*Arkansas Autism and Developmental Disabilities Monitoring (AR ADDM) Program*

## Autism Spectrum Disorder (ASD) Surveillance Year 2010 Findings

**& Comparison with Arkansas 2002 Baseline Prevalence Study**

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## Background & Purpose

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## Background

- **Autism and Developmental Disabilities Monitoring (ADDM) Network**
  - In 2000, the Centers for Disease Control and Prevention (CDC) funded researchers in several states to develop programs to determine and monitor the prevalence of autism spectrum disorders (ASDs)
- **Arkansas ADDM timeline**
  - 2002 → Statewide surveillance (baseline)—ASD and ID (Intellectual Disability)
  - 2008 → Pulaski county only (pilot)—ASD only
  - 2010 → Statewide surveillance (completed)—ASD only
  - 2012 → Statewide surveillance (in progress)—ASD and ID
  - 2014 & 2016 → New CDC Funding Opportunity Announcement pending

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## AR ADDM Goals (What We Report)

- To provide as complete a count as possible of the number of children with ASD in a specific place and time (prevalence) and identify changes over time
- To describe characteristics of children with ASDs in the state
- To compare ASD prevalence among different groups of children and in different areas of the state
- To communicate information about the impact of autism and related conditions on the state's healthcare and education systems

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## 2010 & 2012 ADDM Network Surveillance Coverage Area

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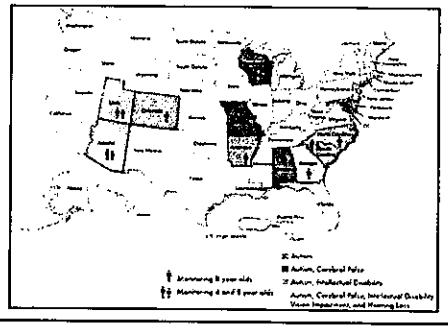
## ADDM Network Sites – Tracking Years 2010 & 2012



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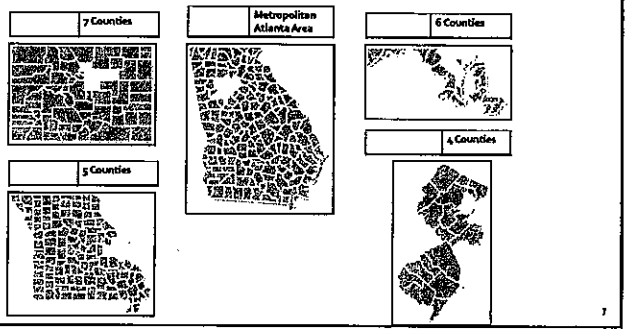
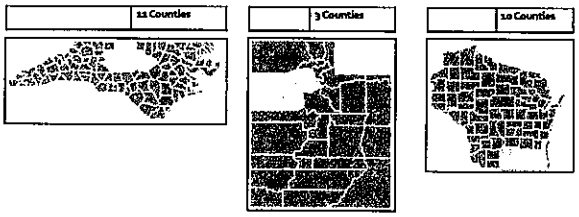
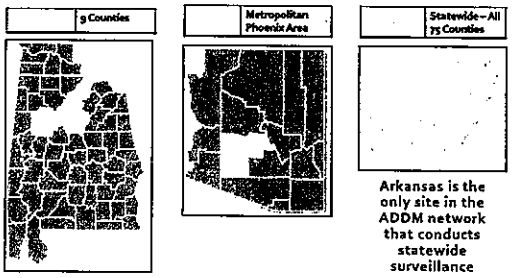
## ADDM 2010 & 2012 Surveillance Coverage Area by Site




## ADDM Surveillance Coverage Area by Site (*continued*)

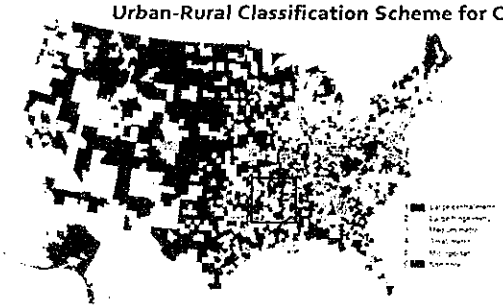



## ADDM Surveillance Coverage Area by Site (*continued*)




Arkansas is the only site in the ADDM network that conducts statewide surveillance

2006 National Center for Health Statistics
*Urban-Rural Classification Scheme for Counties*



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## Methods

Target Population & Case Ascertainment

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## Methods

- **Target population → 8-year-old children in AR in 2010**
  - CDC's baseline study showed 8 years as age of peak prevalence
- **Multi-source, population-based surveillance system**
  - Health service records → diagnostic & delivery
  - Public school records
- **Standardized methodology of case finding, record review/abstraction, and clinician review**
  - Does not rely on a previous diagnosis of ASD

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## Steps to Finding a Case

1. **FIND** → Find children with possible ASDs by requesting records with certain clinical diagnosis codes (health sources) and all records in Special Education (school sources)
2. **SCREEN** → Screen evaluations of children for "triggers" that may indicate the presence of an ASD
3. **ABSTRACT** → Collect relevant information from the record into a secure database
4. **EXPERT REVIEW** → All evaluations for a child are reviewed by experienced, trained clinicians who score the record and look for diagnostic features (DSM-IV criteria) for an ASD (DSM-5 in future)

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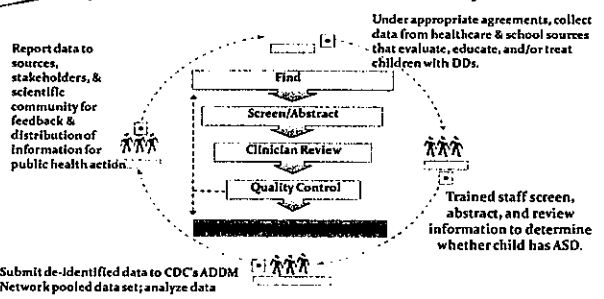
## Summary of AR ADDM Surveillance System

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## Characteristics of Arkansas Autism Surveillance System AR ADDM SY2002 & SY2010

Abstracted and [illegible] Confirmed Cases

AR ADDM SY2002 [illegible]

| | SY2002 | SY2010 |
|---|---|---|
| [illegible] | 293 | 253 |
| [illegible] | 7,547 | 7,773 |
| [illegible] | 5,908 | 6,391 |
| [illegible] | 1,632 | 1,973 |
| [illegible] | 1,137 | 1,228 |
| [illegible] | 525* | 1,228 |
| [illegible] | ***251*** | ***605*** |
| [illegible] | 206 | 496 |
| [illegible] | 120 (58%) | 298 (60%) |

*Streamlined abstraction in SY2002

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## Highlights of Findings

2002 vs. 2010

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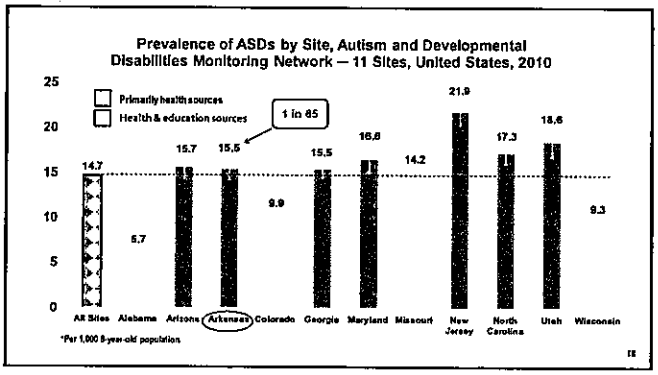


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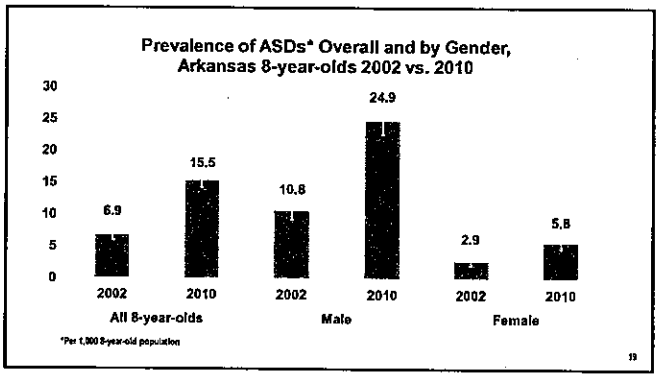


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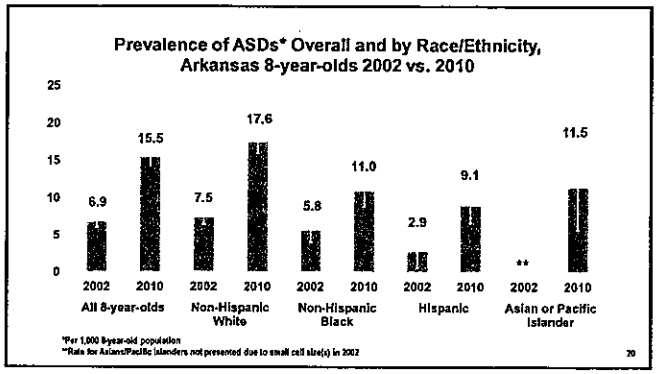


**Arkansas Statewide & Regional ASD Prevalence 2010**

| | ASD confirmed cases | Population 8-year old | Prevalence per 1,000 population | 95% LCL | 95% UCL |
|---|---|---|---|---|---|
| **State Total** | **605** | **38,956** | **15.5** | **14.3** | **16.8** |
| Northwest Region | 231 | 13,365 | 17.3 | 15.1 | 19.5 |
| Southwest Region | 53 | 4,184 | 12.7 | 9.3 | 16.1 |
| Central Region | 164 | 10,561 | 15.5 | 13.2 | 17.9 |
| Northeast Region | 109 | 7,349 | 14.8 | 12.1 | 17.6 |
| Southeast Region | 48 | 3,497 | 13.7 | 9.9 | 17.6 |

LCL = lower confidence limit; UCL = upper confidence limit

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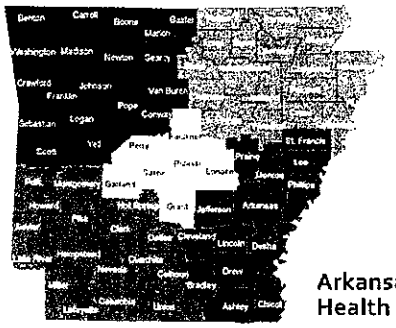
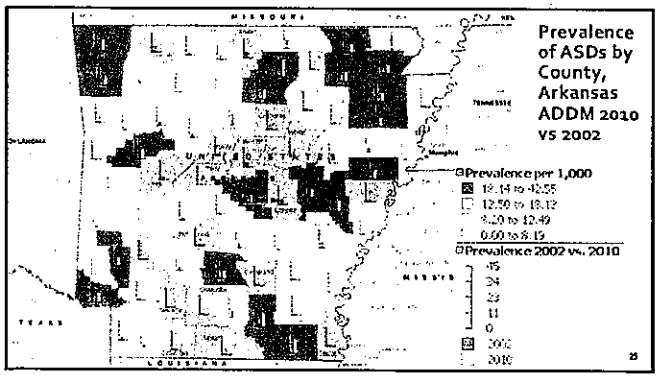


## Arkansas Statewide & Regional ASD Prevalence: 2002 vs. 2010

| | Surveillance Year 2002 | | | Surveillance Year 2010 | | |
|---|---|---|---|---|---|---|
| | ASD confirmed cases | Population 8-year old | Prevalence per 1,000 population | ASD confirmed cases | Population 8-year old | Prevalence per 1,000 population |
| *State Total* | *251* | *36,317* | *6.9* | *605* | *38,956* | *15.5* |
| Northwest Region | 70 | 11,261 | 6.2 | 231 | 13,365 | 17.3 |
| Southwest Region | 26 | 4,437 | 5.9 | 53 | 4,184 | 12.7 |
| Central Region | 91 | 9,460 | 9.6 | 164 | 10,561 | 15.5 |
| Northeast Region | 44 | 7,071 | 6.2 | 109 | 7,349 | 14.8 |
| Southeast Region | 20 | 4,088 | 4.9 | 48 | 3,497 | 13.7 |

## Prevalence by County

2002 vs. 2010



## Characteristics of Arkansas' 8-year-old Children with ASDs

Intellectual Ability & First Comprehensive Evaluation

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## Intellectual Disability (ID)

- AR ADDM was one of seven sites with data on ID
  - 95% of AR cases had IQ scores available
    - 2nd highest after NC (96%)
    - Collaboration & data quality → ADE

| Among Kids with ASD: | With ID (IQ ≤ 70) | No ID (IQ > 70) |
|---|---|---|
| **Arkansas** | **5.2 per 1,000 (35% of cases)** | **9.5 per 1,000 (65% of cases)** |
| ADDM Network (All Sites Combined) | 4.7 per 1,000 (31%) | 10.2 per 1,000 |

ADDM Network ASD cases with Intellectual Disability:
48% of black children, 38% of Hispanic children, 25% of white children
White children were more likely to have ASD without ID than Black or Hispanic children; Black children with ASD were more likely to have ID than White or Hispanic children.

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## Special Education Eligibility

| | |
|---|---|
| Autism | 60 |
| Emotional disturbance | 2 |
| Specific learning disability | 3 |
| Speech or language impairment | 16 |
| Health or physical disability | 10 |
| Multiple disabilities | 3 |
| Intellectual disability | 6 |
| Total no. of ASD cases with special education records | 496 (82% of 605 cases) |

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## First Evaluation for Developmental Concerns

- ***Healthy People 2020* objective:**
  - Increase the proportion of children w/ ASDs who have their first evaluation by 36 months
    - Arkansas → 35%
    - ADDM Network → 44% [Range 33% - 59%]
- **% who have a mention of developmental concern by 36 months:**
  - Arkansas → 90%
  - ADDM Network → 89% [Range 83% - 94%]
- **Median age at first evaluation:**
  - Arkansas → 45 months
  - ADDM Network → 44 months [Range 33 – 45 months]

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## First Evaluation (*continued*)

- **Median age of earliest documented ASD diagnosis (any subtype):**
  - Arkansas SY2010 → 61 months (highest in Network)
  - ADDM Network SY2010 → 53 months (range 46 – 61 months)
  - Arkansas SY2002 → 59 months
- **% who have previous diagnosis (DSM-IV-TR) in records:**
  - Arkansas → 69%
  - ADDM Network → 72% [Range 59% - 88%]

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## Age of ASD Diagnosis by Subtype (DSM-IV-TR)

| Subtype of Earliest Diagnosis: | Autistic Disorder | ASD/PDD | Asperger Disorder |
|---|---|---|---|
| Distribution of Subtypes—ARKANSAS | 53% | 31% | 17%* |
| Distribution of Subtypes—ADDM Network | 43% (range: 19-72%) | 46% (range: 21-73%) | 11% (range: 7-17%) |
| | | | |
| Median Age of Earliest Diagnosis—ARKANSAS | 55 mos | 63 mos | 75 mos |
| Median Age of Earliest Diagnosis—ADDM Network | 48 mos (range: 37-59) | 50 mos (range: 39-63) | 74 mos (range: 68-84) |

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## Previous ASD Classification

- Arkansas 2010 → 77% of children had either an ADE eligibility for autism special education services at school or had an ASD diagnosis or both
  - Remaining 23% of children identified with ASD had documented symptoms of ASD, but had not yet been classified as having ASD by a community provider
  - ADDM Network 2010 → 80% [Range 65% - 90%]
  - AR ADDM 2002 → 82%

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## Bottom Line

- ASD prevalence in Arkansas has more than doubled from 1 in 145 (SY2002) to 1 in 65 (SY2010) among 8-year-olds.
- We are still challenged to:
  - Improve recognition and documentation of symptoms of ASD, particularly among children without intellectual disability and children in all racial/ethnic groups
  - Decrease the age when children are first evaluated for ASD, first receive an ASD diagnosis, and are first enrolled in community-based supports

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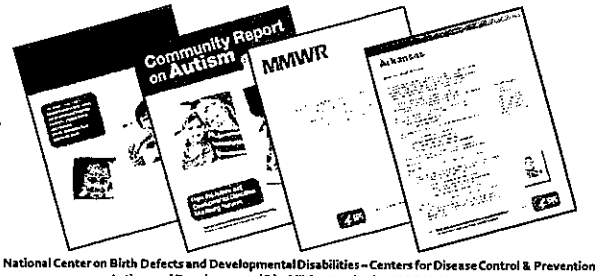
## More Resources Available from CDC's ADDM Network




National Center on Birth Defects and Developmental Disabilities – Centers for Disease Control & Prevention
Autism and Developmental Disabilities Monitoring (ADDM) Network
http://www.cdc.gov/addm

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**For questions or comments, please contact:**

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