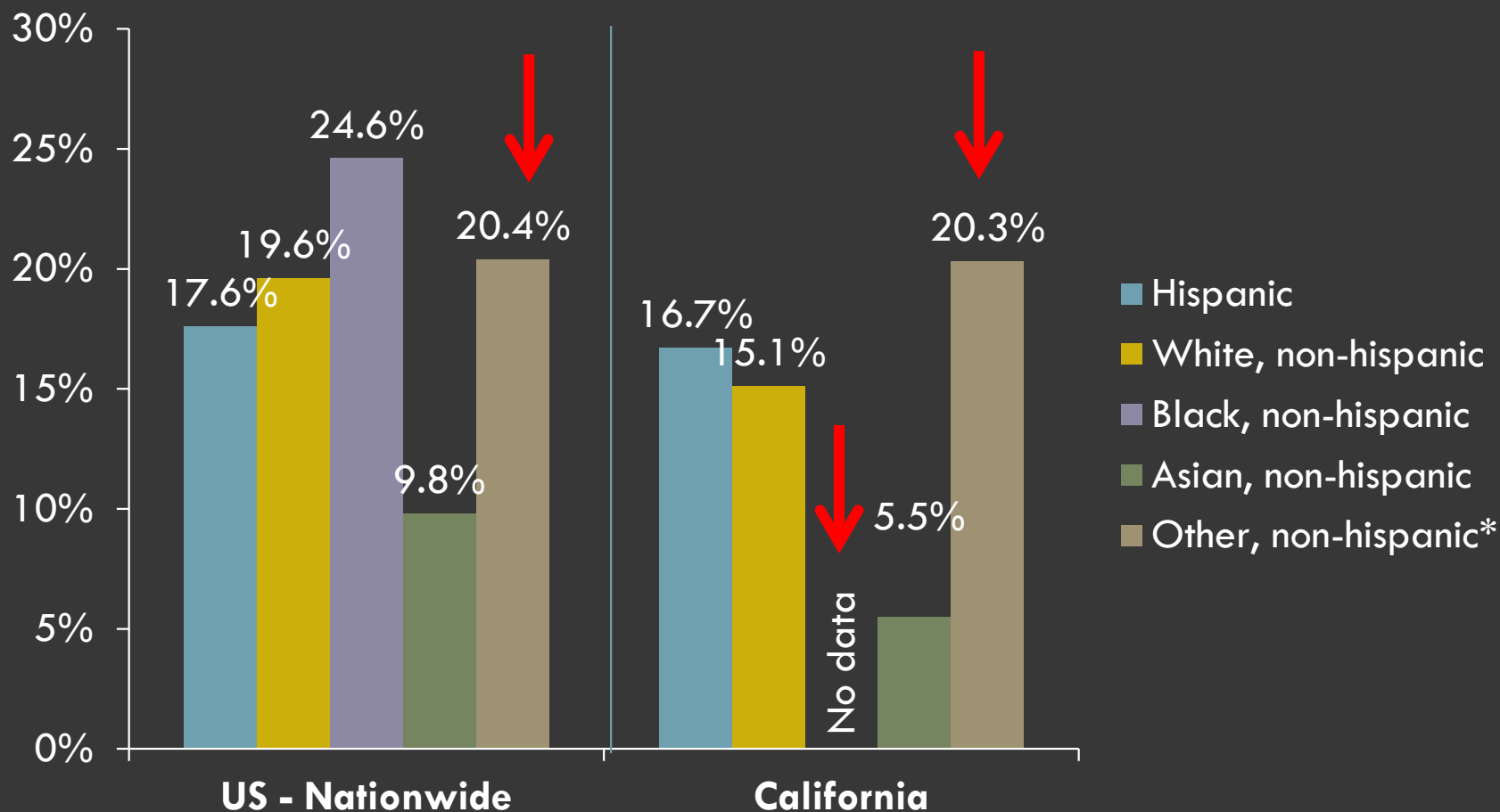


# CSHCN Prevalence by Age: CA vs. Nation (2016)



- Please interpret with caution: estimate has a 95% confidence interval width exceeding 20 percentage points or 1.2 times the estimate and may not be reliable.

# CSHCN CA vs. Nation: Racial and Ethnic Prevalence (2016)



\* All of these data have very wide confidence intervals, which can result in a less precise estimate, but specifically the Other, nonHispanic data for California is (10.4 - 35.8). Please view this data with caution!

# Discussion of prevalence within CA vs. Nation

- Higher prevalence in the US than CA overall and across all age groups
- Race/ethnicity data unclear
- We want to be able to interpret these data, but wide confidence intervals don't allow for conclusive interpretation
- What might some of the reasons be that California has a lower (15.5%) prevalence than the US as a whole (19.8%)?

# MCHB Goals for CSHCN

- **Community-Based Services** - ensure community services are organized for easy use by families
- **Early Continuous Screening** - Ensure children are screened early and continuously for special health care needs
- **Access to Medical Home/Access to Care\*/Unmet Needs\*** - increase the number of CSHCN who have a medical home that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective

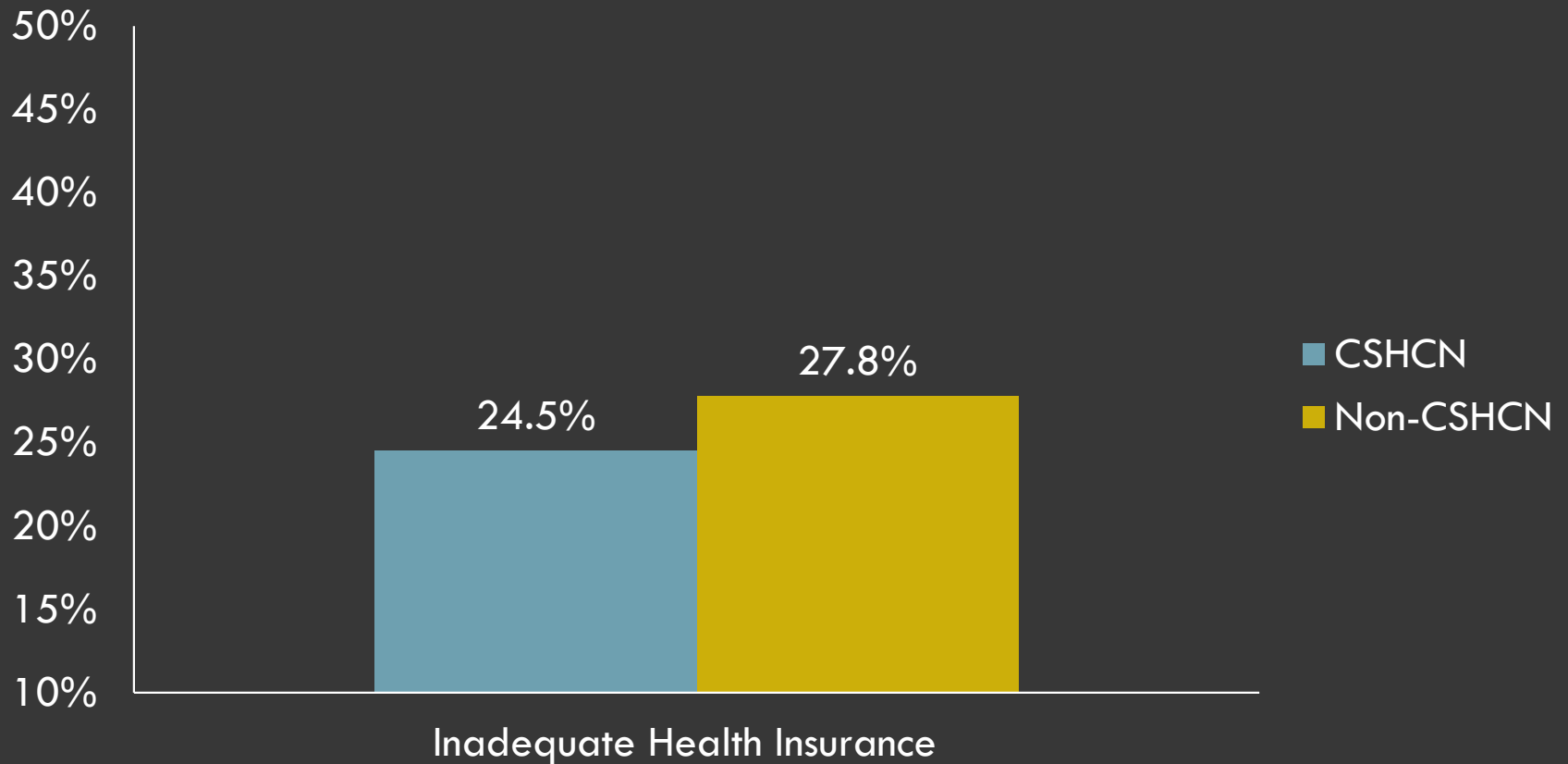
\*Not mentioned in MCHB goals, but may be implicit

# MCHB Goals for CSHCN

- **Transition to Adulthood** - increase the percentage of adolescents with SHCN who have received the services necessary to transition to all aspects of adult life, including adult health care, work, and independence
- **Adequate Insurance** - increase number of children who are adequately insured
- **Families as Partners** - Ensure families are partners in decision making

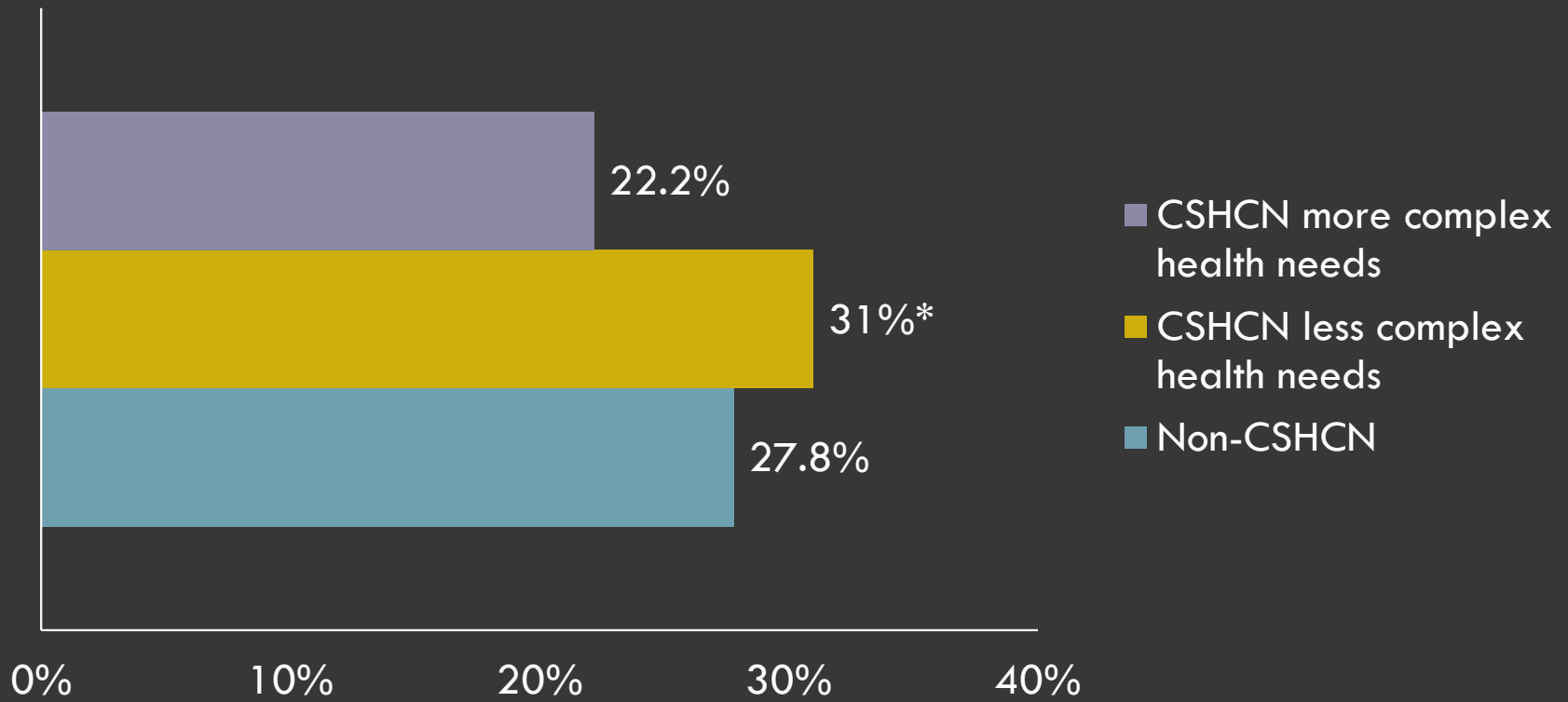
# Goal: Adequate insurance for CSHCN

## Inadequate Insurance for CSHCN in CA



# Goal: Adequate insurance for CSHCN

## Percent of Inadequate health insurance by complexity of need in CA

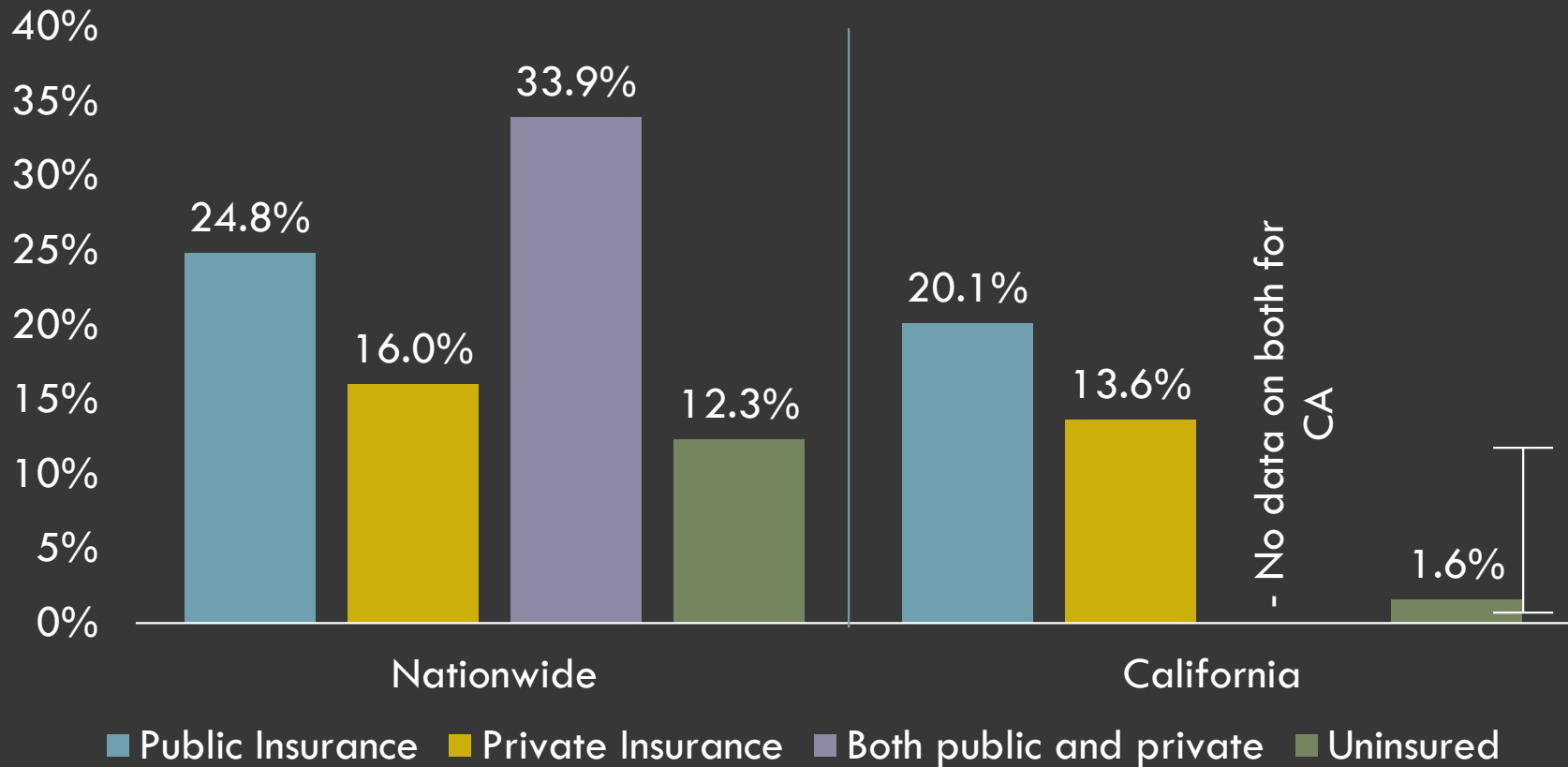


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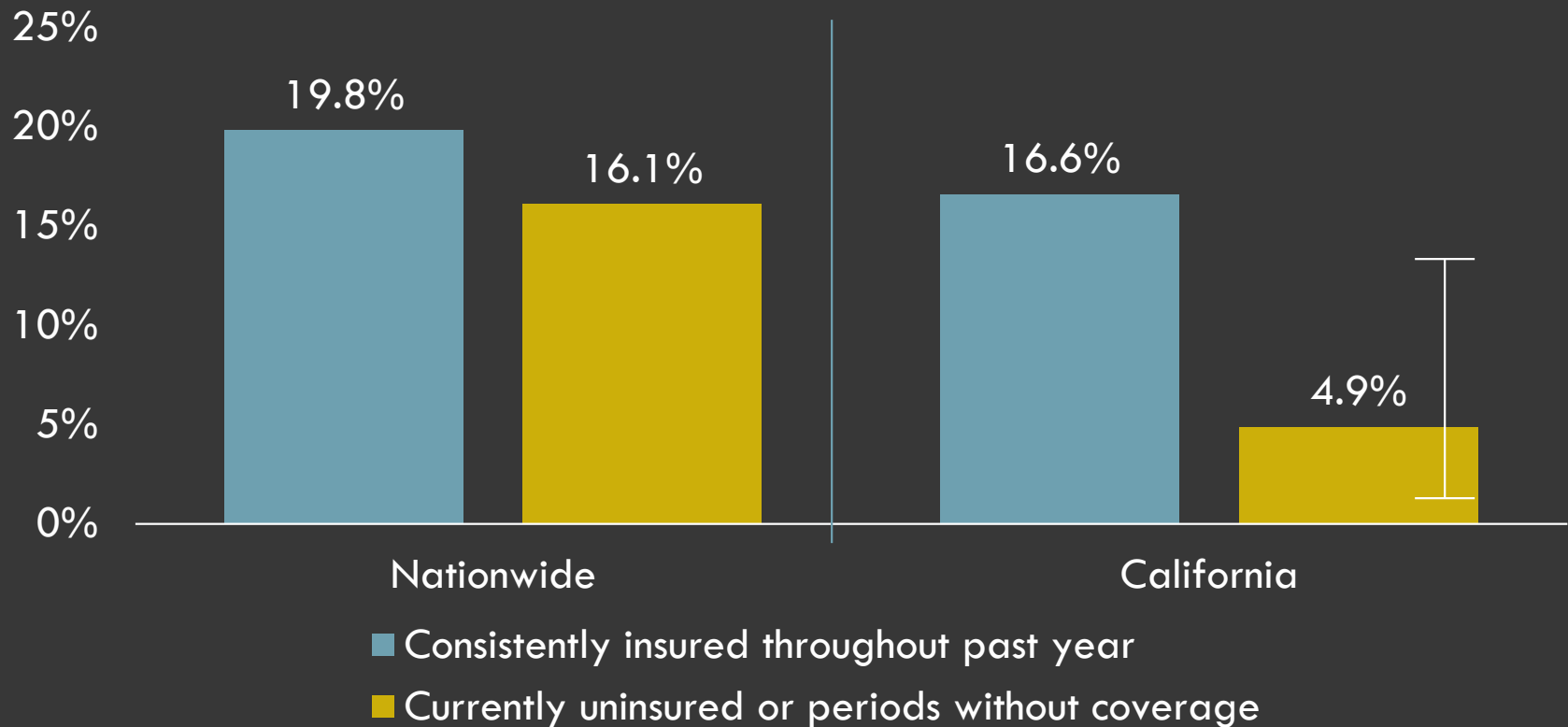
# Goal: Adequate Insurance for CSHCN AND Community-Based Services

## Private vs. Public Insurance for CSHCN in CA and the US



# Goal: Adequate Insurance for CSHCN AND community-based services

Percent of children with special health care needs (CSHCN), ages 0 through 17 with subgroup for consistency of health insurance coverage



# Goal: Access to Medical Home and Unmet Needs

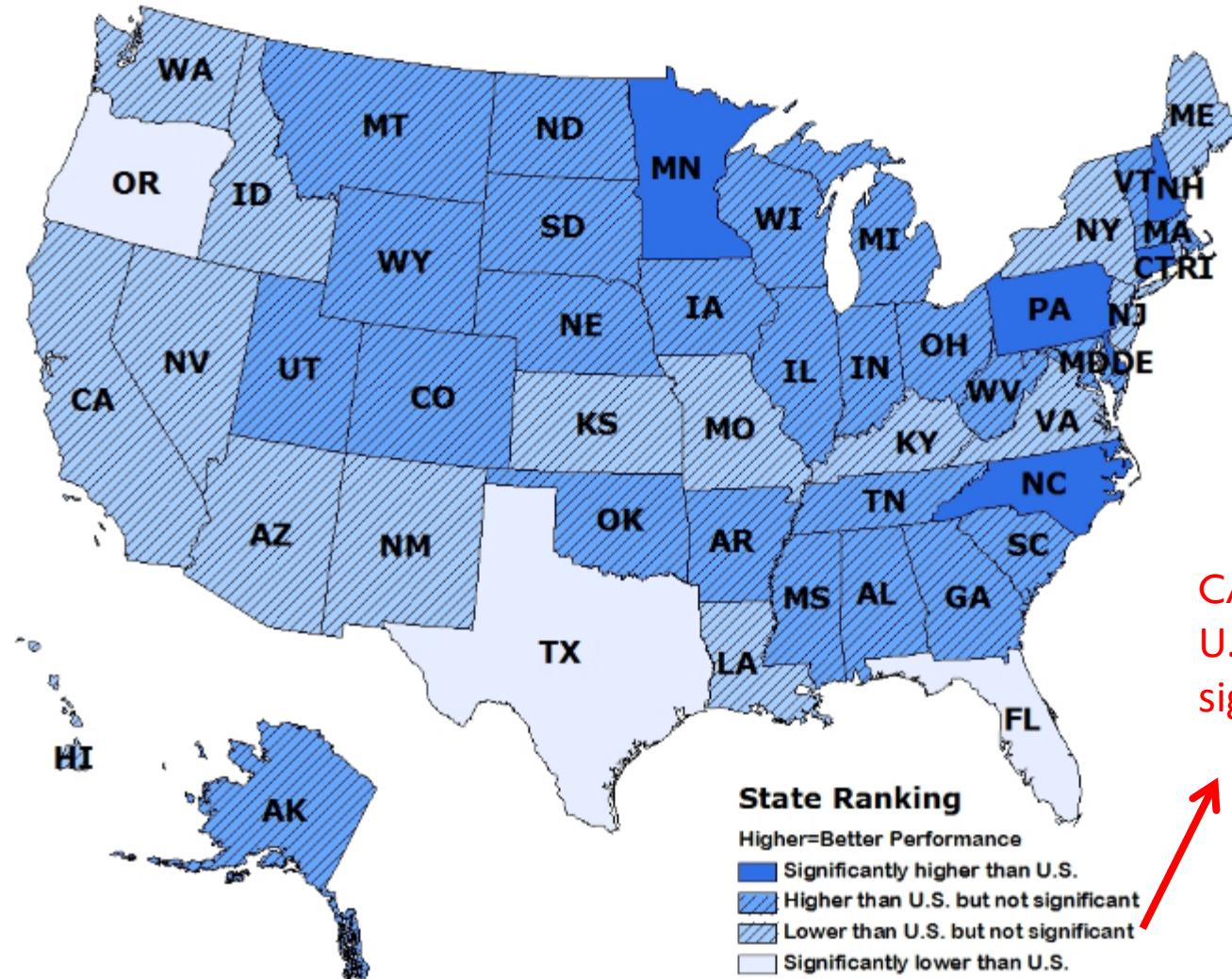
<b>National Performance Measure 11: Percent of children with special health care needs, ages 0 through 17, who have a medical home</b>		<b>Care MEETS medical home criteria</b>	<b>Care does NOT meet medical home criteria</b>
Nationwide	%	43.2	56.8
	Confidence Interval	(41.2 - 45.1)	(54.9 - 58.8)
	Sample Count	5,691	5,696
	Population Estimate	6,121,436	8,062,553
California	%	39.4	60.6
	Confidence Interval	(29.2 - 50.5) !	(49.5 - 70.8) !
	Sample Count	84	96
	Population Estimate	554,762	854,784

# Title V National Performance Measure #11: Percent of children with special health care needs, ages 0 through 17, who have a medical home

2016 National Survey of Children's Health

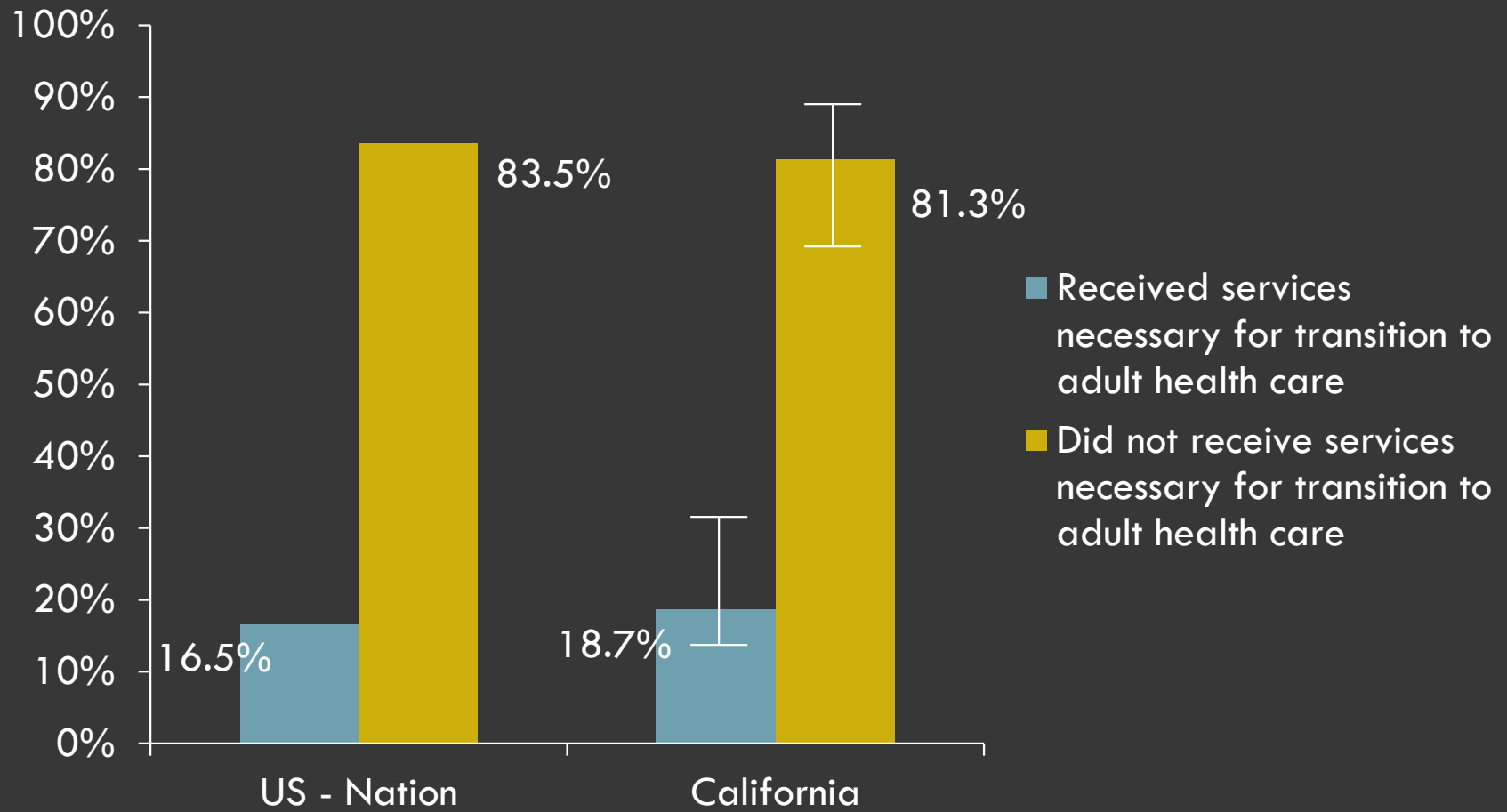
Nationwide: 43.2% of children met indicator

Range Across States: 31.3% to 57.4%

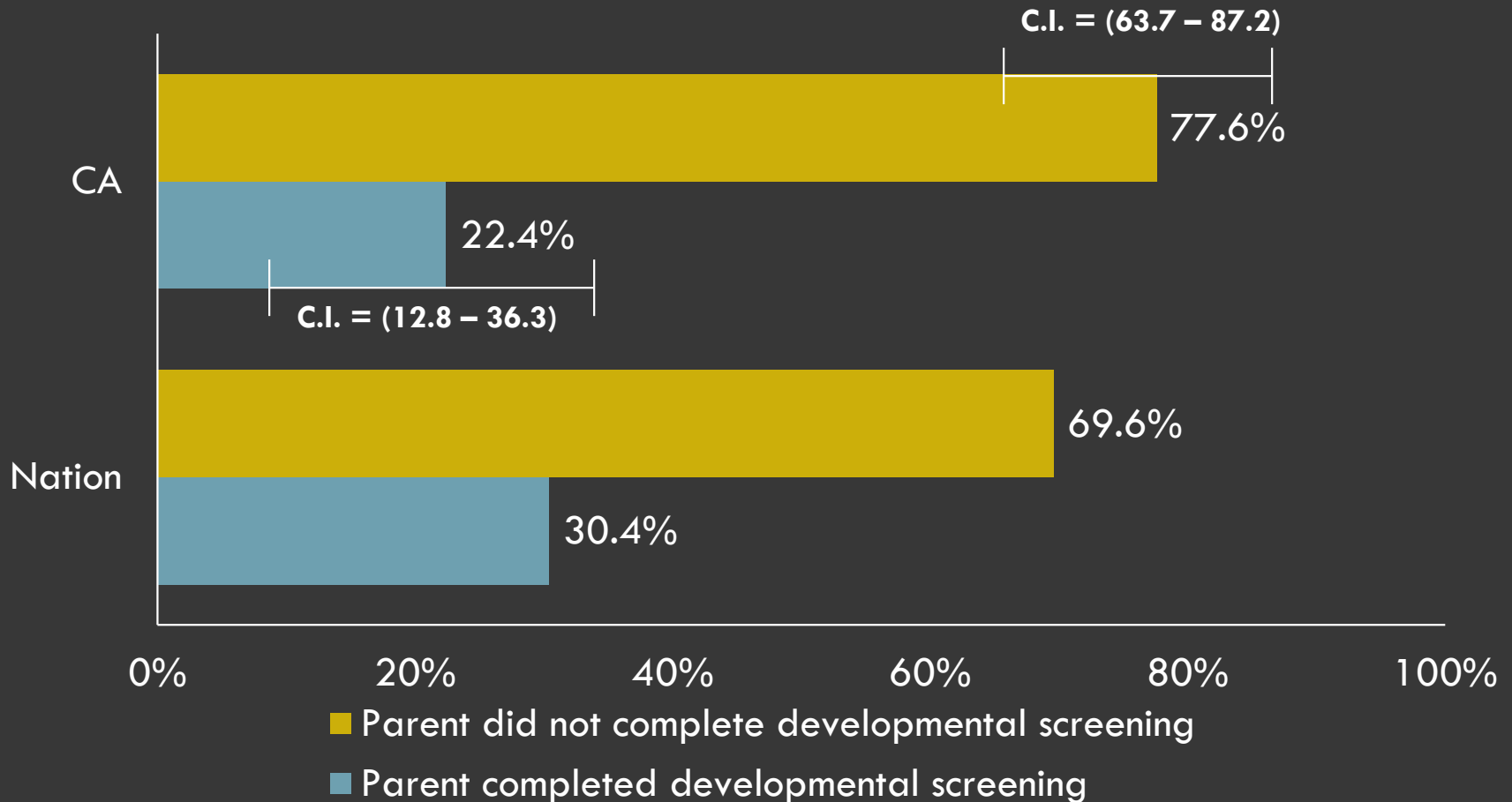


CA is ↓ than U.S. but not significantly

# Goal: Transition to Adult Care, CSHCN

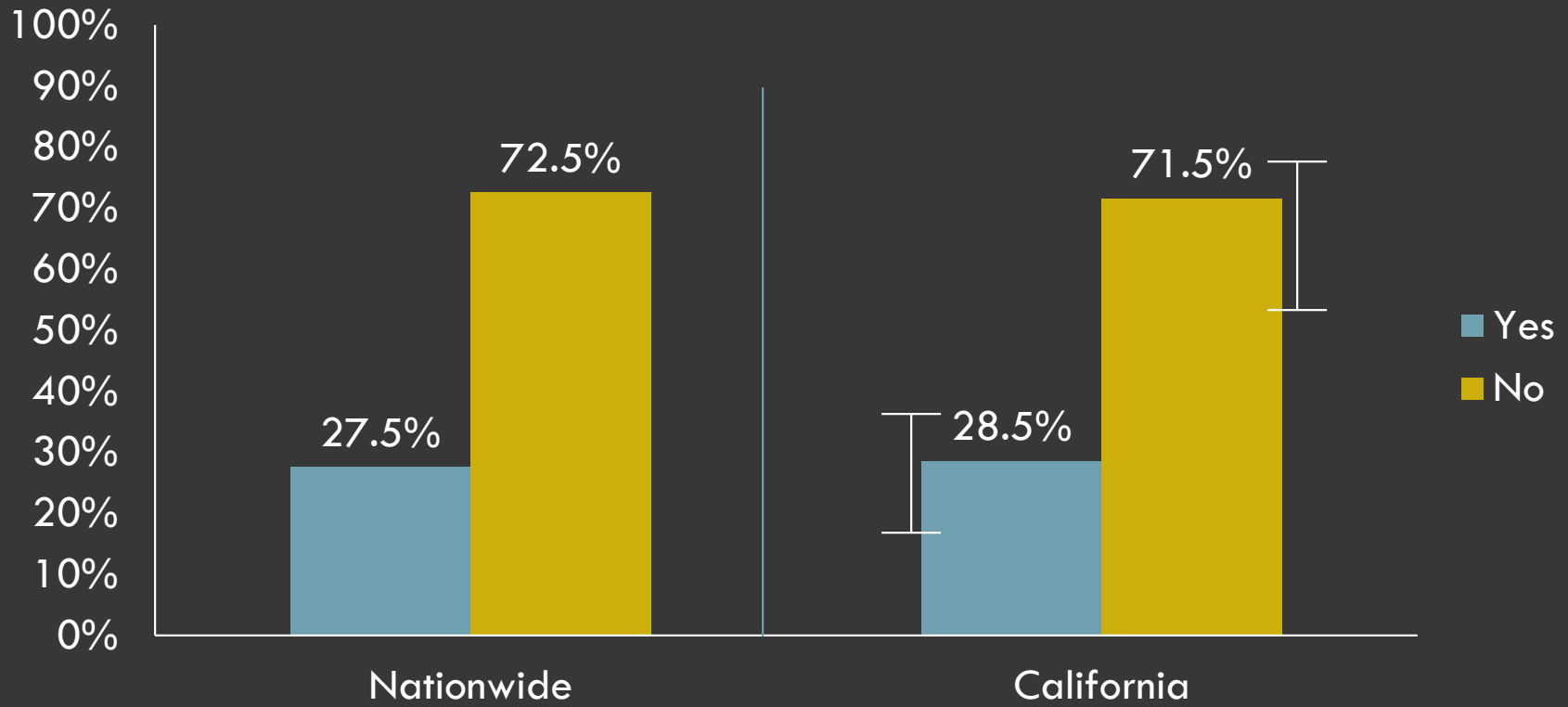


# Goal: Continuous Screening



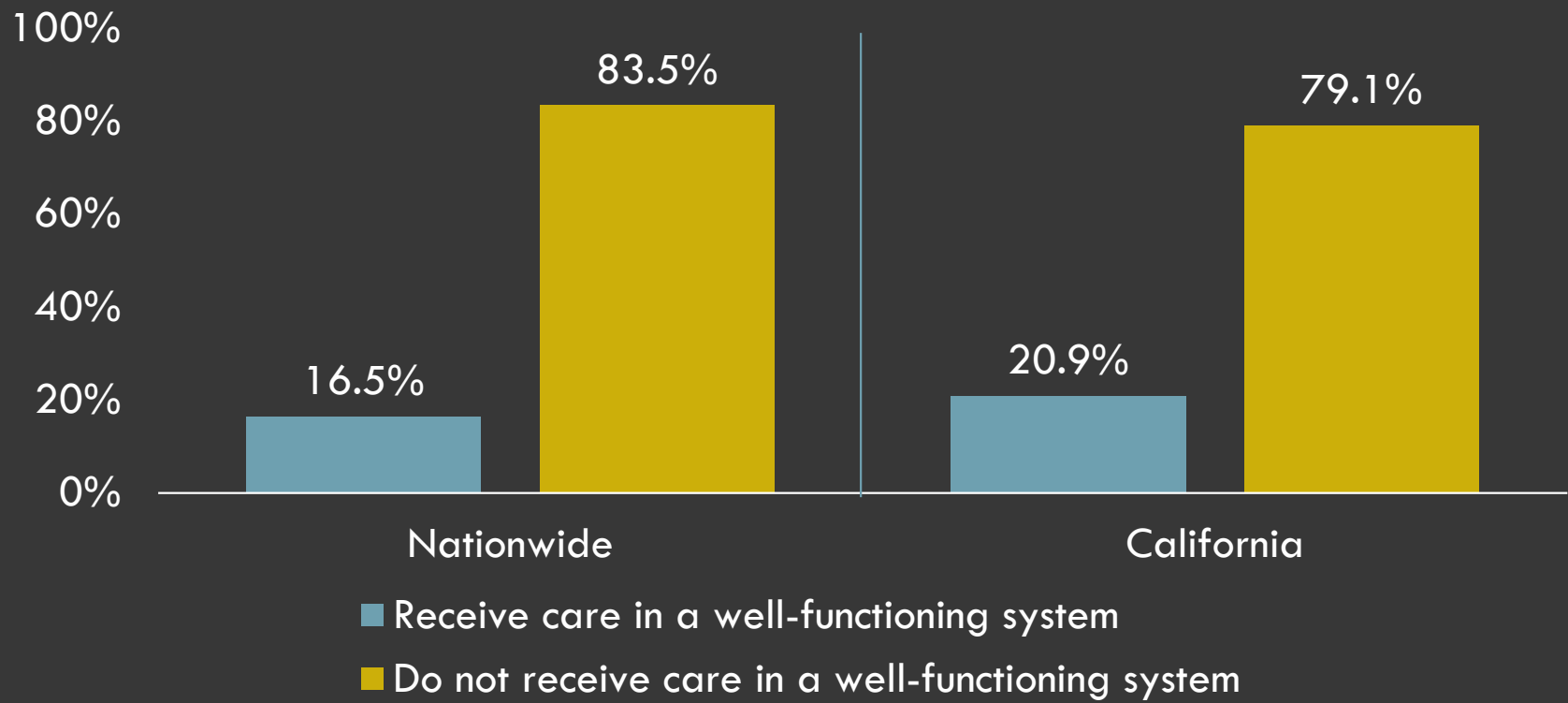
# Goal: Community-Based Services for CSHCN (Special Education)

Is this child, age 1-17 years, currently receiving services under a special education or early intervention plan?



# Goal: Community-Based Services and Unmet Needs

**National Outcome Measure 17.2: Percent of children with special health care needs (CSHCN), ages 0 through 17, who receive care in a well-functioning system**





# Data Implications

- **Community-Based Services**
  - CSHCN not receiving care within well-functioning systems
  - Special ED and early intervention services utilization is low
  
- **Early Continuous Screening**
  - Goals not met for the US and CA
  
- **Access to Medical Home/Access to Care/Unmet Needs**
  - The data are unreliable, but less than 50% for needs met for Medical Home (both CA and US)
  
- **Transition to Adulthood for CSHCN**
  - The majority are not receiving appropriate transition services in CA and nationally

# Data Implications

## □ Adequate Insurance

- Barely  $\frac{1}{4}$  of CSHCN are receiving adequate insurance in CA
- Adequacy of insurance is worse for those with more complex needs
- Most CSHCN in CA receive public insurance, but there are no data on uninsured

# References

- 1. Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health. 2016 National Survey of Children's Health (NSCH) data query. Retrieved [mm/dd/yy] from [www.childhealthdata.org](http://www.childhealthdata.org). CAHMI: [www.cahmi.org](http://www.cahmi.org).
- 2. Ghandour, R. M., Jones, J. R., Lebrun-Harris, L. A., Minnaert, J., Blumberg, S. J., Fields, J., ... & Kogan, M. D. (2018). The Design and Implementation of the 2016 National Survey of Children's Health. *Maternal and child health journal*, 1-10.

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