

# An Introduction to the Survey of Pathways to Diagnosis and Services, 2011

Rosa M. Avila, MSPH



Centers for Disease Control and Prevention  
National Center for Health Statistics

**SAFER • HEALTHIER • PEOPLE™**

**National Conference on Health  
Statistics**

**Washington, DC**

**August 7, 2012**

# Purpose

- Describe the design and content of the 2011 Survey of Pathways to Diagnosis and Services.
- Present key findings about the health care and diagnostic history of children with developmental conditions.
- Describe how researchers can access the data files to conduct their own analyses.



# Survey of Pathways to Diagnosis and Services, 2011

- **Sponsor:** National Institute of Mental Health, with American Recovery and Reinvestment Act funds.
- **Conducted by:** CDC's National Center for Health Statistics.
- **Survey sample:** The 2009-2010 National Survey of Children with Special Health Care Needs (CSHCN), a nationwide random-digit-dial telephone survey.
  - CSHCN: increased risk for chronic conditions and need health & related services beyond that required by children generally.

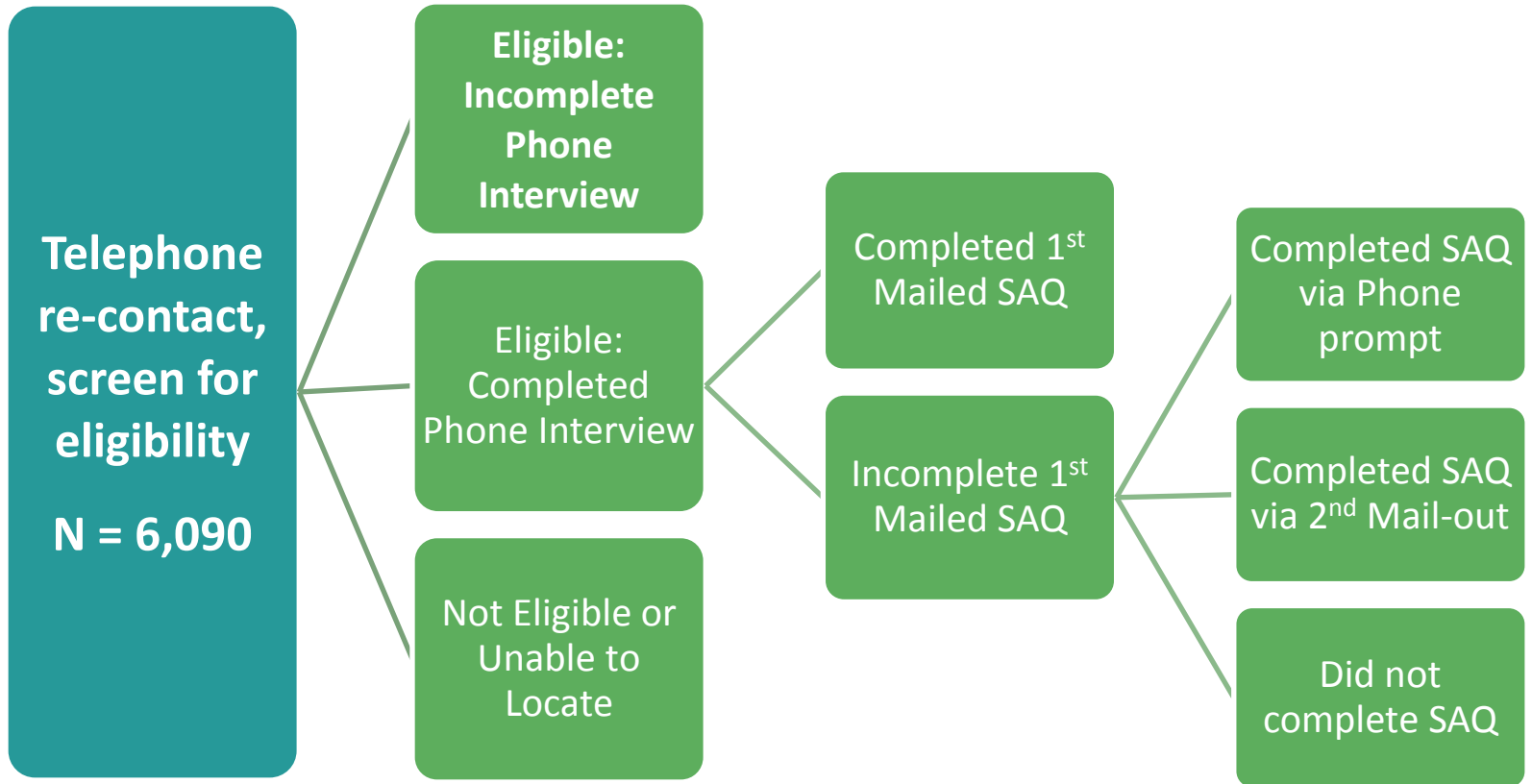


# Survey of Pathways to Diagnosis and Services, 2011

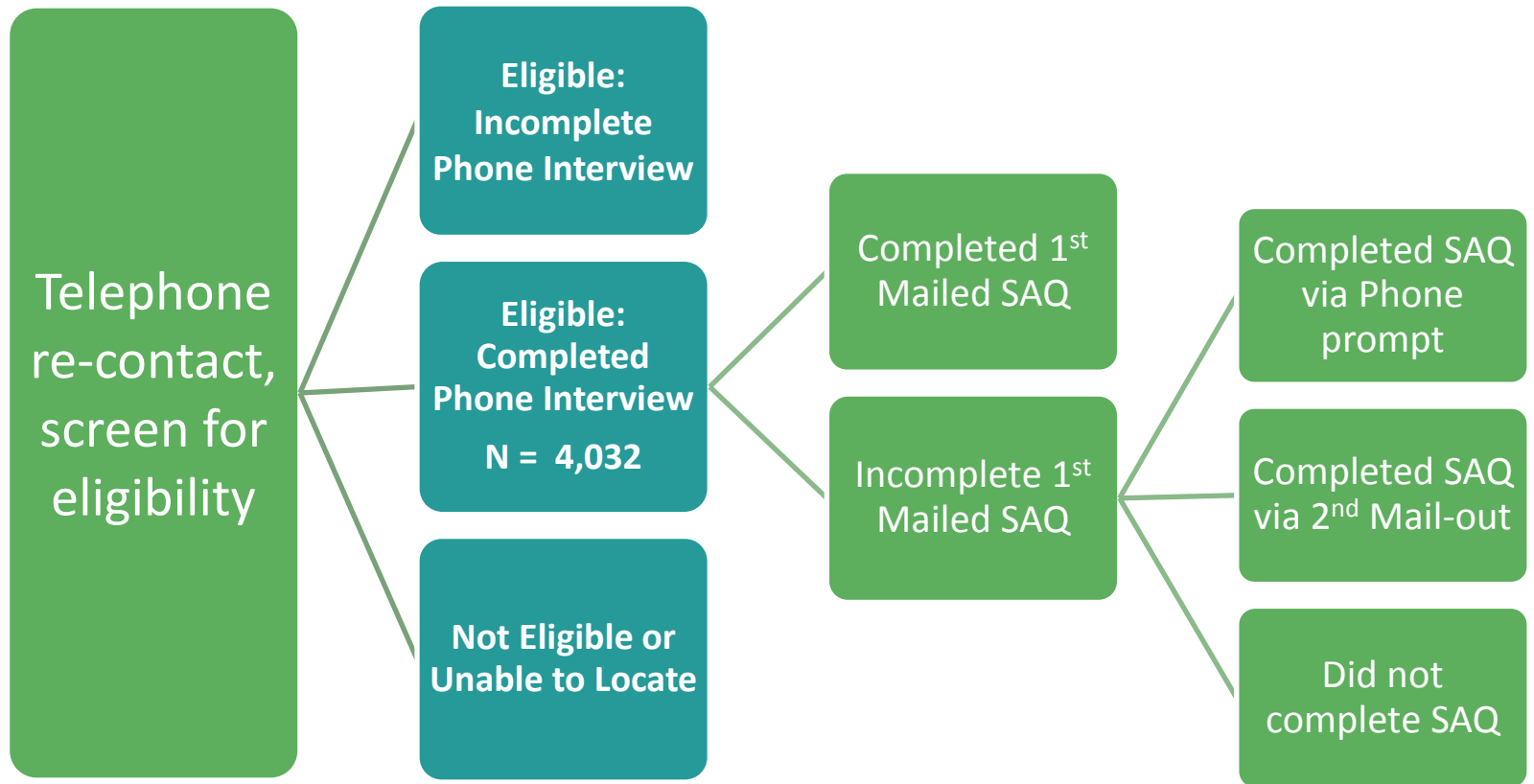
- **Eligibility:** CSHCN aged 6-17 years identified as having ever been diagnosed with Autism Spectrum Disorder (ASD), Intellectual Disability, and/or Developmental Delay.
- **Respondent:** Parent or guardian knowledgeable about the health of the child.
- **Mode:** Telephone survey followed by a mailed Self-Administered Questionnaire (SAQ).



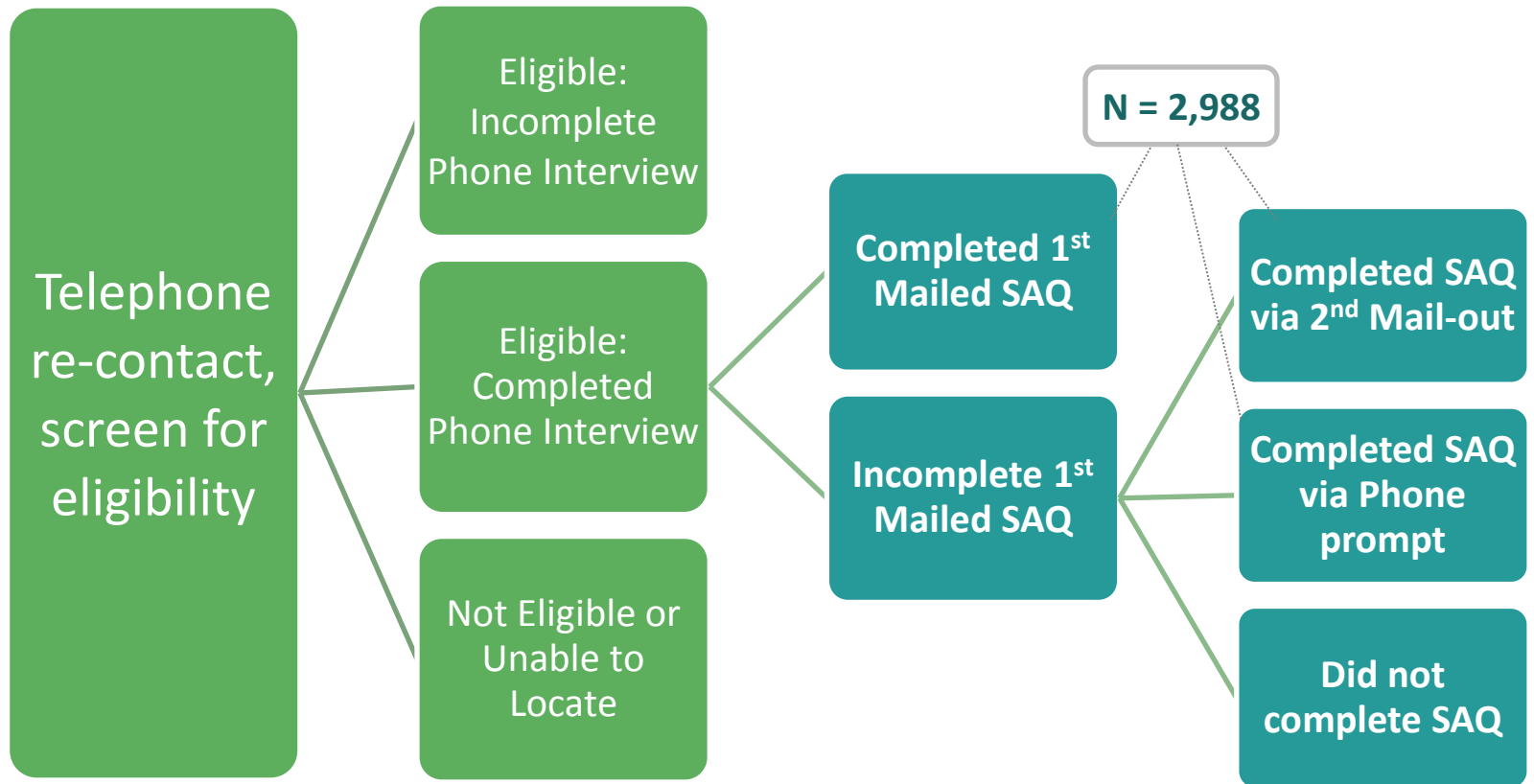
# Survey Design



# Survey Design



# Survey Design



# Sample Sizes

- 4,032 completed telephone interviews.
  - 1,420 CSHCN currently have **ASD**.
  - 657 CSHCN currently have intellectual disability (**INT**) but have no ASD.
  - 1,441 CSHCN currently have developmental delay only (**DEV**).
- Based on Parent/Guardian Report





# Content

Telephone Questionnaire - Emergence of symptoms; diagnostic experience; current behavioral, diagnostic, and functional status; clinical treatments and educational services used; and other parental concerns or perspectives.

SAQ - Includes the Children's Social Behavior Questionnaire, and the Strengths and Difficulties Questionnaire, and questions on the CSHCN's positive skills.



# What can you do with Pathways Data?

Analysis plan for the following examples:

- Compare CSHCN with ASD to INT and DEV.
- Data were weighted to permit nationally representative estimates.



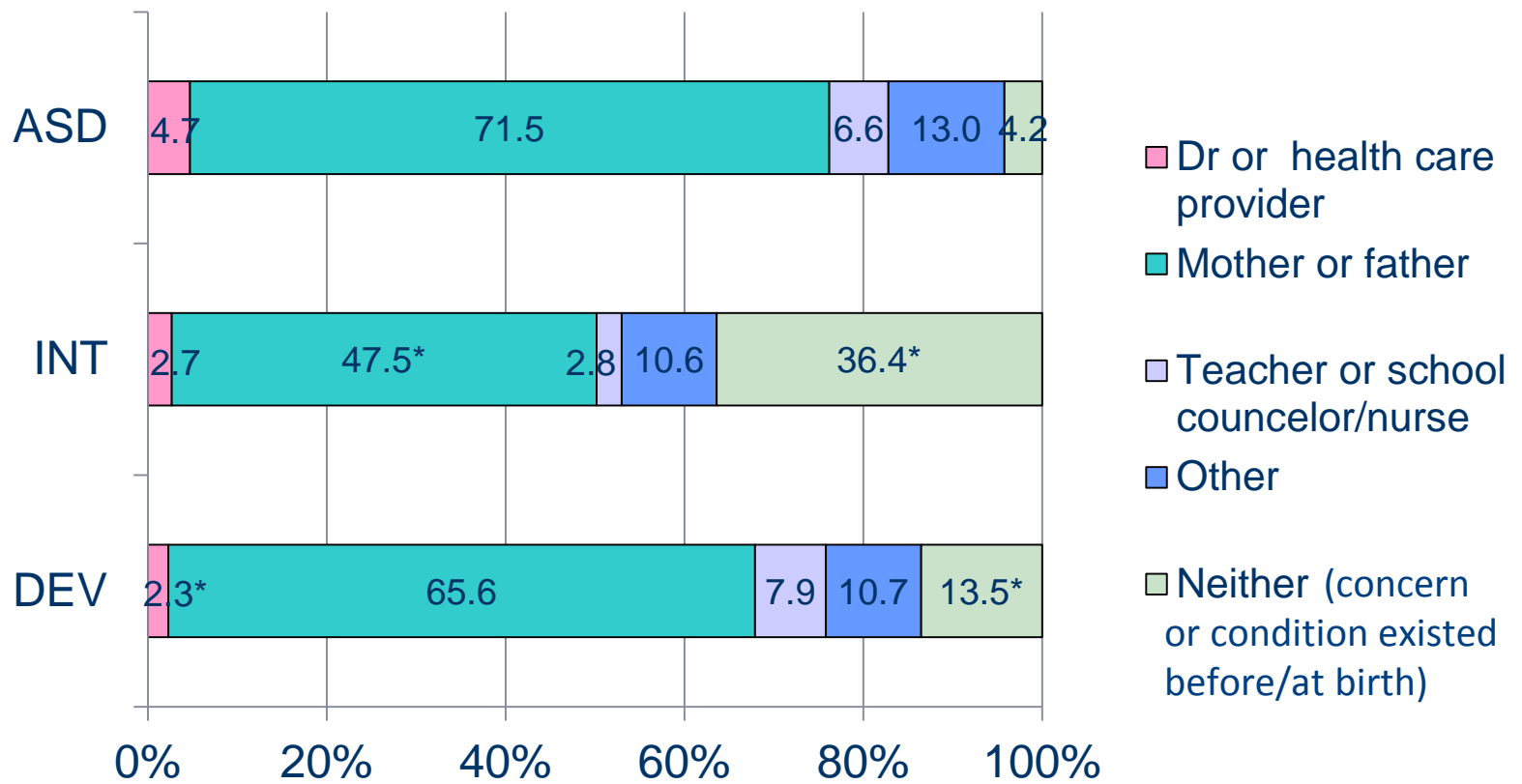
# Socioeconomic & Demographic Characteristics

<i>Selected Characteristics</i>	<i>Percent</i>		
	<i>ASD</i>	<i>INT</i>	<i>DEV</i>
<u><i>Sex</i></u>			
Male	82.1	51.4*	66.9*
Female	17.9	48.6*	33.1*
<u><i>Age in Years</i></u>			
6 to 11	54.7	42.0*	50.3
12 to 17	45.3	58.0*	49.7
<u><i>Race &amp; Ethnicity</i></u>			
Hispanic	13.0	11.0	14.5
Non-Hispanic Black	10.7	18.7*	18.4*
Non-Hispanic White	66.2	57.9	60.4
Non-Hispanic Other	10.1	12.4	6.8

\* Estimates are significantly different compared with ASD



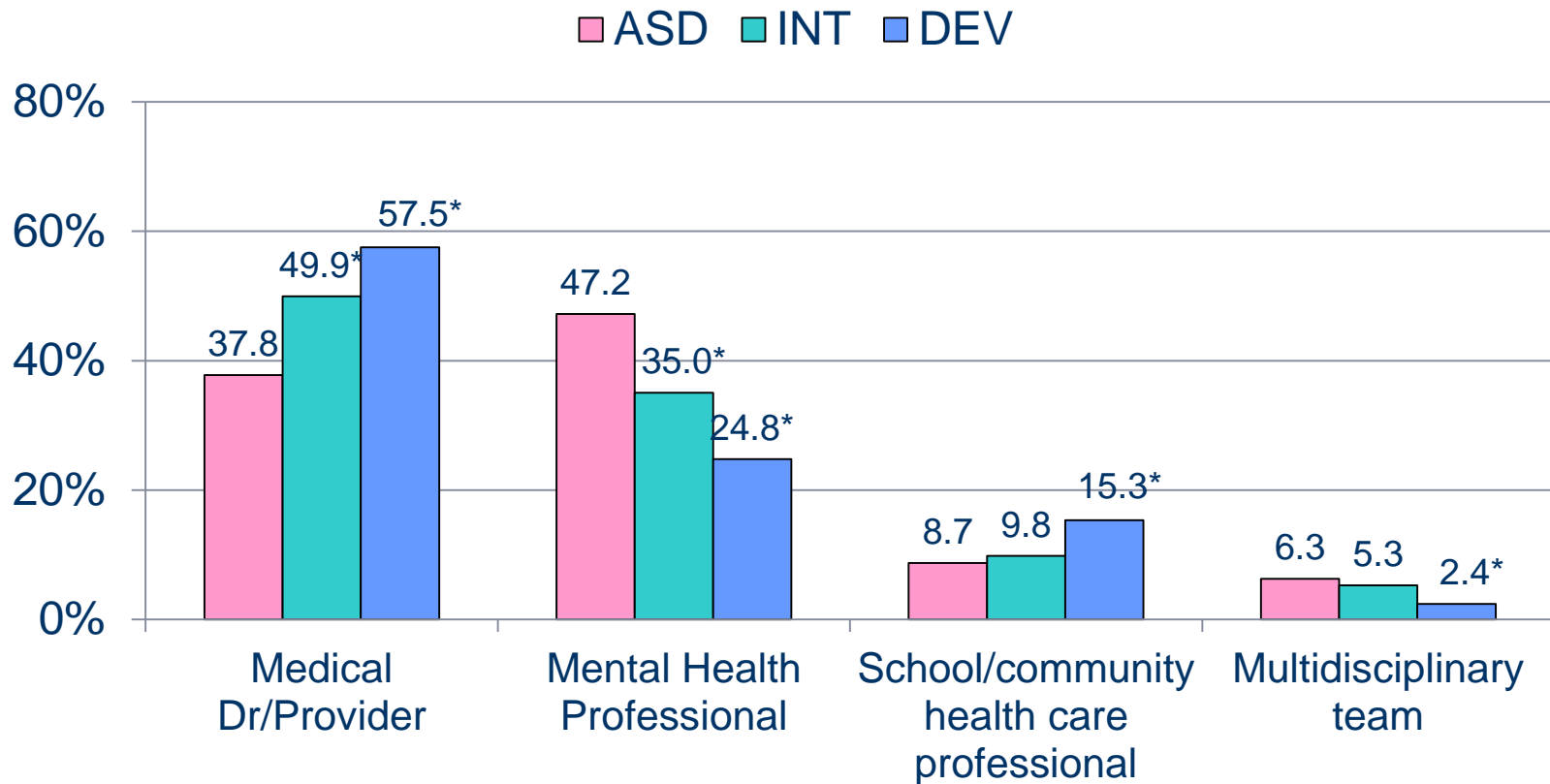
# Person First Concerned with Child's Development



\* Estimates are significantly different compared with ASD



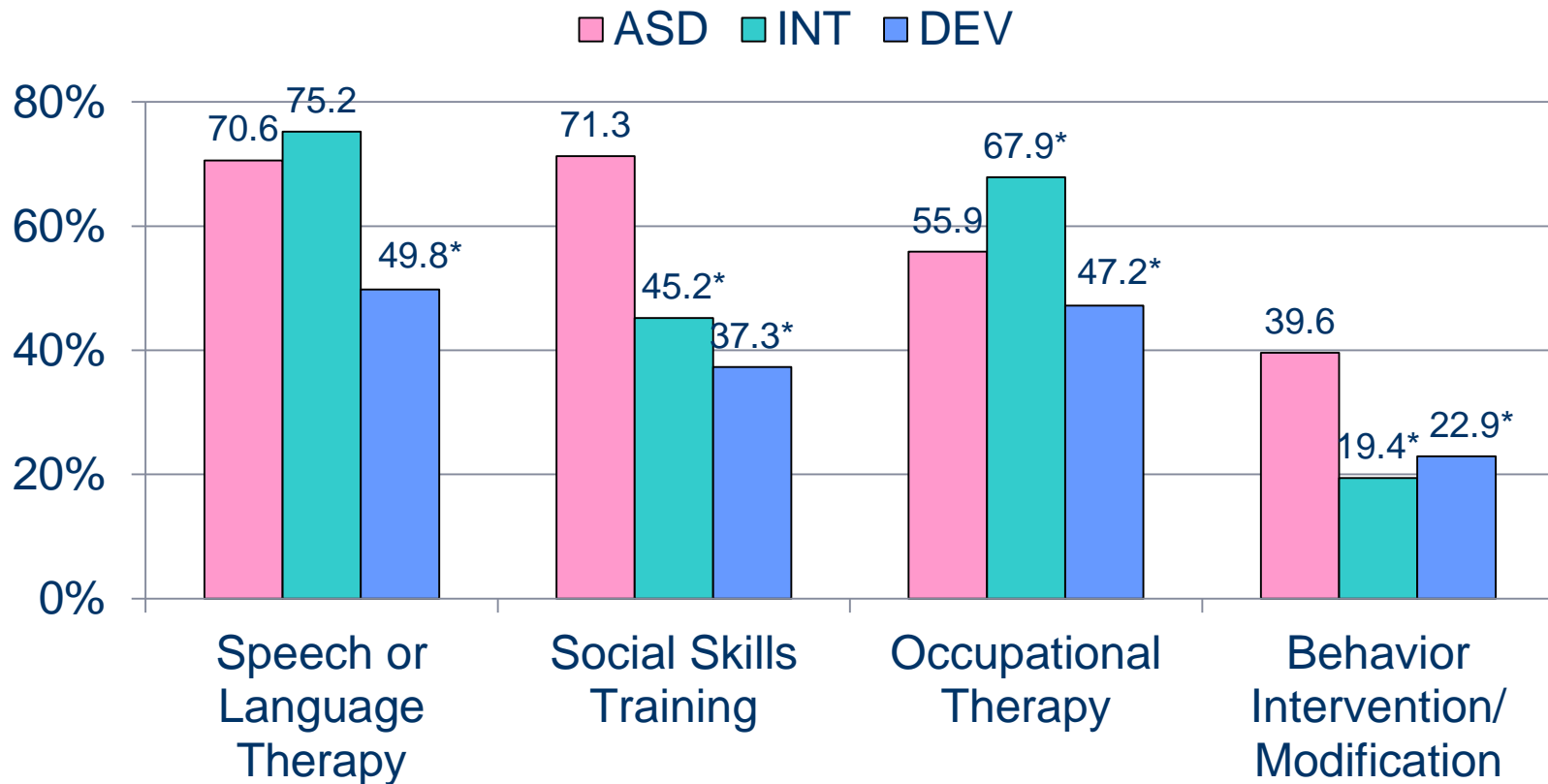
# Type of Doctor/Health Care Provider Who First Diagnosed Condition



\* Estimates are significantly different compared with ASD



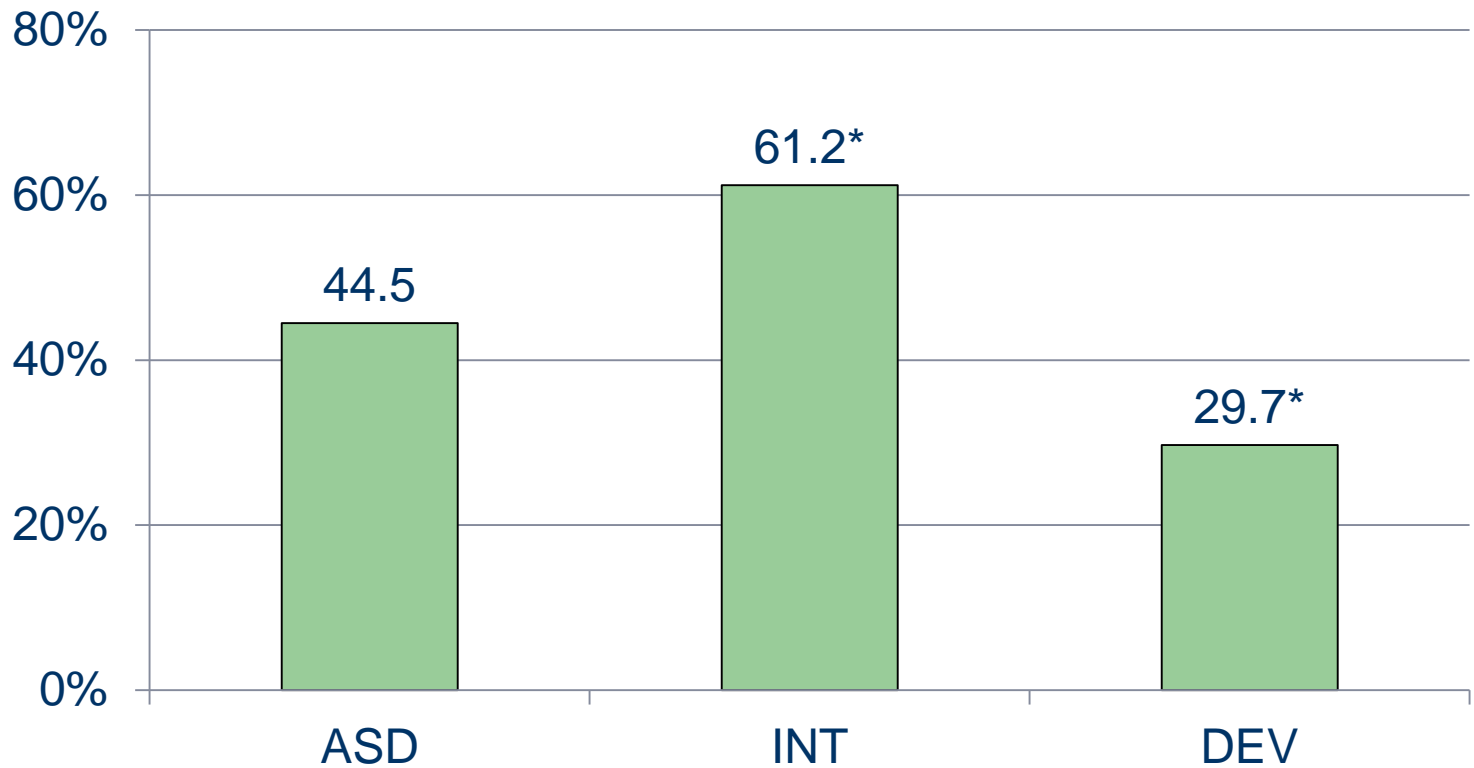
# Selected Health Care Services Currently Used



\* Estimates are significantly different compared with ASD



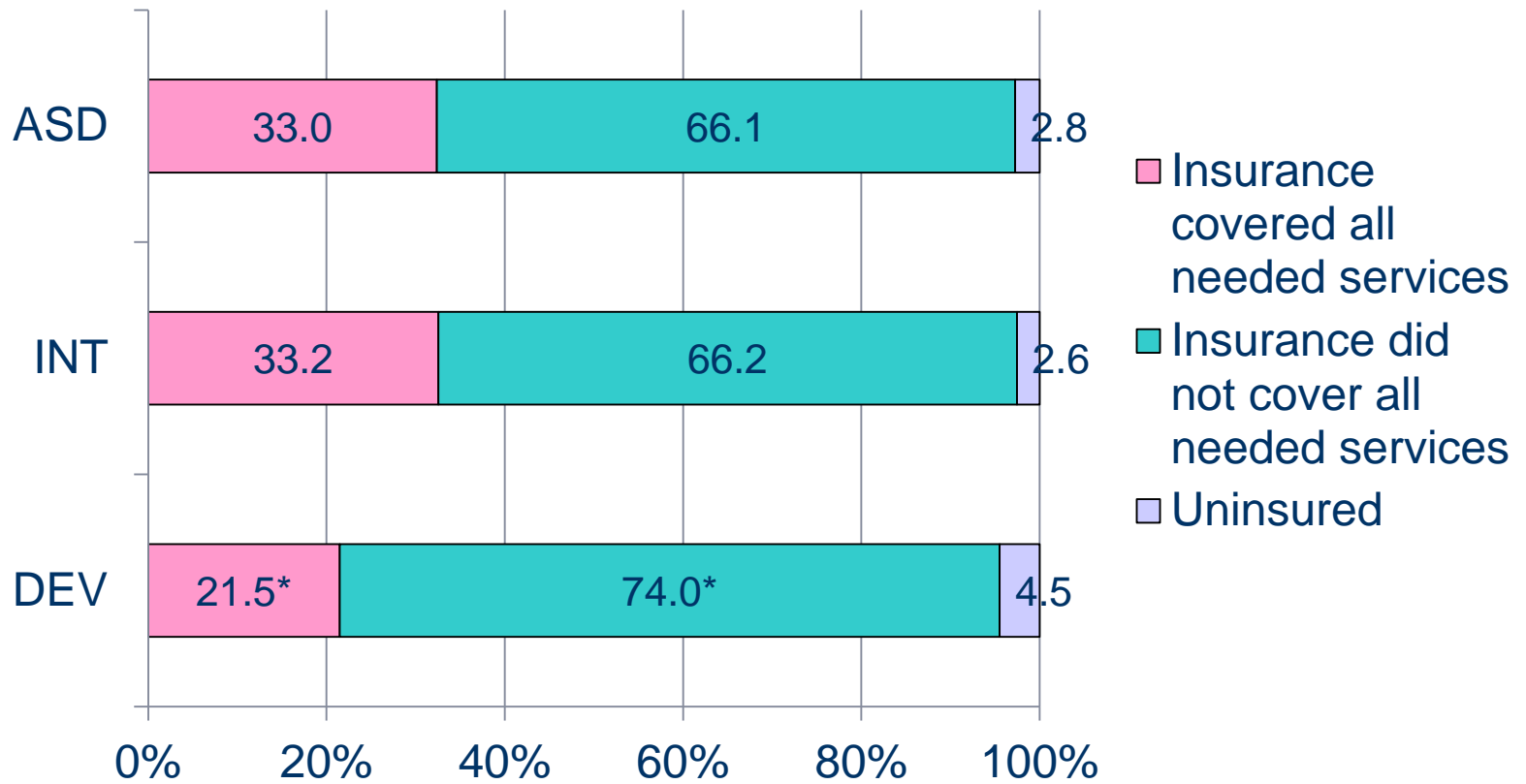
# CSHCN Who Received Early Intervention Services Before Age 3



\* Estimates are significantly different compared with ASD



# Adequacy of Health Insurance Coverage for Needed Health Services

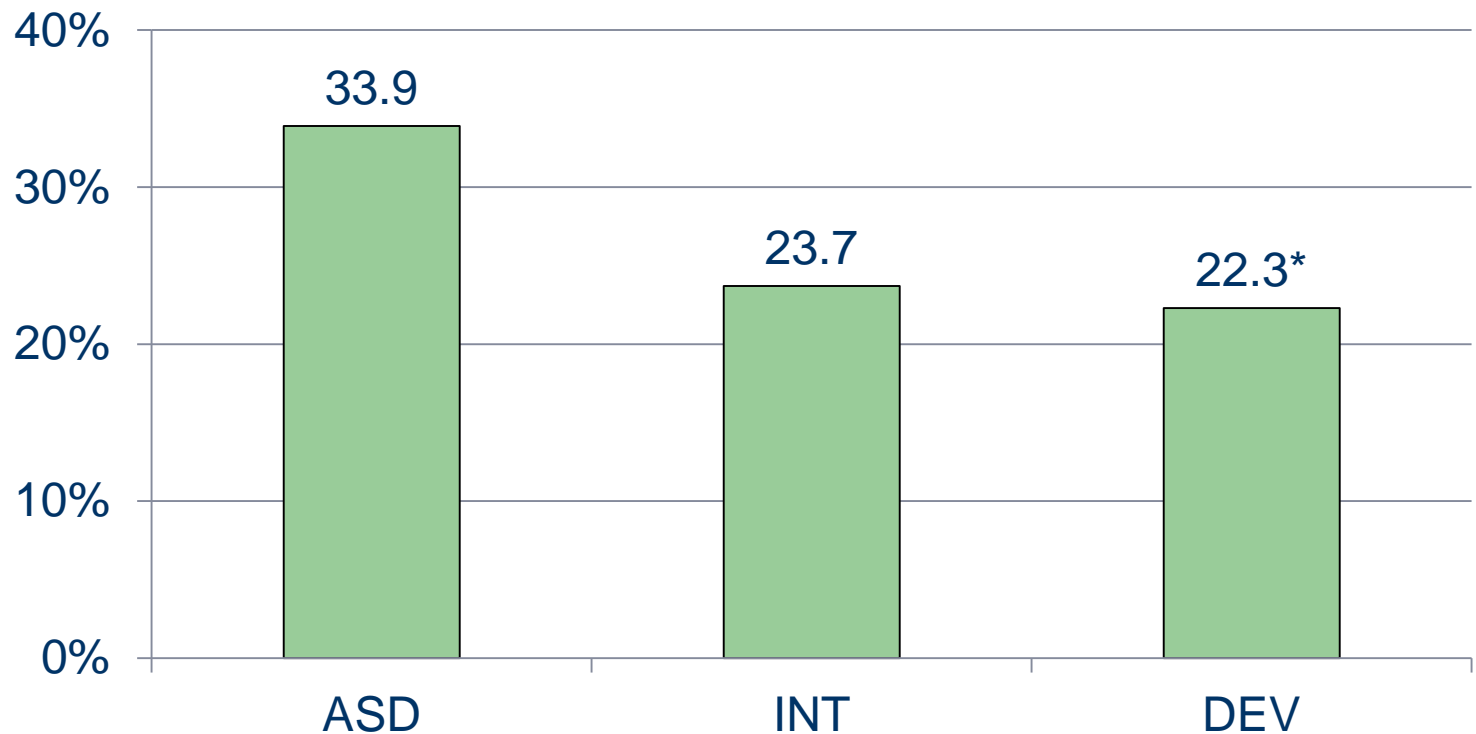


\* Estimates are significantly different compared with ASD





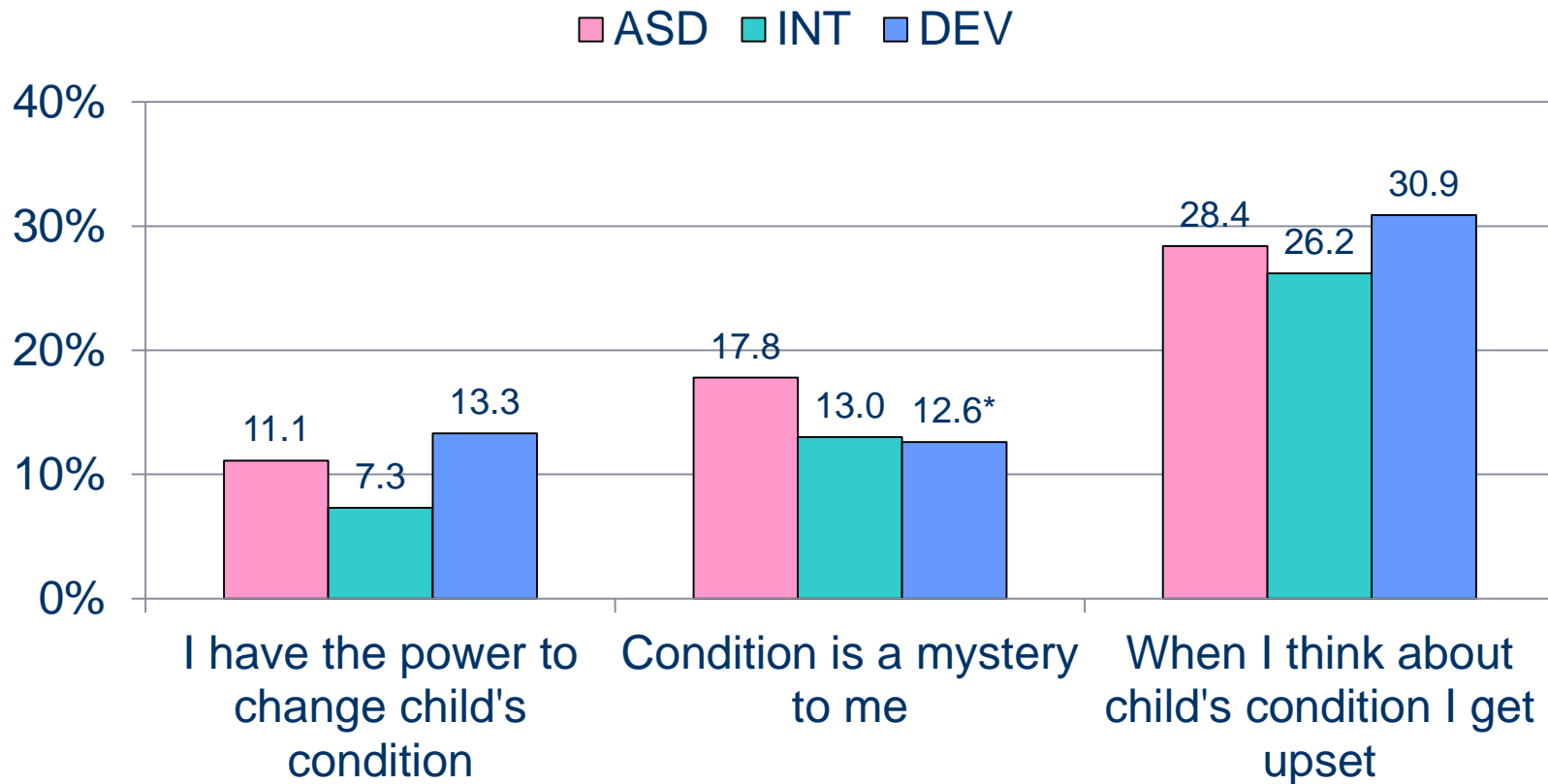
# CSHCN Who Ever Wandered Off or Became Lost in Past Year



\* Estimates are significantly different compared with ASD



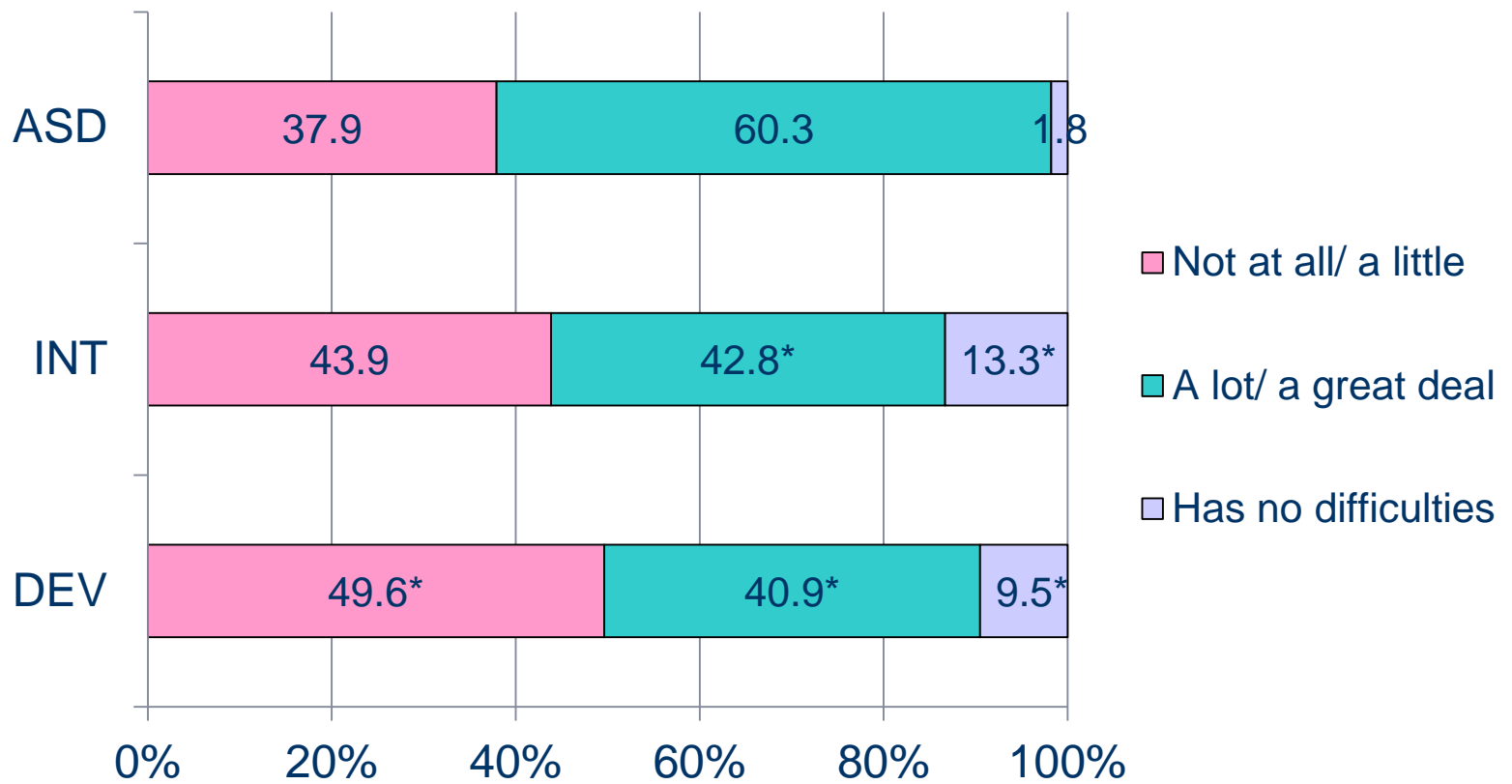
# Parental Perception: Parent/Guardian Definitely Agree



\* Estimates are significantly different compared with ASD



# CSHCN's Emotion, Concentration or Behavioral Difficulties Burden Family



\* Estimates are significantly different compared with ASD



# Analysis Using Pathways Data

*The Survey of Pathways to Diagnosis and Services provides the **largest nationally representative survey data on the health care and diagnostic history of CSHCN identified as having (or having had) ASD, INT, and/or DEV.***

- Data files and supporting materials are publicly available for anyone to use.
- Pathways data can be linked to the 2009-2010 NS-CSHCN.



# How to Access Pathways Data

The Pathways home page is located at:  
[www.cdc.gov/nchs/slaits/spds.htm](http://www.cdc.gov/nchs/slaits/spds.htm)

- The home page includes:
  - Data files and methodology reports
  - Questionnaires and codebooks
  - Sample SAS programs
  - Sampling weights for nationally representative estimates

Data not publically available can be accessed through the NCHS Research Data Center: [www.cdc.gov/rdc/](http://www.cdc.gov/rdc/)



# Now Available...

**Data Brief** titled, “*Diagnostic History and Treatment of School-Aged Children with Autism Spectrum Disorder and Special Health Care Needs*” on May 24<sup>th</sup>, 2012.

[www.cdc.gov/nchs/products/databriefs.htm](http://www.cdc.gov/nchs/products/databriefs.htm)



# Contact Info

SLAITS@CDC.GOV

Visit us at: [www.cdc.gov/nchs/slaits.htm](http://www.cdc.gov/nchs/slaits.htm)

