

History of Developmental Disabilities at CDC

MADDSP/MACDP Partners Meeting October 16, 2009

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The National Center on Birth Defects and Developmental Disabilities

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

Developmental Disabilities at CDC

The Framework

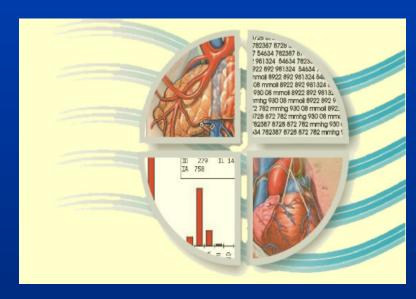
- Epidemiology: A core function of CDC
- The Public Health Model
- Surveillance:Understanding Prevalence
- Why study Developmental Disabilities?
 - What we know (now)
 - What we were asked (then)

- The Contributions of a Single Community
- MADDS
- MADDSP
- 1990s: Concerns over rates of autism
- Applying MADDSP Methods in Brick Township, NJ
- MADDSP's Contributions
- 2000: Expansion of Efforts
- The ADDM Network
- The Study to Explore Early Development (SEED)



Epidemiology

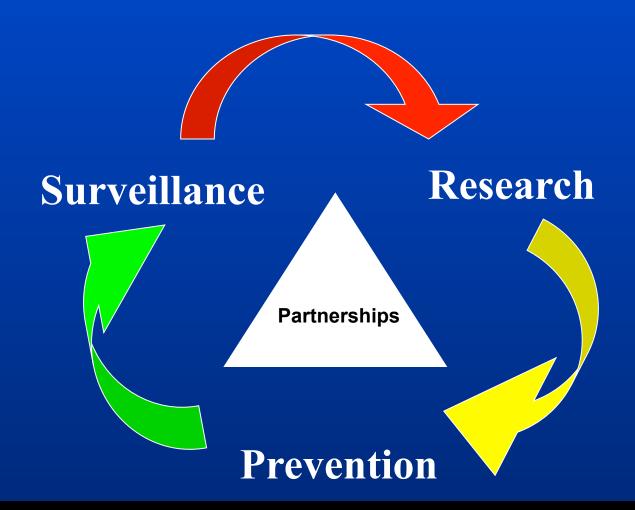
The branch of medicine that deals with the study of the causes, distribution, and control of disease in populations.







Public Health Model





What is Public Health Surveillance?





The ongoing, systematic collection, analysis, and interpretation of data (e.g., regarding agent/hazard, risk factor, exposure, health event) essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control

Why Study Developmental Disabilities? What we know now, 2009...





Definition of Developmental Disabilities (DD)

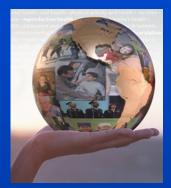
Developmental Disabilities Act of 1978 (PL 96-602)

A group of severe chronic conditions that are attributable to an impairment in physical, cognitive, speech or language, psychological, or self care areas that are manifested during the developmental period (younger than 18 (or 21) years of age)

Crocker, 1989; Yeargin-Allsopp et al. 1992



Why are DDs an Important Public Health Issue?



13% of children in the United States have a disability

2% of all children will require lifelong care for their disability

Boulet, Boyle, Schieve. Health Care Use and Health and Functional Impact of Developmental Disabilities Among US Children, 1997-2005. Arch Pediatr Adolesc Med. 2009;163(1):19-26.



Incremental Lifetime Cost Estimates For Developmental Disabilities: Children born in 2000 (2003 Dollars)

Developmental Disability	Total Lifetime Costs for Incident Cohort (in millions)	Per-person Lifetime Costs
Mental Retardation/ Intellectual Disability	\$51,237	\$1,014,000
Cerebral Palsy	\$11,470	\$921,000
Vision Impairment	\$2,102	\$417,000
Hearing Loss	\$2,484	\$566,000

Centers for Disease Control and Prevention. Economic costs associated with mental retardation, cerebral palsy, hearing loss, and vision impairment --- United States, 2003. MMWR Morbidity and Mortality Weekly Report 2004;53(3):57-59.



Why Study Developmental Disabilities? What we were asked, 1979







1979: How many children have a developmental disability?



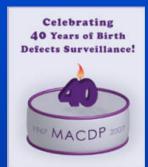








Goal: Establish Methods for Tracking Developmental Disabilities



1968: Surveillance for Birth Defects

1979-80: Request for presentation of data on ID and CP





1981: EIS Officer assigned to Birth Defects Branch to study

DDs

1981-83: Pilot study of MR/ID in DeKalb County, GA







Growing the Roots...

How do we answer this important public health question?

- Partnership with Georgia
 Department of Health
- Partnership with Georgia
 Department of Education





Individuals with Disabilities Education Act

- Enacted by Congress in 1975 to ensure that children with disabilities had the opportunity to receive a *free appropriate public education*
- Guides how states and school districts provide special education and related services to eligible children with disabilities
- Disabilities covered by IDEA include (§§300.304 through 300.311)
- autism
- deaf-blindness
- deafness
- emotional disturbance
- hearing impairment
- mental retardation
- multiple disabilities

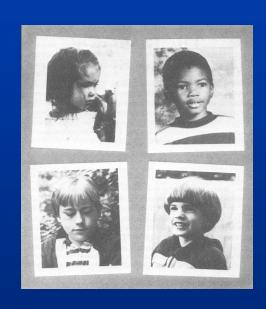
- orthopedic impairment
- other health impairment
- specific learning disability
- speech or language impairment
- traumatic brain injury or
- visual impairment (including blindness)





Purpose of Developmental Disabilities Surveillance at CDC

- To conduct ongoing tracking of children affected with developmental disabilities (DDs) in an effort to
 - Identify rates,
 - · Trends, and
 - Patterns of occurrence of DDs
- To inform public health







MADDS Study Population and Methods

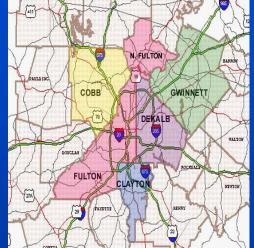
Who: Ten-year old children in

1985, 1986, 1987

Where: Clayton, Cobb,

DeKalb, Fulton, and

Gwinnett



DDs Monitored:

Cerebral Palsy, Intellectual Disability, Hearing Loss, Visual Impairment and

Epilepsy

Methods:

Population-based, active record review at

multiple sources

Multiple sources:

9 school systems (2 with decentralized records)

24 clinical sources





Landmark Publications: MADDS

Yeargin-Allsopp M, Murphy CC, Oakley GP, Sikes RK. A **Multiple-Source Method for** Studying the Prevalence of **Developmental Disabilities in Children: The Metropolitan Atlanta Developmental** Disabilities Study. Pediatrics, 1992, 89:524-30.

A Multiple-Source Method for Studying the Prevalence of Developmental
Disabilities in Children: The Metropolitan Atlanta Developmental
Disabilities Study

Marshalyn Yeargin-Allsopp, MD*; Catherine C. Murphy, MPH‡; Godfrey P. Oakley, MD*; R. Keith Sikes, DVM, MPH‡; and the Metropolitan Atlanta Developmental Disabilities Study Staff§

ABSTRACT. The Metropolitis Atlanta Developmental Disabilities Study is the first US, population-based epidemiologic study of the prevalence of mental retardation, cerebral palsy, hearing impairment, and visual impairment among school-age children. The study population consisted of children who were 10 years of age between 1965 and 1987 and whose mothers were residents of the five Georgia counties of Clayton, Cebb, DeKalb, Pulton, and Gwinnett at the time of the child's birth. Since children with developmental disabilities are identified by and receive services from various health, social service, and education systems, a multiple-source case iden-tification method was used. This study is unique in that individual school records were used to identify children with the four disabilities. Use of a multiple-source method made it possible to confirm specific conditions and to classify subtypes of disabilities. About 95% of the children with one or more of these four disabilities were initially identified through the school systems. This appreach is much less costly than conducting medical and ssychologic assessments on populations of children. In ddition, this method made it possible to estimate accuties (ie, the number of children previously identified with these disabilities for the purpose of providing servioss). The prevalence rates found in this study, per 1000 10-year-old children, were as follows: mental retardation, 10.3; cerebral palsy, 2.5; hearing impairment, 1.0; and visual impairment, 6.6. This population-based method for surveillance of developmental disabilities can be useful to those who seek to judge the effectiveness of revention strategies for these conditions, to those who meed to plan for services for persons with these condi-tions, and to those who conduct epidemiologic studies searching for environmental and other causes of these conditions, Padiatrics 1992,89:624-630; blindness, cerebral pairy, draftens, developmental disability, handicap, mentel retardetion, prevalence studies

From the "Division of Barth Divisios and Divisiogenesial Disabilities, Certain for Environmental Health and Injury Cosmid, Centers for Disease Content, US Department of Health and Situates Services, Alberts, Gall, and [O

Epidemicking, Derbish et Francis Heisen, Geologia Department et Hanne Rousson, Affrein, Gh. Giozanne Billings, Mitgler, Gan Stanling, Tim Calenar, Mit, Neury Johnson, Derg, Bubshit, Hidghen, Mrk. Birenda Silmende, Mrl. Eufliness Malensey, Steam Seven, Hills, and Ruber Travellines. Mrl. Mill. Scient Seven, Hills and Ruber Travellines. Mrl. Mill. Securised for publication for http://doi.org/seid-Mrs. 21,1991.

Reptite Segunds to (META) Centers for Disease Cannol, MS F-97, 1608 Clahon Rd. Atlanta, GA 50033. FEDATRICS (ISSN 0031-009). Copyright © 1992 by the American Academic of Publishins.

624 PEDIATRICS Vol. 89 No. 4 April 1992

ABBREVIATIONS, DD, developmental disability: MR, mental re

Developmental disabilities (DDs) are a group of severe chronic conditions that are attributable to an impairment in physical, cognitive, speech or language, psychologic, or self-care areas and that are manifested during the developmental period. The need for supportive services is sometimes included in the delinition.1 Population-based prevalence rates for these conditions are generally not available for the school-age children have some type of DD, repre-senting an annual cost to state health departments of almost \$128 million for services.²³ Quantifying the magnitude of childhood morbidity from these disebilities is difficult because (1) developmental disabilties represent a large group of heterogeneous discr-ders, for which case definitions often vary; (2) the conditions are not uniformly recognized at birth or even before school entry; and (3) identification of cases often requires use of multiple data sources. Understanding the population-based prevalence of developmental disabilities can be useful to those who seek to judge the effectiveness of prevention strategies for these conditions, to those who need to plan for services for persons with these conditions, and to those who conduct epidemiologic studies searching for environmental and other causes of these condi-

Much of the information on the descriptive epidemiology of DDs has been obtained from studies outside the United States and, therefore, generalization to the United States may not be appropriate. "Score investigations of the occurrence of DDs in children are hospital-based follow-up studies of graduates of reconstal intensive care units and, thus, may have been subject to selection bias." Although the Collaborative Periodic Project, conducted by the Nicelaborative Periodic Project, conducted by the Collaborative Periodical Project, and the Communicative University of the Nicelaborative Periodical Project, and the Communicative University of the State of t



Prevalence

- The total number of cases of a condition in a given population at a specific time.
- Without qualification, usually refers to a situation at a specific point in time (point prevalence).
- Not a "rate"
- Period prevalence: total number of persons known to have the condition during a period of time.
- Birth prevalence: number of persons having the condition derived from (survivors of) a birth cohort.



MADDS: Prevalence of Five Developmental Disabilities Per 1000 Ten-Year-Old Children, 1985-1987

	<u>Total</u>		Estimates from
	<u>N</u>	<u>Rate</u>	Previous Studies
Intellectual Disability	1074	12.0	3.1-43.6
Cerebral Palsy	204	2.3	2.0-3.0
Visual Impairment	61	0.7	0.3-0.6
Hearing Loss	100	1.1	0.6-2.3
Epilepsy	538	6.0	4.0-9.0







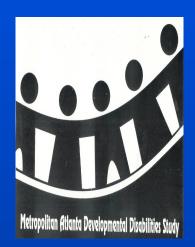
A Base of Support

State of Georgia

- Department of Education
- Department of Human Resources
 - Division of Mental Health/Mental Retardation/Substance Abuse
 - Division of Family and Children's Services
 - Division of Public Health
 - Children's Medical Services
 - Health Department
 - Vital Records
- Georgia Learning Resources System/Child Serve
- Georgia Psycho-educational Centers
- State schools

Other sources

- CDC- Metropolitan Atlanta Congenital Defects Program (MACDP)
- Hospitals, clinics, selected physicians
- Private schools
- Early education programs
- Social service agencies (private)





Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- Population-based
- Five counties in metro Atlanta
- Active surveillance based on record review
- Intellectual disability, cerebral palsy, vision impairment and hearing loss; <u>autism</u> added for 1996 study year
- Children aged 3-10, 1991-1994 and 1996 for autism; 8 year olds in future
- Multiple sources (schools, clinics/medical sources)



MADDSP: Types of Data Collected

- Demographics: child and parent names, race, ethnicity, gender, residence, DOB
- School service data: school, spec ed eligibility category
- Psychometric test results: intelligence, adaptive, autism
- Hearing and Vision test results
- Physical findings (CP)
- Verbatim descriptions of behaviors (Autism)
- Associated medical conditions
- Other developmental disabilities





Landmark Publications: MADDSP

Schendel DE, Berg CJ, Yeargin-Allsopp M, Boyle CA, Decouflé P. Prenatal Magnesium Sulfate Exposure and the Risk for Cerebral Palsy or Mental Retardation among Very Low Birthweight Children aged 3-5 years. <u>Journal of the American Medical Association</u> 1996; 276:1805 1810.

1997 CHARLES C. SHEPARD SCIENCE ACUARD

Presented annually to CDC/ATSDR scientists for outstanding contribution to the scientific literature.



Presented to:

Cynthia J. Berg, Coleen A. Boyle, Diana E. Schendel, Marshalyn Yeargin-Allsopp, and Pierre Decoufle Prenatal Magnesium Sulfate Exposure and the Risk for Cerebral Palsy or Mental Retardation Among Very Low-Birth-Weight Children Aged 3 to 5 Years





The Association between Cerebral Palsy or Mental Retardation and Prenatal Magnesium Sulfate Exposure in Atlanta Infant Survivors

Prenatal Magnesium Sulfate Exposure

Yes No OR 95% CL

(CP 1 (0.9%) 30 (7.7%) 0.11 0.02, 0.81

MR 2 (1.8%) 22 (5.8%) 0.30 0.07,1.29

(Schendel et al. JAMA 1996:276(22);1805-1810)



Public Health Concerns: Autism Spectrum Disorders





Concerns Over Possible Raising Rates of Autism in the 1990s

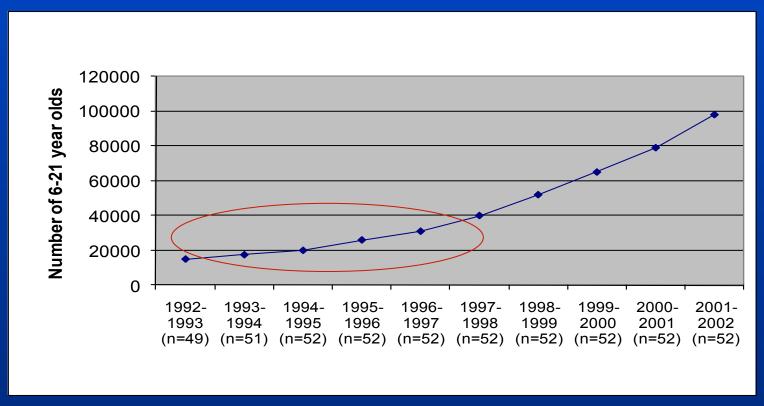
How many children are there with autism in the United States?

- Service provider data based on number of individuals
- Population-based surveillance to determine prevalence





Number of Children with Autism Served under IDEA, Part B, 1992-93 to 2001-02, 6-21 years

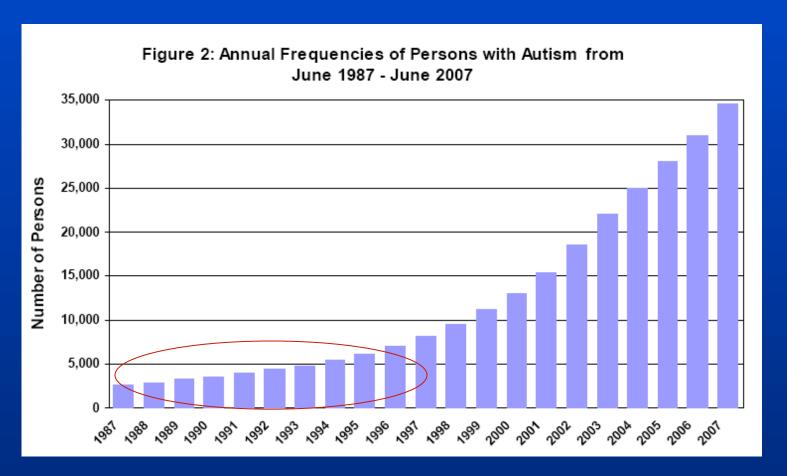


State DOE reporting of autism eligibility mandated in 1992

Source: U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS)



California Department of Developmental Services





www.dds.ca.gov

Issue in Brick

CDC will advise on autism concerns

State, federal health officials will meet tomorrow to discuss parents group's findings.

By DAVID P. WILLIS TOMS RIVER BUREAU

BRICK TOWNSHIP - State officials will ask federal disease experts for help to determine if the township has a higher than normal number of autism cases.

State health officials will meet tomorrow with experts from the Centers for Disease Control and Prevention's developmental disabilities branch to discuss concerns raised by a parents group, Brick Parents of Special Services and Education, or Brick POSSE.

In Brick

Parents autism

A group of Brick residents has managed to secure state and federal assistance in probing a potentially high number of autism cases among children.

By ALAN WHEELER Stall Writer

BRICK - State officials have asked a federal agency to investigate a solential "cluster of autism" emong township shift dren.

Lon Fishman, the state Department of Health commissioner, wants help in re-sponding to inquiries received by the day partment from a group of Brick residents.

Because of its expertise in autism, Fishman has contacted The National Institute of Child Health and Human Development in Bethasda, M.D.
Initially, this issue was raised by a group of citizens from Brick Township

Cluster suspected

Autism research possible in Brick

By REGINA MCKNEEY HEALTH WRITER

A FEDERAL official said yester day the government might be willing to fund a study probing the roots of Brick Township's suspecied autism cluster, an incurable develonmental disorder once largely blamed on bad parenting.

Marie Bristol-Power, an autism expert with the National Institute of Child Health and Human Development in Botheade, Md., an arm of the National Institutes of Health, said the agency is particularly interested in the unfortunate pairing

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THE STAR-LEDGER

FRIDAY, JAP

Parents fear a cluster of autism in Brick Township

Health officials call a meeting in Trenton to discuss the concerns

By Joe McCaffrey and Angela Stewart

· · · Federa, and state health officials plan to meet today in Trenton to dischilchood autism cases in Ocean cisability. Quanty that have surfaced in a comamunity neighboring one where a can- we began hearing over and over number of autistic adults and of iler cluster raised fears last year.

earlier this week that two of their mosed before they mached age 3. three children cave been diagnosed

again," said Eobhie Gallagher, 34, duer in New Jersey at 12:000.

A couple from Brick Township who explained her 5-year-o'd son and tota Sen, Robert Torricetii (D-NJA) E-year-old daughter were book diag-

Maney Richardson executive dias sutistic and that they have identi- meter of The New Jersey Center for Town. fied at least 32 other youngsters from Dutreach and Services for the Autism cuss a possible concentration of the township with the developmental. Community in Ewing Township, also known as COSAC said rough esti-' I'm from Brick I'm from Brick' mates by her organization put the

Richardson, who has an adult son according to COSAC. with autism and aupports a "thorough investigation' of the Brick

characterized by intrained verbal and males but its cause is unknown, ents of Special Services and Educa-

It was after Gallagher and her husband Bill enrolled their children in thinking back to no cases, was not able to positively say a special school and started attend. She read last year whether the 32 cited cases represent this parent support grouns for autism bigh childhood cano a higher than normal number in one that they became convinced there boring Dover Powre was a "chister" a group far larger Autism is a lifelong disorder often than the predicted statistical average, of autistic children in Brick Leominster, Mass. nonverbal communication, less of Township. They go: together with about 50 miles wes speech and social isolation. The discotter parents of autistic children and lighter believes that order is four times more common in. formed a group called POSSE, Par-

She also came n other duster of an



Brick Township Prevalence Investigation

- Study Characteristics:
 - Children 3-10 years of age (N=8,896)
 - Residence in 1998 was Brick Township
- Case Identification:
 - Schools, special programs
 - Physician/other diagnosticians
 - Parent groups/self referrals



- Case Verification
 - Special examination- diagnosis of autism: ADOS
 - Review of available records



Brick Township, New Jersey: Prevalence of ASD, 3-10 Year Old Children

Prevalence

95% CI

Rate per 1,000

Autism Spectrum

Disorders

60/8,896

5.1 - 8.7

6.7

Autistic Disorder

36/8,896

2.8 - 5.6

4.0

Bertrand J et al. (2001) Prevalence of Autism in a United States Population: The Brick Township, New Jersey, Investigation. *Pediatrics*, 108(5): 1155-1161.



Landmark Publications: MADDSP Prevalence of Autism in metro Atlanta

Age group	N	Prevalence rate per 1,000
3-10 year olds	987	3.4 (3.2-3.6)
3-5 year olds	346	3.1 (2.7-3.4)
6-10 year olds	641	3.6 (3.3-3.9) 4.2 (8 year olds)

Denominator: 289,456 3-10 year old children in metropolitan Atlanta in 1996

Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. Journal of the American Medical Association. 2003;289:49-55



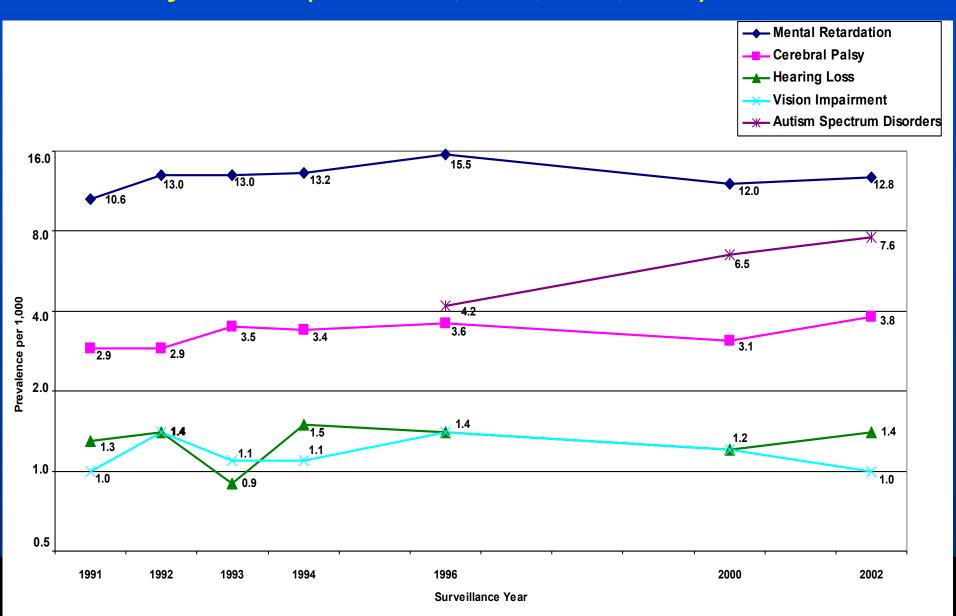


Landmark Publications: MADDSP HHS Secretary's Award for Distinguished Service: The Autism Public Health Response Team

DeStefano F, Karapurkar T, Thompson William, Yeargin-Allsopp M, Boyle C. Age at first Measles-Mumps-Rubella vaccination in children with autism and school-matched controls Pediatrics 2004;113(2). 259-266.



Prevalence of ID, CP, HL, VI and ASDs Among Children in MADDSP 8 year olds (1991-1994, 1996, 2000, 2002)





Impact of MADDSP



- Provision of data which served as an impetus for universal newborn hearing screening
- Examination of economic costs of developmental disabilities
- Evaluation of neuro-developmental status of children with a metabolic or endocrine disorder
- Understanding the long-term consequences of DD (e.g., follow-up on DD functioning as adults).
- Support early identification to decrease the number or severity of DDs (e.g. percent of children with a DD identified by EI/Part C)
- Autism and Childhood MMR Vaccine
 - Important contributor to the pool of population-based epidemiologic studies that have not, to date, demonstrated an association between MMR or any other measles-containing vaccine and autism
 - Public use data set created from the MMR vaccine and autism study-extending the study's value into the public realm

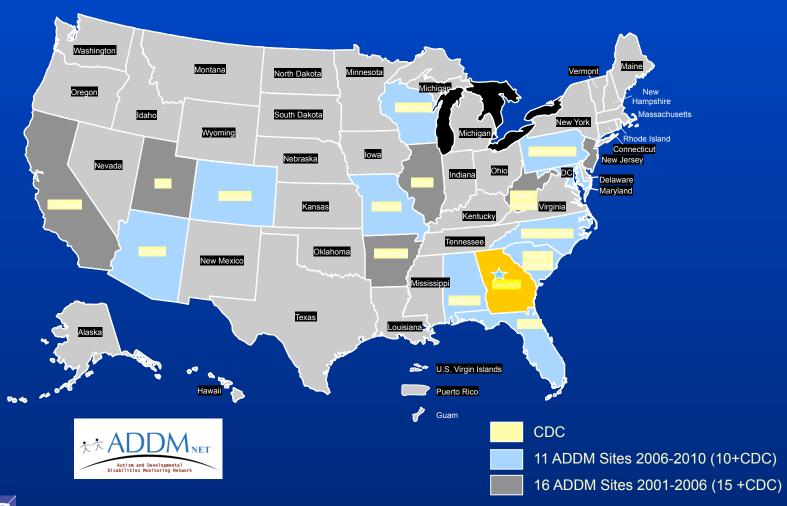


Expansion of Efforts: MADDSP Serves as a National Model





Autism and Developmental Disabilities Monitoring (ADDM) Network







Autism and Developmental Disabilities Monitoring (ADDM) Network

 ADDM Network Mission: Working together to understand the magnitude and characteristics of the population of children with autism and related developmental disabilities to inform science and policy.

Goals:

- Obtain as complete a count as possible of the number of children with an ASD in each project area
- Provide comparable, population-based ASD prevalence estimates in different sites
- Provide data to characterize the ASD population
- Study whether autism is more common in some groups of children than in others and whether rates are changing over time (trends)
- Improve the consistency of identification of people with ASDs



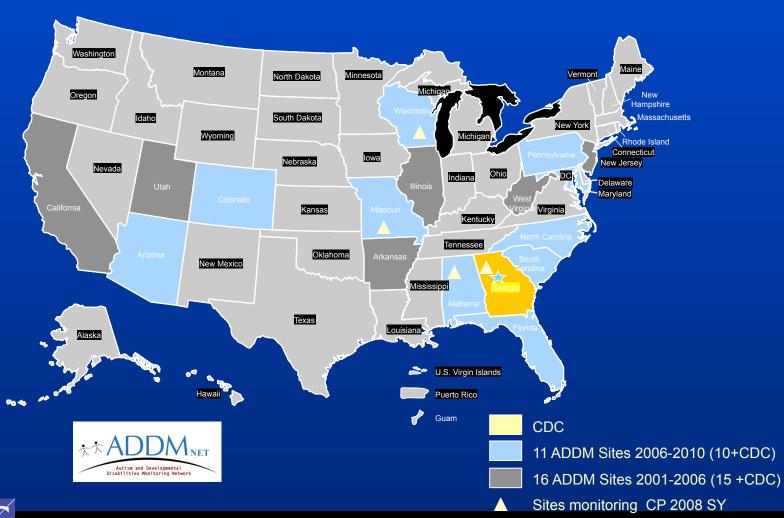


ADDM Prevalence Estimates 2007

- Results from the largest US multi-site collaboration to monitor ASDs underscore that ASDs are conditions of urgent public health concern.
- For the majority of communities represented, ASD prevalence ranged from 5.2-7.6 per 1000 children
- Some variation
 - ASD prevalence significantly lower in 1 site (AL) and higher in 1 site (NJ).
 - Average of 1 in 150 children
 (range from about 1 in 100 to 1 in 300)
- How many children in the U.S. have an ASD?
 - Estimated: 560,000 children between 0-21 years



ADDM: Expanded Cerebral Palsy Monitoring





The goals of the ADDM CP Network

- Obtain a complete count of the number of children with CP in each project area.
- Provide comparable, population-based CP prevalence estimates in different sites.
- Study if CP is more common in some groups of children than in others, and if rates are changing over time.
- Improve the consistency of identification of children with CP.



ADDM: Expanded Cerebral Palsy Monitoring

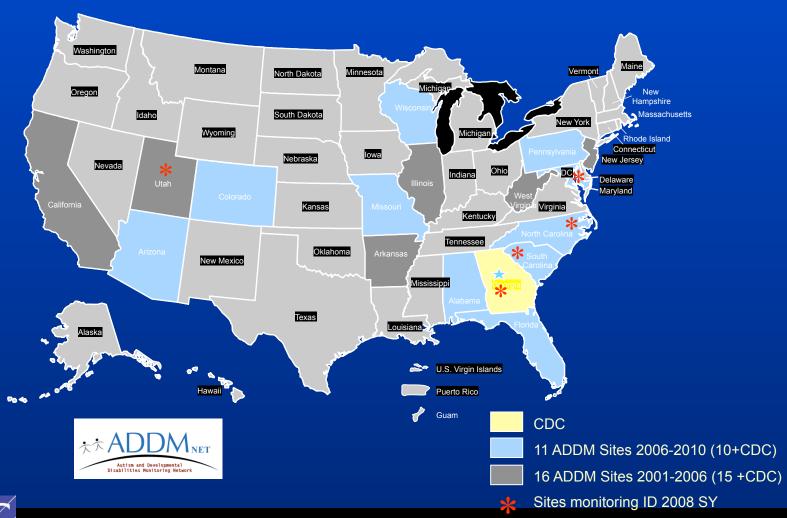
- 3 sites (AL, GA, WI) conducted CP surveillance in 2002.
- Site-specific rates were similar (3.3-3.8 per 1,000) with average of 3.6 per 1,000 8-year-old children.
- Male: female ratio was 1.1 (GA) to 1.6 (AL, WI).
- Spastic CP was the most common subtype (77% of all cases), primarily represented by bilateral spastic CP.



Prevalence of Cerebral Palsy in 8 Year-Old Children in three areas of the United States: A Multisite Collaboration. March 3, 2008 Pediatrics.



ADDM: Expanded Intellectual Disability Monitoring





Prevalence of ID across ADDM: 2002-2006 SY

Study Year	Georgia	North Carolina	South Carolina
2002	13/1000	15/1000	20/1000
2004	11/1000	17/1000	17/1000
2006	11/1000	17/1000	20/1000





Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)





ℤ CDC, 6th CADDRE site

SAFER • HEALTHIER • PEOPLE™





Study to Explore Early Development (SEED)



- Multi-state collaborative study to help identify factors that may put children at risk for autism spectrum disorders and other developmental disabilities.
- Case-cohort study design: population-based ascertainment (2700 children):
 - ASD cases
 - Neurodevelopmentally Impaired Comparison Group (NIC)
 - Sub-cohort





Study to Explore Early Development

Center for Autism and Developmental Disabilities Research and Epidemiology

- Main research areas
 - ASD phenotypic variation
 - Subgrouping for etiologic analysis
 - Infection and immune function, including autoimmunity
 - Reproductive and hormonal features
 - Gastrointestinal features
 - Genetic features
 - Sociodemographic features



CADDRE/SEED Research Partners

- Kaiser Foundation (California)
- California Department of Health
- •Colorado Department of Public Health
- University of Colorado
- Johns Hopkins University
- Drexel University
- Kennedy Krieger Institute
- University of North Carolina
- University of Pennsylvania
- Michigan State University

National Advocacy Partners

- American Academy of Pediatrics
- American Academy of Cerebral Palsy and Developmental Medicine
- National Institutes of Health
- Autism Speaks
- Autism Society of America
- First Signs
- Organization for Autism Research
- Reaching for the Stars: A
 Foundation of Hope for
 Children with Cerebral Palsy
- •Parents of Infants and

Child en with Kernicterus

Developmental Disabilities Branch

Metropolitan Atlanta Partners

- Metro Atlanta School Systems
- •Atlanta Area School for the Deaf
- Georgia Academy for the Blind
 - Georgia School for the DeafGeorgia DHR
- •Children's Medical Services
- Child Neurology Associates
- Children's Healthcare of Atlanta
- •Emory Autism Resource Center
 - Emory Children's Center
 - Emory Clinic
 - Grady Health System
 - Marcus Institute
- Psychological Sciences Institute
- Woodlawn Developmental Pediatric Center
 Georgia Department of Vital Statistics

Metropolitan Atlanta Advocacy Partners

- Georgia Walk for AutismASA-GA Chapter
- •CADEF: The Childhood Autism Foundation

ADDM Surveillance Partners

- Alabama Autism Surveillance Program
- Arizona Developmental Disabilities Monitoring Program
- California Department of Health
- Colorado Department of Public Health
- University of Miami
- Johns Hopkins University
- Missouri Autism and Developmental Disabilities
 Monitoring Project
- University of North Carolina
- University of Pennsylvania
- South Carolina Developmental Disabilities
 Surveillance Program
- Utah Registry of Autism and Developmental Disabilities
- Wisconsin Autism and Developmental Disabilities
 Monitoring Project
- Florida State University

International Research Partners (Denmark)

- Ministry of Science, Technology and Innovation
- University of Aarhus
- Staten Serum Institute
- University of Odense/Odense University Hospital
- University of Copenhagen

SAFER • HEALTHIER • PEOPLE™



2009: How many children have a developmental disability?













Acknowledgements







Thank You!



