# How we know 1 in 71 children in Arizona have ASD

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# History of ASD Surveillance

- 1994 Centers for Disease Control and Prevention
  - Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)
- 1997 Brick Township, New Jersey
  - Children ages 3 – 10 years
  - AD 4.0 per 1,000
  - ASD 6.7 per 1,000

# History of ASD Surveillance

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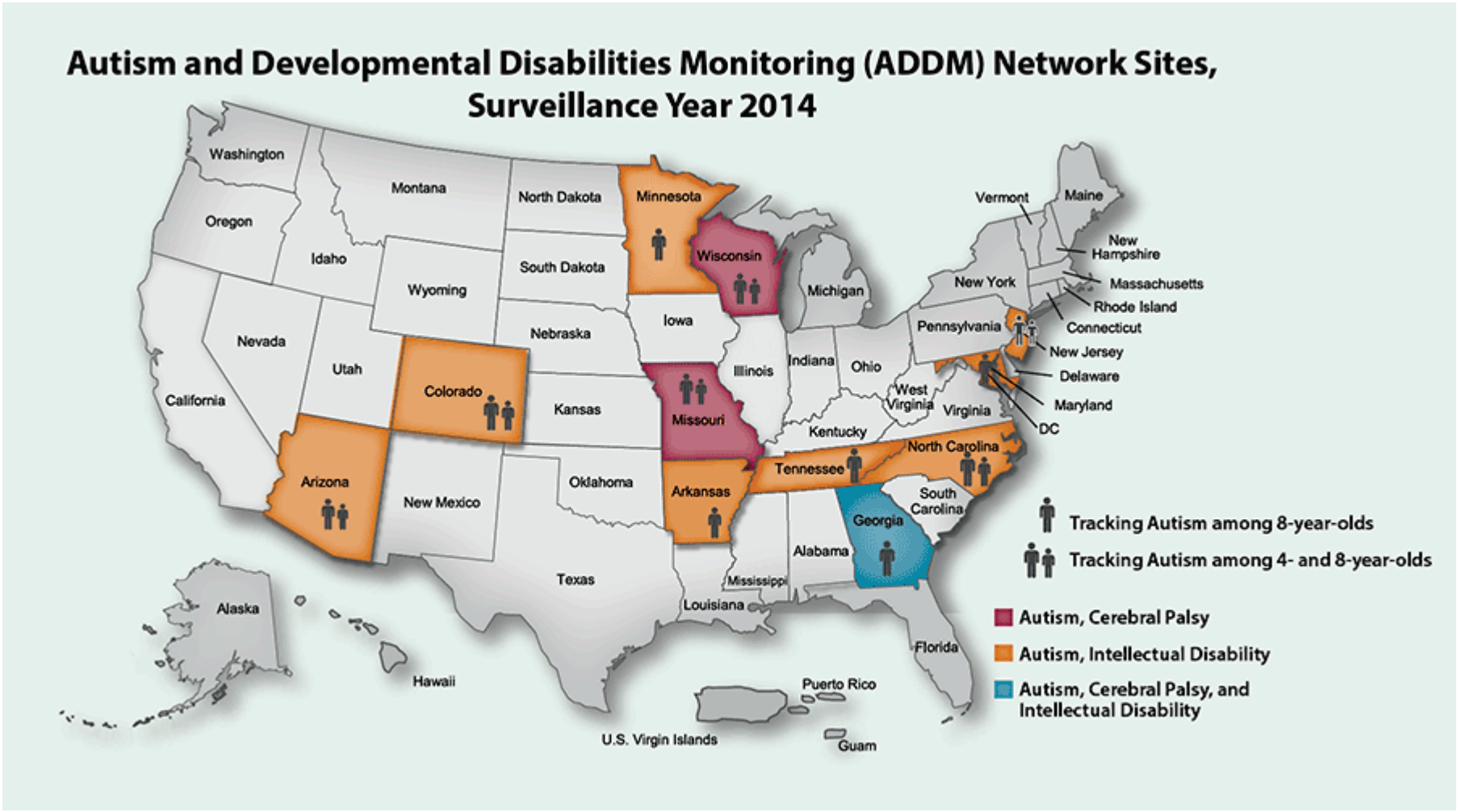
- 1997 Brick Township, New Jersey
- 2000 Autism and Developmental Disabilities Monitoring (ADDM) Network


Autism and Developmental Disabilities Monitoring (ADDM) Network Sites, Surveillance Year 2014
Washington
Oregon
California
Nevada
Idaho
Montana
Wyoming
Utah
Arizona
Colorado
New Mexico
North Dakota
South Dakota
Nebraska
Kansas
Oklahoma
Texas
Minnesota
Iowa
Missouri
Arkansas
Louisiana
Wisconsin
Illinois
Michigan
Indiana
Ohio
Kentucky
Tennessee
Mississippi
Alabama
Georgia
Florida
South Carolina
North Carolina
Virginia
West Virginia
Pennsylvania
New York
Vermont
Maine
New Hampshire
Massachusetts
Rhode Island
Connecticut
New Jersey
Delaware
Maryland
DC
Alaska
Hawaii
Puerto Rico
U.S. Virgin Islands
Guam
Tracking Autism among 8-year-olds
Tracking Autism among 4- and 8-year-olds
Autism, Cerebral Palsy
Autism, Intellectual Disability
Autism, Cerebral Palsy, and Intellectual Disability

# ADDM Network Goals

- Population-based ASD prevalence estimates
- Consistent methods for identification of people with ASD
- Answers
  - Is autism more common in some groups of children than in others?
  - Is the proportion with ASD changing over time?
  - What are the characteristics of the ASD population?

# Population-Based

- Inclusion
- Clinic-based studies
  - Biased toward children with access to clinical services

# MADDSP Method

## Multisource, records-based methodology

Screen health and education records (multiple data sources) in community

↓

Abstract information in records

(e.g., behaviors related to ASD, co-occurring conditions, and test data)

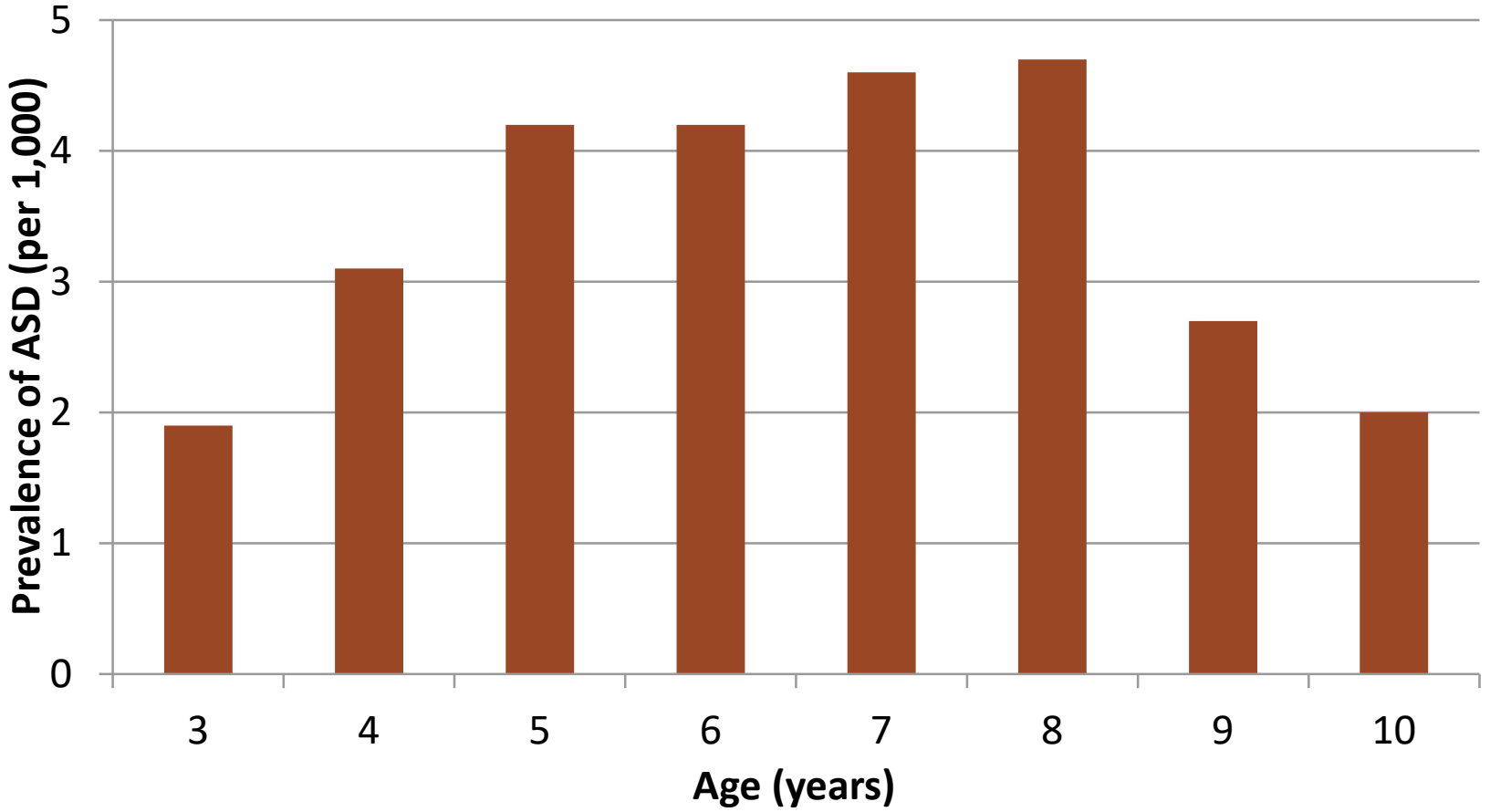
↓

Review abstracted information to determine if the child meets case definition(s)

# ADDSP

- Arizona Developmental Disabilities Surveillance Program
  - Goals of the Study
    - Determine the prevalence of autism spectrum disorders among children age 8 in Maricopa County
    - Determine the characteristics of children with ASD
      - Where they receive services
      - Age at diagnosis
      - Proportion with comorbid intellectual disabilities
      - Demographic characteristics
      - Is prevalence changing over time?

# MADDSP 1996



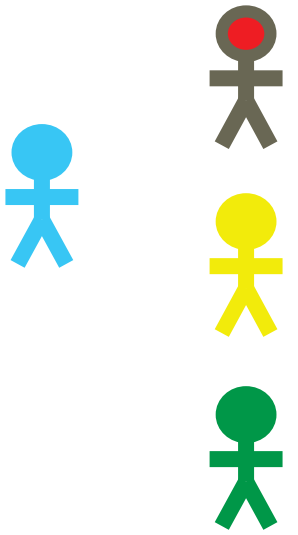

Rice C & Karapurkar T. CDC Seminar, February 2002.

# Data Collected

- Demographic, educational, medical
  - Child / maternal identifiers
  - DOB, race, gender
  - 1° exceptionality
  - Developmental / psychometric tests
  - Medical conditions
  - Other DD
- Behavioral
  - Verbatim abstraction of behavioral observations

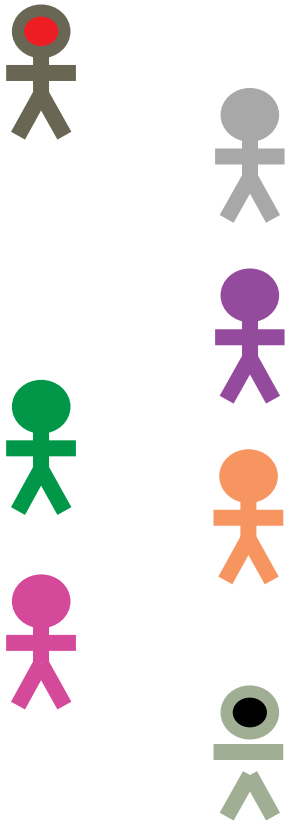
# Why We Need Personal IDs

**Clinic 1(n=4)**



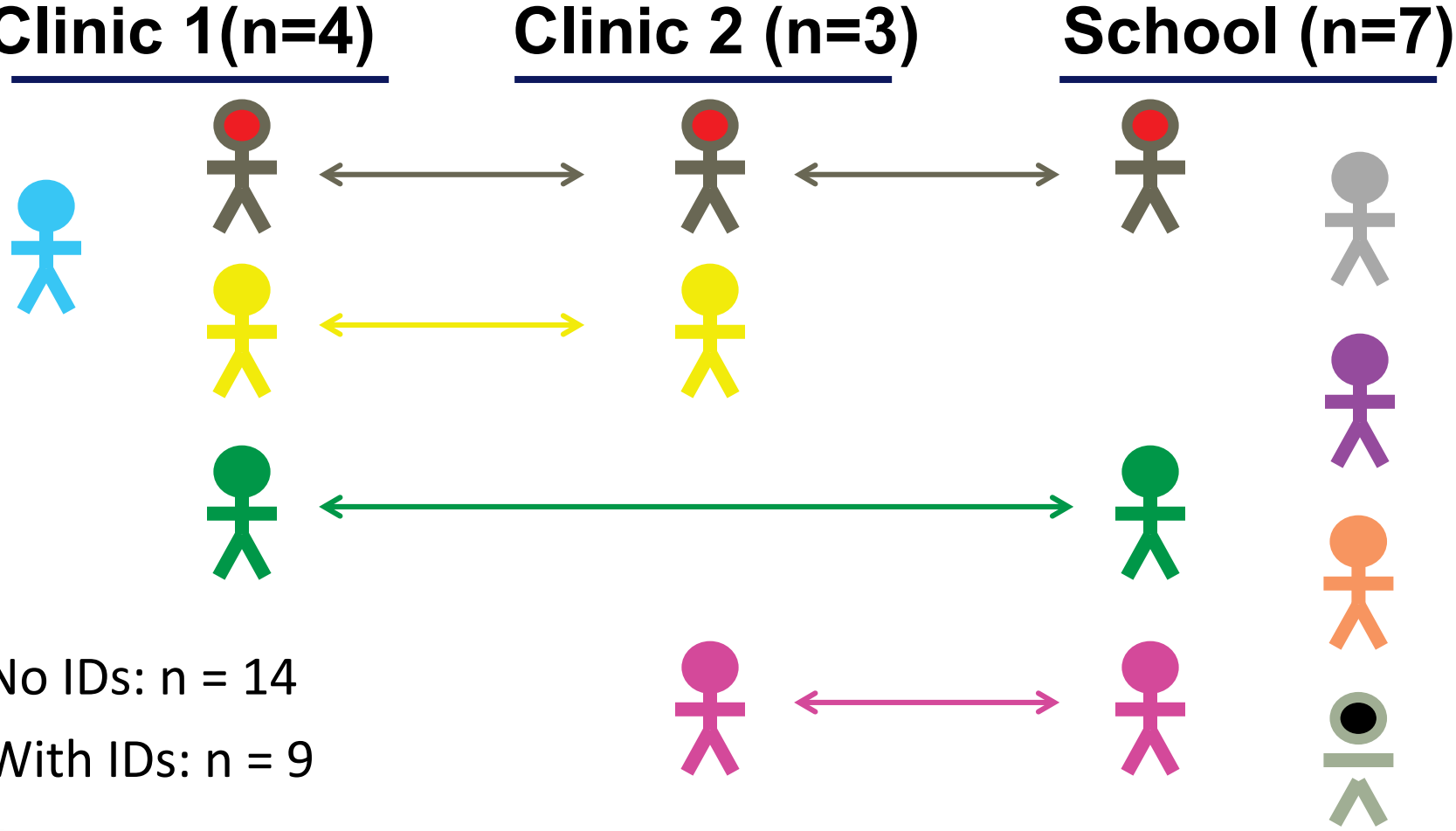
**Clinic 2 (n=3)**

**School (n=7)**



No IDs: n = 4 + 3+ 7 = 14

# Why We Need Personal IDs



# Confidentiality & Data Security

# HIPAA

- Health Insurance Portability & Accountability Act
- Federally-mandated privacy protections for certain individually identifiable health information

# HIPAA & Public Health

- HIPAA permits protected health information (PHI) disclosures w/o written patient authorization for specified public health purposes to public health authorities legally authorized to collect and receive information for these purposes
- Also permits disclosures that are required by state and local public health laws

# FERPA

- Family Educational Rights and Privacy Act
- Federal law protecting privacy of student educational records
- Applies to all schools receiving funds from U.S. Dept. of Education

# FERPA

- FERPA exemption
  - The agency may disclose personally identifying information from a students record without parental **if the disclosure is to an organization conducting studies for, or on behalf of, education agencies or institutions to improve instruction**. 34 CFR 99.31(a)(6)(i)(C)
  - The organization must conduct the study in a manner that does not permit personal identification of parents and students by individuals other than representatives of the organization and must destroy the information when no longer needed for the purposes for which the study was conducted. 34 CFR 99.31(a)(6)(ii)(A) and (B)

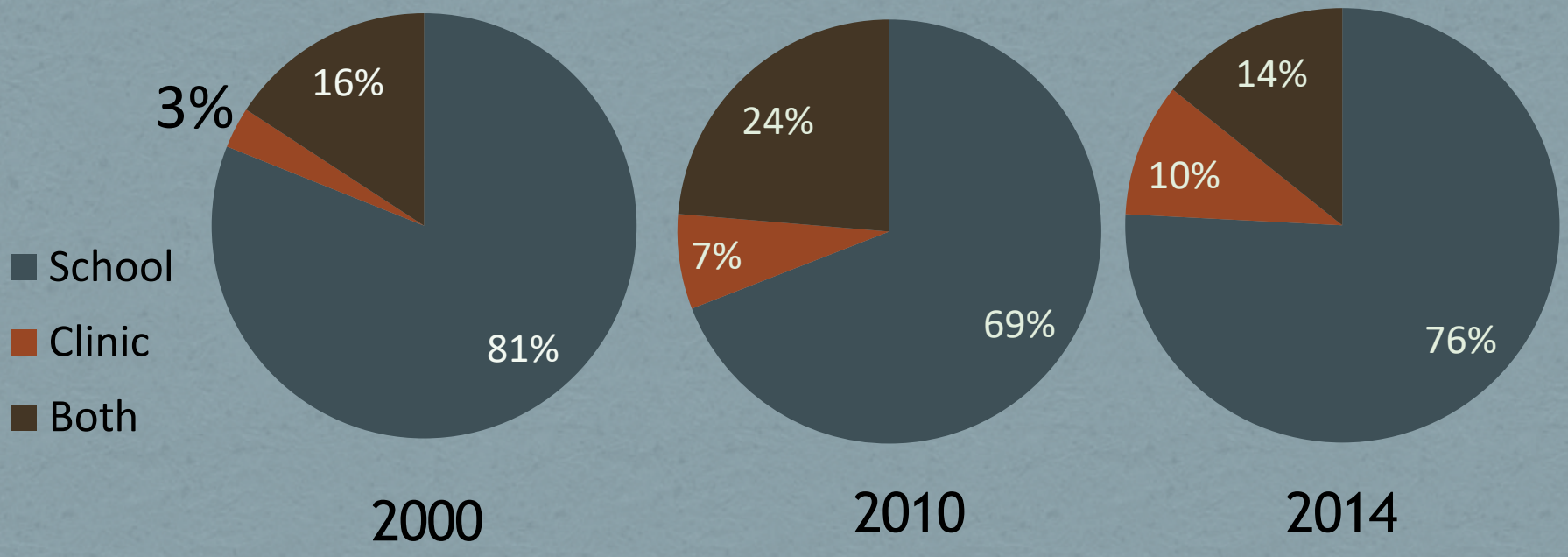
# Data Confidentiality & Security

- Training
  - Confidentiality and security protocols
    - Shielding record
    - Laptop storage
    - Awareness of surroundings if engaging in necessary discussion
    - Laptop locks
    - No faxing or emailing of data
    - No personal identifiers shared with outsiders (not even CDC)
    - Random rounding / truncation of census data
- Technology
  - Fully encrypted hard drive
  - Secure database

# AZ Data Sources

- Special Educational Records
  - All public schools in selected districts in Maricopa County
- Clinical Records
  - Phoenix Children's Hospital
  - St. Joseph's Hospital Developmental Clinic (now defunct)
  - Future: Banner Health

# Educational/Clinical Data AZ 2000, 2010, & 2014



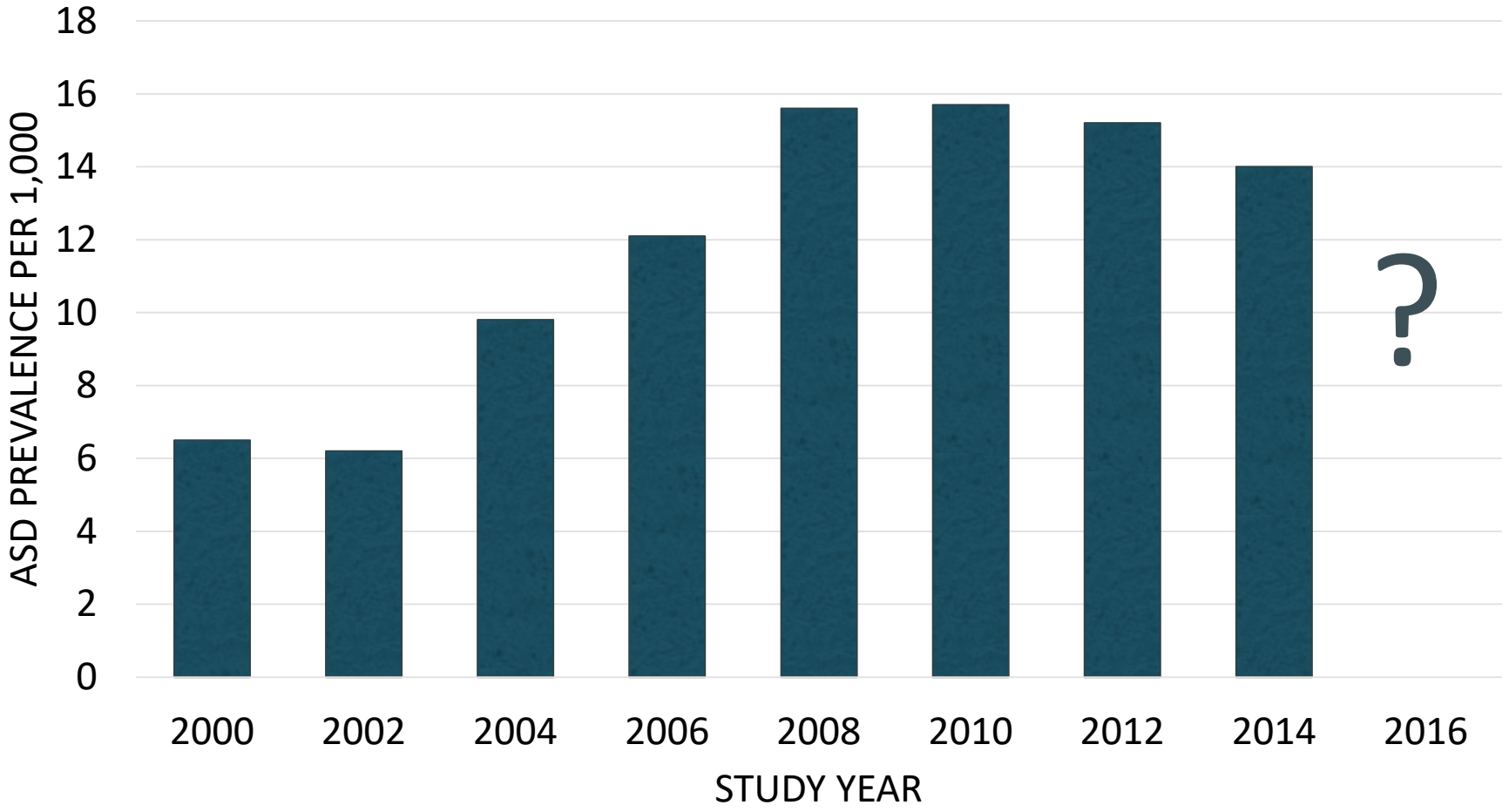
# MADDSP Method - Advantages

- Population-based rather than administrative-based
- Gathers information on case status, co-occurring conditions, and ages of evaluation and diagnosis
- Collects information from multiple sources (i.e., education and health sources)
- Collects information the same way using the same criteria for all children
- **Does not rely on previous diagnosis or classification**

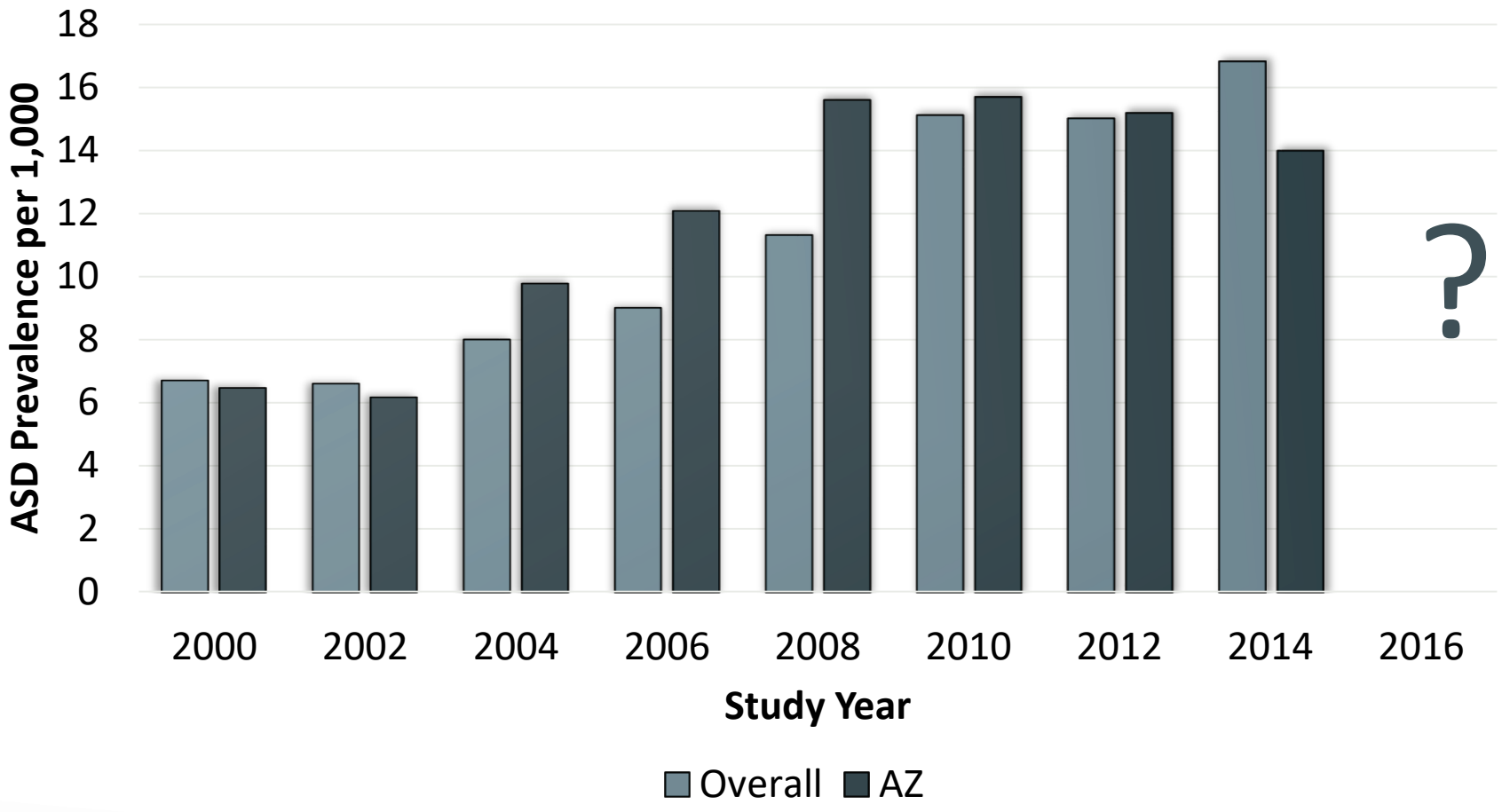
# ASD Prevalence in the AZ Site

| Year | per 1,000 | 1 in |
|---|---|---|
| 2000 | 6.5 | 154 |
| 2002 | 6.2 | 161 |
| 2004 | 9.8 | 102 |
| 2006 | 12.1 | 83 |
| 2008 | 15.6 | 64 |
| 2010 | 15.7 | 64 |
| 2012 | 15.2 | 64 |
| 2014 | 14.0 | 71 |
| 2016 | collected, undergoing analysis | |

# Prevalence of ASD AZ



# Prevalence of ASD – ADDM Network & AZ



# MADDSP Method - Disadvantages

- We look at records not children
  - Some affected children have no records at our sources
  - We may be wrong about case status
- Time consuming
  - 2 years effort to collect & evaluate 1 year of data
  - Collection of verbatim descriptions of behaviors
- Resource intensive
  - Case status review is a lengthy process by highly trained (expensive) exerts

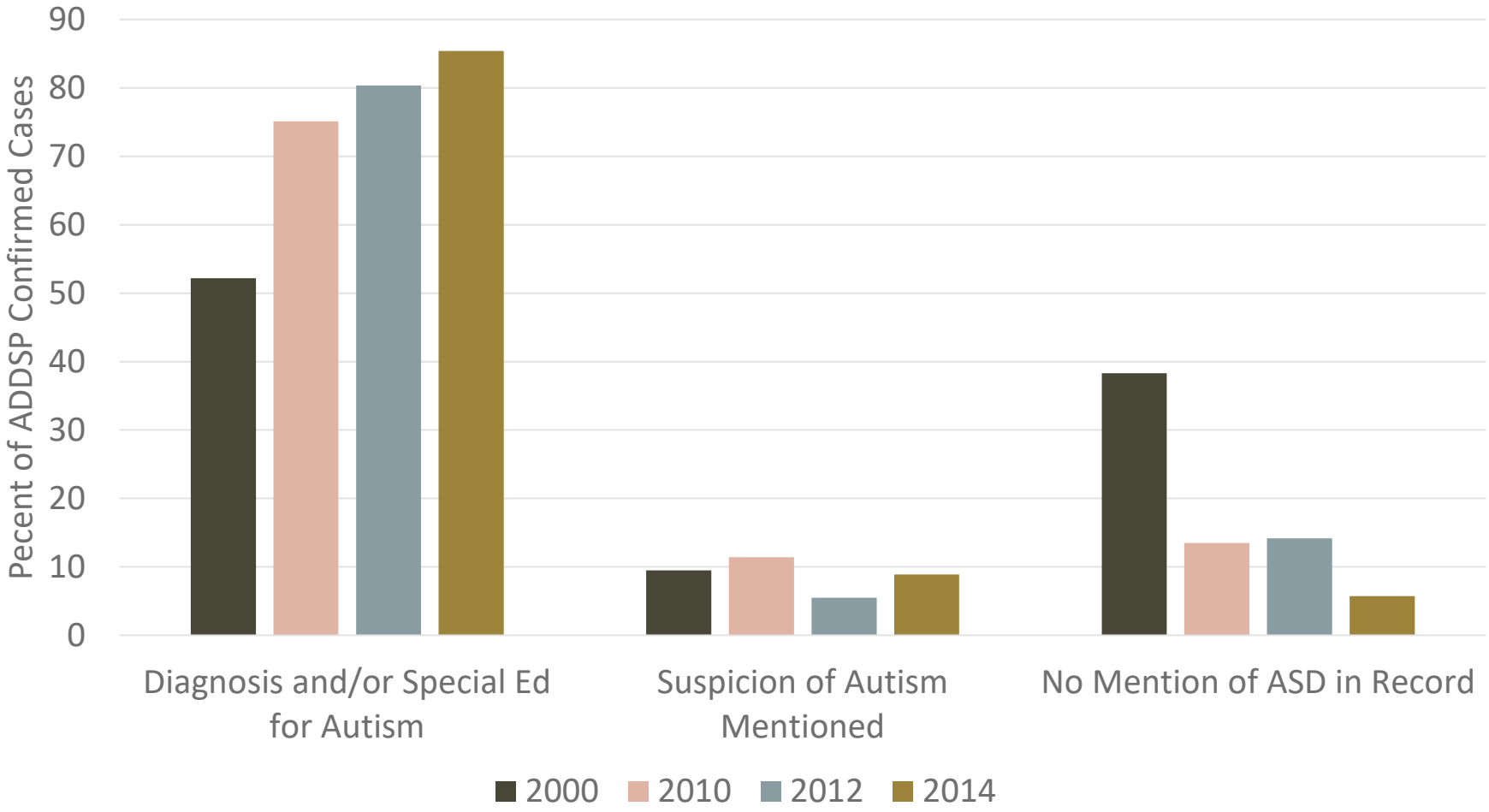
# Future ADDM

- Funding 1/1/2019 – 12/31/2022
- Study years: 2018 & 2020
- 10 sites
- Collection on 8 & 4 year olds in the entire study area

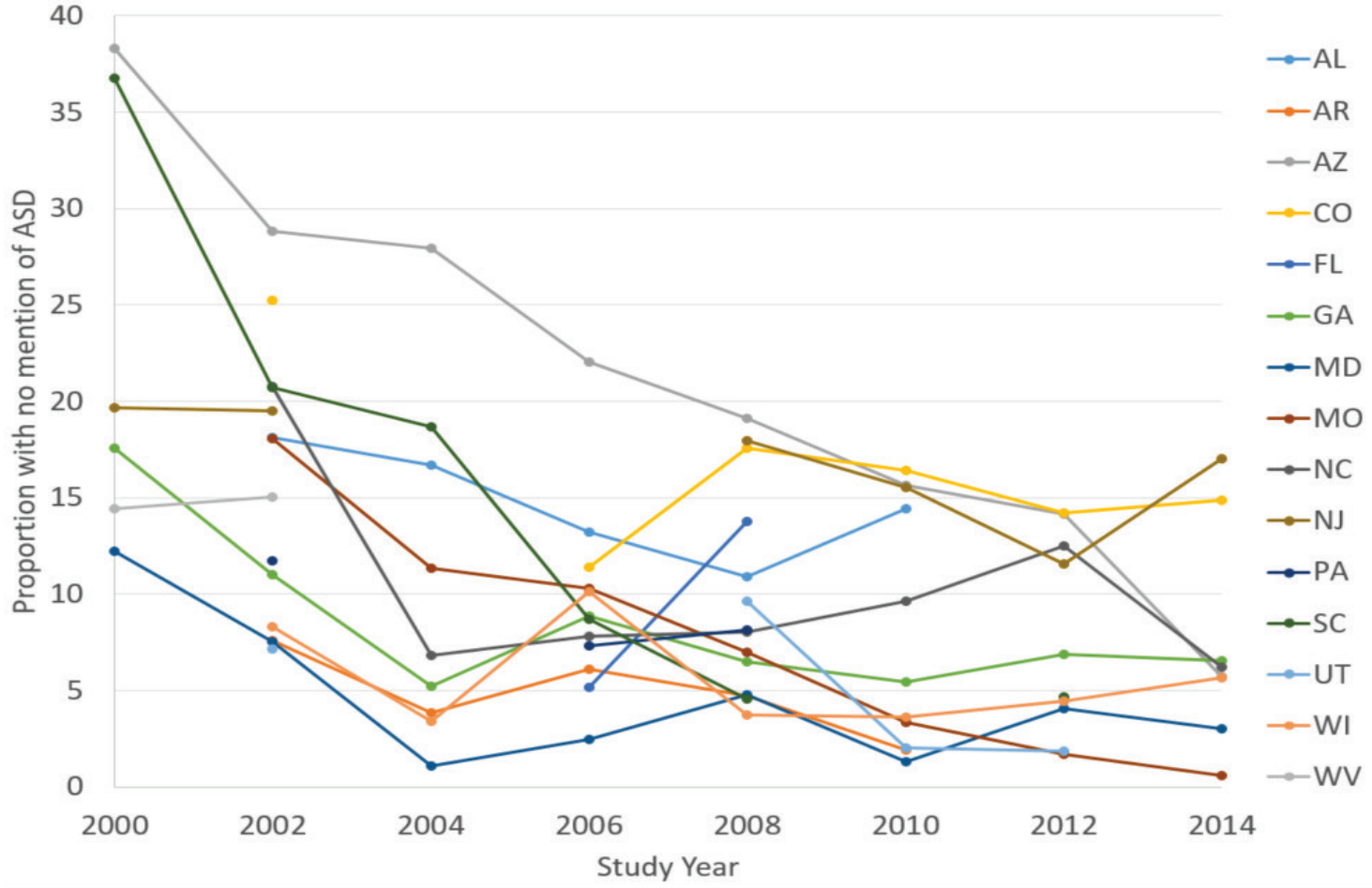
# New ADDM Protocol

- Inclusion
  - Clinical diagnosis
  - Autism Special Education Exceptionality
  - Children whose records have a “clinical statement”
- Discontinuing collection of behavioral descriptors

# Community Recognition



# % ADDM confirmed cases with no mention of ASD in their record



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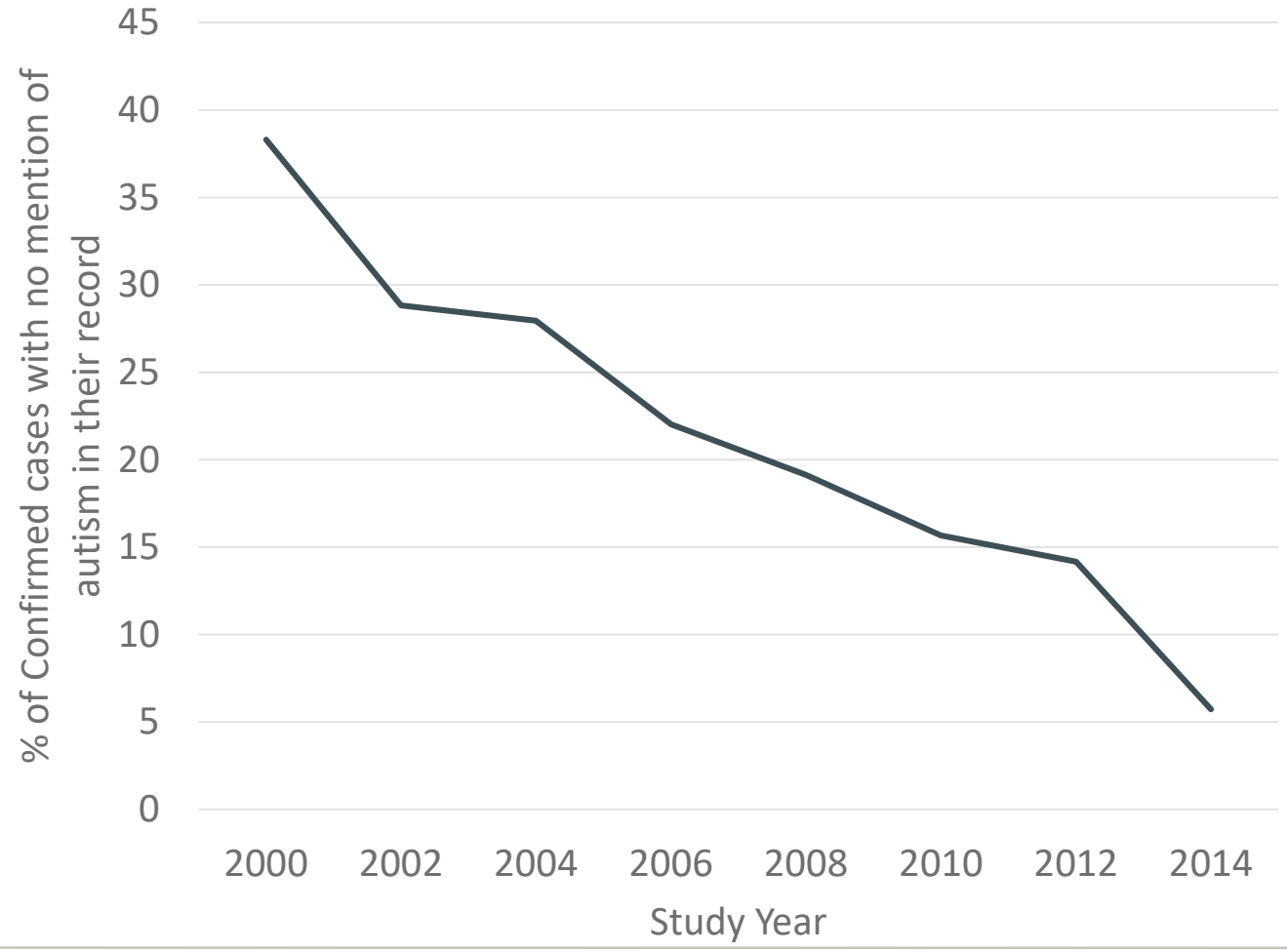

# Benefits of New Protocol

- Old protocol
  - Required: comprehensive evaluations by a qualified professional
- New protocol
  - Identifying information
  - Indication that the child
    - Has a diagnosis
    - Qualifies for services based on criteria for ASD

# Division of Developmental Disabilities

- Records of eligible children
- No comprehensive evaluations
- Limited utility under old protocol

# % of DDD eligible cases identified by ADDSP

| Study Year | % Found |
|---|---|
| 2000 | 76.4 |
| 2002 | 74.3 |
| 2004 | 74.2 |
| 2006 | 80.9 |

# % of DDD eligible cases identified by ADDSP

| Study Year | % Found | % Missed |
|---|---|---|
| 2000 | 76.4 | 23.6 |
| 2002 | 74.3 | 25.7 |
| 2004 | 74.2 | 25.8 |
| 2006 | 80.9 | 19.1 |

# Change Data Collection…

- … change results

# Questions?

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