

**A Critical Review of the Performance of the
Interagency Autism Coordinating Committee**

July 10, 2012

*The Canary Party
The Elizabeth Birt Center for Autism Law and Advocacy (EBCALA)*

Canary Party
(855) 711-5282 • canaryparty.org

Elizabeth Birt Center for Autism Law & Advocacy
(347) 709-5304 • ebcala.org

History of the Interagency Autism Coordinating Committee

In 2006, Congress passed federal legislation that allocated hundreds of millions of dollars to address the autism epidemic. There was little doubt our nation was facing a crisis of unparalleled proportion or that we urgently needed to address it. Legislators on both sides of the aisle collaborated and eventually united to pass the Combating Autism Act (CAA) to do so.

Part of the legislation called for the creation of a panel of experts to develop a strategic plan for autism research. This panel was to consist of medical experts, philanthropists, activists, and parents nominated by their peers and selected for their expertise, leadership, integrity, and commitment. The panel was to be known as the Interagency Autism Coordinating Committee (IACC) and a variety of views about the causation and possible treatments for autism were to be represented. Dr. Tom Insel of the National Institute of Health, under the direction of the Department of Health and Human Services, was appointed to lead it.

At the convening of the first IACC meeting, the rate of autism in the United States was widely accepted as 1 in 166 and that rate was considered an alarming increase over what had previously been considered a rare condition. Today, that rate has skyrocketed to 1 in 88 among children born in 2000. Despite this incredible increase over a short six-year period, and despite the hundreds of millions of dollars given to the IACC through the Combating Autism

Act to address it, the autism epidemic has proven to be substantially more serious than anyone imagined when the legislation was first passed. More troubling, it shows no signs of abatement. And nothing that has come out of the spending authorized in the Combating Autism Act offers even a remote hope for halting the increase.

Despite Congress's original intention, few can argue that the IACC thus far has been effective. Worse, significant evidence exists to demonstrate that this did not have to be so. From the controversial appointment or retention of committee representatives, to the troublesome history of committee members themselves, to the lack of accountability for the few advances made in autism research, to the questionable direction of the Strategic Plan, it is fair to state that the IACC is not living up to Congress' and the public's expectations.

Further, substantial concern exists that the situation is only getting worse. With a less representative panel than ever slated to begin working this July, we worry if any serious advancement for people with autism will be made now or in the near future. We urge the taxpayers of the United States and the leadership of our nation, along with the committee members themselves (both past and present), to critically examine their approach to the autism epidemic so that we may adequately and immediately address these shortcomings.

Critique of the Newly Appointed IACC Members

A new panel of IACC appointees will begin their service on July 10, 2012. Per the CAA, committee members must first be nominated and then selected from a pool of candidates to serve. A variety of philosophies about autism causation, prevalence, and treatment are supposed to be represented.

Unfortunately, the new panel appears to be anything but representative. Of the 11 appointed panel members, there is only one who represents the view of tens of thousands of parents that autism is a medical condition that can and should be prevented and treated. Lyn Redwood, RN, represents those parents and served on the previous committee as well. She is also the mother of a fully recovered

child, and the only person representing families who has been a consistent advocate for environmental research funding, including independent vaccine safety science.

These highly qualified candidates that share similarly representative perspectives, however, were not appointed.

- **Jake Crosby**, a graduate student in Public Health at George Washington University, is an autism activist, contributor to the Age of Autism, affected by Asperger's Syndrome. Crosby provides a unique perspective based on his own recovery experience and comes from a self-advocacy position that advocates prevention of new cases of autism along with the development of

treatments that can allow other affected individuals to recover from the most disabling aspects of autism.

- **Dr. Martha Herbert, MD, PhD**, a Harvard pediatric neurologist, researcher, and author. The first and most accomplished neurologist making the connection between the autistic brain and environmental factors, Herbert has published dozens of groundbreaking articles as well as a book on whole body treatment for people with autism. Specializing in researching the causation involved in autistic regression and the medically affected ASD population, she frequently interacts with the wider autism community and participates in and lectures at national conferences.
- **Lisa Ackerman**, Executive Director of Talk About Curbing Autism (TACA), is the mother of an affected child. TACA is a national organization that provides educational workshops, parent mentoring, support group meetings and special outreach to Spanish-speaking families. It serves more than 30,000 families.
- **Peter Bell** is Executive Vice President of Autism Speaks, the world's largest autism organization, and has more than 10 years of advocacy in the autism community. Father of an affected teenager with complex biological issues, Bell is a leading advocate for national insurance reform, working throughout the country, state by state, lobbying for insurance coverage for basic ASD treatment needs. He also specializes in young adult and adult life transitions, training and services.
- **Wendy Fournier** is President of the National Autism Association, an East Coast-based organization with chapters in many states. NAA provides grants to ASD families in crisis, parent mentoring, hosts a major annual national conference on biomedical and behavioral interventions, and even provides scholarships to attend the conference. NAA also funds treatment research that will have a direct impact on people living now with autism, specializing in funding biomedical treatment research. Fournier is active in government lobbying on behalf of ASD families and developed the first anti-wandering initiative for ASD families. NAA serves over 20,000 families.
- **Doreen Granpeesheh, PhD, BCBA**, founder and executive director of the Center for Autism and Related Disorders, Inc. (CARD). She serves on multiple advisory

boards, including the State of California's Autism Advisory Taskforce and The Lewin Group's External Advisory Committee for the Study of Health Outcomes in Children with Autism and Their Families. She also founded ACT Today (Autism Care and Treatment Today!), a national nonprofit that grants funding for resources and treatments to disadvantaged families.

- **Valerie Paradiz, PhD**, an adult with Asperger's and a parent of an individual with ASD. Paradiz has 25 years of education and advocacy experience and is the author of Integrated Self-Advocacy ISA Curriculum and Elijah's Cup. She is also the Director of the Autistic Global Initiative at the Autism Research Institute.
- **Isaac Pessah, PhD**, of the MIND Institute. An environmental science researcher considered to be one of the most accomplished and innovative autism researchers, Pessah is one of a handful of researchers comprehensively studying the relationship between the environment and autism and has published dozens of studies on this subject.
- **Cindy Schneider, MD**, Medical Director, Center for Autism Research and Education, and mother of two teenagers with ASD. Schneider has treated more than 2000 patients on the spectrum, and was one of the original doctors in the Autism Research Institutes' "Autism Think Tanks" in the 1990s.

Instead of these experienced representatives who are widely admired in the autism parent community, an ideologically biased panel of representatives was selected for the current IACC. In fact, not only are the positions and qualifications of the new appointees in stark contrast to those mentioned above, there is widespread speculation within the autism community that they were selected for their hostility to investigation of environmental causes of autism, including vaccines.

For example, one newly appointed member, **Matt Carey**, father of an affected child, is best known in the autism community by a pseudonym he uses on a UK blog. He represents no national organization and actively opposes all vaccine safety research while he attacks parents who advocate for it. Under his pseudonym, Carey is best known as an ardent defender of Dr. Paul Offit, the wealthy developer of Merck's rotavirus vaccine.

Dr. Jose Cordero has served at the CDC for 27 years, oversaw the early days of the autism epidemic, and did nothing but mount a “learn the signs” campaign to address it. Cordero is also on record for pressuring the journal *Pediatrics* to publish a deeply flawed vaccine safety study in Denmark. Worse, he allocated millions of taxpayer dollars to Danish research Dr. Poul Thorsen, who was indicted by Department of Justice for 13 counts of wire fraud and 9 counts of money laundering of CDC money allocated to autism research. Dr. Cordero has never been held accountable for his failure to sound the alarm on the autism epidemic during his tenure at the CDC.

James Ball represents an autism organization representing few families. **Dennis Choi** is on the staff of the Simons Foundation, a research organization that is solely committed to a genetic causation model of autism; Choi was formerly an employee of the pharmaceutical giant Merck, one of the world’s top-three vaccine manufacturers. There is also concern about his level of commitment to serving on the IACC given a track record of poor attendance.

Alison Singer is the mother of an affected child and a previous representative of Autism Speaks on IACC. She resigned from Autism Speaks regarding differences of opinion about vaccine research but was allowed to keep her IACC seat. She now serves as President of the Autism Science Foundation, an organization she started that is funded at least in part by vaccine makers. **Idil Abdull**, is a mother of an affected child, represents no national organizations, and has promoted vaccination in concert with local public health officials.

Scott Robertson and **John Elder Robison** are both high functioning adults with Asperger’s, representing only the top 5% of people affected by autism. Robison is the author of a well-received memoir, but did not graduate from high school (in contrast to Crosby who is studying

for a graduate degree in Public Health). **Noah Britton** is an additional high functioning Asperger’s representative; his most notable activity is leading a comedy troupe called “Asperger’s are Us” that makes light of the suffering of affected individuals and families. While we support including self-advocates, the dichotomy of function level within the community means that the majority of individuals, who are more severely affected, are under-represented on the committee.

Dr. Anshu Batra is the mother of two boys on the autism spectrum. Her main role in the autism community appears to be that of a public advocate for the American Academy of Pediatrics in their fight against vaccine safety research. Dr. Batra represents no national autism organization. She has written no books, conducted no research on autism, and it is unclear whether her medical practice specializes in any kind of autism treatment.

Dr. David Mandell is a psychiatrist and researcher who also represents the Autism Science Foundation, despite its small size. His apparent goal is to develop new interventions for autism treatment, primarily using pharmaceuticals.

Astonishingly, even though significant evidence exists to show autism is an environmentally caused disease, no environmental scientist has been appointed. This seems not only illogical, but also highly irresponsible.

It is hard to interpret the composition of the new IACC as anything but a stinging rebuke to those who believe autism is a treatable, medical condition with underlying environmental causes and who proposed qualified candidates to represent that view. It is even harder to believe any real progress will be made under the direction of the new committee members on the environmental triggers of autism.

The Troublesome History of Panel Members

Throughout the IACC's existence there have been a number of incidents that give many stakeholders great pause. These incidents reflect not only a lack of urgency and responsibility on behalf of many of those serving on the panel, but in some cases, a blatant lack of professionalism and compassion. They are truly troubling.

Additionally, important conflicts of interest that legitimately raise concerns over the independence of the panel have gone unaddressed. For example, it is no secret that among parents vaccines are widely considered to play a significant role in the development of autism. Although controversial and widely dismissed by sophisticated public relations campaigns, far more science supports vaccines as a causal factor in autism than mainstream press coverage suggests. Most notably, our federal government has been quietly rewarding compensation for autism in association with vaccine injury for decades, lending support to the association that parents have recognized for years. A *Pace Environmental Law Review* article published in 2011 documented these previously hidden cases of autism and vaccine injury in great detail.

Despite this association between vaccine injury and autism, Dr. Tom Insel continues to head the IACC, even though he has a brother who became wealthy as the developer of a mercury-containing vaccine. Dr. Insel appeared at a National Autism Association conference in Atlanta, Georgia in 2007 and suggested that one day there was hope to create a vaccine to prevent autism. The insensitivity of this comment to the audience he was addressing cannot be overstated.

Dr. Insel's demonstrated his unwillingness to adequately investigate vaccine safety when he rescinded a committee vote in favor of vaccine research. In December 2008, the

IACC had approved two studies to address vaccine safety and autism. In a dramatic turn of events, Dr. Insel called for a re-vote on a previously voted-on and approved element of the Strategic Plan of the Combating Autism Act. The re-vote to reverse this previous decision was a surprise to the public members of IACC and was not listed on the meeting's agenda.

Other incidents also bring Dr. Insel's fitness to serve into question. For example, in April 2007, he refused to ride in an elevator with a mother and her affected child on their way to hearings about autism. He also had to publicly apologize to IACC member Lyn Redwood for a note found on the floor during an IACC meeting that was written by panel member Dr. Story Landis. In it, Landis questioned the motives of parents such as Redwood who were seeking vaccine research, while also suggesting that the most severe cases of vaccine injury should be investigated.

The autism rate has doubled on Dr. Insel's watch. None of the research that IACC has funded under his direction has led to significant advances in understanding autism causation. No funding has significantly improved the lives of those with autism. As hundreds of thousands of affected individuals now reach adulthood, IACC has done virtually nothing to prepare the country for this reality. The most promising area of research, environmental causation, has been studiously avoided and is likely to be avoided going forward under his stewardship. This failure of leadership, together with conflicts of interest, procedural lapses, and the decision to appoint an unrepresentative body of new committee members, speak to Dr. Insel's unfitness to continue as Chair. IACC needs new leadership and new members if it is to succeed in its mission.

Concerns with the Strategic Plan

In addition to the unbalanced philosophical composition of the panel members, coupled with the history of troublesome behavior and conflicts of interest, there is also great concern that the money dedicated towards addressing autism research and treatment is not being allocated responsibly or effectively. For example:

1. The panel is excessively focused on early intervention. There is very little money allocated towards helping children older than age of 3.
2. There is little focus on the services needed among an aging population of affected people, such as living assistance, job placement, and housing.
3. There is significant over-investment in genetic and genomic research, especially since autism is an environmentally caused disorder. None of this research has produced findings of diagnostic or therapeutic value. Indeed, despite claims that autism is highly heritable, no inherited gene of major effect has ever been found. Despite claims of progress in genes of minor effect and gene mutations, no consistently replicable findings have been produced.
4. There has been no accountability on behalf of the IACC panel for a lack of progress in either addressing or stopping the autism epidemic. Despite hundreds of millions of dollars spent on autism research, not a single new case of autism was prevented.
5. Significant research gaps, such as the specific role of the environment in the causation of ASD, are not being addressed. A recent analysis by The Coalition for SafeMinds showed that, in 2009, only 7% of research funding went to environmental causation.

Critique of the 2011 Summary of Advances

Thus far, very little understanding about autism or the treatment of it has been advanced by the IACC, in spite of its web page which claims otherwise. A thoughtful examination of the most recent research shows it has achieved little.

For example, the Strategic Plan research in 2011, which consisted of 20 different studies, is categorized as helping facilitate answers to 7 different questions about autism.

These were the actual answers they found:

1. When should I be concerned? (2 studies)

Answer: By 1 year old, pediatricians should be checking.

2. How can I understand what's happening? (4 studies)

Answer: You can't. It's genetic.

3. What caused it? Can it be prevented? (5 studies)

Answers: Yes. No. It's genetic. It's environmental. It's genes and the environment.

4. Which treatments will help? (3 studies)

Answer: Most medications don't work. Social engagement targets should be added to behavioral therapy goals. The LEAP model helps only if a teacher implements it well.

5. Where can I go for services for adults? (1 study)

Answer: Nowhere, even though the needs are high.

6. What does the future hold for adults? (3 studies)

Answer: (1) Nothing alarming. In the UK, there are just as many ASD children as adults, and since nothing has really changed over time, everything should be fine. (2) We don't know. We have to research it more. (3) Technology will help somehow.

7. What other infrastructure and surveillance needs must be met? (2 studies)

Answer: We need more studies, more early detection, and more services.

To summarize, in spite of spending millions of dollars just in 2011, we learn that autism is genetic, environmental, a combination thereof, and that really, they still aren't sure.

We learn that most medications don't work. That therapy only works if the teacher is good. That social goals should be set for affected children. That there are no services for adults. That there is an increase in ASD, but there's not an increase in ASD. And that pediatricians should be on the lookout for autism by one year of age.

The monumental waste of time, money, resources, and effort that went into confirming, or confusing, that which could have been identified through common sense and daily life is stunning. None of these studies did anything to advance the quality of life for those affected by autism and their families. We can and must do better immediately.

Demand for Change

At the current rate of 1 in 88 American children, autism is a national health emergency. The time is long past due for the Department of Health and Human Services to start treating it like one. We are deeply dismayed by the federal government's failure to respond to this crisis effectively and as such, seek the following:

1. That the Department of Health and Human Services, under the direction of Secretary Sebelius, declares autism a national health emergency. The human and financial toll of autism is catastrophic. The problem cannot be solved unless it is first acknowledged.
2. That those who have been in charge of autism policies in this Administration, including Dr. Insel, chair of the IACC, be fired. The rate of autism has risen steadily on Dr. Insel's watch. We expect accountability. The new members of IACC should all be dismissed, and the new Chair of IACC should commence a new search for committee members.
3. That Secretary Sebelius meet with a group of representatives from FOCUS Autism, a coalition of organizations representing over 100,000 people, to discuss the autism health emergency. We do not sense that she understands the urgency of this situation.
4. That the General Accounting Office study past autism funding to see why almost all money went to genetic research, which we now know, based on peer-reviewed science, is not the predominant factor in autism. Environmental research has been grossly underfunded. We want to understand if corporate interests or other improper interests distorted research priorities.
5. That the Center for Disease Control and Prevention rescind their recommendation for day of birth vaccination against hepatitis B. There is no medical reason for this intervention at such an early and fragile point in infant development. The CDC has never demonstrated the medical necessity for this extremely serious intervention. Peer-reviewed science has shown an association between day of birth hepatitis B vaccination and autism. Vaccination against hepatitis B, unless the mother is herself infected, should occur around puberty when children themselves might be at risk of contracting the disease.

6. That the Government Reform and Oversight Committee of the U.S. House of Representatives hold hearings in the near future on the role of federal authorities in this crisis. No Congressional committee has looked seriously at the conflicts of interest in federal activity on autism in almost ten years. As part of this process, Congress must examine the Vaccine Injury Compensation Program and how it has been quietly acknowledging autism as a vaccine injury for almost 25 years. We need real inquiry by Congress into this debacle.

Every 20 minutes a child is diagnosed with autism. It affects every aspect of the child's life, his or her family members' lives, and the community. In some states, we now have as many as 1 in 29 American boys falling somewhere on the spectrum. The argument that this is due to better diagnosis on the one hand, and bad diagnosis on the other, is outrageous and irresponsible. Even Dr. Insel has admitted the rise in autism cannot be attributed to better diagnosis, stating, "...there is no question that there has got to be an environmental component here."

Given his own admission that autism is absolutely on the rise; given that there is no such thing as a genetic epidemic; given that since the enactment of the Combating Autism Act in 2006, we have not only not advanced our understanding of autism, but have watched it explode in incidence, we demand that our Administration take our concerns seriously and act expeditiously to do better.

To continue to ignore the urgent needs of our most vulnerable population is a moral failing the likes of which our nation has perhaps never seen. Unless we do something drastic immediately, this is destined to be our legacy.

We must choose to be the kind of government that is willing to honestly, thoroughly, independently, and adequately investigate the autism epidemic, regardless of where it may lead; to acknowledge any role we may have inadvertently played in its causation or continuation; and to use all of our strength, talent, and resources to do whatever it takes to make it right.

Our children, and the world's children, deserve nothing less.