THE NEW JERSEY AUTISM REGISTRY

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What is New Jersey?

- 203 miles long and 60 miles wide
- Highest population density in the U.S.
- Average 1,030 people per sq. mi.
- North Jersey has the most shopping malls in 1 area in the world with 7 in a 25 sq. mile radius
- Jack Nicholson, Bruce Springsteen, Bon Jovi, Meryl Streep, Jerry Lewis, Frank Sinatra,
- 1st baseball game
- 1st intercollegiate football game
- 110,000 Births Per Year
Autism and New Jersey

- 2007 – MMWR – NJ rate 1 in 94
- 2014- MMWR- NJ rate 1 in 45
- On June 21, 2007, the New Jersey State Legislature UNANIMOUSLY passed Assembly Bill Number 2306 mandating an Autism Registry.
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
  - A 14 month Process
Autism Registry Structure

- The Autism Registry is one of several at the State
  - Birth Defects Registry (1983, 2005)
  - Newborn Biochemical Screening (1964)
  - Early Hearing Detection & Intervention (1977)
  - Autism (2007; 2009)
    - Regulation – 26:2-185 et seq.
    - Rules - N.J.A.C. 8:20-2.1
  - Referral – link to services through SCHS Case Management units
  - Resources - $500,000
  - Gov.’s Council for Medical Research and Treatment of Autism funded by moving violations
Effectiveness of a Law: Number of Children Reported to the NJ Autism Registry before and after enactment

YTD 2014=2178 and Est for 2014=3267
Who should be registered?

- All Children who are:
  - 0 to 21 years of age
  - Resident of New Jersey
  - Diagnosed with Autism per DSM

- Providers CANNOT register for
  - Autistic-like features, or at-risk for Autism
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 they DIAGNOSE or FOLLOW a child with autism, they are required to register that child.

Newly diagnosed children will be mostly likely registered by the diagnostician i.e. Pediatric Specialists

Previsouly 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 Has Been Registering

- Hospitals
- CMU
- EI
- Med/Prof Offices


Graph showing the number of registrations for hospitals, CMU, EI, and Med/Prof Offices from 2009 to 2013.
Can Parents Say No?

- But,
  - Parents have the right to Opt-Out of providing their personal identifying information. HOWEVER, each 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 the Opt out option.

- What do Families have to do to Opt Out?
  - Give the providers a written statement requesting to opt-out
  - Student remains in the provider’s case file
  - Must provide all the other required information
What about HIPAA?

- This is public health surveillance and a state law:
  - 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 get the parents’ consent to provide the information
Use of the Registry Data

- Link Children with Services
- Policy and planning of services to children with autism and their families
- Conduct epidemiological analyses of autism in NJ:
  - Assessing factors that are associated with autism such as:
    - Geographic factors
    - Birth factors
    - Select familial factors
Registry Goal 1
Link Children with Services

- Once the child is registered:
  - A letter is sent to the family with resource information
  - County Case Management is alerted
  - At least 3 attempts are made to offer services
Resources

- County-Based Case management 0 to 21 yrs old
- State Parent Advocacy Network (SPAN)
- Family Centered HIV Care Network
- 10 Child Evaluation Centers throughout NJ
  - Provide Tertiary and Cleft Lip/Palate Services
- Early Intervention Services
- Catastrophic Illness in Children Relief Fund program
- NJ FamilyCare
- Division of Developmental Disabilities
- Division of Disability Services
- Division of Medical Assistance and Health Services Medicaid and/or Waiver programs
- Social Security
Registry Goal 2
Policy and Planning of services to children with autism and their families.
How Many Have Been Reported?

14,000+
Percent of Diagnosis by Type

Data as of Oct 6, 2014 based on N=12,611
Age of First Diagnosis by Type

Data as of Oct 6, 2014 based on N=8,828
Example 1 of How are Registry Date are used: Children in the Autism Registry who were in NJEIS for Birth Years 2001-2008 by County

- In Early Intervention
- Not in Early Intervention
Example 2 of How Registry Data are used: Experiences from our Behavioral Health Providers

- Serving lots of children and young adults with an ASD, but are focusing more on the psychiatric or behavioral issues than the ASD
- Previously screened-out children with an ASD because they did not fit the traditional therapeutic models
- In-patient hospital units are overwhelmed trying to find appropriate placements
- More residential placements and support services for families are needed, as the children move toward adulthood and the parents age
Registry Goal 3
Conduct epidemiological analyses of autism data

- Assess factors that are associated with autism such as:
  - Geographic factors
  - Birth factors
  - Select familial factors
Many factors have been identified, studied, postulated, questioned, etc. to be related to Autism.
DNA/Genes

- Gene mutations that occur during development of the embryo (de novo)
- Gene mutations passed down through the parents DNA (ie. Recessive)
- 85% of children with Autism have no identified genetic cause (as yet)
Environmental factors affecting the embryo

- These factors include:
  - Air Pollution
  - Water Pollution
  - Exposure to toxins such as lead, plasticizers or phthalates
  - And more!

- Epigenetics
  - Epigenetics is the study of gene regulation and organization that occurs independent of changes in a gene’s “code,” or DNA sequence.
  - Typical brain development and function depend on the right genetic “switches” being flipped on or off at the right time.

Some environmental factors such as Histone methylation is one such epigenetic switch that may influence Autism
How Environmental Risks Overwhelm the Genome

As the fetal brain is growing, the expression of its genetic blueprint can be influenced by non-genetic factors in the outside world. A pregnant mom’s diet and other lifestyle choices, along with her exposure to chemicals and pollutants in food, air, water and household objects, affect the way the fetus’s brain develops. These environmental risk factors can be thought of as different streams of water flowing into a sink: only if the sink overflows—that is, if enough negative factors add up—will certain serious disorders result.

Environmental Risk Factors
- PBDEs (flame retardants)
- Other persistent organic pollutants
- Pesticides
- Not enough dietary folate or other B vitamins
- Lack of exercise
- Smoking
- Stress

Environmental risks add up to fill the sink. If it overflows, a disorder such as Rett syndrome may result.

Genetics
Genetics determines the size of the sink. Inherited vulnerability for certain disorders makes the sink smaller—therefore easier to overflow.
<table>
<thead>
<tr>
<th>Age of Embryo (in weeks)</th>
<th>Fetal Period (in weeks)</th>
<th>Full Term</th>
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**Major Morphological Abnormalities:**
- Heart
- Upper Limbs
- Eyes
- Lower Limbs
- Teeth
- Palate
- External Genitalia
- Ear

**Not Susceptible to Teratogens:**
- Dividing Zygote, Implantation and Gastrulation

**Prenatal Death:**
- Not susceptible to teratogens

**Functional Defects and Minor Morphological Abnormalities:**
- CNS
Long Reach of Environmental Factors...Epigenetics

**Grandmaternal effects**

Effect must pass an additional generation to be potentially transgenerational epigenetic inheritance through the gametes for grandmaternal effects.
Environmental Toxins over time

Toxins in the Environment include prescription drugs in water sources, Perchlorate, Phthalates, Pesticides, PCBs, Mercury, Arsenic, Lead, BPA, etc. Many with a half life of 20+ years.
Infant and Perinatal Risk Factors

- These factors include:
  - Epidural caudal anesthesia use
  - Labor induction
  - Short labors (< one hour)
  - Vaginal bleeding
  - Prolonged labor
  - Prematurity (<33 weeks)
  - Maternal age (older)
  - Paternal age (older)
  - Prenatal androgen exposure (fetal testosterone)
  - Low birth weight (<2500 grams)
  - Ultrasound use
  - Tocolytic use (steroid/smooth muscle relaxation medications to prevent pre-term labor
    - Terbutaline (trade names Brethine, Bricanyl, Brethaire, or Terbulin))
Birth Weight in Grams

Percent of Births

- <1000: 1.4, 0.7, 0.5, 0.7
- 1001-1500: 1.5, 0.8, 0.6, 0.7
- 1501-2500: 9.2, 6.7, 5.1, 6.6
- >4500: 1.7, 1, 1.4, 1.1

N=11,025
Excludes 2500-4500 gram category
Gestational Age

N=11,482
Excludes Term 37-41 weeks

N=11,482
Excludes Term 37-41 weeks
Mothers 35+ at Delivery from 1990-2010

US Data from 2012 National Vital Statistics Report
Age of Mother at Delivery in 2008

N=10,312

Percent of Mothers

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Autism Registry</th>
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<th>North Dakota</th>
<th>US</th>
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<td>6.3</td>
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<td>6.0</td>
<td>4.2</td>
<td>1.7</td>
<td>2.6</td>
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N=10,312
New Perinatal Risk Factor being researched: Inflammation

- Fever during pregnancy was reported twice as often by mothers of children with autism compared to mothers of typically developing children. It was 2.5 times more frequent than "typical" among mothers of children with developmental delay.

- However, when the researchers looked at those mothers who reported taking medication for their fevers, these were no more likely to have a child with autism or developmental delay than were mothers who reported no fever.

- Another recent study based on CHARGE data found that mothers who were obese or diabetic had a higher likelihood of having children with autism, notes Irva Hertz-Picciotto, Ph.D., CHARGE’s principal investigator at UC Davis. The common link may be inflammation, she says. Fever is produced by acute inflammation. Obesity and diabetes are associated with chronic inflammation.
Future Changes
Autism Registry Changes?

DSM IV To DSM V

No more discreet DX types
- 2 Criteria: 3 Levels
- Social Communication DIS is separated out from Autism

Professional Meetings

• Regional meetings with Autism Diagnosticians from various disciplines to discuss the changes

New Registration form
Co-Morbid Conditions of Autism Spectrum Disorders

- Tourette Syndrome
- Tuberous sclerosis
- Intellectual DIS
- Motor and Coordination Problems
- Speech and Non-Verbal learning disorder
- Seizures
- ADHD
- Neuroinflammation and immune disorders
- Anxiety, Depression, Bipolar Disorder
- Fragile X Syndrome
Why collect these details about the DX

Details about the ASD

- Functional Level
- Severity
- Type of Services

Better Prevalence Information

Better Policy and Planning
Questions?
For more information, Please contact

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