CDC Autism Activities Update

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The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention

National Center on Birth Defects and Developmental Disabilities (NCBDDD)

Specific Programs Related to ASDs

- **Surveillance/Monitoring**
  - Who is affected?
- **Epidemiologic Research**
  - Examine population risk/protective factors
- **Early Diagnosis**
  - “Learn the Signs. Act Early.”

ADDM NET
Autism and Developmental Disabilities Monitoring Network

CADDRE
Center for Autism and Developmental Disabilities Research and Epidemiology

ADDM NET

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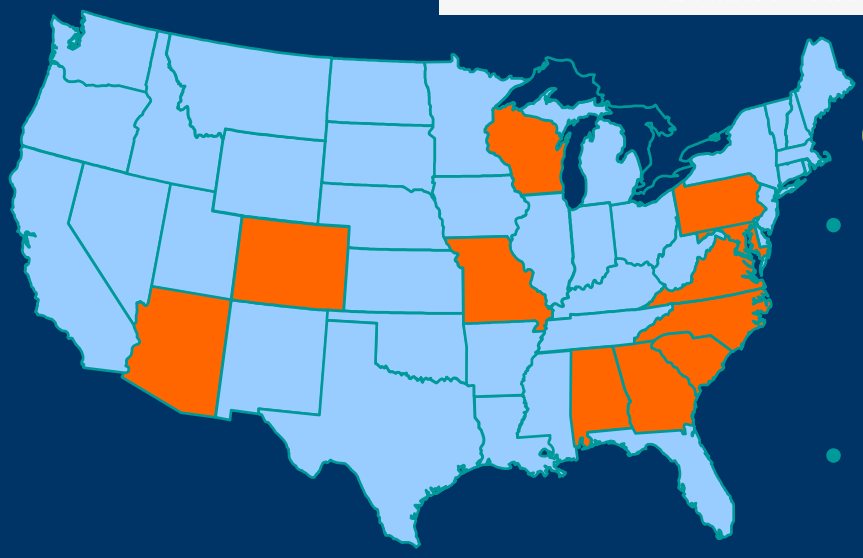
CDC



Current ADDM Sites

Goals

- Accurate and comparable population-based estimates of the prevalence of ASD in selected regions of U.S.
- Describe the characteristics of children with ASD
- Examine trends in prevalence
- To improve the consistency of identification of people with ASDs

- Average of 1 in 150 children

Recent Publications Using ADDM Data

- Multiple Births (Van Naarden Braun et al., *Autism Research* 2008)
  - ★ no association with ASDs,
  - ★ moderate association with ID, and
  - ★ strong association with CP.
- Parental Age (Durkin et al., *AJE* 2008)
  - ◆ Association between advanced parental age and risk of a child developing autism. Also, increased risk associated with being firstborn or of low birth order.

In press

- Mandell et al. Racial and Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders. *American Journal of Public Health.*
- Shattuck et al. The timing of identification among children with an autism spectrum disorder, *American Academy of Child and Adolescent Psychiatry*.
- Wiggins et al. Developmental regression in children with an autism spectrum disorder identified by a population–based surveillance system, *Autism.*

Impact Planned for Next 3-5 Years: **Surveillance**

- ADDM Network will release its 2nd and 3rd prevalence reports (2004 and 2006 SY)
- Report on prevalence changes over 4 time periods
- Prevalence reports for CP (2006 SY) and ID (2002, 2004, 2006 SY)
- Numerous investigator initiated analyses and manuscripts.
- Early ASD programs - combine direct screening of records of in the community to determine the prevalence of ASDs

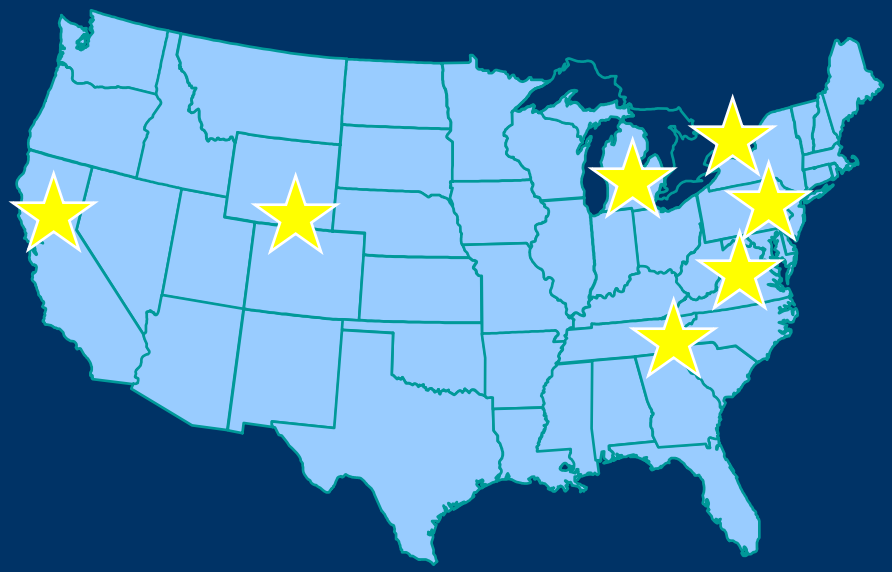
Fully Utilizing Investments in Scientific Infrastructure: ADDM

- Restore 5 autism surveillance sites
  - Recover lost investment
  - Allow for greater evaluation of trends
- Conduct follow-up studies
  - Look at specific subgroups of individuals affected by autism
  - Indentify and inform investigation of causes
- Provide a network to assist states, territories, and other countries with technical assistance related to ASD and Developmental Disabilities surveillance
- **Merge/link administrative databases to track the involvement of people with ASD in healthcare, education, etc.**

Expansion of Efforts in Surveillance

- Conduct autism surveillance in 4 year-old children and younger
  - Currently conducted in two sites only
- Conduct autism surveillance in young adults
  - Transition to adulthood
  - Help communities plan for services
- Utilize national surveys and other existing data systems to monitor changes in DD community identification
- Coordinate early identification and screening with surveillance
- Supplement existing Surveillance projects to track additional neurodevelopmental disorders

Centers for Autism and Developmental Disabilities Research and Epidemiology



- Colorado Department of Public Health and Environment
- Kaiser Permanente Division of Research
- Johns Hopkins University
- University of North Carolina at Chapel Hill
- University of Pennsylvania
- CDC-Georgia CADDRE
- ***Michigan State University***

SEED Research Areas

Compare 3 groups of children

- **with autism**
- **with other developmental problems**
- **without developmental problems**

•**Physical and behavioral characteristics** - to better understand the full range of characteristics that are associated with autism and other developmental problems.

•**Health conditions**– to learn more about a range of health conditions and disorders that might affect children with and without autism.

•**Risk factors**– to learn more about health conditions and factors that affect the mother's pregnancy and the child during infancy and the first few years of life, about genes, and about the relationship between genetic and non-genetic factors leading to autism and other developmental problems.

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Impact Planned for Next 3-5 Years: **Research**

SEED data will help answer these questions:

What are major factors in pregnancy and early childhood that may increase the risk of autism ?

- Infection and immune function
- Reproductive history and hormonal function
- Gastrointestinal function
- Sociodemographic factors
- Lifestyle in pregnancy
- Parental occupation
- Select mercury exposures

What is the role of genes and family history in autism?

- Do the above environmental factors increase (or decrease) risk in individuals with genes related to autism?

What are the associated behavioral, developmental, medical, physical, and biologic features of autism?

Fully Utilizing Investments in Scientific Infrastructure: SEED

- **Increase enrollment pace in SEED**
  - Allow for rapid data collection and analysis
  - Quickly obtain information needed to answer important questions about causes of autism
  - Reduce follow-up, increase efficiency
- **Conduct genetic and other biomarker analysis**
  - Fully utilize biobank of samples collected from SEED participants
  - Biomarkers examined to provide clues
  - Increase capacity to store these valuable specimens
- **Increase SEED sample size (double)**
  - Allow for epidemiologic studies of gene-environment interaction on a population level
  - Large sample size needed to make meaningful conclusions

Expansion of Efforts in Research

- **Gene/Environment Interaction**
  - Support ancillary studies within population-based epidemiologic studies, to collect nested, case-control data on environmental risk factors during preconception, and during prenatal and early postnatal development, as well as genetic data that could be pooled as needed
  - Both domestic and international projects
    - ★ Utilize Denmark collaboration
- **Environmental studies**
  - Initiate studies on environmental factors identified in the 2007 IOM report
- **Sibling studies**
  - Conduct a multi-site study of the subsequent pregnancies of 1000 women with a child with ASD to assess the impact of environmental factors
- **ASD and Neurotypcial comparison studies**
  - Complete a large-scale, multi-disciplinary, collaborative project that longitudinally and comprehensively examines how biological, clinical and developmental profiles of children, youths and adults with ASD change over time as compared with typically developing individuals

Learn the Signs. Act Early. Campaign




- Raise *awareness* of developmental milestones and early warning signs of developmental delay.
- Increase *knowledge* about the benefits of early action and early intervention.
- Increase parent-provider *dialogue* on the topic of developmental milestones and disorders.
- Increase *early action* for developmental disorders

Learn the Signs. Act Early.

“Act Early.” Initiatives

- Regional summits hosted in Regions V, VI, VII, IVa in collaboration with HRSA and AUCD
  - Completion of summits in all regions by June 2010
- Act Early mini-grants to states aid in continued collaboration and materials dissemination
- Development of communication materials to aid families and providers in Acting Early
- Collaborative Research Awards – positive parenting; aiding allied health professionals to act early; evaluation of regional summits
- Model projects – family physicians and autism/dev screening

Objectives for the Act Early Summits

- Increase awareness of the "Learn the Signs. Act Early." campaign and its impact in target regions
- Develop common understanding among stakeholders of opportunities, challenges and barriers to early identification and diagnosis
- Develop state teams to initiate and/or enhance state wide early identification, diagnosis and service provision and coordination for families with ASD
- Create national web-based forum to disseminate promising evidence-based practices for stakeholders to use to develop innovative approaches in their states

National Center on Environmental Health (NCEH)

National Center on Immunization and Respiratory Diseases (NCIRD)

For more information:
www.cdc.gov/autism