

# APPENDIX I

## CRITIQUING THE CDC 2012 REPORT ON THE 2008 AUTISM RATE

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For all of the talk about the rise in the rate of Autism, I seem to be one of the few who have noticed that there are major flaws in the statistics released by the United States Center for Disease Control (CDC) in March 2012, which concluded that the rate of Autism was 1 in 88 in the 14 communities surveyed in 2008. The numerous red flags that I found while reading the statistics compel me to question the legitimacy of these findings. However, everyone that I heard or read commentate on this report seem to be ignoring or coming up with excuses for these questionable numbers.

### Note:

*ALL REFERENCES TO PAGE NUMBERS ARE IN ACCORDANCE TO THE PDF DOWNLOADABLE VERSION:*

<http://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf>

*THE INTERNET VERSION IS JUST ONE LONG CONTINUOUS WEBPAGE:*

[http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s\\_cid=ss6103a1\\_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w)

### 1 IN 88?

According to the first paragraph of the second column of page 3:

#### **“Case Ascertainment**

ADDM is an active surveillance system that does not rely on professional or family reporting of an existing diagnosis or classification to ascertain ASD case status. Case determination is completed in two phases. The first phase involves screening and abstraction of records at multiple data sources in the community. All abstracted evaluations then are compiled and reviewed by trained clinicians to determine ASD case status in the second phase of the study. In the first phase, a broad net is cast to screen thousands of records and identify a subset of children with general symptoms of ASDs, whereas a much more strict case definition is applied during the second phase of the study. Because children's records are screened at multiple data sources, developmental assessments completed by a wide range of health and education providers are included. Data sources are categorized as either 1) education source type, including evaluations to determine eligibility for special education services or 2) health source type, including diagnostic and developmental assessments from psychologists, neurologists, developmental pediatricians, physical therapists, occupational therapists, speech/language pathologists, and other providers. Agreements to access records are made at the institutional level in the form of contracts, memoranda, or other formal agreements. All ADDM Network sites have agreements in place to access records at health sources; however, four ADDM sites (Alabama, Florida, Missouri, and Wisconsin) have not been granted access to records at education sources, and in one site (Colorado), parents are notified directly about the study and may request that their children's education records be excluded.”

**Question:** How can you have a reliable study to come up with a single set of statistics in which you use medical records only for some test subjects, education records only for others and both records for yet other? This leads me to ask, what is the rate of Autism among those for whom you...

1. ...only had medical records?
2. ...only had educational records?
3. ...had both medical and educational records?

According to the second paragraph of the second column of page 3:

“In the first phase of the study, ADDM Network sites identify source records to review based on a child's year of birth and either 1) eligibility classifications in special education or 2) International Classification of Diseases, Ninth Revision (ICD-9) billing codes (Box) for select childhood disabilities or psychological conditions. Children's records are screened to confirm year of birth and residency in the surveillance area at some time during the surveillance year. For children meeting age and residency requirements, the source files are screened for certain behavioral or diagnostic descriptions defined by ADDM as "triggers" for abstraction (e.g., child does not initiate interactions with others, prefers to play alone or engage in solitary activities, or has received a documented ASD diagnosis). If abstraction "triggers" are found, evaluation information from birth through the current surveillance year is abstracted into a single composite record for each child.

In the second phase of the ADDM methodology, the abstracted composite evaluation files are de-identified and reviewed systematically by trained clinicians to determine ASD case status using a coding scheme based on the American Psychiatric Association's Diagnostic and Statistical Manual-IV, Text Revision (DSM-IV-TR) (1) criteria for ASDs. A child is included as meeting the surveillance case definition for ASD if he or she displays behaviors at any time from birth through the end of the year when the child reaches age 8 years, as described on a comprehensive evaluation by a qualified professional, that are consistent with the DSM-IV-TR diagnostic criteria for any of the following conditions: Autistic Disorder; Pervasive Developmental Disorder–Not Otherwise Specified (PDD-NOS, including Atypical Autism); or Asperger Disorder.”

It is important to note that when they speak of the 8 year olds on whom the surveillances were conducted, they are talking about examining all of their records from the child's birth to 8<sup>th</sup> birthday. The significance of this is important to note when examining the mythology of the 2010 and 2012 surveillances, which are due to be published in 2014 and 2016 respectively.

**Question:** Did those who conducted these surveillances ever meet the children that they diagnosed, or were they basing their assessments exclusively the subjective observations recorded by those who may not have the training necessary to recognize Autism?

The next section is found on page 7:

#### **“Overall ASD Prevalence Estimates**

When data from all 14 ADDM sites in the 2008 surveillance year were combined, overall estimated ASD prevalence was 11.3 per 1,000 (one in 88) children aged 8 years (range: 4.8 [Alabama]–21.2 [Utah]) (Table 2). Overall estimated prevalence of ASDs was significantly lower in Alabama (4.8 per 1,000) than in any other site. Utah had the highest estimated ASD prevalence (21.2 per 1,000), which was significantly higher than all other sites except Arizona and New Jersey. The overall estimated ASD prevalence in New Jersey (20.5 per 1,000) was significantly higher than in any other site except Utah.

On average, estimated ASD prevalence was significantly higher in ADDM sites that had access to education sources compared with sites that relied solely on health sources to identify cases (RR: 1.5; 95% CI = 1.4–1.7;  $p < 0.01$ ). Relative differences among sites in prevalence estimates and 95% CIs are compared by access to education records and population size covered (Figure 1). In sites with access to both health and education sources, the proportion of ASD cases identified exclusively from education sources ranged from 10% in Arkansas to 72% in Arizona. One site (Colorado) was able to access education records in only one county but completed the study in six additional counties based on health records alone. In the one Colorado county with access to both education and health records, estimated ASD prevalence was almost twice as high (11.8 per 1,000) as in the six Colorado counties with access to health sources only (6.4 per 1,000). For this reason, Colorado results from the one county with access to both education and health records are considered to represent all children with ASDs more completely than results from the remaining six counties.”

Read the second paragraph closely because it acknowledges that the different methodologies used amongst the different surveillance programs affected the final results. I find it puzzling that no one seems to have a problem with what seems to me to be the most obvious flaw in how this surveillance study was conducted.

**Questions:**

1. Why is there such wide disparity between the Autism rates of different parts of the United States?
  - a. The rate of diagnosis in Utah is 4.42 times higher than the rate of Alabama.
  - b. The male to female ratio of Utah is 2.7 times higher than Alabama.
  - c. If you go to Table 2 on page 8 of this same report,
    - i. ...you will find that there were 2 different types of surveillance programs. One of these methodologies was used in Arapaho County (southeast Metro Denver). The other was used in the Adams, Broomfield, Boulder, Dever, Douglas, and Jefferson counties (Metro Denver, excluding Arapaho County). The rate of diagnosis in Arapaho County was 1.8 times higher than the rest of Metro Denver. The rate was also 2.9 times higher for Asian/Pacific Islanders.
    - ii. ...the Asian/Pacific Islanders diagnosis rate is 8.7 times higher [in Arizona than in Florida]. However, they must be basing this on combining Colorado's two surveillance studies together to generate one state-wide statistic. If you separate them, as is done in Table 2, then non-Arapaho County Metro Denver's .9 per 1,000 rate of Autism would be used instead of Florida's 2.2 per 1,000. Arizona's rate of 19 per 1,000 Asian/Pacific Islanders is 21.1 times higher than that of Metro Denver (excluding Arapaho County).
2. If diagnosing Autism by medical records alone is less than entirely accurate...,
  - a. ...then should not the statistical results from those sites that could not and/or did not use both medical and educational records be discarded as fallible?
  - b. ...and the statistical results do include fallible studies that should have been discarded, are all of the statistical results presented then in the report fallible?
  - c. ...how can any Autism diagnosis that a child might receive during their pre-school years be considered credible?
3. If the Autism diagnosis that many children receive during their pre-school years is credible, how is it that the explanation for the disparity of the rate of Autism in Colorado considered credible?
4. If the statistical results do include fallible studies that should have been discarded, then are all of the statistical results presented in the report fallible?

The next section follows the previous one on page 7:

**"Prevalence by Sex and Race/Ethnicity**

Combining data from all 14 ADDM sites, estimated ASD prevalence was 18.4 per 1,000 (one in 54) males and 4.0 per 1,000 (one in 252) females (RR: 4.6 for all sites combined). ASD prevalence estimates were significantly ( $p < 0.01$ ) higher among boys than among girls in all 14 ADDM sites, with male-to-female prevalence ratios ranging from 2.7 in Utah to 7.2 in Alabama.

Estimated ASD prevalence also varied by race and ethnicity (Table 2). When data from all sites were combined, the estimated prevalence among non-Hispanic white children (12.0 per 1,000) was significantly greater than that among non-Hispanic black children (10.2 per 1,000) and Hispanic children (7.9 per 1,000). Estimated ASD prevalence was significantly lower among Hispanic children than among non-Hispanic white children in nine sites and significantly lower than among non-Hispanic black children in five sites. Only one site (Florida) identified a significantly higher ASD prevalence among Hispanic children compared with either non-Hispanic white or non-Hispanic black children. New Jersey was the only site that identified approximately the same estimated ASD prevalence among non-Hispanic white children, non-Hispanic black children, and Hispanic children. Estimates for Asian/Pacific Islander children ranged from 2.2 to 19.0 per 1,000 although wide confidence intervals suggest that these findings should be interpreted with caution."

**Questions:**

1. If Autism knows no ethnicity, why is there such a disparity between the Autism rates of whites and non-whites?
2. Why was the ethnic ratio of the Arizona test subjects not consistent with the ethnic ratio for the State of Arizona? According to the Arizona fact sheet produced in conjunction with the CDC's main report, the ethnic ratio of the test subjects was:

White: 46.1%

Black: 5.5%

Hispanic: 43.6%

Asian or Pacific Islander: 2.7%

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Arizona-fact-sheet.pdf>

According to a 2010 ASU survey, the ethnic ratio of the State of Arizona was:

Hispanic or Latino: 29.6%

Non-Hispanic White: 57.8%

Non-Hispanic Native American and Alaskan Native: 4%

Asian and Pacific Islander: 2.9%

Other: 2%

Non-Hispanic Black: 3.7%

<http://csrd.asu.edu/data/infographics/racial-makeup-arizona>

**Other Questions from this section:**

1. How can these statistics be viewed as representative of the entire United States when the survey was only done in 14 communities?
2. If vaccines are causing Autism, why is the rate of Autism not declining proportionately to the percentage of parents that are refusing to have their children vaccinated?
3. For all the speculation about possible environmental factors in "causing" Autism, the leading advocates who are using this report as proof that they are right...,
  - a. ...would you not expect to find a higher rate of Autism in urban areas (where there are far more environmental risks to people's health) than in rural areas?
  - b. ...would doing surveillances in urban areas only inflate the Autism rate statistics?
  - c. ...were any of these communities considered rural communities, or were they all urban areas?Here is the information that I was able to glean from the "Fact Sheets" published for each state:

**Alabama:** 32 continuous southern counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Alabama-fact-sheet.pdf>

**Arizona:** "A subset of Maricopa County including metropolitan Phoenix, Arizona"

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Arizona-fact-sheet.pdf>

**Arkansas:** Little Rock

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Arkansas-fact-sheet.pdf>

**Colorado:** Denver

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Colorado-fact-sheet.pdf>

**Florida:** Miami-Dade

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Florida-fact-sheet.pdf>

**Georgia:** Atlanta

<http://www.cdc.gov/ncbddd/autism/states/ADDM-network-fact-sheet.pdf>

**Maryland:** 6 continuous northeastern counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Maryland-fact-sheet.pdf>

**Missouri:** 5 continuous east-central counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Missouri-fact-sheet.pdf>

**New Jersey:** Newark

<http://www.cdc.gov/ncbddd/autism/states/ADDM-New-Jersey-fact-sheet.pdf>

**North Carolina:** 11 continuous north-central counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-North-Carolina-fact-sheet.pdf>

**Pennsylvania:** Philadelphia County

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Pennsylvania-fact-sheet.pdf>

**South Carolina:** 23 continuous southeastern counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-South-Carolina-fact-sheet.pdf>

**Utah:** "Part of 1 county in northern Utah"

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Utah-fact-sheet.pdf>

**Wisconsin:** 10 southeastern counties

<http://www.cdc.gov/ncbddd/autism/states/ADDM-Wisconsin-fact-sheet.pdf>

d. ...why was there no surveillance done in the...

- i. ...10, as well as 12 of the 13, states with the lowest population density (Maine-38, Oregon-39, Kansas-41, Nevada-42, Nebraska-43, Idaho-44, New Mexico-45, South Dakota-46, North Dakota-47, Montana-48, Wyoming-49 & Alaska-50)? Utah-40; was the only one of the 13 to be surveyed.

<http://2010.census.gov/2010census/data/apportionment-dens-text.php>

- ii. ...16, as well as 24 of the 26, states with the lowest population (Louisiana-25, Kentucky-26, Oregon-27, Oklahoma-28, Connecticut-29, Iowa-30, Mississippi-31, Kansas-33, Nevada-35, New Mexico-36, West Virginia-37, Nebraska-38, Idaho-39, Hawaii-40, Maine-41, New Hampshire-42, Rhode Island-43, Montana-44, Delaware-45, South Dakota-46, Alaska-47, North Dakota-48, Vermont-49 & Wyoming-50)? Arkansas-32 & Utah-34; were the only two of the 26 to be surveyed.

<http://www.census.gov/compendia/statab/2012/tables/12s0014.pdf>

### INTELLECTUAL ABILITY

The section begins at the end of page 9 and ends in the middle of page 11. It deals with the subject of Autistic IQs. Most of the information on these pages is in the form of charts, the following is a merging of the commentary that appears immediately before and after these charts:

"When data from these seven sites were combined, 38% of children with ASDs were classified in the range of intellectual disability (i.e., IQ  $\leq 70$  or an examiner's statement of intellectual disability), 24% in the borderline range (IQ 71–85), and 38% had IQ scores  $>85$  or an examiner's statement of average or above-average intellectual ability. The proportion of children classified in the range of intellectual disability ranged from 13% in Utah to 54% in South Carolina. The two sites with the highest proportions of children classified above the range of intellectual disability (IQ  $>70$ ) were Utah (87%) and New Jersey (73%). In all seven sites reporting data on intellectual ability, a higher proportion of females with ASDs had intellectual disability compared with males, although the proportions differed significantly (52% for females and 35% for males;  $p < 0.01$ ) in only one site (North Carolina). When data from these seven sites were combined, 150 (46%) of 328 females with ASDs had IQ scores or examiners' statements indicating intellectual disability compared with 608 (37%) of 1,653 males."

I have four problems with this information:

1. The same problem that I have with this entire report; the statistics are all over the place. There is a huge disparity between Utah (13%) and South Carolina (54%) in percentage of those who were classified in the "intellectual disability" range. It also clearly states that, "The two sites with the highest proportions of children classified above the range of intellectual disability (IQ  $>70$ ) were Utah

(87%) and New Jersey (73%).” These same two states have the highest rate of Autism among the fourteen test sites (per 1,000 test subject: Utah 21.2, New Jersey 20.3). South Carolina (11.1 per 1,000) has the second lowest rate of Autism of the seven sites for which we have IQ statistics, the fourth lowest among all fourteen sites that participated in the survey. So what possible theories can I come up with to explain these results? I have two:

- a. The environmental factors that increase the risk for Autism also increase the IQs of Autistics.
  - b. The subjective Autism diagnostic criteria was applied in a manner in Utah and New Jersey which resulted in many of their higher functioning children being diagnosed, but was applied in a different manner in South Carolina resulting in many of their higher functioning children not being diagnosed.
2. The second problem that I have is that it does not tell us how many of the Autistics were non-verbal and non-communicative. There is an abundance of documentation showing that those who try to estimate the intelligence of those who are non-verbal wrongly assume that the subject probably has low intelligence. They are later proven wrong once the subject obtains the ability to use an augmentative communication device. This gives them the opportunity to demonstrate that they have far more intelligence than the evaluators assumed that they had.
  3. Some Autistics have difficulties processing auditory information. This does not mean that the Autistic is deaf, but that their brain cannot turn the sound waves that it is detecting into coherent words.

“Most IQ testing is language-based, which falls into the WISC/Weschler family. Raven's Progressive Matrices is a visual based IQ test which requires much less interaction with the tester, and people on the spectrum tend to do much better on Raven's.”  
(Tara Marshall, BA, SLPA [Speech Language Pathology Assistant] & Self-Advocating Autistic)

For the statistics to be meaningful the evaluators need to have used both testing methods and provide separate data for both.

4. The results are broken up into 3 statistical categories: IQ < 70 (intellectual disability), IQ = 71–85 (borderline) and IQ > 85 (average or above-average intellectual ability). For the record, my IQ was tested at 140 back when I was in 3rd grade, which is borderline genius. Although it is well known in the Autism community that some Autistics do have genius IQs, the individuals that prepared this report did not seem to think that it was important to note just how many Autistics do have such high IQs.

Many Autistic self-advocates, including myself, are frustrated that so much effort is put into presenting the most negative view of Autism possible that they have presented a distorted view of what Autism is. If the Autism community is going to help Autistics achieve their fullest potential, then the Autism establishment needs to present “the truth, the whole truth and nothing but the truth” about Autism. Any study on Autistic IQs that tops out at “above average intelligence” is not telling the whole truth about Autism.

#### **2010 AND 2012 SURVEILLANCES (DUE TO BE REPORTED IN 2014 AND 2016 RESPECTIVELY)**

[http://www.cdc.gov/NCBDDD/autism/states/ADDM\\_fact\\_sheet\\_2012.pdf](http://www.cdc.gov/NCBDDD/autism/states/ADDM_fact_sheet_2012.pdf)

1. Why are the twelve states that are participation doing one of four completely different types of surveillances based on different “packages of issues”?
  - a. Autism: Arkansas and Colorado
  - b. Autism, Cerebral Palsy: Alabama, Missouri and Wisconsin
  - c. Autism, Intellectual Disability: Arizona, Maryland, New Jersey, North Carolina, South Carolina and Utah
  - d. Autism, Cerebral Palsy, Intellectual Disability, Vision Impairment, and Hearing Loss: Georgia

Why does it matter that the CDC seems to be grouping these different studies together in some states, but not others? Many Autistics have various degrees of intellectual, visual and/or auditory issues. Therefore, testing for these issues in some, but not all, could therefore affect the end results.

## 2. Why 4 year-olds being monitored...

- a. ...in just 6 of the 12 surveillance site (Arizona, Missouri, New Jersey, South Carolina, Utah and Wisconsin)?
- b. ...when all the monitors have to go on are medical records due to the fact that these children have not started school yet and therefore have no school records? After all, it was clearly stated earlier in this report when addressing the disparity in the Colorado surveillance, areas in which they used medical records only showed a much lower rate of Autism than those that used both medical and school records. If this assessment is correct, then the inclusion of 4 year-olds in the surveillance should result in a lower rate of Autism in these states.

The 4 year-old children do have school records are in some type of early intervention programs because they have already been noted as being delayed in some aspect of their development. If this is the case, then they are not monitoring the rate of Autism in the general public, but of the specific segment of the population who have already been diagnosed with a developmental disability. To conduct a study in this manner would cause the Autism rate to explode.

In light of this fact, it should be noted that four of these six states that are monitoring 4 year-olds as well also had the highest rate of Autism in 2008. The following list shows the rate of Autism by state per 1,000 children:

Utah 21.2\*  
 New Jersey 20.3\*  
 Arizona 15.6\*  
 Missouri 13.9\*  
 Pennsylvania 13.3<sup>†</sup>  
 North Carolina 12.7  
 Maryland 12.1  
 Colorado 11.8  
 Georgia 11.5  
 South Carolina 11.1\*  
 Arkansas 10.5  
 Wisconsin 7.8\*  
 Florida 7.2<sup>†</sup>  
 Alabama 4.8

*\*STATE IS 1 OF THE 6 THAT ARE INCLUDING 4 YEAR-OLDS IN THEIR SURVEILLANCE.*

*<sup>†</sup>STATE PARTICIPATED IN THE 2008 SURVEILLANCE, BUT IS NOT PARTICIPATING IN THE 2010 OR 2012.*

4 different surveillance "packages of issues" x 3 different set of records available x 2 different age criteria = 24 different variation of surveillances being done at 12 separate surveillance sites to generate 1 bottom line statistic.

The VECC (Vaccine/Environmental Causes Crusaders) have been accusing the APA (American Psychiatric Association) of deliberately trying to undermine them with the purposed changes to the diagnostic criteria for Autism. If the surveillance of the 4 year-olds with medical records only has the same effect on the nationwide Autism rate as the medical-records-only surveillances done in Colorado, then these Crusaders should turn against the CDC in 2014 when they report that the rate of Autism had declined. On the other hand, these CDC reports are at the heart of their justification for their crusade. In other words, they would be biting the hand that feeds them. If the rate of Autism does not decline, possibly showing a continued increase, then the CDC will have disproven their own explanation for why there is such a disparity in the rate of Autism from surveillance site to surveillance site.

### **MY EXPLANATION FOR THE DISPARITY IN THE RATE OF AUTISM FROM SURVEILLANCE SITE TO SURVEILLANCE SITE**

The subjective Autism diagnostic criteria was applied in a manner in Utah and New Jersey which resulted in many of their higher functioning children being diagnosed, but was applied in a different manner in South Carolina resulting in many of their higher functioning children not being diagnosed. No matter how

good and scientifically anchored the diagnostic protocol for Autism may or may not be; it is still up to subjective individual human beings to apply it. A patient may indeed have test results that show they are delayed in a certain area of development that would suggest Autism. However, this same patient's testing may also show that they are well advanced in other areas. Because the professional establishment does not recognize Autism as a paradox, the very evidence that proves that the patient is Autistic may actually be used to dismiss Autism as a diagnosis. This can result in the Autistic receiving an alternative diagnosis or no diagnosis at all.

I am sure many in the professional community took serious offense to the notion that a high school educated Autistic would question their effectiveness in diagnosing Autism. If this is so, then they need to come up with a very good explanation for the disparity in the rate of Autism from surveillance site to surveillance site.

#### **CONCLUSION OF MY CRITIQUE OF THE CDC'S 2012 AUTISM REPORT**

As I said at the beginning, there are so many flaws in this report that I am amazed that it has been accepted. I believe that the number one reason for this is that the driving forces in the Autism community are focused on the gloom and doom. They present the notion that there is no hope for Autistics outside of their expensive research, treatments, therapies and other services. That is why it does not surprise me that they simply accepted the bottom line result, which perfectly suited their agenda, without scrutinizing the data that was used to come to this conclusion.

The CDC, continues to this day, to waste more money on more flawed studies in order to present a meaningless rate of Autism statistic to the public every other year. It is my option that the money that has been wasted on these flawed studies could be put to better use in the Autism community. Most notably would be dissemination of information that can improve the quality of life of Autistics and their loved ones, and research into issues that are important to Autistics because of how they impact our lives personally.

#### **IS THE INCREASED RATE OF AUTISM THE RESULT OF IMPROVEMENTS IN DIAGNOSTIC METHODOLOGY?**

For all of the advances that have been made in the area of diagnosing Autism, I am still meeting Autistics/Aspies at a monthly adult Autism/Asperger's meeting that I attend who went undiagnosed into their adult years. One member started off being diagnosed with Autism, had it changed to a non-Autism diagnosis, then had it changed a mild form of Asperger's. Although he has been diagnosed with "mild" Asperger's, he definitely has the hardest time of all of our group's regular attenders when it comes to understanding what is being shared. I have met a number of individual in their early 20s who are having the same outward struggles that I had when I was their age. When I talk to them, they express the same inner struggles that are common among Autistics/Aspies, but they have an ADHD diagnoses. Because of this, I have never succeeded in convincing them to try dealing with their struggles the same way some of Autistics have learned to deal with ours.

Furthermore, I started volunteering in an elementary school library for the 2012-2013 school year. I was told that in one of the kindergarten classes, there were six children being tested with in the first month of the school year. That is not to say that all 6 of them will receive Autism diagnoses, but it does point out the possibility that the system set up to recognize Autism during a child's preschool years could have failed one or more of the children in that class.

How could this have happened? No matter how good the diagnostic specialist may or may not be at their trade, they are not called upon unless one of three individuals recognizes the signs of a condition they are not specifically trained to recognize. First, would be the child's pediatrician, assuming that the child has one. The other two, are the child's parent's, assuming that the child has both. For many children, it is up to the untrained judgment of a single individual to recognize that their child may have a problem that requires the assistance of a specialist.

#### **MY EXPLANATION FOR THE INCREASE IN THE RATE OF AUTISM**

1. **The DSM-IV:** Prior to the publishing of the Diagnostic and Statistical Manual-Version IV in 1994, all Autistics were what is today referred to as "Low Functioning Autistics"/"Severely Autistic." The existence of "Asperger's"/"High Functioning Autistics"/"Mildly Autistic" was not recognized. Therefore,



there was no explanation for the atypical aspects of such individuals. It was inconceivable that those who had exceptionally high IQs, such as myself, could have a learning disability or an inability to function in social settings with our peers.

2. **An extreme societal emphasis on “exciting the senses”:** It is a well-established fact that many Autistics can be hypersensitive to sensory input. It is also a well-established fact that you can draw larger crowds by creating an environment that excites the senses of your target group. This practice may increase a company's profit margin, but it is extremely detrimental to an Autistic's ability to function in every area of their life. As a result, Autistic issues that are inherently mild in many Autistics to where they might not be noticed in an Amish type society are being enflamed to uncontrollable level.

I am not saying that we need to all live like the Amish, but I do know that there are a few movie theaters that will have an occasional “sensory friendly” showings. The Autistic community would greatly benefit if other business realized that there is a large market of those who would function a lot better if they could conduct their business in environments that are not trying to excite their senses.

3. **American society has become a more touchy feely society, especially for men:** When I grew up in the 70's and 80's, men did not hug men, period. We might give each other a high 5, high 10 or a hand shake; but we did not hug each other. To do so meant you were gay, which society used to condemn. In the 90's, societal expectations were reverse and men had to start hugging each other or else they would be labeled as having “male bonding issues.” Furthermore, couples are now expected to show level of public affection that would have been deemed inappropriate when I was growing up, which is nothing compared to what was considered appropriate and inappropriate for my parents and grandparents.

It is a well-established fact that many Autistics have sensory issues that cause them to not want to be touched. Autistic who have much milder sensitivities may not have had noticeable problems when society was not expecting them to let everyone touch them as they do now.

4. **Over diagnosis of Autism, especially by the VECC:** I have gone back and forth over whether or not I should reveal the identity of the Autism organization that I am about to express my grievance towards. However, in order to avoid a war that I do not want to have with them, best to simply state that this organization claims NIMH (National Institute of Mental Health) includes, “Loses language or social skills,” to its list of “possible indicators of Autism.” *NO IT DOES NOT!* Here's the link to the NIMH webpage that addresses this issue:

<http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/what-are-the-symptoms-of-asd.shtml>.

The organization that I will not name at this time, acting on behalf of the VECC, claims that the NIMH recognizes the LOSS of “language or social skills” as a symptom of Autism. Although NIMH DOES recognize that Autistics LACK of language and social skill are PART of the diagnostic criteria, they DO NOT make any statements that support the VECC's claims that their child's LOSS of “language or social skills” automatically constitutes an Autism diagnoses.

### **My View of the VECC**

It should first be noted that the VECC (Vaccine/Environmental Causes Crusaders) is a term that I came up with. It describes individuals in the Autism community who are determined to prove that Autism is caused by vaccines and various environmental causes. “Age of Autism” is probably the leading Facebook page dedicated to espousing their view points. I have never crossed paths with any such person that has objected to me referring to them as “Vaccine Crusaders.” In fact, many of them refer to themselves as “Warriors.” This entire movement was started by Andrew Wakefield, a now disgraced Gastroenterologist (who was stripped of his license to practice medicine by the “General Medical Council” of Great Brittan) that the VECC view as a martyr.

In 1993, I was the head of a children's puppet troop at Word of Grace Church in Mesa, AZ. Two years later, I noticed that several members of my former troop were involved in the church's children's choir. One of them was in third grade when I last saw her. As I watched, I noticed that one of the girls who was

two years younger than her had caught up to her in height. Then it occurred to me, she had not grown an inch in the two years since I last saw her. When I saw her mother after the service, I asked her what had happened. She said that the girl had some behavioral issues in the fourth grade and that her teacher, concluding that she had ADHD, said that she needed to be put on Ritalin.

When her mom told me this, the first thing I recalled was she had no behavioral nor hyperactivity issues when she was in my troop. The second was that her mother was about to be remarried when I last saw them. Remarriage is known to be a major stressor for children because it brings a lot of uncertainty into their fragile world. I was upset, not at the mother who trusted her daughter's teacher and doctors, but at the teacher and doctors for being so quick to put the girl on medication that they never considered the possibility of alternative explanations.

This is one of many reasons why those who know me know that I am in no way a member of the pharmaceutical fan club. Yes, I am open to the possibility that any chemical compound that you put in your body could have adverse side effects. So why am I not supportive of their crusade against the pharmaceuticals? Because they have turned their claims that the side effects of the vaccines constitute Autism into grounds to completely hijack the Autism community. There is so much information that can be disseminated that could improve the lives of Autistics and their loved ones, but Autistics who want to share it often have to take a back seat. The non-Autistic VECC, who are the dominant force in the Autism community here in Phoenix, believe their cause takes precedence over the desire of those Autistics who want to educate the public about how to improve the quality of life of Autistics and their loved ones. The extremist elements of the VECC go as far as to say that "high functioning Autistics," like myself, should not be allowed to speak at all because we are "not Autistic enough" to speak on their children's behalf. Only the parents, most of whom are not Autistic at all, should be allowed to speak for their Autistic children.

I, with the backing of my church (Covenant of Grace Christian Fellowship), started the AAC (Autism Ambassadors Corps), October 2010. The AAC *"...is a coalition of autistics and neurotypicals who seek to bring the entire autism community together in constructive dialog in order that all parties may obtain mutual understanding and admiration for each other."* To accomplish this, I have invited all of the local Autism organizations for whom I have contact information, to various meetings and conferences. Only "Asperger's Parents Network," "AZ ASSIST," "SEEDs for Autism," "AZ-ASAN" and "Joni & Friends" have ever shown up. The VECC has, to this point, declined all of these invitations.