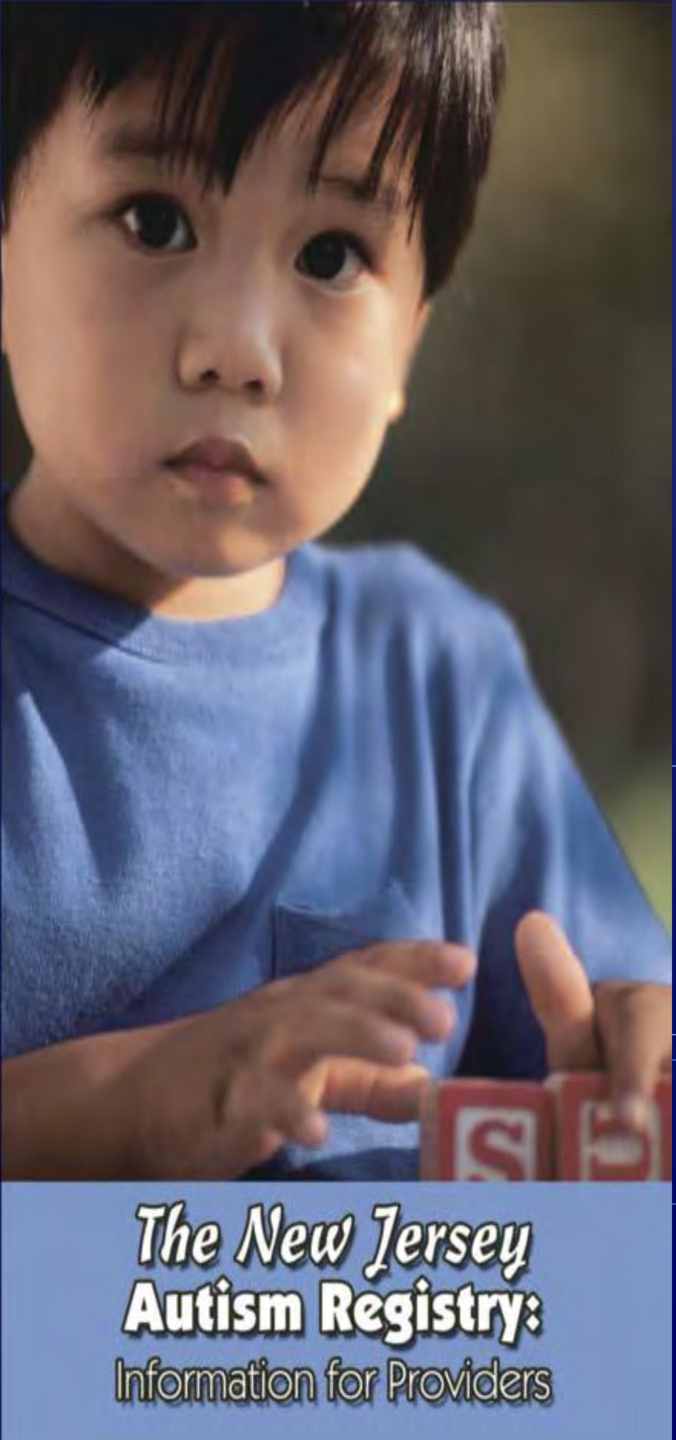


THE NEW JERSEY AUTISM REGISTRY

NJ Department Of Health,
Special Child Health Services, Early Identification
& Monitoring Program

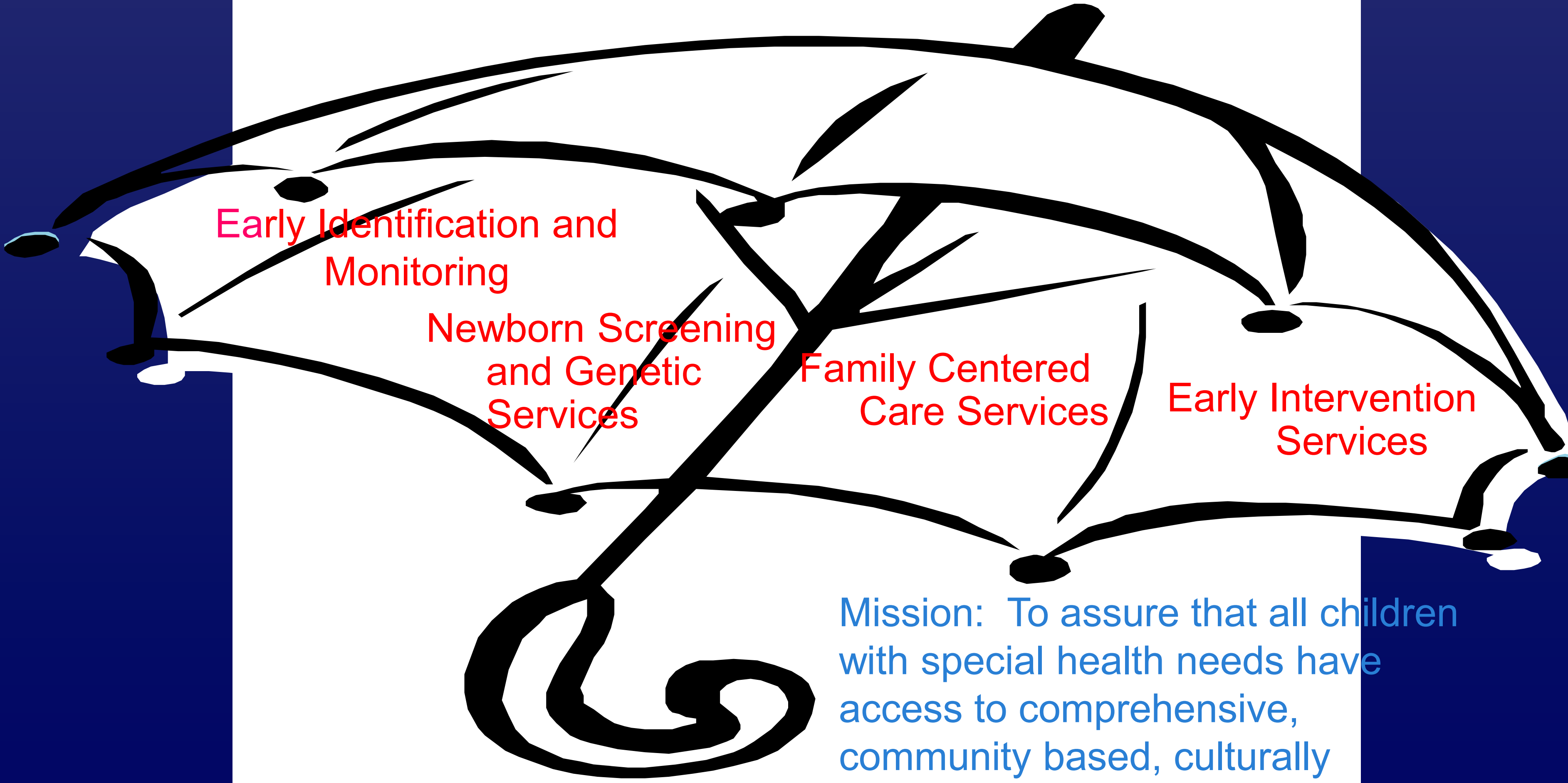
Autism

- Brick Township, New Jersey, Autism cluster – 6.7 per 1000 children (Bertrand J, et.al. Pediatrics. 2001 Nov;108(5):1155-61).
- In 2007, New Jersey has the highest rate of Autism in the US – 1 in 94 (CDC, 2007 – MMWR)
- 2007 – MMWR The lifetime per capita incremental societal cost of Autism is $3.2 million. (Ganz ML.. Arch Pediatr Adolesc Med. 2007 Apr;161(4):343-9.)

NJ Responds:

- On June 21, 2007, the New Jersey State Legislature *UNANIMOUSLY* passed Assembly Bill Number 2306 mandating an Autism Registry.
- A-2306 signed into law on September 12, 2007 as P.L.2007, c.170 (N.J.S.A. 26:2-185 et seq).
- This law requires the Department of Health to maintain a registry of reported autism diagnoses.

New Jersey Department of Health
Special Child Health and Early Intervention Services



Early Identification and Monitoring

Newborn Screening and Genetic Services

Family Centered Care Services

Early Intervention Services

Mission: To assure that all children with special health needs have access to comprehensive, community based, culturally competent, and family centered care.

History of Early Identification and Monitoring

- 1926 - Crippled Children's Commission appointed
- 1928 - first requirement for reporting of "crippled children"
- 1983 law - reporting of children diagnosed through age 1 with congenital defect(s)
- 1985 - rules adopted
  - Purpose of law: establish a birth defects registry…epidemiological *surveys…plan for and provide services*
  - Commissioner authorized referral of Birth Defects reports to County Case Management Units

THE NJ WAY

- REGULATORY (LAWS)
- RULES
- REPORTING TO REGISTRY
- REFERRAL TO SERVICES
- Resources

NJ Health
New Jersey Department of Health

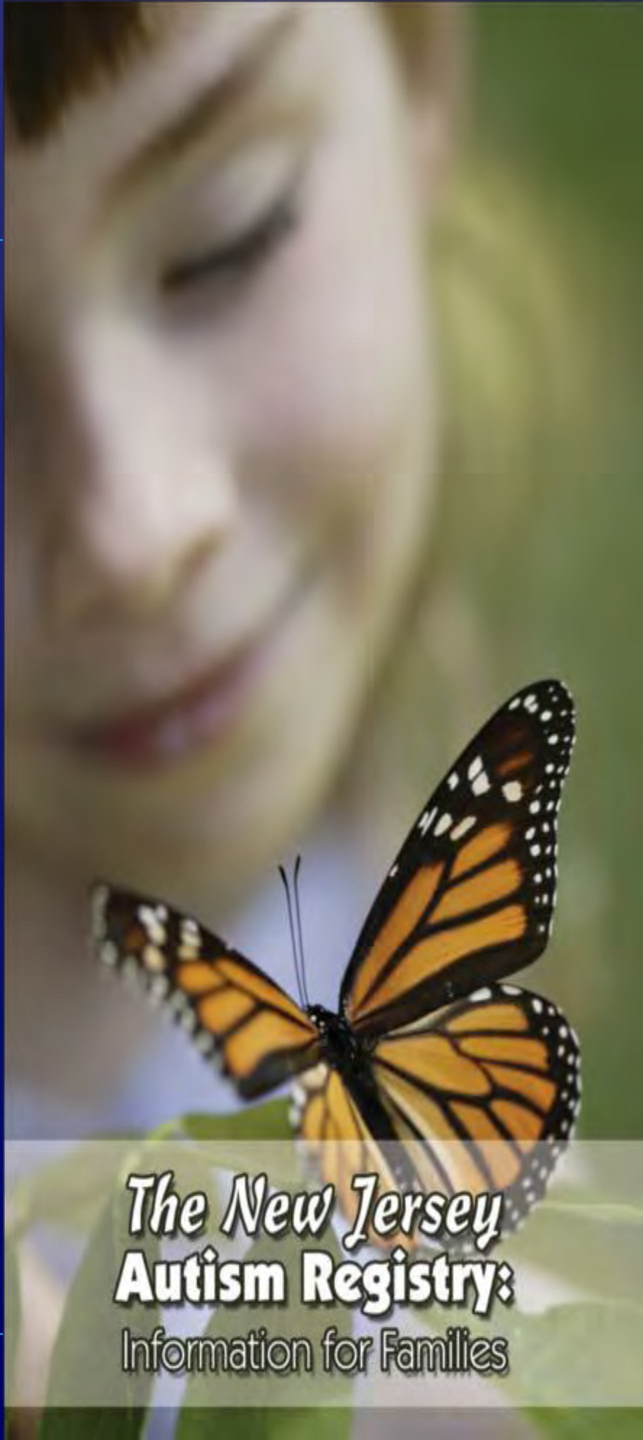
Autism Registry Structure

- Regulation – 26:2-185 et seq.
- Rules - N.J.A.C. 8:20-2.1
- Registry – Use BDR
- Referral – link to services through SCHS Case Management units
- Resources - $500,000 State General Fund (starting in SFY 2010 moved to funding from a revenue account)

Several Mandates=1 Registry

Laws Requiring Reporting:

- Birth Defects Registry (1983, 2005)
- Newborn Biochemical Screening (1964)
- Early Hearing Detection & Intervention (1977)
- Autism (2007; 2009)



The New Jersey Autism Registry: Information for Families

Developing the Autism Registry

- Convened panel of stakeholders
- Included child/adolescent psychiatrists, medical directors of neurodevelopmental centers, consumers, and pediatricians
- Designed and piloted The Autism Supplemental Form
- Promulgated Administrative Rules

Use of the Registry Data

- To plan for and provide services to children with autism and their families.
- Conduct more thorough epidemiological analyses of autism in NJ by:
  - Assessing factors that are associated with autism such as:
    - Geographic factors
    - Birth factors
    - Select familial factors

Who Must Register?

- **All health care professionals licensed pursuant to Title 45 and are qualified by training to make a diagnosis of autism are required to register a child to the Autism Registry.**
- If you DIAGNOSE or FOLLOW a child with autism, you are required to register that child.
- Newly diagnosed children will be mostly likely registered by the diagnostician i.e.. Pediatric Specialists
- Previously diagnosed children should be registered by the health care provider who is serving as the child’s medical home and providing follow up care.

Who is included in the Autism Registry?

- N.J.A.C. 8:20-2.3 directs the reporting of any person:
  - Birth through the age of twenty-one
  - Living in New Jersey
  - Diagnosed with Autism
  - Providers CANNOT register for ASD, Autistic-like features, or at-risk for Autism

What about HIPAA?

- This is public health surveillance:
  - HIPAA does not apply
  - Consent is not needed
  - All children with Autism must be represented in the registry
  - If we call a practice for follow-up information, they do not have to consent the parents to provide the information

Can Parents Say No?

- NO, But:
  - Parents have the right to Opt-Out of providing their personal identifying information. HOWEVER, the child must still be represented in the Registry.
  - What do Providers have to do?
    - Inform the parents or the child if they are over 18 years and living independently about the requirement to register and their option to Opt out.
  - What do Families have to do to Opt Out?
    - Give the providers a written statement requesting to opt-out
    - these remain in the provider's case file
    - Must provide all the other required information

What Type of Information is needed to Register

- Child's demographics such as the date of birth, gender, and race
- Contact information such as name and address of the child and parent(s)
- Diagnostician and the person submitting the form
- Diagnosis and diagnostic tools used to evaluate the child
- Age symptoms were first noted
- Sibling information

How to Report to the Autism Registry

All health care professionals report by:

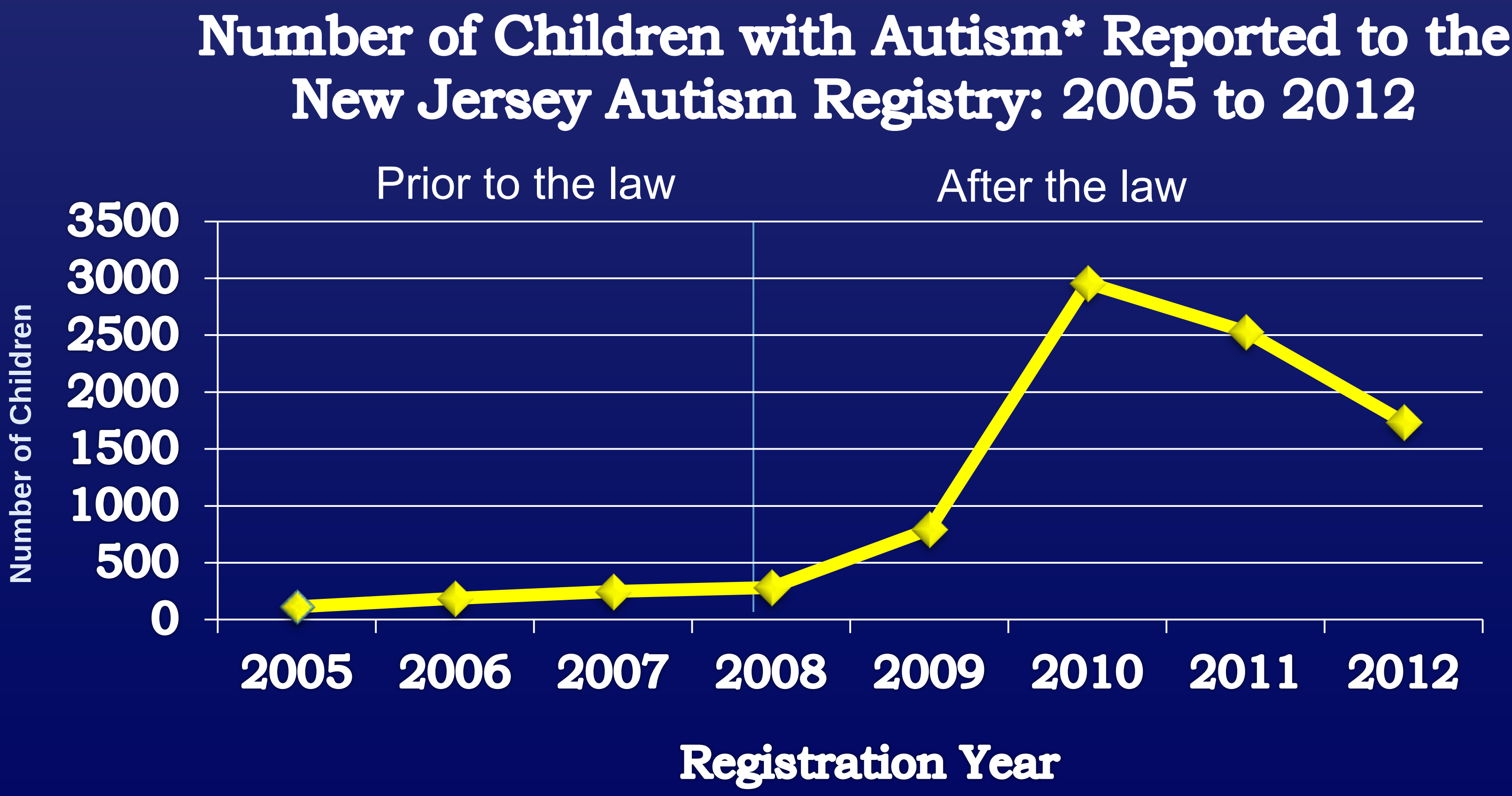
- Completing a paper copy of the SCH-0 (Special Child Health Registration) and the SCH-1 (Autism Supplemental Information) Forms available at http://www.state.nj.us/health/fhs/sch/schr.shtml and mailing it to the Department of Health OR
- Completing an electronic registration through the

  Birth Defects & Autism Reporting System (BDARS)

How Many Have Been Reported?

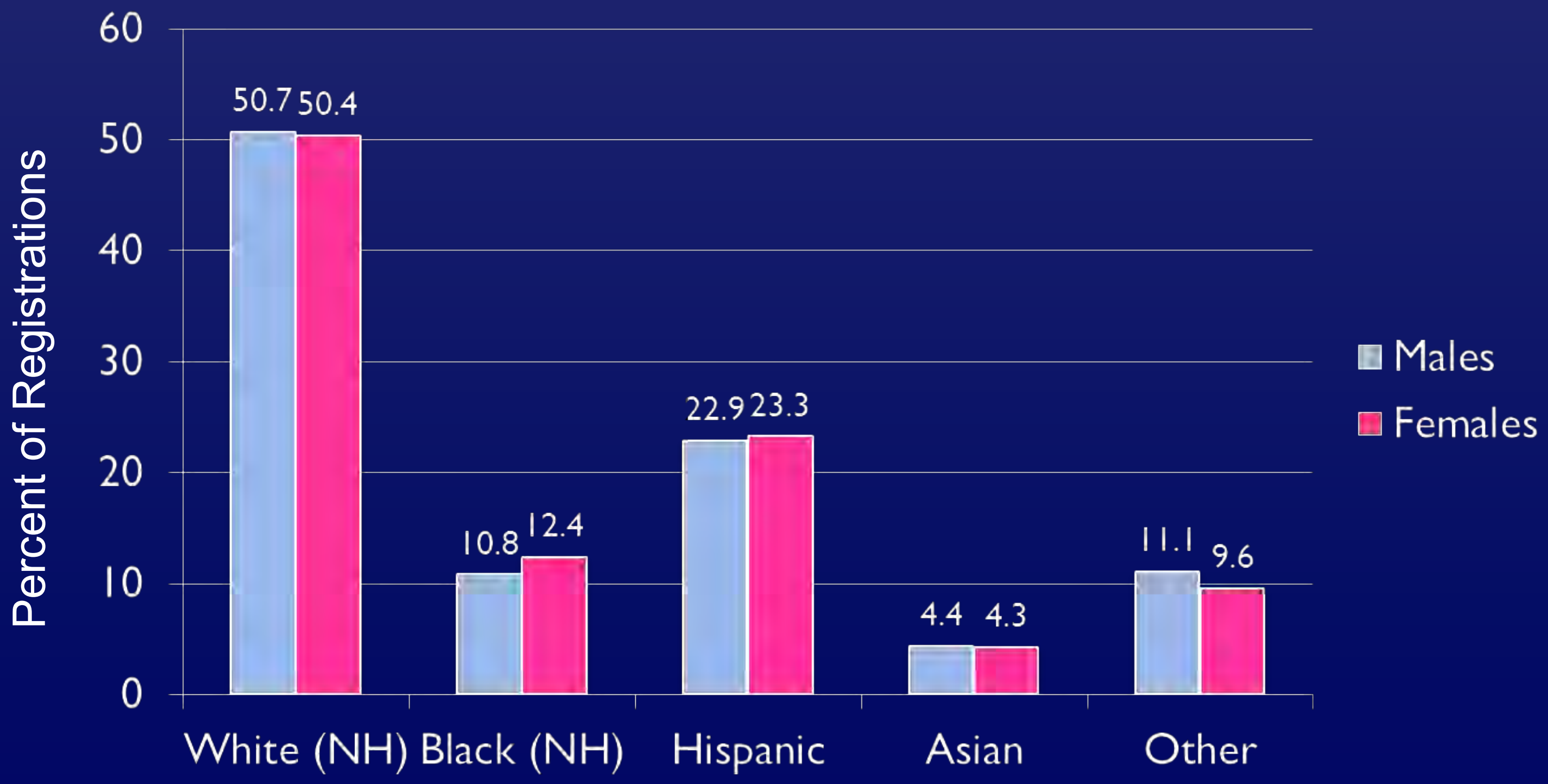
10,000+

Reporting of Autism



*Autism includes Autistic Disorder, Pervasive Developmental Disorder-NOS, Asperger Syndrome, Rett Syndrome, & Child Disintegrative Disorder

Race and Gender



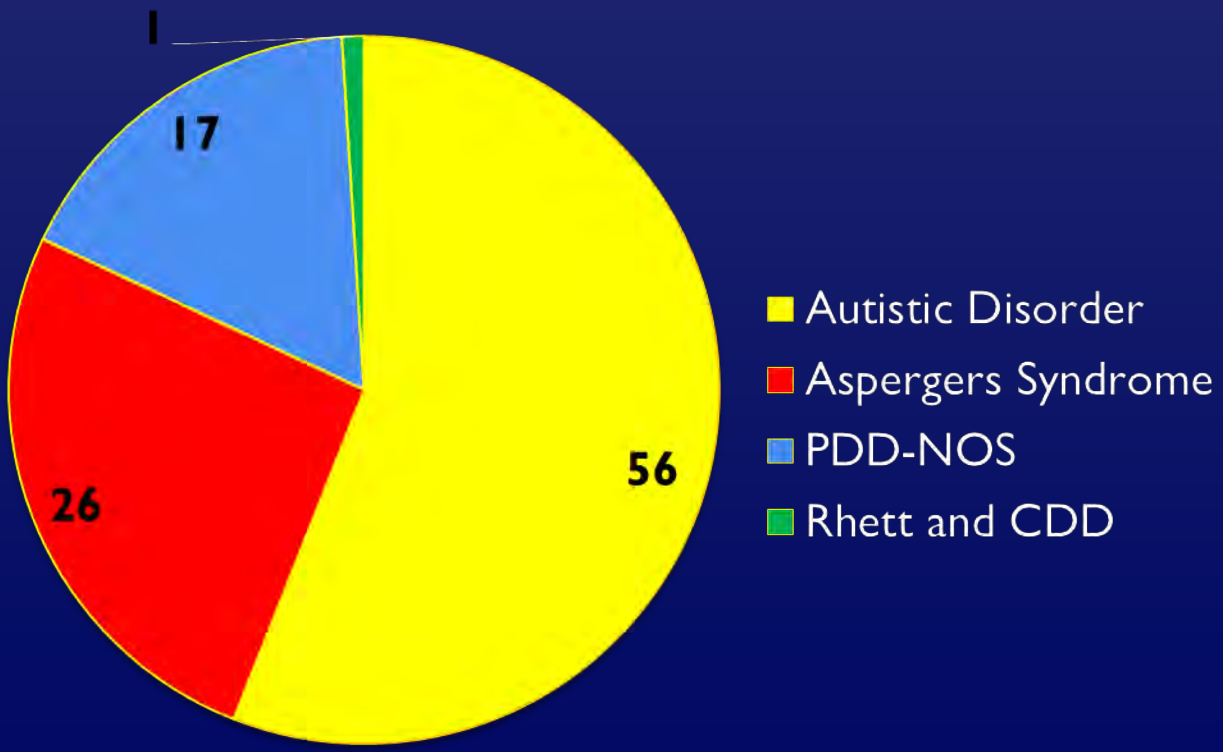
Other includes Native American, Multiple, Other and Unknown

Age of DX by Gender and Race

	Age of First Diagnosis	Age of Diagnosis
Male		
Mean	4.5	5.6
Median	3.4	4.4
Female		
Mean	4.5	5.5
Median	3.4	4.2
Total		
Mean	4.5	5.6
Median	3.4	4.3

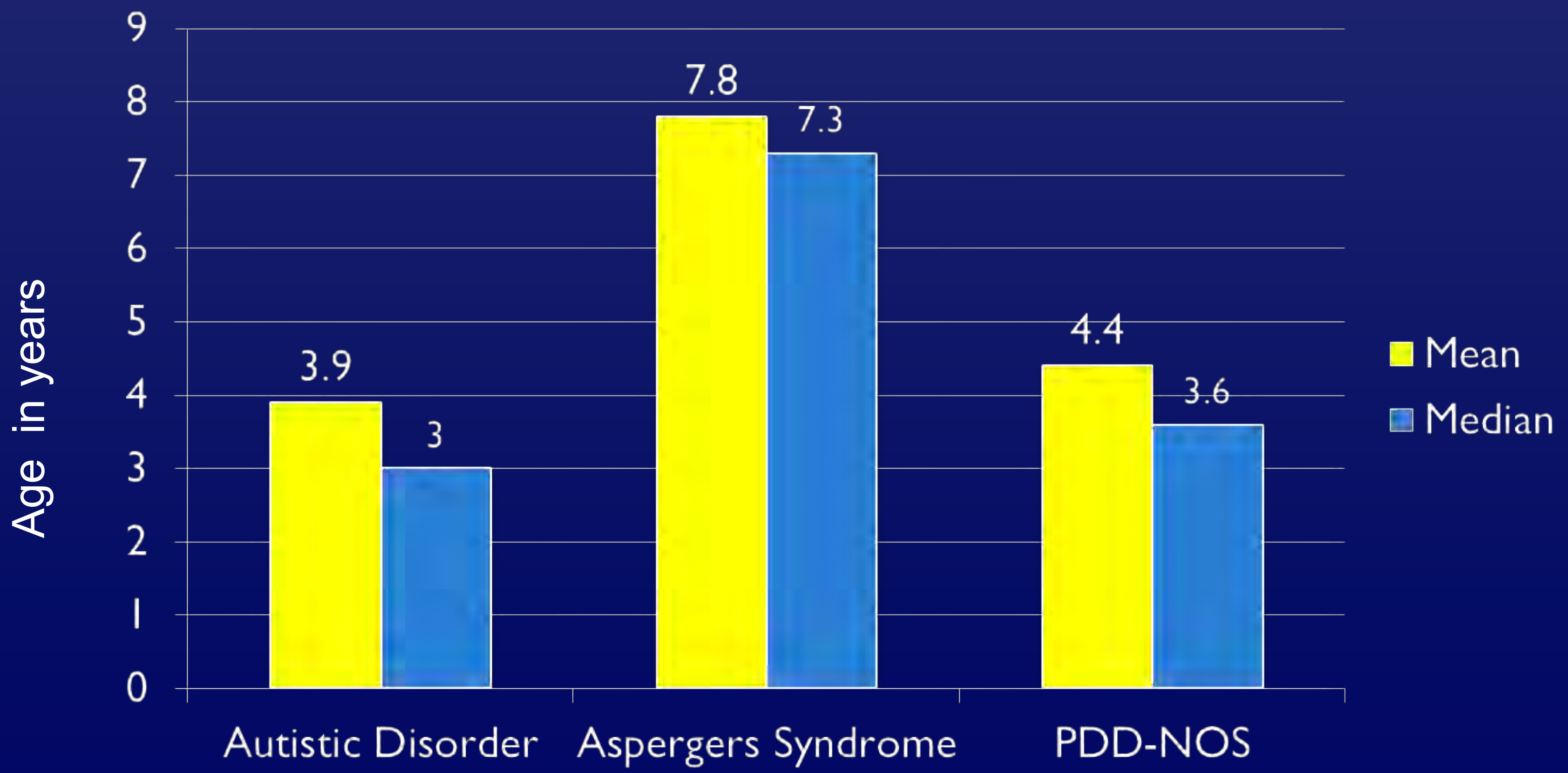
	Age of First Diagnosis	Age of Diagnosis
White (NH)		
Mean	4.6	5.8
Median	3.5	4.6
Black (NH)		
Mean	4.4	5.3
Median	3.5	4.1
Hispanic		
Mean	4.1	4.8
Median	3.3	3.8
Asian (NH)		
Mean	3.9	4.8
Median	3.3	3.7
Other		
Mean	5.3	6.5
Median	4.1	5.5

Percent of Diagnosis by Type



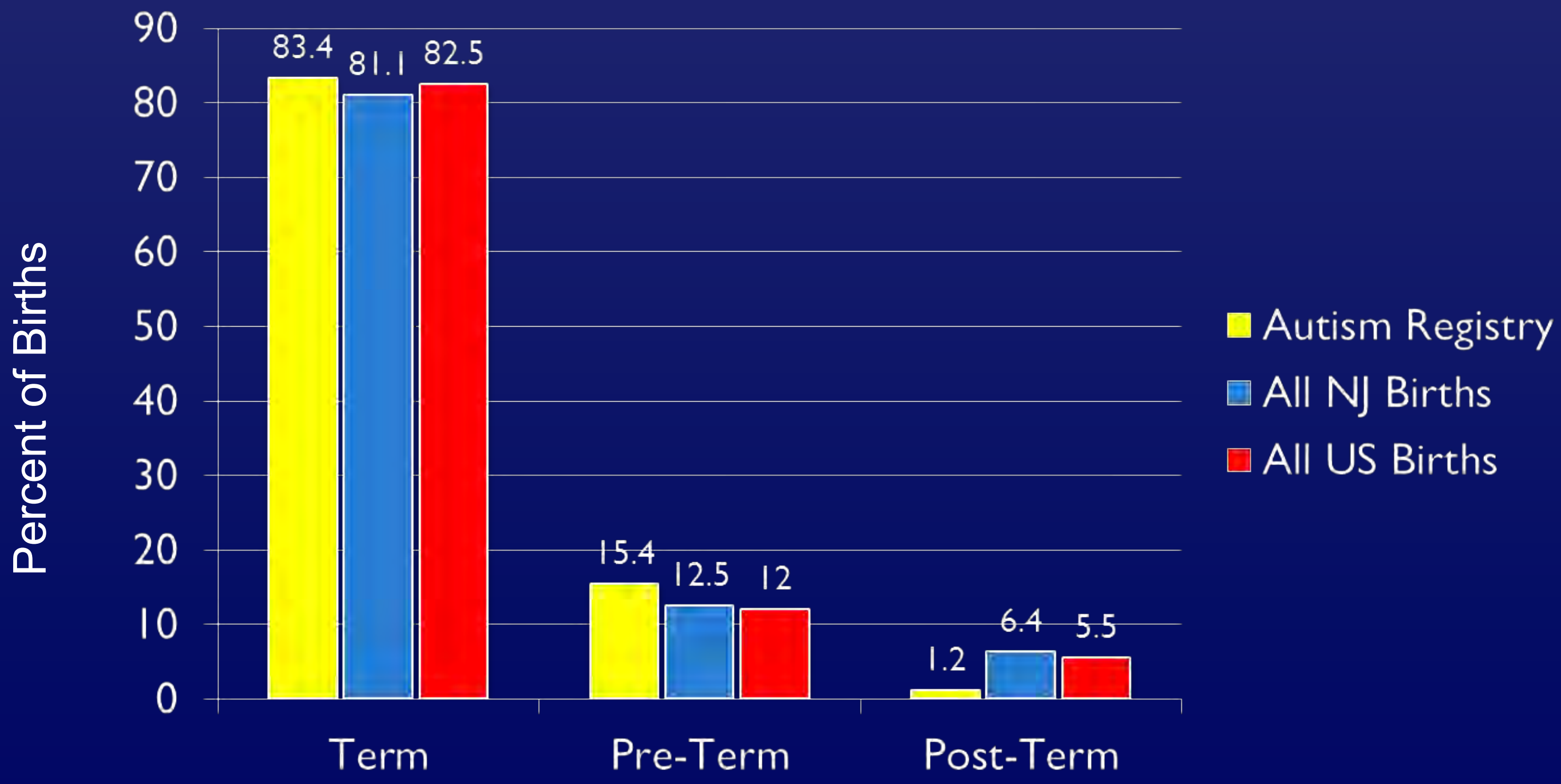
Rett’s and CDD make up less than 1% of registrants

Age of First Diagnosis by Type



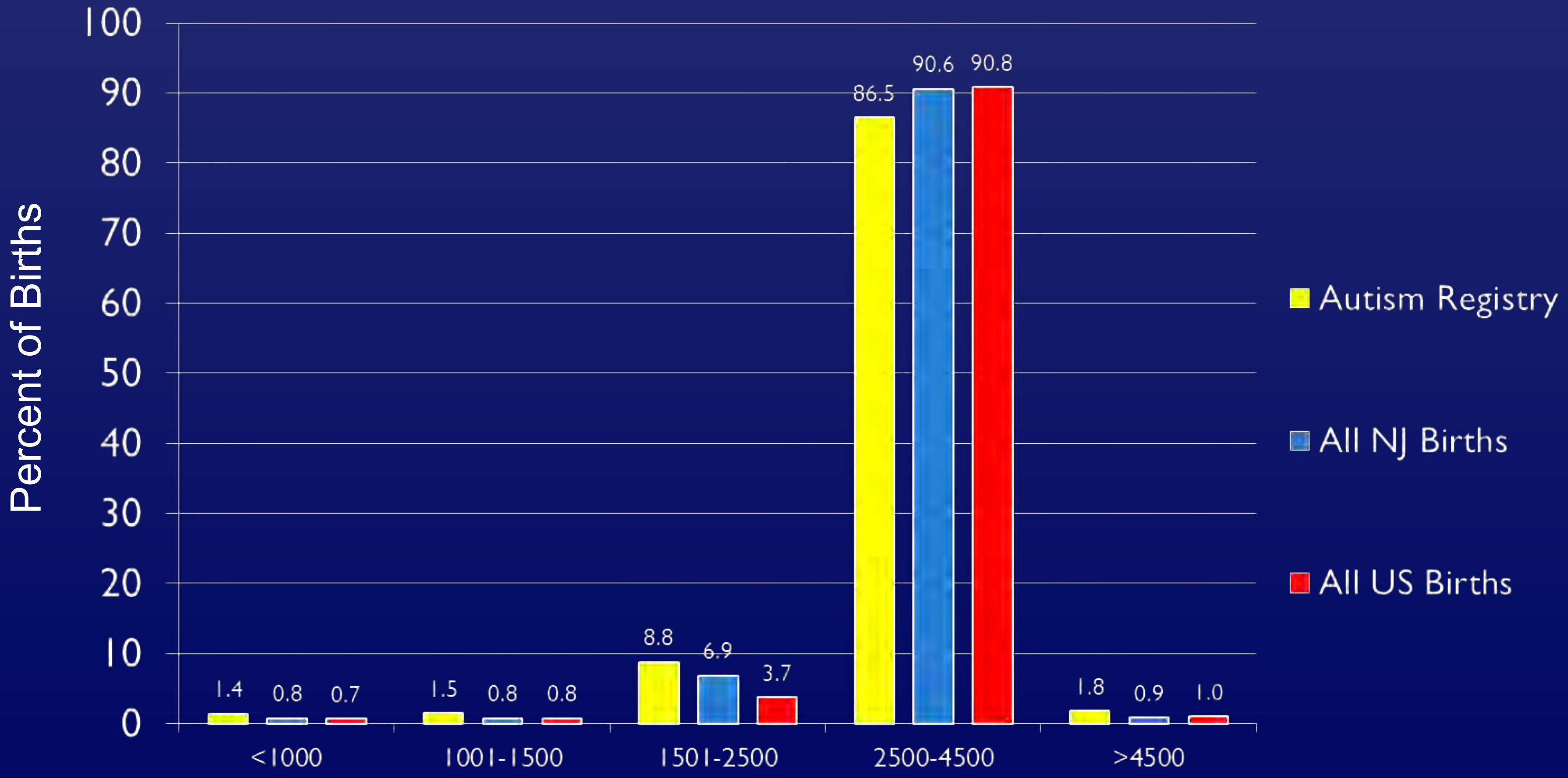
Rett's and CDD make up less than 1% of registrants

Gestational Age



US Data from 2010 National Vital Statistics Report

Birth Weight



US Data from 2010 National Vital Statistics Report

Why Does It Work

- Law and rules (BDR, UNHS, NBS, Autism)
- Long historical precedents – Families First!
- Funding from multiple sources
  - CDC (surveillance - BDR & EHDI)
  - MCH Block grant (BDR, Case Mgmt., EHDI)
  - HRSA (UNHS)
  - State (case mgmt.)
  - County Freeholders (case mgmt.)
  - Hospital (fee for blood spot kit - NBS)
- Part of an integrated system
- Data part of the program

For More Information

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