Autism Spectrum Disorder (ASD) Surveillance Year 2010 Findings & Comparison with Arkansas 2002 Baseline Prevalence Study

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Background & Purpose
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
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
2010 & 2012 ADDM Network Surveillance Coverage Area
ADDM Network Sites – Tracking Years 2010 & 2012

- Autism
- Autism, Cerebral Palsy
- Autism, Intellectual Disability
- Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss

Monitoring 8 year olds
Monitoring 4 and 8 year olds
ADDM 2010 & 2012 Surveillance Coverage Area by Site

- **Colorado**: 7 Counties
- **Georgia**: Metropolitan Atlanta Area
- **Maryland**: 6 Counties
- **Missouri**: 5 Counties
- **New Jersey**: 4 Counties
<table>
<thead>
<tr>
<th>State</th>
<th>Counties</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Carolina</td>
<td>11 Counties</td>
</tr>
<tr>
<td>Utah</td>
<td>3 Counties</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>10 Counties</td>
</tr>
</tbody>
</table>
Arkansas is the only site in the ADDM network that conducts statewide surveillance.
Methods

Target Population & Case Ascertainment
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
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)
Summary of AR ADDM Surveillance System

Trained staff screen, abstract, and review information to determine whether child has ASD.

Under appropriate agreements, collect data from healthcare & school sources that evaluate, educate, and/or treat children with DDs.

Report data to sources, stakeholders, & scientific community for feedback & distribution of information for public health action

Submit de-identified data to CDC's ADDM Network pooled data set; analyze data

Find

Screen/Abstract

Clinician Review

Quality Control

Final Case Determination
## Characteristics of Arkansas Autism Surveillance System
**AR ADDM SY2002 & SY2010**

### Abstracted and Reviewed Records, and Number of Confirmed Cases
**AR ADDM SY2002 & SY2010**

<table>
<thead>
<tr>
<th></th>
<th>SY2002</th>
<th>SY2010</th>
</tr>
</thead>
<tbody>
<tr>
<td># of participating health &amp; education sources</td>
<td>293</td>
<td>253</td>
</tr>
<tr>
<td># of records requested</td>
<td>7,547</td>
<td>7,773</td>
</tr>
<tr>
<td># of children for whom records were requested</td>
<td>5,908</td>
<td>6,391</td>
</tr>
<tr>
<td># of records abstracted</td>
<td>1,632</td>
<td>1,973</td>
</tr>
<tr>
<td># of children for whom records were abstracted</td>
<td>1,137</td>
<td>1,228</td>
</tr>
<tr>
<td># of children reviewed for ASD by clinician reviewers</td>
<td>525*</td>
<td>1,228</td>
</tr>
<tr>
<td># of confirmed ASD cases</td>
<td>251</td>
<td>605</td>
</tr>
<tr>
<td>Confirmed cases receiving special education services</td>
<td>206</td>
<td>496</td>
</tr>
<tr>
<td>Number &amp; percent of confirmed cases receiving special services w/ autism eligibility (primary spec ed. eligibility category only)</td>
<td>120 (58%)</td>
<td>298 (60%)</td>
</tr>
</tbody>
</table>

*Streamlined abstraction in SY2002*
Highlights of Findings

2002 vs. 2010
Prevalence of ASDs by Site, Autism and Developmental Disabilities Monitoring Network – 11 Sites, United States, 2010

*Per 1,000 8-year-old population
Prevalence of ASDs* Overall and by Gender, Arkansas 8-year-olds 2002 vs. 2010

*Per 1,000 8-year-old population
Prevalence of ASDs* Overall and by Race/Ethnicity, Arkansas 8-year-olds 2002 vs. 2010

*Per 1,000 8-year-old population
**Rate for Asians/Pacific Islanders not presented due to small cell size(s) in 2002
## Arkansas Statewide & Regional ASD Prevalence 2010

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

LCL = lower confidence limit; UCL = upper confidence limit
Arkansas Public Health Regions
Arkansas Statewide & Regional ASD Prevalence: 2002 vs. 2010

<table>
<thead>
<tr>
<th></th>
<th>Surveillance Year 2002</th>
<th>Surveillance Year 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ASD confirmed cases</td>
<td>Population 8-year old</td>
</tr>
<tr>
<td>State Total</td>
<td>251</td>
<td>36,317</td>
</tr>
<tr>
<td>Northwest Region</td>
<td>70</td>
<td>11,261</td>
</tr>
<tr>
<td>Southwest Region</td>
<td>26</td>
<td>4,437</td>
</tr>
<tr>
<td>Central Region</td>
<td>91</td>
<td>9,460</td>
</tr>
<tr>
<td>Northeast Region</td>
<td>44</td>
<td>7,071</td>
</tr>
<tr>
<td>Southeast Region</td>
<td>20</td>
<td>4,088</td>
</tr>
</tbody>
</table>
Prevalence by County

2002 vs. 2010
Prevalence of ASDs by County, Arkansas ADDM 2010 vs 2002
Characteristics of Arkansas’ 8-year-old Children with ASDs

Intellectual Ability & First Comprehensive Evaluation
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:

<table>
<thead>
<tr>
<th></th>
<th>With ID (IQ ≤ 70)</th>
<th>No ID (IQ &gt; 70)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arkansas</td>
<td>5.2 per 1,000 (35% of cases)</td>
<td>9.5 per 1,000 (65% of cases)</td>
</tr>
<tr>
<td>ADDM Network (All Sites Combined)</td>
<td>4.7 per 1,000 (31%)</td>
<td>10.2 per 1,000</td>
</tr>
</tbody>
</table>

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.
## Special Education Eligibility

<table>
<thead>
<tr>
<th>Primary Special Education Eligibility</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>60</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td>2</td>
</tr>
<tr>
<td>Specific learning disability</td>
<td>3</td>
</tr>
<tr>
<td>Speech or language impairment</td>
<td>16</td>
</tr>
<tr>
<td>Health or physical disability</td>
<td>10</td>
</tr>
<tr>
<td>Multiple disabilities</td>
<td>3</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>6</td>
</tr>
</tbody>
</table>

**Total no. of ASD cases with special education records**: 496 (82% of 605 cases)
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]
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%]
## Age of ASD Diagnosis by Subtype (DSM-IV-TR)

<table>
<thead>
<tr>
<th>Subtype of Earliest Diagnosis:</th>
<th>Autistic Disorder</th>
<th>ASD/PDD</th>
<th>Asperger Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distribution of Subtypes—ARKANSAS</td>
<td>53%</td>
<td>31%</td>
<td>17%*</td>
</tr>
<tr>
<td>Distribution of Subtypes—ADDM Network</td>
<td>43% (range: 19-72%)</td>
<td>46% (range: 21-73%)</td>
<td>11% (range: 7-17%)</td>
</tr>
<tr>
<td>Median Age of Earliest Diagnosis—ARKANSAS</td>
<td>55 mos</td>
<td>63 mos</td>
<td>75 mos</td>
</tr>
<tr>
<td>Median Age of Earliest Diagnosis—ADDM Network</td>
<td>48 mos (range: 37-59)</td>
<td>50 mos (range: 39-63)</td>
<td>74 mos (range: 68-84)</td>
</tr>
</tbody>
</table>
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%
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
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
For questions or comments, please contact:

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