

## Statement from SafeMinds: March 27, 2014 Top Ten Things to Know About the CDC Report on Autism Prevalence. A 29% increase in two years. Not Just Genetics. Not Just Increased Awareness and Better Diagnosis!

On March 27, 2014 the CDC published "Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010" (MMWR Surveillance Summaries / Vol. 63 / No. 2). The study finds the rates of autism spectrum disorders (ASD) of children born in 2002 have increased to 1 in 68, up from 1 in 88 of children born in 2000. With males five times more likely to develop autism, the prevalence rate increased from 1 in 54 in boys born in 2000 to 1 in 42 in boys born in 2002. SafeMinds is in the process of reviewing the most recent report but has these comments based on preliminary data presented to the autism community. A more detailed analysis will be available soon at www.safeminds.org.

## Problems with the ADDM Data

- 1. **No Unified Process:** After a decade, the CDC has still not unified the review process among ADDM sites as it pertains to access to school-based health records, meaning there are site to site differences in the study. CDC notes that the lowest prevalence rates were found in states in which little or no access to education records was available (Alabama, Colorado, Missouri, and Wisconsin). When these four states are removed, total prevalence is 1 in 58, not 1 in 68.
- 2. **Design Flaw:** The CDC states that the study covers about 9% of the 8 year olds in the country, "the surveillance sites were not selected to be representative of the entire United States, nor were they selected to be representative of the states in which they are located" and considers this a weakness in the analysis.
- 3. Unable to Track Prevalence Data Over Time: The ADDM collection sites are determined every four years based on a competitive process and funding availability, and the collection sites constantly change which makes it difficult to track prevalence in the same states over time. This latest report is not an 'apples to apples' comparison to the previous ADDM network report. This report references the following states: Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin. States previously included, Florida, South Carolina, and Pennsylvania, are absent. There is also no evaluation of the high prevalence Somali Cluster in Minnesota.
- 4. Subtype Analysis Will Be Lost with Implementation of DSM-V: CDC provides that children with different subtypes or forms of autism are diagnosed at different average ages (autistic disorder: 48 months; ASD/PDD: 50 months; Asperger disorder: 74 months). The subtypes are different in the DSM-V redefinition of autism spectrum disorders and will change future ADDM reports again, making it difficult if not impossible to track trends over time. In this report, the CDC confirms that beginning in 2014 they expect rates of autism to decrease in the surveillance due to the new, more restrictive definition of autism spectrum disorders in the DSM-V
- 5. **Still No Focus on Severity or Co-Morbid Diagnoses:** While the current ADDM study reports declining intellectual disability in the portion of children for which they had data in some states,

after a decade, the CDC has failed to address the severity of autism and co-morbid diagnoses in this surveillance. Severity factors are vital in planning for education and lifetime service needs. Co-morbid diagnoses are important in looking at causation, treatments, quality of life, and total health care costs.

## Problems with the reporting of the data

- 6. Inaccurate Information Regarding Thimerosal Exposure: Thimerosal was not completely removed from vaccines in 2002. The concerns regarding the use of mercury (thimerosal) in infant vaccines surfaced in July of 1999 and it took several years for manufactures to alter their production process to remove or reduce thimerosal content. Vaccines that were being made during these transition years that contained thimerosal continued to be released with 2 year expiration dates, which means children in this report were still receiving thimerosal containing vaccines. Infants in high risk categories were also recommended to receive flu vaccines with mercury starting at 6 months of age and annually thereafter. In addition, the CDC Advisory Committee for Immunization Practices recommends that all pregnant women receive flu vaccines during pregnancy of which the vast majority contained mercury. The fetus accumulates mercury at higher levels than the mother and exposure to mercury during pregnancy is documented to cause neurological harm. Therefore it is impossible to report that there is no association between mercury in vaccines and autism prevalence.
- 7. Refusal to Acknowledge the Role of Thimerosal Exposure: The CDC's own original data uncovered by SafeMinds through FOIA over a decade ago showed that exposure to mercury in vaccines in the first 6 months of life (when comparing to zero exposure) increased the risk of developing autism 11 fold<sup>1,2</sup>. In 2000, SafeMinds published Autism, a Novel Form of Mercury Poisoning, which detailed the science confirming the similarity between the symptoms of autism and symptoms of mercury poisoning. Despite accumulating scientific evidence of the harm associated with exposure to vaccine levels of thimerosal from animal studies, CDC continues to utilize poorly designed epidemiological studies (such as this report) which are not designed to address the issue of thimerosal exposure, in order to quell public concern.
- 8. **Refusal to Look at Environmental Causation Including Vaccine Exposure:** Given that the ADDM researchers had access to medical records, a valuable opportunity to evaluate immunizations, adverse reactions, and the development of autism has been ignored. We have had **two decades** of lost opportunities, which shows no sign of changing. The paper states," Other topics of interest focus on socioeconomic indicators as well as perinatal risk factors such as timing of conception, weight gain during pregnancy, parental age, and interpregnancy interval." The CDC failed to mention the many other factors which studies are showing increases autism risk, including air pollution, pesticides, proximity to toxic release sites, and medications such as acetaminophen and anti-depressants. While the CDC/HHS continue to tell the public that there is no link between vaccine injury (and exposure to mercury) and the onset of autism, a study conducted by EBCALA<sup>3</sup> and published in the peer-reviewed Pace Law Review confirmed that the government has compensated at least 83 families in the Vaccine Injury Compensation Program whose child suffered a vaccine induced brain injury resulting in the onset of autism.

<sup>&</sup>lt;sup>1</sup> http://www.safeminds.org/research/library/GenerationZeroPowerPoint.pdf

<sup>&</sup>lt;sup>2</sup> http://www.safeminds.org/research/library/GenerationZeroNotes.pdf

<sup>&</sup>lt;sup>3</sup> http://www.ebcala.org/unanswered-questions

- 9. Inadequacies in Coordinating a federal response to Autism: While the CDC indicates in this report that the Interagency Autism Coordinating Committee (IACC) is the federal coordinator of autism activities, a recent GAO Report<sup>4</sup> found that the data provided by the IACC used to coordinate autism research activities was outdated, not tracked over time, inconsistent, and incomplete. These weaknesses limited the IACC's ability to monitor its progress on its coordination and monitoring efforts—which, in prior work, GAO established as a best practice for inter-agency collaboration, as well as a federal internal control standard. In addition, these weaknesses limited agencies' ability to use these data to identify coordination opportunities and avoid the potential for unnecessary duplication. This is among the reasons SafeMinds is asking Congress to provide accountability in the reauthorization of the Combating Autism Act this year.
- 10. CDC Repeatedly Fails to Acknowledge Autism as an Epidemic: Despite the dramatic increase in the number of children being diagnosed over the past two decades with autism, CDC continues to refuse to acknowledge autism as an epidemic. There is an urgent need for a coordinated federal response to the increase in the prevalence of autism and the development of a National Strategy that will address the increasing needs of our developmental disability service system, special education, vocational training, independent living and healthcare services that individuals with autism desperately need. Recognizing autism as an epidemic is the first step in mobilizing national resources to urgently address these ever increasing needs.

SafeMinds remains concerned that the CDC is not maximizing taxpayer provided resources. The ADDM data is slow to be published and has recognized flaws from the outset. CDC should only enroll states that allow access to school related data. CDC should keep the **same states in the** ADDM study through its duration so time trends can be observed. While the CDC is publishing the latest ADDM data, they have yet to publish any findings from the ten year old SEED study. Originally the SEED study was supposed to include a vaccine and thimerosal component. What are the findings in the SEED study and why have they not been published? The failure of the CDC to publish findings in a timely fashion points to their failure to treat autism like the national emergency that it is. The CDC has the ability to track flu cases in real time, but takes four years or more to publish autism data.

For more information about these issues, please visit our website at http://safeminds.org.

Autism Prevalence Findings Over Time CDC - ADDM Network			
Birth Year	Prevalence		
1992	1 in 150		
1994	1 in 150		
1996	1 in 125		
1998	1 in 110		
2000	1 in 88		
2002	1 in 68		

<sup>&</sup>lt;sup>4</sup> http://www.gao.gov/assets/660/659147.pdf

ADDM Site	Prevalence in children born in 2002	Surveillance area for 2002 study	Prevalence in children born in 2000	Surveillance area for 2000 study <sup>5</sup>
Alabama	1 in 175	9 counties in northeast and central Alabama	1 in 210	32 counties: Bibb, Blount, Calhoun, Cherokee, Clay, Cleburne, Colbert, Cullman, Dekalb, Etowah, Fayette, Franklin, Greene, Hale, Jackson, Jefferson, Lamar, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, Pickens, Shelby, St. Clair, Sumter, Talladega, Tuscaloosa, Walker, and Winston
Arizona	1 in 64	Part of 1 county in metropolitan Phoenix†	1 in 64	A subset of Maricopa County including metropolitan Phoenix, Arizona
Arkansas	1 in 64	All 75 counties in Arkansas	1 in 95	Pulaski County (metropolitan Little Rock, Arkansas)
Colorado	1 in 101	7 counties including metropolitan Denver	1 in 85	Arapahoe County (metropolitan Denver, Colorado)
Georgia	1 in 64	5 counties including metropolitan Atlanta	1 in 84	5 counties: Clayton, Cobb, DeKalb, Fulton, and Gwinnett (metropolitan Atlanta)
Maryland	1 in 60	6 counties in suburban Baltimore	1 in 80	6 counties: Anne Arundel, Baltimore, Carroll, Cecil, Harford, and Howard
Missouri	1 in 70	5 counties including metropolitan St. Louis	1 in 72	5 counties: St. Louis, St. Louis City, Franklin, Jefferson, and St. Charles
New Jersey	1 in 45	4 counties including metropolitan Newark	1 in 49	Union County (metropolitan Newark, New Jersey)
North Carolina	1 in 57	11 counties in central North Carolina	1 in 70	11 counties: Alamance, Caswell, Chatham, Davidson, Durham, Forsyth, Guilford, Orange, Randolph, Rockingham, and Wake.
Utah	1 in 53	3 counties in northern Utah	1 in 47	Part of 1 county in northern Utah
Wisconsin	1 in 107	10 counties in southeastern Wisconsin	1 in 129	10 counties: Dane, Green, Jefferson, Kenosha, Milwaukee, Ozaukee, Racine, Rock, Walworth, and Waukesha
South Carolina	(not included in current report)		1 in 90	23 counties: Allendale, Bamberg, Barnwell, Beaufort, Berkeley, Charleston, Chesterfield Clarendon, Colleton, Darlington, Dillon, Dorchester, Florence, Georgetown, Hampton, Horry, Jasper, Lee, Marion, Marlboro, Orangeburg, Sumter, and Williamsburg
Florida	(not included in current report)		1 in 139	1 county (Miami-Dade) in south Florida
Pennsylvania	(not included in current report)		1 in 75	Philadelphia County

## Comparison of ADDM Sites Used in 2002 and 2000 Birth Year Studies

http://www.cdc.gov/ncbddd/autism/documents/ADDM-2012-Community-Report.pdf