

**Outcomes from a March 2010
National Autism Survey
Evaluating the Satisfaction
With the
US Government's Investment and Approach
To Investigating Causes of Autism**

*There is the need to regard Autism Spectrum Disorders as an urgent public health concern.
(CDC)*

Author: Beth Clay

20 April 2010

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Introduction: In March 2010, an online survey was launched to seek current perspectives from individuals in the autism community as it relates to the United States (US) government's handling of autism research. The survey was promoted on Facebook, Twitter, and through email. Several organizations and electronic information resources were gracious enough to post online or email an announcement of the survey for their constituents to be informed. These included Unlocking Autism, SafeMinds, *Age of Autism*, and the *Schafer Autism Report*.

In the Eyes of the Community They Serve, How are the CDC and NIH Doing? While I am a woman of many opinions, it is not my opinion that matters when it comes to evaluating the focus and investment of US government agencies into autism research. Rather it is the opinion those who are living with autism, individuals themselves, parents, grandparents, siblings of individuals with autism as well as medical and educational personnel working with individuals on the spectrum.

Who Might Benefit From This Report? The White House, Legislators, Policymakers, Autism and related organizations, researchers, educators, families and the media.

More than 2,000 People Responded: It was hoped with the launch of the survey to have at least 1200 respondents in order to give the survey the power to be a 'national' survey. With 2090 individuals completing the survey of 14 questions, 12 of which were multiple choice questions, the goal was achieved. Question 13 requested demographic information including city, state, and country. Because there are many aspects of the government's interaction with autism, research, services, and education, a final question was posed that provided the opportunity for a personalized text response. Sixteen hundred (1,600) individuals took the time to offer their personal comments on the government's handling of autism spectrum issues.

Key Findings:

- 90.4% of the autism community is not satisfied with the level of resources and approach that the US government is taking in their investigating the causes of autism.
- Over 40% not satisfied at all with NIH's spending on autism research. Only 1% completely satisfied.
- 41.6 % of respondents are completely dissatisfied with the NIH autism research focus.
- 43 % are not satisfied at all with the quality of research funded by the CDC as it related to autism statistics?
- 58.3% are not satisfied at all with the research conducted by or funded by the CDC regarding any potential relationship between autism and vaccine injury?
- 94.1% want to see more research funding on environmental toxins and their potential relationship to autism and other neurodevelopmental disorders?
- 90.2% want to see parents have a greater say in what the government funds relative to autism spectrum disorders research?
- 90.3% want to see studies comparing vaccinated and unvaccinated individuals to determine if there is a difference in the rates of autism and other medical conditions?
- 60.6% of respondents were parents of a child with autism who also has or has had gut issues.

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A Diverse Group Responded: While the largest group of responders (1592) was parents of someone with autism, 17.5% of responders were non-parents, thus giving the survey a diverse group of respondents. This was followed by 8.3% (173) of individuals who knew someone with autism (but did not fit into another category); 4.8% (99) grandparents; 4.1 percent (86) of respondents were individuals living with autism; 4% (83) educators; 1.8% (38) health care professionals; 0.5% (11) siblings; and five people (0.2%) of respondents did not know anyone with autism. Ninety-nine (99) percent of the respondents were in the United States, with 29 international individuals responding.

A Decade of Involvement in the Autism Community: Eleven years ago, I was introduced to the autism community as a part of my duties leading the health oversight team for the US House of Representatives Committee on Government Reform and Oversight. The first congressional hearing that I coordinated focusing specifically on autism occurred on April 6, 2000, and was entitled, "Autism: Present Challenges, Future Needs – Why the Increased Rates?" At the time, we as a Committee were focusing on the research activities of two agencies within the US Department of Health and Human Services, the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

More than 50% of the parents who answered this survey have a child who was not born (or was just born) at the time of this initial hearing. These parents would not have been among the thousands who reached out to the Committee seeking answers and assistance during my tenure.

Given that CDC and NIH were the Committee's original focus, and these two organizations continue to receive the lion's share of autism research funding and focus in the government, it seemed prudent to focus on these same agencies when seeking perspectives from the autism community.

In April 2000, Dr. Coleen Boyle testifying on behalf of the CDC stated,

"I want to begin by assuring the parents that we have heard from today that CDC is concerned about autism, and that we are working hard to find the causes of autism and other developmental disabilities so that all children will have the opportunity to have a healthy and productive future...CDC's role in preventing developmental disabilities including autism is to track the disease rates in the population and to identify causes of this condition. CDC can then establish prevention programs and then evaluate how well these programs work. We do not know if autism rates are going up. Early studies found autism rates in the range of 4 to 6 per 10,000 children, using a narrow set of criteria. More recent studies have reported rates averaging 12 per 10,000 children, but these studies have used different criteria than the earlier studies. CDC is not certain how much of the reported increase is due to changes in the definition of autism or an improved recognition of this condition over time. We also do not know if other factors have contributed to the larger numbers of children seeking treatment...It should be pointed out that factors known to be associated with autism include genetic factors and events that occur before birth. CDC recognizes how important it is to identify the causes of autism as well as to ensure the safety of vaccines... CDC agrees with the committee and the parents who have testified today

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that autism has a significant and profound adverse impact on the lives of children and families and communities where it occurs. We must track this disorder, we must identify the preventable causes, and we must institute effective prevention programs...”

Dr. Deborah G. Hirtz of the National Institute of Neurological Disorders and Stroke [NINDS], on behalf of the National Institutes of Health testified:

“... I want to explain that we at the NIH share the sense of urgency that autistic individuals and their families and advocates feel with regard to unlocking the mysteries of this devastating disorder. .. We now know that autism is much more common than we previously thought. Estimates vary widely, but recent studies suggest that as many as 1 in 500 people may be affected by some form of autism. Recent reports suggest that the number of children with autism may be increasing substantially. It is not clear whether the reported increases can be accounted for by improved or expanded diagnosis, or by the increasing availability of services for autism and it would be necessary to study the trends of that prevalence over time. The NIH recognizes the pressing need to look into these issues and to do this work and is actively working to design studies that can give us knowledge in these areas... I would like to add that autism research is a major priority for the NIH, and we are committed to continuing to work to expand our efforts...”

In the developing of this paper, I emailed both Dr. Hirtz and Dr. Boyle with their above quotes and asked respectively: “...wanted to check back with you for insights on what the NIH has accomplished in the last decade to uncover the cause(s) of autism.” And “...what specific studies the CDC has conducted to investigate the causes of autism.”

The NIH response came from the National Institute of Mental Health (NIMH) and referenced the NIMH and the Interagency Autism Coordinating Committee websites as well as NIMH Director, Dr. Tom Insel’s blog on Autism, where he wrote, “...the main driving force behind NIMH’s focus on autism is the evolving view of mental disorders as developmental brain disorders. In that sense, rather than being an exception, autism has become a prototype for understanding a range of mental disorders, from schizophrenia to anxiety disorders....This makes autism especially relevant. Autism is the paradigmatic developmental brain disorder, with genomic and environmental factors leading to onset in the first three years of life. ..Most important, early detection confers the opportunity for early intervention and even preemption of the disability associated with this disorder. These are exciting times in autism research, with multiple risk genes identified and the beginning of an effort to identify environmental factors. ..” (Insel, 2009)

The CDC response to my inquiry sent me to their website which states: *More people than ever before are being diagnosed with an ASD. It is unclear how much of this increase is due to a broader definition of ASDs and better efforts in diagnosis. However, a true increase in the number of people with an ASD cannot be ruled out. We believe the increase in ASD diagnosis is likely due to a combination of these factors. By studying the number of people diagnosed with an ASD over time, we can find out if the number is rising, dropping, or staying the same. We can*

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also compare the number of children with ASDs in different areas of the country and different groups of people. This information can help us look for causes of ASDs and helps communities plan for services.” (Centers for Disease Control and Prevention)

The CDC staff also provided a copy of the second edition of the *SEED Newsletter*. SEED stands for the Study to Explore Early Development which started two years ago and according to the newsletter over 2300 families have agreed to participate. One of the components of this study talked about in the newsletter is a “Diet and Stool Diary” in which parents write down everything their child eats for three days and then detail how often your child poops and what it looks like. (Centers for Disease Control and Prevention, 2010) To be clear, they are not; however, asking parents to send poop samples to the CDC for analysis.

Autism Statistics: At the time of this first hearing, the two agencies disagreed on the prevalence rates of autism. NIH stated that 1 in 500 children in the United States are likely on the spectrum while the CDC stated 12 in 10,000 (1 in 833). Three years later, the *Journal of the American Medical Association* published a paper co-authored by Dr. Boyle showing data from 1996, which found a prevalence of autism of 1 in 333. Seven years later, the CDC would finally publish both their 2000 and 2002 data which showed a rate of 1 in 150. It is unclear why the CDC takes so long to publish their study findings. We can only guess at what the legislative and public health response might have been if Congress was told in 2000 that the rate had grown from 1 in 10,000 in the late 1970s to 1 in 333 in 1996 to 1 in 150 in 2000. By the time seven years later that the original data was published for the 2000 study, the CDC had already conducted a second and third study which showed a 57% increase of autism in four years. If the rates had grown from 1 in 333 in 1996 to 1 in 150 in 2000 and then 1 in 100 in 2006, what will the rate be in the 2010 data? In December, with this the CDC called autism an “urgent public health concern”.

The CDC does not plan to release its latest data until the first quarter of 2011.

Survey Responses: As mentioned above, there were 12 multiple choice questions. The questions and the participants’ responses follow.

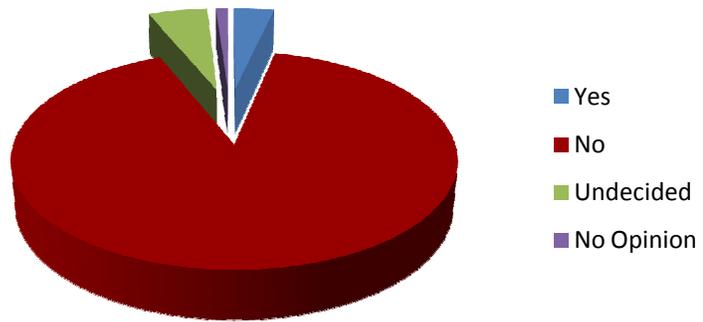
Question: CDC’s most recent data show that between one in 80 and one in 240 children with an average of one in 110 has an Autism Spectrum Disorder (ASD). Are you satisfied with the level of resources and approach that the US government is taking in their investigating the causes of autism?

90.4% are not satisfied with the government’s level of resources and approach to investigating the causes of autism.

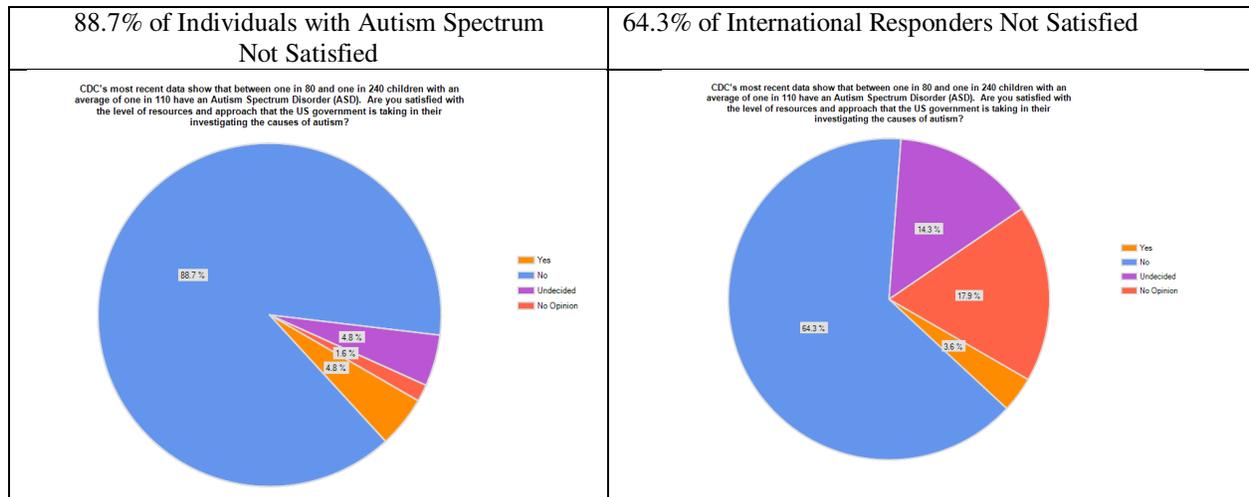
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Response Of 2086	Response Percent
Yes	3.5 %
No	90.4 %
Undecided	5.2 %
No Opinion	1.0 %

Are You Satisfied with Government Response?



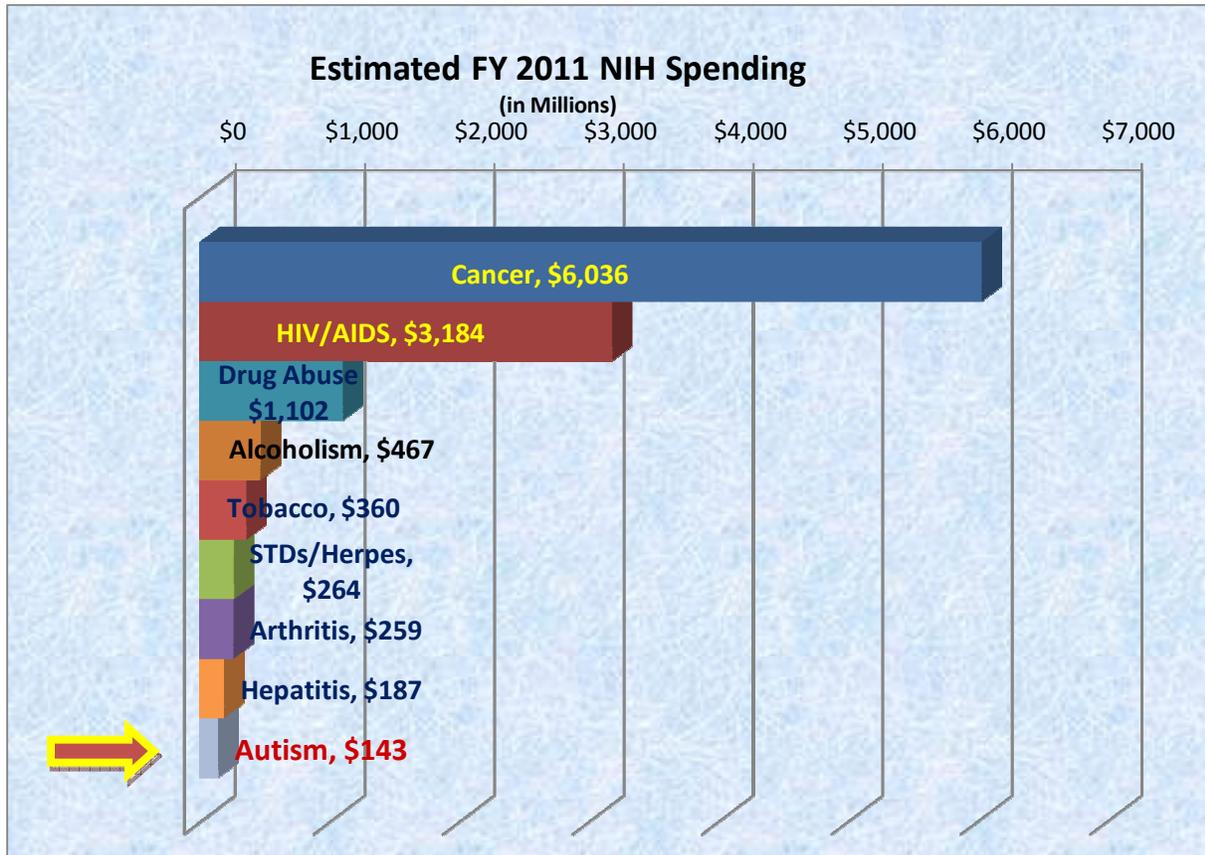
In comparing the entire set of responses to the subset of 62 individuals who self identified as being on the autism spectrum, the findings are very similar. 88.7% are not satisfied with the level of resources and approach the government to investigate the causes of autism. The majority of the international responders were also dissatisfied.



NIH Spending on Autism: When we began our investigation in 2000, it was estimated that the NIH was spending between \$40 and 60 million dollars on research each year. By 2006, because of direction from Congress the budget had doubled to \$108 million.

According to the NIH Budget Office, in Fiscal Year (FY) 2006, the NIH spent \$108 million on autism spectrum disorders research. In FY 2007 they spent either \$93 or \$127 million depending on which of their two methodologies one chooses to follow. FY 2008 actual spending was \$118 million. FY 2009 the actual spending was \$132 and the ARRA spending was \$64 million. The estimated FY 2010 budget for autism research was \$136 with another \$52 in ARRA funds. The estimated FY2011 budget is \$143 million.

Where Does Autism Rank as an NIH Priority? \$143 million is a significant amount of funding. But how does it compare to other budget categories at the NIH? There are 219 diseases or disease categories ranked at the NIH. The estimated cancer and HIV/AIDS research budgets for FY 2011 are \$6 billion, and \$3.1 billion respectively. Autism ranked 109 out of 219 categories. If funding levels are an accurate measure of priority, then alcoholism research is 3 times more important to the NIH than autism, drug abuse, 7.7 times more important and STD/herpes is almost twice as important.¹



With this ranking of 109 out of 219, it is not surprising that only 1% of respondents are completely satisfied with the NIH research funding on autism.

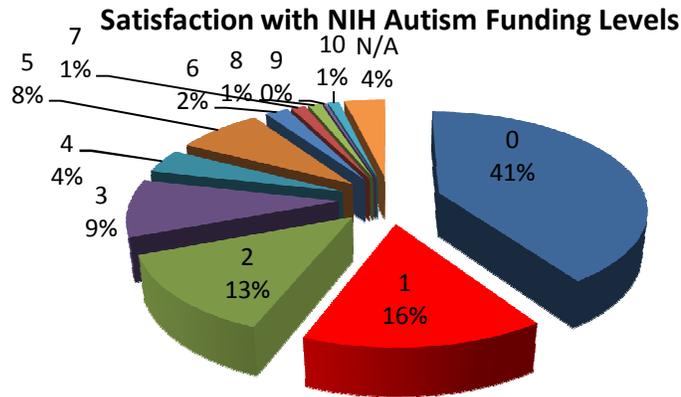
Question: On a scale of 0 to 10 with 0 being not satisfied at all and 10 being completely satisfied, how satisfied are you with the National Institutes of Health's (NIH) funding levels on autism research?

Over 40% are completely dissatisfied and the NIH rating average was 2.76 out of a possible 10. In looking at the subset of respondents who responded who are on the autism spectrum, the average rating of 3.31, with 34.4% completely dissatisfied. The average rating from international responders was 2.46 with 37.9% being completely dissatisfied.

¹ <http://report.nih.gov/rcdc/categories/>

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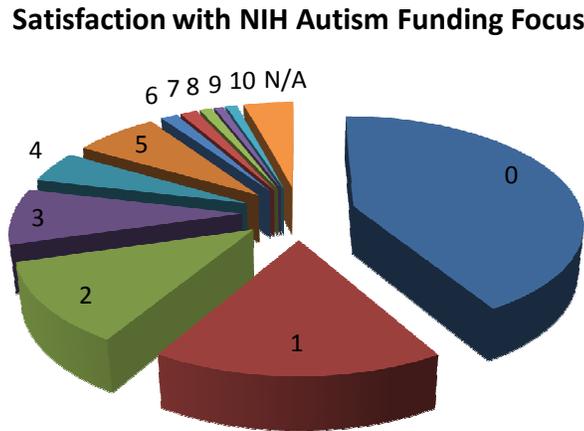
Scale	Response
0	838
2	321
3	194
4	83
5	161
6	44
7	26
8	24
9	7
10	21
N/A	77



Funding Focus: One cannot evaluate the performance of an organization simply on how much funding is devoted to autism research. Therefore, a question was posed on the satisfaction with studies and the focus of studies conducted or funded by the NIH.

Question: On a scale of 0 to 10 with 0 being not satisfied at all, and 10 being completely satisfied, how satisfied are you with the studies (or study focuses) that the NIH conducts or funds relative to autism spectrum disorders?

Score	Percentage
0	41.6
1	17.0
2	11.9
3	8.3
4	4.7
5	7.0
6	1.4
7	1.4
8	1.0
9	0.8
10	0.9
N/A	4.1



41.6 % of respondents are not satisfied at all with the NIH autism research focus. The rating average was 2.69 out of 10. The average rating by those who self identified as being on the autism spectrum was 3.25 out of 10, with more than 33% completely dissatisfied. The international response to NIH research was identical to its response on funding levels.

CDC Autism Research Spending: In FY2006 the CDC reported to Congress their actual spending on autism research for FY2004 had been approximately \$13.2 million and for FY2005 an estimated \$14.8 million. The FY2010 budget for autism at the CDC was just over \$22 million.

At that same April 2000 hearing discussed above, Dr. Bernard Rimland, Founder of the Autism Research Institute gave the following testimony:

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“As a parent and a full-time professional researcher, I am bitterly disappointed with the medical establishment's dismal record with regard to autism over the past 60 years. The medical schools as well as the Government agencies have consistently supported outmoded, unproven and even disproven ideas, including the one that autism was caused by “refrigerator mothers” who did not love their children, thus causing autism. The medical establishment was opposed to behavior modification, or what is now called the ABA approach...They have ignored and continue to ignore the long series of studies conducted both in the United States and Europe showing that the elimination of foods containing gluten and casein from the diet brings about marked improvement in many autistic children. They have consistently ignored the series of 18 consecutive studies conducted by researchers in six countries which show that almost half of all autistic children and adults respond favorably to high doses of Vitamin B6 and magnesium, with no adverse reports...Tens of millions of dollars have been spent on nonproductive lines of research while virtually no money at all has been given to research on methods of alternative medicine which are far more promising in terms of both safety and efficacy.

The most interesting questions are not being asked. Why does the majority of any population survive such epidemics as autism, the bubonic plague, Legionnaire's disease, polio and AIDS, while relatively few succumb? The very obvious answer and the most probable answer is that the survivors have healthy, effective immune systems...It is well-known that the immune system must be adequately supplied with many nutrients if it is to function properly, including especially Vitamins A, C, E, B6, and a number of minerals, including zinc, magnesium, and selenium. Nutritional levels of these substances are not only harmless, but they are essential to good health.”

This statement reflected the opinion of many at the time that the government has consistently been out of step with parents.

In December 2009, the Centers for Disease Control and Prevention (CDC) published data from a 2006 study evaluating the prevalence of autism spectrum disorders (ASDs) in eight year old children in eleven Autism and Developmental Disabilities Monitoring (ADDM) Network sites in the United States. The study noted a 57% increase in prevalence of autism in 8 year olds from 2002 to 2006 in ten of the sites. The CDC concluded that approximately one percent of the children born in 1998 have autism and underscored “...the need to regard ASDs as an urgent public health concern. Continued monitoring is needed... Research is needed to ascertain the factors that put certain persons at risk...”

The first prevalence study of the ADDM Network in 2000 found that 6.7 per 1,000 children aged 8 years had an autism diagnosis (1 in 150).² In 2002, a second and larger prevalence study

² <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>

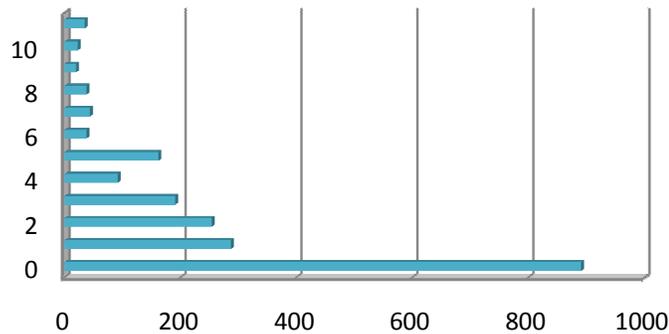
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within the network was conducted with similar findings. “Prevalence was stable in the majority of sites for which 2 years of data were available, but an increase in West Virginia and a trend toward an increase in Georgia indicate the need for ongoing monitoring of ASD prevalence.”³

Question: On a scale of 0 to 10, with 0 being not satisfied at all and 10 being completely satisfied, how satisfied are you with the quality of research funded by the US Centers for Disease Control and Prevention (CDC) as it related to autism statistics?

Score	Percentage
0	43.0
1	13.8
2	12.3
3	9.2
4	4.4
5	7.8
6	1.8
7	2.1
8	1.8
9	1.0
10	1.1
N/A	1.7

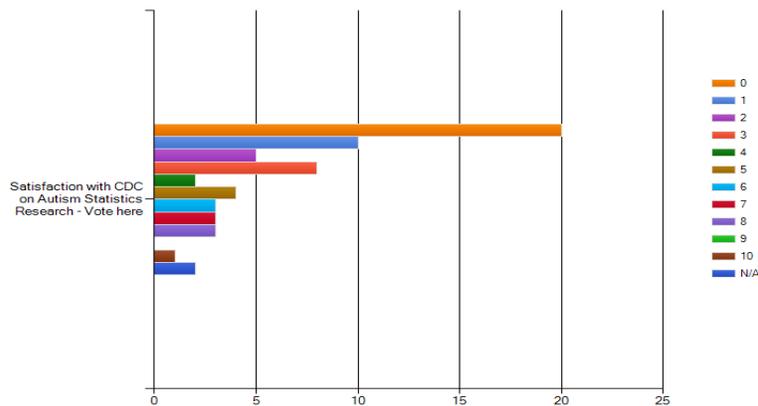
Satisfaction with Quality of CDC's Autism Statistics Research



43 percent of responders were not at all satisfied with the quality of CDC’s research on autism statistics. The average rating out of a possible 10 was 2.86. The responses from those who self identified as being on the autism spectrum was similar, with 32.8% completely dissatisfied and average rating of 3.46.

Individuals with autism satisfaction level with quality of CDC’s autism statistics research.

On a scale of 0 to 10, with 0 being not satisfied at all and 10 being completely satisfied, how satisfied are you with the quality of research funded by the US Centers for Disease Control and Prevention (CDC) as it related to autism statistics?



³ <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a2.htm>

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39.3% of the international respondents are completely dissatisfied with the quality of research funded by the CDC as it relates to autism statistics, with an average rating of 2.13.

Focus of Government Funding Autism Research

A number of topics have arisen in the last ten years in regards to research needs. Three leading issues that have been high priorities for the community:

- ❖ Research looking at environmental toxins and their potential relationship to autism and other neurodevelopmental disorders.
- ❖ Studies comparing vaccinated and unvaccinated individuals to determine if there is a difference in the rates of autism and other medical conditions.
- ❖ Parents have an increased say in what the government funds relative to autism spectrum disorders research.

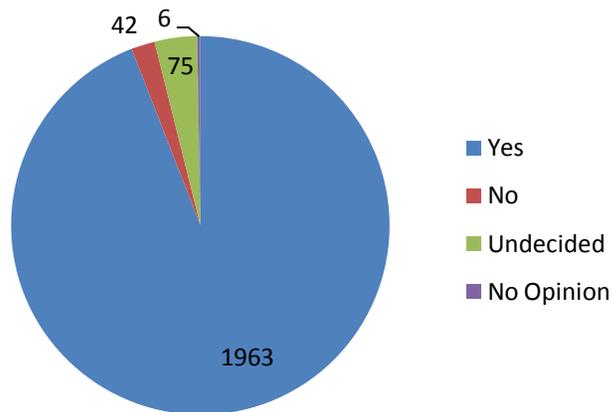
To determine if these truly were high priorities for the community, questions were included to cover these topics.

Environmental Research: 94.1% want more research.

Question: Do you want to see more research funding on environmental toxins and their potential relationship to autism and other neurodevelopmental disorders?

<u>Response</u>	<u>Percent</u>
Yes	94.1%
No	2%
Undecided	3.6%
No Opinion	0.3%

Do You Want More Environmental Research and Potential Relationship to Autism?

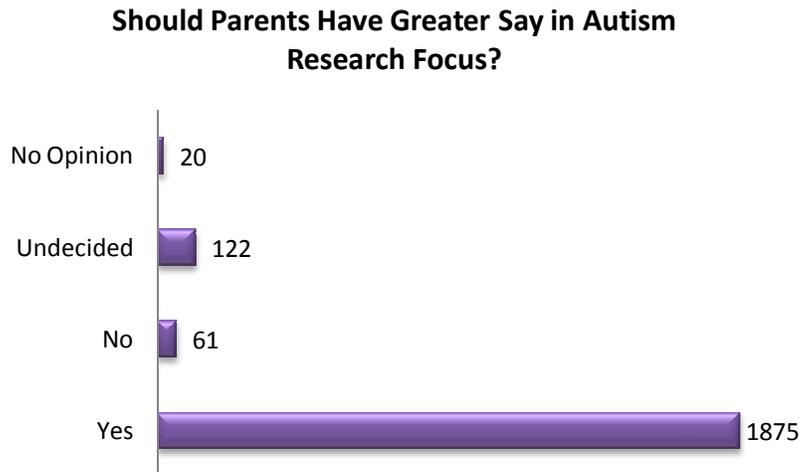


83.9% of respondents who self identified as being on the autism spectrum answered yes to this question with 12.9% answering no. 89.7% of international respondents want more environmental research. **100% of parents of children infants to three years want more environmental research.**

Parent Input – 90% want more parent input into research direction.

Question: Do you want to see parents have a greater say in what the government funds relative to autism spectrum disorders research?

<u>Response</u>	<u>Percent</u>
Yes	90.2
No	2.9
Undecided	5.9
No Opinion	1.0



90.2 % want parents to have more input on where government research funds go.

82.3% of respondents who self identified as being on the autism spectrum answered yes to this question with 11.3% answering no and 6.5% undecided. 89.7% of international respondents want parents to have more say in autism research focus.

The Elephant in the Room that Public Health Wants to Go Away: The Potential Link Between Vaccine Injury and the Autism Epidemic.

The science is far from conclusive that there is no link between vaccine injury and onset of autism in some individuals. In March, the autism community and many Constitution loving Americans were shocked to read an interview with Secretary of Health and Human Services Kathleen Sebelius in *Readers Digest* in which she states that the agency had made an attempt to censure the media in regarding questioning vaccine safety issues:

"There are groups out there that insist that vaccines are responsible for a variety of problems, despite all scientific evidence to the contrary. We (the office of Secretary of Health and Human Services) have reached out to media outlets to try to get them not to give the views of these people equal weight in their reporting." (Allen, 2010)

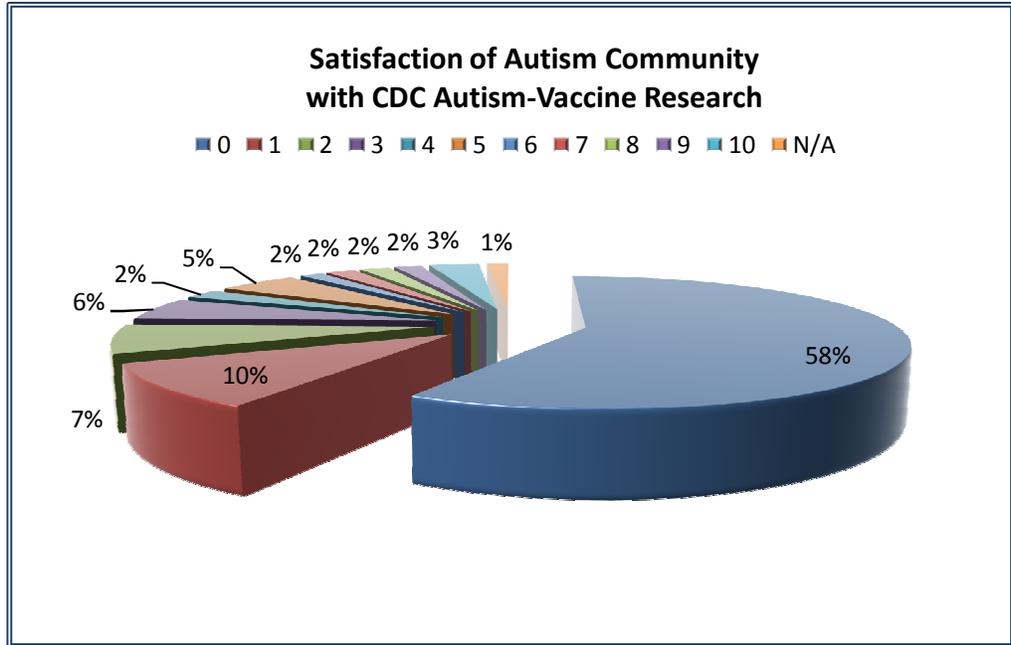
Two questions relative to vaccines were asked.

Question: On a scale of 0 to 10, with 0 being not satisfied at all and 10 being completely satisfied, how satisfied are you with the research conducted by or funded by the CDC regarding any potential relationship between autism and vaccine injury?

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CDC Scores 2.69 out of possible 10 on Autism-Vaccine Injury Research.

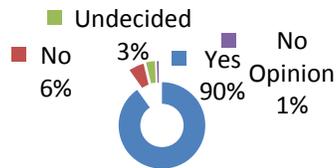
Only 3.2% of autism community is completely satisfied.



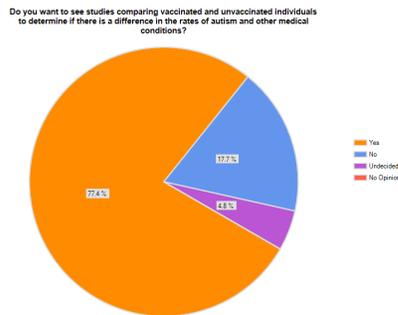
Question: Do you want to see studies comparing vaccinated and unvaccinated individuals to determine if there is a difference in the rates of autism and other medical conditions?

<u>Response</u>	<u>Responders</u>
Yes	1881
No	116
Undecided	70

Desire for Studies evaluating rates of autism and other conditions in vaccinated versus unvaccinated populations



77.4% of individuals who self identify as being on the autism spectrum want to see studies comparing vaccinated and unvaccinated populations.



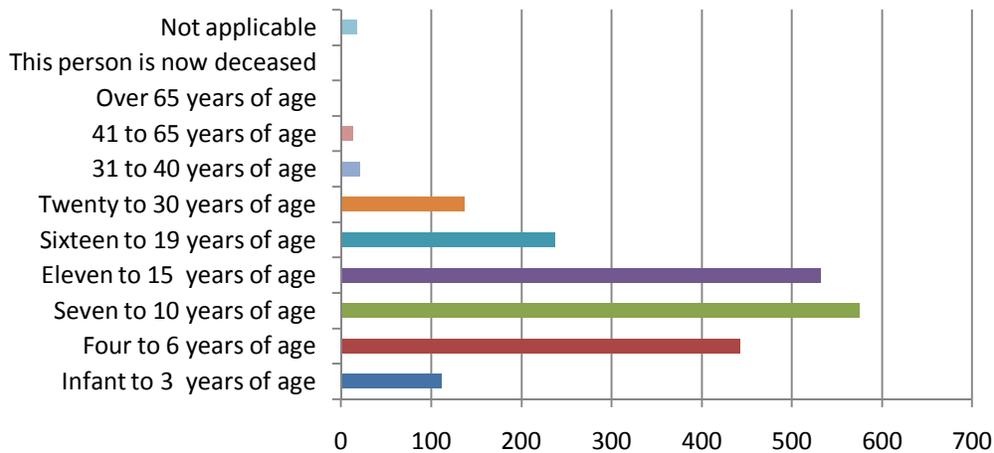
86.2% of international respondents want to see the vaccinated versus unvaccinated populations research.

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Demographics: In addition to knowing the relationship of the 2000+ responders to someone with autism, the survey gathered data on the age range of the autism population the responders were affiliated with.

Question: The person with autism that you are thinking of in this survey falls into which age range as of March 2010?

Age of Individual Respondent Is Affiliated With



Of responders who self-identified as being on the autism spectrum, 62.9% stated they were also the parent of someone living with autism; 22.6% were educators; 14.5% have a sibling with autism; 8.1% identified as being a health care professional who treats individuals with autism; and 1.6% (1 individual) stated they were also the grandparent of someone with autism.

Age of Autism Onset

Much discussion took place in our investigation about children born with autism and those who were born ‘normal’ and acquired autism. Dr. Rimland’s testimony in the April 2000 hearing:

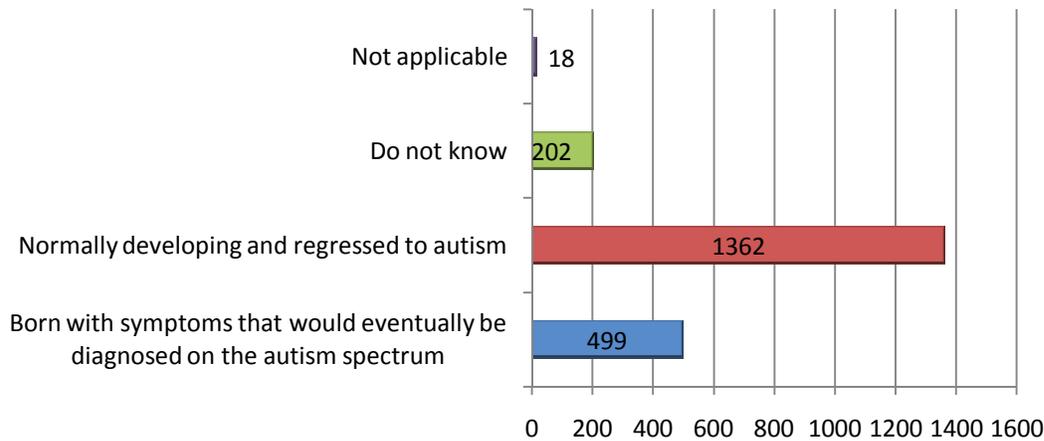
My book, “Infantile Autism,” published in 1964 was the first systematic attempt to marshal the evidence for a genetic relationship to autism, so I am certainly not hostile to that idea. However, genes do not begin to account for the huge increase in the incidence of autism. There is no such thing as an epidemic due to gene problems. The increase ranges from 250 to 500 percent in various places, as other people have pointed out here. As the editor of the Autism Research Review International, I have just reviewed a very large number of studies on the genetics of autism...Genes are not the answer to the question, even though, at one time, I was very much in favor of looking at that hypothesis. I am still interested in the hypothesis, but it is certainly not responsible for the increase in autism. The people who claim that the vaccines are safe claim that autism naturally occurs at about 18 months, when the measles/mumps/rubella vaccine is routinely given, so the association is merely coincidental and not causal. But the onset of autism at 18 months is a recent development. Autism starting at 18 months rose very sharply in the mid-1980’s, when the MMR vaccine was introduced. For the previous 30 years—we have been collecting information from children born in the fifties, sixties, seventies, and so forth—there were twice as many kids reported with the autism started at birth as there were kids whose parents reported that the autism started at 18 months. Starting in about the 1980’s, when the MMR vaccine was introduced, those two curves converged. Over a period of several years, the number of kids whose autism started at 18 months rose to twice as high as the number starting at birth....

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As a parent and a full-time professional researcher, I am bitterly disappointed with the medical establishment's dismal record with regard to autism over the past 60 years."

Question: Age of Onset of Autism. Was the person you are thinking of when responding born with autism, or did they develop typically and develop the symptoms of autism later?

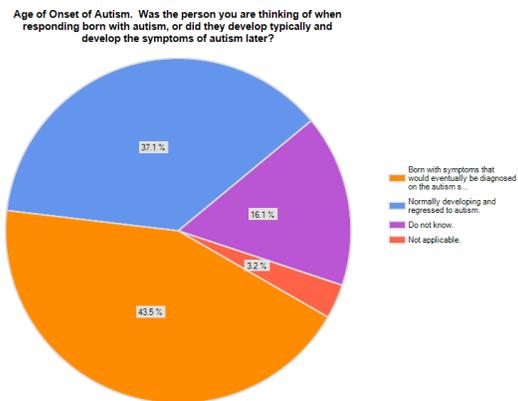
Age of Onset of Autism



65.4% Normally developing and regressed to autism.

This answer drew the largest difference between the individuals who self identified as being on the autism spectrum and the respondents as a whole.

Only 37.1% of individuals who self-reported as being on the autism spectrum stated that they developed normally and regressed into autism. While 43.5% stated they were born with symptoms that would eventually be diagnosed on the autism spectrum.

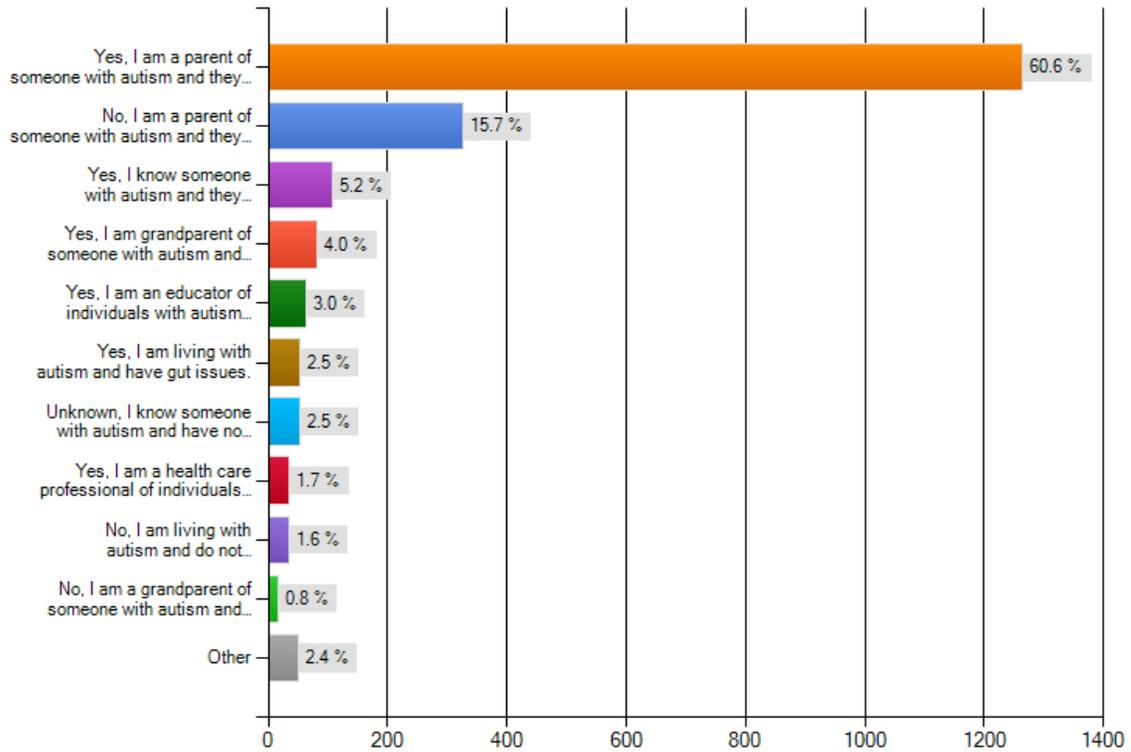


One of the biggest correlating medical concerns raised during our investigation was irritable bowel and other gastrointestinal issues. We heard repeatedly that doctors were not investigating the reason for chronic diarrhea or treating the conditions. Rather, parents were repeatedly told that 'diarrhea was just something kids with autism got.'

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Question: Gut Issues and Autism. It has been reported that many individuals living with autism have irritable bowel or other digestive issues including food sensitivities and changes in behavior when some foods are present in the diet. Is this true for the person you are thinking of when responding to this survey?

Gut Issues and Autism. It has been reported that many individuals living with autism have irritable bowel or other digestive issues including food sensitivities and changes in behavior when some foods are present in the diet. Is this true for the person you are thinking of when responding to this survey?



More than 60% of parents who responded have a child with autism and gut issues. Families' often find the dietary and gastrointestinal issues are addressed; the behaviors associated with autism often improve. The incessant screaming and toe walking as it turns out may be related to the gastric pain. Research continues to show that there is a gut-brain connection.

The final question: If I learned anything during my tenure on Capitol Hill, it was that parents and people advocating on behalf of the autism community are passionate, dedicated and caring people. Their personal views, something that cannot be expressed by scoring a question are very important. Therefore the final question was an open ended question.

Question: Multiple choice responses can be limiting. So, this is your chance to give a personalized message response. What is your personal opinion about the government's handling of autism spectrum issues?

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With 1600 individuals responding to this question; a future article will offer an in-depth analysis. Below are three snapshots, (1) Responses from the entire set of responses that reflect frequent themes of comments; (2) A snapshot from the subset of individuals who self identified as being on the autism spectrum and (3) A snapshot of international responders.

Twenty-one comments that reflect common themes in the 1600 responses:

1. In short, I believe that the government does not ask questions that they do not want the answers to.
2. What really sucks it's that while my husband is in Iraq fighting for that war, I'm fighting one here to get help for my little girl...
3. With everything that has gone on regarding autism, vaccines and autism, and the environment and autism and our government's pitiful action regarding it, it would truly make one believe that all of these children being injured is acceptable to you. With the constant addition of more and more vaccines and the continued rise of children being diagnosed, it's beginning to look like you want this to happen.

Doing the wrong things is far worse than doing nothing. Parents are tired of the same old smoke and mirrors routine - we're smart, educated people who can read research studies - it's about time you did the right thing for these children. The continued increase in ASD is an absolute disgrace.

4. The government is doing little research, providing extremely limited services for young adult transition, providing inadequate school resources for children with autism.
5. For such a wide-spread and debilitating disorder, not enough is being done to research it, not enough is being done to intervene at all ages, and not enough is being done to help those with autism lead productive lives. It's a fight from beginning to end.
6. I think it is horrible how much is available in some states but the funds and coverage by insurance is limited at best in others. It is AMAZING how much money we spend between co-pays, private therapies and specialists and my son is only 3!

The government needs to contribute more to this alarmingly rising epidemic. My son is improving thanks to all of the intervention he has received but we still have a long and expensive road ahead...

7. I find the government's handling of autism very poor. Well designed studies looking at COMBINED and CUMULATIVE toxic burdens from vaccines, the environment, viruses, etc. is needed. And it needs to be done by truly independent researchers, not ones connected to big pharma, who have much to lose if any vaccines are shown to be contributing to this or any other illnesses.
8. They are not doing enough. They need to take it much more seriously.

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9. Morally bankrupt and inexcusable are the first two things that come to mind. The U.S. government's handling of the autism epidemic is a travesty. It is a complete violation of government by the people, for the people and of the people as far as I am concerned. Perhaps when the ASD rate reaches 1 in 2 there will be enough of us to make our voices heard!
10. We need more focus on long term services and supports, transition and employment first policies in addition to beefing up our focus on environmental insults.
11. Pathetic. My daughter was diagnosed nine years ago and nothing has changed in terms of funding of services or meaningful research. Despite the fact that even the head of the NIH says that there must be an environmental component due to the exponential yearly increase, at no level of government do I see any sense of urgency to find a cause which may lead to effective treatments.... Instead there seems to be a coordinated campaign to discredit parents like me (highly educated) who watched my child regress and scientists who are listening to the parents and trying to conduct meaningful research.

Why is autism still considered a mental health disorder and diagnosed behaviorally? It should be taken out of the DSM and placed in medical texts as a whole body disorder, affecting the GI, Immune, toxilogical systems, etc. My daughter is almost twelve and just recently broke 50 pounds. Has chronic loose stools, documented GI inflammatory response and failure to thrive. Her immune function is dysregulated and she has chronic crystals in her urine that make her scream in pain and pull her hair out. All of these medical issues and the government still has the research driven by psychologists and psychiatrists (Thom Insel - head of the IACC - who has a few conflicts in the family) as a "mental health issue."

Give me a break. These are the same geniuses who were blaming autism on refrigerator mothers 50 years ago and their theories and research aren't much better now i.e. older mothers, too much TV, that elusive bad gene, etc.) Now wonder we have a plethora of eye gaze and gene studies.

The system is broken. There are blatant conflicts of interest in research publication and pharma oversight. We are no better than we were with tobacco science decades ago, except it is being condoned and facilitated by our own government.

Julie Gerberding the former head of vaccines at the CDC was allowed to make the transition to work for a vaccine manufacturer. Are we really supposed to believe that she was making independent objective decisions in her former government role which affected the health and safety of children - including my own - while being courted by big pharma? Also, why aren't insurance and Medicaid required to fund medically necessary, research based treatments. Why is autism still allowed to be discriminated against?

My daughter would be better off if she had cancer or Downs. I am disgusted and disillusioned at all levels.

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12. Horrible. We need actionable studies now. We need to have decent studies on demographics, vax vs unvax, environmental toxin studies, and studies on primates.
13. I do not believe our government wants to touch the idea that vaccines could possibly have anything to do with the increase in autism. I'm not only a parent of a child with autism but also a teacher in the public school system for the past 16 years. I also see in the school system what a rise in the school population autism is becoming. These children could not have been diagnosed as something else! Let's get to the bottom of the real issue of what is causing our children to have all of these developmental disabilities...it cannot just be in the genes ! Let's get real for a change...I'm tired of being tired over this whole issue.
14. I am a strong supporter of President Obama, but disappointed that Michelle Obama chooses to focus on the noncontroversial issue of childhood obesity when autism is crippling so many American families and jeopardizing the next generation. If the autism crisis isn't solved, it will bankrupt our educational and health care systems. There is a desperate need for serious research into the causes and treatments of autism. This is not a partisan issue. It's time to stop dismissing as "lunatic fringe" the parents and scientists who are questioning vaccine safety and, instead, put some real research into the issue. It may not be the first time in history that mainstream opinion has ultimately proven wrong.
15. I could not be more disappointed in the handling of autism spectrum issues by my government. The CDC and NIH will one day be held accountable, by the American people, for what they have not done as well as what they have done.
16. I don't think they have done anything to stem the epidemic that autism has become.
17. How far does it have to go before we really look at what is going on? The numbers just keep growing! Shouldn't we be trying to find out why? I guess it is easy not to care ... until someone you know and love is affected by Autism.
18. I feel as though I am in this on my own and only have the help of other parents of autistic children or educators. The medical profession has done very little to help our son.
19. My 14-year old son has autism. He regressed into autism following his MMR vaccination. He has documented inflammatory bowel disease, GERD and immune deficiency. He is not able to have a spontaneous bowel movement; he is suppository dependent. He has been on elemental formula for two years because he cannot digest food properly. He has pain every day. He is nonverbal. He becomes self injurious and aggressive when he is in pain. His childhood has been full of pain, doctors' visits, blood draws and sleepless nights. This is no way to live.
20. I want more answers, more help, and more research. The rising number of this disorder in our country's children is terrifying. I feel the cure and/or prevention is in front of us, but our resources are too limited. My son was not born with this and now at 4 years old he should be talking; he deserves answers.

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21. As a mother of a teen who is severely affected by autism I see the problems of autism growing. Parents need help and we are not getting it. People with autism are invisible in our country. I continue to work hard for my son and others with autism but it is a sorry state that we are in. WE NEED HELP!!!

There were a few comments that were supportive on the government, one in particular stands out:

The Government is doing a good job in the autism research. Most parents want immediate answers but there are no immediate answers in any kind of research. They have to be patient. Also, some parents are constantly blaming the government or vaccines or doctors for their child's disorder. I know it is frustrating as I am a parent with a teenage son with very high functioning autism and I have not been through the ordeal of having a non-verbal child or other problems that some autistic kids have. I do not believe that it is the vaccine and the researchers need to focus on other issues or scientific facts instead of wasting their time with the research where the results have been established by different countries just to satisfy the 'neurotic' parents who want to blame someone. It is not anyone's fault...why autism seems to have risen in numbers is because kids are diagnosed with it earlier and the signs are seen earlier and caregivers, parents etc. notice some abnormalities sooner and sometimes it is because they want to give a name to any kind of a disorder. We are living in a high tech world, we shouldn't expect to be in the age of science during our parents' and grandparents' time...there were autistic kids, adults then too...but they were not labeled as such and hidden away and known as weird or odd...We've all known people like that!!!Well it is the same for our children but not it has a definite name and autism spectrum is such a wide term that it seems to qualify with all aspects of disorders. On a final point, I do not believe autism is curable (it is not a disease or a virus) but a child with intervention and therapy and learnt social skills can become a so-called 'normal' addition to society...it is a learnt behavior and I see it in my teenage son who is graduating this June from HS and off to college. He has accepted his disability, and it doesn't stop him from trying but he does realize that some situations are not agreeable to him...if he wants to be accepted, he may have to tolerate it and then have a meltdown in private! Thank you

The following are a snapshot of the responses that came from those who self identified being on the autism spectrum:

1. The programs I was put in related to my Asperger's in public school were very ineffective, and in the end did more harm than good. I was constantly treated in an incredibly condescending manor, as if I were some kind of stupid robot with no common sense or basic understanding of myself. It took a huge toll on my self-confidence and ended with my school forcing me to drop out due to poor performance. I can't speak for many other activities the government handles related to autism, but the way high-functioning autistics are handled by the public school/special education system is something that definitely needs to be overhauled.

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2. There are 5 children within 25 houses of me who are autistic. YIKES!!! I believe every child who is autistic or ADHD should be tested for all environmental toxins as well as the mothers.
3. I believe vaccinations are only a co-factor and maybe not the prime source of autism. However, I am also convinced that profitable companies stand to lose in uncovering the real problems and that the medical arena still contains a great deal of prejudicism towards this disability. It was hard to answer questions on funding because it's not the amount and focus as much as it is looking for the REAL truth...Thanks for your time.
4. Autism is one manifestation of the many toxic injuries that our government is aware is caused by consumer product and environmental toxins. Like all the other cause and effect toxic injuries, they are ignoring the facts and allowing ever more toxic substances to be released into all our environments. It's time to stop the poisoning!
5. I think the government had better take some responsibility and put more research dollars into treatments such as the DAN protocol and especially to make it part of mainstream healthcare so everyone can afford it.
6. Autism is an expensive proposition for parents. We need research, but we also need SERVICES! The federal gov't should mandate services on IEP's for ASD's or they should provide funding for services.
7. Not enough funding for services. We desperately are in need of educating our educators as well.
8. The government does not understand nor are they sensitive to persons with autism.
9. I want to see you focus much more on getting adults and children both an intensive wraparound support system of real care, services, support and advocacy--help with our real needs, instead of focusing so much on the cause and cures for autism. Acceptance of our different abilities--is key.
10. More *unbiased* research needs to be done on vaccines and endocrine disruptors like plastics, as well as other environmental toxins. There is far too strong an allegiance between pharmaceutical companies and government, which makes me doubt that the truth will ever come out on this important topic, and that makes me very sad for future generations of children.

Of the international responders, many of the responses reflected on their own country's issues.

1. I am working with young children with ASD for the past 10 years in India, and believe and practice biomedical intervention. We've seen many vaccine injured kids too in India. Research is needed in terms of vaccine safety, giving only most necessary vaccines, spacing between vaccines, comparative studies between vaccinated and unvaccinated kids. In India, we are seeing many kids from middle and upper class families being affected. The parents who in this case being well educated and professionals, like doctors or engineers and others, very religiously follow the complete vaccination chart for their kids by the time they come to us. The Pediatricians too scare them of various diseases if they do not vaccinate their children. C- Section deliveries too also becoming a lifestyle among many mothers these days in many of the developing countries, which includes India.

Lot more thinking has to be done in research in the area of autism and many factors play a role in causing autism.

2. Stop spending money on genetics and look into environmental causes.
3. I live in Malta (Europe). Whilst in America parents are fighting to make a baseline acknowledgment for curing Autism....here there isn't even awareness what is Autism? Complete SILENCE....and nothing is mentioned about recovery. NO biomedical intervention, NO ABA, NO HBOT therapy, NO DAN's!! OT's are not specifically trained to help autistic kids and one will not find an OT who does private practice, that is that has his/her own set up. So children are given OT (state funded) only once a month and believe me leaves a lot to be desired from such OT practices. OT's on the work place lack proper structure and funds to work with Autistic kids. Also to have speech therapy (state funded) you have 45mins once a month!!!! ...I follow America because I hope that someday.....maybe.....it serves as a baseline and it becomes international standard procedure. In the meantime I have to treat my kid contacting professionals outside the country especially regarding DAN therapist and HBOT!
4. In India public awareness is very poor about AUTISM. Government of India not taking care about the problems facing the child and parents. For researches requires and government should give incentive or reward for the studies. Then only more public will take care on researches.
5. As a Canadian I only wish we had greater research programming and attention towards the obvious alarming increase in Autism. Those who say it is only being named more clearly and stats have not changed are wrong. I have worked in the disability field, social services and education for over thirty five years and the frequency of autism now is alarming and should be a national priority. The cost to families and society at large if we do not discover cause and treatment will have widespread consequences.

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Conclusions: It has been ten years since Congress launched an in depth inquiry into what the CDC and NIH were doing to investigate the epidemic increases in the rates of autism spectrum disorders. This national survey shows major dissatisfaction by the autism community with the amount of resources committed to the investigations as well the focus and quality of much of the research. The community wants research looking at environmental toxins and their potential relationship to the autism epidemic and other neurodevelopmental disorders. The autism community also wants to see a study comparing diagnoses between vaccinated and unvaccinated populations. The autism-vaccine injury question is far from settled science.

Furthermore, the autism community overwhelming desires for parents to have a greater say what the government funds. Autism remains fastest growing disability in the country. The rates of autism continue to skyrocket.

The overwhelming requests from the autism community: **“Listen to Us!” and “Help Us!”**

About the Author: Ms. Beth Clay serves as Senior Vice President of Capitol Strategy Consultants, Inc., where she works with clients on their Executive and Legislative branch interactions, strategic and media planning, and grassroots campaigns. Prior to entering the private sector, Ms. Clay served as a Senior Professional staff member on the Committee on Government Reform with Chairman Dan Burton and subsequently the Subcommittee on Human Rights and Wellness. She led oversight activities regarding health research, practices, and regulation. These included extensive investigation into the epidemic rise of autism, vaccine injury, ADHD, and other health related investigations affecting children, seniors, and military members.

Prior to her service on Capitol Hill, Ms. Clay served seven years at the National Institutes of Health in administration and committee management capacities within the international, alternative medicine and rare disease organizations of the NIH. Ms. Clay's volunteer activities have included scouting, children's and veterans' charities, human rights and hospice.

Disclosures: Ms. Clay conducted this survey completely independent of any of her professional duties. No organization or entity provided funding for the conduction of this study. Ms. Clay has previously consulted with the Autism Society of America and the Coalition for SafeMinds. She is a former (founding) Board member of the National Autism Association and currently consults with numerous organizations involved in health freedom and dietary supplements. She is a registered lobbyist and among her current clients is the Vaccine Injured Petitioner's Bar Association. The Association nor any of its members had no input or access to the survey instrument or data or any drafts of this report.

Contact: autism@bethclay.com

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