

Surveillance of Developmental Disabilities: Birth Defects and Special Education Linkage

Kim Van Naarden Braun, PhD

Epidemiologist
Surveillance Team Lead
Developmental Disabilities Branch,
National Center on Birth Defects and Developmental Disabilities

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Definition of Developmental Disabilities

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. 1992a



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Why are DDs an Important Public Health Issue?



17% of children in the United States reported to have a developmental disability¹

2% of children have a serious developmental disability²:

Intellectual disability, Cerebral palsy, Hearing loss,
Vision impairment and/or Epilepsy

¹Boyle CA, Decouffé P, Yeargin-Allsopp M. Prevalence and Health Impact of Developmental Disabilities in US Children. *Pediatrics*. 1994; 93:399-403

²Yeargin-Allsopp et al. Multiple source methodology for studying the prevalence of developmental disabilities in children Metropolitan Atlanta Developmental Disabilities Study. *Pediatrics*. 1992; 89:624-60.



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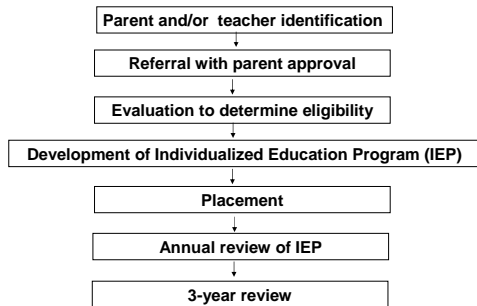
History of Special Education Rights

- 1975: Public Law 94-142, Education for All Handicapped Children Act
“...all children with disabilities have available to them...a free appropriate public education”
- 1990: Revision of Act: Individuals with Disabilities Education Act (IDEA)
- 1997: Revision to support inclusion of transition services.
- 2004: Reauthorized as Individuals with Disabilities Education Improvement Act
- 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)



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Special Education Process



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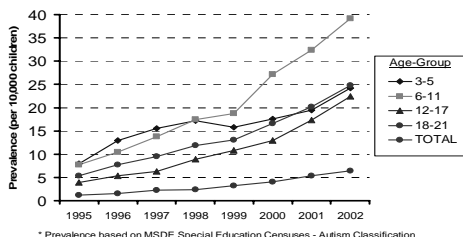
Using Special Education Data for Counting Children with DDs

- Department of Education
Dec. 1 counts
- Population-based
record review



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**Department of Education:
Prevalence* (per 10,000) of children with an autism special education classification in Maryland, by age and year**



* Prevalence based on MSDE Special Education Censuses - Autism Classification



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Source: MD State Department of Education

Population-based record review



Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)



Autism and Developmental Disabilities Monitoring (ADDM) Network

Prevalence of ASDs among 8-year-olds in 2000 and 2002 per 1,000 = 6.5 per 1,000 or 1 in 150.



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Genesis of CDC's DD Surveillance Efforts



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 in DeKalb County, GA



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Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- To provide ongoing, systematic monitoring of prevalence and characteristics of selected developmental disabilities (DDs);
- To assess possible relationships between birth characteristics and the occurrence of DDs;
- To examine the social, emotional, medical and educational consequences of DDs; and
- To provide a framework for initiating special studies of children with the selected DDs through a large case series of such children.



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Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP)

- 5 counties in metropolitan Atlanta
- Ongoing, population-based, active monitoring program for CP, autism, intellectual disability, hearing loss, vision impairment
- Multiple sources (educational, clinical, service)
- Children age 8 (i.e., born in 1998 for SY 2006).



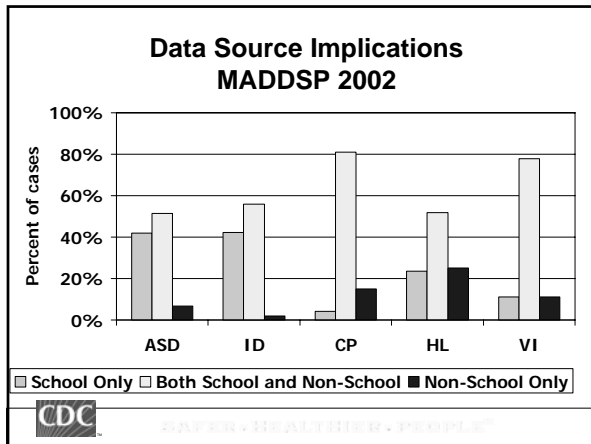
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MADDSP Data Sources

- GA Department of Education (ED) 
 - Metro Atlanta school systems – special education
 - State schools
 - Regional psychoeducational programs
- GA Department of Human Resources (DHR) 
 - Division of Public Health/CMS
 - Division of MH/DD/AD
- Pediatric hospitals and associated clinics
- Diagnostic centers
- Other clinical providers



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Access to Records

Goal: to get as complete a count of all children with select developmental disabilities (DDs) living in the 5 county metro-Atlanta area during the study period of interest.

Institutional or agency permission to review records with source authorization is the best way to accomplish this goal.

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Access to Records

- Memorandum of Agreement with GA State Department of Education and GA Department of Human Resources. CDC serves as an authorized representative of the State DHR.
- MADDSP is considered public health surveillance for review of medical records (HIPAA).

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Disability Monitoring in a Nutshell

- **Identify** potential cases at multiple educational and health sources
- **Screen** source files for CP indicators (“triggers”): CP diagnoses, physical findings associated with CP.
- **Abstract** CP diagnoses, physical findings and other relevant data from source files.
- **Clinician review** of abstracted data to determine CP case status.

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Case Criteria for All Disabilities

A case is defined as a child:



- who is 8 years old during the study year of interest;
- whose parent(s) or legal guardian(s) reside in the study area at some time during the study year of interest; and
- who meets the study case definition for one or more of the developmental disabilities being monitored.

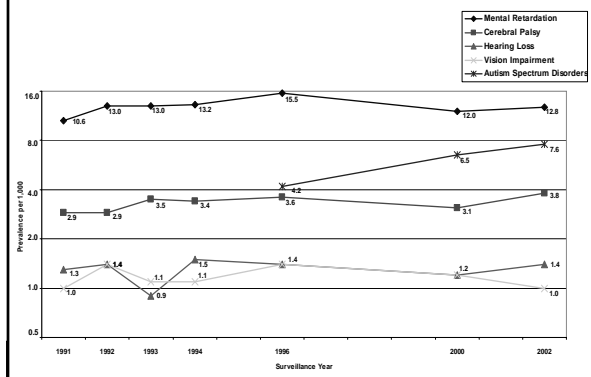
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Types of Data Collected

- Demographic
 - Child and maternal identifying information
 - Date of birth, race, gender
- Educational
 - Special education eligibility category
 - Psychometric test results (intelligence, developmental, adaptive, autism-specific)
- Medical/Clinical
 - Physical findings (CP)
 - Associated medical conditions (e.g. epilepsy, DS)
 - Other developmental disabilities
- Behavioral
 - Verbatim abstraction of behavioral features

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



Data Linkages

Deterministic method

- Georgia Vital Statistics
 - Birth certificates
 - Death Certificates
- Metropolitan Atlanta Congenital Defects Program (MACDP)
- Georgia Centers for Medicare and Medicaid Services (CMS)
- Census



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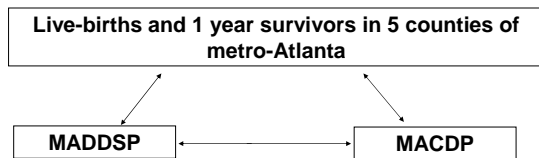
Common Attributes: MACDP & MADDSP

- Common ascertainment area, 5 counties of metro-Atlanta
 - MACDP: maternal residence at time of delivery
 - MADDSP: parent or legal guardian residence when child is 8 years of age.
 - Subset of MADDSP cases are also born in 5 counties (~60%)
- Ongoing active record review at multiple sources



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Linkage of MADDSP & MACDP



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Co-occurrence of BDs and DDs

Decouffé et al, *Pediatrics*, 2001.

Aim:

- Quantify associations between ID, CP, HL and VI and specific types of birth defects

Rationale:

- For majority of children, the etiology of their DD is unknown.
- If specific structural defects are strongly associated with specific DDs, may provide clues to prenatal origin as well as markers for early intervention.



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Co-occurrence of BDs and DDs

Decouffé et al, *Pediatrics*, 2001.

Methods

- Linkage of MADDSP and MACDP
 - Children born between 1981-1991, 3-10 years old in 1991-1994 surveillance years

Results

- Among those with a major birth defect 7.2% had a DD compared with 0.9% with no birth defect (PR: 8.3).
- Birth defects originating in nervous system and chromosomal defects resulted in highest prevalence ratios.



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MADDSP & Special Education Data: 2 Datasets for Identifying Children with DDs

- MADDSP
 - 8-year-olds
 - Review of child's record, extensive abstracted data
 - Consistent case definition
- Special Education Database
 - 3-10-year-olds (data are available on 3-21 year olds)
 - Linked longitudinally
 - Type of exceptionality and/or service
 - Length of time in special ed
 - Race/ethnicity, sex



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Analyses using Special Education Data and MACDP linkage

- Orofacial Clefts
- Congenital gut anomalies
- Congenital heart defects
- Eye and ear defects



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Background Orofacial Clefts and DDs

- Children with orofacial clefts often face numerous health issues including multiple surgical procedures, otitis media and feeding difficulties.
- Health issues may pose risk for cognitive and developmental problems:
 - Learning disorders
 - Speech and language disorders



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Use of Special Education Services by Children with Orofacial Clefts

Yazdy et al, Birth Defects Research (Part A), 2008,

Objective:

To evaluate the use of special education services by children with OFCs in metropolitan Atlanta using population-based data



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Methods Orofacial Clefts and Special Education

1 year survivors 1982-2001 in 5 counties of metro-Atlanta

Linkage with MACDP

- 1) Isolated Cleft Lip (CL), 2) Isolated Cleft Palate (CP),
- 3) Isolated Cleft Lip and Cleft Palate (CLCP), 4) No defects

Linkage with Special Education Database 1992-2004

- 1) In special education (25 exceptionalities & services)
- 2) not in special education



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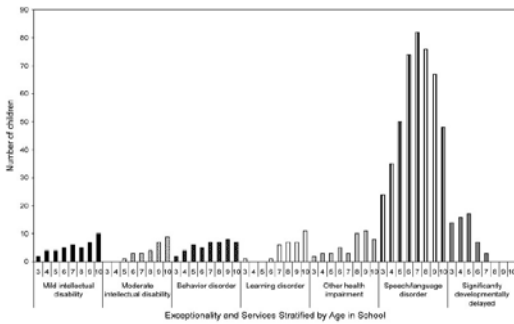
Results Orofacial Clefts and Special Education

	Not in spec ed %	In spec ed %	Prevalence Ratio
No birth defects	92.0	8.0	Referent
All OFCs	74.1	25.9	3.2
Isolated OFCs	77.1	22.9	2.9
Isolated CP	76.6	23.4	2.9
Isolated CL	86.5	13.5	1.7
Isolated CLCP	73.2	26.8	3.3



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Exceptionalities and services of children with OFCs (1992-2004)



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Conclusions

Orofacial Clefts and Special Education

- Approximately 3 times more likely to use special education services and enter the system at an earlier age.
- Most common exceptionality or service was speech and language followed by significant developmental delay (younger children)



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Strengths

Orofacial Clefts and Special Education

- First population-based assessment of special education use by children with OFCs.
- High sensitivity for case ascertainment
- Longitudinal nature of special education data allows monitoring of movement of children between exceptionalities and duration of services.



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Limitations

Orofacial Clefts and Special Education

- No data on private and home schooled children
- In-and out-migration
 - Sensitivity analyses indicated little change in prevalence ratios
- Special education services not analogous to developmental disability, unable to examine co-occurring developmental needs



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Public Health Implications Orofacial Clefts and Special Education

- Allow providers and families to be proactive and prepared for early intervention and educational needs
- Assist in public health and education planning for service provision



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Acknowledgements: “It Takes A Village”

MADDSP Staff

- | | | |
|-----------------------------|----------------------|-------------------------|
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MACDP STAFF

- Debra Adams
- Fran Baxter
- Cyndi Bowker
- Jo Anne Croghan
- Joann Donaldson
- Joan Garcia
- Teri Hurlburt
- Debbie Nurmi
- Charlie Peters
- Wendy Sklenka
- Patti Stevens
- CJ Alverson
- Mike Atkinson
- Tiffany Colarusso
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Thank you!



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