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1 IN 88 CHILDREN: A LOOK INTO THE FEDERAL RESPONSE TO RISING RATES OF AUTISM

HEARING

BEFORE THE

COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED TWELFTH CONGRESS

SECOND SESSION

NOVEMBER 29, 2012

Serial No. 112–194

Printed for the use of the Committee on Oversight and Government Reform

Available via the World Wide Web: http://www.fdsys.gov
http://www.house.gov/reform

U.S. GOVERNMENT PRINTING OFFICE

80–405 PDF WASHINGTON : 2012

For sale by the Superintendent of Documents, U.S. Government Printing Office
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1 IN 88 CHILDREN: A LOOK INTO THE FEDERAL RESPONSE TO RISING RATES OF AUTISM

Thursday, November 29, 2012

HOUSE OF REPRESENTATIVES,
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM,
Washington, D.C.

The committee met, pursuant to call, at 2 p.m., in Room 2154, Rayburn House Office Building, Hon. Darrell E. Issa [chairman of the committee] presiding.

Present: Representatives Issa, Burton, Gosar, Labrador, Meehan, DesJarlais, Gowdy, Ross, Farenthold, Kelly, Cummings, Maloney, Norton, Kucinich, Tierney, Lynch, Connolly, Quigley, Davis, Yarmuth.

Also Present: Representatives Posey, Smith of New Jersey, Buchanan, Barrow, Moran and Matheson.

Staff Present: Ali Ahmad, Communications Advisor; Alexia Ardolina, Assistant Clerk; Kurt Bardella, Senior Policy Advisor; Robert Borden, General Counsel; Will L. Boyington, Staff Assistant; Molly Boyl, Parliamentarian; Lawrence J. Brady, Staff Director; Ashley H. Callen, Counsel; Sharon Casey, Senior Assistant Clerk; John Cuaderes, Deputy Staff Director; Howard A. Denis, Senior Counsel; Adam P. Fromm, Director of Member Services and Committee Operations; Linda Good, Chief Clerk; Frederick Hill, Director of Communications and Senior Policy Advisor; Christopher Hixon, Deputy Chief Counsel, Oversight; Mark D. Marin, Director of Oversight; Tegan Millspaw, Professional Staff Member; Mary Pritchau, Professional Staff Member; Laura L. Rush, Deputy Chief Clerk; Scott Schmidt, Deputy Director of Digital Strategy and Press Secretary; Cheyenne Steel, Deputy Press Secretary; Rebecca Watkins, Deputy Director of Communications; Jeff Wease, Deputy CIO; Jaron Bourke, Minority Director of Administration; Yvette Cravins, Minority Counsel; Ashley Etienne, Minority Director of Communications; Jennifer Hoffman, Minority Press Secretary; Carla Hultberg, Minority Chief Clerk; Elisa LaNier, Minority Deputy Clerk; Suzanne Owen, Minority Health Policy Advisor; and Dave Rapallo, Minority Staff Director.

Chairman ISSA. The Committee on Oversight and Government Reform will come to order. This hearing on "1 in 88 Children: A Look Into the Federal Response to Rising Rates" will come to order.

The Oversight Committee exists to secure two fundamental principles: First, Americans have a right to know that the money Washington takes from them is well spent; and, second, Americans

deserve an efficient, effective government that works for them. Our duty on the Oversight and Government Reform Committee is to protect these rights. Our solemn obligation is to hold government accountable to taxpayers because taxpayers have a right to know what they get from their government.

We will work tirelessly in partnership with citizen watchdogs to deliver the facts to the American people and bring genuine reform to the Federal bureaucracy. This is our mission. And I might say today in many cases we're dealing with people who, because of this affliction, may never pay taxes, but, in fact, their families and others pay for an entire life

Congress spends a lot of time discussing and debating issues and determining by our philosophical beliefs what the role of government should be. As we have seen in these debates surrounding TARP, stimulus, healthcare reform, these kinds of issues ofttimes come down to where you fall on an ideological spectrum.

Today is no such thing. We're having a hearing focused on something that spans the ideological left to the ideological right. We're drawing attention to something that has no political affiliation, no partisan allegiance, and sometimes, and we believe today, not nearly enough focus on something that does not shorten life, but dramatically or even slightly, but usually more than slightly, reduces the quality of life both for the individual and for their families.

I'm a father. As far as I know, I'm one of the fortunate ones; I'm not the 1 in 88. But right now, if the numbers are accurate, and if they continue to grow from the now 1 in 88 that in some way are ASD affected, we, in fact, have an epidemic. It could be that some of the 1 in 150 at the start of the previous century was too low; that, in fact, people were simply not diagnosed. But few people believe that, in fact, there aren't factors in our society, in our behavior, in the air we breathe, the water we consume or others that are affecting how many people will be afflicted.

We're going to hear from a distinguished panel first of people who do this for a living, try to get to the causes, prevention—I won't say cure today, but at least the treatment, the understanding, and perhaps in some cases truly something that would mitigate their suffering.

I know they're frustrated. Congress, although we put nearly a quarter of a billion dollars a year directly into research, has not put the kind of dollars, perhaps, that could bring specific outcomes sooner.

On our second panel, a number of individuals will say that, in fact, one of the problems is we're looking on one side of the equation and not nearly enough on what to do for the victims of various parts of autism. The fact is they're all right. There is not enough money being placed on the various possible causes of autism. There is not enough study. Our government does not collect statistics as well as perhaps someday soon we will so that, in fact, we can find out what the true number is, crosscheck every aspect of how that number, which is a human being, came to be afflicted.

The truth is we have a lot to do. I will not claim that I have come here timely. This is the last few days of my first 2 years as chairman, and this is our first hearing. What I will promise you here today is that we will stay involved in this issue. We will stay in-

volved through staff and through, if appropriate, additional hearings.

I also would say to our first distinguished panel that one of the most important priorities I place today is, in fact, that we work with you and help you in this process; that we be a conduit to the rest of Congress on this important issue.

In a few moments I'll be swearing in—I'm sorry—I'll be recognizing by unanimous consent a number of Members who would not ordinarily be here at a hearing because they are involved in this issue but serve on other committees.

Additionally, I want to apologize to all of those people who, rightfully so, would be well to be heard here today. I could have had a second panel of at least 20 witnesses from organizations and brought from affected individuals. We had the difficult job of selecting just six, and, as the ranking member will undoubtedly agree, six is already a fairly large single panel. That's one of the reasons I pledge to you today that any organization or individual that in the next 7 days provides to us, as required by our rules, in electronic format—or if you give it to us in paper, we will try to scan it—we will include your statements and your information in the record. We will hold the record open so that the many who could not be heard live in testimony will, in fact, be at least in the record.

I want to particularly recognize Brian Hooker with Focus Autism, the American Academy of Children, and—I see it's a long, long title. I'm sorry—who, in fact, has been one of the people who has championed for today's hearing, and a number of others. They've been essential in my getting a better understanding.

I also would like to thank—and we will be recognizing two witnesses—or two Members on each side—the former chairman of the full committee, Dan Burton, who years ago began a process of focusing on some aspects of this terrible disease.

We, in fact, don't know enough. Our goal is to know more. Today is but a down payment on that.

With that, I'd like to thank the ranking member for his assistance in putting together today's hearing and recognize him to his opening statement.

Mr. CUMMINGS. Thank you very much, Mr. Chairman. And I do thank you for holding today's hearing.

Before I get started, I want to pay special note, as you have already done, to our friend who is leaving, Mr. Burton. Over my 17 years on this committee, this has been an issue that he has constantly put forth and constantly made sure that we tried to address as best we could.

So, Mr. Burton, I want to thank you for your vigilance, and I want you to know that although you may be leaving the Congress, as the chairman has said, we will continue to fight. And I know you will, too.

Mr. Chairman, we have learned much about autism spectrum disorders over the past decade. Taxpayer-sponsored research has identified risk factors and evaluated therapies to assist with some symptoms. Physicians and parents now have a better understanding of the developmental signs and the symptoms allowing for

earlier detection. And educators have experience with new methods and approaches for assisting children with autism.

Congress has also acted to help individuals with autism and their families in significant ways. In 2010, we passed the Affordable Care Act, which contained significant new protections. Insurers may no longer discriminate against individuals based on preexisting conditions. Insurers may no longer impose lifetime caps on healthcare coverage. New plans must include screening for autism without additional costs to the parents. And young people diagnosed with autism spectrum disorders may remain on their parents' health insurance plans until they are 26 years old. These are real and significant protections that will improve the lives of millions of American families.

Even with this progress, there is still more to learn, and there is still more to do. While autism affects all racial, socioeconomic, and ethnic groups, some studies have shown that African-American, Hispanic, and Asian children are less likely to receive an early diagnosis. These delayed diagnoses cause minority children to be further behind in the development of language and motor skills. We must be vigilant in emphasizing early detection and intervention for all our children, as an early diagnosis can make a critical difference in the lifelong development of a child.

We must also continue to invest Federal research dollars in new and evolving therapies to improve the lives of those with autism spectrum disorders. In my district we house the Kennedy Krieger Institute, an internationally recognized institution dedicated to improving the lives of individuals with developmental disorders. These institutions improve the quality of life, education, and continued development of those affected by autism spectrum disorders, and we must continue to support that.

Today's hearing is an opportunity to examine what has been done about autism spectrum disorders to date and what more needs to be done in the future. There are many experts, individuals, and groups who can help us in this effort.

And I want to take this moment to thank all of you for being here. As the chairman said, there were so many people interested in this issue, so many who wanted to speak. But I want to say to you what I said to Bob Wright of Autism Speaks a little earlier today. I thank you for caring about somebody other than your children and yourselves, because what you are doing here today is raising this issue so that other children other than those—or other folks other than those that may be in your own families, maybe your friends, will benefit in the future. In other words, you are touching the future, and you are making it possible for those who are going through the autism spectrum disorders to have a better future. And so I thank you all for what you are doing.

And as I said to Bob Wright, you must stay the course. One of the things that I have learned from being in Congress these 17 years is that in order for these causes to move forward, you have to keep banging the drum, and you must drum—keep banging louder and louder and presenting your case so that after it's all over, there's not, as my mother would say, motion, commotion, emotion, and no results.

I want you to be successful in what you're doing. Life is short. And so what we must do is try to use our energy so that we can get the best possible results. And I am so glad the chairman said what he said about sticking with this, addressing it, and we encourage all of you to work with us as we move forward.

And with that, Mr. Chairman, I thank you.

Chairman ISSA. I thank the gentleman.

I now recognize the former chairman of the full committee Mr. Burton for 5 minutes.

Mr. BURTON. Thank you, Mr. Chairman.

Let me start off by saying, contrary to what has been stated in the media over the years, I am not against vaccinations. I believe that vaccinations have a very important place in our society and have given us one of the best health regimens in the history of mankind. People live longer and live better and have less disease because we have vaccinations.

What we have always opposed is putting toxic chemicals or metals in the vaccinations. Thimerosal contains mercury. When I was a boy, we used to have mercury in thermometers. And they said if you break that thermometer, and the mercury gets on your hands as years went by, that was toxic.

In Indianapolis, we had a school where the—in the chemical laboratory in the health science room, they broke a vial that had some thimerosal in it. They evacuated the school, they burned the clothes of kids that came in contact with it, and the fire department came in with all kinds of equipment to make sure they weren't exposed to it.

Women who are pregnant, they say don't eat fish that has mercury in it, and they caution them that there are certain kinds of fish you don't eat. You don't drink water that has any mercury it in.

There's all kind of reasons not to be exposed to mercury, and yet we continue to put it in vaccinations as a preservative.

In 1929, they came up with thimerosal. They tested it on 29 people that had meningitis. They all died of meningitis, but they said that mercury in the vaccinations or the thimerosal didn't cause any of the problem. It was not a contributing factor. So ever since 1929, it has never been completely tested, and they continue to use it in vaccinations. It wasn't so bad when a child got 1 vaccination or 2 or 3, but when they get as many as 28 or 29 before they go in the first grade, it really hurts them. It causes a cumulative effect. The brain tissues do not chelate it. It stays in there, and it causes severe, severe problems.

Now, I had, during the chairmanship which I had in this committee, when I was chair for 6 years, we had about 4 years of hearings. We had people from all over the world, scientists from every part the world, doctors from every part of the United States who testified. And people from CDC and FDA said there's no evidence that the thimerosal causes any neurological problems in people who are vaccinated.

And then we kept on and kept on, and finally we had some people from FDA and CDC who came and testified and said there is no—get this word—there is no conclusive evidence that the mer-

cury in the vaccinations causes neurological disorders. No conclusive evidence.

Now, that word "conclusive" ought to stick in everybody's minds, because what it means is there is a possibility. And my question has always been, and I am convinced, that the mercury in vaccinations is a contributing factor to neurological diseases such as autism and Alzheimer's. I'm convinced of it after all those years we had hearings.

But that word "conclusive," "there is no conclusive evidence," creates a doubt. And my question to the presidents and CEOs of pharmaceutical companies has always been, if there's any doubt, if there's any doubt that the mercury in vaccinations can cause a neurological problem, then get it out. You shouldn't put mercury in any form in the human body, especially in children in vaccinations, or adults, in my opinion.

When we get a vaccination for flu, every year we get a flu vaccination, we have thimerosal, fellows. I don't know if you know that or not. They are injecting a certain amount of mercury in your body, and over a period of time, I believe it does have an adverse impact on the neurological system of adults, and I think it's a contributing factor to other diseases, such as Alzheimer's.

Let me just say that the thing we need to do is always err on the side of safety. If the pharmaceutical industry were to go to single-shot vials, then you would eliminate the possibility of neurological problems from vaccinations because there wouldn't be any mercury in it.

And the last thing I want to say real quickly—I've got 27 seconds—is we passed a Vaccine Injury Compensation Fund to compensate those people who are injured by vaccinations, and it was supposed to be something that was—people could work with the government to get that money. The pharmaceutical companies were putting money into that fund. But it's so hard for a person who's had a damaged child or a damaged adult to get any money out of that fund. It's unbelievable. And we need to reevaluate that fund to make sure people who are damaged by mercury in vaccinations need to have access to that so they can at least have some compensation to help with the rest of their lives. These people are going to live 60, 70 years, and they are going to be a burden not only on the families, but on society itself.

Chairman ISSA. I thank the gentleman. The gentleman yields back.

I now ask unanimous consent that our colleagues, Mr. Posey of Florida, Mr. Barrow of Georgia, and Mr. Matheson of Utah, be allowed to sit on the dais and ask questions at the conclusion of other seated Members. Without objection, so ordered.

It's now my pleasure to recognize the distinguished gentleman from Illinois Mr. Davis for 5 minutes.

Mr. DAVIS. Thank you, Mr. Chairman. And I thank you for calling this hearing.

As one who has spent much of my adult life working as a professional in the areas of health planning, health research and delivery, I firmly believe that the Federal Government has an important role to help understand autism spectrum disorders and to address the needs of our citizens with autism across their life spans.

I, too, want to commended the former chairman of this committee, my good friend Dan Burton, for using his position as chairman and beyond to focus on this particular issue and cause the committee and others to continuously take a hard look at it.

Dan, I commend you for your efforts and certainly wish you well as you revert back to private life.

I'm very proud to represent a premier institution involved in the research and service provision of people with autism, specifically the Therapeutic School and Center for Autism Research operated by the Easter Seals in my congressional district as a part of the Illinois Medical District, which is the largest medical district in the country.

This one-of-a-kind facility is unique in the Nation because it combines on a single campus educational, research, training, early intervention, school-to-work transition, and independent-living capabilities. The continuum of services to persons with autism is impressive and will help advance a research-driven context for teaching, learning, and clinical and medical interventions related to autism.

As an ardent advocate of persons with all types of disabilities—physical, mental, or developmental—I strongly supported the provisions of the Patient Protection and Affordable Care Act that protect families and individuals affected by autism spectrum disorders.

I want to thank all of the witnesses for coming to join with us.

Again, Mr. Chairman, I thank you for calling this hearing and look forward to our discussions here this afternoon, and I yield back the balance of my time.

Chairman ISSA. If the gentleman would yield his remaining time to the gentleman from Ohio, I would appreciate it.

Mr. DAVIS. I would be delighted to do so.

Chairman ISSA. Mr. Kucinich is recognized for 2 minutes.

Mr. KUCINICH. Thank you very much, Mr. Chairman.

Having had the opportunity to work with Mr. Burton on this for the last 10 years, I remember well, as I'm sure Mr. Burton does and some members of this committee do, a time when a provision was snuck into a bill on a homeland security that essentially shielded from lawsuits the manufacturers of thimerosal. This is 10 years ago. And you know what? No one of the Members that have been here less than 10 years, no one knew where that provision came from. It came out of nowhere and ended up getting buried in a conference report, and, of course, it passed.

And, you know, I mention this because it's not as though we just discovered this matter. And while I salute the chair for holding this hearing, we didn't just discover this. And my own theory is while there are studies that are out there that are implicating environmental factors in autism, think about this for a minute. We know, as Mr. Burton laid out, the component of thimerosal that—one of the components supposedly to stabilize it is mercury. Well, we all know that mercury is more than a contaminant, it's an environmental toxin. But it doesn't only exist in liquid form. You know, mercury can also be inhaled. And I would guess, and this is just my theory, that we're not only talking about drug manufacturers here, we might be talking about coal companies, too.

You know, we have to be aware. There are reasons why we—why this Congress and this government has not effectively addressed this issue, and when you have Lilly and others, Eli Lilly and others, contributing millions of dollars to try to affect the outcome of elections.

I will tell you, while I—I salute this chair for taking this on, because at the bottom of this you have special interest groups who would resist any deeper research on it because it's going to affect their bottom line. Meanwhile, you have children all over the country turning up with autism.

So this is a new beginning, I salute the chair for making it, but this goes way beyond thimerosal, and you can start thinking about coal. Thank you.

Chairman ISSA. I thank the gentlemen on all sides.

I now ask unanimous consent that our colleague from New Jersey Mr. Smith be allowed to participate in today's hearing. Without objection, so ordered.

And I will announce that if any individuals would like to be in a little more comfortable situation, we do have an overflow room. And if they would just let our staff know, they would make sure that if they gave up their seat here, that they would be able to be in the overflow room. It may be more comfortable for some of our guests.

I now turn to our first panel.

The distinguished Dr. Alan Guttmacher is Director of the Eunice Shriver National Institute of Child Health and Human Development at the National Institutes of Health. And I actually knew the namesake of your organization during her time.

And Dr. Coleen Boyle is Director of the National Center of Birth Defects and Developmental Disabilities at the CDC.

With that, pursuant to the requirements and rules of this committee, would you please rise to take the oath, and raise your right hands.

Do you both solemnly swear or affirm that the testimony you are about to give will be the truth, the whole truth, and nothing but the truth?

Thanks. Please be seated.

And let the record indicate both witnesses answered in the affirmative.

You are important witnesses, and we will not stop you if you go slightly over 5 minutes. But we do have a large second panel, and I would ask that you bear in mind that all of your opening statements and additional extraneous material you may choose to submit to us will be placed in the record. So if you abbreviate or go off message, it doesn't change the official record for you.

With that, Dr. Guttmacher, you are recognized.

WITNESS STATEMENTS

STATEMENT OF ALAN GUTTMACHER

Dr. GUTTMACHER. Thank you, Mr. Chairman. I'm also a pediatrician and medical geneticist, and a member of the Interagency Autism Coordinating Committee, or IACC, reauthorized most recently by the Combating Autism Reauthorization Act of 2011.

Let me thank the Congress for its continued support of research and other activities regarding autism spectrum disorders. That support has made possible remarkable advances in autism research and helped to better identify and meet the needs of people with ASD and their families.

ASD includes diverse conditions that share distinctive styles of or impairments in communication skills and social interactions, as well as restricted, repetitive, or stereotyped behaviors. The combination and degree of impairments vary, creating an array of conditions that range from what many would see as normal to significantly disabling. Two decades ago ASD was thought rare. Today, with CDC's latest prevalence estimates, it is a national health priority.

The IACC plays a pivotal role in bringing together Federal agencies, nonprofit organizations, and the public to identify priorities and strategies to address them. It includes individuals on the autism spectrum; parents of children and adults with ASD; other advocates, researchers, and service providers; and officials from Federal agencies.

The IACC welcomes public comment at all full committee meetings, regularly invites written public comment, and holds town halls. Thus, a diversity of perspectives on ASD informs IACC activities and recommendations. It is a committed group. While the law requires 2 meetings a year, the committee and its subcommittees meet as many as 17 times a year.

The law charges the IACC to update a strategic plan annually. We are drafting, as always, with autism community input, a 2012 update to reflect the latest advances, remaining gaps, and emerging needs in autism research. The plan encompasses priorities from fundamental biology to services across the life span.

Over the past decade autism research funding has grown substantially. The NIH leads Federal research efforts on ASD, investing $169 million in fiscal year 2011, three times more than 10 years ago. In 2009 and 2010, $122 million in additional American Recovery Reinvestment Act funds were also invested.

As Congress has emphasized, early diagnosis and intervention are critical. This year NIH-funded researchers identified brain pattern aberrations at as early as 6 months of age in infants who went on to develop autism, the earliest such changes ever recorded in autism, and one of a number of recent findings to suggest that the factors causing autism may operate very early in development.

Last year researchers demonstrated that doctors' offices can use a short questionnaire to screen inexpensively for ASD at the 1-year well-child visit. Another promising diagnostic tool, a 1-minute test to detect eye-gaze patterns specific to autism, had nearly 100 percent specificity in infants as young as 14 months.

But early diagnosis is viable only if effective interventions are available. Recent ASD trials have validated early interventions to improve health outcomes and quality of life. For instance, a recent behavioral intervention study showed improved IQ, language, and social development in young children. And progress is also being made on interventions for adults. A recent study showed, for instance, that for the many adults with ASD who have impaired abil-

ity to recognize faces, a computerized training program improved facial recognition skills.

Many recent advances have come from NIH's Autism Centers of Excellence program, which currently supports nine centers and networks across the country, with two additional awards expected in 2013.

The research covers a variety of topics aligned with the IACC's strategic plan, including nonverbal ASD, genetic and environmental risk factors, potential treatments in determining why ASD is five times more common among boys.

We do not know the causes of ASD, but recent findings highlight the need to focus on both environment and genetics. NIH and CDC have established large research networks to collect extensive data on environmental exposures and health outcomes, and conduct powerful analyses to identify factors that contribute to autism. Those networks explore possible causative factors in the environment before, during and after pregnancy. Just this week one of these networks published a study that suggests prenatal and early-life exposure to car emissions is associated with autism.

On the services front, HRSA has invested substantially, improving physical and behavioral health of people with ASD, practitioner training and service provision. In fiscal year 2012, Congress appropriated over $47 million to HRSA for autism and other developmental disorders. This supports 43 interdisciplinary training programs, which provide services and trainingto 41 States and include autism intervention projects for underserved populations.

Federal agencies also use public-private partnerships to maximize our work, such as NIH's National Database for Autism Research, which coordinates with other autism data repositories to enhance researchers' access to data. Programs like these that involve collaboration with patients and families bring together hundreds of researchers and clinicians with tens of thousands of people nationwide affected by ASD.

The Administration of Intellectual Developmental Disabilities, with help from several nonprofit organizations, supports the AutismNOW Project, offering a call center, Web-based clearinghouse of resources, and twice-weekly autism webinars. The NIH-supported Association of University Centers on Disabilities is improving early identification of autism through 25 Act Early Ambassadors who train physicians in identifying, diagnosing, and managing ASD.

In conclusion, since the establishment of the IACC, a wide variety of research, service, and education expertise have come to bear on autism. Research is rapidly translating to practical tools for use in the clinic and the community. Federal agencies are coordinating efforts to identify best practices to support the lifelong education, health, and employment needs of people on the spectrum.

Thank you for this opportunity to provide testimony on such an important topic.

Chairman ISSA. Thank you, Doctor.

[Prepared statement of Dr. Guttmacher follows:]

Testimony before the Committee on Oversight and Government Reform United States House of Representatives

Autism-related Issues

Dr. Alan Guttmacher, M.D.
Director, Eunice Kennedy Shriver National Institute of Child Health & Human Development
National Institutes of Health
U.S. Department of Health and Human Services

For Release upon Delivery
Thursday, November 22, 2012
Expected at 2:00 p.m.

Good morning Chairman Issa, Ranking Member Cummings, and distinguished members of the Committee. Thank you for the opportunity to provide testimony today. My name is Dr. Alan Guttmacher, and I am a pediatrician and Director of the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). I have been a member of the Interagency Autism Coordinating Committee (IACC) — created by the Children's Health Act of 2000 (CHA), reestablished by the Combating Autism Act of 2006 and reauthorized by the Combating Autism Reauthorization Act of 2011 (CARA) — since my arrival at NICHD in 2009. I have been invited to testify on behalf of NIH and the IACC regarding the status of biomedical research, services programs, and interagency coordination of activities related to autism spectrum disorder (ASD).

The IACC appreciates Congress' continued support of research and services related to ASD. With the reauthorization of the Combating Autism Act, the Department of Health and Human Services (HHS) and Federal and private partners have continued — through the IACC — to engage with the public and work collaboratively on autism-related activities. These efforts have enabled remarkable advances in the field of autism research and helped us to identify and meet the service needs of all people affected by autism, individuals, and families alike.

ASD is a diverse collection of disorders that share common impairments in verbal and nonverbal communication skills and social interactions, as well as restricted, repetitive, and stereotyped patterns of behavior. The degree and specific combination of impairments can vary from one individual to the next, creating a heterogeneous disorder that can range in impact from mild to significantly disabling. Two decades ago, ASD was considered a rare disorder. Today, with the Centers for Disease Control and Prevention's (CDC's) March 2012 estimates of 1 in 88 children in the United States being identified with an ASD, this disorder has become an important national health priority, affecting virtually every community across the country. In 2006, Congress passed the Combating Autism Act to strengthen Federal coordination of issues related to ASD and to enhance public-private collaborations in order to

accelerate research to improve the lives of people with ASD and their families. Congress reauthorized the Combating Autism Act in 2011, allowing the continuation of these efforts, including the work of the IACC.

The IACC has played a pivotal role in helping Federal agencies, non-profit organizations, and members of the public work together to identify priorities and strategies to address key issues of importance to the autism community. I will briefly discuss the IACC's membership, its transparent process, its collaborative activities, the framework provided by the IACC's Strategic Plan, and its current activities. I also will share examples of efforts under way in various agencies within the Department, some recent advances in ASD research, and how the IACC's Strategic Plan with extensive input from the public has facilitated these advances.

Since its beginning in 2000, the IACC has provided both an important forum for public discussion of autism issues and a framework for research and services that incorporates the needs identified by affected individuals and families, advocates, providers, researchers, and other community members. The membership of the IACC includes both representatives of Federal agencies and public members, representing a diverse set of stakeholder groups within the autism community, creating a critically important public-private dialogue on issues related to autism. Currently, the IACC includes three people with ASD, several parents of children and adults with ASD, members of the advocacy, research, and service provider communities, and officials from the following Federal agencies and offices that are involved in ASD research or services provision: Department of Defense (DoD), Department of Education (ED), HHS's Administration on Intellectual and Developmental Disabilities (AIDD)/Administration for Community Living (ACL), Agency for Healthcare Research and Quality (AHRQ), CDC, Centers for Medicare & Medicaid Services (CMS), Food and Drug Administration (FDA), Health Resources and Services Administration (HRSA), five institutes of NIH, and the NIH Director. Major autism research and services organizations represented on the IACC include Autism Science Foundation, Autism Society, Autistic Self Advocacy Network, Autism Speaks, SafeMinds, Simons

Foundation, and Somali American Autism Foundation. The diversity of the IACC's membership serves to foster dialogue on a wide variety of issues of importance to the autism community.

In addition to the voices and perspectives added by its members, the IACC has served as a forum for public participation by having public comment periods at every full IACC meeting, regularly inviting written public comment, and conducting formal requests for information from the public and holding town hall meetings. The IACC has provided a high level of transparency for the public by actively disseminating information about its activities via e-mail, the IACC website, webcasts, and Twitter. By including both Federal and public members, and by fostering public engagement through a variety of means, the IACC ensures that a diversity of ideas and perspectives on ASD are brought to the table to inform the IACC's activities and recommendations. While the law requires the IACC to meet twice a year, the IACC and its subcommittees have met between 7 and 17 times a year since 2007, for a total of 67 times. This includes full committee and subcommittee meetings, planning groups, workshops, and town hall meetings.

Under the Combating Autism Act, enacted in December 2006, the IACC is charged with developing and annually updating the IACC's Strategic Plan for ASD research. In fulfilling these requirements, the IACC met many times and gathered extensive public input in 2007 and 2008 to shape its first comprehensive IACC Strategic Plan, released in January 2009; updates were issued in 2010 and 2011. The new IACC reauthorized under CARA is currently in the process of drafting a 2012 update of the IACC's Strategic Plan that reflects the latest advances and progress in the field of autism research, as well as remaining gap areas and emerging needs. The IACC developed its original 2009 IACC Strategic Plan with a great deal of participation from the public, including planning meetings, town hall meetings, and requests for information, and has continued gathering public input to inform subsequent updates.

The public's participation in IACC meetings and planning efforts, combined with the contributions of scientific and subject matter experts and all the major Federal agencies and private funders, resulted in a plan that provided a clear path to move autism research forward in targeted, innovative ways to help public and private agencies prioritize activities. The first IACC Strategic Plan was organized into six chapters that reflected the needs expressed by the community: early and accurate diagnosis, better understanding of how autism develops, enhanced ability to identify risk factors, development of new and more effective interventions and treatments, the need for more research to inform and enhance services, and the development of better approaches to meet the changing needs of people with ASD over their entire lifespans. In 2010, the IACC also added a chapter on the infrastructure needed to support a robust research effort. As you can tell, the IACC's Strategic Plan has a broad scope, in part because it was developed through the cooperation of both research- and services-focused agencies and private organizations. While the IACC's Strategic Plan focuses on research as the law requires, it encompasses a range of research that goes from fundamental biology of ASD to inform new diagnostics and therapies, to the actual development of necessary tools and approaches, and finally to research that can inform and enhance services programs to meet the needs of people with autism across the lifespan.

Research Funding

Over the past decade, funding has grown significantly for research on the underlying biology and risk factors associated with ASD, as well as research that seek better treatments, earlier diagnoses and better, more effective services. The NIH leads Federal biomedical research efforts on ASD. The NIH invested $169 million in ASD research in fiscal year (FY) 2011, more than 40 percent above FY 2008 levels. In FYs 2009-2010, $122 million in funds made available through the American Recovery and Reinvestment Act (ARRA) were also invested across these areas, with the largest proportion of funding devoted to identifying genetic and environmental risk factors. The first IACC Strategic Plan was completed just as NIH received the significant additional funding from ARRA, so, with a strategic plan in place to guide priorities, NIH allocated

the additional funding between FY 2009 ($64 million) and FY 2010 ($58 million) to support a variety of projects addressing the most critical research needs highlighted by the IACC. Including these ARRA funds, the overall NIH investment in autism research was an unprecedented $218 million in FY 2010, more than double the funding prior to the Combating Autism Act.

CDC leads surveillance research efforts and establishes United States prevalence for autism. Dr. Coleen Boyle will provide more details on CDC's surveillance work in her testimony.

Research Advances

I'd like to share with you some of the exciting scientific advances we have seen in ASD research as a result of the increased investment in autism research. Since the passage of the Combating Autism Act, there has been a groundswell of activity on multiple fronts, from game-changing scientific discoveries reshaping the field of autism research to real-world applications that can help people with ASD and their families now.

Diagnosis and Intervention

One of the main provisions of the Combating Autism Act was support for early diagnosis and intervention. CDC conducts surveillance and reports that the median age of earliest known ASD diagnosis documented in children's records varied by diagnostic subtype (Autism Disorder: 48 months; ASD/PDD: 53 months; Asperger Disorder: 75 months) and varied by sociodemographic group and geographic location. With recent advances, diagnosis by age 14 months is now a realistic possibility, and researchers are actively pushing the detection window to even younger ages. In April 2011, NIH-funded researchers demonstrated that a simple, low-cost, practical screening tool involving a checklist that takes only five minutes for a parent to complete in doctors' offices can be used to detect ASD during a child's one-year well-baby check-up. The checklist includes questions about the child's emotions, eye gaze, communication, gestures, and other behaviors.

More than 100 pediatricians in San Diego County, CA participated in a study using the tool to screen over 10,000 one-year-old children and found that the checklists accurately identified children with ASD and other developmental delays in 75 percent of cases. Impressively, all pediatricians who participated in the study decided to continue using the tool in their practices after the study ended because they recognized the tremendous potential benefit it could provide by identifying autism earlier, allowing them to direct families toward early interventions that can help support positive outcomes earlier in life. Another promising diagnostic tool in development is a simple, 1-minute test that detects eye gaze patterns specific to infants with autism. Researchers at University of California, San Diego who received funding from NIH found that this test, which assesses the infants' preference for looking at videos of moving geometric shapes versus social movement, identified infants as young as 14 months old who had autism with nearly 100 percent specificity based on their preference for staring at moving geometric shapes. These promising diagnostic tools, combined with CDC's health education campaign, "Learn the Signs. Act Early," can improve early identification and provide great potential for reducing the age of diagnosis, thus allowing children and their families to get the services and supports they need when those services and supports can help the most.

Of course, early diagnosis is only valuable if effective interventions are available. Recently published results from several successful trials of early interventions have validated approaches that are effective in young children, creating real promise of improved health outcomes and quality of life for children with ASD. In a recent NIH-funded study, children from 18-30 months old with autism who participated in an innovative, high intensity developmental behavioral intervention called the Early Start Denver Model (ESDM) showed normalized brain activity and greater improvements in autism symptoms, IQ, language development, and social behaviors, when compared to another group of ASD children that participated in a 2-year community intervention. In another groundbreaking study, a group of investigators jointly funded by HRSA and NIH reported that an intervention designed to enhance social engagement in toddlers improved social, language, and cognitive outcomes. Early interventionists have noted an

encouraging research challenge – the community is taking up new approaches that are being proven effective so quickly that it is difficult to find "control groups" for behavioral intervention trials. While this can complicate efforts to conduct randomized control trials, it is encouraging to know that parents and community practitioners are putting innovative strategies into practice quickly.

In addition to early interventions, progress is being made in developing interventions to help adults on the autism spectrum. A recent NIH-funded study showed that a computerized training program for adults with ASD who showed initial impairment in their ability to recognize faces, a disabling aspect of ASD for many on the spectrum, resulted in improved face recognition skills.

Many of these recent advances in early diagnosis and intervention were supported through NIH's Autism Centers of Excellence (ACE) program, which was expanded under the Combating Autism Act. The ACE program was renewed in September 2012, and currently supports nine centers and networks at major research institutions across the country, with two additional ACE awards expected next year. The research conducted within the ACE program covers a variety of topics that are aligned with priorities identified in the IACC's Strategic Plan, including nonverbal ASD, genetic and environmental risk factors, possible links between ASD and other genetic syndromes, potential treatments, and possible reasons why ASD is more common among boys than girls.

Risk Factors and Prevalence

We do not know the causes of ASD, but very recent findings comparing identical and fraternal twins suggest the importance of focusing on both environmental and genetics factors. NIH and CDC are continuing to strengthen research investigations into possible environmental risk factors for autism, establishing large research networks with the capability to collect extensive sets of data on environmental exposures and health outcomes, and to conduct powerful analyses to determine which risk factors may contribute to the development of autism.

Population-based studies are the gold standard in epidemiology research. Large sample sizes and rigorous study designs allow researchers to examine many variables at once. Such networks, like NIH's Childhood Autism Risks from Genetics and the Environment (CHARGE) and Early Autism Risk Longitudinal Investigation (EARLI) are utilizing data from medical records, interviews, questionnaires, developmental assessments, and physical exams to explore a host of possible risk factors, focusing heavily on factors in the environment before, during, and after pregnancy. It will take a few more years for these research networks to mature fully, but already, published findings are contributing to the understanding of environmental and genetic factors that may increase the risk for autism. For example, the CHARGE study has identified a number of possible risk factors that may potentially contribute to the development of autism, including: air pollution; mitochondrial dysfunction; immune dysfunction; maternal metabolic conditions such as obesity, diabetes, and hypertension; and maternal influenza infections and fever. In addition to its findings on potential risk factors, CHARGE investigators have reported that use of prenatal vitamins may serve as a protective factor, reducing the risk of having children with autism. In another study, funded by CDC and Kaiser Permanente Northern California, researchers showed that widely-used antidepressant medications taken during pregnancy may also contribute to the risk of having children with autism. Further research on these and other potential risk and protective factors is warranted.

Services

In addition to research to develop improved diagnostic tools and interventions, and to understand the causes of autism, interventions and supports are also are available to help people with autism and their families today. HRSA is helping to pave the road from research to practice. Through funds provided by the Combating Autism Act Initiative (CAAI), HRSA has invested substantially in autism interventions to improve physical and behavioral health of people with ASD, practitioner training, and service provision models. HRSA-funded investigators are examining critical questions, such as the impact of co-occurring health conditions in autistic individuals and the effectiveness of parent-mediated and peer-mediated

behavioral interventions. HRSA's health professionals' training programs are designed to reduce barriers to screening and diagnosis by increasing professional capacity and raising awareness about ASD among providers in the community. Interdisciplinary training initiatives targeted health care providers (psychologists, pediatricians, speech language pathologists, social workers, nutritionists, nurses, physical therapists, occupational therapists, geneticists and genetic counselors, dentists, health administrators, and others), other professionals who work with children (special educators, child care providers and others), and families who have children with ASD/developmental disorders (DD).

In FY 2012, Congress appropriated approximately $47 million to HRSA for activities associated with autism and other developmental disorders. This funding supports: 43 Leadership Education in Neurodevelopmental Disabilities (LEND) interdisciplinary training programs, providing services and training to 41 States, with many extensive training and services across multiple States, further extending the reach of the LEND training programs. The funding also supported 10 Developmental-Behavioral Pediatrics (DBP) training programs; three research networks and 14 autism intervention research projects examining areas of particular interest to families and addressing the needs of underserved populations; 13 State demonstration grants; two resource centers; and a national evaluation. All activities continue to be coordinated with the CDC's activities and with priorities of the IACC.

Highlights of HRSA Investments

Reducing Barriers: Reported increases in the number of children who received diagnostic evaluations over the course of the grant period provide an early indication of progress toward the goal of reducing barriers to ASD services. Including those who received diagnostic evaluations from a CAAI-supported LEND program in grant year 2008–2009, nearly 92,000 children were evaluated over the 3-year grant period.

Interdisciplinary Training: To address the shortage of health care professionals who are qualified to provide screening and diagnostic evaluation for ASD and other DDs, the LEND and DBP programs expanded their training resources and assisted local agencies and practices in building their capacity to provide community-based ASD services. During the 2009-2010 grant year, the LEND and DBP programs collectively trained close to 2,500 medium-term trainees (40-299 hours of training) and 1,400 long-term trainees (300 or more hours of training), with increases of 13 percent and 22 percent respectively during the 2010-2011 grant year.

Intervention Research: To improve the health and well-being of children with ASD, research grantees conducted studies addressing such topics as the efficacy of ASD interventions, early identification of ASD in minority populations, family well-being and transition to adult services, and developed consensus-based guidelines to support professionals in providing treatment for children with ASD. Together, research grantees developed eight medical guidelines, one comprehensive guideline report, 14 toolkits for providers and parents to use in monitoring and managing ASD symptoms, and seven new behavioral measures for assessing a child's progress.

Public-Private Partnerships

In all of the autism research and services activities discussed, interagency coordination and public input facilitated by the IACC have played an important role. While I have described in brief some of the autism-related research and services activities undertaken by Federal agencies, it is important to recognize the critically-important role played by private organizations that fund research and provide services to the autism community, and that government, private organizations and the public need to work closely together to succeed in providing the biomedical innovations, evidence-based interventions, services, and supports needed by the autism community.

Examples of joint initiatives that are moving the field forward to enhance researchers' access to data include NIH's National Database for Autism Research (NDAR), which is federating with several other autism data repositories such as the Autism Speaks' Autism Genetic Resource Exchange (AGRE), and the public/private-funded Interactive Autism Network (IAN). In the community, programs like AGRE, IAN, and the Autism Treatment Network (ATN) that involve direct outreach to and collaboration with the patient community are bringing together hundreds of researchers and clinicians with tens of thousands of people nationwide affected by ASD, in the search for new and improved screening tools, enhanced understanding of the biology of ASD and ASD risk factors, effective interventions and services that will help people with ASD reach their fullest potential

Federal IACC member, the Administration on Intellectual and Developmental Disabilities (AIDD)/ACL, with the help of non-profit organizations, including the Arc of the United States, the Autistic Self Advocacy Network (ASAN), and the Autism Society, is supporting the AutismNOW Project, an innovative dissemination network to provide access to high-quality resources and information on community-based services and interventions for people with ASD and their families. AutismNOW offers a call center, web-based clearinghouse of resources, twice-weekly webinars on a variety of topics related to autism, and regional events for the community to connect in-person.

Conclusion

Since the passage of the Combating Autism Act, we can see how the establishment of the IACC has brought a wide variety of research, services, and education expertise to a challenging area and has served to focus efforts across the Federal government, also fostering collaboration with private efforts. This remarkable effort continues to bring Federal agency representatives, parents, people with ASD, clinicians, scientists, and others together to work as an interactive team to address this critical issue. In doing so, it has produced the IACC's Strategic Plan that is updated annually to guide and focus Federal research efforts and catalyze public private

partnerships, while also providing a forum for public discussion and identification of additional needs from the community. With the reauthorization of the Combating Autism Act, the IACC has added new members to participate in the dialogue, in an effort to broaden the outreach of the IACC and infuse it with new perspectives.

On the research front, we have seen some remarkable progress in understanding the prevalence of ASD, developing screening methods and interventions with potential to be used to identify and treat ASD in very young children, and understanding the risk factors that may contribute to the development of ASD. This research is rapidly moving toward translation into practical tools that can be used in the clinic and community settings to change outcomes for people with ASD. In this time span, Federal agencies have also coordinated efforts to enhance critical services programs, identify best practices to support the education, health, and employment needs of people on the spectrum, and develop new mechanisms and strategies to enable broad access to healthcare, services, and supports.

The Combating Autism Act established the IACC to provide advice to the Secretary of HHS regarding matters related to ASD, to create a forum where the public could be actively involved in the process, and to develop a strategy to guide national research efforts. The enactment of CARA has supported the continuation of this work. While there has been unequivocal progress, much remains to be done to take gains that have been made and turn them into the foundation for future advances that will result in improvement in quality of life for people with ASD and their families.

Again, thank you for this opportunity to provide you with testimony on this very important topic.

Chairman ISSA. Dr. Boyle.

STATEMENT OF COLEEN BOYLE

Ms. BOYLE. Good afternoon, Chairman Issa, Ranking Member Cummings, and distinguished members of the committee. Thank you for the opportunity to be here today. I am Dr. Coleen Boyle. I'm an epidemiologist and Director of the National Center of Birth Defect and Developmental Disabilities at the Centers for Disease Control and Prevention. CDC works to keep America safe from health threats of all kinds.

Our FY 2012 autism budget is about $21 million, and today I'm going to describe how we use those funds.

Autism spectrum disorder, ASD, is an important public health concern in the United States. ASD is a group of developmental disorders characterized by unusual patterns in communication, behavior, and attention. While there's no known cure, research is yielding innovative screen tools to detect ASD in early childhood and new behavioral therapies that can improve outcomes.

CDC data indicate that more children are being identified with an ASD than previous years. The toll of ASD is significant and has profound implications for affected children and their families. CDC works steadfastly to alleviate this burden by tracking ASD, promoting the early identification, and addressing the unanswered questions through the research.

CDC supports ASD surveillance or tracking in 12 States: Utah, Colorado, Arizona, Missouri, Wisconsin, North Carolina, New Jersey, Maryland, South Carolina, Arkansas, Alabama, and Georgia. Through our Autism and Developmental Disabilities, or ADDM, Network. ADDM's goal is to draw comparable, population-based prevalence estimates in different sites over time.

In March of this year, CDC released updated estimates of the prevalence of—from the ADDM Network, based on our 2008 data, indicating that 1 in 88 children had been identified with an ASD. This is greater than the prevalence of 1 in 10—1 in 110, released in 2009, based on 2006 data, and 1 in 150, released in 2007, based on 2002 data. While there's no simple explanation for the increase, we know that it is due at least in part to improved diagnosis and increased recognition.

Data from the ADDM Network provide more than just a prevalence estimate, and because of this data, we know that ASD remains nearly five times more common in boys than girls. We know that the largest increase over time are among Hispanic and African-American children and children without intellectual disability. We know that the prevalence varies widely, the identified prevalence varies widely, from 1 in 210 to 1 in 147, and that although more children are being diagnosed at earlier ages, there are far too many that are not diagnosed until it's too late to receive the full benefit of early services.

Overall it's clear that families and children need help, and our data is helping to provide that. Research tells us that the earlier a child is connected to services, the greater the benefit. CDC works to increase early identification by offering free tools and assistance to States through our "Learn the Signs. Act Early." program. We provide these tools to healthcare professionals, childcare providers,

and parents, with a focus on minority and economically disadvantaged populations.

CDC is also working with our Federal partners to provide national goals in early screening, diagnosis, and service enrollment, giving communities as well as the Federal Government a benchmark to measure progress.

To identify causes of ASD, we must first understand the risk factors. CDC's Study to Explore Early Development is the largest epidemiologic study of ASD in the country, and it involves sites in Georgia, North Carolina, Massachusetts, Iowa, California, and Pennsylvania.

CDC works to identify factors that put children at risk, including genetics, environmental, maternal health, and behavioral factors, with a special emphasis on the interaction between environment and genetic factors.

We are an active member in the Autism Coordinating Committee, and we really provide that epidemiologic and public health perspective.

CDC contributes to the development of the IACC Strategic Plan for Autism Research, and our activities are key components of that plan.

ASD is an important and an immediate public health concern. More children than ever are being identified, and families and communities are struggling with the financial burdens, the complex healthcare decisions, and the service needs. We know it is frustrating to have more questions than answers, and we share that frustration and are committed to improving our understanding of what is putting our children at risk.

CDC will continue to document the burden of ASD in States through our ADDM Network; develop resources and help States improve early identification through our "Learn the Signs. Act Early." program; and maintain our important epidemiologic focus through the SEED research network to understand why some children are more likely to develop autism.

Thank you for the opportunity to present this testimony, and I'd be happy to answer questions.

[Prepared statement of Ms. Boyle follows:]

Testimony before the Committee on Oversight and Government Reform United States House of Representatives

Autism Spectrum Disorder

Coleen A. Boyle, Ph.D.
Director, National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services

For Release upon Delivery
Thursday, November 22, 2012
Expected at 2:00 p.m.

Good afternoon Chairman Issa, Ranking Member Cummings, and distinguished members of the Committee. Thank you for the opportunity to be here today. I am Dr. Coleen Boyle, Director of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC). CDC continually works to keep America safe from health threats of all kinds. The Budget includes $21.265 million in FY 2012 for CDC's autism work. Today, I will focus my remarks on how CDC uses those funds in our autism portfolio and on CDC's role on the Interagency Autism Coordinating Committee (IACC).

Introduction

Autism Spectrum Disorder (ASD) continues to be an important public health concern in the United States and around the world. ASD is a group of developmental disorders characterized by unusual patterns in a person's communication, behavior, and interactions with others. Symptoms of ASD are usually present after a child's first birthday, but before three years of age, and can be identified by observing a child's behavior and development. While there is currently no known medication or treatment to cure ASD, intensive research efforts are yielding progress on the development of innovative screening tools that can be used to detect ASD in early childhood and behavioral therapies that can improve cognitive function and social development in children and adults with ASD.

Data from CDC indicate that more children are being identified with ASD than in previous years, though many of these children are not being identified as early as they could be. The emotional toll on families and communities is staggering, and the economic burden can be significant. Because of the long-term effects of ASD, the lack of a known cause or cure, costs, and concerns about the increasing identified prevalence, ASD have profound implications for affected children, families, educators, healthcare professionals, local and national organizations, and the Federal Government.

CDC is supporting communities by tracking ASD, helping families through early identification efforts, and addressing unanswered questions through research into the risk and protective factors associated with autism.

Supporting communities by tracking ASD

To better understand the prevalence of ASD in the United States, and to gain insights into potential causes, CDC expanded surveillance of autism and developmental disabilities in additional geographic areas of the United States. CDC now supports surveillance programs in 12 States: Utah, Colorado, Arizona, Missouri, Wisconsin, North Carolina, New Jersey, Maryland, South Carolina, Arkansas, Alabama, and Georgia. This collaborative body, known as the Autism Developmental Disabilities Monitoring (ADDM) Network, seeks to develop or improve programs that track the number of children with ASD in their States. The goal of the ADDM Network is to provide comparable, population-based estimates of the prevalence rates of autism and related disorders in different sites over time.

In March 2012, CDC released updated estimates of prevalence from the ADDM Network (the third report in a continuing series of reports) indicating that 1 in 88 children had been identified with an ASD. This number compares with an identified prevalence of 1 in 110 in 2009, estimated using data from surveillance year 2006. In 2007, we reported a rate of 1 in 150 children, based on data from 2002.

While there is no simple explanation for the increase, we know that it is due in part to improved methods for identification and diagnosis, and to increased public awareness partly resulting from the expansion of behavioral health services in local communities. However, we do not know exactly how much of the increase is due to these factors. To better understand the causes of the increase, we need to continue tracking ASD and continue working with our colleagues at NIH and in the broader scientific community to improve identification of risks and protective factors associated with autism.

Based on the methods we use for tracking autism, we know more than just how many children have ASD. For example, we know that ASD remains nearly five times more common among boys than girls. We also know that the largest increases in identified prevalence over time were among Hispanic, African-American children, and children without intellectual disability. Some of the most recent increases can be attributed to greater awareness of ASD and improved identification of children with ASD within communities. However, this explanation can only account for part of the increase over time, since more children were identified with ASD among all racial and ethnic groups and at all levels of intellectual ability.

In the 2008 reporting cycle, we also saw more variation in prevalence estimates across sites than in previous years, fluctuating anywhere from 1 in 210 to 1 in 47. We know that some of this variation is due to differences in the way children are identified and served in their communities. Our data also show that more children are being diagnosed at earlier ages, which is a positive trend because of the value of early intervention. Still, most are not diagnosed until after four years of age, when it may be too late to receive the full benefit of early intervention services. The one thing these data tell us with certainty is that more children and families need help.

Through CDC's work in tracking ASD over the past 15 years, we know more about which children are more likely to have ASD, at what age they are likely to be diagnosed, and we know whether progress has been made in early diagnosis of children with ASD. Communities need this type of information to plan for services and to understand where improvements can be made to help children and their families.

Helping families through early intervention

While we know that many individuals with ASD will need support throughout their lives, a growing body of research tells us that the earlier a child is identified with an ASD and connected to services, the greater the benefit of intervention will be to that child. And unfortunately, the data tell us that there are many children with ASD who are not being diagnosed as early as they could be. CDC is working hard to change that, offering free tools through our "Learn the Signs. Act Early." program, which aims to improve the early identification of children with ASD. We are putting these tools in the hands of healthcare professionals, childcare providers, and parents, with a special focus on minority and economically disadvantaged populations. CDC is also working with States and local communities to improve early identification. Notably, we have worked with partners from other Federal agencies to develop national goals in early screening, diagnosis, and enrollment in services for children with ASD giving communities, for the first time, a benchmark to measure progress.

Answering unanswered questions through research

CDC knows that people want answers about autism, and so do we. To identify the causes of ASD, the scientific community first needs to better understand the risk factors for ASD. CDC's surveillance data serve as a guide for our autism research and for the research of other scientists across the country. At CDC, we are conducting the Study to Explore Early Development (SEED), which is helping to identify factors that put children at risk for ASD. SEED is looking at many potential risk factors including genetic, environmental, maternal health, and behavioral factors. One key strength of SEED is that it offers an in-depth look not only into the characteristics of ASD, but also the interaction with environmental and genetic factors. We completed the first phase of this study in 2012 and recently began the second,

which we hope will ultimately help us to better understand what makes one child more or less likely to have an ASD.

CDC also conducts epidemiologic studies using national survey data on children's health. These studies include indepth assessments of differences in ASD prevalence in various demographic subgroups, family impact of having a child with an ASD, and assessment of co-occuring health conditions and health care needs in children with autism and other developmental disabilities. We have also used ADDM surveillance data and survey data to assess factors that might be contributing to the observed increases in autism prevalence.

ASD is one of a few conditions that have a Federal committee tasked with coordinating research efforts. The IACC has played a pivotal role in helping Federal agencies, non-profit organizations, and members of the public work together to identify priorities and strategies to address key issues of importance to the autism community. CDC is an active member of the IACC, providing an epidemiologic and public health perspective on ASD. As a member of the IACC, CDC seeks to engage other Federal agencies and public stakeholder groups and individuals in a complementary and cooperative fashion that is consistent with and responsive to Congressional direction and intent. CDC's work informed the development of the IACC Strategic Plan for Autism Research and CDC's autism activities are key components of this comprehensive plan to address ASD.

It has become clear that there are likely several complex causes influencing what makes one child more likely to have an ASD than another. This is a challenging and complex disorder to unravel. While we search, it is important that we not lose sight of the many individuals, families, and communities struggling with ASD today.

Conclusion

ASD is an important and immediate public health concern. More children than ever before are being identified with ASD. Families and communities are struggling with financial burdens, complex healthcare decisions, and need for services. We are bringing our collective resources to bear to understand what is putting our children at risk for autism. We at CDC will continue providing communities with essential data on the prevalence of ASD so that they can adequately plan for services to meet the needs of these children. We will continue developing resources that help identify children with ASD as early as possible so they can benefit from the early intervention services that can help them reach their full potential. And, we will continue the important research to better understand why some children are more likely to develop autism than other children.

Thank you for the opportunity to present this testimony to you today. I would be happy to answer any questions.

Chairman ISSA. Thank you both.

I'm going to recognize myself first. And I'll ask both the experts to forgive me for being very basic in a couple of questions, but I hope that it sheds a balance on this hearing.

Dr. Boyle, as far as you know—or either of you—is autism—does autism in history predate all vaccines? In other words, was there autism before there were vaccines?

Ms. BOYLE. I would turn to my colleague, my physician colleague, but I would say definitely.

Chairman ISSA. Doctor?

Dr. GUTTMACHER. Autism was first not described until 1943 by a constituent, actually, of Mr. Cummings at—Leo Kanner, who was a child psychiatrist at Johns Hopkins, who first noticed 11 individuals with similar patterns of behavior that he described and coined the term "autism" to describe.

Chairman ISSA. But were those likely or documentably things we can look back into history—and I want you to say with certainty or with likelihood, because I think it's important for all the people that are dealing with this question.

Dr. GUTTMACHER. Absolutely. I know that Dr. Kanner's view and, I think, others' is that this probably existed before, just no one had noticed the pattern. There's only descriptions of individuals from well before the immunization era who would have what we would take today to be autism-spectrum-type disorder. It's not well documented before. I think there's heavy suspicion that it existed before vaccination.

Chairman ISSA. Okay. Now I'm going to follow up with that.

Is it fair to say that today the state of science—and I think Dr. Boyle said this very well—is that autism of various types has multiple causes, in each of your opinions?

Dr. GUTTMACHER. Absolutely. And they have both a genetic/biological basis and also an environmental basis.

Chairman ISSA. So, again, I am trying to be very basic, and I apologize, but I think for all of us as we go through this, it's important to sort of build on something.

So it's fair to say that autism, like cancer or like other diseases often, is a group of afflictions, meaning that although the characteristics may be similar, in fact, there are multiple causes and, thus, likely multiple treatments and/or multiple forms of prevention.

Dr. GUTTMACHER. I think it's not only fair to say, but I think, as simple as that question may be, it's the most important question in some ways to ask, because it explains some of the challenge in trying to figure out autism, but also points the direction to do it. Until we can better understand the biological bases of these different forms of autism, it will make it difficult to understand any of them.

Chairman ISSA. I want to ask each of you one of the toughest questions, and I inherit this series of hearings, but I want to inherit them new.

Is it fair to say that we can rule nothing out in absolute terms from being a contributor?

You heard the gentleman from Ohio talk in terms of mercury coming in air form. Obviously, the former chairman spoke of the possibility of vaccines having a direct relationship.

Is it fair to say that these multiple causes that we suspect, the fact is we can rule nothing out, including—and I'm not stating as a fact, I really am stating as a question—including things we haven't yet looked at? Is that possible that there are yet more causes that will be viewed, and nothing can be ruled out?

Dr. GUTTMACHER. It's certainly true that those things we haven't looked at yet we can't rule out for sure. I think that there have been some things looked at very heavily that, while it's always difficult for science to rule anything out as a possibility for occasional individuals, I think the sort of gradations of suspicion, and there's some various kinds of possible factors have been looked at so carefully that we can rule them out as being involved in the vast majority of individuals.

Chairman ISSA. I'm going to ask one last question. And I'm really feeling like this is so far above my head that as I continue to study and work with people, I'll learn more. But one of them that wasn't mentioned in either of your opening statements, but I believe is now under suspicion, is the age of parenting. Would either of you feel comfortable talking in terms of we as a society are waiting 'til later, both on the male and female side, to have children, and science is cooperating with us. Do you believe that that is an area that needs further study?

Dr. GUTTMACHER. It does need further study. There is certainly some evidence to suggest that paternal age particularly does have some correlation with rate of autism. It's clear, though, that's not a factor. I can note many, many older fathers have children who do not have any form of autism; many younger fathers have children who do have quite frank autism. So it's—in any given situation, it's not, you know, the factor. But does—in a public health sense does it play a role? It does.

Chairman ISSA. Thank you.

And I apologize. I didn't have time to ask any questions related to what to do with people once they are afflicted. And, quite frankly, I don't think I've done enough justice to the fact that there are so many interest groups, each of which is fragmented into components, that I didn't even mention here today.

I thank the ranking member and would recognize him here for his questions.

Mr. CUMMINGS. Thank you very much, Mr. Chairman.

Just kind of following up on what the chairman just asked. You know, in talking to the folks behind you, there seems to be a frustration. I see everybody's—I wish you could see them behind you. They're shaking their heads. There is frustration with regard to coordination of efforts, with regard to, you know, research.

And I guess what I—and I—I hinted in my opening statement that I want us to try to move towards trying to make a difference. I know that's why the chairman feels, too. You know, we don't know how long we're going to be sitting on these panels and in the Congress, but we want to use our time effectively and efficiently.

And what can we do to help the folks behind you get to the coordination, the kind of things that they are looking for to have an

impact, because they are thoroughly frustrated. So, I mean, can you help me with that? Can you help us?

Dr. GUTTMACHER. I think we can also share your frustration. I think all of us are frustrated at the rate of progress in terms of really understanding autism, having interventions that make a difference. So we clearly share that frustration. Perhaps because we're involved in it, we have, obviously, a different perspective on the frustration, but we not only understand that others have it, but do share it.

I think in terms of what the Congress can do, I think some of you have already done, clearly, in terms of funding for this area, but also, I think, in terms of the role of the Interagency Autism Coordinating Committee in specifically the area you mention the frustration; that is, coordination. I think the IACC has done a very good job in its relatively few years of existence, in fact, in coordinating both work among Federal agencies, but also coordinating the Federal agencies and the advocacy organizations, individuals, and others to really try to come up with the community viewpoints about what should the priorities be within research; what should the priorities be in terms of service delivery, intervention, et cetera. So that I think that while there's always room for a better coordination, I think the coordination among agencies is much better than it was a number of years ago. And, in fact, across other areas of scientific research——

Mr. CUMMINGS. But you also said we can do better.

Dr. GUTTMACHER. I think we can do better, but I think we are doing a lot better. I would point to this as actually one of the areas in science where there is particularly good coordination at this point in time. Good enough? No. But particularly good? Yes.

Mr. CUMMINGS. Let me ask you this: Major Federal efforts to confront significant health crises have been mounted in the past. Breast cancer, Alzheimer's and AIDS have all been a focus of major efforts. How do you think the Federal effort to confront autism spectrum disorders compares to those other Federal efforts?

Dr. GUTTMACHER. Well, certainly scientifically they each present their own challenges and their own opportunities, but different kinds of challenges. One of the particular ones the chairman already referred to in terms of the diversity of conditions, they are all lumping as one here. So I think that presents its own challenges.

It also presents some particular coordination challenges as well. I think it's hard to compare, you know, one sort of disease movement versus another. They need to all, I think, be crafted with acknowledgment of the particular qualities of the disease or diseases that you're trying to approach.

Mr. CUMMINGS. Let me ask you—yes, Dr. Boyle.

Ms. BOYLE. I was going to say that, I mean, autism, like breast cancer, is a very complex, very complex issue. And although it may not seem that, we—with Federal dollars, we've made considerable investment in research and programs and tracking. So—and we're just starting to see some of the benefit from that. We're starting to see some of the research come out.

And, I mean, there really is an explosion of information, a lot more to be done, particularly on the environmental perspective. A

lot more focus has been on the genetics. And I think, you know—and that's been a discussion at the IACC level. We need to be moving more into the nongenetic-related aspects.

Mr. CUMMINGS. Let me ask you this: The Interagency Autism Coordinating Committee is the tip of the spear in the Federal efforts to strategically address autism. Is the Committee's ability to accomplish its mission hampered by the absence of adequate representation from both private and—and nonprofit—nonprofit sector? And would the Coordinating Committee be better positioned outside of NIH since treatment and services are important elements in the mission of the Committee? And then you can answer that, and I'm finished.

Dr. GUTTMACHER. The newly reauthorized Committee is larger than its predecessor, and I think that has been an advantage to the Committee. It has more membership. I think like any committee it struggles with if you were to craft what's the perfect membership of the Committee. You struggle with wanting to clearly be inclusive, at the same time making the Committee effective in terms of size, et cetera.

I think that the Committee tries to make sure about the inclusion by, in fact, inviting public comment at its meetings, having town halls, other kinds of things, so that even those not represented directly on the Committee have a voice in the room.

Mr. CUMMINGS. Thank you.

Chairman ISSA. Dr. Boyle, do you have anything?

Ms. BOYLE. No. I would agree with that, sir.

Chairman ISSA. I thank the gentleman.

I now ask unanimous consent that the distinguished gentleman from Virginia Mr. Moran be allowed to sit in this hearing. Without objection, so ordered.

I now would also ask unanimous consent that Mr. Burton has waived 2 minutes of his 5 minutes so that he can show a video before he begins. So if the video could be shown, and then the gentleman will have 3 minutes afterwards.

Mr. BURTON. Thank you, Mr. Chairman.

Let me preface my remarks by saying I know there's many causes of autism, but the one we're talking about today, as far as I'm concerned, is the mercury in vaccinations and in the environment. And the University of Calgary in Canada has done this research, and I want everybody in the room, but particularly my colleagues, to see what the research shows.

[Video shown.]

Chairman ISSA. Gentleman may continue.

Mr. BURTON. Thank you very much, Mr. Chairman.

You know, there's an old saying: One picture is worth a thousand words.

I have read I don't know how many studies on this whole issue, and I think I've had some of you doctors before. I think, Dr. Boyle, you've been before our committee before, when I was chairman. And I have great respect for you and for the FDA and HHS. I think you do a great job. But sometimes I think maybe outside influences have too great an impact on the scientific research that's necessary to find cures for major problems.

Now, we've gone from 1 in 10,000 children known to be autistic to 1 in 88. It is worse than an epidemic; it is an absolute disaster. And how anybody can look at that study and see the actual brain cells deteriorating when put next to a very small, minute amount of mercury, it mystifies me. How can anybody at the CDC and the FDA watch something like that and say that the mercury does not have an impact on neurological problems?

Now, granted, it may be from other things besides vaccinations, but vaccinations that contain mercury should not under any circumstances be injected into any human being, especially children, who have a very fragile immune system. And children get as many as 28 or 30 shots before they go to the first grade. My grandson got nine shots in 1 day, and it turned him into a horrible situation that we found banging his head against the wall, couldn't go to the bathroom, all kinds of things. These people will tell you all about that.

So all I would—I would pray to you, beg you to go back to FDA and HHS and say, come on, let's get with it. There may be other causes, but let's get mercury out of all vaccinations, which is a contributing factor. If you do that, and you can go to single-shot vials, it costs, what, a penny, 2 cents apiece, it won't hurt anything.

And I don't mind if the pharmaceutical companies get legislation passed here that protects them from class-action lawsuits as long as they help the Vaccine Injury Compensation Fund and get mercury out of these vaccinations.

Please. I'm leaving. I'm not going to be here anymore. You won't have to watch me up here anymore. But please go back and work on it, will you?

Thank you.

Chairman ISSA. I thank the gentleman.

And now recognize the gentlelady from the District of Columbia, Ms. Norton.

Ms. NORTON. Thank you, Mr. Chairman.

Actually, I would have liked to have heard the response, given how— but I don't want to take from my time.

Chairman ISSA. I apologize. The gentlelady is right.

Did either of you have a response? I realize there was not an embedded question necessarily there. But if either of you want to make a comment on the video if you are familiar with it. It will be a part of the record. You could do it afterwards. But if you had a comment now, we would certainly welcome it.

Ms. BOYLE. Well, I would be happy to make a comment about the vaccines themselves. So, since 2001, thimerosal has been removed from all vaccines given to children, with the exception of a——

Chairman ISSA. Please. We said that the record will remain open for all comments, including ones you may want to make as a result of this, so you will have an opportunity to voice yourself completely.

Please, Dr. Boyle.

Ms. BOYLE. As I say, with the exception of the multi-vial flu vaccine.

Chairman ISSA. Thank you.

The gentlelady may begin.

Ms. NORTON. Thank you, Mr. Chairman.

I have a couple of questions that really have to do with just who we are talking about.

It would probably be the case that many, many of these children who may have some features of autism were not recognized early. And you indicated how difficult it is to backtrack and do something about it. So I assume that there are millions of people walking around or not.

Now, where we do recognize what is seen as a disability, the IDEA says there must be services provided in school and the rest now. So a child might be able to get, I don't know, all matter of services, services relating to speech and to movement, very primary services. Then this person graduates out of school, where there is no IDEA. What does—so I have to assume that there must be parents and relatives with such children who are not recognized, got whom nothing was done. What are we doing about these young people or older who have not had any services? Do they have anything like IDEA available to them, any services that they automatically qualify for? If not, what do we do with them.

Ms. BOYLE. I think that is a real challenge. This topic about understanding transition from childhood to adult and sort of the services associated, the benefits, the impact of autism across the lifespan is really important.

Ms. NORTON. But my question goes to what do we do to the child who is no longer a child, 18 or 19, the mother and father have done all they could? This is an adult children; these may be aging parents. What does that young person do?

Dr. Guttmacher.

Dr. GUTTMACHER. I think, Congresswoman, it is clearly a real challenge for our society. And as you well know, your historic interest and support for the Down Syndrome Caucus, many of the issues you are bringing up here as applied to autism are extremely similar, if not identical, to those for children who have become adults with any kind of disability.

Ms. NORTON. Except that we can recognize Down syndrome.

Dr. GUTTMACHER. Exactly. So that is clearly an advantage of having been diagnosed earlier in life and getting services.

Ms. NORTON. What are we doing with these young people, Doctor?

Dr. GUTTMACHER. Well, the first thing we are trying to do is to diagnose more effectively early on.

Ms. NORTON. No, I want to know today. You have such a person; they weren't diagnosed effectively, who is 21 years old. What do I as a parent do with this young person?

Dr. GUTTMACHER. Well, the first question is even if it is recognized at the age of 21, often individuals who we would now describe as being on the ASD spectrum or simply seeing their families having particular character traits or whatever and are never, quote-unquote, diagnosed, I think the question for any of these, for parents of young adults and for the young adults themselves, is trying to find the best fit in society in terms of employment, et cetera.

Ms. NORTON. Thank you, Doctor. I have one more question and my time is running out. In other words, there is nothing that we are doing to them. It looks like we don't have any mandated serv-

ices for them and that it falls—that the Affordable Health Care Act may help to provide some medical services. But this is tragic if we have not found—not a bridge but a way to accommodate an adult who may still become a functioning member in some way in society.

But this is the question, before my time runs out. I have often noticed that parents of highly educated people come forward and speak up for Down syndrome, middle-class parents. Why is that? Is there a difference in who recognizes? Is there a difference in who gets it, an ethnic difference, a class difference in who gets or recognizes this disease or this condition, or is it an across-the-board condition.

Dr. GUTTMACHER. It is an across-the-board condition. There clearly are issues, again, because it is not always diagnosed. Those that have greater access to higher quality medical care, since it is usually a medical diagnosis that is made, tend to have the diagnosis made more frequently. So those who, for various reasons, of barriers to access are less likely to have the diagnosis.

Ms. NORTON. What is the minimum age that we should be looking to, if we have a child, to see whether autism is perhaps there?

Dr. GUTTMACHER. As I mentioned in my testimony, there is now a checklist approach that is being used right around 1 year of age in the hope to make the diagnosis at that point. And we hope eventually even younger. The younger we can make it, the better.

Ms. NORTON. Thank you, Mr. Chairman.

Chairman ISSA. Thank you.

Dr. Boyle, I think you had an additional statement.

Ms. BOYLE. Well, a couple points on that last one. So we do have tools to help parents identify children as early as possible. Those are free. They are on our Web site. And the most important thing that parents——

Ms. NORTON. They know it. The mother knows it; the father knows it. It is, what is available?

Ms. BOYLE. We have information about what to do with it, how to have a conversation with your physician, so really guiding parents with that.

Ms. NORTON. Thank you, Mr. Chairman.

In other words, it is up to the family to try to figure it out.

Chairman ISSA. I thank the gentlelady.

And thank God that there are families who care so much, and that is always a big part of it.

With that, we go to our first doctor on the panel, Dr. Gosar, for 5 minutes.

Mr. GOSAR. Thank you, Mr. Chairman. First of all, I would like to acknowledge my colleague, Mr. Burton, for making this instrumental and representing so many people out there.

One of the things I wanted to ask, Dr. Boyle, in your testimony, is I didn't hear a prevalence about diet.

Ms. BOYLE. Excuse me?

Mr. GOSAR. I didn't hear a pertinent aspect of focusing on diet.

Ms. BOYLE. Diet. So we do, within the context of our epidemiologic study, we do a ask about information about diet.

Mr. GOSAR. It seems to me in the coordination—and I see the frustration. I was a practicing dentist for 25 years. I am also celiac sprue, by the way, so I can understand their frustration. It is mor-

tifying. When you try to go for studies, I mean, the coordination of studies is inherently poor, absolutely horrible, I mean, even as recently as last year.

But we have people that are so motivated in these families. You know, when I would give post-ops to families, you would get about twice the support. With autistic families, they are begging for more support. I mean, you are getting tenfold heuristic type of aptitude in findings. And I am finding more from them than I am from the medical research. And it seems to me we are focusing something wrong here.

We should be focusing on the family. They are telling you what is going on. And they are frustrated because the research is cylindrical. They are not sharing; they are not coordinating at all. And they are telling you what is going on and what is wrong. And we should be focusing on the family and utilizing that as a coordinating factor.

Now, I want to get back to diets. You know I have got family history with this and the genetic factoring. You know, we got to spend more time looking at the genetics, because there is a trigger mechanism. And celiac sprue is one of those. Looking at casein as well. There are so many things. You cannot point to me to a disease factor, point to one of them, I dare you, and we will find a dietary problem with it. I mean, diabetes, heart disease, I mean, thyroid conditions, you name them, MS, you are going to find a dietary aspect.

So part of the problem we ought to be focusing on is the dietary aspects. In aspects—to my colleague from D.C., is we ought to be looking at, how do we help parents in a dietary format? This is what my experience was. I spent every night after my practice closed going through aisles in a grocery store looking at everything on the aisle to make sure it didn't have a gluten or wheat. Do you know how long that took? It is unbelievable what these people have to do, absolutely unbelievable. And we got researchers who don't listen to them. To me this is just absolutely incredible. And I think it is a slap in the face for these people to be looking at those aspects.

And here is how effluent it was: One of my siblings has a son they said was autistic. Thank God one of my sisters is a physician. In going through this tirade, we found out that she had celiac sprue. And she wondered, I wonder if this is the problem for her son. Isn't it interesting, we had a kid who was diagnosed or labeled as autistic, that as soon as we took him off of wheat, gluten, and milk products, this kid sits, reads, does everything appropriately. And I think we can manage this practice a little differently.

Sometimes we are in the forest, and we don't even understand what we are looking in the trees, is manage these disease processes by family, by looking at that as our core group, and then start listening to people, asking a question. That is what we as physicians were taught to do, is ask questions and listen. And I think that is part of the biggest problem that we see in this research aspect, is we are not listening.

And I think I see that frustration all over your face. I mean, Holy Cow, the genetic aspect. Just to give you an example, you know, we were scheduled to be part of a genetic study for celiac sprue,

which is inherently a big process to autism. There are 10 kids in my family. Out of the all the grandkids, out of the 17 grandkids, 13 have celiac sprue. You would think you would use our family, you would think. Boy, sad excuse we didn't. So we are missing the boat here, and we need to have better coordination, much better than what I am seeing here currently, so thank you.

Chairman ISSA. The gentlewoman yields back.

Now, I appreciate that this is a hearing that many have waited a long time for and that it is popular, but I would ask please that we neither have the positive nor the negative from here forward if possible.

And with that, we go to the gentleman from Ohio, Mr. Kucinich, for 5 minutes.

Mr. KUCINICH. Thank you very much, Mr. Chairman.

In preparing for this hearing, I was looking at some interesting studies and some information to follow up on questions of the relationship between autism and environmental mercury, namely mercury that is airborne as a result of the combustion of coal.

The United Nations environment program, in a piece called "Mercury Control from Coal Combustion," says the burning of coal is the single largest anthropogenic source of mercury air emissions, having more than tripled since 1970. Coal burning for power generation is increasing alongside economic growth. The releases from power plants and industrial boilers represent today roughly a quarter of the mercury releases to the atmosphere. This is from a report called "Mercury Control from Coal Combustion."

There was a report, actually a study, that was done by the University of Texas Health Science Center that showed what is called a statistically significant link between pounds of industrial release of mercury and increased autism rates. The study pointed out that community autism prevalence was reduced by 1 to 2 percent with each 10 miles of distance from the pollution source.

Now, the background of this study was that during the time period studied by the Texas team, they quoted the USCPA estimating environmental mercury releases at 158 million tons annually nationwide in the late 1990s. I am waiting for more updated figures, but it is probably even greater than that.

Dr. Guttmacher and Dr. Boyle, when will—first of all, Dr. Guttmacher, are you aware of any studies other than this Texas study that has created a link between neurotoxic chemicals and the environment and increased rates of autism?

Dr. GUTTMACHER. I am certainly aware of other studies.

Look, for instance, the one I mentioned earlier that was just published in the last week looking, for instance, at auto emissions and proximate auto emissions in pregnancy and early in life as a factor in terms of a causal relationship, who knows, but clearly an association between that exposure and autism rates.

Mr. KUCINICH. But they have probably gone down since you have had catalytic converters.

Dr. GUTTMACHER. Presumably.

Mr. KUCINICH. I am speaking of coal-burning power plants, which are being used and have been used in great frequency over the last couple of decades. Now, are you aware——

Dr. GUTTMACHER. I certainly do not know all of the studies in the autism literature. I would be happy to look into that and provide additional information for the record.

Mr. KUCINICH. Dr. Boyle.

Ms. BOYLE. Other than the one from Texas that you are referring to from a couple years ago, I am not sure if there is another ecologic study like that. There have been a number of environmental studies that are at the individual level but not at the sort of population ecologic level.

Mr. KUCINICH. Well, it seems to me that if not in this Congress, the next Congress, that it would be timely given the fact that this issue is out there and the amount of coal that has been burned in the last couple of decades, that a study be funded, that we actually look at it and determine whether or not the University of Texas study is confirmed or disconfirmed.

The points of this study talk about, of course, exposure, neurodevelopment, the pace of neurodevelopment, vulnerability with respect to age and also developmental vulnerabilities that begin with pregnant mothers. Of course, genetic susceptibility, as you pointed out—you know, Dr. Gosar pointed out—that is always a factor. But now we know that the amount of emissions may be a factor. That is one of the things that is posited by this University of Texas study.

So, Mr. Chairman, as we move forward with this, because there is inevitably an amount of work that has to be done here that goes way beyond the politics and goes to pure science or to science, that I think it would be helpful for us to, for the Congress to back a study that would determine once and for all whether the degree to which autism is linked to mercury-releasing sources, specifically the burning of coal and with respect to the University of Texas study, the amount of emissions and the proximity of those emissions.

And I just want to say in conclusion that all these families who are here, you have Members of Congress on both sides of the aisle who are dedicated to trying to find out what is going on here and to try to do it in the interest of your family and future generations as well, so thank you for your presence here.

Chairman ISSA. And thank you, Mr. Kucinich.

We now go to the gentleman from Pennsylvania, Mr. Meehan.

Mr. MEEHAN. Thank you, Mr. Chairman.

And I would like to thank Drs. Boyle and Guttmacher for being here today.

Let me just start my commentary by saying that as a first-term congressman we are often impacted by issues that are brought to our attention by the constituents we serve. I can tell you that I don't know of another issue that has affected more of my constituents that have demonstrated a greater degree of frustration than this particular issue. And so it is new to me, and I am listening to your testimony. But let me ask a question. I know that we saw you studied this in 2007. We saw 1 in 150 children so diagnosed. And then, in 2009, 1 in 110. And now we have diagnosed 1 in 88. So just in a short period of time—and 1 in 54 boys—have you ever seen anything in which there has been such a dramatic progression

in the incidence of diagnosis in a 6-year period in your experience with the CDC?

Ms. BOYLE. Well, most of my experience actually has been within the context of developmental disabilities. And we do look at trends and other developmental disabilities.

Mr. MEEHAN. Has anything had a trend with this kind of accelerating pace?

Ms. BOYLE. Actually, there is a paper published a couple months ago looking at trends of all developmental disabilities, and the only one that showed an increase was attention deficit hyperactivity disorder.

Mr. MEEHAN. I am talking, at the CDC, we deal with a broad variety of health crises at certain points in time. Has anything accelerated in your experience to this degree in a 6-year period?

Ms. BOYLE. Well, again, relative to my area of expertise.

Mr. MEEHAN. How about in general? You are in the CDC. What do you know about in general?

Ms. BOYLE. Right. Well, again, thinking specifically about what is going on with autism, we have been looking at trends over time. And as you point out there has been an increase. We do know that some of that increase is due to how children are identified and diagnosed in the community so there have been changes over time that contribute in part. Our system monitors the number of children. We don't have all of the information about what is happening in the context that influences how children are identified.

Mr. MEEHAN. I guess what I am saying is, and these are your words not mine, as we have seen this remarkable acceleration just in the diagnoses, and in your words, it was, this is a public health concern. Would you explain to me why this is not a public health crisis, why this isn't an issue that is on the front burner of the CDC every day?

Ms. BOYLE. This is a very important issue to the CDC, and we are using the strengths of CDC to approach this issue. We are monitoring—what CDC does in its excellence is basically tracking and monitoring epidemiologic research and prevention.

Mr. MEEHAN. Dr. Boyle, thank you.

Because I know what you are saying is you are supporting.

Dr. Guttmacher, the facts are clear; this has been accelerating at a remarkable pace, at least in terms of the diagnoses. What is being done to have a genuine comprehensive plan in which we are looking for accountability year to year on the progress that is being made in terms of what we are doing to better understand this issue.

Dr. GUTTMACHER. That is a very important question, Congressman. I think part of it again goes back to the IACC having been created and asking for it to every year come up with an updated plan. I can tell you based, I haven't checked my emails in the last couple of hours, obviously, but based upon simply the flurry of activity over the last few days alone, there really is work among——

Mr. MEEHAN. Flurry because of our hearing.

Dr. GUTTMACHER. No, no, no. Because it is that time of year where we are aware that the year is coming to a close and really trying to put together this year's plan in a very thoughtful way.

Mr. MEEHAN. Who is in charge of this? Who wakes up in the morning and says, this is my priority, I am going to drive this train and make sure something happens today? Who is in charge of it?

Dr. GUTTMACHER. I would say there are a number of people that are doing it. The head of the IACC is Dr. Thomas Insel, who is the director of the National Institute of Mental Health at NIH. But there are multiple. And again, I think it shows. You asked about how important is this to CDC. It is very important. I know how it is important. I can tell you to NIH, it is extremely important to NIH, and that is why, in fact, there are a number of institutes at the NIH that include autism as part of their research portfolio.

Mr. MEEHAN. What does it take for us to develop a comprehensive national strategy with real accountability and timelines?

Dr. GUTTMACHER. I would say that, again, the IACC in many ways accomplishes that. If you think that that is lacking, then I would think it is a question really for the Congress to figure out how best to put that together. Because, clearly, as I think the hearing appropriately reflects, there are a lot of medical issues here. But there are a lot of issues about the lives of those who have autism that have nothing to do directly with medicine per se.

Mr. MEEHAN. I get that. But where is the dynamism in which that emerging evidence is being challenged and being used in a dynamic concept to hurry to a discovery, at least an advance in this, as opposed to what may be just sort of a, I hate to say it, and there are so many different aspects, but as an outside observer, I see it as being sort of willy-nilly, and this is the next thing that gets funded today, and somebody tomorrow, as opposed to a real focus on a critical path.

Dr. GUTTMACHER. Again, I think that there are multiple parties involved in this who are really quite concerned about this, who work in a regular way to try to advance this. Frustration absolutely is there, absolutely understandable. But as Dr. Boyle said, I think in fact in recent years, we have seen clearly acceleration in progress in this. Is it sufficient? No. Is it accelerating? Yes.

Mr. MEEHAN. We have seen it accelerated in diagnoses, so we need to have the same intensity I believe.

Mr. KELLY. [presiding.] Your time is expired.

Mr. MEEHAN. Thank you, Mr. Chairman.

I yield back.

Mr. KELLY. The chair at this time would ask unanimous consent that our colleague from Florida, Congressman Vern Buchanan, be allowed to participate in today's hearing.

Without objection, so ordered. Glad to have you aboard, Congressman.

Now, my friend from Massachusetts, Mr. Tierney.

Mr. TIERNEY. Thank you, Mr. Chairman.

I appreciate that. Thank you for our witnesses and all of the folks that are taking the time to be here today as well. I did want to start by just addressing a concern that my colleague Ms. Norton had with what can we possibly do for those children that are aging out, so to speak, of the services on that. We did have a Higher Education Opportunity Act a couple of years ago, a provision that was carried in the House, and Senator Kennedy carried it in the Senate, for colleges and community colleges to address programs in

sustainability for at least those on the spectrum that were able to be addressed and be helped by that. Unfortunately, in the next iteration of the budget, it didn't get funded again. But I think we can all put some attention on that and deal with some families at least on that, helping people have that ability. And I would look for others on this subcommittee that might feel that that is worthwhile pursuing on that, and we can do that again and perfect it a little better please.

Dr. Boyle,you mentioned in answer to Mr. Burton's question that since 2000, that thimerosal was removed from all of the vaccines except the multi-vial for vaccines on that basis. Can you answer me why just as a matter of precaution to eliminate that whole issue, it isn't removed from them as well?

Ms. BOYLE. I should have said since 2001. And I am not a vaccine expert, but my understanding, and I will clarify for the record about this, is that the multi-use vials are used—are needed in certain context from an international or a global perspective, but I will clarify that for you.

Mr. TIERNEY. If you would, just because why is it a necessity that they are used everything, and it could be diminished in some way and substituted with others, and anything on that basis I think would be helpful on that.

Also, to either or both of you on that, is there a differentiation between incidence of diagnosed autism in other countries opposed to the United States? Is it region specific, or are there other concerns like that, or is it generally the same pervasiveness throughout?

Ms. BOYLE. So in most developed countries that do have data on autism, the prevalence has been comparable, about 1 percent. There was a recent study that was supported by Autism Speaks in South Korea that showed a much higher prevalence, a 2.6, or 1 in 38, for a prevalence. That was done very differently. It was a community screening program or a study versus a different method that we use here in the U.S.

I do want to mention one thing though within the context of our monitoring network here in the U.S. The prevalence varies considerably, so there are some States that have comparable prevalence rates to that South Korea study.

Mr. TIERNEY. So what are we doing to try to determine? If there are higher rates in some States or some parts of some States than others, are there a good number of studies going on to find out what is different about the environment in those areas than others, and how is that all being determined and coming out? What are the outcomes of those studies?

Ms. BOYLE. So a monitoring network continues to track the prevalence. We are trying to identify children at a younger age so we have a component to identify children at age 4. We are doing studies to try to understand what is impacting that prevalence rate, both from a community perspective, understanding how children are identified and diagnosed in the community, as well as changes in risk factors and modeling how those changes in risk factors over time might have influenced the rate.

Mr. TIERNEY. So my colleague was talking about diet and other family incidences like that. Is there part of this monitoring that en-

tails going into an area with a very high incidence of autism diagnosis and actually interviewing those families to find out what might be distinctive about their experiences or their history?

Ms. BOYLE. That is a great question. And actually, we a have a second research program, as well as many activities that are ongoing at the National Institutes of Health. So we have a research component in 6 States in the United States to do just that; to interview families, to get more detailed information from medical records, to compare families of children who have autism versus those who don't and get a better sense of what is different.

Mr. TIERNEY. In what stage are those studies? How far have they progressed?

Ms. BOYLE. So that is called the Study to Explore Early Development. We have just completed the first phase, so we have 2,700 families that have enrolled in that study. We have started a second phase, so we are now in the analytic phase of that and really hope to be having data come out in the next year.

Mr. TIERNEY. And other than a geographic way of identifying those people, are you doing something also with minority and low-income groups to determine why the prevalence is higher there, interviewing subsets of those groups?

Ms. BOYLE. So we are incorporating—so our studies try to get everyone in the population, and to get everyone in the population is always challenging. But that is what epidemiology is all about; it is to be representative of the population so you don't have a bias there. So yes.

Mr. TIERNEY. Thank you.

Mr. KELLY. The gentleman yields back. I now recognize myself for 5 minutes.

Dr. Guttmacher, you are the only pediatrician here today. In one of my other roles in life right now, besides serving in Congress, I am also a grandfather for seven children, two little girls, one 5-weeks old today and one will be 4-weeks old on Sunday. So are you saying that somehow there is a window of the first year that parents should be looking at different behavioral activities in these children to maybe get an earlier idea that the child may be affected?

Dr. GUTTMACHER. Absolutely. We do think the first year and potentially before that is crucial. It is interesting, for instance, that the NIH and others supported a study that was done in San Diego, which involved local pediatricians doing a survey of their patients, a quick office-based 5-minute kind of questionnaire to try to diagnose children with autism about 1 year of age to see whether this could be done. Not only did that study show that it could be effective, it was so convincing to the pediatricians that when the study was over and therefore funding was over, all of the pediatricians in the study elected to continue to do that in their practices because they were so convinced that this was important for their patients.

So I think, absolutely, more and more, we want to make a diagnosis early because then we can get interventions and services to kids and their families in a way that we can make a difference, and the earlier we start them, the better the impact.

Mr. KELLY. Dr. Boyle.

Ms. BOYLE. This is key, since we don't know how to prevent autism and we do know there are great benefits from early identification, we want to identify children as early as possible. And CDC has a campaign. It is called Learn the Signs, Act Early. And it is really targeting parents and health care providers. And it has tools to really help parents as early as 3 months, 1 month, to understand what the appropriate developmental milestones are so your daughter, your daughter-in-law really can take advantage of those materials.

Mr. KELLY. Well, my wife and I spend a lot of time with them so it would really be important, also.

Ms. BOYLE. Yes.

Mr. KELLY. I am always holding them and doing something with them. And the older ones I am reading to, I should be looking for things that I would never have been aware of before. Now, I do represent an area that has impoverished rural areas. And I am sure a lot of the members feel the same way because we don't all represent just one group of people but a lot of people. So how are the people in the impoverished areas, how do they get accesses? How do we get to them? How do we give them the opportunity to find out what they need to know also? Is there a method? I keep hearing people, well, they can go online. Well, you know, the area that I represent, there is not a lot of people that can go online to do this.

Ms. BOYLE. One thing I think neither Dr. Guttmacher nor I brought up today is we represent two agencies within the context of HHS. And there are others that are represented in the Interagency Autism Coordinating Committee whose voices you need to hear about, too. So the Health Services Resources Administration focuses on training physicians in rural areas to really try to target. And then our colleagues in the Administration on Developmental Disabilities also do work here. And the Department of Education. So there is a lot of work here, and you are just hearing really from the two of us. And the IACC is really trying—I know it has its challenges—but it is really trying to bring together all of those voices in the Federal Government in a coordinated way so that we can really help everyone really be the group that reaches out to all.

Mr. KELLY. Doctor, do you have any follow up to that?

Dr. GUTTMACHER. I would just say that there are various regional approaches. Before I came to the NIH a number of years ago, I was the only medical geneticist in the State of Vermont, rural area, and saw numerous families and kids with autism. And that was part of a regional network that tried to approach the questions. The particular challenges of providing both good diagnosis and good care to kids in rural areas, it is a difficult challenge, as it is in any area that has barriers to access, be it rural or urban. There are various kinds of government programs that try to do that.

Mr. KELLY. And I thank you. Dr. Boyle, anything in the horizon at all, anything you see coming that could be a cure?

Ms. BOYLE. Again, we have been focusing on understanding the preventible causes versus the cure part.

Mr. KELLY. Well, I want to take this opportunity. Mr. Burton and I share an awful lot of passion for a lot of different things, but we are both grandparents. I have often said that if we could ever ex-

change and take the place of whatever it is of our children or our grandchildren, we would gladly do so. So I thank you. And he has departed again, but what a great effort. And I think Mr. Meehan hit the nail on the head. We will continue to pursue this as long as we can. You deserve an answer, and we will keep working towards that means. Okay. Right now—Mr. Lynch is not here. Mr. Quigley.

Mr. Davis, you are recognized, sir, for 5 minutes.

Mr. DAVIS. Thank you very much, Mr. Chairman.

Although estimates vary, research on the prevalence of autism spectrum disorders suggests that black and white children are impacted at comparable relates with lower incidences observed among Latino children. Is there consensus on this data?

Ms. BOYLE. You are correct. So our most recent data shows that the prevalence among African American children and white children is fairly comparable, and the Hispanic—Latinos is lower.

Mr. DAVIS. Is it possible that lower rates among Latino children reflect a lack of awareness within the community, and that might be the reason?

Ms. BOYLE. That could be the case. In the program I was talking about earlier, which was Learn the Signs, Act Early, we are actually trying to target Latino Hispanic populations working with our State colleagues. We have all of our materials translated into Spanish specifically to try to do that. So we are, within the context of the work we are doing, really trying to impact that.

Mr. DAVIS. Dr. Guttmacher, are you in agreement?

Dr. GUTTMACHER. I am in agreement and would bow to Dr. Boyle and the CDC for their expertise in this.

Mr. DAVIS. It has been suggested that children can be diagnosed as early as 14-months old, giving those children and their families the benefit of early intervention and treatment. However, children of color are routinely diagnosed at a later age than their white counterparts. What barriers exist to early diagnosis of all children, and are there any socioeconomic barriers that prevent parents or physicians from recognizing the early signs of autism among children of color?

Dr. GUTTMACHER. I think there are issues of access to quality care. Having access to longitudinal care, for instance, the pediatrician or family physician who sees the child. The same provider who has seen the same child over time can more easily pick up lack of appropriate developmental progress, et cetera, than a physician who is or other health care provider who has seen the child only for episodic care. So I think some of the questions of access, et cetera, no question. For a diagnosis that is principally made in the medical context, there are issues of access here.

Mr. DAVIS. So if a family did not have say primary care physicians for both themselves and their children, then it is possible that there might be a later diagnosis than if they had this ongoing care all along?

Dr. GUTTMACHER. I think it is possible. It creates—you know, this is—there are, obviously, many challenges to making this diagnosis earlier would have happened long ago. And this adds I think to the challenges for both the family and for the health care providers in doing that.

Mr. DAVIS. Let me ask this question. Once diagnosed individuals with autism spectrum disorders have average medical expenditures between four and six times greater than the rest of the population. The Harvard School of Public Health has estimated that it can cost $3.2 million to care for an individual with autism over the course of a lifetime. Although insurance covers some of these costs, intensive behavior therapies often paid out of pocket can cost as much as $60,000 per year. For families of average or limited means, that means that limited access will also occur to treatment. What level of access do low-income children have to behavior or therapeutic interventions before they reach school age?

Dr. GUTTMACHER. That varies by locale certainly to some degree in terms of what provisions are based in the community and their level of availability. No question that for any family, even a family of great means, the challenges of appropriately caring for a child with autism are financial challenges along with the other challenges they represent. For those of lesser means, clearly, the financial impact can be even relatively greater.

Mr. DAVIS. Are we making any real progress with that issue?

Dr. GUTTMACHER. I think we are making progress. Again, it is frustratingly slow. But we are making progress in terms of coming up with more interventions that make a difference. And ideally one wants to have an array of options for interventions because different interventions will be more successful for one individual from one family than another. But also that access to them will vary, so that it is one of the reasons for not saying, gee, we are happy we have interventions, but say, instead, well, we made progress in interventions, but we clearly need to develop more.

Mr. DAVIS. Thank you very much.

I yield back, Mr. Chairman.

Mr. KELLY. I thank the gentleman.

The gentleman from Florida, Mr. Posey.

Mr. POSEY. Thank you very much, Mr. Chairman.

Dr. Boyle, my predecessor, Congressman Weldon was a well respected competent medical doctor and a great deal of esoteric expertise on this subject that I will probably never have. But I glean from him some certainty that he felt thimerosal in vaccines definitely was a contributing factor to autism. And I read not very long ago an article that it said, until the wonderful people like us introduced vaccinations to Africa, the African children basically were autism-free. They never heard of autism, never had a case. Are you familiar with that? Did you ever hear that before?

I wonder if the CDC has conducted or facilitated a study comparing vaccinated children with unvaccinated children yet? Have you done that?

Ms. BOYLE. We have actually done a number of studies looking at the relationship between thimerosal vaccines and autism and other developmental disabilities. There have been—since actually over the last decade, there have been numerous studies looking at the relationship between vaccines and aspects.

Mr. POSEY. That the CDC conducted?

Ms. BOYLE. Some of them were conducted by the CDC; others were conducted by——

Mr. POSEY. How many would you say, would you estimate?

Ms. BOYLE. I would actually have to check with the specific numbers, but I know there were two. One large study looking at various neurodevelopmental disorders and the second one that focused specifically on autism. And those are fairly recent studies.

Mr. POSEY. Would you see that my office gets a copy of those please?

Ms. BOYLE. Of course.

Mr. POSEY. Do you believe an additional study will provide useful data in assessing the safety of childhood vaccines?

Ms. BOYLE. The IOM has evaluated this issue back in 2004 and again most recently in 2011. And you know, their conclusion, again, it is not just looking at the work that was done at CDC but with a total body of evidence, was suggesting that vaccines and their components did not increase the risk for autism.

Mr. POSEY. My time is very limited here. So, clearly, definitely, unequivocally you have studied vaccinated versus unvaccinated?

Ms. BOYLE. We have not studied vaccinated versus unvaccinated.

Mr. POSEY. Okay. Never mind, so just stop there. That was the meaning of my question. You wasted 2 minutes of my time.

What steps has the CDC undertaken to ensure the integrity of the research that was performed by Dr. Thorson, who, as you know, has been indicted for misconduct and misallocation of resources?

Ms. BOYLE. So Dr. Thorson, who was a co-investigator on a couple of studies that came out on autism, was really just one investigator. And that body of evidence related to vaccines and autism.

Mr. POSEY. Have you gone back to validate the variety of studies he participated in? I mean, you know this guy is a humongous scumbag, one of the most wanted men on earth, and you relied upon him for data to determine whether thimerosal had a negative effect.

Ms. BOYLE. So two studies don't conclude a body of work. The body of work that is relating vaccines to autism is a large collection of studies.

Mr. POSEY. You told me you only had two studies related to vaccines, vaccinated and unvaccinated, so you must figure two studies must have some weight. I am running out of time quickly here. You mentioned that you only have thimerosal in multi-vial. Why is that?

Ms. BOYLE. I was actually going to get that information for the committee.

Mr. POSEY. Okay. Because I would think if they only have it in multi-vial, if they eliminated having it in all the other vials, there was a reason.

Ms. BOYLE. There is definitely a reason, so I was going to clarify that. There are single-dose vials and multi-dose vials.

Mr. POSEY. And they took it all out of everything but the multi-dose vials?

Ms. BOYLE. That is correct.

Mr. POSEY. How many multi-dose vials are there?

Ms. BOYLE. I can provide you that information.

Mr. POSEY. I have seen a chart that ranks the longevity of the 30 nations with the best mortality rates in the world, starting with Iceland, Sweden, Singapore and on down. We didn't even make the

top 30. We are the 34th. And ironically, we require more vaccinations than any other country that is healthier and has a less mortality rate than us. Do you see any correlation whatsoever, either one of you, to the 34th worst mortality rate and the most vaccinations to the ones with the least required vaccinations and the lowest mortality rate? They also have children that, you know, passed age 20 in those countries, too.

Dr. GUTTMACHER. There are many factors, obviously, involved in longevity for any country. The one thing we do know about vaccinations is that they are among the major public health reasons why generations today live much longer than previous generations. They are perhaps the most successful public health movement in the world.

Mr. POSEY. Nobody is talking about we are against vaccinations. We are talking about thimerosal in vaccinations and multiple, you know, bomb blast of vaccines in a short period of time on very—thank you, Mr. Chairman. My time is up.

Mr. KELLY. I am sorry, the gentleman's time is expired.

Did you want to answer.

Dr. GUTTMACHER. No, thank you.

Mr. KELLY. Very good.

The next person, the gentleman from Kentucky, Mr. Yarmuth.

Mr. YARMUTH. Thank you very much, Mr. Chairman.

Thanks to the panel for your testimony. Those who know me and now those who don't, I wear these bracelets every day. These are bracelets that were the brain child of a young woman in my district, who is now 16. She has a younger brother who is autistic. She started at 11 raising money for research in autism by selling these bracelets for $3 apiece. She has now raised over $600,000. Her name is Michala Riggle. She has already financed a $250,000 study in one aspect of autism.

And I raise that not just because I like to brag on her because she is an incredible person, but also to illustrate the kind of civilian activity that is going on in this field. And it is represented here clearly today. We are here as Representatives of the government trying to find out whether there is anything the government should be doing that we are not doing. Obviously, there have been a lot of concerns expressed here about frustration and the activities of government.

A lot of what we can do is fund things. We do know how to spend money. And we do have this across-the-board cut coming up, so-called fiscal cliff, if we don't act. We are very much dealing with spending priorities. Last year, we, for instance, passed a defense appropriation bill that allocated $2 billion more than the Defense Department actually requested. We still gave oil companies $4 billion a year in subsidies that they don't say they need. So my question is, if you had another $2 billion or $4 billion, what could you do with it, and how would you spend it?

Dr. GUTTMACHER. One thing I would say, before I would spend the dollars, is I would not want to displace the private efforts, the efforts that you mentioned, because I think part of the reason why autism research advances is the combination of Federal funding, but also having private organizations, advocacy organizations, who have research efforts as well. And often, these research efforts

are—there are many things I have mentioned already in my testimony that is supported both by Federal dollars and by private dollars. And also, of course, the important input of the families, individuals with autism, who themselves inform the research and help shape the research agenda. So no matter what the money, we should keep that partnership.

I think in terms of money, clearly, I think, as Dr. Boyle also talked about, that we can see the particular scientific opportunities right now in terms of better understanding environmental factors. Many people I know have been concerned that there has been too much focus on genetic factors on autism. I would argue that, in fact, understanding those are very important for understanding the environmental factors, because we know it is a combination of both. So to figure out the combination, it is great that we better, still not fully, but better understand the genetic ones, so now we can focus more on what the environmental factors are, because after all those are the ones we can influence and control in terms of investments and, again, investments looking very early in life to better figure out what the etiology is. But then, also, investments in terms of intervention, so that we have more effective interventions and more options in terms of interventions. And again, I think more research and more work in trying to figure out how to best have an impact on the lives of those living with autism, both in childhood but very particularly in adulthood as well, so that I think there are a number of areas where we can wisely invest money.

Mr. YARMUTH. Dr. Boyle.

Ms. BOYLE. Thank you very much for the question.

Mr. YARMUTH. I wish I could offer you the money.

Ms. BOYLE. Yeah, but anyway, we do get requests all the time from the States, so we fund States, both to do surveillance and to do research. And particularly in the area of surveillance, the State has good knowledge about what is going on within their context, so they can plan for services. They can address some of the many issues that came up today about disparities and diagnosis among racial and ethnic groups. That would be one of the places we would really like to be able to fund more States.

And similarly, to get answers faster, we have worked very hard over the last 5 years. And it is not really we. It is our academic and State partners who have worked very hard over the last 5 years to develop our research base. And we are just at the cusp of actually being able to explore that. And more dollars would actually allow us to do work faster and to really be able to put as much energy into getting good answers for all of the questions that we heard today.

Mr. YARMUTH. Thank you very much for your testimony.

Mr. KELLY. Thank you.

Mr. Smith from New Jersey.

Mr. SMITH. Thank you, Mr. Chairman.

And I appreciate the committee allowing me and others to sit in on this. And I want to thank Dan Burton for his extraordinary work. He is truly a champion. I sit next to him in Foreign Affairs and he is a great Member of Congress and a great leader on combatting autism.

Dr. Guttmacher, in your testimony, you state that since passage of the Combatting Autism Act, there has been a ground swell of activity suggesting, and I think unwittingly suggesting, that this has been about a half-dozen a year effort.

As you may know, I introduced legislation as far back as 1997 that became law in 2000, it is Title 1 in the Children's Health Act, that establish the Centers of Excellence, the Interagency Autism Coordinating Committee, and really began a robust effort that continues to this day. And of course, the reauthorizations have been very important.

My point is we have been at this in a comprehensive way for more than a dozen years, and there is a sense of impatience that we all have. "Frustratingly slow" I think was the word that was just used. But I want to just make a point. Resources often follow a demonstrable need. I know that we were able to marshal huge amounts of money to combat AIDS, the pandemic of AIDS. And Henry Hyde led the effort. George Bush, it was his idea. And we spent billions in combatting AIDS, particularly in Sub-Saharan Africa, because the demonstrable need was married up with the resources to try to make a difference.

I think it hurts the effort, but we have to be accurate, when the 1 in 88 number was first released, horrible number, terrible number. The Associated Press Mike Stobbe writes on March 29th lead, "Autism cases are on the rise again, largely with a wider screening and better diagnosis, Federal health officials said Thursday."

Dr. Guttmacher, you were asked in a New York Times article about that question of epidemic, and you said, yes, it seems to be more common, but the jury is still out. The bottom line is you asked two questions rather than perhaps answer it. And again, you have got to go where the science is, and I deeply respect that. But it is now a couple of years later, and I would appreciate it if the jury is still out whether or not it is just better surveillance, especially in light of what Autism Speaks has discovered in South Korea. The 1 in 38 study that they funded makes it very clear that when you go further into a study, into the weeds in terms of asking the right questions, more rather than less seems to be the case. And I am wondering if you could comment on that South Korean study.

Secondly—so jury out study, if you could speak to that.

Africa, I chair the Africa, Global Health, Global Human Rights Committee. I have been working on the Foreign Affairs Committee for 30 of my 32 years in the U.S. House of Representatives. We never saw a prevalence spike like we have seen on autism in Africa as we have seen in the last 15 or so years. I had the first hearing ever on global autism. What we got back from those who testified was that there, and the WHO backs this up, there are probably tens of millions of cases of autism in Africa, Sub-Saharan Africa, in particular, and nobody knows why. I was in Nigeria giving a speech on combatting human trafficking, and a man came up and told me, he says you can't believe how many children in Nigeria are living with autism. And of course, in a developing country, it is very, very hard to overcome. It is hard in this country, even harder there. So if you could speak to those issues. Dr. Walter Zahorodny, who is our principal investigator for New Jersey—he is

here today and is a very good friend, a very, very competent man. My question regarding New Jersey, we have the second highest rate. Are the other States just as high, but they haven't done or the methodology has not been as keen and as effective, again, suggesting that we have a worse epidemic than some would suggest?

Your thoughts if you would on whether or not gut flora is a contributor. We know immunity is found in the intestines. There has been a, I think, a nexus between the two. There is very suggestive research on that, that a lack of the gut flora, particularly in women who are pregnant, may contribute, we don't know, to this problem.

And finally, and I am almost out of time, but the idea of like with AIDS research, having an Office of AIDS Research that can really number out what their recommendations, put price tags to it, shouldn't we have that also in our efforts to combat autism?

Dr. GUTTMACHER. Congressman, let me try to respond to all of those questions. Please let me know if I haven't responded to all of them.

First of all, I assume you did not want to leave the impression that it has only been in the last couple of years that the IACC has had a role. I know that your long-term leadership of the autism coalition made sure that that was put into effect a number of years ago and I think has long had an impact. I was only trying to emphasize I think there has been as it has both grown in terms of membership and also I think gotten more experience has become more effective with time is what I was trying to say.

I think in terms of the South Korean study and the 1 in 38 there are obviously some methodologic issues with that, but there are methodologic issues with almost everything. I think it is a very well done study. Does it show that the rate is increasing? Unfortunately, we don't know because there was not a precursor study in South Korea. It would be very important and interesting to see a few years from now, were that repeated in South Korea with the same rigorous methodology, what numbers they see. Clearly, we know for sure that some of the increase in terms of the rates that CDC cites, and again I would bow to Dr. Boyle on this because she has more expertise, clearly we know that much of that is due to increased and better diagnosis, which is laudable. Whether that explains the whole thing, I don't think that we scientifically know for sure. I think that there is enough of a reason to be—to some degree, obviously, this is a hugely important question. To some degree, it is not so important because, regardless of the answer, we know, a, that there are environmental factors at play here, and we need to identify them; b, we know it is a common public health problem, so we need to take it seriously. So regardless of whether the rate is increased or not, a hugely important question to answer, but in terms of what we do, much of what we do would be the same in either case. I think for instance——

Mr. KELLY. Doctor, the time is expired, so if you could just summarize very quickly.

Mr. KELLY. The time has expired.

Dr. GUTTMACHER. I think it's important. When it's those kinds of questions—in fact, we obviously know that the rate of cesarean sections is much higher than it used to be. What's the difference between being born by cesarean section and born vaginally? One of

the big differences is exposure to gut flora. What gut flora? What flora colonize the gut of the infant at birth? Could that play a role? We don't know. It's one of those many environmental things that we should be looking into.

Mr. KELLY. Thank you, Doctor.

Now I recognize the gentlelady from New York. Nice to have you with us.

Mrs. MALONEY. Thank you. And thank you for calling this hearing.

Autism is becoming a growing epidemic in the United States, and it definitely needs to be addressed. And I want to compliment, really, Congressman Burton for his leadership. He's not here now. I think—is he here?—for being the chairman of this committee and doing such a fine job. But you've really focused on this, and I think you've made some progress. And I want to thank you for your leadership on this issue and so many others, and express my gratitude to you and how much I've enjoyed working with you.

Now, the numbers that he pointed out earlier, that it used to be 1 in 10,000 kids got autism, it's now 1 in 88, and I'd like to ask Dr. Boyle, why? And I don't want to hear that we have better detection. We have better detection, but detection would not account for a job from 1 in 10,000 to 1 in 88. That is a huge, huge, huge jump.

What other factors could be part of making that happen besides better detection? Take better detection off the table. I agree we have better detection, but it doesn't account for those numbers.

Ms. BOYLE. So just to put it in context, better detection is accounting for some of it.

Mrs. MALONEY. I know some, but what other factors? I don't want to hear——

Ms. BOYLE. Our surveillance program counts cases of autism and establishes the prevalence. It doesn't tell us all the answers to the questions as to why.

Mrs. MALONEY. Okay.

Ms. BOYLE. So we are doing a number of studies to try to understand the "why," and one of the things that we've looked at, we've tried to look at what's changed in the environment, things we know are risk factors for autism, things like preterm birth and birth weight.

Mrs. MALONEY. Well, are you looking at vaccinations? Is that part of your studies?

Ms. BOYLE. Let me just finish this.

Mrs. MALONEY. I have a question. Are you looking at vaccinations? Is that part—pardon me?

Ms. BOYLE. So there is a large literature, as I mentioned.

Mrs. MALONEY. Are you having a study on vaccinations and the fact that they're cramming them down and having kids have nine at one time? Is that a cause? Do you have any studies on vaccinations?

Ms. BOYLE. There have been a number of studies done by CDC on vaccinations of——

Mrs. MALONEY. Could you send them to the ranking member and the chairman here?

Ms. BOYLE. Yes.

Mrs. MALONEY. Now, I want to tell you a story. We all react to our lives. And I remember people talking about hormone replacement, it's going to save women's lives, you've got to take it. Yet every nurse I talked to said go to the bank, it causes cancer. Every relative that got cancer said they got it because of the hormone replacement.

I'm hearing the same kinds of stories on vaccination. I must have had 50 different parents write me or come to me and say, I had a healthy child, yet then they have 10, 9, 6 vaccinations at one time, and that child changed overnight and was knocking their head on the wall, and it was a changed child. In fact, I had a family in my office today where the mother broke down crying, saying, My child was wonderful, bright, precocious, talking. She took those vaccinations, and the child became very incredibly sick and has never recovered. So I'm interested in any studies on vaccinations and trying to understand that.

Now, it used to be that you'd go and get a vaccination. My child never got more than three at a time. And in the State of New York, children are recommended to get six shots every 2 months throughout the first year of a child.

And my question is, why does the schedule of these vaccines—vaccinations require a child to receive so many shots in such a short period of time? You could—you could—you could plan those shots over a period of time.

I'm for vaccinations. They prevent disease. I'm totally for it. But why do you have to cram nine, six at one time when the verbal evidence seems so strong from so many people that they had a healthy child until they got vaccinated?

And you've got to just listen, you know, to—I remember smoking. I was on the city council. I sat through so many hearings where they vowed smoking was not bad for your health. It's common sense that it was bad for your health. Then finally the Surgeon General said it was bad for your health.

The same thing seems to be here with the vaccinations. There's too much verbal evidence coming from parents where they break down, I had a normal child, I gave him a vaccination, and then they—they became—they came down with autism.

So it keeps to me we should—I would—I'd start spacing it out. Why do we have to have nine vaccinations, six vaccinations every 2 months? Why can't we do it over 2 or 3 years and space it and wait for the scientific evidence or whatever?

Mr. KELLY. Gentlelady's time has expired.

Mrs. MALONEY. May she answer that question?

Mr. KELLY. If you could—if you could summarize.

Ms. BOYLE. Sure. There is a Federal advisory committee that determines the vaccination schedule. And the reason— and, again, I'll—we'll clarify this and get you more information, but the reason—the reason they cluster the vaccines is really to try to make sure that everyone gets it. People don't—and again, we're trying to make sure vaccines go to all children. And not everybody goes to the doctor routinely, so they use—they use that opportunity to make sure that happens.

Mr. KELLY. Thank you.

The chair now recognizes the gentleman from Florida Mr. Buchanan.

Mr. BUCHANAN. Thank you, Mr. Chairman. I also want to recognize, Congressman, for all your leadership over the years on this issue. A lot more work to be done, but I want to applaud you for that.

Let me just focus back on the vaccines. Some of my colleagues have brought that up today. Is it true that we have over 40 vaccines? And I'm not against vaccines, all of them, either. But let me just say, because I know there's a lot of evidence that they're good, but don't we get, like, 40-some vaccines, our children, today? Is that the number? I'm hearing upward of 40?

Yeah, either of the doctors. Just out of curiosity.

Dr. GUTTMACHER. There is exact number, and it varies somewhat. I think 40 is a little bit high. But it's a——

Mr. BUCHANAN. Why would it—why would it be—just to point it out—why is it twice what France is, three times Finland, a lot of these other countries? And I know because there's a lot of people that move in and out of France, a lot of diversity. I just don't understand why our kids are getting so many shots.

And I think of my father-in-law in a different standard just in terms of common sense where he's elderly, but he's taking eight pills. They found out that a lot of them have effects and impacts on other pills.

And that's why I don't know that we're spending enough time and energy looking at this, where our kids are getting twice the shots of everybody else.

And I just have—you know, my sons, it seems like they're older now, in their late twenties, but they might have had seven or eight. And I'm just going by people that I represent in our area that feel strongly that this has to be looked at in a very, very aggressive way that we are overvaccinating our children.

Doctor, either one of you.

Ms. BOYLE. We know vaccines save lives. There is a recent analysis that was presented at the pediatric meetings in April, and I actually have the numbers from that for you. It was estimated that 42,000 lives were saved, 20 million cases of disease were prevented, and 13.6 billion in direct medical costs were saved. And that's for each birth cohort.

Again, there are complexities in terms of the schedule, there are complexities in terms of the types of vaccines, and this is all carefully thought out by an advisory committee that oversees this process.

Mr. BUCHANAN. Have they looked at the impact—and I'm not a chemist or anything, but when you put all these drugs or vaccines into children, the impact that these various vaccines might be having, combinations? I mean, I—here's what I get back to. We've got one in one—you know, in 2005, according to autism, it was 1 in 166 children. Today, it's 1 in 88. We brought that up a couple times. Boys, it's 1 in 54. They're saying 40 years ago—whether it's true or not, this is what they are saying, I'd be interested in your thoughts—it's up 1,000 percent. So when you look at 40 years ago, maybe we got 6 shots, now we are getting 40 shots, is there possibility of any correlation?

Either of you.

Ms. BOYLE. I mentioned earlier—excuse me, I mentioned earlier that there is a body of evidence now, accumulated over the last 10 years, looking at the relationship between vaccines and autism. And that was evaluated in 2004, again very recently in 2011, which didn't support an association between vaccines and autism from a population perspective.

Mr. BUCHANAN. Doctor, do you have anything to add to that?

Dr. GUTTMACHER. I would agree she's—that's correct.

Mr. BUCHANAN. Let me ask you the other thing. They're saying that the person in their lifetime, the care cost is 2.3 million. Do you agree with that number, for autism? That's the number I got.

Dr. GUTTMACHER. I don't have a specific number. I'd be happy to provide additional information for the record on——

Mr. BUCHANAN. But I think it's 2.3 million. And they say that it costs the country—I didn't realize it was to this magnitude—$137 billion a year annual costs, costs this country for care of autism. Do you agree with that number?

Either of you.

Dr. GUTTMACHER. Again, I would not have the data to agree or disagree. I know that it's a high number.

Mr. BUCHANAN. I just want to let you know we've got to spend more time and resources and fix this problem because it's—obviously, it's out of control.

Thank you. I yield back.

Mr. CUMMINGS. Mr. Chairman?

Mr. BUCHANAN. Yes.

Mr. CUMMINGS. Thank you very much. You know, I'm just sitting here, and I'm listening to all this. There's something wrong with this picture. There's something wrong. It's—and, you know, the gentleman, I thought, asked some very good questions; matter of fact, the whole panel.

When you've got this combination of shots, and you go from 1 in 10,000 to 1 in 88, it seems to me somebody would say, wait a minute, let's put the brakes on this, and at least let's try to figure out whether—if I'm giving a baby nine shots in a day whether that—I mean, how much impact that's having. I don't know how we—I mean, it just seems logic. I mean, if they gave me nine shots, I would—you know, I don't know what that—and then I know you said there's a body of evidence with regard to vaccines.

Mr. Chairman, I don't know where we go from here, but I—we—I mean, it just seems to me somebody ought to say, wait a minute, let's put some brakes on this. I'm not trying to say don't deal with vaccines. Just look at, you know, whether the multiple-shot situation is causing this.

And I wish you could see the people behind you. There are grown men that have been crying behind you, and women crying. And it's just—I just—I just hope that we can—I mean, I mean, you hear the frustration coming from here. And I'm just sitting here saying, wait a minute. Seems like somebody would say, is there something, maybe, there is an issue here? And if we're going to err, let's err on the side of keeping children safe even if we have to, you know, do a pause and give one shot a day.

And thank you very much, and thank the gentleman for yielding.

Chairman ISSA. [Presiding.] If I may take a liberty of the chair for a moment. It is our intention to include in future hearings—and the gentleman from Indiana is here—a narrow but specific request—and I put both of you, even though you may not be the witnesses—of the question of drug interactions where the FDA approves individual drugs and individual vaccines, but by definition does not necessarily thoroughly study interactions of any sort that can happen with 1, 5, 9, 20 different ones.

That's a different hearing, but it is one that we wanted to talk about, because one of the questions that we see every day, and I appreciate the understanding, is that both prescription drugs and nonprescription drugs, when interacted, do things that were not tested by the FDA.

So as part of our ongoing relationship with the FDA primarily, that is a series of questions we expect to explore not because we want to further burden and slow down the approval process, but because ultimately that is one of the answers that we are only now getting more evidence that there has to be a systematic approach to dealing with all of what we put in our bodies.

And Mr. Gosar, when he was here earlier, you know, talked about food, food being something that you can't control. But at the same time, drugs have to be looked at in terms of what somebody may eat or drink in proximity to. So I'm not asking you for any information today, but I did want you to be aware that we have done a number of things with FDA, and we do intend on going down some path related to that, and I thank the gentleman for bringing it up.

We now go to the distinguished and patient gentleman from Utah for 5 minutes, Mr. Matheson.

Mr. MATHESON. Thank you, Mr. Chairman, for holding the hearing. And thank you. I'm not a member of this committee, and I appreciate your allowing me to sit in and participate today.

Chairman ISSA. You may tell your friends that this is a committee that represents all jurisdictions of all parts of the Congress. So we would be loathe not to include people from the other distinguished committees that we often ask the same questions on the same subjects with.

Mr. MATHESON. I certainly appreciate that, Mr. Chairman and Ranking Member. And I appreciate the witnesses being here today.

We've heard a lot about the 1 in 88 number. I come from a State where it's 1 in 47. And I've heard a couple of other Members ask questions about differences in incidence in different regions. And I'm one that represents a State that's sort of at the one end of the scale, from Utah.

And I've heard a lot about this from my constituents, and I—I've always been an advocate for responsible funding and research for NIH to try to figure out what's going on with this issue.

I'd like to ask both of you if you can tell me, based on your organizations' research, have you been looking at these geographic disparities, where the State of Utah is 1 in 47 instead, and can you offer me any information that helps me understand why my State has a different number from the national average?

Ms. BOYLE. I would go back to some of the comments I made earlier in that differences in how States identify and serve children.

Since our program, our tracking program, utilizes those—those sources, those record sources, to identify children, and that varies from State to State. And that—those numbers in many ways are a reflection of that.

Some of our States don't have access to education records, and since we were dealing with 8-year-old children or school-age children, and they're served through IDEA and special education, that makes a difference as well.

Mr. MATHESON. Can you tell me, though—I appreciate there may be differences in methodology, but is my State better at it? Is that what you are telling me? Or is there something else going on in my State? Has there been any conclusion to these studies that talk about things done differently in different States?

Ms. BOYLE. So we—we are looking at both differences in how children are identified as well as differences in risk factors across States to try to get a better sense of that.

Mr. MATHESON. Is there a target date when there may be a result? You say you're looking at it now. Do we know when there may be some answers?

Ms. BOYLE. Well, there are some answers. So from the report that we put out in 2008, what we could see is that children who were coming into the system were more likely to have a community diagnosis. So their community physicians are more likely to be aware of autism and coming into the system. And that's changed over the 10 years that we've been monitoring.

Mr. MATHESON. I understand there are differences. I'm trying to figure out have you validated that that is what's—that is what's going on, where there's a 1 in 47 rate in Utah. I'm just trying to figure out why the number is different in my State——

Ms. BOYLE. One other example is we're actually doing—we're not doing, Autism Speaks is funding a special study in South Carolina. So using one of the ADDM sites, they're looking in a much more in-depth way to see, in fact, you know, is that number in South Carolina low. So, again, we're—it's a puzzle, and we're putting all the pieces of the puzzle together that way.

Mr. MATHESON. I'm not a statistician. I just see a big difference in numbers. So it would be helpful if we could understand why that number's different.

In my limited time I'd like to ask one other question. Can any of you tell me about any new therapy approaches that are emerging for effectiveness in treating autism?

Dr. GUTTMACHER. In terms of therapy, in terms of behavioral interventions and other kinds of things that are being—they're emerging, that are being developed, in terms of something like a medical therapy, I think we're much farther away from those kinds of interventions, though one would hope that eventually we would have those to offer as well.

Mr. MATHESON. Thank you, Mr. Chairman. I'll yield back.

Chairman ISSA. I thank the gentleman.

Would the gentleman yield his remaining time to Mr. Burton?

Mr. MATHESON. Yes.

Mr. BURTON. Thank you, Mr. Chairman.

I just have one question: Why did the FDA and HHS take thimerosal out of all the children's vaccines except just the one or two

or three? I mean, I'd just like to know why they took the thimerosal out if there was no problem and leave it in just a couple.

Dr. GUTTMACHER. I think neither of us are vaccine experts, and we'd be happy to look into that and provide additional information for the record.

Mr. BURTON. I would like an answer, because I think most people would really like to know. Thank you.

Chairman ISSA. I thank both of you. I thank you for agreeing to answer that for the record.

And by unanimous consent, I allow Mr. Posey to ask one additional question of this panel. Then we are going to go to the large second panel.

Mr. POSEY. It's to you, Mr. Chairman. In the course of answering this, one of the witnesses told me that the fugitive doctor had been involved in a couple studies with CDC, and I have information here that he was involved in 21 of the 24 studies. And I would like to submit that to the record, Mr. Chairman.

Chairman ISSA. Without objection, so ordered.

Chairman ISSA. Again, I'd like to thank our distinguished first panel. Again, we will accept additional information for the record.

I know you've been in front for a long time. I might suggest that you take advantage of our conference room in the back and leave when you choose to, but if you can stay for a while and watch it on the monitor, it may help you in additional items for the record.

So with that, we're not going to—we're going to suspend. We're not going to leave the room. And if the clerk would please change over for the next panel so we can get started immediately.

Chairman ISSA. Ladies and gentlemen, we really did not recess. So if our witnesses would now take their assigned seats. I suspect the second panel will take a very long time, but will be equally interesting.

And I do want to thank all of you for your patience. This is a very long time for many of you to sit here.

We now recognize our second panel, starting with Mr. Bob Wright, who is the cofounder of Autism Speaks.

Mr. Scott Badesch is the president of the Autism Society.

Mr. Mark Blaxill is a member of the board of directors of SafeMinds.

And I would ask that Mr. Kelly introduce and make a short statement about the witness he helped bring here.

Mr. KELLY. I thank the chairman.

One of the great honors I have is representing northwest Pennsylvania and Mercyhurst College. Mr. McGarry, Bradley McGarry, is with us today. Mercyhurst is one of the leaders, if you didn't know this, around the country starting in 1986 addressing these types of problems, and they have been the forerunner. Mr. McGarry has spoken all over the country about the initiatives that can be taken and the ability to help those with lesser degrees of autism to integrate into society and make great contributions.

So, Mr. McGarry, it's so nice to have you here and representing Mercyhurst. You do great things. And in 2008, your program, the Asperger Initiative at Mercyhurst, is one that's being looked at all over the country and is the perfect model that lets us to go forward

and address some of these issues. So, Mr. McGarry, thank you so much for being here.

Chairman ISSA. I thank you both.

Mr. KELLY. I yield back, Mr. Chairman.

Chairman ISSA. Thank you.

And we now recognize Mr. Michael John Carley. He's the executive director of the Global and Regional Asperger Syndrome Partnership.

And last, but not least, we recognize Mr. Ari Ne'eman. He is the president of the Autistic Self Advocacy Network.

Again, as you saw in the first panel, pursuant to the rules of this committee, I'd ask you all rise now to take your oath, and raise your right hands.

Do you all solemnly swear or affirm the testimony you are about to give will be the truth, the whole truth, and nothing but the truth?

I have carefully viewed, and all answered in the affirmative.

Please take your seats.

You are a large panel, and you have a lot to say. I would only mention that there are 20 groups behind you who were not fortunate enough to be seated with you. So please, to the greatest extent possible, make sure you finish right at 5 minutes so that we can get to Q and A, much of which will help with issues that may be beyond your opening statements.

With that, we recognize Mr. Wright.

STATEMENT OF BOB WRIGHT

Mr. WRIGHT. Thank you, Chairman Issa.

Chairman ISSA. I'm afraid your microphone is not quite on or close enough. Could you also pull it a little closer. There's a sort of skill we gain here of getting to the mic and really getting to it. It goes with being a Congress Member for a long time.

Mr. WRIGHT. Let's see how we do here.

Chairman ISSA. You have what it takes.

Mr. WRIGHT. Well, thank you, Chairman Issa, very much for having us.

And, Ranking Member Cummings, thank you so much for being here.

We also—I also want to thank Dan Burton for all the work that he's done over many years to bring awareness and attention to and discussion of and action on autism. Very, very important.

I'd also like to recognize Mr. Smith, who has done an extraordinary job as well all over the country and with the coalition and many others, and I'm personally involved with him in many. So thank you for everything you have done for all of us.

I want to say I'm here because of my grandson Christian, who is now 11 years old. And my daughter Katie is sitting back here, and my wife Suzanne. And he was a boy that was 2 years old, and we thought he was very precocious. He seemed to be brighter than average, he walked early, he had enormous vocabulary, and then he lost everything. And I'll tell you without any secret that my—my daughter, you know, firmly believes that vaccines were the relationship that triggered him into this pit.

So we lost a little boy we knew. It wasn't like he was a disabled person who got more disabled. He was a boy, and we lost him. And that's what led us to found Autism Speaks.

We could take care of Christian, but we saw so many others out there. And I traveled around the country, and I sat in meetings, similar to the meeting you're having here, where I would ask questions about autism. I went to universities, I went to medical schools, and I got the worst answers imaginable. Actually I heard some of the same answers here just a few minutes ago on the panel. It must be they're on a Twitter thing or something. It was, we don't know, but we're sure; or, we're sure, but we don't know, but we really don't know, but we're sure. And that was a lot of the issues, why are the numbers so high and so forth?

So we got into this and said—we called around to find like-minded people, and that's how Autism Speaks got founded. And we've been fortunate. We've raised a considerable amount of money. We have 250 full-time employees around the country. We have 90 walks. We have 400-some-odd thousand who walk for us here. We have activities outside the United States.

But all of that's based on that little boy. And the fact that in all my business career, I was shocked that I was so ignorant of all the situation; and then when I got into it and tried to learn, I was even more shocked that nobody was helpful and that we were just trapped and amazed here of obviously escalating issues, all kinds of things.

So I'm going to try to answer a couple of things, or at least bring some help here.

We talked about the 1 in 88, which is exactly—that is the U.S. Number. Now, the CDC is what a—what they call a passive—it's a passive resource. They go around and they look at medical records that are in—that are existing. That's a variable. And they also look at school records. That's a variable. They do not talk to children. There's no clinical evaluation, no talk to parents or anything. And that's—that partly accounts for some of the differences when you go around the country. Some schools have better records; some school don't. Some—whatever. And that's what they do.

The Korean study that we financed, which is the most—it's the—it's the gold-plated model on how to do this. We went through the same process in Korea with Koreans, with Japanese, with Americans, and we ended up finding out that there was about 1 percent of the population, which is just what we had here.

But then a second thing happened. Parents wanted to offer comments about what we were doing, because we were only doing the school records and all that sort of thing. And the school district said fine. It's 100,000 in population area in Seoul. And the school—we asked parents that wanted to come in that they could come in and offer comments and so forth.

Well, they came in on all kinds of issues, and we separated them out to 2 years. And out of that we actually had 1 more percent of the entire community of that same community diagnosed with autism. We brought people in. So the number is 2.657 percent. I have no reason to believe that that number won't be duplicated in the United States with that methodology. That's why we are financing this effort to convince the CDC that—they don't actually have dis-

agreement with the number. Their position was, we don't have any money. We can't afford that. That costs more money. We only do this.

And that sort of speaks for itself.

But I'll also tell you that——

Chairman ISSA. If you could do that in summation, please.

Mr. WRIGHT. I'll also tell you that we have—they spend almost no money, almost no money on autism; $20 million, $30 million, including all—all of the—all of the—the safety issues. That's a—that's—we could fix that in an hour for about $35 million a year on top of what they do.

So the name of this committee, the Oversight Government Reform, there's a real issue there. I wish they weren't even involved with us, but they're the only ones that did prevalence. We are on page 7 of their—their 2-page top priority list, and autism is right at the bottom of it. I don't know why Dr. Boyle, but the nature of, I guess, being in the large—large—they all want to say, we have no money. We don't have any priority. I can't get anybody to hear. And I don't complain enough. So this is about speaking up.

Chairman ISSA. Thank you very much.

[Prepared statement of Mr. Wright follows:]

AUTISM SPEAKS™
It's time to listen.

Written Testimony Provided for the
House Committee on Oversight & Government Reform

Bob Wright
Co-founder, Autism Speaks

November 29, 2012

Good afternoon, Chairman Issa, Ranking Member Cummings, and members of the committee. I am Bob Wright, co-founder of Autism Speaks. Thank you for inviting me to testify.

More than seven years have passed since my wife, Suzanne, and I founded Autism Speaks. During that time, we have seen the prevalence of autism in America nearly double – from 1 in 166 children in 2005 to 1 in 88 today, including 1 of every 54 boys. The prevalence of autism has increased by 1,000 percent over the last 40 years. This year alone, approximately 46,000 children will be diagnosed with an autism spectrum disorder – that's more than pediatric AIDS, juvenile diabetes, and childhood cancer combined. Yet even these alarming statistics may understate the true picture – the most comprehensive study to date, completed last year in South Korea, found a prevalence rate of 1 in every 38 children. The methodology used in this study is now being replicated in South Carolina, with funding from Autism Speaks, and may well yield similar findings. There is no getting around the facts: autism has become an epidemic.

The incremental lifetime cost of caring for a single person with autism is staggering – as much as $2.3 million. The annual cost of autism in the United States is now estimated at $137 billion – a figure that exceeds the gross domestic product of 139 countries. These spiraling costs are borne not just by families but by taxpayers at the federal and state level, as well as by localities. Consider as well the cost to our economy – when one of every 54 boys is diagnosed with autism, 2 percent of the productivity of our nation's male workforce is diminished. The toll on our families, however, is unimaginable. A diagnosis of autism too often leads to divorce, personal bankruptcy or shattered careers. A spouse in Michigan has to give up working in order to care fulltime for a child with autism at home. A family from Alabama is uprooted as they search for jobs in states where treatment for their child with autism will be covered by insurance. Parents in Utah are forced to surrender custody of their children to the state because they cannot care for their needs. And most shamefully, we see the U.S. Marine back home in Texas after being wounded in combat in Iraq having autism treatment denied to his son.

These burdens on families can be addressed, the costs can be reduced, and the quality of life for individuals with autism improved. But it will require new thinking, engaged leadership, and a concerted effort bridging all sectors of our society.

Autism Speaks began as an idea to give a voice to millions of struggling families around the nation and has materialized into the world's leading autism science and advocacy organization. We are dedicated to funding research into the causes, prevention, treatments, and for those who desire a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Since our founding seven years ago, Autism Speaks has committed more than $180 million in private funding to research and has supported innovative scientific and clinical programs such as the Autism Speaks Autism Treatment Network, a network of hospitals, doctors, and researchers across the United States and Canada dedicated to improving the care of children with autism. Our research efforts also have led to improved screening tools that can be used by pediatricians and more effective behavioral and medical treatments for people with autism throughout the lifespan. Our awareness activities include the worldwide "Light It Up Blue" project on World

Autism Awareness Day (April 2nd) and the "Learn the Signs" campaign with the CDC and Ad Council which has generated over $316 million in donated media.

Autism Speaks provides resources and support for families in the autism community, handing out thousands of free tool kits and awarding hundreds of thousands of dollars in grants for community programs, camp scholarships, and families in crisis each year. In 2012 alone, our Autism Response Team and Autism Treatment Network have responded to over 25,000 phone calls and emails from families looking for assistance. Recently, our AutismCares program allocated $120,000 in private funding to help families impacted by Hurricane Sandy.

Through the work of our government relations team in state capitals and on Capitol Hill, individuals with autism have better access to applied behavior analysis (ABA), the most widely used behavioral intervention for treating autism, and other critical health care services. Thirty-two states, representing 75% of the US population, now have comprehensive autism insurance coverage, and beginning in 2013 many federal civilian employees will gain access to behavioral health treatments through the Federal Employees Health Benefits Program.

We are incredibly proud of what Autism Speaks has accomplished. We cannot, however, go it alone. We need a strong federal partner.

Our families are not asking for a blank check from the federal government. We are asking for real help that delivers meaningful results more quickly to our community and with a transparency that provides accountability to taxpayers. We are asking our elected leaders to recognize that there is a public health crisis racing across this nation and we are not keeping pace. We need a plan and we need it now.

Autism Must Be a National Priority

I want to say this again: the rate of autism in America is now 1 in 88 children, including 1 in 54 boys. It has become alarmingly apparent that we are no longer dealing with just a public health crisis, but a public services crisis as well. As this population continues to grow, our ability as a society to care for people with autism falls further behind.

Real families struggle every day with autism and those struggles do not end when a child with autism becomes an adult. A recent study found that more than one-third of young adults with autism have no paid job experience or post-secondary education in the first six years after high school. In other words, they most likely live at home with nothing meaningful to do during the day. That is a sobering statistic when you consider that more than half a million children with autism will reach adulthood within the next decade.

But with this sobering reality comes a meaningful opportunity for this country. We know that there are effective therapies that will improve the life-trajectory of people with autism. This means that with more effective translational research and better access to supports and services for the individuals I described, we can help them lead more independent lives and in some cases join the workforce. The trend that contributes to the $137 billion in annual costs can be reversed dramatically for the country as a whole and for the people affected. In the current fiscal crisis,

this potential reduction in current and future costs should be appealing to both sides of the aisle and across the ideological spectrum.

Clearly, we have a long way to go in meeting the needs of people with autism and their families. The status quo isn't working. We have to do better, and we have to act now. It is time we commit to a **comprehensive national strategy** for autism.

A Comprehensive National Strategy is Essential

***First**, we must continue to fund a robust research effort but should do so more smartly.*
We are only beginning to grasp the complex connections between genes and environment in autism. There is now growing evidence that certain environmental factors, including chemicals, toxins, infections during pregnancy, maternal nutrition and parental age, can affect brain development in combination with an underlying genetic predisposition. Recent studies are pointing the way to the development of medicines that could reduce the core symptoms of autism and help improve communication and social skills. Novel behavioral health interventions are being tested that can be started with young infants, as well as implemented later in life to help adolescents and adults develop the skills they need to be successful, productive adults. These new treatments have the potential to significantly impact lives and reduce the burden of autism to families and society. The federal commitment to autism research through the Combating Autism Act (CAA) has been an important first step in better understanding the causes and underlying pathology of autism. Autism has historically received a fraction of the research funding of many less prevalent disorders, and even under the CAA, autism research comprises about one-half of one percent of total NIH research funding. The research into environmental factors I have noted is an example of an area of research that was mostly neglected prior to the CAA. Further, the Interagency Autism Coordinating Committee (IACC) established by the CAA has served as a convening function for scientists and autism advocates to have a dialogue with the National Vaccine Advisory Committee on the important vaccine safety issue.[1] These steps have been important, but much more can and needs to be done. What continues to be lacking is a policy that directs funding according to a strategic plan, measures meaningful progress, operates with a sense of urgency, and assures accountability. We need a national commitment – much the way the country has committed to address the AIDS crisis or Alzheimer's disease – to invest the resources needed to solve this growing public health crisis. We must demand results that improve the lives of people with autism today, not just in the future. Through a smarter investment in research we can unlock the door not only to autism, but a variety of brain disorders.

***Second**, we must commit to diagnosing children with autism, regardless of background, no later than 18 months of age, and increasing access to early intervention.*
Five years ago, the American Academy of Pediatrics recommended that all children be screened for autism at 18 and 24 months, and that appropriate referrals be made if autism is suspected. This is crucial because we know that early intervention can alter the life trajectory of children with autism. Today the average age of diagnosis remains close to five years. Geography, ethnicity, and race may place a child at a particular disadvantage in getting a timely diagnosis.

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[1] Louis Z. Cooper, Heidi J. Larson, and Samuel L. Katz, *Protecting Public Trust in Immunization*, Pediatrics 2008:122; 149

Research shows that children from ethnic minority backgrounds must go to the doctor many more times before receiving a diagnosis and thus, they begin receiving services at a much older age. Autism is not something that a child outgrows. We must develop new and better ways to increase access to early diagnosis for all children no matter what their background is.

***Third**, we have to develop and make available effective medicines and treatments for the debilitating aspects of autism.*
Too often, scientific discoveries gather dust on laboratory shelves or are entombed in the pages of academic journals. We need to speed to market products that improve the lives of people with autism. For our part, Autism Speaks recently established a not-for-profit affiliate, ***Delivering Scientific Innovation to Autism (DELSIA)***, to help do this work. From Washington, we are looking for the National Center for Advancing Translational Sciences (NCATS), NIH's newest center, to take a key role in fostering collaboration between public and private efforts at real world solutions. This committee can be instrumental in providing oversight for this opportunity.

As we develop the technologies of tomorrow, we must fully utilize the treatments and interventions of today. Right now, autism is considered a treatable disorder. But ten years ago, many experts didn't believe it was. Today, we can change the course of a child's development and outcome. Research has shown that early intensive behavioral intervention significantly increases IQ, language abilities, and daily living skills, while reducing the disabling effects of autism and the demands on taxpayers for avoidable costs, such as special education. Autism is not a static disorder; we can treat it and help those affected lead better, more fulfilling lives.

***Fourth**, we must recognize and address the disparities in access to proven behavioral health treatments.*

We have long known the benefits of behavioral interventions in autism, including the use of ABA. In 1999, the Surgeon General of the United States reported that "[t]hirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." Yet today families across the country continue to fight for behavioral health benefits, negotiating a complex maze of state and federal laws and insurance company practices.

Consider this – civilian employees of the federal government who for the first time in 2013 will gain coverage for ABA through the Federal Employees Health Benefits Program because administrators finally came to acknowledge the therapy as a valid medical intervention. But over in the military, the administrators of the TRICARE program view ABA differently and offer only benefits limited to active duty personnel. Even wounded warriors who retire because of combat-related injuries cannot get ABA treatment for their children.

Here is a classic example of two agencies within the same government heading in opposite directions on the same issue. It is appalling that our military families end up with the short end of the stick. Getting help for any child, let alone the child of a parent who has honorably served our country, should not be so difficult. We can do something right now to help these families – we can enact a National Defense Authorization Act (NDAA) that clarifies the coverage of behavioral health treatment for autism. The House passed a version of the NDAA that assures all Department of

Defense members of the military, regardless of their duty status, will receive autism insurance benefits for their dependents. Now it is time for the Senate to pass a bill with the same provision.

This same incongruity can be found all across America. Repeatedly, we find families overjoyed to gain coverage for ABA when their state enacts autism insurance reform. They are happy because they have the good fortune to work for an employer with a state-regulated health plan. Their neighbors, however, may not be so fortunate. Because many employers self-fund their health plans, they are exempted from following state insurance laws. Their plans are regulated by the federal government under ERISA. Two families, same problem, but different outcomes. This is fundamentally unfair, illogical and, with autism prevalence on the rise, unsustainable.

***Fifth and finally**, we need to address the needs of adults with autism for continuing education, employment, housing, and community integration.*
With early identification and intensive intervention, some children with autism can lose their diagnosis, but most children with autism become adults with autism. To be frank, we do not know very much about the life experiences of adults with autism; only 2% of total autism research funding is spent on lifespan issues. Young adults with autism face real challenges. The majority of adults with autism are unemployed or underemployed, a tragic waste of potential. Hiring people with autism is smart business – just ask Walgreens, TIAA CREF, AMC Theatres or any of the other national employers who have made the investment in our community.

Executive Order 13548, which has increased the percentage of disabled workers in the federal workforce, has been an important step in the right direction, as has been a proposed rule calling on federal contractors to set a goal of hiring people with disabilities for at least 7 percent of their workforces. People with autism generally follow rules and pay close attention to details. They want to work. Give them the support they need and they will succeed. It's time for corporate America to recognize the potential of employing people with autism. They will find a partner at the National Governors Association, whose chairman, Delaware Governor Jack Markell, has made his top initiative increased employment opportunities for people with disabilities.

Like all Americans, adults with autism should be able to choose where they live, with whom they live, and how they live. But the great demand for housing among people with developmental disabilities and the lack of appropriate support services often force families to decide whether to make their own housing arrangements or wait indefinitely for an adult child with autism to move out of the family home. A broad range of housing and support options must be available to meet the needs of people with autism. These options must not be limited by government-imposed restrictions. Where people choose to live should drive where the government directs our money.

People with autism and their families should have the ability to save and plan for the future. The Achieving a Better Life Experience (ABLE) Act would allow tax-advantaged savings accounts for employment support, housing, and other life needs of people with disabilities. These accounts would be subject to much the same rules as 529 college savings accounts and would not jeopardize eligibility for Medicaid and other means-tested federal programs. A bipartisan majority of House members and 40 Senators have signed on to co-sponsor ABLE. This is readily achievable in the current Congress and would bring relief to parents who face their own financial cliff – what happens to their child with disabilities when they are no longer around to support them? I ask the members of this committee to help pass ABLE in this Congress. In this time of

fiscal cliffs, this is a common sense solution that will help disabled individuals and their families achieve even greater independence.

If the list of what must be accomplished seems long, it is because the stakes are very high. On a personal scale, there is this harsh reality: ten years ago, even five years ago, many people in this committee room would have known autism only from what they read in the newspaper or saw on television. Today, they are the parents, grandparents or relatives of affected children. Autism has become ubiquitous. Autism has changed our lives, and it continues to change the lives of millions of Americans. We must face up to the crisis. We are ready to join you as a partner. One in 88 can't wait.

Chairman ISSA. And we now go to Mr. Badesch, with the same microphone problem you will all have. It's an acquired skill, and I appreciate you all for learning it.

STATEMENT OF SCOTT BADESCH

Mr. BADESCH. Thank you, Mr. Chairman, Ranking Member Cummings, and the other members of the committees.

My wife and I are the very proud father of Evan Badesch, who's a 25-year-old son who is—with autism who attends Marshall University, which, like the other school represented on this panel, is thriving and helping so many with autism. But he is one of the more fortunate with autism.

The Autism Society of America is the Nation's largest and oldest grassroots organization dedicated to the autism spectrum. As has been discussed today, the incidence of autism has shown marked increase as the CDC surveillance rates, currently at 1 of 88 births. Many children and adults may not be properly diagnosed, and this number may actually be higher than the actual incidence.

We applaud the work of the CDC and appreciate the partnership we have with CDC, and particularly efforts we are working with the CDC on addressing better some of the questions asked earlier about how we can increase the growing disparity of the—the autism diagnosis rates among people of color and other ethnicities and geographic locations.

We would suggest that currently the services for autism are difficult at best to navigate, and often when services are provided, they may not be individualized or be the best approach for the needs of the individual.

The Autism Society is about helping people today and preparing them for tomorrow. And we believe that government services, if funded by government dollars, should have focus on advancing an individual's quality of life in measurable and meaningful ways. We need to reexamine how government services can be provided not on a limited definition of services, but rather based on an individual's needs.

As I noted, today there is a significant disparity in the need for available funds for both long term and support—and to support people with disabilities. This disparity has resulted in very long waiting list for services throughout our country, and estimates of that waiting list being anywhere from 80,000 individuals nationally to as many as 200,000 people who go without services each day.

Meeting the significant need will not only require expansion of services, but we believe it requires us as a society and government to think differently about the way services are delivered.

An individual today who's diagnosed ineligible for services and then put on a waiting list is denied the critical services that we all know could help him or her move forward in addressing quality-of-life needs.

We recognize that funds are limited, and we would encourage the committee to examine ways that if funds have to be cut, that they not be cut at the expense of individuals, but at the expense of unnecessary duplication and administrative services.

We also would encourage the government—this committee in its role to look at the public schools. Our public schools are required

by law to provide every child with an appropriate education, and, unfortunately, 50 percent of students with disabilities are either dropping out, or not graduating, or not receiving appropriate degrees. This is very difficult when we look at how to help those children in adult life.

We also believe that government services must be outcome based, and we must encourage that those services aim to help a person maximize his or her independence in self-sufficiency. And we also have to take a recognition that as a Nation, while we are very concerned about an unemployment rate when it goes above 5 or 6 percent, the reality is that for the individuals with people with disabilities, that rate is as high as 78.5 percent.

Government's responses are most effective also when resources are available under one umbrella. Any parent or any individual who's had to navigate the system will say it's impossible to navigate. The committee must—needs to also look at how we can more effectively, and we would argue at a much lower cost, coordinate the government's response through a one-stop model or centralization of information.

We also would encourage this committee to look at the issue of Medicaid portability. When a person moves from one State to another, he or she loses their Medicaid community support services and has to start over again. This is particularly of concern to military families when they get relocated from one base to another.

Finally, I want to mention about the Combating Autism Act and the Interagency Coordinating Council. With all respect to our prior speaker, we would disagree with a lot of what he said. This is a group that in concept could do a great job with coordination, but in reality it's not. If a body is going to be, in fact, a coordinating body, it has to include public—private and not-for-profit sectors. We have to be an equal partner at the table. It also has to include government representatives from the Department of Labor, Justice, Housing and Defense. And it also has to meet.

We also support, very strongly encourage the continued funding of training components of the Combating Autism Act.

Finally, I would just like to encourage, as said prior to all this, the need for adult services is extensive. When you talk about a fiscal cliff, the greatest cliff that occurs in our community is that when a person turns 21, and absolutely no services are available for that person when they need.

And, again, we thank the committee, and I'll happy to answer any questions when all the other speakers are over.

Mr. MEEHAN. [Presiding.] Thank you, Mr. Badesch.

[Prepared statement of Mr. Badesch follows:]

AUTISM SOCIETY

Improving the Lives of All Affected by Autism

Chairman Issa, Ranking Member Cummings and Oversight and Government Reform Committee members...

Thank you for the opportunity to testify before the committee on the federal response to the rise in autism diagnoses and the allocations of government resources. I am the proud father of a 25 year old son with autism and serve as the President of the Autism Society of America, the nation's largest and oldest grassroots organization dedicated to the autism spectrum.

Since 1965, our organization has been a leader in assisting literally millions of people effectively impacted by autism. We are a volunteer driven organization with more than 100 local and state affiliates throughout the nation. Our priority is to help people meet their needs today while empowering them to be prepared for what may come tomorrow. We work to assure that every person with autism be provided opportunity to access the highest quality of life possible and treated with dignity and respect. We are also proud that since our founding all aspects of our organizations work is inclusive of people living with autism.

As the committee knows, the incidence of autism has shown marked increase in CDC surveillance studies-currently occurring in 1 out of 88 births. Many other children and adults may not be properly diagnosed and the numbers impacted by an autism diagnosis goes well beyond the individual. Autism is a whole body, whole life condition that affects not only the individual but also the entire family.

The significant increase in incidence represents individuals and families facing tremendous stress, it also places significant strain on an already overextended service system. Unfortunately because of this the reality for most individuals with autism is dismal. We must change the national discussion on how to address autism. The future of a child diagnosed with autism, should not depend on family resources, ethnicity, gender geographic location or the school they attend. Access to appropriate services must be provided as early as possible, when this occurs the lifetime costs can be reduced by as much as two-thirds.

Despite evidence that autism can often be identified at or before 18 months the CDC states that the median age for an autism diagnosis is between 4.5 and 5.5 years, even when developmental concerns were recorded before age 3.
The cost of autism over the lifespan is approximately 3.2 million dollars per person; 60% of those costs occur in adulthood when mandated services provided through Individuals with Disabilities Education Improvement Act have ended.

Currently, the government service system is difficult at best to navigate and too often when services *are* provided they may not be individualized or be the best approach for the needs of

the individual. The Autism Society believes that government services should help focus on advancing an individual's quality of life in measurable and meaningful ways. We need to re-examine how government services can be provided, not on limited definitions of services but rather based on an individual's need.

Today there is significant disparity nationwide in the need for and the availability of publicly funded long-terms services and supports for people with disabilities. This disparity has resulted in very long waiting lists. Estimates of the number of people with developmental disabilities in the U.S. waiting on various lists for services range from 80,000 to 200,000.

Meeting these significant needs will not only require expansion of services, we believe it requires us to think differently about the way services are delivered.

An individual determined by diagnosis to be eligible for services, when on a waiting list is being denied those critical services and has very limited options if they are unable to pay for private fee services or if they cannot access other services provided by the nonprofit or private sector community.

We recognize the realities of limited funding and encourage the committee to examine Medicaid funds spent on unnecessary administration and duplication at the expense of service provision. An example is a family that applies for services based on a diagnosis in one state needs to be reassessed for that disability if he or she moves to another state. This is an unnecessary cost to both the federal and other state governments.

We would also recommend that public schools must be prepared to provide a quality education for each child and prepare them for employment, advanced education and independent living so they are able to be successful adults. Reports from the National Center for Educational Statistics and the Department of Education show that only 43% of people with disabilities will graduate high school with a diploma. This means that 57% (likely comprised largely of students with developmental disabilities) either drop-out of school or receive a certificate of attendance that severely limits their ability to attend college or pursue competitive employment.

Related to education, Senator Harkin's Restraint and Seclusion Bill is critical for students with autism. Our society should not allow unnecessary restraint and seclusion of students with autism; they need to be present in the classroom in order to graduate with the strong educational foundation that prepared a student for the greatest degree of independence in employment and living – critical components of success in adulthood.

Quality of life for a person living with autism depends not only on the foundation that is provided in childhood but often requires ongoing supports that are specific to individual needs.

Government services must encourage work, family and savings (all common American values) for those who access social support services. Problems such as poverty are very common for people with developmental disabilities and can result in dependence on government support as

well as high rates of unemployment. Justifiably, concern rises when the national unemployment rate is above 5 or 6%. The Department of Labor reports that the unemployment rate is 78.5% for individuals with disabilities.

Government's response can be most effective when resources are available under one umbrella organization and allow more flexibility in the use of funds to help the unique needs of that individual. The committee may also examine how to more effectively coordinate the government's response through one-stop models and centralization of information.

The rules of Medicaid portability must be examined. When a person moves from one state to another, he or she loses their Medicaid Community Supportive Services and starts over again on the waiting list in their new state of residence. This has significant impact on our military families and has caused some families to maintain residence without jobs in order to maintain services.

The Combating Autism Act established the Interagency Autism Coordinating Committee which is, in concept, a great idea. But I ask you, how can true coordination occur if it is not comprised of adequate representation from both the private and not-for-profit sector? We suggest that this coordinating body must meet regularly and be made up of representatives from HHS, but also from the Departments of Labor, Justice, Housing and Defense. We also challenge the committee to examine where, in the federal government structure, IACC should be placed. When is within NIH, the coordination effort may be defined as health and research rather than focused broad-based service provision.

The Autism Society applauds the efforts of many organization and government agencies that have led the way in examining the important clinical research related to autism. Research is essential, but we believe there is an imbalance of funding directed at services or applied research. I would ask that the committee to examine the need for more service funding before any increases in research funding is provided.

Finally, I would like to encourage the committee to examine the real need for an increased federal response to the needs of adults living with autism. And each one should be given the opportunity to be a gainfully employed adult. It is not only the right thing to do, it will save tremendous resources to individuals, families and the government when those willing and able to work are provided the opportunity to earn a living wage. We must also provide a safety net for adults who still require services. I would also encourage the committee to examine the older adults with autism who are being cared for by aging parents. Again and again we hear that one of the biggest fears of parents is who will care for their child when they are no longer able.

I appreciate the interest from this committee in addressing how our nation can be more effective and responsive to people living with autism.

Thank you.

Mr. MEEHAN. Mr. Wright, you have one quick point?

Mr. WRIGHT. A piece information just came to my attention. The Senate just passed the TRICARE Amendment, restoring all military personnel ABA therapy with a retired end service. It's taken 5 years to do that, 5 years.

Mr. MEEHAN. Mr. Blaxill, you are now recognized for your testimony.

STATEMENT OF MARK BLAXILL

Mr. BLAXILL. Good afternoon. I'm honored to be here to represent SafeMinds, grateful to the chairman and to Congressman Burton for his terrific work, and I'm humbled by the opportunity to represent the community of autism families.

I would like to enter into the record—well, we had collected testimonials in the last couple days from over 300 autism families who wanted to attend the hearing but could not, and you can read their statements here.

Mr. MEEHAN. Without objection, so ordered. We will include that in the record.

The testimonials have been placed in the official hearing folder. Due to the volume they are not able to be printed.

Mr. BLAXILL. I wrote a book on autism. It argues that autism is a new condition.

In 1935, Leo Kanner wrote this book. It's 537 pages long. Not a whisper of autism in any of it. Three years later, he saw the first child with autism, a family from Mississippi that came all the way up to visit him, and he'd never seen a child like Donald Triplett before. In 1943, he wrote his famous paper in which he argued, "Since 1938 there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far that each case merits a detailed consideration of its fascinating peculiarities."

Before 1930, the rate of autism in the world and in America was effectively zero. Today, nearly 70 years after Kanner's paper, reported autism rates are 1 in 88. In New Jersey, 1 in 29 boys born in 2000 were diagnosed as autistic. What's going on? Why are so many American children sick?

I think we have to face reality. We need to be clear: Autism is a public health crisis of historic proportions, worse than poliomyelitis. It's devastating a generation of children and their families. We need to face that reality. Autism is a national emergency.

We skip to slide 5. There's a summary here of historical autism surveys in America. For a long time we had low rates in America, about 1 in 10,000.

Keep flipping. There we go.

Then around 1990, something new and terrible happened to a generation of children. Autism rates didn't just rise, they multiplied. This escalation covered both full-syndrome autism and the broader autism spectrum, including Asperger's.

Some people claim this isn't real, that we're just doing better diagnosing. That's just wrong. If you read the old literature, the old surveys, they looked for everybody, and they couldn't find people. They didn't miss 99 percent of the children with autism. It's not hard to find a child with autism. It's obvious when they're autistic.

The notion that we're just doing better diagnosing—even in the CDC studies, they're using the same methodology. So when you see those number rising, that's not because the methods are changing, it's because there are more cases.

In the midst of this crisis, the Federal agencies responsible for the health of our children have failed in their duty. CDC's negligence has led the way. Many of us believe CDC has actively covered up evidence surrounding autism's environmental causes. NIH, meanwhile, has received the lion's share of funding, money they've wasted on status quo research and gene studies. It's absurd to focus on genetic research in this crisis. There's no such thing as a genetic epidemic.

I'll skip past a couple of examples of malfeasance. I'll just say that in the financial world, the result of pressure to manipulate numbers to provide the answers that bosses want has a name; it's called securities fraud. In medicine there are similar pressures; they are called special-interest politics and even peer review. And what CDC has given us is the medical equivalent of securities fraud all to avoid the inconvenient reality of the autism epidemic.

In the face of a national emergency, government agencies, especially CDC and NIH, have performed poorly and behaved badly. We need accountable, new leadership on autism at NIH and CDC. We need an advisory committee that believes in combating autism, not newly stocked with—one newly stocked with appointees who actually oppose that mission. We need a Combating Autism Act that truly combats autism. We need to stop investing in the autism gene hunt and identify what has changed in the environment that could possibly have injured so many children. The scope and the magnitude of these changes, it's complicated, yes, but it can't be that complicated. There have to be a very small list of things that could have changed.

Ultimately we need to face and answer the question why are so many children sick. We'll only do that hard work if agency leaders are held accountable to the American people, not powerful interests in the medical industry.

So we're asking you the members of the committee, for your help. Please, let's not make this hearing a one-time episode. Please stay on the job in the next Congress. Root out the failures, the waste, the fraud, the negligence and the abuse in these agencies that aren't doing their job. We need CDC and NIH to do their jobs, and they're not. There's a crisis. We need your help.

Thanks very much for your time.

Mr. MEEHAN. Thank you. Thank you, Mr. Blaxill.

[Prepared statement of Mr. Blaxill follows:]

Testimony of Mark Blaxill
Board Member, SafeMinds
Before the
Committee on Oversight and Government Reform
US House of Representatives
November 29, 2012

Good afternoon Mr. Chairman and Members of the Committee. I am honored to be here today on behalf of the non-profit organization, SafeMinds, grateful to Chairman Issa for today's invitation and humbled by the opportunity to represent the community of autism families.

(Slide 1) In addition to my comments, I have provided a more extensive report from SafeMinds and documents for the record.

(Slide 2) In 1935, John Hopkins professor named Leo Kanner wrote the world's first textbook on *Child Psychiatry*. In 527 pages and 43 chapters, Kanner described every psychiatric condition in children know to medicine at the time. There was no condition remotely resembling autism.

In 1938, Oliver and Mary Triplett left Mississippi with their five year old son Donald to visit Kanner, by then considered the world's leading authority on children's development. When Kanner met Donald he was fascinated. He had never seen a child like him.

In 1943, Kanner wrote a paper inspired by Donald. "Since 1938," he wrote, "there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits-and, I hope, will eventually receive-a detailed consideration of its fascinating peculiarities."

The oldest child of the eleven described was born in 1931. Kanner subsequently diagnosed hundreds of children with autism, but never found a case born before 1930. The historical record is clear: before 1930, the rate of autism was effectively zero.

(Slide 3) Today, nearly 70 years after Dr. Kanner's paper, reported autism rates are 1 in 88 American children born in the year 2000. In some states, the rate is higher than 1 in 50.

(Slide 4) In New Jersey, 1 in 29 boys born in 2000 were diagnosed autistic.

What's going on? Why are so many American children sick?

Let's be clear. Autism is a public health crisis of historic proportions. Worse than poliomyelitis. It's devastating a generation of children and their families. We need to face up to the reality. Autism is a national emergency.

(Slide 5) Here's a summary of historical autism surveys in America. For a long time, reported U.S. autism rates were low, estimated at about 1 in 10,000. Then around 1990 something new

and terrible happened to a generation of children. Autism rates didn't just rise, they multiplied. This escalation occurred in both "full syndrome autism" and the broader autism spectrum, including Asperger's syndrome.

Some observers have claimed this rise is not real. That numbers are going up because of "better diagnosing." While it is true that we now diagnose autism with better tools, that doesn't mean there is some "hidden horde" of overlooked autism cases. The old surveys didn't just miss 99% of children with autism. Anyone who reads them will see the obvious: it's clear the researchers were diligent in finding cases and confident that they found the vast majority of children. It's horrible but true; reported rates of autism have risen simply because there are more cases of autism.

In the midst of this crisis, the federal agencies responsible for the health of our nation's children have failed in their duty. CDC's negligence has led the way. Many believe CDC has actively covered up the evidence surrounding autism's environmental causes

NIH has received the lion's share of Congressional funding, money they have wasted on status quo research and gene studies. It's absurd to focus on genetic research in this crisis, there's no such thing as a genetic epidemic.

(Slide 6) CDC first started investigating environmental causes in 1999 in Brick NJ. Their survey data showed that autism rates went from zero in 1989, to 1 in 128 four years later. But they used statistical tricks (and the fact that autism surveys miss many three and four years olds) to publish a finding that there was no increase.

(Slide 7) A CDC analyst also discovered in 1999 that higher levels of infant exposure to a mercury compound in vaccines increased autism risk more than tenfold relative to zero exposure. The analyst wrote about this result to his supervisors: "It just won't go away," he said. But he and his colleagues used more statistical tricks and published a finding that made the risk go away.

In the financial world, the result of the pressure to manipulate numbers to provide the answers bosses want has a name - securities fraud. In medicine there are similar pressures: they're called special interest politics and peer review and what the CDC has given us is the medical equivalent of securities fraud. All to avoid the inconvenient reality of the autism epidemic.

In 2006, Congress gave the NIH a mission to "combat autism." You authorized $850 million for that mission. Frustrating to most in the autism community, NIH spent most of that money on the great autism gene hunt while blackballing environmental researchers and defying parent concerns. It's been a colossal waste of money and time. Not a single case of autism has been prevented. Not a single child received improved treatments. American families deserve better.

In 2011, autism parents asked Congress to fix the bill. We told you that when you spend that much money on the wrong things, you haven't just wasted taxpayer dollars, you've

compounded the problem by reinforcing the denial. Unfortunately, Senate leaders didn't take the time they needed to fix the problems; they simply extended the old bill for three more years and the House went along rather than see nothing move forward.

(Slide 8) In the face of a national emergency, government agencies, especially CDC and NIH, have performed poorly and behaved badly. We need accountable, new leadership on autism at the NIH and the CDC. We need an advisory committee that believes in combating autism, not one newly stocked with appointees who oppose the mission, who want us to surrender to autism and oppose prevention and treatment research. We need a Combating Autism Act that truly combats autism. We need to stop investing in the autism gene hunt and identify what has changed in the environment that could have possibly injured so many children.

We need to conduct *independent* research into the great unmentionables, mercury and vaccines, connections that we've documented in the earliest cases. (I have provided to the Committee copies of my book, *The Age of Autism* which provides this history). These are the only environmental factors identified so far that are plausible causes for the magnitude and timing of this crisis.

Ultimately, we need to face and answer the question, why are so many American children sick? We will only do that hard work if agency leaders are held accountable to the American people, not powerful interests in the medical industry. So we're asking you, the members of the Committee for your help.

The autism community owes a debt of gratitude to Congressman Burton for his dedication to these issues. We hope as he retires from Congress, that other members of this Committee and Congress will continue his good work in seeking the truth about autism.

Don't make this hearing a one-time episode. Stay on the job in the next Congress. Root out the failures, the waste, the fraud and the abuse.

There's a crisis and we need your help.

Thank you for your time.

Attachments:
Slides

Blaxill Bio
SafeMinds Autism Report
SafeMinds Thorsen Report
EBCALA Paper Unanswered Questions

Mark Blaxil Bio

Mark Blaxill is the father of a daughter diagnosed with autism, a director of *SafeMinds*, Chairman and co-founder of the Canary Party, Editor-at-Large for *Age of Autism*, and a frequent speaker at autism conferences. He writes often on autism, science and public policy issues for *Age of Autism* and has published a number of articles, letters and commentaries on autism in journals such as *Public Health Reports*, the *International Journal of Toxicology*, the *Journal of Autism and Developmental Disorders*, *Neurotoxicology* and *Medical Hypotheses*. He has also been invited to peer review articles in journals such as the *New England Journal of Medicine*, the *American Journal of Epidemiology*, *Pediatrics* and the *International Journal of Toxicology*. As part of his advocacy work, he has testified before the Immunization Safety Review of the Institute of Medicine (2001), served on a Blue Ribbon Panel on Vaccine Safety (2004), initiated a symposium sponsored by the National Institute of Environmental Health Sciences entitled "Environmental Factors in Neurodevelopmental Disorders" (2005) and a workshop sponsored by the Institute of Medicine entitled "Autism and the Environment: Challenges and Opportunities for Research" (2007). He was a panelist at a "Meeting on Evaluating Reasons for ASD Trends" co-sponsored by the Centers for Disease Control and Autism Speaks (2011).

He received a bachelor's degree *summa cum laude* from the Woodrow Wilson School of Public and International Affairs at Princeton University and an MBA with distinction from Harvard Business School. In his professional career, he spent 25 years at The Boston Consulting Group, where he was a Senior Vice President. Recently, he co-founded 3LP Advisors, an advisory firm focused on intellectual property transactions, where he is a Managing Partner. He has published a business book, *The Invisible Edge: Taking Your Strategy to the Next Level Using Intellectual Property* (Portfolio, March 2009) and has recently co-authored a book on autism, called *The Age of Autism: Mercury, Medicine and a Man-made Epidemic*, (Thomas Dunne, September 2010).

Mr. MEEHAN. Mr. McGarry, you are now recognized for your testimony.

STATEMENT OF BRADLEY MCGARRY

Mr. MCGARRY. Thank you, Mr. Chairman, for the opportunity to address this committee and to discuss the rise in autism spectrum disorders, its impact on postsecondary education, and the allocation of government resources for ASD.

As we've discussed, the CDC now indicates that 1 of every 88 births in America results in a child diagnosed and living with autism spectrum disorders. As these numbers are staggering, students diagnosed with ASD are now of age where they are applying to higher-education institutions across the United States in the same record numbers. It is estimated that within the next 2 years, 1 of every 100 college applicants will have an ASD diagnosis, and this is just the beginning of the wave that has been characterized as epidemic.

In 1984, the Learning Differences Program at Mercyhurst University has educated and assisted nearly 1,000 students with disabilities to succeed in college, earn a degree, and go on to make a difference in the world.

In 2008, Mercyhurst introduced the Asperger Initiative at Mercyhurst to meet the unique needs of the growing population of college students diagnosed with Asperger syndrome and ASD. The AIM program focuses on building a foundation of self-advocacy, social skills, and sound academic progress.

Thanks to an appropriations grant in 2009, we did receive $100,000 from the U.S. Department of Education, and we were able to launch the AIM program. Two short years later, in 2011, Best Colleges Online ranked our Asperger Initiative at Mercyhurst number 3 in the Nation on their list of impressive special college programs for students with autism.

Mercyhurst President Tom Gamble emphasized that Mercyhurst believes that capable students, if given the environment and opportunity to succeed, will do just that. Dr. Gamble has committed Mercyhurst to continuing the development of the Asperger program.

Very few colleges and universities across the United States offer a program of collegiate support like AIM for the cohort—for this cohort of students. Too few are equipped to educate college and postsecondary students diagnosed with ASD. We have found that AIM students are able to excel academically, but most have a great need for internships and job coaching. Few have ever held a part-time job or understand the nuances of the workplace.

The Department of Labor and Industry's Office of Vocational Rehabilitation has been helpful in providing support for our AIM students, but is limited to only supporting students or employees, and neither internships nor job coaching are covered under current OVR restrictions.

Jane Thierfeld Brown cautions in her book, Students with Asperger Syndrome: A Guide for College Personnel, "The 1 in 88 number of incidence cited by the CDC will begin to be realized when overeducated and under- or unemployed adults with AS are brought into the welfare and social services systems. Individuals

without jobs will pose a burden on their families, on insurance companies, and on Federal and State social services. This is not only unnecessary, but also critically unfair to a large group of people in our society. To prevent this scenario, changes must begin now."

Mercyhurst is dedicated to educating and preparing all of our graduates for productive careers. We've tried to develop partnerships and have with Verizon Foundation, the PNC Bank Foundation, Conquer the Canyon, and other private donors. The next step for the AIM program is to fund and launch our internship program for our seniors and provide job coaches as needed to prepare them for the workplace.

The AIM program has been cited as a model program and has implemented a majority of the innovative components of the program with limited resources and opportunities beyond the commitment of the university. It is our hope that a strong consideration is made for allocations of government resources to fund programs like the Asperger Initiative at Mercyhurst that assists students not only in receiving a college education, but also in helping them become productive citizens in our society.

As a provider and a father, I strongly feel we need to act now before the task before us becomes insurmountable.

Thank you again for your time and this opportunity.

Mr. MEEHAN. Thank you, Mr. McGarry, for your testimony.

[Prepared statement of Mr. McGarry follows:]

Committee on Oversight and Government Reform

29 November 2012

TESTIMONY by: **Bradley McGarry, M.A.** | Coordinator Asperger Initiative at Mercyhurst (AIM) program - Mercyhurst University, Erie, Pennsylvania

Thank you for the opportunity to address this committee and discuss the rise in Autism Spectrum Disorders; its impact on post-secondary education; and address the allocation of government resources for ASD. This testimony covers a discussion of the statistics of this disorder; the needs of this population and their ability to become productive citizens; and a vision for the critical next steps.

STATISTICS

As you know, the CDC now indicates that 1 of every 88 births in America results in a child diagnosed and living with an Autism Spectrum Disorder. As these numbers are staggering, students diagnosed with ASD are now of age where they are applying to higher education institutions across the United States in the same record numbers. It is estimated that within the next two years, approximately one of every 100 college applicants will have an ASD diagnosis and this is just the beginning of the wave that has been characterized as "epidemic."

Since 1984, The Learning Differences Program at Mercyhurst University has educated and assisted nearly 1,000 students with disabilities to succeed in college; earn a degree and go on to make a difference in the world. Students with learning, sensory, and physical disabilities experience intellectual and personal development as they work toward graduation with the help of our award-wining programs, recognized by K&W Guide and Peterson's Guide to Exemplary Programs for Students with Learning Disabilities. Our newest program (and only one-of-its-kind in Pennsylvania) is called AIM--the Asperger Initiative at Mercyhurst for students diagnosed with Autism Spectrum Disorder (ASD).

The Asperger Initiative at Mercyhurst, (AIM) focuses on building a foundation of self-advocacy, social skills, and sound academic progress. Students interact with faculty and a qualified staff of professionals all over campus and receive a full complement of educational and social services. In 2008, Mercyhurst introduced the AIM Program to meet the unique needs of the growing population of college students diagnosed with Asperger Syndrome (AS) and (ASD). Our goal is to prepare all our graduates for a productive life and remove barriers to their ability to be successful in a college or vocational environment.

Thanks to an Appropriations grant in 2009, supported by then Pennsylvania Congresswoman Dahlkemper and Senators Casey and Specter we received $100,000 from the US Department of Education and were able to launch the AIM program. In 2011 Best Colleges Online ranked the

Asperger Initiative at Mercyhurst #3 in the nation on their list of Impressive Special College Programs for Students with Autism.

Mercyhurst President, Tom Gamble emphasizes that Mercyhurst believes that capable students, if given the environment and opportunity to succeed, will do just that. Dr. Gamble has committed Mercyhurst to continuing the development of the Asperger Program.

VOID

No other college in northwestern Pennsylvania and very few across the entire Commonwealth and United States offer a program of collegiate support like AIM for this cohort of students. Many colleges and universities teach teachers how to become Special Education teachers and educate students on the spectrum. Too few are equipped to educate college and post secondary students diagnosed with ASD.

VISION

We have found that AIM students are able to excel academically but most have great need for internships and job coaching. Few have ever held a part-time job or understand the nuances of the work place. The Department of Labor and Industry's Office of Vocational Rehabilitation has been helpful in providing support for our AIM students but is limited to only supporting "students" or "employees" and neither internships or job coaching are covered under current OVR restrictions.

We met with members of the US Department of Education, Research to Practice Division OSEP less than a year ago and have hit a brick wall as far as finding funding to advance our AIM program. Two-follow up teleconferences were held – the first with the Director of Research, Training and Education at the Maternal and Child Health Bureau of HHS – where the Combating Autism Act is administered. We learned that although the Act was reauthorized and extended existing appropriations for 3-more years. No NEW programs have been invited. (Senator Casey sponsored this bill in the Senate.) Our second teleconference was with the manager of Transition and Postsecondary Programs for Students with Disabilities at the Department of Education. Again we learned there are no NEW funding appropriations available for new programs.

Jane Thierfeld Brown, Ed.D. cautions in her book ***Students with Asperger Syndrome: A Guide for College Personnel***

> "The 1-in-88 number of incidence cited by the CDC will begin to be realized when overeducated and under- or unemployed adults with AS are brought into the welfare and social service systems. Individuals without jobs will pose a burden on their families, on insurance companies and on federal and state social services. This is not only

unnecessary but also critically unfair to a large group of people in our society. To prevent this scenario, changes... must begin now. "

Mercyhurst is dedicated to educating and preparing ALL our graduates for productive careers. We have developed partnerships with the Verizon Foundation, PNC Bank Foundation, Conquer the Canyon, and private donors. The next step for the AIM program is to fund and launch an Internship program for our seniors and provide job coaches as needed to prepare them for the workplace.

Mercyhurst plans to share our best practices, the Four Domains, applicant rating form, three-tier stratification of services, faculty training programs and peer mentorships in a white paper and professional development session this coming April during Autism Awareness Month. We have invited the 16-member colleges and universities in the Conference of Mercy Higher Education as well as all post-secondary institutions in the tri-state area of northwestern Pennsylvania, western New York and eastern Ohio.

Some of the innovative components of the AIM Program include the following.
The AIM Program has identified and developed four domains that are essential for students on the spectrum to be successful in higher education and vocational endeavors.

- The first is **Academic Social Progress (ASP)**. In this domain we track class participation, appropriate social engagement within the classroom, and preparation for course materials.
- Second, **Independence** tracks things such as living independently, organization, preparation and selection of meals and managing money.
- Third is **Social**. Here we monitor the social interaction within the program, on-campus, and in the community.
- **The last domain is Emotional where we monitor student's ability to adjust to the rigors of college life.**

We track these domains and program participation and have developed an **AIM GPA** that assists us in evaluating student progress and compare students of a given cohort.

Students who participate in the AIM program gain access to numerous services to assist them in being successful on campus.

- Some students choose to live in specialized AIM housing where a Hall Director trained in ASD, lives in a communal environment with the students. The students live with another person, yet have their own bedroom, which is an uncommon luxury at Mercyhurst.

- The Peer Mentoring Program consists of students meeting with a Peer Mentor Volunteer at a minimum of 2 to 4 hours per month. AIM Students also have a separate opportunity to be mentors themselves to adults with more severe disabilities at a local agency in Erie.

- Social Skills Training.

- Individualized Course Planning

- Weekly meetings with Program Academic Counselors

- Peer and graduate-level tutors

- Notetakers

- Testing accommodations
- Availability of assistive technology (i.e. Kurzweil readers and iPads)

- Priority registration

- Social group outings
    - Washington, DC
    - Grand Canyon National Park "Conquer the Canyon"
    - Niagara Falls National Park
    - Other local and campus outings

The AIM Program has been cited as a model program and has implemented a majority of these components with limited resources and opportunities beyond of the commitment of the university. It is our hope that a strong consideration is made for allocation of government resources to fund programs like the Asperger Initiative at Mercyhurst that assists students not only in receiving a college education, but also in helping them become productive citizens in our society.

Thank you again for your time and this opportunity.

The Asperger Initiative at Mercyhurst (A.I.M.)

AIM in the news
http://www.mercyhurst.edu/learning-differences/asperger-support/in-the-news/

Brad McGarry and AIM Program featured in Chronicle of Higher Education (p.43)
http://www.saabnational.org/docs/convergence2012.SAAB_Feature.pdf

Mercyhurst joins global initiative to shine blue light on autism
http://www.mercyhurst.edu/news/news-releases/article/?article_id=2591

AIM #3 Ranking
http://www.bestcollegesonline.com/blog/2011/05/25/10-impressive-special-college-programs-for-students-with-autism/

The Conquer the Canyon with AIM News Release
http://www.mercyhurst.edu/news/news-releases/article/?article_id=2764

Information page for Conquer the Grand Canyon with AIM
http://www.conquerthecanyon.com/mercyhurst/AIM

YouTube link for Conquer the Canyon
http://www.youtube.com/watch?v=14Wcl38TXU8&feature=youtu.be

Demand surges for Mercyhurst's autism summer program
http://foundations2011.blogspot.com/2011/07/mercyhurst-featured-article.html

Asperger Initiative Continues to Grow
http://merciad.mercyhurst.edu/content/aspergers-initiative-continues-grow

Washington Watch Grant for the AIM Program
http://www.washingtonwatch.com/bills/show/ED_69730.html

Story about AIM profiling one of our recent graduates
http://www.pottsmerc.com/article/20120202/NEWS/120209888/-1/LIFE/pa-university-program-helps-autistic-students?mobredirect=true

Mercyhurst AIM Program Ranked Nationally
http://www.mercyhighered.org/news_mercyhurst.html

Mr. MEEHAN. Mr. Carley, you are now recognized for your testimony.

STATEMENT OF MICHAEL JOHN CARLEY

Mr. CARLEY. Mr. Chair, I would ask for just a little bit of leeway, since having only been asked to speak Monday morning, I haven't had the same amount of editing time as many of my colleagues. Just a minute or 2 would be most——

Mr. MEEHAN. Do your best, and we'll work with you.

Mr. CARLEY. Thank you very much.

As the executive director of both ASTEP and GRASP, and on behalf of both my boards, I would like to thank all the members of the committee here for having me to speak.

I bring two concerns, both of which shed light on a population of people on all sides of the spectrum and all sides of the many controversies that exist in the autism/Asperger world who are simply overwhelmed. And I hope to be able to stress the negative consequences on us all when so many are enduring financial, logistical, and emotional stresses of a magnitude that might surprise you.

My first concern is the more standard apprehension concerning the direction and prioritization of government funding. Currently the emphasis is on government research, and there is good herein, as well as fairness, for there is a vastly disproportionate amount of research funding for autism when compared with infinitely less prevalent conditions.

All that said, however, research is based on the future and not where our greatest need lies, which is in the present. Today the services we collectively offer is paltry in comparison with the true need that's out there right now.

The majority of our families still do not have the appropriate services, interventions, or educations available to their children, and adults on the spectrum are starved for appropriate housing, therapies, and employment opportunities. And if fiscal concerns are indeed something which we measure things by, then let's think of that adult who if they are able in a job employment program to become a taxpaying, productive member of society rather than existing on government support seems to me like a financial no-brainer. And for those who are not able to participate in programs like that, think of the productivity that is lost because the parents can't produce like they used to. Why we never consider the fiscal costs of not providing services is still a mystery to me.

And I disagree with some of the testimony we have had here before. We are not amidst a health crisis. We are amidst a services crisis.

My second concern has to do with how we implement whatever direction we take in terms of the tone or the language being used. Now, tone or language may seem like PC, self-help, feel-good spin to a lot of people, and I understand that, but it's not for someone on the spectrum who grows up having to hear words like "cure," "disease," "defeat," and "combat," words that have no medical basis given the genetic component of autism. For though we may improve dramatically, we're born with this, and we will die with this, and such negative self-imagery makes self-esteem so much harder

to achieve for an individual who is at a psychological disadvantage enough as it is.

We have to remember that the majority of this population now can read what's being written about them and hear what's being said about them. And as we all grow, whether on the spectrum or not, we need to hear about what we can do, not what we can't do.

Autism is simply more complicated than any of us want it to be. Try as we may, we cannot sloganize it, we can't dumb it down. And historically our refusal to accept the complexities of this vast spectrum has created a competition of suffering amongst ourselves that has made the autism world and its politics one of the most emotionally unhealthy atmospheres you could ask to work in. Is this because we're all so overwhelmed, thanks to unmet service needs, to process these different lives in a more productive manner? I think the answer is yes.

Now, I was lucky. When my then 4-year-old son and I were diagnosed with Asperger's in late 2000, I was at a point in my life where I had a family, I had a career. It was a weird life. I was a starving playwright by night and a minor league diplomat during the day, working in such places as Bosnia and Iraq. But there was proof that there was possibility within my son's diagnosis. Most other parents might have resorted to praying that their child could have a future. Thanks to my diagnosis and a life lived up to that day, I had the advantage of evidence-based conviction, not hope, and self-esteem was the most formulative factor in all of that.

Now, granted, I am at one end of the spectrum, and I understand that to many parents I will seem like the possible and not the probable. But I also would never invalidate that the prognosis for me was once not so good, nor that my behaviors haven't dramatically changed for the better. And what is considered probable has changed immensely over the last 10 years, and that is a credit to everybody working in the autism world. Self-esteem again was the most predominant quality that got me to that point, because, unlike other people on the spectrum who are brilliant, I don't have that kind of a brain.

And lastly, it's an ethical mistake whenever we sacrifice the possible in the name of the probable. As national nonprofits like government thus far——

Mr. MEEHAN. One question. Is there one more point you wanted to make, or is this your conclusion?

Mr. CARLEY. This is the concluding paragraph.

Mr. MEEHAN. Take your time. I didn't mean to rush you that much, but I thought you had another whole point you were developing.

Mr. CARLEY. I'm good, sir, no.

As national nonprofits like government thus far, we, too, have often failed to lead. Our centrists have frequently been too hesitant, but more damaging are the militants on opposite ends of the controversies who have pandered to their members' anger, anxiety or depression with alarmist rhetoric, misinformation, fight talk, and all this encouraging the search for a bad guy, somebody to blame, thereby pouring gasoline on the fires of the people that are looking to us for leadership instead of helping them with messages of acceptance, respect, openness to a path that may be different

from what was expected, and helping them get the services they need.

I ask this administration as well as our community to lead and to help these constituents in such a way that will not just be acceptable to the polls or pander to any ill-conceived notion that an injustice was done or that there's something in the water. I cannot stress enough my disappointment that the conversation on vaccines is still evident. Despite the immense——

Mr. MEEHAN. Mr. Carley, at this point, I appreciate that, but in respect to each of the panelists, I have given you a significant period to go on, but please appreciate that we will take your testimony in its written form and ensure that it is part of the written record. Thank you so much.

[Prepared statement of Mr. Carley follows:]

As the Executive Director of both ASTEP and GRASP, the latter being the largest chapter and membership organization in the world of adults diagnosed along the autism spectrum, and on behalf of both my boards, I would like to thank all the members of the House Committee on Oversight and Government Reform for inviting me to speak here today.

My concerns are twofold; the first being the more standard apprehension concerning the direction and prioritization of government funding. Currently the emphasis is on research, and there is tremendous good herein. The scientific work being conducted on spectrum wiring, serotonin levels, or nerve function will someday teach us about the brains of farmers, executives, and machinists, in addition to those of people on the spectrum. And yes, there is a vastly disproportionate amount of research funding for autism when compared with infinitely-less prevalent conditions. However, we ask that if research is going to be the primary focus, that government lead, and not pander. 30 million dollar grants given to study the merits of chelation therapy—as a bone to groups who believe people like myself are chemical accidents caused by vaccines—only boost the perceived legitimacy of these groups so that now we see outbreaks of preventable diseases, especially in California and Minnesota. This is not serving the American people.

All that said, however, research is geared towards the future, and not where the greatest need lies, which is in the present. Today, the amount of services we collectively provide is like one page out of War and Peace when compared with what's needed. The average working family with a child with autism is overwhelmed, as are the average adults on the spectrum. The majority of families still do not have the appropriate services, or educations available to their children, and adults on the spectrum are starved for appropriate housing, and employment opportunities.

My second concern is less specific, but greater in spirit, and that is having to do with how we *implement* whatever direction we take, in terms of the tone, or the language being used. Call it, if you will, an emphasis on the singer, not the song.

Tone, and language may seem like pc-nonsense semantics to many, but not to someone on the spectrum who grows up having to hear words like "cure," "disease," "defeat," and "combat"—words that have no medical basis given the genetic component of autism (for though we may improve dramatically, we're born with this and will die with this) and given the harm these words cause there is also no ethical basis for their usage. Especially when the words come from not just misguided ad campaigns, but coming from people who might genuinely love us, people who use these words because they learned them from experts on TV . . . Such negative self-imagery makes self-esteem so much harder to achieve for an individual who is at a psychological disadvantage enough as it is. We have to remember that the vast majority of this population can read what is being written about them, and

hear what is being said about them. And as everyone of us grows, spectrum or not, we need to hear about what we *can* do, not just what we can't.

Autism is more complicated than any of us want it to be. The spectrum ranges from many famous people now being diagnosed in retrospect to the severely challenged non-verbal individual who may never hold down a job or enjoy an intimate relationship. And when the controversial and highly criticized DSM-5 comes out, we won't even be referring to it as a spectrum. We will all be diagnosed with autism, further disallowing our human need to compartmentalize. There are good things and bad things about this last point, but historically this vast spectrum, and our refusal to accept its complexities, has created a competition of suffering that has made the autism world and it's politics one of the most emotionally-unhealthy atmospheres you could find. The sooner we reject the ability to communicate as the measuring stick of happiness the better.

My son and I were diagnosed one week apart from one another in late 2000. Having already started a family, and had a career, I did not switch to praying (once we got the news) that my son could have a future. Thanks to my diagnosis, I *knew* he could. I had the advantage of evidence-based conviction, not hope. Granted I am one end of the spectrum, but I would also never invalidate that the prognosis for me was once not good, and that my behaviors have certainly changed. I am perhaps to many parents the possible and not the probable. But my relative luck is greatly due to my youthful, stubborn instinct that I could not think myself lesser because I processed thoughts, emotions, and experiences differently. One certain law of ethics is that we make tremendous mistakes when we sacrifice the possible in the name of the probable. My son's initial prognosis too, twelve years later, has since been discarded for a better outlook thanks in part to the positivity of the supports he has enjoyed. He has had good songs, but great singers.

As non-profits we too have often failed to lead. Our centrists are often too central, but more damaging is that the militants on opposite ends in particular, have pandered to their members' anger, anxiety or depression with alarmist rhetoric and fight talk—thereby pouring gasoline on their fires—rather than help them with messages of acceptance, respect, and openness to a path that may be different from what was expected. I ask this administration as well as our so-called community to lead in a way that will not just be acceptable to the polls, but that will also guide people on the spectrum and their loved ones on the path to building lives with the potential for emotional strength. Despite the immense progress we've achieved surrounding what is summoned by these words "autism" or "Aspergers," our members on all sides are overwhelmed with financial, logistical, and emotional stresses that cause them the aforementioned anger, anxiety, or depression; real enemies that lead to costly mistakes, and that increased services would dramatically reduce. Thank you for listening.

Michael John Carley received his B.A. from Hampshire College in 1986 and his M.F.A. from Columbia University in 1989. In addition to being an author, he serves as both the Executive Director of GRASP, and the Executive Director of ASTEP.

As the Executive Director of GRASP, the largest organization in the world comprised of adults on the autism spectrum, he has made over 90 speaking engagements to conferences, hospitals, universities, and health care organizations.

As the new Executive Director of ASTEP, he works with corporations helping them to understand the needs of their spectrum employees and has spoken at several Corporate Diversity conferences.

He has appeared in the media widely, most notably in the New York Times, Washington Post, NY Newsday, the London Times, the Chronicle of Philanthropy, the Chronicle of Higher Education, NEWSWEEK OnAir, ABCNews, BBC News, Huffington Post, Exceptional Parent, Psychology Today, and on radio with Terry Gross' *Fresh Air*, and *The Infinite Mind*. NPR News also aired a 12-minute story in June of 2006 that featured he and GRASP. Carley was also featured in the documentary, "On the Spectrum." His articles have been published in magazines such as Autism Specrum News, Autism Spectrum Quarterly, TAP (The Autism Perspective), Autism/Asperger Digest; and in newsletters such as the OARacle. His first book, *Asperger's From the Inside Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* (Penguin/Perigee), was released in April, 2008, and he has recently completed his second book, *The Last Memoir of Asperger's Syndrome* (TBD).

He was the inaugural FAR Fund Fellow in 2003; and he has since received NYFAC's Ben Kramer Award (2008), the BCID Award for Service (2009), Columbia University's Herbert M. Cohen Lecture (2011), and Eden II's Peter McGowan & John Potterfield Achievement Award (2011).

Until 2001, Mr. Carley was the United Nations Representative of Veterans for Peace, Inc. In that time, he was known primarily for his work in Bosnia, and in Iraq as the Project Director of the internationally acclaimed *Iraq Water Project*. Prior to 2001 he was a playwright who enjoyed 15 productions and 10 readings of his plays in New York.

Along with his (then) 4-year old son, he was diagnosed with AS in November of 2000. He lives with his wife, Kathryn Herzog, and 2 sons in Brooklyn. In his spare time, he coaches travel baseball.

Mr. MEEHAN. Mr. Ne'eman, at this point in time, I recognize you for your testimony.

STATEMENT OF ARI NE'EMAN

Mr. NE'EMAN. Thank you, Mr. Chairman, Ranking Member Cummings, and esteemed members of the committee.

My name is Ari Ne'eman. I represent the Autistic Self Advocacy Network, an organization run by and for autistic people. I also previously served on the Interagency Autism Coordinating Committee. And let me just say, as an autistic person and as a taxpayer, I want to thank you for giving self-advocates a seat at the table today.

I would like to begin with a story. Earlier this year, I was visiting a service provider in New York, and I happened to meet a young man my age. We will call him Joe, and Joe is autistic, like me, but unlike me, Joe doesn't speak. He had come in with his father to try and find a job, and I had the chance to sit down with him and his dad and ask them questions. And Joe, despite not speaking, found ways to be very actively involved in that conversation. He pointed at what he was interested in, shook his head at what he wasn't. He had plenty to say, and few people had ever bothered to pay attention. No one had ever given Joe the simple support of a communication device. That technology exists. It has for years. We just don't invest in it. And I think about Joe a lot at times like this because the current autism research agenda largely ignores his needs.

I am a big believer in the old maxim, in God we trust, everyone else please bring data. So if you don't mind, I would like to point to some of the data in the autism research agenda and see what it shows us. In 2010, NIH spent about $217 million on autism research. Of that, only 2 and a half percent went to research on improving the quality of services; only 1 and a half percent went towards research on autistic adults and our needs. Now, when you compare that to the percentage of the research agenda focused on causation and biology, the attention paid to the needs of us here today is laughably small.

I am not here to speak for all autistic people. That is impossible. But I am here to speak for the right of every autistic person to get the support they need to speak for themselves and not to be written off as victims or burdens.

Now some have tried to justify the lack of attention paid to services and adult issues through talk of an epidemic. I don't happen to subscribe to that theory, but if we wanted to study it and evaluate it scientifically, a very simple step we could take would be to research the prevalence of autism in the adult population.

The United Kingdom, in fact, conducted that study and found a comparable rate of autism in adults as in children. We should be doing that here, and regardless of the result, we would gain valuable information on supports for autistic adults.

I want to highlight three additional points, noted at more length in my written testimony. First, I think it is very important to stress that there are really severe racial, income, and gender disparities in the autism world. As was mentioned earlier, African American children are diagnosed significantly later than Caucasian

children. Department of Education data has also showed us that low-income and minority youth on the spectrum have the lowest rates of employment and higher education access in the years after they leave school.

We also know that gender plays a big role. Many believe that the 4 to 1 ratio of boys to girls being diagnosed is at least partially a self-fulfilling prophecy with girls less likely to be identified because they don't fit the stereotype.

Second, I think it is important that we recognize that when we talk about autism services, we are mostly talking about services with the word disability, not autism on them. So we have to talk about programs like IDEA and Medicaid, and a few words on Medicaid in particular. The vast majority of disability services are financed through Medicaid. If that program were block granted or otherwise significantly cut, those services would be devastated. I cannot emphasize this enough. Ending a robust Federal commitment to Medicaid means ending any meaningful chance we have to support autistic people.

Third and finally, I want to stress the importance of building a pathway to employment for my community. Our current disability service provision system actually makes it very hard for people who want to work to enter the workforce. If you are leaving school, you have to choose between going without support or committing to exit the workforce in order to qualify for SSI and Medicaid. Quite frankly, that is just bad public policy. If you want autistic people to be taxpaying citizens, and we want to be, we need a service system that emphasizes employment.

The Affordable Care Act has made some progress toward those ends. Another good example of what more we could do can be found in the TEAM legislation, a bipartisan collection of bills on transition for youth with disabilities introduced by Representatives Harper and McMorris Rodgers.

In closing, I want to point out that historically most disability movements have a certain life cycle, and autism is no exception. In the beginning, most public attention focuses on questions of cure and causation, but with time, both advocates and policymakers realize that the real issues relate to helping support and defend the civil rights of people today. Now, in autism, that process is still going on, but I am confident, I am confident because I believe this is a civil rights issue, and I believe that the United States of America can guarantee the civil rights of all of its citizens.

Thank you very much. I look forward to your questions.

[Prepared statement of Mr. Ne'eman follows:]

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U.S. House Committee on Oversight & Government Reform

November 29th, 2012

Key Issues:

- Federal autism research funding is in need of re-balancing to increase allocation of funds focused on improving the quality of service-provision and addressing the needs of Autistic adults and adolescents.
- The Autistic adult population has been largely ignored in autism policy discussions to date – future federal policy must work to try and address this issue.
- Significant racial, gender and income disparities exist in access to autism diagnosis and services.
- The Medicaid program is the primary financing mechanism for autism and disability related service-provision and support. The federal role in Medicaid remains absolutely crucial and must continue to emphasize systems change transformation towards more integrated settings for people with disabilities.

Chairman Issa, Ranking Member Cummings and esteemed members of the Committee, thank you for the invitation to speak to you today on federal policy regarding the autism spectrum. My name is Ari Ne'eman and I represent the Autistic Self Advocacy Network (ASAN), the leading national advocacy organization run by and for Autistic adults speaking for ourselves. As an Autistic person, I want to begin by thanking the committee in particular for hearing from self-advocates – that is not always a given in the autism world and I am profoundly grateful to both the majority and minority members and staff for ensuring that we are represented at this hearing about us.

Over the last decade, we have seen growing public attention towards the autism spectrum, in part driven by rising rates of diagnosis. Although additional public attention has provided an opportunity for greater visibility to the idea of autism, such visibility historically has not translated into attention or resources on the issues that matter most to Autistic people and our families.

There are a variety of reasons for this – one of the most prominent of which is the history of under-representation of adults on the autism spectrum in policy conversations about us. Additionally, one of the most important things to remember in discussing federal policy regarding autism is that the vast majority of publicly financed resources that those of us on the autism spectrum interact with carry the word disability rather than the word autism. As a result, my testimony will touch on both federal policy that is specific to autism as well as general disability policy issues, such as Medicaid, that significantly impact Autistic people and our families.

First, the majority of federal attention focused on autism in particular comes in the form of research funding. While we have been pleased to see an increase in federal autism research dollars over the course of the past decade, it is very important that we evaluate how we are spending that money. I am a big believer in the old maxim, "In God we trust, everyone else please bring data," so let's turn to the data and see what it shows us.

Of the approximately $217 million dollars that the National Institutes of Health (NIH) invested in autism research in 2010 (the most recent year for which data is available), only a meager 2.45% went towards improving the quality of services and supports available to Autistic people and our families. Only 1.5% went towards research that addresses the needs of Autistic adults. When compared to research on questions of causation, etiology and biology and diagnosis, the percentage of the autism research agenda focused on the actual needs of Autistic people in order to improve their quality of life is miniscule. We are pro-research, but the research agenda must be re-balanced to incorporate both causation and quality of life.

This matters. It matters more than I can possibly articulate, but I will try to do so, nonetheless. I remember recently visiting a service provider in Manhattan earlier this year to learn more about how we can improve disability employment outcomes for people with severe disabilities. While I was there, a non-speaking Autistic man in his mid-20s came in with his father. They were

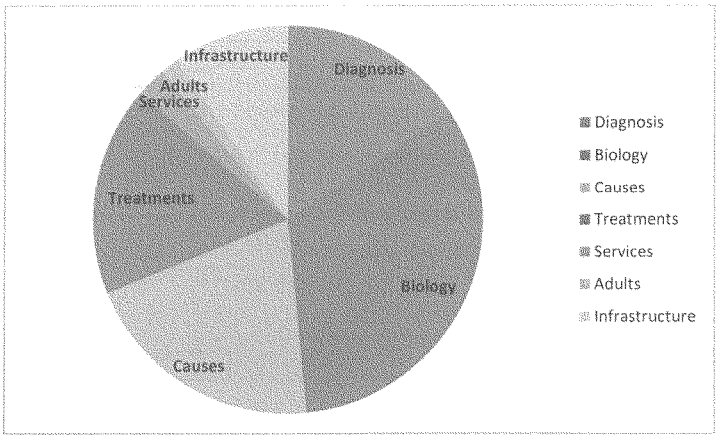
looking for some help trying to find him a job or at least something meaningful to do with his day. I asked him some questions and his father helped give responses, but it was immediately clear that his son knew exactly what I was saying, he pointed out what he was interested in, he shook his head at what he had no interest in, he raised his hands when he was excited. He had plenty to say and clearly rarely got the opportunity. I think about that young man – who probably wasn't that much older or younger than me – often, and particularly at times like this.

Members of the Committee: Why can't we do better for him? Why can't we give him a chance to communicate more clearly, to not only sit here and testify before Congress someday but also be able to tell his supporters and friends what he wants for his life, to tell his parents that he loves them and how important they are in his life? Some people say that until we unravel the causation of autism, that is impossible. That is quite simply not the case – Augmentative and Alternative Communication technology has existed for many years now and can empower even those of us who cannot speak to make their voices heard.

If we invested a mere one-tenth of the amount of money that we currently pour into causation into empowering Autistic people to communicate, that young man and hundreds of thousands more like him would be able to communicate their needs to us today. I am not here today to speak for every Autistic person – that's impossible. What I am here for is to argue for every Autistic person to have the same opportunity to communicate that I have come to enjoy thanks to the support that I have been lucky enough to receive in my life.

Some might wonder if this gap is being filled by private sector research dollars, explaining the lack of federal investment in these areas. The data suggests otherwise – the two largest private sector autism research funders – Autism Speaks and the Simons Foundation – devote even less to these areas, with Autism Speaks investing approximately 1% of its research budget to studies on the quality of services to Autistic people (and less than one quarter of a percent to Autistic adults) and the Simons Foundation making no investments in either area. It cannot be doubted that when it comes to the needs of Autistic people today both the public and private research agendas are quite simply not responsive to the priorities of the Autistic community, itself.

2010 NIH Autism Research Funding By Category Area



Source: IACC/OARC ASD Research Portfolio Analysis Web Tool, Office of Autism Research Coordination, National Institute for Mental Health

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Now, this is important for multiple reasons. First, there are fundamental issues of equity when the vast majority of research dollars raised in our name is spent on things that have little to no practical impact on our quality of life. Beyond that though, we are as a country in the midst of a rather extensive conversation publicly financed programs, including Medicaid, Medicare and Social Security. These programs, most notably Medicaid, finance the great majority of services and supports that Autistic people interact with throughout our lifetime.

If we are going to have conversations on controlling costs while increasing rather than reducing the quality of service and the number of people served, it is absolutely imperative that we fund research that can support those types of outcomes. There is precedent for making progress on both quality improvement and cost savings in disability service-provision – the success of de-institutionalization and community living supports provide a perfect example of this – but research has to play an important role.

The disproportionate emphasis on questions of causation has at times been justified as a means of addressing concerns about the rising rate of autism diagnoses, with some expressing concern about an "autism epidemic". While the possibility of increasing incidence cannot be fully discounted, a growing amount of evidence suggests that may not the case.

If we want to put the idea of an "epidemic" to the test, one of the most compelling lines of research we could pursue is an epidemiological study of the rate of autism among the adult population. A recent study of this nature conducted by the United Kingdom's National Health Service found a comparable rate of autism in adults as in children in England[1]. Many of the Autistic adults identified by this study faced significant employment and housing related challenges. Should the CDC conduct a similar study in the United States, we would gain valuable information not only on the question of whether or not autism rates are in fact rising but also on the service and support needs of the older segment of the Autistic community.

It is important to realize that when we talk about outcomes for Autistic people, we need to discuss more than just questions of biology and even severity of impairment. Recent studies have found that racial and income disparities play a significant role in determining what happens to youth on the autism spectrum after we leave school. Studies of Medicaid-eligible children show that African-Americans are diagnosed significantly later than Caucasian children[2].

We also know that gender plays a big role – women and girls on the autism spectrum are largely ignored in most research and policy discussions. Many believe that the 4 to 1 ratio of boys to girls being diagnosed with autism has become something of a self-fulfilling prophecy, with girls less likely to go diagnosed because they fail to fit the stereotype of what an Autistic person looks like. Indeed, in clinic samples Autistic girls are more likely to possess accompanying intellectual disability, suggesting that girls without accompanying cognitive impairment or language delays may be going unrecognized[3,4].

As Autistic children grow into Autistic adults, the research shows that racial and income disparities continue to persist. Compared to youth with other disabilities, Autistic young adults are less likely to have employment or higher education opportunities in the six years after leaving high school. At least one-third of Autistic youth have no higher education or paid employment experience after school. For African-American, Hispanic and low-income youth, the rate of unengaged youth is significantly higher. This reinforces the need for serious investment in post-secondary transition for youth with significant disabilities to try and address this gap before the upcoming generation of Autistic youth is condemned to a lifetime of social exclusion and un- and under-employment.

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[2] Mandell, D.S., Listerud, J., Levy, S.E., Pinto-Martin, J.A. (2009). Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children With Autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41, 1447–1453.

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One possible solution can be found in the TEAM Acts, a collection of three bills introduced by Congressman Gregg Harper and Congresswoman Cathy McMorris-Rodgers, each of which proposes to invest in transition-focused services in our public school, voc rehab and developmental disability service-provision systems.

I was fortunate – although my family is by no means wealthy, they had the means to hire a transition support consultant when I was preparing to leave high school. Because of that, I was able to live independently, go to college and find successful employment. Not all autistic youth are getting the same opportunities. We need to invest in research and service-provision across the lifespan to fix that.

So, this leaves us with one question: what does our service-provision system need to better deliver on employment, inclusion and quality of life for Autistic people across the lifespan? First, it is important to recognize that our system depends on the Medicaid program. The vast majority of services and supports geared to Autistic people and our families are financed by Medicaid. If that program were to be block granted or subjected to ill-advised per capita spending restrictions, those services would be significantly reduced or eliminated. I cannot emphasize this enough: ending a robust federal commitment to Medicaid means ending any meaningful chance to support Autistic people, our families and all people with disabilities towards dignity and independence. We cannot allow that to happen.

Second, we need to think seriously about how we can support Autistic youth into entering the workforce. The Affordable Care Act's end to pre-existing condition discrimination and introduction of new health insurance exchanges open up significant opportunities in that direction by opening up the private health insurance market to our community. Further reforms are needed, however, most particularly to the Supplemental Security Income program which currently forces transitioning youth to choose between living without support or committing themselves to a life of poverty by swearing that they cannot work as a pre-condition for receiving services. Through the development of diversionary programs that can support youth exiting high school into the workforce without having to go on SSI in the first place, we can build more economic opportunities for the next generation of Autistic youth. These reforms would particularly impact the great number of Autistic people who are currently ineligible for Medicaid-financed supports due to not meeting level of care requirements.

Third, we need to think seriously about how we can transition away from legacy infrastructure. The Department of Justice has undertaken extraordinarily important efforts in this regard through enforcement of the Supreme Court's 1999 *Olmstead v. L.C.* decision, requiring states to offer services in the most integrated settings. To that end, additional federal investment in shifting away from institutional care and sheltered workshops would be very important and help to address cost-growth in Medicaid-financed long term services and supports while improving the quality of service-provision. Today, thirteen states have no large state-run institutions and some states have eliminated institutionalization altogether for people with intellectual and developmental disabilities. Through programs like Money Follows the Person and other Medicaid transformation initiatives, we can continue that progress. Targeted autism-focused investment in the Protection and Advocacy system, which has provided crucial rights protection and systems change advocacy, would also be exceedingly valuable.

In closing, I want to thank the Committee members for allowing my community – the Autistic community – the opportunity to have a voice in these discussions. The challenges society currently faces in integrating and supporting Autistic people and our families are not new. We have faced these challenges and made tremendous progress with other disability groups in the past. I believe that at the end the day this is a civil rights issue. I believe in the ability of the United States of America to guarantee the civil rights of all of its citizens. Autistic people want and deserve the same things that anyone else wants – inclusion in our communities, the opportunity to go to school and get a good job, the chance to make our voices heard about the things that matter to us. With your help, we can make that a reality.

Mr. MEEHAN. Thank you, Mr. Ne'eman.

And thanks—thank you to each of the panelists.

Now, in regular order, the chair will recognize Mr. Burton from Indiana.

Mr. Burton.

Mr. BURTON. First of all, I want to thank you all very much for being so patient. I mean, we grilled those people for, what, about 3 hours, and you had to sit there, so I want to tell you I am amazed that your posteriors could survive that long. That is the first thing.

The second thing I would like to say is that Abraham Lincoln said, Let the people know the facts and the country will be saved, and one of the problems that we have is that I don't think there is enough information getting out to the people who are not affected. I was like that; I didn't know much about autism until my grandson became autistic. And then all of a sudden it became a cause celebre for me, and I was fortunate I was chairman at the time, so I had the resources at my disposal to do something about it.

So I asked my staff, I want you to get a copy of this whole hearing, every one of you. You can get it on the Internet. What is our Internet web site? Governmentoversight.house.gov. Governmentoversight.house.gov. And I would urge all of you to disseminate this whole hearing and try to get as many people as possible to look at that because more people, the more people that know what is going on and understands it, the more likely we are to get some kind of positive result out of the FDA and HHS.

And they get a lot of money. I don't know why in the world they can't allocate more money for this whole issue, and that is why it is important that you keep beating the drum.

I am retiring. This is my last year in office here. I have been here 30 years, but my last year, but I want you to know, any of you that have a need, any of your organizations, you get a hold of me, and I will do anything I can to help you because this is something I feel very strongly about.

Now the other thing I want to talk about is we have what is called the Vaccine Injury Compensation Fund. It has $2.4 billion in it, and it is not being disseminated to people who have damaged children. And it is because we have a system, which was supposed to be user friendly, that is not user friendly. We have special masters that are saying, you know, we can't prove or can't make sure that this person deserves any money out of that fund, and so I think it is important that we beat the drum on that because there is $2.4 thousand million in there, and there is a lot of money for people who really could use it, and that was put in there by the pharmaceutical companies to help people in a user-friendly way to solve these problems.

I think that is about all I have to say, except I am very sympathetic to all of you. We have had I don't know how many hearings on this subject over the past decade, but the problems just keep getting worse and worse and worse, and we really need you not only to be the foot soldiers but the people that are going to lead the charge to make this a cause celebre for everybody, even those who aren't affected by autism. It will affect everybody—autism,

that knows anything about autism because these people are going to live, as we said before, you have all mentioned this to a degree, these people are going to live for some time, and they are going to be a burden not only on the families but on society.

We had people come before my committee whose children they were afraid of, they would lock the doors when the kids got out of control because they were so big, people that mortgaged their homes and lost everything they had taking care of their kids. That is not widely known, and that is why it is important that you guys keep beating the drum and get the message out there, not just for your family but for everybody in our society.

Thank you, Mr. Chairman. I yield back.

Mr. MEEHAN. Thank you, Mr. Burton, and thank you for your passionate advocacy on this issue for your tenure, and we genuinely appreciate your leadership and look forward to hoping that we can continue to carry the mantle.

At this moment, let me recognize the distinguished ranking member, Mr. Cummings.

Mr. CUMMINGS. Thank you.

I want to thank all of you for shedding so much light on the subject. You know, I think my frustration comes with regard to trying to make sure that we take your pain, as I was telling you, Mr. Wright, that has now been turned into a passion, to make sure you carry out your purpose to help the folks that you want to help, and I am sitting here trying to figure out, how do we effectively and efficiently use your energy and your passion so we get something done?

You know, I was listening to you, Mr. Blaxill, and basically, if I understood you correctly, it seems as if you feel that there has been a lot of game playing, and I don't know if you used the word "fraud," but you came pretty close, and, you know, as I listen to you all, I think about how these numbers are increasing. We are marching into a very, very serious situation.

And I know, Mr. Ne'eman, you said don't call it an epidemic or whatever you said, but this is serious stuff. You have got—and you all know, but I am just listening to you. I am sure you have got parents who have to give a lot, and so their productivity is affected. We have got people who are struggling with this and not getting the services that I guess could make them even more productive, am I right? Is that what you are saying, Mr. Carley?

Mr. NE'EMAN. It is, it is. And I do want to reinforce. This is, in fact, very serious my concern with the rhetoric of epidemic is that it stands in contravention to a growing amount of science exploring whether or not we are seeing a rise in incidence or a rise in diagnosis, but, B, I am concerned about the population that Congresswoman Norton mentioned earlier, many of whom are my members and Mr. Carley's members, who have often gone for decades without diagnosis or who have been misdiagnosed. The perception that autism is some recent new thing has been very damaging in part because it has meant when we talk about autistic adults at all, which we do very rarely, we never talk about their needs. We always talk about it as something very recently on the horizon or about to be on the horizon, and we have to recognize this is a very serious situation. It is a very serious situation now, and it is a cri-

sis not of epidemic or public health but of unmet need and of human right.

Mr. CUMMINGS. And that goes to my very question, and maybe you can address this, somebody. Tell me the kind of services that are lacking that you would like to see provided, again so that we can try to figure out how we can use our dollars effectively and efficiently to not only—I think it was you, Mr. Carley, who said, you know, yeah, we have got to look at the future, we have got to do our research—somebody said this—but we have got to also make sure that we deal with the now because the people in this room, I take it, are going to go home, and they are going to have to wrestle with this with love and affection 24/7, so while they are—I guess they have two situations. One, they are reaching into the future and saying, you know what, we want to understand what is happening here, we want to know the causes, we want to see if there are cures or whatever, we want that; but we also need some help right now, right now. And what help is that? I guess that is what I am trying to get to.

Mr. CARLEY. It is a myriad of things. I mean, for parents of more challenged children, we are talking about ABA therapy in the home. We are talking about a variety of educational strategies. We are talking about an appropriate education and perhaps, you know, just some aftercare if the child is significantly challenged enough.

For someone that isn't as challenged, we need much more enforcement of IDEA in the schools. The schools are still able to circumvent that. I know it is budgetary, but it is still a problem that needs to be fixed.

Adults themselves, they need appropriate housing. Adults need therapeutic options. When you grow up living in the behavioral minority and you are living in a world that confuses you a lot, you need to talk to somebody about that, but most of all, especially for adults, those employment programs, putting them into being productive use. This is not a population of people that are short on brain cells. It is social deficits. It is executive functioning issues. It is hidden curriculum issues. It can be put to work.

Now, if I may, though, just backtrack because, again, we have heard so much about prevalence rates and the confusion of where did these numbers come. Not once have I heard today the fact that the DSM–IV, which is what diagnoses people and constructs what the criteria is for who deserves a diagnosis, not once has anybody said here today that one of the reasons for the expanding diagnosis was the expanding criteria to what meets a diagnosis.

First off, the inclusion of Asperger syndrome in 1994 certainly opened up the book to a plethora of people, including myself, who never otherwise beforehand would have qualified for an autism spectrum disorder, but even traditional autism, the definition was changed in that book.

I may get these numbers wrong, but in the old book, I believe it was six mandatory criteria for a diagnosis of autism. So if you got five but not six, back in those days, it was mental retardation. Now I believe it is eight optional out of a field of 16 possible criteria. That blows those numbers off the roof.

Mr. CUMMINGS. Thank you. I see my time is up.

Mr. MEEHAN. Mr. Cummings, it does seem to be. Would you want to be recognized for a minute if Mr. Blaxill has a quick comment to be made?

Mr. CARLEY. I would like to operate on the service question if possible.

Mr. BLAXILL. Excuse me, I was talking.

Mr. MEEHAN. If you can, we are trying to extend a courtesy to allow this important question. Mr. Blaxill, if you will, you did raise your hand.

Mr. BLAXILL. Thank you. I want to raise two points just to correct the record. First of all, the 1 in 88 numbers, one of the problems with what the CDC does is they don't break out the categories, so we don't even have the tools to inspect the claim that there has been diagnostic expansion if the inclusion of Asperger syndrome made a difference.

To the extent there is data in the CDC numbers, Asperger syndrome is a very small proportion of the total categorized cases, less than 10 percent, so the notion that we have had diagnostic expansion, you know, that dog don't hunt as an explanation.

And DSM–IV, if you actually read what the designers of DSM–IV wrote about it, they said it was supposed to be a corrective narrowing of the diagnosis. That was their intention. So I think this notion that we have got diagnostic expansion is a dangerous one.

Another point I want to make, and I didn't have a chance to make it, the great unmentionables, vaccines and mercury as causation factors. If we have an environmental epidemic, which is what I think common sense will tell you we have, we have to look at plausible candidates that could possibly explain the inflection point that we saw in 1990, and so far, the best candidates we have are mercury. And there is a lot of evidence that supports mercury as a causative factor and a damaging factor, and the vaccine issue is a tough one. There are, contrary to what CDC representatives said, there have been no studies of the total health outcomes of an unvaccinated population as compared to a vaccinated population. The studies that have been done cover only one preservative and one product. We haven't looked at combinations. We haven't looked at the totality, and those studies are often done poorly. And what we hear about are the studies the CDC has been done, which I would argue, there has been statistical trickery, but if you actually look at the record, mercury, for example, there was one paper that was written showed that 43 out of the 58 studies on mercury and autism or heavy metals and autism were positive. It is the other 15 that we hear about in the press.

So the scientific record is very supportive of the environmental concerns that parents and families have. It is complicated. There is controversy, obviously. But the notion that the controversy is settled or that all the evidence weighs on one side, that is politics in science, that is not an issue of the evidence.

Mr. MEEHAN. Thank you.

Thank you, Mr. Blaxill.

Regular order. I now recognize myself for 5 minutes of questioning.

But, Mr. Wright, this testimony today has been revealing, and in many ways, what struck me has been the fact that we can have

been at this issue for so long, and there is such a wide divergence just even in the scientific definition of where we are, the accurate identification. You have spent a great deal of your time, resources, and passion in this issue.

Now, one of the things I was trying to explore, and I know you have been discussing, we have got this Interagency Autism Coordinating Committee that the government has, but it seems to be missing the mark if we can be so far off on this. So give me your impression of what we should be doing right now.

Mr. WRIGHT. What we need is a national strategic plan. There are many government agencies that are doing a lot of good things, but they are not necessarily together. The money is significant, but it isn't necessarily spent in as thoughtful a way as possible. There needs to be a combination of the CDC, the NIH, and the FDA as an example to actually undertake the correct research, stay with it, especially in safety research on vaccines going forward, and there needs to be some place—it should be—there should be an assistant secretary of health. The ASH title has been around for a long time. Somebody has to coordinate all this activity and try to make—that is where you bring in services. The NIH doesn't do services. They will just tell you that we don't do services. CDC doesn't do services. So you have got—but yet it is done inside of Health and Human Services, but it is not coordinated. So a national plan, a national strategic plan would be what I would advocate to try to pull that together. I think it is a very important thing.

It also involves continuing medical education for pediatricians, it also involves going to medical schools. There is nothing. You know, mental conditions occupy a fraction of time in medical school. Then people go into practice, and what we deal with is a lot of ignorance. So you have to keep—that has to be organized. So that would be my fondest hope.

Mr. MEEHAN. Mr. Badesch, did you have a comment?

Mr. BADESCH. I would just suggest, with all respect, that the IF doesn't coordinate.

Mr. MEEHAN. I am sorry?

Mr. BADESCH. That the IF doesn't coordinate. And that until we recognize, as Mr. Wright says, that we have to look, this is a national societal issue. And you can't have a body that is tied into, as Mr. Wright said, into a health research mode looking at this whole element of autism. The service needs are there, the civil rights issues. When you don't have the Department of Education sitting at the table or every single parent and——

Mr. MEEHAN. Or Department of Labor might be another suggestion or even the Department of Justice.

Mr. BADESCH. It has to be a coordinated body. And with respect to the administration, we have talked to them, and I think they understand that now. But it has to start, in our opinion, from moving IACC, which as Mr. Smith knows is a great concept, but it is in the wrong place, and it has to have a societal commitment that we are going to address this need as a lifespan issue from birth to death, and until then, we are not going to get anything. IACC—I have been the president of the Autism Society for a year and a half. IACC, despite what they say, they have never approached us,

so if they are doing a national plan, God love it, you would think they would approach the largest grassroots organization. I assume they haven't approached most of us at this table. That is a major problem.

Mr. MEEHAN. Mr. Blaxill, if I understood your testimony, you identified that there has been extensive research going on in something that you would suggest isn't even relevant to the discovery of what is going on with the genetics, was I correct in that?

Mr. BLAXILL. Yeah, that is correct. I mean, we have spent tens of millions, hundreds of millions on what I call the great autism gene hunt, you know, when common sense would tell you that if you have gone from 1 in 10,000 to 1 in 88, something is changing.

Mr. MEEHAN. Who in addition adopts your position, and why would that issue not have been raised prior to today?

Mr. BLAXILL. Well, I think it comes back to the strategic planning issue. When a group of us pushed for the Combatting Autism Act of 2006, one of the critical provisions of that was the idea of a strategic plan to make IACC and to make the NIH funding mechanisms accountable to the public.

I spent 25 years in management consulting. I was a senior partner at one of the top management consulting firms in the world. If there is anything I can claim to be an expert in, and I hate to invoke expertise because that is often a way to keep the people out, but I am an expert in strategic planning. And I was asked to participate in one workshop at NIH, and I can tell you that the process that we were engaged in was an interesting one. It had nothing remotely——

Mr. MEEHAN. Were you shut out with respect to your commentary, or was there——

Mr. BLAXILL. It was just an occasion to gather a group of people for a meeting, and the leaders of the NIH did what they wanted to do in the first place anyway. It wasn't accountable in any meaningful way. They didn't—it was—you got into the details, but there was an attempt not to have a strategy. It was an attempt to defend the status quo.

Mr. MEEHAN. My time is up, but you know one of the things that Mr. Issa has clearly stated the intention of this committee to continue to look at this, and that would be, you would arm us if you would help us with identifying the kind of questions that you would like to have asked if we have these same individuals from that coordinating committee sitting at this table, that would help us articulate in your voices the kind of inquiry that would shake that and produce a result that would help us deal just on the front end, and I am sympathetic to all your issues on the back end as well, but my time has run out, and so at this point in time——

Mr. WRIGHT. I would suggest that those answers might be urgency, goals, milestones, time frames, and passion.

Mr. MEEHAN. In that order?

The chair now recognizes Mr. Davis.

Mr. DAVIS. Thank you very much, Mr. Chairman.

And I want to also commend all of you for your patience, for your passion, for your interest, and for your hopes because notwithstanding the frustration that we all express, if you didn't think there was some possibility that something could happen, you

wouldn't be here, and that is an indication that wherever there is life, I have been told, that there is hope.

You know, I was reminded of a poet who suggested that some people see things that are and ask, why; but I dream of things that have never been and ask, why not? It seems to me that you are saying, why can't we have the services that we need? Why can't we have the kind of diagnoses that are accurate and give us the best chance and the best possibility? Why can't we even find—although we know it is difficult, we know that resources are scarce, that money is short, but we also know that priorities determine how we use whatever resources that there are, and so you are asking really all of those questions.

I am one who believes that this fellow Sam Cooke was probably pretty accurate when he wrote the words about change coming, when he says that I was born by the river in a little tent, and just like that river, I have been running ever since. It may be a long time coming, but I know some change is gonna come.

I can think of illnesses and the way we have handled them in the past, and maybe there wasn't much hope. I remember living in a county where there was one physician for the whole county. Well, it took some time, but there is more than one physician in that county now. And so, quite frankly, you give me a great deal of hope that there is possibility that when we add all of the factors together and when the American people will have spoken, we will see some movement, and we will see some possibility.

Mr. Ne'eman, let me ask you, you mentioned this whole business of different kinds of disparities, which is something that I have been dealing with all of my life. Could you speak a little bit more and elaborate on what those disparities are and how you see them?

Mr. NE'EMAN. Absolutely. So we know that AfricanAmerican and Hispanic children are diagnosed later in life. It was mentioned earlier in the hearing that we see lower rates of diagnosis in the Hispanic population, and I really thank you for asking that question, Congressman, because it gives us an opportunity to call attention to the fact that we aren't doing a very good job of cultural competency in diagnosis for English language learners, for racial and ethnic minorities, for low-income communities, for women and girls, and also particularly for adults.

When we look at insurance coverage and efforts to address insurance coverage needs for individuals on the autism spectrum, often the emphasis is very specifically on children, and adults are not included in State laws or Federal research efforts that emphasize these needs. All of the incidence statistics you heard earlier focused on 8-year-olds. We don't look at the population beyond that. I also think we can't underestimate the role of poverty in this. To be a disabled person is to choose essentially between accessing no supports or going on the SSI program, which places extremely Draconian limits on the income you can earn and what you can save. People on SSI can't save more than $2,000 in assets. Until we address the systemic poverty that forces people with disabilities, including autistic people and our families, to be held behind economically, we are not going to be able to address the racial, income, and gender disparities in the autism world.

Mr. DAVIS. I thank you very much, and let me thank again all of our witnesses and all of those who have come, and please note that there are some individuals in public office who share much of the hope and much of the concern and much of the anxiety that you have expressed, and I thank you, Mr. Chairman, and yield back the balance of my time.

Mr. MEEHAN. Thank you, Mr. Davis, and the chair recognizes the skilled capacity with which you were able to get the great Sam Cooke into the record.

The chair now recognizes the gentleman from New Jersey, Mr. Smith.

Mr. SMITH. Thank you very much, Mr. Chairman.

I want to thank our panelists for their wonderful insights and incisive testimony. You know, one of the issues that Mr. Badesch raises and admonishes the committee to look at the increased Federal response to the needs of adults living with autism, and I think that is echoed by other panelists and by all of us. We have not done even a scintilla of what we need to be doing to address that important issue.

I would like to focus on older parents, the need for support. I think they have few parallels. I have known many autistic families, and there is a burden that they carry that is so grossly underappreciated, and so many of them do it with such grace and with such dignity, great courage, and I think we need to recognize that. But what I am finding, and I know we all find this, that many of those parents who have older children who are autistic, and they are no longer children, they are adults, are facing a fright that they may soon pass on, what happens to their child, and even physically the inability to deal with a, particularly a young man who has got strength and they increasingly do not.

I hosted Chuck Colson's daughter, who wrote a wonderful book called "Dancing With Max," who goes through her whole life and what it has been like, and that is one of the concerns she expressed with us. So perhaps, Mr. Wright or Mr. Badesch, if you could speak to it, others as well, this idea of older parents and aging out.

And, secondly, Mr. Wright, if you could, speak to the—you laid out five very specific points, pillars for a national strategy. We are in the second decade, obviously, and pardon me, you know, if you don't like the language, but my wife has a severe immunity disease called myasthenia gravis, and a very severe case of it, when we talk about defeating and combatting and curing, we mean it. She deals with it, and she will say it herself. And I do certainly understand where you are coming from, but we do need—I think combatting is a way of rousing people to say more resources to the fight.

But, Mr. Wright, if you could speak to the five points, and then talk about the older parents and the older children.

Mr. WRIGHT. There are two. Just right on the table right now, there are two service issues that are in front of Congress, and one of them is the ABLE Act, which is not confined to autistic children, but the disabled, and it is as to savings, and that has 240 cosponsors in the House and can't get to the floor, but you only need 218 votes. So I would urge you to try to get that to the floor and get that passed with 240 cosponsors. That is something that can help

families, especially working on aging children when the parents are able to put some money into that account.

The second one is there is sitting out here now that there is autism insurance for home or office or wherever in 32 States covering 75 percent of the population of the country that has to be brought back here to Congress so the ERISA companies, who are exempt from that, which are the largest companies in the country and occupy roughly half the working population, we now have half the working population in the smaller companies protected but not the larger ones. That has to be done by Congress. That has to get on the table. In past years, that was not a difficult proposition. It is an equity issue. You have a small grocery store that is local, and they have coverage, and the chain store right next door doesn't provide the coverage. So there is two issues here that relate again to families and to give them service opportunities and hopefully reduce their debt burden and especially ABLE, which is a planning issue, especially as people age out.

Housing is an enormous issue. We are going about it on a State-by-State basis. I don't know how to bring that to the Federal Government at this point in time, but it is going to have to get coordinated. It is very difficult.

Mr. BADESCH. I would mention one of the things with aging parents, and particularly we now have a large group of individuals 80s, 90s, who are the primary caretaker for an adult child, 60 or 70. The portability of Medicaid is a major issue, because sometimes when that person needs a caretaker, if that is the condition, the caretaker lives in another State, the individual moves to the State and has to get put on a waiting list, it could be 5, 6 years, which makes absolutely no sense to us.

The other issue is I think we have to do a better job of working with those parents and providing more options. The lack of housing for adults and particularly in community settings is dismal, and until we start recognizing, and again I think Mr. Ne'eman said this is a civil rights issue, when housing authorities don't—when they define their services to disabilities as having handicap ramps, they are falling a little short. So when we put more services and make those that are responsible for certain things in the communities, make those services available for people with autism, it is going to make it easier for an adult with a child.

Mr. BLAXILL. I want to make a point about aging out and services. I think if we think about when the inflection point and the increased rate of autism was around 1990 or thereabouts, that is about 22 years ago, and so what we are looking at, you know, just say that the leading edge of the epidemic is 22 years old, those kids are just now leaving the special education system. They are well cared for in their families by and large, they are cared for in the special education system, but as they age out, we are facing a tsunami of unmet needs for services, desperate families, aging parents, and, you know, the nightmare of every parent late at night at the bar when you are talking about these things at get-togethers is, what happens when my child—when I die, what is going to happen to my child when I die because the vast majority of these children can't advocate for themselves when they become adults. They are going to be disabled. They are going to be dependent. They can

be abused. They can be taken advantage of and not cared for, and with often tragic outcomes, and we haven't begun to see the wave of difficulties that we are going to face. If we are going to have rational policy, we need to face up to that, and it is going to be a massive problem.

Mr. MEEHAN. Thank you.

Thank you, Mr. Smith. Did you have——

Mr. SMITH. If I could——

Mr. MEEHAN. The chair will indulge you with that.

Mr. SMITH. Just very briefly. You mentioned the Brick study, and I invited CDC and the ATSDR to Brick Township. ATSDR ruled out that there was environmental pathway. You mentioned that there is a black balling. Could you elaborate on that, if not now, certainly for the record of environmental researchers by NIH.

Mr. BLAXILL. I could certainly provide for the record. We have all sorts of private conversations with scientists. SafeMinds funds science. We wish we had the resources of Autism Speaks. We wish Autism Speaks—and I know Bob is an advocate of environmental research, but we would love to see more from Autism Speaks. We would love to see more from NIH. We do work, a modest amount, so we are in contact with scientists. And the private conversations you have with scientists is that there are third rails. There are politically incorrect issues. There is—there are career consequences for doing a certain kind of study, and there have been ritual punishments of certain scientists out there, some very public, some more private, and there are innumerable, there are many examples of those. That is—and when the scientists say, oh, we should let the scientists take care of that, no. It is not a self-regulating process because, in fact, the leaders of NIH enforce the orthodoxy of the scientific establishment, and if you take on third rail questions, those are suppressed. We have many examples of those. I could provide some more.

Mr. MEEHAN. Thank you, Mr. Smith.

The chair now recognizes the gentleman from Pennsylvania, Mr. Kelly.

Mr. KELLY. Thank the chair.

Mr. Davis made a good point when he talked about the Sam Cooke song about change is gonna come, although in most of our lives, there is an old adage that change usually occurs at a time of tragedy or crisis. And I think we are far past both of those right now.

I want to redirect, though, a little bit. Mr. McGarry is here from Mercyhurst. Mercyhurst recognized this a long time ago. I am going to say mid 1980s, right? But then all of a sudden, in 2009, you came out with the AIM program, which is the Asperger's Initiative at Mercyhurst. Would you share a little bit with us what you have been able to do. I know you have spoken—I am from Pennsylvania. You have also presented internationally what Mercyhurst is doing, some of the innovation you have brought in. Again, if you would, tell us how you share some of that information, how you are able to disseminate to other people because I think there is—once we become aware, we can usually fix things. The more awareness, the better it is, and we had a chance to visit a little bit today. I admire what you have done not only in your

academic life but in your personal life, I know you are a person of passion. If you could share a little bit with the people here today with what Mercyhurst is doing in the AIM program.

Mr. MCGARRY. Sure. Two parts of the question, what are we doing to disseminate information. Mercyhurst participated in May in Pennsylvania; we had the opportunity to have the first inaugural Conference on Autism in the Higher Education Setting. And Mercyhurst and five or six other institutions presented there on some of what we are trying to do, and 32 different colleges and universities were represented in the audience of that conference to learn what they could do to start implementing some of the programming and things that we are offering.

What we are offering at Mercyhurst is not rocket science. It is not a brand new treatment option. Some folks have talked about applied behavioral analysis, and we have collaborated with our program at Mercyhurst in ABA, but we are doing a lot of tracking in looking at the students and saying we have identified four main domains that we feel are very essential for our students in the academic setting as well as vocational: And they are academic social progress; independence; social; and emotional. So we tried to track those four things specifically because what we are finding is if our students are lacking or having difficulty on two of those domains, the probability that they are going to be successful in the higher education setting and/or a vocational setting drastically decreases. So we are going to continue to kind of work on that.

Another thing that we are doing is a peer mentoring program, and what we found is many of the students in our program have been in mentoring partnerships, but they have never been the mentor, so we have just recently implemented our peer mentoring program where our students do meet with peer mentors at the university, but they also are going to be going down to social service agencies within Erie that have other folks that have severe disabilities and are going in as a mentor to them to say, I have accomplished something, I am a college student, people said I would never be here, and I am, and I want to help you and mentor you in what obstacles you need to face and get you through those obstacles as well. So that is some of the things we are doing.

Mr. KELLY. As you and I talked today, we talked about employment opportunities, and the idea that these are folks that can live a very productive life; they can be a big part of what it is we do as a country, and I think it is the awareness. And I really appreciate your coming here today and what you have done with your life. The more we become aware about it, the more we understand how to handle it, the more we can adapt and bring these people in with us and understand there is a light at the end of the tunnel. We talked to Bill Gates, you want to talk about somebody who can be successful that has an autism disorder, but if you can, the 24 percent are actually employed, right? There is a lot of adults that can't get work. Just a little bit of that impact of what we could do to change that because I think there is a great opportunity that these people have a meaningful life, something that they feel good about, that they get up in the morning, and they can't wait to contribute.

Mr. MCGARRY. Absolutely. Yeah, I think our vocational and our internship. Unfortunately, we have a stigma, and we are working with students that have autism and are Asperger, some of the vocational opportunities that are presented to Mercyhurst are far beyond the skills and the caliber of what our students can achieve, and so we need to have a strong awareness that, as some other panelists have said, autism is not necessarily an intellectual issue. If we can train and work on some of the social skills and the executive functioning, they can far exceed expectations and do some jobs much better than the rest of us can. And we just need to train society to understand that and give these students the specific skills to accomplish that.

Mr. KELLY. Amen. If I could, Mr. Chairman.

Chairman ISSA. [presiding] Without objection.

Mr. KELLY. Would you share the conversation we had, and we talked about the one student and the professor was outlining or giving them an assignment, I thought that was absolutely phenomenal because what we see sometimes we don't get it, you can't tell a book by its cover. Share that because I thought that was really uplifting.

Mr. MCGARRY. I had a—in the AIM program, we send a letter to every single faculty member stating that this student in your class is being supported by the Asperger Initiative, and if you or that student need resources, we are available. The faculty member contacted me on the second or third day of class and said, Brad, this student, I explained an assignment that was worth 60 percent of the grade in my course. And the student looked at me, and I really am not sure if he understood a word of what I was saying, and so can you work with him and help me work with him? That assignment was supposed to take 10 weeks. That student the following Tuesday turned that assignment in, and that professor said it was the most incredible piece of student graphic art that he had seen in 25 years. So we know that there is a misrepresentation from what we think is being heard and what is being processed and the caliber of students that we are working with.

Mr. KELLY. Thank you for being here and thank you for dedicating your life to making sure these people do have a life.

Thanks so much, and I yield back, Mr. Chairman.

Chairman ISSA. Thank you, Mr. Kelly.

As promised, this was a long and well worthwhile hearing. We learned a great many things that both we and the public were not aware of. We didn't have an opportunity to hear from witnesses who had genetic links that they could see in their own families. We certainly did not hear from the witnesses who are women who recognize in their own lives that the under- evaluation because of perhaps differences in behavior between men and women lead there to be a discrepancy in recognition and a discrepancy in perceived challenge to women versus men.

We certainly learned that the State of Utah has found a way to identify differently or better or more than other States. We certainly learned that, in fact, a passive discovery system is not going to get us or any other country in the world to an accurate number or to seek out people we could help and help early. This and more will be things that this committee will continue working on as part

of the legacy of my predecessor, Mr. Dan Burton, for many years. There is nothing we heard today that is off limits for us to continue to explore. This committee stands ready to take your additional comments and questions as promised. There is a C–SPAN audience. We may perhaps get additional letters. We will try to include those in the record whenever possible.

Lastly, I don't believe we covered every interest group, either, with our witnesses who are here today. So because there are so many organizations involved that want to be heard, I would only ask all of you, when you work with other organizations or groups of individuals, that you explain to them that this committee will have a permanent staffing, at least as long as I am chair, to try to continue to consolidate information and to get government to do its job more effectively, more efficiently and, if at all possible, find additional funds to continue dealing with all aspects of this disease. And with that, this committee stands adjourned.

[Whereupon, at 5:45 p.m., the committee was adjourned.]

OPENING STATEMENT FOR REP. DAN BURTON
Committee on Oversight and Government Reform Full Committee Hearing
"1 in 88 Children: A Look into the Federal Response to Rising Rates of Autism"
November 29, 2012
2:00pm/ 2154 RHOB

I want to thank Chairman Issa for scheduling this important hearing on autism during this lame duck session. As many of you know, because of my grandson's diagnosis with autism in the late-90s, I took it upon myself to learn about autism. During my tenure as Chairman of the House Committee on Government Reform (1997-2002), and the subcommittee on Human Rights & Wellness (2003-2004), I held no fewer than 20 hearings examining the state of federal scientific research into the cause of and treatment for autism.

I am proud of the work we did to raise awareness of autism and draw more attention to the need for research; and I am firmly convinced that the work

we did back then laid the groundwork for the historic Combating Autism Act and the $1 Billion in Federal research into autism that is happening today.

However, alongside the momentum gained from the Combating Autism Act, the realities bear out that we need to do more. On March 30, 2012, the Centers for Disease Control and Prevention (CDC) released their latest figures on the number of autistic kids in America. The numbers are sobering. Thirty years ago it was estimated that autism affected only 1 out of every 10,000 individuals. The latest CDC figures put the number at 1 in 88 American children (1 in 54 boys); a 550% jump in cases since 2000.

What does this mean? This means that the epidemic of autism is an immediate crisis to our education

system, our health care systems, our long-term housing and care system for the disabled, and most especially, to an ever increasing number of families across the country. Autism is a condition that can be treated to a degree but it has no known cure; which means that this is a crisis that is simply not going to ``go away."

I believe that our Nation's educational, labor, housing, law enforcement and medical communities are currently ill-equipped and undertrained to handle this lost generation of autistic individuals and that it is going to take a national commitment driven from the highest levels to marshal the necessary resources and energy to catch up. Autism has no cure and it is not a life-threatening disease.

That means that the autistic children of today will be the autistic adults and autistic seniors of tomorrow. Our Nation is ill prepared to deal with the complex challenges posed by a generation of autistic individuals. There have been far too many stories in the media of police, firefighters, and teachers ill-prepared to cope with an autistic individual and tragedy has resulted. We need to change that.

We need prominent and influential leaders to step forward and spark a national debate on autism. We need to know what's working, what isn't working and what research is most promising. What are we doing to fight this disease and what more can be done? These are key questions I'm hoping our witnesses can address today.

For these reasons, earlier this year I introduced the "White House Conference on Autism Act" (H.R. 3489), to require the President of the United States to convene a White House Conference on autism charged with developing policy recommendations on ways to address the autism epidemic and its impact on Americans.

When I started my research into autism what I found was deeply disturbing, and for the last several years I have fought hard to raise awareness of this disease, and increase research into the causes of autism, as well as new treatments for those suffering with autism.

Unfortunately, a great deal of misinformation has been thrown around in public and private about my

focus on mercury in medicines as a possible factor in the autism epidemic.

I do not want to take away from the focus of today's hearing - A Look into the Federal Response to Rising Rates of Autism - but I would be remiss if I didn't mention my past associations with the theory of mercury-linked autism. I'm not a scientist and never have claimed to be, but while I was Chairman of this Committee I heard from many credible scientists and experts who are convinced that mercury is a contributing factor; and the theory is no less worthy of exploration than the theories being propounded today that the pregnancy weight of the mother or the age of the father at conception influences whether a child becomes autistic.

When you have no idea what is causing a disease, policymakers and scientists should never be afraid to investigate any plausible theory. In fact, researching possible environmental factors is a central component of today's research on autism.

Regrettably, lost in the controversy over mercury is the issue of the Vaccine Injury Compensation Program, which I hope some of our witnesses can speak to. In the 1980s, Congress created the Vaccine Injury Compensation Program to shield medical professionals and vaccine manufacturers from liability if an individual suffered an injury from a vaccine. The compensation fund, which currently contains over $3 Billion, was created to protect the vaccine supply and to insure that all who were injured by a vaccine received compensation in a no-

fault, compassionate, easy to use manner. Congress intended for families to be compensated quickly and fairly; and when the evidence was close as to whether or not the medical condition in question was vaccine related or not the court should always err in favor of the injured.

Our investigations found that over the years the system had broken; and what was supposed to be quick and fair became slow and contentious. There has been no Congressional oversight of the Vaccine Injury Compensation Program in the last decade, and the system has not improved; if anything it has gotten worse.

It is time for Congress to revisit this issue and consider substantially reforming this program. For

the public to trust vaccine policies, it is vitally important to have a National Vaccine Injury Compensation Program that is efficient, effective, and fair to those who may have suffered injury from vaccines.

Again, I'd like to thank Chairman Issa and his staff for scheduling today's hearing. And although I am retiring from Congress I am not retiring from the fight against autism, because I firmly believe as a nation we have a collective responsibility to do everything we can to not only stop the further spread of this disease but to help the millions of children, adults and families afflicted with this disease.

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Opening Statement
Rep. Elijah E. Cummings, Ranking Member

Hearing on "1 in 88 Children: A Look into the Federal Response to Rising Rates of Autism"

November 29, 2012

Mr. Chairman, thank you for holding today's important hearing. Thank you also for conducting it in a bipartisan manner and working with us on witnesses and written testimony for the hearing record.

We have learned much about Autism Spectrum Disorders over the past decade. Taxpayer-sponsored research has identified risk factors and evaluated therapies to assist with some symptoms. Physicians and parents now have a better understanding of the developmental signs and symptoms, allowing for earlier detection. And educators have experimented with new methods and approaches for assisting children with autism.

Congress has also acted to help individuals with autism and their families in significant ways. In 2010, we passed the Affordable Care Act, which contains significant new protections. Insurers may no longer discriminate against individuals based on preexisting conditions. Insurers may no longer impose lifetime caps on health care coverage. New plans must include screening for autism without additional costs to the parents. And young people diagnosed with Autism Spectrum Disorders may remain on their parents' health insurance plans until they are 26 years old. These are real and significant protections that will improve the lives of millions of American families.

Even with this progress, there is still more to learn and do. While autism affects all racial, socioeconomic, and ethnic groups, some studies have shown that African American, Hispanic, and Asian children are less likely to receive an early diagnosis. These delayed diagnoses cause minority children to be further behind in the development of language and motor skills. We must be vigilant in emphasizing early detection and intervention for all our children, as an early diagnosis can make a critical difference in the life-long development of a child.

We must also continue to invest federal research dollars in new and evolving therapies to improve the lives of those with Autism Spectrum Disorders. In my district, we house the Kennedy Krieger Institute, an internationally recognized institution dedicated to improving the lives of individuals with developmental disorders. These institutions improve the quality of life,

education, and continued development of those affected by Autism Spectrum Disorders, and we must continue to support them.

Today's hearing is an opportunity to examine what has been done about Autism Spectrum Disorders to date, and what more needs to be done in the future. There are many experts, individuals, and groups who can help us in this effort. One of these individuals is Ms. Simone Greggs, founder of the nonprofit autism support group, All the Love.

Mr. Chairman, at this time, I ask unanimous consent that Ms. Greggs' full written statement be entered into the hearing record.

Mr. Chairman, at this time, I also ask unanimous consent that the Committee allow Representative Jim Matheson to participate at today's hearing.

Mr. Chairman, let me conclude by acknowledging the dedication and commitment of our colleague, Mr. Burton, who has made this one of his core issues during his tenure in Congress. Regardless of any political differences we may have, I want to commend his spirit, which has been dedicated to the best interests of children across this country.

Thank you.

Statement for the Record
Rep. Chris Murphy
House Oversight and Government Reform Committee Hearing

1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autism

Thank you Chairman Issa and Ranking Member Cummings for holding this important hearing. As the father of two young boys, I'm very concerned about this issue and hope that this hearing represents just another step in our journey to find the root cause of autism spectrum disorder.

Autism affects a growing number of American families throughout the U.S. The number of those diagnosed with autism has doubled since 2005 and autism is one of the leading mental disorders in children. Its effects are being felt now more than ever. Just this year, the Centers for Disease Control and Prevention released a study that found that 1 in 88 children in the United States has autism. Furthermore, the study showed that 1 in 54 boys have autism, a rate higher than the national average. The rate for girls is 1 in 252 girls. By comparison, this is more children than are affected by diabetes, AIDS, cancer, cerebral palsy, cystic fibrosis, muscular dystrophy or Down syndrome – combined.

Autism knows no political or geographical boundaries and we all must come together to address this ever growing public health crisis. Last year, we did just that when we were able to pass the *Combating Autism Reauthorization Act* unanimously in the House and Senate. More recently, the Senate passed a long overdue measure to ensure that all military families affected by the disorder are able to access effective treatment options for their children. It is my hope that the final National Defense Authorization Act will include this provision and the 23,000 TRICARE beneficiaries diagnosed with autism will be able to receive the treatment they need.

The struggles felt by the diagnosed individuals and their families extend into the financial stability of the home. It has become increasingly expensive to live with autism today. Autism Speaks estimates that the lifetime cost for a person with intellectual challenges has risen to $2.3 million. When including all medical and non-medical costs, it is estimated that autism spectrum disorder costs the United States $137 billion annually. The sad reality is that many families forego services because they are simply unaffordable.

I am inspired by the dedication and persistence of parents and allies of children with autism. Their activism has led to the creation of a number of important groups, such as Autism Speaks, and has led to a number of bills being passed here in Washington and in state capitals across the nation. It is because of their passion and advocacy on behalf of their children, family members and loved ones that we are making progress today. My state of Connecticut is fortunate to have one of these leaders in Shannon Knall from Simsbury, Connecticut. I, like many other policymakers in Connecticut, have called on Shannon for her knowledge, expertise and guidance as we work to address this incredible challenge.

Again, thank you Chairman Issa and Ranking Member Cummings for holding this hearing and I look forward to working with both of you in the future as we move towards a comprehensive strategy to deal with autism.

Background Report

Poul Thorsen, MD, PhD

CDC Researcher – Fugitive from Justice

November 2012

Tax evasion, money laundering, wire fraud, violations of dual employment regulations leading to dismissal from a leading research university -- all connected with embezzling grant money through an elaborate scheme of falsifying invoices and forging signatures.

With all these criminal irregularities, how can anyone trust the data this researcher produced? Why haven't calls for retracting his studies gone out? The money aside, Poul Thorsen's research has had a profound influence on vaccine policy – both here in the USA and abroad. Ultimately the health community's acceptance of his research as being beyond reproach raises concerns about the safety of all children receiving vaccines. If data were altered to fit the desired outcomes, then outcomes using this research become tainted, especially the National Academies of Science Institute of Medicine's (IOM) strong reliance on his work for determining the potential for harm from thimerosal in vaccines. The details of these issues are summarized in this report.

SafeMinds is a non-profit organization founded to restore health and protect future generations by eradicating the devastation of autism and associated health disorders induced by mercury and other man made toxicants. As part of SafeMinds' ongoing activities to inform the public and policy makers about the many research irregularities that continue to undermine the public trust in government health agencies and impede progress in curtailing the epidemic increase of autism rates, we are making available a background report on Poul Thorsen, a key figure in the building of a shaky foundation of research that denied justice to thousands of families whose children suffered a vaccine related neurological injury (brain and nervous system) that developed into autism spectrum disorder (ASD or autism).

This information has previously been provided to Congressional staff as part an ongoing education program to bring legislators' attention to the needs of the autism community including those who came to the community as a result of a vaccine related brain injury. With the recent announcement that Dr. Thorsen was placed on the top of the "Most Wanted" list form the Inspector General of the Department of Health and Human Services (HHS); SafeMinds has decided to make this full report public.

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Federal Charges: October 25, 2012, the Office of the Inspector General added Dr. Poul Thorsen to their "OIG Most Wanted Fugitives" List[1] Of the many concerns about Dr. Thorsen; the most troubling aspect is the April 13, 2011 Federal indictment.[2] The United States Attorney's Office in the Northern District of Georgia issued a public statement[3] announcing that a federal grand jury had indicted Poul Thorsen, (MD, PhD) 49 years old of Denmark on 13 counts of wire fraud and 9 counts of money laundering. United States Attorney Sally Quillian Yates stated that Thorsen "is alleged to have orchestrated a scheme to steal over $1 million in CDC grant money earmarked for autism research."

Nature online printed the following announcement on April 20, 2011[4]:

Research fraud: *Prosecutors in the United States are seeking to extradite a Danish scientist researching the relationship between autism and vaccines, who, they allege, stole more than US$1 million in research funding. Poul Thorsen was a visiting scientist at the Centers for Disease Control and Prevention (CDC) in Atlanta in the 1990s. US prosecutors say that after returning to Denmark in 2002, Thorsen submitted false invoices from the CDC to Aarhus University, which unknowingly transferred funds to his personal account. He was last week charged with 13 counts of wire fraud and 9 of money laundering.*

The Indictment: The Criminal Indictment No. 1: 11-C R-194 United States of America v. Poul Thorsen[5] states that beginning around February 2004 and continuing through February 2010, that "aided and abetted by others known and unknown, did knowingly devise and intend to devise a scheme and artifice to defraud and to obtain money and property by means of materially false and fraudulent pretenses, representations, and promises and omissions of material facts, well knowing and having reason to know that said pretenses, representations and promises were and would be false and fraudulent…" The indictment provides that Thorsen submitted false invoices and created private bank accounts at the CDC Federal Credit Union to which he had monies wired to pay invoices (from a CDC laboratory using false signatures) and then used the monies (close to $1 million) to purchase a Harley Davidson motorcycle, two automobiles and a home listed as a 4 bedroom, 5 bath 2688 sq ft home at 2657 Briar Lake Road, Atlanta, Georgia 30345.

The Justice Department provides that it will seek to recover all of the property that Poul Thorsen purchased, however; Dekalb County tax records[6] show that the aforementioned home is no longer owned by Thorsen. It is now owned by another CDC associated individual (Janet Henry)[7]. The Briar Lake Road home listed in the indictment in April 2011 was foreclosed on by the lender in March 2011 after a default on the $405,000 owed. It appears that a bank sale was conducted in

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[1] https://oig.hhs.gov/fraud/fugitives/index.asp
[2] http://www.rescuepost.com/files/thorsen-indictment.pdf
[3] http://www.justice.gov/usao/gan/press/2011/04-13-11.html
[4] 20 April 2011 | *Nature* 472, 264-265 (2011) | doi:10.1038/472264a
http://www.nature.com/news/2011/110420/full/472264a.html?s=news_rss
[5] http://www.rescuepost.com/files/thorsen-indictment.pdf
[6] http://web.co.dekalb.ga.us/TaxCommissioner/TCDisplay.asp?ParcelStatus=Y&pin=2546557
[7] A search on 11/1/12 of the HHS Employee directory finds Janet Henry listed as a contractor in the CDC's Office of Noncommunicable Diseases, Injury and Environmental Health, National Center for Chronic Disease Prevention and Health Promotion (***janet.henry@cdc.hhs.gov***)

August 2011, thus removing the property from Thorsen's ownership (and the Justice Department's reach). Available data show that there was an attempt to sell the listed home for almost $500,000, the price was dropped repeatedly and then withdrawn from market.[8]

If convicted on all counts: Poul Thorsen could face up to 260 years in prison and $22.5 million in fines.[9,10]

Poul Thorsen: Thorsen stands as the principal investigator (lead-researcher) on all CDC-funded Danish research used to counter arguments from families claiming their children suffered vaccine injuries including, among other conditions, the onset of symptoms of autism spectrum disorder.

Dr. Thorsen acted as a visiting scientist at the (CDC) Division of Birth Defects and Developmental Disabilities. He successfully promoted the idea of awarding research funds to Aarhus University in Denmark to study the relationship between autism and vaccines. According to the indictment, he "provided input and guidance for the research to be conducted."

It would appear that he built a strong relationship with CDC staff, and beginning in 2001 began a relationship that has underwritten his entire career. Beginning in 2001, Dr. Thorsen lists himself as affiliated with both a) the Developmental Disabilities Branch, Division of Birth Defects, Child Development, and Disability and Health, National Center for Environmental Health, Centers for Disease Control and Prevention, Atlanta and b) Danish Epidemiology Sciences Centre, Aarhus University. He is further listed as the corresponding author of the paper.[11] A year later he removed the Aarhus University affiliation from his next publication and only listed his CDC affiliation with colleague Dr. Diana Schendel.[12]

At the time his article was published in 2003, "Thimerosal and the Occurrence of Autism: Negative Ecological Evidence From Danish Population-Based Data", Thorsen claims an affiliation with the Danish Epidemiology Science Centre, Department of Epidemiology and Social Medicine, University of Aarhus, Denmark.

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[8] Conversation with realtor with access to Georgia MLS systems confirmed that Thorsen had owned the property, that it had been listed for sale in the high $400'000s and then dropped at least 3 times in price into the $300,000s before being removed from the market by the bank which had foreclosed on Thorsen in March 2011.

[9] http://www.naturalnews.com/032216_Thorsen_fraud.html

[10] http://www.justice.gov/usao/gan/press/2011/04-13-11.html "The indictment charges THORSEN with 13 counts of wire fraud and 9 counts of money laundering. The wire fraud counts each carry a maximum of 20 years in prison, and the money laundering counts each carry a maximum of 10 years in prison, with a fine of up to $250,000 for each count."

[11] Identification of biological/biochemical marker(s) for preterm delivery. Thorsen P, Schendel DE, Deshpande AD, Vogel I, Dudley DJ, Olsen J.Paediatr Perinat Epidemiol. 2001 Jul;15 Suppl 2:90-103.PMID: 11520403

[12] Public health issues related to infection in pregnancy and cerebral palsy. Schendel DE, Schuchat A, Thorsen P. Ment Retard Dev Disabil Res Rev. 2002;8(1):39-45 Source Division of Birth Defects and Developmental Disabilities, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia 30341, USA. dcs6@cdc.gov

CDC's Dr. Schendel is co-author on 36 papers with Dr. Thorsen and has continued to collaborate with Dr. Thorsen even after the indictment. PubMed provides that she is co-author on two articles in the second half of 2011 and most recently an article published in October 2012.[13]

Effect on long-term US policy making: Dr. Thorsen was actively engaged with the American Psychiatric Association (APA) in the development of the highly controversial fifth edition of the Diagnostic and Statistical Manual (DSM-5). The work group is chaired by Dr. Susan Sweedo of the National Institutes of Health. According to the brief bio on the APA website[14] Dr. Thorsen listed his position in January 2010 as Adjunct Associate Professor, Department of Epidemiology and Biostatistics, School of Public Health, Drexel University, Philadelphia, PA, USA. The APA website notes that Dr. Thorsen requested a 'leave of absence' from the work group. [15]

Thorsen claims on the bio he provided the APA that he started his first project in 1987 while still a medical doctoral student, and that he "managed a considerable number of studies on autism, national as well as international" further claiming his research career began in 1992. From a search of the internet and Dr. Thorsen's indications, he has authored or co-authored more than 90 scientific articles and book chapters.

1996	Began work on the Danish National Birth Cohort
1997-2000	Visiting scientist, CDC
2000-2008	Associate Professor, Department of Epidemiology, School of Public Health, University of Aarhus, Denmark,
2008-2009	Research Professor, Department of Epidemiology, Rollins School of Public Health, Emory University, Atlanta, Georgia, USA,
1999-present	Associate, Department of Epidemiology, Johns Hopkins University, Baltimore, Maryland, USA.
1998-2005	March of Dimes, PERI grantee
1999-2008	CDC appointed principal investigator on the "Epidemiologic studies of reproductive and developmental outcome – Denmark."

During the period 2000-2008, the bio claims that Dr. Thorsen established the research group known as "North Atlantic Neuro-epidemiology Alliances" (NANEA) originally initiated to do research on Cerebral Palsy in 1999-2000. He provides that in January 2010, more than 30 researchers are affiliated. NANEA's main research areas were:

a) Autism
b) Cerebral palsy
c) Neuropsychological development
d) Preterm birth
e) Down syndrome, and
f) Hearing loss

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[13] Cytokines and Posthemorrhagic Ventricular Dilation in Premature Infants. Ambalavanan N, Carlo WA, McDonald SA, Das A, Schendel DE, Thorsen P, Hougaard DM, Skogstrand K, Higgins RD; for the Cytokine and Generic Database Subcommittees of the Eunice Kennedy Shriver National Institute of Child Health Human Development Neonatal Research Network.Am J Perinatol. 2012 Oct;29(9):731-740. Epub 2012 Jul 6.
[14] http://www.dsm5.org/MeetUs/Documents/Neurodev/Thorsen%20-%20Disclosure%20-%201-22-10.pdf
[15] http://www.dsm5.org/MeetUs/Pages/BioPoulThorsen.aspx

On the APA DSM-5 working group website it states Thorsen participated in the *Autism and Other Pervasive Developmental Disorders Conference* in February 2008.[16] The DSM-5 has come under criticisms for proposing changes to the criteria for diagnosing autism spectrum disorders that would in some opinions prevent up to 75% of higher function or Asperger's individuals from qualifying for services.

In contradiction to Thorsen's claims, the evidence shows he was not involved in autism research until the 2002 article on the MMR vaccine and autism. Prior to this, most of his publications focus on sexually transmitted diseases, infections during pregnancy, and neonatal research – more of a shotgun approach to vaccines and public health issues rather than a bull's-eye topical focus that most feel make one an expert in a field.

Thorsen Broke Other Rules as Well: In January 2010, Aarhus University issued a formal statement[17] distancing itself from Poul Thorsen, confirming that the University discovered shortages of funds in the CDC grant accounts. This was reported to the Danish Agency for Science, Technology and Innovation (DASTI). DATSI conducted an internal investigation and referred the matter to the police. The letter states:

"In March 2009, Dr. Thorsen resigned his faculty position at Aarhus University. In the meantime, it has come to the attention of Aarhus University that Dr Thorsen has continued to act in such a manner as to create the impression that he still retains a connection to Aarhus University after the termination of his employment by the university. Furthermore, it has come to the attention of Aarhus University that Dr. Poul Thorsen has held full-time positions at both Emory University and Aarhus University simultaneously. Dr. Thorsen's double Full-time employment was unauthorized by Aarhus University, and he engaged in this employment situation despite the express prohibition of Aarhus University."

In addition to the criminal acts uncovered, Aarhus publicized that Thorsen violated the rules of employment for the University. This demonstrates a pattern of unethical behavior by Thorsen, one indicating that rules do not matter – that he is above the law, above university rules, and likely above ethical standards of good science.

Tax Evasion: Danish Journalist Ulla Denielsen reported via a blog that the Danish government sought to prosecute Poul Thorsen for tax evasion. In 2009 the prosecution charged Poul Thorsen, with gross tax evasion concerning an amount of fully 6, 4 million DKK (US$ 1.13 million). For this, the Prosecution claims Poul Thorsen must be punished with prison. As stated in the indictment, Poul Thorsen during the years 2001-2005 evaded income from fees, salary or the like for 6,430,768 DKK. Thorsen's attorney sought to have the charges be dismissed. A hearing scheduled for March 29, 2012 dismissed the charges on technicalities based on deficits in the indictment, not because Thorsen was exonerated from the charges.[18,19]

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[16] http://www.dsm5.org/research/pages/autismandothepervasivedevelopmentaldisordersconference%28february3-5,2008%29.aspx
[17] http://www.rescuepost.com/files/thorsen-aarhus.pdf
[18] http://nbjour.wordpress.com/2012/03/14/danish-high-profile-tax-case-postponed-again/
[19] http://nbjour.wordpress.com/2012/04/13/breaking-prosecutor-wants-danish-highest-court-to-reconsider-dismissed-thorsen-tax-case/

The CDC-Denmark Study Outcomes: The CDC provides on its website a complete list of the articles published as a result of the CDC collaboration in Denmark.[20] Poul Thorsen is a co-author in 21 of the 24 papers.

Autism Related Papers: Thorsen's entry into the autism research realm began in 2002 with the publication of the first Aarhus/CDC paper. In the decade since, he has co-authored 21 papers (2 in a Danish journal, duplicates to two English language publications, so in essence 19 studies.) (Exhibit 1) These publications started after he returned to Aarhus University in 2002; beginning in 2005 he claimed he was affiliated with North Atlantic Neuro-Epidemiology Alliances, Department of Epidemiology and Social Medicine, University of Aarhus, Aarhus, Denmark.

An article published online in April 2010 again with CDC employee Dr. Schendel lists Dr. Thorsen without any affiliation, but living in Atlanta. A May 2010 paper fails to include Thorsen's affiliation. In a paper published in June 2011 (and published online a year before), Dr. Thorsen is listed as being employed at the Institute of Public Health at the Department of Epidemiology, University of Aarhus, Aarhus, Denmark. One of his co-authors again is CDC employee Diana E. Schendel, Ph.D.

From June 2011 to November 2012 (following the US federal indictment) 16 papers were published as peer-reviewed literature and posted on PUBMED listing Poul Thorsen as a co-author. The CDC continues to promote research he is affiliated with as recently as October 2012 on the agency's website.[21] These more recent studies list him as employed at the Department of Obstetrics and Gynecology, Lillebaelt Hospital, Kolding, Denmark.

An inquiry to Lillebaelt Hospital, Kolding Denmark on March 20, 2012 confirmed that Poul Thorsen is indeed employed there and provided his email address Poul.Bak.Thorsen@slb.regionsyddanmark.dk.

An internet search for Poul Bak Thorsen found that Thorsen continues his involvement in research, but now referred to as "Poul Bak Thorsen" or "PB Thorsen." His research team provided a poster session at the Society of American Gastrointestinal and Endoscopic Surgeons (SAGES) in early March in San Diego. It is unclear whether Dr. Thorsen came to the United States himself (since the Department of Justice has extradition orders for him with the Danish government to face criminal charges). Immigration is supposed to have his passport flagged.

Aarhus Receives Major Funding in 2012: It was widely announced in early March in Denmark, that the Aarhus University will receive a grant for the project to be known as 'The Lundbeck Foundation's Initiative for Integrative Psychiatric Research' (iPSYCH). The grant of

[20] http://www.cdc.gov/ncbddd/developmentaldisabilities/documents/Articles-Completed-Denmark.pdf
[21] http://friendsnippets.net/phlic/sciclips/issues/v4issue41.html

DKK 121m (approximately $21.5 million) from the Lundbeck Foundation is the largest grant ever awarded to Danish psychiatric research. It will look at five mental health conditions including autism's connections between genetics and the environment.[22]

The Lundbeck Foundation[23] is a commercial foundation that holds 70% of the shares in the Lundbeck Group, a global pharmaceutical company working on brain disorders. Lundbeck Group has at least eight mental health drugs in phase II and III development stages with two in registration process. A Lise Bech Jellesmark - Thorsen is listed as a PhD research student at a Lundbeck Foundation activity at Aarhus.[24] It is not known at this time if there is a relationship between Lisa and Poul.

NANEA: The North Atlantic Neuro-Epidemiology Alliances, Department of Epidemiology and Social Medicine, University of Aarhus, Aarhus, Denmark (referred to as NANEA) received $16 million in grant funds from the CDC. A March 2010 article in a Danish newspaper [25] details how the project was 'gold plated' because of the American money, and due to its funding it grew larger than the actual Department of Epidemiology at the university and thus moved to its own headquarters. The article states, *"In the first years of the employees live in a world of glitz and pampering." We run in a huge Mercedes! 'Is the watchword, and it's true. Every time a scientist travels into the country to gather data, it is in business class, says Anja. Lise says that the Danes are visiting in Atlanta, where they are impressed when a limousine rolls up in front of the hotel door to take them to meetings with the CDC. Delicious dinners, expensive brands of alcohol and stay in luxury get-aways as Denmark's castles are on the program when the traffic goes the other way and money the men from the USA visiting Denmark."*

This article implies there may have been other interests involved in NANEA (which may have created a financial conflict of interest on the CDC funded grants) and states that several of the employees were paid sums in addition to their government salary, an action that is considered illegal in Denmark. A timeline of potential interest is also provided in the article:

NANEA's Rise and Fall

2000	NANEA created with CDC grant of $7.8 million (Poul Thorsen to run)
2007	CDC provides another $ 8.2 million.
2008	Poul Thorsen moved to Atlanta, but remained as scientific and administrative head of NANEA
Winter 2008-2009	AU discovers there are no funds for research done at NANEA. Poul Thorsen assures them money will come from the U.S. and provides declarations of grants as documentation.
March 2009	Poul Thorsen resigns his position at Aarhus University. NANEA disbanded. but projects continue under new management.

[22] http://www.au.dk/en/about/news/single/artikel/record-breaking-grant-new-research-project-to-investigate-the-causes-of-mental-disorders/
[23] http://www.lundbeckfoundation.com/
[24] http://www.cirro.dk/profile?username=lisethorsen
[25] www.information.dk/227065 (in Danish) and http://translate.google.com/translate?hl=en&sl=da&u=http://www.information.dk/227065&prev=/search%3Fq%3DNorth%2BAtlantic%2BNeuro-Epidemiology%2BAlliances%26hl%3Den%26client%3Dfirefox-a%26hs%3DB05%26rls%3Dorg.mozilla:en-US:official%26prmd%3Dimvns&sa=X&ei=Wq2TUN_dAqvM0QHcnYG4Cq&ved=0CDoQ7gEwBA (translated to English)

Spring 2009	University of Aarhus discovers three letters acknowledging grants from the CDC were apparently falsified, just as the CDC does not acknowledge a letter on an outstanding amount of NANEA first appropriation. In all, falsified signatures appear on documents totaling nearly two million dollars.
May 2009	Science, Technology and Innovation Council submit a police report. The notification is not directed against any named person.
Fall 2009	University of Aarhus discovers that Poul Thorsen has maintained a dual appointment as associate professor in Denmark and a professor at Emory University in Atlanta that the University of Aarhus did not approve.
January 2010	University of Aarhus director Jorgen Jorgensen denounces Poul Thorsen in a message to NANEA-project partners. The message also mentions the fraud case
February 2010	Savannah Morning News takes up the case and the other media follow.
March 2010	Østjyllands Police investigators continue to raise a charge against the key person.

Other articles from the same news sources indicate that at least one other scientist is under investigation.

Conclusions and Questions that Remain

The Danish Vaccine Studies are tainted: Years before the criminal activities came to light studies from Thorsen had been called into question based on conflicts of interest, design flaws and quality issues. These same studies were used by the US government as the basis to refute any link between vaccine injury and the onset of the symptoms of autism spectrum disorders.

Two evaluations provide an analysis of the Danish and other CDC funded studies. The first, from then Congressman Dave Weldon, a physician with training in immunology presented at the Autism One conference.[26] The second is a summary provided by SafeMinds, entitled, "Vaccines and Autism – What Do Epidemiological Studies Really Tell Us?"[27] Also provided by SafeMinds is an analysis by Mark Blaxill of the Danish study published in *Pediatrics* which concludes the paper provided distorted and misleading information. Thorsen is a co-author of the paper with Madsen.[28]

In April 2012, Brian Hooker published an article online at *Age of Autism*[29] which detailed information received from the CDC through the Freedom of Information Act (FOIA) (emails and other communications) which indicated that the statistical value of the research is questionable, that the early research did, in fact indicate that autism "rates are still going down" after the elimination of thimerosal from Danish Vaccines. JB Handley also discusses the Danish studies

[26] http://www.vce.org/mercury/Weldon.pdf
[27] http://www.safeminds.org/news/documents/Vaccines%20and%20Autism.%20Epidemiology%20Rebuttal.pdf
[28] http://www.safeminds.org/research/Blaxill-DenmarkAutismThimerosalPediatrics.pdf
[29] http://www.ageofautism.com/2012/04/revisiting-denmark-more-rotten-than-ever.html

fraudulent outcomes on *Age of Autism*, which also provides links to a CDC letter (Signed by Dr. Jose Cordero[30]) to the Editor of *Pediatrics* asking that the paper be published (after it was rejected by two other journals).[31]

As a sidebar, a March 2012 email from Dr. Madsen, the lead author in the *Pediatrics* paper, confirms that thimerosal was removed from vaccines in Denmark in 1992 and also states that he (Dr. Madsen) is no longer involved in epidemiology research.

In the dozen years since the House Committee on Oversight and Government Reform first looked into the government's handling of the epidemic rise in rates of autism spectrum disorder and its possible link to vaccine injury, the CDC became party to a $16 million investment in Denmark to obtain research studies to exonerate the vaccine program. As much as $2 million of that investment is alleged to have been absconded by Poul Thorsen, the researcher who came to the CDC as an employee, earned enough trust at the CDC to influence grant direction, and in a breach of federal policy, acted as principal investigator of the program where he had directed the funds.

Even after being indicted by the US Government for mail fraud and money laundering, Dr. Thorsen continues to collaborate with at least one CDC employee (Diana Schendel) and his papers promoted on the CDC website. Thorsen also faced charges of tax evasion in Denmark which were dismissed for technical reasons (which means the matter remains available for refilling). He continues to be employed in Denmark. The US has yet to extradite him, although he may have entered the US to make a poster session presentation in San Diego in early March 2012. As of late October 2012, Thorsen is listed among the "Most Wanted Fugitives" by the Office of the Inspector General of HHS.

Many questions remain regarding the gross mismanagement of $16 million and the management of the criminal case. They include:

Question: Can it be that Thorsen acted alone? (Many feel it is unlikely.) Are the CDC and/or Aarhus University seeking to make Thorsen a scapegoat?

Question: Is it possible for the very same Justice Department that used Thorsen's research against families seeking compensation in the Vaccine Injury Compensation Program to present an unbiased and effective prosecution?

Question: Who were the career CDC employees who allowed Dr. Thorsen to become principal investigator of the Denmark study? (Ethically he should not have been allowed to since he played a significant role in developing the grant and seeing it awarded to Denmark. He in essence personally benefited from the grant which he helped direct to Denmark -even before the criminal activity).

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[30] Dr. Cordero was Founding Director of the National Center on Birth Defects and Developmental Disabilities who has since left the CDC now serves on the Interagency Autism Coordinating Committee as a public member.
[31] http://www.ageofautism.com/2010/03/first-fraud-dr-poul-thorsen-and-the-original-danish-study.html

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Question: Does the CDC continue to fund research in Denmark?

Question: Who at the CDC/HHS was responsible for overseeing the $16 million dollar grant to Denmark? How did they not see the fraud?

Question: More than 18 months after the indictment, what is the status of the prosecution?

Question: Why are the Danes not cooperating on the extradition?

Question: Did Thorsen actually enter the US in March 2012 unnoticed? If so, how did he do so unnoticed?

Congressional Oversight Needed: The Poul Thorsen management in and of itself calls for oversight. Given the importance the research (he was pivotal in managing) has played in both the IOM's review of the matter as well as the emphasis placed on this data by the government in the Autism Omnibus proceedings of the National Vaccine Injury Compensation Program, an inquiry is urgently needed. Autism has gone from a national epidemic to a national emergency with rates 73% higher than the initial inquiry in 2007 of children born in 1995.[32,33]

SafeMinds and the Elizabeth Birt Center for Law & Advocacy on behalf of the community have asked the Congress to take action on this matter. (www.safeminds.org & www.ebcala.org)

Concluding Comments

The entire history of research evaluating the possible link between exposure to toxins such as thimerosal, vaccine injuries and the dramatic rise in the prevalence in autism rates in the United States shows a history of research irregularities.

Examples of this include the now infamous Verstraeten Vaccine Safety Datalink Study, the initial findings of the generation zero analysis uncovered by SafeMinds through FOIA Requests[34] found "Autism risks were the highest of all the diagnostic codes, with a relative risk at one month of 11.35 between the high and zero exposure groups." Dr. Verstraeten appears never to have written this initial data up in a report. Instead he worked with his CDC colleagues to produce a second generation of the data which was presented at Simpsonwood.[35]

The report generated from the 'generation one' data reduced the relative risk by more than 75 percent (but still found problems with exposure to thimerosal through infant vaccines.) By the time this data was presented publicly for the first time, at the Boston meeting of the IOM, Dr.

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[32] The CDC released data in March 2012 indicated the prevalence of autism of children born in the United States in 2000 is 1 in 88, with the rate for boys at 1 in 54. This is a 73 percent increase from their first report in 2007.

[33] While there is no reference to the thimerosal debate in the CDC report, the 2000 US birth cohort would have been exposed to thimerosal in their infant vaccines, while Denmark removed all preservatives from their children's vaccines in 1992.

[34] http://www.safeminds.org/research/library/GenerationZeroPowerPoint.pdf

[35] http://www.safeminds.org/government-affairs/foia/Simpsonwood_Transcript.pdf

Thomas Verstraeten had negotiated and accepted a job with a vaccine manufacturer in his home country of Belgium, out of the reach of US authorities including Congress.

The IOM proved unable to separate their desire to protect immunization policies from their charge to investigate vaccine injuries and neurodevelopmental delays such as autism. The federal investment in research as noted by Dr. Weldon has put too heavy an emphasis on epidemiology, which cannot truly answer the question, while ignoring more objective studies such as laboratory, animal and clinical research. (And evidence indicates that the CDC may have directed the IOM through their contracting mechanism to develop the conclusion the agency desired. A transcript[36] of the January 12, 2001 closed door meeting of the IOM panel (before the actual review had begun) that was leaked had provided several statements by the IOM coordinator Dr. Kathleen Stratton and Committee Chair, Dr. Marie McCormick. They include:

From Page 33: Dr. McCormick: *...[CDC] wants us to declare, well these things are pretty safe on a population basis...*

From Page 74: Dr. Stratton: *...The point of no return, the line we will not cross in public policy is pull the vaccine, change the schedule. We could say it is time to revisit this, but we would never recommend that level. Even recommending research is recommendations for policy. We wouldn't say compensate, we wouldn't say pull the vaccine, we wouldn't say stop the program.*

Page 97: Dr. McCormick: *...we are not ever going to come down that [autism] is a true side effect.*

In March 2004, the IOM Immunization Safety Review Committee in an egregious exclusion of 'hard data' of a number of animal studies in favor of solely rely the CDC funded epidemiological evidence, would (including those in which Thorsen played a role) issue a report that concluded "The body of epidemiological evidence favors the rejection of a causal relationship between thimerosal-containing vaccines and autism."

The CDC which is responsible for promoting immunizations, funded all of the studies that were used by the IOM, who was under contract with the CDC to evaluate the possible links between vaccines and autism. The IOM conclusions, which according to the transcript references were pre-determined, (and strongly influenced by CDC) were used to deny justice to 5,000 families with claims in the Vaccine Injury Compensation Program and to deter future research.

In a contradiction to the IOM report, a June 2004 private email, the IOM Chair, Dr. McCormick stated, "The committee accepts that under certain conditions, infections and heavy metals, including thimerosal, can injure the nervous system."[37]

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[36] http://www.putchildrenfirst.org/media/6.4.pdf
[37] http://www.putchildrenfirst.org/media/6.17.pdf

Dr. Bernadine Healy a former Director of the National Institutes of Health (NIH) the largest U.S. federal agency responsible for conducting and supporting medical research and a highly respected research scientist published an article in US News and World Report in which she stated, "So as a trigger, vaccines carry a ring of both historical and biological plausibility."[38]

Dr. Healy stated in a CBS interview in 2008:[39]

"...there is a completely expressed concern -- that they don't want to pursue a hypothesis [vaccine=autism] because that hypothesis could be damaging to the public health community at large by scaring people. First of all, I think the public's smarter than that. The public values vaccines. But more importantly, I don't think you should ever turn your back on any scientific hypothesis because you're afraid of what it might show... the more you delve into it, if you look at the basic science, if you look at the research that's been done in animals, if you also look at some of these individual cases, and if you look at the evidence that there is no link, what I come away with is the question [whether vaccines contribute to autism] has not been answered."

With the Thorsen indictment, one sees the credibility of all of the data the CDC funded to be questionable. One can only ask what evidence remains if the Verstraeten paper and all of the Thorsen papers were struck from the debate. A full consideration for a retraction of the 21 Thorsen authored papers funded in the CDC-Denmark project is needed. A reconsideration of the effect of the removal of these papers from government's charge that vaccines and their ingredients have no connection to the epidemic increase in autism rates to 1 in 88 children born in 2000 is warranted.

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[38] http://health.usnews.com/health-news/managing-your-healthcare/brain-and-behavior/articles/2008/04/10/fighting-the-autism-vaccine-war

[39] http://www.cbsnews.com/8301-500803_162-4090144-500803.html

safeMinds

Exhibit 1

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HOUSE COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM HEARING ON AUTISM

Thoughts regarding current interagency coordination on research, research focus of the Feds, and proposed improvements regarding interagency coordination, research focus and funding:

- Need for increased **accountability** for funded agencies and projects to show productivity and promise with delivering research related to the project for accessibility and transportability of the results into the service, research and teaching fields.
- Need for focus on **implementation science**: great deal of funding has gone for pilot work, tests of feasibility and usability studies. However, studies demonstrating the actual transportability and applicability of the interventions by consumers have not been at a pace effective for bringing research to practice.
- Innovations in **technology** should be at the forefront of research focus.
- The application and review process for federal funding is an effective process. However, for the grantees, the process is a long and disruptive process, making it challenging to continue without interruption to daily work during grant cycles. As such, **longer grant cycles** or options for continuation of grants showing specific criteria for adequate process would be most useful, particularly for groups working on long-term systems change and implementation; these studies that take several years of full activity to demonstrate their full value and merit and the funding likely dissipates prior to full implementation and the monies are then not guaranteed to the same grantees and projects may result in unfinished work.
- Much research has focused on etiologies and singular methodologies for intervention. Though important, the literature has also shown that etiology is likely complex with a number of potential causalities. In addition, research also suggests that there is not one intervention of choice and that often a combination of interventions result in optimal outcomes. As such, while study into the multiple etiologies and comprehensive treatment packages continues to be essential, given this complexity and the need to bring the research as we know into practice, we must also invest at current and ongoing on **training others** who will be able to begin to apply what we know with fidelity.
- A great deal of funding has been provided to University-based research teams collaborating with one another across the country. Though important, there must be funding also allocated to teaming between the University **research** teams and the University and/or community **service** teams and agencies who must be much more integral in informing the research plan and are often responsible for implementing the practices.

- There has been an abundant focus on the genetic and environmental causes of the disorder. Though genuinely important to better understand contributing causal factors and thus potential interventions, it is also important that the focus be turned to **implementation issues**: current interventions, the ability for interventions to be effectively trained, applied with fidelity and maintained by those in service fields (e.g., schools, community mental health agencies).
- Innovative programming focused on models for effective teaming and collaboration focused on transporting awareness, information and training across communities and systems (school, home, medical, community) is also needed—though **cross agency collaboration and coordination** is continually promoted, effective means for conducting this has not been outlined and there are apparent struggles in agencies knowing how to effectively do so and still maintain their current structure, policies, procedures and so on.
- Despite a stated emphasis of the IACC Strategic Plan, **adults on the spectrum** have not yet attained the focus needed given the intensive push on early evaluation, identification and intervention. However, many of these individuals are quite capable of having active roles in society and reaching personal potential should individuals receive adequate training for how to support and challenge them.
- In addition, those with **ASD and severe levels of cognitive impairments** have been relatively understudied and underserviced given the intense focus on inclusive practices and individuals of all levels being pushed into general education without the adequate training and awareness of special education and general education teachers. Again, the IACC Strategic Plan notes this as an area of needed focus but this shift has not yet been realized.
- With the cost to society currently $35-90 billion, developing systems for shared responsibility of the community and engagement in the collaboration and care of these special individuals is essential to their community integration, assist and outcomes. An intensive effort at **community education and training** and models for effectively providing and evaluating such practices is needed so that it can be replicated in communities across the United States and meet another stated emphasis of the IACC not yet met.
- Many very **basic strategies** can be easily taught in formats that are accessible and practical for a wide range of providers inclusive of school personnel, medical providers, and community caregivers so that the interventions used are proactive, consistent and accessible to all who will be in contact with those with an ASD in community settings. Various programs such as HANDS in Autism and OCALI have a state or regional influence but could be accessible more nationally with funding mechanisms dedicated to supporting these efforts.
- In several points above, it is clear that the **research to practice gap** remains. Service programs must be a greater voice in informing research priorities as well as practical aspects relating to effectively carrying out the proposed research design and implementation. Those in service will ultimately need to utilize the proposed interventions in practice and will greatly inform what is most needed, will be utilized within the parameters of practice and so on. Without this collaboration a great hazard is spending time and money on efforts that cannot or will not be replicated—a gap between research and practice. Further, quality work and innovations are likely already occurring at the service level but have not been adequately and empirically

evaluated to establish their merit. Yet research is often conducted for newly evolved practices that are rapidly conceptualized and carried out without adequate piloting and troubleshooting beforehand, sacrificing a fully conceptualized, developed or useable and feasibly model by service groups.

- IACC has made a grand effort at attempting to inform and gain insight from a wide consumer base inclusive of service providers. However, such effort should continue to expand to include **input from a wider consumer base**.

Many areas emphasized above have been noted within the Interagency Autism Coordinating Committee 2011 Strategic Plan for Autism Spectrum Disorder Research as identified priorities for upcoming research. The above are to add emphasis to these areas with a strong need for representation and input by leaders in the field of Implementation Science who understand the needs and the practicalities of making systems changes. The shift to Community Based Participatory Research and to Effectiveness Research as well as the large focus on implementation within the community across a range of providers of various backgrounds and experience is a significant shift from the traditional research on single interventions by trained therapists in highly controlled settings.

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The vision of All The Love, Inc. is to raise awareness about Autism in the African American, Hispanic, and other minority communities. We seek to advocate for early detection and race related research. Our main goal is to make sure that resources are available to underserved communities by pointing them in the right direction.

All the love means lending a helping hand and caring for special people. Jeremiah

My son, Jeremiah, was diagnosed with Autism when he was in the second grade. The diagnosis came only after several tests, a mis-diagnosis, and bad advice as to the cause of his outbursts, erratic behavior and inability to get along with his peers. Although it was good to finally know the true cause of his behavior and difficulties in school, I did not always know how best to help him.

The road was not easy and I grew weary along the way. I researched Autism and discovered that I didn't have to fight alone. I hired an advocate and a lawyer to help me navigate and chart a pathway of success for my son.

I now know that my purpose and destiny is to share what I have learned and lend a helping hand to those in need. God honors a good servant and I am proud to serve. I want parents to know that you are not alone and I am here to share my story and offer guidance and support. All The Love will help you by providing grants and resources to lighten your load.

Best,

Simone

All the Love, Inc.

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1 in 88 children in the United States has an Autism Spectrum Disorder.

Testimony

As a mother of a child who suffers from Autism I advocate daily for my son to have a better quality of life. I have also started a nonprofit organization called All The Love, Inc. The purpose of All The Love, Inc. is to raise awareness about Autism and the importance of early detection in the African American, Hispanic, and other minority groups. African American and Hispanic children have the highest number of reported cases of Autism (to date) in the United States.

In speaking with parents from all around the globe I have come to understand that parents are not only concerned about finding a cure for Autism. They struggle to *live* with Autism. Parents continue to have unwavering and unconditional love for their children while experiencing glimmers of hope, a subdued unsteady existence caused by an indecisive government and an irresolute economy. Parents' are mainly concern about what will happen to their children as they get older – transition to adulthood.

In a book entitled *Fearless* written by Max Lucado, he asks a thought provoking question. "If you could hover a *fear magnet* over your heart and extract every last shaving of dread, insecurity, or doubt, what would remain? I envision the day where my fear will dissipate and trust our government to act in the best interest of our autistic children by asking parents what we need or rely upon the most to insure our children's success.

My son Jeremiah met all developmental milestones within normal limits. Yet, Jeremiah was misdiagnosed. In school, his teachers suggested that academic

performance, inconsistent and unpredictable behavior were the result of separation anxiety which stemmed from my divorce and his father relocating to New York City. It was also proposed that I also put Jeremiah on medication and I refused. Is medication a quick fix for schools? Denouncing to have my son medicated and frustrated I began to share my concerns about my son's behavior with his pediatrician. She suggested that that I have my son tested. At the conclusion of these series of test (over a span of time) evidence revealed that Jeremiah's exhibited restricted areas of interest, repetitive behaviors in combination with language and socialization difficulties was an indication of the possibility of a Pervasive Developmental Disorder which is on the Autism Spectrum.

African American and Hispanic children with Autism tend to be diagnosed later than other children with Autism. The reasons for later diagnoses include a lack of access to quality, affordable, culturally competent health care, according to Martell Teasley, an Associate Professor in Florida State's College of Social Work who has conducted a comprehensive review of research literature on autism and specifically African-American children. In addition, the stigma attached to mental health conditions within the black community contribute to misdiagnoses of autism, and underuse of available treatment services.

Parents must take an active role in their children's education and healthcare. It is important that we know our rights as parents when dealing with educators and administrators within the school system. I battled and won my fight against the local school system to get my son placed in an appropriate educational situation. He now attends a private school that specializes in educating children with Autism.

According to the CDC 95.9% of Black children do have medical insurance. However, many of these children are poor and receive healthcare via Medicaid, limiting their options for physicians. Lastly, parents must understand their rights and become familiar with the laws, like the American Disabilities Act that prohibits discrimination based on a disability.

Autism is not something a child simply "grows out of", there are many necessary treatments, therapies and school-based programs that can assist children with overcoming some of these developmental challenges. "Prepare to be asked how Medicaid and other important programs helping those affected by Autism can be cut" Autism Society, President Scott Badesch wrote in a message this week to the group's members. In January, funding for most federal programs is set to be slashed by at least 8.2 percent under a process known as sequestration, which was triggered last year when Congress failed to reach a budget deal.

Unless federal lawmakers act, the consequences could be severe for Americans with disabilities, advocates say, with more than $100 billion in automatic spending cuts touching everything from special education to research and disability employment programs. (Disability Scoop, 2012) As it stands right now, health insurance companies do not cover services that are required for children who have Autism. Most of these services are paid by the parents and are deemed an out of pocket expense.

Autism is a developmental disorder that is characterized by impaired development in communication, social interaction, and behavior. Autism statistics from the U.S. Centers for Disease Control and Prevention (CDC) identify around 1 in 88 American children as on the autism spectrum–a ten-fold increase in prevalence in 40

years. Careful research shows that this increase is only partly explained by improved diagnosis and awareness. Studies also show that autism is four to five times more common among boys than girls.

An estimated 1 out of 54 boys and 1 in 252 girls are diagnosed. All children should be screened for autism at 18 months and again at 2 years of age, and at any time a parent raises a concern about autism spectrum disorders. Some children might not show the signs of developmental delays (social, emotional and cognitive) an action or event marking a significant change or stage in development. This is the first step that a parent can take although it does not suggest that your child has Autism. An early diagnosis and intervention are associated with better outcomes that may lead to identifying a potential diagnosis of Autism.

People all around us need our help and I charge you to become more aware about the disparities that exist amongst children with Autism. Our children depend on these services and we as parents want to our government to aid in our success and help our children to maximize their fullest potential.

Our children are a blessing! the bible says that *Every good gift and every perfect gift is from above, coming down from the Father of lights with whom there is no variation or shadow due to change.* James 1:17.

TESTIMONY FOR AUTISM HEARING – 11/28/12

My name is Brian Hooker and I hold a PhD in Biochemical Engineering. I am also the very proud father of a neurologically impaired fourteen-year old young man, Steven. Steven received all of his infant vaccines through 15 months of age and subsequently regressed into what is commonly called autism.

Unfortunately, Steven's story has become much more common and we have to ask: What role, if any, did vaccines play in the emergence of symptoms that will be most likely a life-sentence for a generation of children? A life sentence where these children are unable to speak, are unable to take care of simple bodily functions, are in near-constant chronic pain, and struggle to control their behavior? These children will never realize their full potential and their voices will never be heard.

For all the children still to be born, it remains more than relevant to let *our* voices ask: What role, if any, have vaccines played in the rising epidemic of autism—up from 1 in 10,000 cases in 1983 to a staggering 1 in 88 in 2008? Is it merely a coincidence that during this same time period, the vaccine schedule for children in the US has shot up from 10 vaccinations to 49, making our country the most vaccinated nation in the world?

If we simply say over and over again that vaccines are safe and all the studies prove it, might it be lost on all those busy parents that mercury, through the organic compound thimerosal, is still in various U.S. vaccines, at levels many times the EPA toxic exposure limit?

What does the evidence suggest and are we willing to look at it objectively, fairly, with science as our maiden—and with the kids, not politics our guiding light---despite a public health tradition in this country that gives vaccines protected status?

So far, based on my years of research into what the vaccine studies actually find and how they have been conveniently interpreted; and despite

my efforts to engage many at the center of these studies, there appears, sadly, an unwillingness to move beyond protected positions.

And the public is deprived of the full accounting it deserves, as those who might question the safety of vaccines, are marginalized, or worse.

But perhaps that is because the evidence connecting vaccines and their chemical components to neurological impairments, including autism, has not been laid out in the way I am going to reveal now.

While I am the parent of child with what is commonly called autism, my research and scientific focus on the data around the issue of vaccines and autism is what I believe to be most relevant to all of us here today... and most telling.

I know that your concern for the health and safety of our children is unwavering....and that you will be guided by that, above all else.

With that in mind, let me start by saying that over a period of 8 years during which I submitted more than 100 Freedom of Information requests to The Centers for Disease Control--the CDC--most of which were denied, I have nevertheless uncovered evidence of a disturbingly clear connection between infant vaccines and the incidence of neurodevelopmental disorders, including autism.

I have found, further, that many of these vaccines contain mercury in the form of thimerosal at many times the EPA toxic exposure limit.

Despite these facts the CDC consistently denies the existence of a relationship between any vaccine or vaccine component, including thimerosal, and autism, and has worked very hard to bury the fact that thimerosal, a potent neurotoxin, has played a significant role in the current autism epidemic, as shown by their own studies.

On one single day, when my son was 2 months of age, he received 62.5 mcg. of mercury, which exceeded the EPA safe exposure limit by 130 times. Many health professionals will erroneously tell you that mercury has

been removed from of our vaccines. That is not true. The vast majority of seasonal influenza vaccines distributed in the U.S. today contain 25 micrograms of mercury (http://www.vaccinesafety.edu/thi-table.htm). The seasonal flu vaccine, along with the H1N1 vaccine recommended in 2009, is given routinely to pregnant women in their first trimester as well as infants down to 6 months of age. Mercury partitions preferentially to the placenta and then to the unborn child, meaning that for the 2010 flu season, these very tiny unborn children were exposed to 50 micrograms of mercury. Interestingly, as reported by the CDC's own VAERS database, the fetal death rate during that particular period jumped by 4250% as compared to the previous "flu season" (Goldman 2012 Human and Experimental Toxicology, published online Sept. 27, 2012, Attachment 1).

I agree with the Oversight and Government Reform Committee's 2003 Mercury in Medicine Report. Mercury is a known, potent neurotoxin. Placing it in maternal and infant vaccines is at best irresponsible and, at worst, criminal.

Even if you are not willing to condemn injecting infants and pregnant women with toxic mercury-containing vaccines, you would expect that the evidence was at least worthy of the concern and scrutiny of a taxpayer supported health agency like CDC that should be accountable to the public. Yet, over my 8 years and more than a hundred Freedom of Information requests to the CDC regarding the possible link between thimerosal-exposure in infant vaccines and the incidence of neurodevelopmental disorders, including autism, I've encountered a Berlin-wall like resistance. I have been shut out of the information necessary to get to the bottom of the question.

During all these years, the CDC has consistently refused to release the vast majority of the pertinent data, reports and correspondences to me, a father who has a strong right to understand how the CDC conducted its studies and reached its negative conclusions about the relationship between vaccines and autism.

To paint the issue more broadly, the CDC consistently denies the existence of a relationship between *any* vaccine or vaccine component, including thimerosal, and autism, and while doing so, ignores the evidence contained in their own studies.

The initial analysis of the data used in the CDC's own "landmark" study, by Verstraeten et al. published in 2003 in the Journal Pediatrics showed that infants exposed to the highest thimerosal levels in their vaccines at one month of age were 7.6 times more likely to receive an autism diagnosis (Attachment 2, "Generation Zero" study data for Verstraeten CDC thimerosal study). The children exposed to the highest doses of mercury from vaccines were 7 times more likely to receive an autism diagnosis than children who received the lowest doses of mercury!! It is clear that the CDC researchers responsible for this study worked very hard to bury this result via statistical manipulations as even the head researcher, Dr. Thomas Verstraeten entitled an email, regarding the consistent relationship between thimerosal and autism, "It just won't go away" (Attachment 3, Dec. 17, 1999 Verstraeten email to Robert Davis). Yes, the relationship between thimerosal and autism won't go away, no matter how expert the experts are at using science to obscure the data.

Later at a secret CDC-vaccine industry representative meeting held in June, 2000, at the Simpsonwood Retreat Center in Georgia, convened to consider these shocking data, CDC scientist Dr. Phillip Rhodes who coauthored the study, stated, regarding the use of data methods to obfuscate the original disturbing analysis of the data, "So you can push, I can pull. But there has been substantial movement from this very highly significant result down to a fairly marginal result." (Simpsonwood June 2000 Meeting Transcript, p. 107, http://putchildrenfirst.org/media/2.9.pdf).

I was curious as to why the CDC did not publish the initial analysis of the Verstraeten data right away. But these comments by Dr. Rhodes at Simpsonwood made it evident why the CDC needed to revise its inconvenient initial findings. It took until November 2003 for the final analysis to be released via publication in Pediatrics, as the responsible

CDC researchers pushed and pulled for 4 years to make the clear association between thimerosal and autism "go away."

Although the CDC claimed that their landmark study proved there was no relationship between vaccines and autism, Dr. Verstraeten, who left CDC to work for vaccine manufacturer GlaxoSmithKline in July, 2001, stated in 2004 regarding the study's final outcome, "The article does not state that we found evidence against an association, as a negative study would. It does state, on the contrary, that additional study is recommended, which is the conclusion to which a neutral study must come." (Attachment 4, Pediatrics 113:932, 2004)

Rather than doing additional study, the CDC hired the Institute of Medicine (IOM) to hold a meeting on "Vaccines and Autism" in February, 2004. Representatives of CDC and affiliated organizations presented 5 very flawed epidemiology studies, each of which I could discuss at length. Based solely on these five studies, the IOM Immunization Safety Review Committee issued a report in May 2004 stating, "The committee ... concludes that the body of epidemiological evidence favors rejection of a causal relationship between thimerosal-containing vaccines and autism" and "In addition, the committee recommends that available funding for autism research be channeled to the most promising areas," meaning, don't do any more research on thimerosal and autism. Prior to the meeting, the ISR Committee chairperson Dr. Marie McCormick instructed the committee, "we are not ever going to come down that [autism] is a true side effect." (http://putchildrenfirst.org/media/6.4.pdf, p. 97). The CDC specified the outcome of this report before the fact and McCormick made sure the CDC's specifications were met.

In 2009, this report was invoked by the Special Master in the National Vaccine Injury Compensation Program to refuse to award compensation in the autism "test cases" closing the door for any recompense to children maimed by high levels of vaccine-based mercury (http://www.uscfc.uscourts.gov/sites/default/files/vaccine_files/Hastings-Cedillo.pdf).

Are you beginning to see the pattern here?

One of the 5 studies used to dismiss the vaccine-autism link was co-authored by Dr. Poul Thorsen, who has collaborated with the CDC from 1998 to the present time. Dr. Thorsen is featured on the Department of Health and Human Services Office of Inspector General's *Most Wanted Fugitive List* as he was indicted on April 14, 2011 by a Federal grand jury on 22 counts of fraud and embezzlement. Dr. Thorsen was installed as the lead investigator for a cohort of scientists from Denmark to investigate the vaccine autism link using Danish databases. Thorsen's work was funded by a CDC grant of over $10 million dollars. Most of the funds were disbursed after he coauthored the aforementioned thimerosal-autism paper, which was reviewed prior to publication by Dr. Diana Schendel. While compiling the results for this publication, Denmark researchers deliberately withheld critical data that would have revealed a decline in autism rates in Denmark after mercury-containing vaccines were removed from the Danish childhood vaccine schedule in 1992 (Attachment 5). The manuscript was initially rejected by the Journal of the American Medical Association and the Lancet, leading medical journals. Dr. Coleen Boyle of the CDC then took the unusual action of advocating for the paper by submitting a letter pushing for expedited review by the journal Pediatrics (Attachment 6). The letter was signed by Dr. Jose Cordero, then Director of the CDC National Center for Birth Defects and Developmental Disabilities (Attachment 7).

Dr. Thorsen has coauthored 36 peer-reviewed publications in collaboration with the CDC. Since his indictment by a Federal Grand Jury for fraud, he has coauthored four papers in collaboration with Dr. Schendel (Attachment 8).

Why is the branch of the CDC charged with responsiblility for autism research collaborating with a fugitive charged with defrauding the very agency, the CDC, engaging in this critically important research? Why haven't any of his studies been retracted or been subjected to review?

The CDC is playing fast and loose with the truth when it promotes its spin on what scientific studies show about vaccines and autism. What I've disclosed briefly today is the very tip of the iceberg regarding the use of mercury, a known neurotoxin in vaccines.

Please help us expose the malfeasance or downright efforts by the CDC to suppress the truth by bureaucratic spin. There must be a full investigation of the CDC's activities in the vaccine safety program and the National Center for Birth Defects and Developmental Disabilities.

By pursuing such an investigation, you will help bring to light the information hidden in CDC files, some of which I have obtained and am providing to this committee today, that show our children have been and continue to be exposed to dangerous neurotoxins in vaccines, and that these vaccines have been linked to what is commonly called autism.

There is no acceptable reason why mercury should not be banned from all vaccines. The second most toxic substance known to science has no place being injected into infants, pregnant mothers or any human.

Through your efforts, we can take a long needed step toward ending this horrible epidemic and spare a generation of children from what happened to my wonderful, precious son.

The history of this country is, in many ways, based on the idea that powerful political forces are not greater than the power of an idea, especially when that idea is guided by a search for truth, wherever it takes us, and a mission to protect the most vulnerable in our society. Please speak for them.

Thank you for your attention.

Brian Hooker, PhD., P.E.

December 24, 2012

Mr. Will Boyington
Staff Assistant
Committee on Oversight and Government Reform
2157 Rayburn House Office Building
Washington, DC 20515
Via e-mail: will.boyington@mail.house.gov

Dear Mr. Boyington:

Attached is Autism Speaks Co-founder Bob Wright's response to the Questions for the Record attached to Chairman Issa's letter of December 11, 2012. We thank you for the opportunity to provide this response to questions submitted by Congressmen Meehan and Posey.

On behalf of Autism Speaks, please let me once again extend our appreciation for Chairman Issa's interest in autism and in holding a timely hearing. We look forward to working with you and your colleagues in the future to address important issues facing the autism community and stand ready to provide any further information that will assist the Committee.

If you have questions about our comments, please contact me at sspielman@autismspeaks.org or (202) 955-3312.

Sincerely,

Stuart Spielman
Senior Policy Advisor and Counsel
Autism Speaks

Response to Questions
From Bob Wright
Co-Founder, Autism Speaks

1. **Do you believe that vaccines and vaccine components should be studied to determine whether or not they might play a role in the autism epidemic?**

Many studies have been conducted to determine if a link exists between vaccination and increased prevalence of autism, with particular attention to the measles-mumps-rubella (MMR) vaccine and those containing thimerosal. These studies have not found a link between vaccines and autism. It remains possible that immunization might trigger the onset of autism symptoms in a child with an underlying medical or genetic condition. Autism Speaks is funding studies on the underlying biology of autism, including studies to better understand medical and genetic conditions that are associated with autism.

The question of whether vaccines could trigger the onset of autism symptoms in a subgroup of children with certain genetic/medical forms of autism remains poorly studied. Regarding whether more research is needed, Autism Speaks concurs with the opinion provided by the National Vaccine Advisory Committee (NVAC) to the Interagency Autism Coordinating Committee (IACC). NVAC is an independent panel that oversees federal vaccine safety (see http://www.hhs.gov/nvpo/nvac/). The NVAC completed their report in 2009 and the results of that report were included in the 2011 IACC strategic plan, as summarized below:

From the 2011 IACC Strategic Plan for Autism Research:

> "Of note, the Committee receives many public comments that reflect concerns about vaccines as a potential environmental factor in autism. Some members of the public are convinced that the current data are sufficient to demonstrate that vaccines do not play a causal role in autism and argue against using limited autism research funds to do additional vaccine studies when many other scientific avenues remain to be explored. At the same time, those who believe that prior studies of the possible role of vaccines in ASD have been insufficient argue that investigation of a possible vaccine/ASD link should be a high priority for research (e.g., a large-scale study comparing vaccinated and unvaccinated groups). A third view urges shifting focus away from vaccines and onto much-needed attention toward the development of effective treatments, services, and supports for those with ASD.
>
> To address public concerns regarding a possible vaccine/ASD link, it will be important for the IACC to continue to coordinate with the National Vaccine Advisory Committee (NVAC), a Federal advisory committee chartered to advise and make recommendations regarding the National Vaccine Program.

In a 2009 report by the National Vaccine Advisory Committee (NVAC), it was recommended that, in the context of immunization research, the ASD clinical subset of particular interest is regressive autism (National Vaccine Advisory Committee, 2009 (PDF – 630 KB)). Although the NVAC stressed that the temporal occurrence of this regression and the immunization schedule is not evidence of a causal relationship, regressive autism warrants further research in rigorously defined subsets of ASD. The NVAC noted that studies in this subpopulation might involve comparison of immune cytokine profiles between regressive and non-regressive ASD to screen for differential immune system profiles, or prospective immunization responsive profiling in siblings of children with regressive ASD. In addition, the NVAC recommended that studies assess whether adverse events following immunization (e.g., fever and seizures) correlate with risk of ASD, and that immune response profiles be examined in ASD cases with a history of adverse events following immunization."

2. **Do you believe that a retroactive study of vaccinated and unvaccinated children would provide value to the debate over whether vaccines or vaccine components play a role in the autism epidemic? If so, why? It not, why not?**

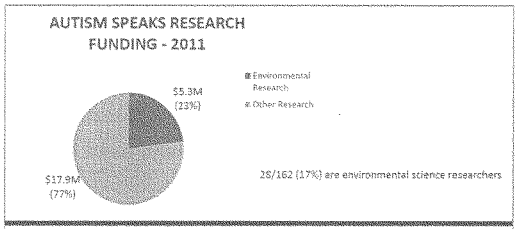
Although a rigorously controlled study of vaccinated versus unvaccinated children would be difficult to carry out due to ethical and feasibility reasons, the question of how simultaneous administration of vaccines could potentially trigger onset of autism symptoms, especially in a genetically or medically vulnerable child, could and should be addressed through research.

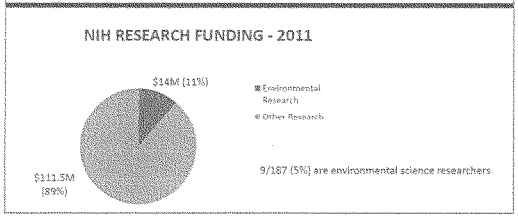
3. **Are you concerned about the proposed changes to the DSM-V definition of autism will affect future research and access to services?**

Overall, the DSM-5 field trial findings do not support the idea that the proposed changes will exclude large numbers of individuals with autism, though further refinements may still be necessary. However, the field trials are based on a relatively small sample of mostly Caucasian school-age children assessed in an academic center. Additional studies with larger samples that include young children and adults from diverse backgrounds in community settings are needed. It will be important to ensure that language barriers, ethnic disparities and gender biases are not interfering with the ability to obtain a proper diagnosis. Autism Speaks is funding both retrospective and prospective studies to determine how the revisions to the diagnostic criteria could affect how diagnoses are made and who can receive services. We want to ensure that all who struggle with autism symptoms will receive the treatment and services they need under future revisions. We are also dedicated to ensuring that autism is recognized as a lifelong condition, for most persons, with evolving needs for services across the lifespan. It is also important to gain a better understanding of how the DSM-5 criteria will affect autism prevalence estimates – which in turn could influence the nation's public health priorities. Autism Speaks is currently funding a study with the Centers for Disease Control and Prevention (CDC) to better address this issue.

4. **What are the total funds raised annually for Autism Speaks? What portion of those funds is dedicated to autism causation research? To environmental factors in autism causation? To the relationship between exposure to vaccines and vaccine components to autism?**

Autism Speaks raises approximately $60 million annually, of which $23-25 million is awarded in research funding on a wide range of topics ranging from basic to applied research, with the goal of understanding the causes of autism and developing more effective treatments throughout the lifespan. Although the percentage of funding devoted to understanding causes varies year to year, as much as 50% of our research budget is devoted to understanding both genetic and environmental risk factors. In 2011, Autism Speaks awarded 23% of its research funding to environmental research. Seventeen percent of scientists funded by Autism Speaks in 2011 focused on understanding environmental risk factors. In contrast, in the same year, NIH awarded 11% of its research funding to environmental research to 5% (N = 9) of its funded scientists. In 2009-11, $10,022,204 was awarded for studies on environmental risk factors, of which $2,324,027 was relevant to the question of the immune system or vaccines and autism.





It should be noted that the Combating Autism Reauthorization Act of 2011 (CARA) authorizes appropriations for autism research, treatment and surveillance totaling $231 million in each fiscal year through 2014. This is divided between the NIH ($161 million), HRSA ($48 million) and CDC ($22 million). Historically, a portion of the autism research funding at NIH has been spent on research that is not autism-specific but rather basic research that may have relevance to autism. In fiscal 2011, Congress appropriated $169 million for autism research at NIH, but according to an analysis by Autism Speaks, only $125 million, or 74%, of that amount was spent

on targeted autism studies. Although NIH coordinates its efforts with Autism Speaks and other private organizations that fund autism research, NIH is ultimately not accountable to the autism community on how research dollars are spent. In the wake of the tragedy at Sandy Hook Elementary School in Newtown, Conn. the need for additional spending on research, mental health services, clinical care, and social supports for those affected by autism and other brain-based disorders is painfully clear.

Some additional facts about NIH autism research funding:

- In last 6 years, prevalence of autism spectrum disorder (ASD) has increased 78%, cost to society has increased more than 300%, yet NIH funding has increased only 69%.
- Since 2007, the per capita autism research funding has decreased from $62/person with ASD to $47.50/person with ASD, as shown in Figure 1.
- Although NIH funding for autism research has tripled over the past decade (Figure 2), the initial amount funded in 2001 (approx. $50M) was very low. Thus, the amount of funding directed toward autism research remains at a relatively low level ($169M). Furthermore, recent increases in federal funding for autism research reported in the IACC portfolio analysis primarily reflect a temporary increase due to ARRA funding, as well as increased reporting by other federal agencies, such as HRSA and Dept. of Ed.
- As shown in Figure 3, only 74% of NIH funding that is counted as autism research is autism-specific; the remainder is for basic research that may have relevance for autism. Thus, rather than spending $169M in 2011, the actual amount directed by NIH to autism-specific research was only $125M.
- As shown in Table 1, funding for other conditions that have similar or lower prevalence/ costs to society is much greater than for autism.

Fig 1. Per capita autism research spending (in dollars)

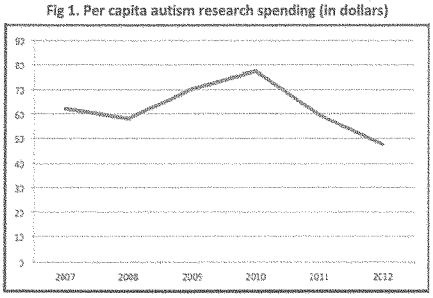


Fig 2. NIH Autism Funding

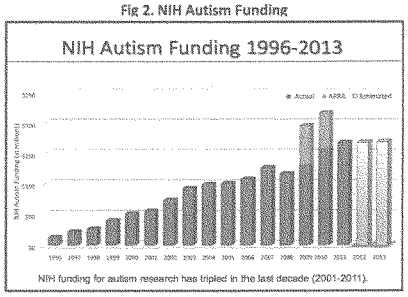


Fig 3. NIH Autism-related versus autism-specific funding

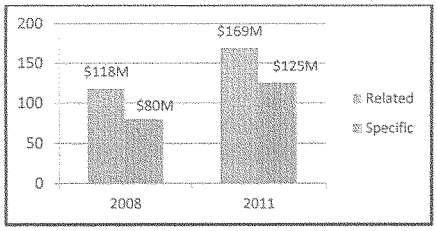


Table 1			
Condition	US Prevalence	2011 funding	Relative to autism funding
HIV/AIDS	0.4 %	$3,059M	18X
Alzheimer's	1.7%	$448M	2.7X
Schizophrenia	1.1%	$264M	1.6X
Autism	1.1%	$169M	n/a

5. **Please provide a list and copies of the studies that Autism Speaks has funded in whole or part.**

Attached please find the following:

1) list of all environmental research grants funded by Autism Speaks in 2011
2) list of all currently active grants funded by Autism Speaks
3) list of all research grants funded by Autism Speaks (for more detail on these research grants, please refer to the Autism Speaks Grants Database at http://www.autismspeaks.org/about-us/grant-search/results/taxonomy%253A9771; there are a total of 520 research grants in this database)

Autism Speaks Funded Environmental Research and Initiatives 2009-11 October 23, 2012

ENVIRONMENTAL RESEARCH 2009-11				
Year	PI	Title	Grant amount	Status
2012	Christian, Parul	Community-based Study of Autism Spectrum Disorders Among 7-9 y Old Children in Rural Bangladesh – vitamin supplementation	$398,942	Awarded in October, 2012
2012	Mortenson, Eric	Investigation of Transgenerational Neurodevelopmental Impacts of Gestational Pharmaceuticals	$100,000	Awarded in October, 2012
2012	Palmer, Raymond	Environmental Exposures Measured in Deciduous Teeth as Potential Biomarkers for Autism Risk	$100,000	In progress
2012	Pessah, Isaac	UC Davis Center for Children's Environmental Health (CCEH) Bridge	$75,000	In progress
2012	Estes, Myka	IL-1beta and IL1RAPL1: Gene-environment interactions regulating synapse density and function in AS	$57,200	In progress
2011	Fallin, M. Danielle	Genome-wide examination of DNA methylation in autism	$450,000	In progress
2011	Zwaigenbaum, Lonnie	BSRC Repository: Gene-Environment Interactions	$674,000	In progress
2011	Patterson, Paul	The Mechanism of the Maternal Infection Risk Factor for Autism	$450,000	In progress
2011	Volk, Heather	Perinatal Exposure to Airborne Pollutants and Associations with Autism Phenotype	$449,690	In progress
2011	Walker, Cheryl	Exposure Questionnaire Validation and Feasibility Study	$208,125	In progress
2011	Lee, Brian	Early life environmental exposures and autism in an existing Swedish birth cohort	$448,423	In progress
2011	Croen, Lisa	Prevalence and Patterns of Medical Comorbidities and Health Care Utilization prior to ASD diagnosis	$299,997	In progress
2010	Naviaux, Robert	Role of Mitochondrial Disorder in ASD: Nucleotide Sequencing in the Genesis and Treatment of Autism	$100,000	Completed
2010	Persico, Antonio	Vertical Viral Transmission as a frequent cause of autism	$99,000	Completed

Autism Speaks Funded Environmental Research and Initiatives 2009-11 October 23, 2012

2010	Hertz-Picciotto, Irva	Early Acetaminophen Exposure and Autism Risk	$19,997	Completed
2010	Barth, Daniel	Role of neuroinflammation in ASD	$118,120	In progress
2010	St. Pourcain, Beate	Genetic variation and gene-environment influences in autistic-like traits	$119,745	In progress
2009	Van De Water, Judy	Evaluation of the immune and physiologic response in children with autism following a vaccine challenge	$660,707	In progress
2009	Davis, Robert	Vaccination with regression study	$16,258	Completed; Project was designed to identify children with regression post vaccination. Several children were identified but all were found to have pre-existing serious medical conditions – follow up grant given to Lisa Croen (see above)
2009	Law, Paul	Interactive Autism Network – vaccine and pre/postnatal medical factor survey	$65,000	Survey completed; Results can be found on IAN website
2009	Hsaio, Elaine	How Does IL-6 Mediate the Development of Autism-Related Behaviors?	$56,000	Project close to completion
2009	Elmer, Brad	A role for immune molecules in cortical connectivity: potential implications for autism	$56,000	Project close to completion
2009	Newschaffer, Craig, Piven, Joseph	Collaborative Risk and Outcome Scientific Study (EARLI-IBIS High Risk Infant Study)	$5,000,000	In progress
		TOTAL	$10,022,204	

Autism Speaks Funded Environmental Research and Initiatives 2009-11 October 23, 2012

ENVIRONMENTAL RESEARCH ACTIVITIES AND INITIATIVES (2009 to present)		
Activity	Collaborative partners	Major activities
BSRC Repository to study genetic and environmental risk factors	Simons Foundation	• Use of standardized exposure instrument to examine environmental factors in high risk cohort
Collaborative Risk and Outcome Scientific Study	NIH, Simons	• $5M to support integration of activities, including environmental exposure assessment, across two NIH funded projects
Epigenetics Initiative	NIEHS, private donors, MIND Institute	• Two research meetings on environmental epigenetics and ASD • Consensus paper on use of blood for environmental exposures on epigenetic expression
Environmental Epidemiology of Autism Research (EEARN) Network	NIEHS	• Focus on combining large existing environmental datasets • 2011 and 2012 RFAs focused on funding large epidemiological collaborations on environmental risk factors • In process: Consensus paper on modifiable risk factors
Environmental Research Targeted RFA (2011 and 2012)	N/A	• 2011 Funded: Development of a standardized exposure instrument for the field • 2012: Under review
Immune Factors and ASD	N/A	• 2011 Think Tank
Risk Communication and Policy	NIEHS, EPA	• Conference and published paper on communicating risk to the community
Bioinformatics Initiative for Environmental Research	NIEHS	• 2011 meeting co-sponsored by AS and NIEHS
Faith and Philip Geier Award in Environmental Sciences	N/A	• 2011: Awarded project on epigenetics and pre- and post-natal environmental risk factors
Collection of environmental exposure questionnaire on AGRE families	N/A	• Investigators can access both genetic and environmental risk factor data for analysis, including linking to geographic information related to air pollution

Autism Speaks Active Research Grants (as of December, 2012)

PI	Institution	Title	Grant type	# years	Start date	End Date	Status	Report Due Date	Award Amount
King, Lydia	Medical University of South Carolina	Autism and Developmental Disabilities Monitoring Network Augmentation with Screening and Assessment	ADDM - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$825,000
Wood, Jeffrey	University of California, Los Angeles	Daily Ratings of ASD Symptoms With Digital Media Devices: An Initial Validity Study	Autism Track - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$300,000
Hazlett, Heather Cody	University of North Carolina	MRI study of brain development in school age children with autism	Basic & Clinical - 2007	3	2/1/2008	12/31/2012	Not due yet	2/28/2013	$449,226
Ebstein, Richard	Hebrew University	Effect of oxytocin receptor inhibitor (Atosiban) during the perinatal period and prevalence of autism spectrum disorders	Basic & Clinical - 2008	3	1/1/2009	12/31/2011	Overdue	3/1/2012	$378,871
Kleinhans, Natalia	University of Washington	Investigation of the link between early brain enlargement and abnormal functional connectivity in autism spectrum disorders	Basic & Clinical - 2008	3	1/1/2009	6/30/2012	Not due yet	8/30/2012	$361,643
Van de Water, Judy	University of California, Davis	Evaluation of the immune and physiologic response in children with autism following immune challenge.	Basic & Clinical - 2009	2	7/1/2010	3/31/2013	Not due yet	5/31/2013	$665,707
Corbin, Joshua	George Washington University	Elucidation and rescue of amygdala abnormalities in the Fmr1 mutant mouse model of Fragile X Syndrome	Basic & Clinical - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$450,000
Jiang, Yong-hui	Duke University	Functional study of synaptic scaffold protein SHANK3 and autism mouse model	Basic & Clinical - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$450,000
Reiss, Allan	Stanford University	Association of Cholinergic System Dysfunction with Autistic Behavior in Fragile X Syndrome: Pharmacologic and Imaging Probes	Basic & Clinical - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$278,593
Webb, Sara	University of Washington	Social Processing, Language, and Executive Functioning in Twin Pairs: Electrophysiological and Behavioral Endophenotypes	Basic & Clinical - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$450,000
McMahon, William	University of Utah	20-Year Outcome of Autism	Basic & Clinical - 2010	3	7/1/2010	6/30/2013	Not due yet	9/1/2013	$450,000

Bahn, Sabine	Institute of Biotechnology	Biomarkers and Diagnostics for ASD	Basic & Clinical - 2010	3	11/1/2010	10/31/2013	Not due yet	1/1/2014	$448,800
Stickgold, Robert	Beth Israel Deaconess Medical Center	The effects of disturbed sleep on sleep-dependent memory consolidation and daily function in individuals with ASD	Basic & Clinical - 2010	3	12/1/2010	11/30/2013	Not due yet	2/1/2014	$292,352
Chance, Steven	University of Oxford	Neuropathology of the social-cognitive network in Autism: a comparison with other structural theories	Basic & Clinical - 2010	3	4/1/2011	3/31/2014	Not due yet	6/1/2014	$384,644
Reznick, James	University of North Carolina	Using Parent Report to Identify Infants Who Are at Risk for Autism Spectrum Disorder (ASD)	Basic & Clinical - 2010	3	6/1/2011	5/31/2014	Not due yet	8/1/2014	$449,856
Hahn, Klaus	University of North Carolina	Bi-directional regulation of Ube3a stability by cyclic AMP-dependent kinase	Basic & Clinical - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$120,000
Leigh, Paul	University of California, Davis	Economic Burden of Current and Future Autism	Basic & Clinical - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$120,000
Levine, Eric	University of Connecticut	Physiological Studies in a Human Stem Cell Model of 15q Duplication Syndrome	Basic & Clinical - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$120,000
Li, Xuekun	Emory University	5-Hydroxymethylcytocine-Mediated Epigenetic Regulation in Autism Spectrum Disorders	Basic & Clinical - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$120,000
Rubenstein, John	University of California, San Francisco	A novel transplantation assay to study human PTEN ASD alleles in GABAergic interneurons	Basic & Clinical - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$120,000
Beaudet, Arthur	Baylor College of Medicine	TMLHE deficiency and a carnitine hypothesis for autism	Basic & Clinical - 2011	2	3/1/2012	2/28/2014	Not due yet	5/1/2014	$120,000
Powell, Craig	University of Texas Southwestern Medical Center, Dallas	Temporally Controlled Genetic Rescue of Shank3 Autism Model	Basic & Clinical - 2011	2	3/1/2012	2/28/2014	Not due yet	5/1/2014	$120,000
Fallin, Dani	Johns Hopkins University	Genome-wide examination of DNA methylation in autism	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,998
Kaiser, Martha	Yale University	Near-Infrared Spectroscopy Studies of Early Neural Signatures of Autism	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,809
Landa, Rebecca	Hugo W. Moser Research at Kennedy Krieger, Inc.	Effects of Self-Generated Experiences on Social Cognitive Development in Young Children with Autism	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,963

Lee, Brian	Drexel University	Early life environmental exposures and autism in an existing Swedish birth cohort	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$448,423
Patterson, Paul	California Institute of Technology	The Mechanism of the Maternal Infection Risk Factor for Autism	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$450,000
Sahin, Mustafa	Childrens Hospital Boston	A Cerebellar Mutant for Investigating Mechanisms of Autism in Tuberous Sclerosis	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,861
Young, Larry	Emory University	Novel approaches to enhance social cognition by stimulating central oxytocin release.	Basic & Clinical - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,228
Goldman, Suzanne	Vanderbilt University	Characterization of the Sleep Phenotype in Adolescents and Adults with Autism Spectrum Disorder	Basic & Clinical - 2011	3	3/1/2012	2/28/2015	Not due yet	4/30/2015	$450,000
Gardner, Judith	Institute for Basic Research in Developmental Disabilities	Very early behavioral indicators of ASD risk among NICU infants: A prospective study	Basic & Clinical - 2011	3	3/1/2012	2/28/2015	Not due yet	5/1/2015	$449,958
Katz, David	Case Western Reserve University	TrkB agonist therapy for sensorimotor dysfunction in Rett syndrome	Basic & Clinical - 2011	3	3/1/2012	2/28/2015	Not due yet	5/1/2015	$443,417
Seltzer, Marsha	Waisman Center	Quality of Life During Midlife in Adults with ASD	Basic & Clinical - 2011	3	3/1/2012	2/28/2015	Not due yet	5/1/2015	$449,998
Simonoff, Emily	Institute of Psychiatry, Kings College London	Why Do People with Autism Spectrum Disorders Fare So Differently in Adult Life?	Basic & Clinical - 2011	3	4/1/2012	3/31/2015	Not due yet	6/1/2015	$442,687
Zwaigenbaum, Lonnie	University of Alberta	Genomic Influences on Developmental Course and Outcome in Infants at Risk of ASD: A BSRC Study	Basic & Clinical - 2011	3	5/1/2012	4/30/2015	Not due yet	7/1/2015	$446,345
Bolton, Patrick	Institute of Psychiatry, Kings College London	Autism Phenotypes in Tuberous Sclerosis: Risk Factors, Features & Architecture	Basic & Clinical - 2011	3	6/1/2012	5/31/2015	Not due yet	7/31/2015	$448,924
Mandell, David	University of Pennsylvania	Estimating the Economic Costs of Autism	Cost of Autism - 2011	2	10/15/2011	4/15/2012	Overdue	6/15/2012	$37,500
Knapp, Martin	London School of Economics	Estimating the Economic Costs of Autism	Cost of Autism - 2011	1	10/1/2011	3/31/2013	Not due yet	5/31/2013	$37,500
Noble, Mark	University of Rochester	Vulnerability phenotypes and susceptibility to environmental toxicants: from organism to mechanism	Environmental - 2008	3	10/1/2008	3/30/2012	Overdue	5/30/2012	$330,000

Ponzio, Nicholas	University of Medicine and Dentistry	Influence of maternal cytokines during pregnancy on effector and regulatory T helper cells as etiological factors in autism	Environmental - 2008	3	4/1/2009	10/1/2012	Not due yet	12/1/2012	$330,000
Patel, Vikram	Sangath Centre	ARTI: The Autism Research & Training Initiative in India	Epidemiology - 2008	3	1/1/2009	7/31/2012	Not due yet	10/1/2012	$179,542
Gross, Raz	Sheba Medical Center	Multi-Registry Analyses - Israel	Epidemiology - 2008	4	5/1/2009	4/30/2013	Not due yet	7/1/2013	$109,978
Parner, Erik	University of Aarhus	Multi-Registry Analyses - Denmark	Epidemiology - 2008	4	5/1/2009	4/30/2013	Not due yet	7/1/2013	$221,868
Sourander, Andre	Turku University	Multi-Registry Analyses - Finland	Epidemiology - 2008	4	5/1/2009	4/30/2013	Not due yet	7/1/2013	$109,945
Stoltenberg, Camilla	Norwegian Institute of Public Health	Multi-Registry Analyses - Norway	Epidemiology - 2008	4	5/1/2009	4/30/2013	Not due yet	7/1/2013	$108,125
Bresnahan, Michaeline	Columbia University	Multi-Registry Analyses - Data Mgt Core	Epidemiology - 2008	4	5/1/2009	5/31/2013	Not due yet	7/31/2013	$198,739
Hultman, Christina	Karolinska Institutet	Multi-Registry Analyses - Sweden	Epidemiology - 2008	4	5/1/2009	5/31/2013	Not due yet	7/31/2013	$108,350
Leonard, Helen	University of Western Australia	Multi-Registry Analyses - Western Australia	Epidemiology - 2008	4	5/1/2009	5/31/2013	Not due yet	7/31/2013	$222,424
Kauchali, Shuaib	University of KwaZulu-Natal	KZN Autism Study	Epidemiology - 2008	3	9/1/2010	8/30/2013	Not due yet	11/1/2013	$180,000
Hepburn, Susan	University of Colorado Denver	Improving Educational Identification in Rural Communities	GAPH - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$200,000
Lee, Li-Ching	Johns Hopkins University	Comprehensive Parent-Mediated Intervention for Children with Autism in Southern Taiwan	GAPH - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$200,000
Fein, Deborah	University of Connecticut	Screening, Diagnosis and Parent Training for Young Children with ASD in Albania	GAPH - 2011	2	4/1/2012	3/31/2014	Not due yet	6/30/2014	$199,909
Hoekstra, Rosa	The Open University	Increasing autism awareness in Ethiopia: The HEAT+ project	GAPH - 2011	2	5/1/2012	4/30/2014	Not due yet	7/1/2014	$199,750
Rahman, Atif	University of Liverpool	PASS: Parent-mediated intervention for autism spectrum disorders (ASD) in South Asia	GAPH - 2011	2	5/1/2012	4/30/2014	Not due yet	7/1/2014	$299,908
Kasari, Connie	University of California, Los Angeles	Developmental and Augmented Intervention for Facilitating Expressive Language	High Risk High Impact - 2008	3	1/1/2009	7/31/2012	Not due yet	10/1/2012	$1,713,958

Piven, Joseph	University of North Carolina	IBIS-EARLI Collaboration	Miscellaneous Grants - 2008	3	1/1/2009	7/31/2012	pending update	10/1/2012	$1,229,110
Newschaffer, Craig	Drexel University	IBIS-EARLI Collaboration	Miscellaneous Grants - 2008	3	1/1/2009	7/31/2012	year 3 "NCE" submitted	10/1/2012	$1,229,150
Paylor, Rich	Baylor College of Medicine	Behavioral Evaluation of Rat Knockout Models of ASD	Miscellaneous Grants - 2010	1	3/1/2011	8/31/2012	Not due yet	10/31/2012	$99,110
Young, Gregory	University of California, Davis	A Centralized Standard Database for the Baby Siblings Research Consortium	Miscellaneous Grants - 2010	2	12/31/2010	12/30/2012	Not due yet	2/28/2013	$172,003
Rogers, Sally	University of California, Davis	Meta Analysis - TTN	Miscellaneous Grants - 2010	1	3/1/2011	2/28/2013	Not due yet	4/28/2013	$19,140
Law, Paul	Hugo W. Moser Research at Kennedy Krieger, Inc.	Assessing the accuracy of rapid phenotyping of nonverbal autistic children	Miscellaneous Grants - 2011	1	7/1/2011	6/30/2012	Not due yet	9/1/2012	$249,996
Weiss, Patrice (Tamar)	University of Haifa	Applying Participatory Design to Develop Technology (ITA Course)	Miscellaneous Grants - 2011	1	8/1/2011	7/31/2012	Not due yet	10/1/2012	$5,000
Anagnostou, Evdokia	Holland Bloorview Kids Rehabilitation Hospital	A multi-site double-blind placebo-controlled trial of memantine vs. placebo in children with autism	Miscellaneous Grants - 2011	2	9/1/2011	8/30/2013	Not due yet	9/1/2013	$199,847
Croen, Lisa	Kaiser Permanente Division of Research	Prevalence and patterns of medical co-morbidity and healthcare use before ASD diagnoses in children	Miscellaneous Grants - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$299,998
Odom, Samuel	University of North Carolina	Early Intervention Professional Development: Evidenced-based practices and Program Quality	Miscellaneous Grants - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$400,000
Walker, Cheryl	University of California, Davis	Gestational Exposure Questionnaire Validation and Feasibility Study	Miscellaneous Grants - 2011	2	2/1/2012	5/31/2015	Not due yet	4/1/2014	$208,126
Volk, Heather	University of Southern California	Perinatal Exposure to Airborne Pollutants and Associations with Autism Phenotype	Miscellaneous Grants - 2011	3	2/1/2012	1/31/2015	Not due yet	4/1/2015	$449,691
Rogers, Sally	University of California, Davis	Strengthening the effects of parent-implemented early intervention to improve symptoms of ASD	Miscellaneous Grants - 2011	3	4/1/2012	3/31/2015	Not due yet	6/1/2015	$765,938
Estes, Annette	University of Washington	Strengthening the effects of parent-implemented early intervention to improve symptoms of ASD	Miscellaneous Grants - 2011	3	6/1/2012	5/31/2015	Not due yet	6/1/2015	$770,829

Fombonne, Eric	McGill University	Epidemiological Study of Pervasive Developmental Disorders in Mexico	Pilot - 2010	2	6/1/2010	11/30/2012	Not due yet	1/30/2013	$120,000
Akbarian, Schahram	Brudnick Neuropsychiatric Institute	Neuronal Epigenome Mapping in Autism	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$119,999
Anand, Rene	The Ohio State University	Deficiency of Nicotinic Receptor-Neurexin Interactions in Autism	Pilot - 2010	2	2/1/2011	3/31/2012	Not due yet	4/1/2013	$119,234
Barth, Daniel	University of Colorado, Boulder	The role of neuroinflammation in ASD-related behaviors, hyper-excitability and epilepsy	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$118,120
Connelly, Jessica	University of Virginia	Epigenetics and the Oxytocin Pathway	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$120,000
Francesconi, Anna	Albert Einstein College of Medicine of Yeshiva University	Regulation of mGluR signaling by lipid domains in Fragile X Syndrome	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$120,000
Luikart, Bryan	Dartmouth College	The Impact of Pten Dysfunction on Neuronal Physiology	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$119,999
Ordway, Gregory	East Tennessee State University	Glia Pathology in Autism	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$119,663
Shattuck, Paul	Washington University	Factors Related to Young Adult Outcomes in Autism Spectrum Disorders	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$120,000
Sikich, Linmarie	University of North Carolina	8-week placebo-controlled trial of oxytocin for treatment of in children with autism	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$120,000
Sonenberg, Nahum	McGill University	Regulation of neuronal translation in Autism Spectrum Disorders	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$120,000
Taylor, Julie	Vanderbilt University	Patterns and Environmental Predictors of Employment and independence among Adults with ASD	Pilot - 2010	2	2/1/2011	1/31/2013	Not due yet	4/1/2013	$114,124
Bambara, Linda	Lehigh University	Peer-mediated Social Skills Training for High School Students with Autism Spectrum Disorders	Pilot - 2010	2	3/1/2011	2/28/2013	Not due yet	5/1/2013	$119,998
Farley, Megan	University of Utah	Functional Outcome Factors in Adults with Autism Spectrum Disorders	Pilot - 2010	2	3/1/2011	2/28/2013	Not due yet	5/1/2013	$118,098
St Pourcain, Beate	University of Bristol	Genetic variation and gene-environment influences in autistic-like traits	Pilot - 2010	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$119,744

Pessah, Isaac	University of California, Davis	UC Davis Center for Children's Environmental Health (CCEH) Bridge	Targeted Q1 - 2012	1	4/1/2012	3/31/2013	Not due yet	6/1/2013	$75,000
Leventhal, Bennett	Nathan Kline Institute	ASD Prevalence by DSM-IV and DSM-5: Total Population Study	Targeted Q1 - 2012	1	5/1/2012	4/30/2013	Not due yet	6/1/2013	$40,600
Paylor, Rich	Baylor College of Medicine	Rat Knockout Models of ASD	Targeted Q2 - 2012	1	9/1/2012	8/31/2013	Not due yet	11/1/2013	$100,441
Scherer, Stephen	Hospital for Sick Children	Examining the Y-Chromosome in Autism Spectrum Disorder	Targeted Q2 - 2012	1	9/1/2012	8/31/2013	Not due yet	11/1/2013	$175,000
Buxbaum, Joseph	Mount Sinai School of Medicine	Identifying high-impact therapeutic targets for autism spectrum disorders using rat models	Targeted Q2 - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$274,347
Mandell, David	University of Pennsylvania	Increasing ASD screening and referral among NYC's Korean Americans	Targeted Q2 - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$400,000
Carpenter, Laura	Medical University of South Carolina	South Carolina Children's Educational Surveillance Study: Comparison of DSM-IV & DSM-5 Prevalence	Targeted Q2 - 2012	3	9/1/2012	8/31/2015	Not due yet	11/1/2015	$179,407
Schwartz, Philip	Children's Hospital of Orange County	An In Vivo, iPSC-Based, Model of Autism	Suzanne and Bob Wright Trailblazer - 2010	1	4/1/2011	9/30/2012	Not due yet	11/30/2012	$100,000
Bassell, Gary	Emory University	PI3K/mTOR signaling as a novel biomarker and therapeutic target in autism	Suzanne and Bob Wright Trailblazer - 2011	1	5/1/2011	10/31/2012	Not due yet	12/31/2012	$100,000
Ashwood, Paul	University of California, Davis	Defining the Underlying Biology of Gastrointestinal Dysfunction in Autism	Suzanne and Bob Wright Trailblazer - 2011	2	10/1/2011	9/30/2013	Not due yet	11/30/2013	$769,943
Atherton, Mark	Brunel University	Tuning Anxiety Out: Exploring the Potential of Noise Cancellation in ASD Sound Sensitivity	Suzanne and Bob Wright Trailblazer - 2012	1	5/1/2012	4/30/2013	Not due yet	7/1/2013	$100,000
Palmer, Raymond	University of Texas Health Science Center, San Antonio	Environmental Exposures Measured in Deciduous Teeth of Children with Autism: A Validation Study	Suzanne and Bob Wright Trailblazer - 2012	1	8/1/2012	7/31/2013	Not due yet	10/1/2013	$100,000
Belinson, Haim	University of California, San Francisco	Pathologic and Genetic Characterization of Novel Brain Cortical Patches in Young Autistic Brains	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$103,000
Buard, Isabelle	University of Colorado Denver	Multimodal neuroimaging of motor dysfunction in autism spectrum disorders	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$114,000
Inan, Melis	Weill Medical College of Cornell University	High metabolic demand of fast-spiking cortical interneurons underlying the etiology of autism	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$110,500

Keehn, Brandon	Childrens Hospital Boston	Understanding the etiological significance of attentional disengagement in infants at-risk for ASD	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$95,000
Knoll, Allison	University of Southern California	Factors influencing early associative learning as a precursor to social behavior heterogeneity	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$107,500
Naples, Adam	Yale University	Brain Electrophysiology of Interactive Social Stimuli	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$107,443
Peca, Joao	Massachusetts Institute of Technology	Neural circuits of social behavior: Rescuing autistic-like behaviors in genetically manipulated mice	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$98,000
Penagarikano, Olga	University of California, Los Angeles	Mechanism and treatment of ASD related behavior in the Cntnap2 knockout mouse model	Translational Postdoctoral Fellowships - 2011	2	2/1/2012	1/31/2014	Not due yet	4/1/2014	$118,000
Puts, Nicolaas	Johns Hopkins University	GABAergic Dysfunction in Autism	Translational Postdoctoral Fellowships - 2011	2	3/1/2012	2/28/2014	Not due yet	5/1/2014	$98,000
Jones, Rebecca	Weill Medical College of Cornell University	Behavioral and neural underpinnings of learning in autism predict response to intervention	Translational Postdoctoral Fellowships - 2011	2	5/1/2012	4/30/2014	Not due yet	7/1/2014	$98,000
Campbell, Daniel	Yale University	Improved early detection of autism using novel statistical methodology	Translational Postdoctoral Fellowships - 2011	2	7/1/2012	6/30/2014	Not due yet	9/1/2014	$102,846
McCoy, Portia	University of North Carolina	Functional and anatomical recovery of synaptic deficits in a mouse model of Angelman Syndrome.	Translational Postdoctoral Fellowships - 2011	2	8/9/2012	8/8/2014	Not due yet	10/9/2014	$114,000
Anderson, Garret	Stanford University	Role of CNTNAP2 in neuronal structural development and synaptic transmission	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$108,700
Carson, Dean	Stanford University	Randomized controlled trial of oxytocin treatment for social deficits in children with autism.	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$104,200
Eggebrecht, Adam	Washington University	Mapping functional connectivity networks in Autism Spectrum Disorder with diffuse optical tomography	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$112,070
Nebel, Mary Beth	Hugo W. Moser Research at Kennedy Krieger, Inc.	Understanding the Brain Basis of Impaired Imitation Learning in Autism	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$112,100

Pati, Soumya	Baylor College of Medicine	Integrative System Biology of iPSC-induced Neurons for Identifying Novel Drug Targets	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$112,100
Speed, Haley	University of Texas Southwestern Medical Center, Dallas	Preclinical therapeutic target validation of glutamate receptors in Shank3 models of autism.	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$115,800
Tenenbaum, Elena	Women & Infants Hospital	Attention & Word Learning in Children with ASD- Translating Experimental Findings into Intervention	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$104,100
Teng, Brian	University of North Carolina	Effects of Oxytocin Receptor Agonists in Mouse Models of Autism Spectrum Disorder Phenotypes	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$99,100
Tudusciuc, Oana	California Institute of Technology	Single-unit recordings in neurosurgical patients with autism	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$112,100
Yuen, Ryan	Hospital for Sick Children	Identifying Genetic Variants on the Y Chromosome of Males with Autism	Translational Postdoctoral Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$103,985
Tierney, Elaine	Hugo W. Moser Research at Kennedy Krieger, Inc.	Double Masked Placebo Controlled Trial of Cholesterol in Hypocholesterolemic ASD	Treatment - 2008	3	12/1/2008	5/30/2012	Due now	7/30/2012	$900,000
Schaaf, Roseann	Thomas Jefferson University	Effectiveness of sensory based strategies for improving adaptive behaviors in children with autism	Treatment - 2008	3	10/1/2008	5/31/2012	Due now	7/31/2012	$449,450
Hardan, Antonio	Stanford University	Pivotal Response Group Treatment for Parents of Young Children with Autism	Treatment - 2010	2	6/1/2010	5/31/2012	Partially submitted	8/1/2012	$199,879
DeThorne, Laura	University of Illinois, Urbana-Champaign	Making Words Meet: Using Computerized Feedback to Facilitate Word Combinations in Children with ASD	Treatment - 2010	2	6/1/2010	11/30/2012	Not due yet	1/30/2013	$178,650
Lord, Catherine	Weill Medical College of Cornell University	Early Intervention in an Underserved Population	Treatment - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$232,402
McDougle, Christopher	Massachusetts General Hospital	Mirtazapine Treatment of Anxiety in Children and Adolescents with Pervasive Developmental Disorders	Treatment - 2010	3	6/1/2010	5/31/2013	Not due yet	8/1/2013	$299,938
Kaufmann, Walter	Childrens Hospital Boston	Pharmacological Treatment of Rett Syndrome by Stimulation of Synaptic Maturation with IGF-1	Treatment - 2010	2	6/1/2011	5/31/2013	Not due yet	8/1/2013	$198,159

Minshew, Nancy	University of Pittsburgh	Evidence-Based Cognitive Rehabilitation to Improve Functional Outcomes for Young Adults with Autism-Spectrum Disorders	Treatment - 2010	3	8/1/2010	7/31/2013	Not due yet	10/1/2013	$300,000
Sahin, Mustafa	Childrens Hospital Boston	Randomized Phase 2 Trial of RAD001 (An MTOR Inhibitor) in Patients With Tuberous Sclerosis Complex	Treatment - 2010	3	11/1/2010	10/30/2013	Not due yet	1/1/2014	$195,000
Brady, Nancy	University of Kansas	Transitions from Augmentative or Alternative Communication (AAC) to Speech: A Pilot Investigation	Treatment - 2011	1	12/1/2011	11/30/2012	Not due yet	2/1/2013	$60,000
Galanopoulou, Aristea	Albert Einstein College of Medicine of Yeshiva University	The role of mTOR inhibitors in the treatment of autistic symptoms in symptomatic infantile spasms	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$120,000
Ingersoll, Brooke	Michigan State University	Effectiveness of Reciprocal Imitation Training for Adolescents with Low-Functioning Autism	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$112,605
Laudenslager, Mark	University of Colorado Denver	Salivary Melatonin as a Biomarker for Response to Sleep Interventions in Children with Autism	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$117,644
Morgan, Lindee	Florida State University	Social-Pragmatic Treatment for Adults with Autism Spectrum Disorder: The Interview Skills Curriculum	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$113,708
Nicholas, David	University of Calgary	Examining Vocational Services for Adults with Autism	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$119,100
Schlaug, Gottfried	Beth Israel Deaconess Medical Center	Comparing AMMT vs. Control Therapy in facilitating speech output in nonverbal children with autism	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$120,000
Smith, Leann	Waisman Center	Transitioning Together: An Intervention Program for Adolescents with ASD and their Families	Treatment - 2011	2	12/1/2011	11/30/2013	Not due yet	2/1/2014	$119,878
Kasari, Connie	University of California, Los Angeles	Deployment Focused Model of JASPER for Preschoolers with Autism Spectrum Disorders	Treatment - 2011	3	12/1/2011	11/30/2014	Not due yet	2/1/2015	$450,000
Wood, Jeffrey	University of California, Los Angeles	Cognitive Behavioral Therapy for Core Autism Symptoms in School-Age Children	Treatment - 2011	3	12/1/2011	11/30/2014	Not due yet	2/1/2015	$450,000
Foss-Feig, Jennifer	Vanderbilt University	Neural mechanisms underlying an extended multisensory temporal binding window in ASD	Weatherstone Fellowships - 2009	2	12/31/2009	6/30/2012	Not due yet	8/30/2012	$56,000

Ash, Ryan	Baylor College of Medicine	In-vivo imaging of neuronal structure and function in a reversible mouse model for autism.	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Berko, Esther	Albert Einstein College of Medicine of Yeshiva University	Advanced Parental Age and Autism: The role of aneuploidy and uniparental disomy in ASD pathogenesis	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Kouser, Mehreen	University of Texas Southwestern Medical Center, Dallas	Shank3 mutant characterization in vivo	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Patterson, Stephanie	University of California, Los Angeles	A Novel Parent Directed Intervention to Enhance Language Development in Nonverbal Children with ASD	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Radoeva, Petya	State University of New York, Upstate Medical University	Social Cognition in 22q11.2 DS Adolescents with ASD vs. without ASD: Imaging and Genetic Correlates	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Seery, Anne	Boston University	Neurophysiological investigation of language acquisition in infants at risk for ASD	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Stadnick, Nicole	University of California, San Diego	The Effectiveness of an Evidence-Based Parent Training Intervention in a Community Service Setting	Weatherstone Fellowships - 2010	2	11/1/2010	10/31/2012	Not due yet	1/1/2013	$56,000
Hus Bal, Vanessa	University of Michigan	Development and refinement of diagnostic instruments for use with adults with ASD	Weatherstone Fellowships - 2010	2	12/31/2010	12/30/2012	Not due yet	2/28/2013	$56,000
Haworth, Joshua	University of Nebraska, Omaha	Perception and production of complex movement variability in children with autism	Weatherstone Fellowships - 2010	2	1/1/2011	12/31/2012	Not due yet	3/1/2013	$56,000
Damiano, Cara	University of North Carolina	Behavioral and Neural Correlates of Reward Motivation in Children with Autism Spectrum Disorders	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$55,533
Filliter, Jillian	Dalhousie University	Preference Acquisition in Children and Adolescents with and without Autism Spectrum Disorder	Weatherstone Fellowships - 2011	2	9/1/2011	9/5/2013	Not due yet	11/1/2013	$55,720
Johnston, Sean	University of Wisconsin-Madison	Macrocephalic Autism: Exploring and Exploiting the Role of PTEN	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000
Luo, Rui	University of California, Los Angeles	Genome-wide expression profiling data analysis to study autism genetic models	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000

Martinez-Pedraza, Frances	University of Massachusetts, Boston	Dissemination of multi-stage screening to underserved culturally-diverse families	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000
Nazor, Kristopher	The Scripps Research Institute, CA	A Stem Cell Based Platform for Identification of Common Defects in Autism Spectrum Disorders	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000
Oksenberg, Nir	University of California, San Francisco	Deciphering the function and regulation of AUTS2	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000
Wainer, Allison	Michigan State University	Using an internet-based program to teach a naturalistic intervention to parents of children with ASD	Weatherstone Fellowships - 2011	2	9/1/2011	8/31/2013	Not due yet	11/1/2013	$56,000
Danial, John	University of California, Los Angeles	Anxiety Treatment for Children with Autism and Intellectual Disability	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$53,500
Edwards, Laura	Harvard University	Neural Correlates of Imitation in Children with Autism and their Unaffected Siblings	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Estes, Myka	University of California, Davis	IL-1beta and IL1RAPL1: Gene-environment interactions regulating synapse density and function in ASD	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Grubb, Michael	New York University	Spatial Attention in Autism Spectrum Disorders	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
McEvoy, Kevin	University of California, Los Angeles	Electrophysiologic Biomarkers of Language Function in Autism Spectrum Disorders	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Muller, Christopher	Vanderbilt University	Evaluating Hyperserotonemia as a Biomarker of Sensory Dysfunction in Autism Spectrum Disorder	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Nair, Aarti	San Diego State University	Thalamocortical Connectivity in Children and Adolescents with ASD-A Combined fcMRI and DTI approach.	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Stavropoulos, Katherine	University of California, San Diego	Stimulus Preceding Negativity and Social Stimuli in Autism Spectrum Disorder	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200
Turner, Tychele	Johns Hopkins University	Why are autistic females rare and severe? An approach to autism gene identification.	Weatherstone Fellowships - 2012	2	9/1/2012	8/31/2014	Not due yet	11/1/2014	$57,200

NICHD Director Guttmacher Questions for the Record
House Committee on Oversight and Government Reform
November 29, 2012

The Honorable Bill Posey

Question 1. In 2001, Dr. Marie Bristol-Power then a Special Assistant for Autism, in the Office of the Director at the NICHD provided a summary of autism (http://www.nichd.nih.gov/autism/presentations/etiology.1.cfm) in which she stated: Autism-No single cause; no single cure – Autism is likely the result of a variety of factors, such as: Genetic, Infectious, Neurologic, Metabolic, Immunologic, and Environmental. Has NICHD given equal treatment, and equal funding to looking at these six identified groups of factors?

Answer: Intellectual and developmental disabilities, including Autism Spectrum Disorders (ASD), are a primary focus of the NICHD's research support. The Institute's portfolio covers a balanced range of topics in autism, including the causes of ASD, epidemiology, treatment, and screening. The Institute also supports professional training and the development of research infrastructure that will facilitate research in ASD across the country.[1] In addition, as a founding member of the NIH internal Autism Coordinating Committee, the NICHD works in close conjunction with other Institutes and Centers at the NIH, each focusing on its particular area of expertise.

The most recent analysis of the distribution of autism research across both Federal and private funders and across types of research is reported in the 2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report.[2] By using the "IACC Autism Spectrum Disorder Research Portfolio Analysis Web Tool,"[3] the reader can see the projects that were funded by all funders, including NIH.

Question 2. I understand that Dr. Bristol-Power has retired. Do you also have a Special Assistant for Autism as the NICHD Director? (If so, what is that person's name?) If not, why not? And is autism the only issue that this person is responsible for, or are they juggling a number of issues?

Answer: Dr. Bristol-Power retired from Federal service approximately 10 years ago. Since I became Director of the NICHD three years ago, NICHD has phased out the "special assistant" role for specific scientific areas; scientific program staff, and the research portfolios they manage, benefit from greater collaboration (such as other developmental disabilities), and are grouped together in extramural research branches within the Institute.

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[1] A more detailed description of the NICHD's activities is available at http://www.nichd.nih.gov/health/topics/autism/researchinfo/Pages/activities.aspx.
[2] http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml.
[3] https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects.

Alice Kau, Ph.D., joined the Intellectual and Developmental Disabilities Branch at the NICHD in 2003. She is responsible for the Branch's Biobehavioral Research Program with primary emphasis on ASD, and leads the Institute's trans-NIH autism activities. Prior to coming to the NICHD, Dr. Kau was an assistant professor at the Kennedy Krieger Institute, Johns Hopkins University.

Question 3. In the hierarchy of science, when looking at drug safety, or environmental exposures, what carries more weight, research in animals such as primates and mice, or retrospective review of medical files?

Answer: Both. There is no universal hierarchy of scientific methodology. All types of effective research are important to answering scientific questions such as those about drug safety. The majority of NIH grants are awarded to investigators across the country whose applications have been evaluated by peer review groups on merit, and are deemed most able to take advantage of scientific opportunities, fill in research gaps, and meet public health needs. Part of the role of peer reviewers is to judge whether the research team for a specific project is proposing to use available scientific methods and tools that best fit the needs of the research project.

Question 4. Do you see autism only as a behavioral condition? Or do you see it as a whole body medical condition?

Answer: Autism certainly affects both behavior and many parts of the body. Currently, the diagnosis of autism is made through observation of behavior, specifically, by evidence of certain social and communicative behaviors. Recent research has revealed more about the biological differences, such as differences in brain structure, activity, and connectivity that may underlie some of these behavioral symptoms. There is also evidence that individuals with autism, as a group, have a higher rate of a range of medical disorders and symptoms. However, the types of medical conditions vary and many individuals with autism have no more medical issues than is expected in the general population. More research is needed to determine the significance of the apparent increased risk for medical conditions in those with autism spectrum disorders. The NIH funded a two-year called "Study of Health Outcomes in Children with Autism and Their Families." This study will use a large database of commercial insurance claims data to describe the physical health conditions and health care utilization of children with ASD, their family members, as compared with a sample of children without ASD and their family members. Results are expected in the spring of 2013.

Question 5. To date, neither the CDC or the NIH has conducted a retroactive study examining health outcomes – particularly neurodevelopmental disorders or autism – examining vaccinated vs. unvaccinated children in the United States. There are databases, including the Vaccine Safety Datalink and state databases where this information in readily available. Why has such a study not been conducted by the NIH? What specific objections does the NIH have to the conduct of such a study? What if any specific value do you believe such a study would provide?

Answer: The NIH and CDC held a workshop in 2006 to explore whether the Vaccine Safety Datalink (VSD) could be used to perform a scientifically valid study of the relationship between

thimerosal and autism. The report (attached) resulting from that workshop "reached consensus that an analysis comparing the rates of autistic disorder (AD)/ASD in the VSD over the time period before, during, and after the removal of thimersol from most childhood vaccines would be uninformative and potentially misleading." Moreover, a 2004 study by the Institute of Medicine, *Immunization Safety Review: Vaccines and Autism (May 14, 2004; available at: http://www.iom.edu/Reports/2004/Immunization-Safety-Review-Vaccines-and-Autism.aspx,* made the following definitive conclusions: "The committee concludes that the body of epidemiological evidence favors rejection of a causal relationship between the MMR vaccine and autism. The committee also concludes that the body of epidemiological evidence favors rejection of a causal relationship between thimerosal-containing vaccines and autism. The committee further finds that potential biological mechanisms for vaccine-induced autism that have been generated to date are theoretical only."

Conducting a prospective clinical trial comparing autism rates in vaccinated vs. unvaccinated children is unethical, as vaccination has known health benefits in preventing many childhood illnesses. Relying on a retrospective comparison of autism rates in vaccinated vs. unvaccinated children is also problematic because families that choose not to vaccinate their children are likely to differ in many ways from families who do vaccinate and these differences may themselves be related to autism risk. Controlling for these and other confounds is particularly difficult in retrospective studies.

The Institute of Medicine (IOM) is currently conducting an Assessment of Studies of Health Outcomes Related to the Recommended Childhood Immunization Schedule. The study is sponsored by the National Vaccine Program Office at HHS. This is an independent assessment surrounding the feasibility of studying health outcomes in children who were vaccinated according to the CDC recommended schedule and those who were not (e.g. children who were unvaccinated or vaccinated with an alternate schedule). The IOM will review scientific findings and stakeholder concerns related to the safety of the recommended childhood immunization schedule. Further, the IOM will identify potential research approaches, methodologies, and study designs that could inform this question, including an assessment of the potential strengths and limitations of each approach, methodology and design, as well as the financial and ethical feasibility of doing them. A report will be issued soon summarizing the IOM's findings and conclusions.

The NIH-funded "Study of Health Outcomes in Children with Autism and Their Families" (described above in response to Q4) will also evaluate the feasibility of using large databases of insurance claims to evaluate a range of risk factors for autism.

Question 6. Do you think that the National Institute of Mental Health should be overseeing autism, or do you believe it belongs in a different institute – such as NICHD? Why?

Answer: The National Institute of Mental Health (NIMH) has the largest portfolio of autism research at NIH, and has effectively chaired the Interagency Autism Coordinating Committee (IACC) since it was created in Public Law 106-310, the Children's Health Act of 2000. In that law, the IACC was established to "coordinate all efforts within the Department of Health and Human Services concerning autism." The Secretary of DHHS delegated the authority to

administer the IACC to the Director of NIH, who re-delegated the authority to the Director of NIMH where it has remained. In its provision amending Sec. 409C of the Public Health Service Act, the Children's Health Act also required that the Director of NIH ("the Director") expand, intensify, and coordinate the activities of NIH with respect to research on autism. Further, the law specified that "The Director shall carry out this section acting through the Director of the National Institute of Mental Health and in collaboration with any other agencies that the Director deems appropriate." The Directors of four other NIH institutes, the National Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, the National Institute on Deafness and Other Communication Disorders, and the National Institute of Environmental Health Sciences, are also members of the IACC. In addition, the NIH Director is a member, and when he cannot attend, the Director of the National Center for Complementary and Alternative Medicine attends in his place.

Question 7. What therapies for autism has the NICHD evaluated and confirmed are beneficial? Are you aware if all of these therapies now available through federal and private insurance programs? If not, how can parents with limited resources obtained access?

Answer: The NICHD's Intellectual and Developmental Disabilities Branch sponsors extramural research on the development of therapies and treatments for ASD, ASD symptoms, and autism-related disorders, as well as the long-term effects of autism interventions. Potential treatment targets include self-injurious and repetitive behaviors, attention issues, language, irritability, and anxiety, co-morbidities such as gastrointestinal problems, and practical life-skills. NICHD-funded research includes projects on a range of interventions, from behavioral to pharmaceutical treatments. Current projects include testing a relationship-focused intervention with young children, the development of face processing expertise, and improving functional money skills, among many others. Several institutes at NIH support interventions for ASD.[4]

In addition, a range of interventions for children, adolescents, and young adults recently have been evaluated by the Federal Agency for Healthcare Research and Quality, whose mission is to improve the quality, safety, efficiency, and effectiveness of health care in the U.S. These reviews examine the effects of available interventions on individuals with ASD and their families. Many of the interventions assessed in these reviews were studies funded by the NIH.[5]

NIH cannot answer the remaining questions under Q7, because it covers issues not within NIH's area of expertise.

Question 8. In 2008 – nearly four years ago – the CDC published a study demonstrating that the rate of autism was much higher than previously believed. Yet, the amount of funding that NIH spends on autism research has remained relatively static – a small

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[4] For a list of currently-funded NIH projects related to autism, see http://report.nih.gov/categorical_spending_project_listing.aspx?FY=2011&ARRA=N&DCat=Autism.

[5] See, Therapies for Children with Autism Spectrum Disorders, at http://www.effectivehealthcare.ahrq.gov/ search-for-guides-reviews-and-reports/?pageaction=displayproduct&productid=651, and Interventions for Adolescents and Young Adults with Autism Spectrum Disorders, at http://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct& productid=1197.

increase – but nothing as dramatic as would be expected by the public with the new findings. While many federal budgets have been relatively flat, why has the NIH not reallocated funding more rapidly within the NIH to dedicated the needed resources to focus on the devastating and rapidly increasing epidemic of autism, particularly among boys for which the autism rate is about 1 in 55? Specifically, what does NIH plan to spend on autism research in each of the next five years? If NIH is not planning to dedicate significantly more resources to autism, please provide the committee with an explanation as to why NIH does not see this as a priority.

Answer: Autism research is a very high priority at NIH, as evidenced by the rapid increase in autism funding from $22 million in FY 1997 to $118 million in FY 2008 to $169 million in FY 2011. Several Funding Opportunity Announcements are currently posted to describe NIH priorities with regard to autism research and solicit grant applications from the scientific community. In addition, special requests for applications to compete for set-aside funds are frequently posted.

One of these programs is the Autism Centers of Excellence (ACE) program. The ACE program is comprised of (a) three centers, focusing research on possible causes of ASD, risk and resilience in ASD, and children with ASD who have limited speech and communication and (b) six networks focusing on causes, preventive interventions, and improved treatment, as well ASD among females and how genetic and environmental factors are associated with the development of ASD. Contingent on the availability of funds, two additional ACE programs are planned to be awarded in FY 2013.

ARRA funds in 2009 provided NIH with a unique opportunity to boost the funding for autism research. In spring 2009, NIH issued a Request for Applications (RFA), "Research to Address the Heterogeneity of Autism Spectrum Disorders", to solicit research proposals for potential funding under ARRA. NIH also supported ASD research with ARRA funding through the Challenge Grants in Health and Science Research and the Grand Opportunities grants. In September 2009, NIH awarded more than 50 autism research grants totaling more than $64 million, in addition to the $132 million awarded to autism researchers through NIH's regular base funding. In FY 2010, NIH committed an additional $58 million of ARRA funds to support new autism research, with the ARRA total for both fiscal years amounting to $122 million. In addition, regular NIH base funding for autism research in FY 2010 grew to $160 million.

Under the President's Budget request for FY 2013, NIH had estimated that autism research would be funded at $170 million. The NIH recognizes the urgent need and autism research will continue to be a high priority.

Question 9. The CDC prevalence studies show a 78% increase in autism rates. If the same increase trends for the 2000 birth cohort continue, the growth rate will go from 1 in 88 to 1 in 22 for children born this year. How is anything NICHD and the NIH done in the last decade going to change the escalation of the autism epidemic?

Answer: It is important to note that the CDC prevalence rates reflect a change in the number of autism diagnoses, not the actual number of people affected. NIH-supported research

demonstrates that nearly 50 percent of the increase in prevalence can be attributed to better ascertainment, changing diagnostic criteria, and better services. An actual increase seems probable, but we cannot say accurately how many more people are affected each year. To understand the cause of autism, science has to be conducted on many fronts. We now have a much better understanding than we did 10 years ago of the heterogeneity of ASD, the emergence of symptoms and different developmental trajectories that children with ASD may take, the co-occurring behavioral and health conditions, and the biology underlying the disorder.

Recent findings on genomic factors associated with autism shed new light on risk for ASD. It has been demonstrated that there are as many as 1,000 rare changes in DNA structure for DNA sequences that contribute to ASD risk. These changes are frequently spontaneous; that is, they are not inherited from parents in the way that we usually think of genetic inheritance. It is possible, though, that the mutations could be found in the father's sperm cells, which continue to divide throughout life. Most of the genetic findings that have been discovered confer risk for a range of brain disorders, and are not specific to ASD. Research into the function of the implicated genes has begun to point to a few common biological pathways, particularly those that stabilize activity between neurons in the brain. These pathways are now the target for research to understand the causes of ASD, and ultimately to identify preventive measures and potential treatments.

Given the complexity of autism risk, there is an increasing focus on research that examines the interface between environmental factors and genetic susceptibility. A list of candidate environmental exposures identified for future study was developed in a workshop of experts supported by the NIEHS and Autism Speaks. The list of candidates for future study, just published in 2012, included: lead, methylmercury, polychlorinated biphenyls, organophosphate, pyrethroid, organochlorine insecticides, endocrine disruptors, automotive exhaust, polycyclic aromatic hydrocarbons, brominated flame retardants, and perfluorinated compounds. These compounds are widely distributed within the environment and have known neurodevelopmental effects that may be relevant to autism. More research is planned to identify and explore the possible effects of these environmental exposures. In addition, the NIH- funded National Children's Study is expected to allow us to examine a combination of biosamples (taken in pregnancy and early in life), and environmental exposures, and to look at the possible causes of a wide range of health and disease. If we are successful in recruiting our goal of 100,000 children into the study, one thousand to several thousand of them are likely to have ASD, and provide us with unique insight into possible origins of these disorders.

In terms of more immediately applicable research, over the last decade, the NIH has supported research activities on screening, diagnosis, and treatment. With recent advances, diagnosis by age 14 months is now a realistic possibility, and researchers are actively pushing the detection window to even younger ages. For example, in April 2011, NIH-funded researchers demonstrated that a simple, low-cost, practical screening tool involving a checklist that takes only five minutes for a parent to complete in doctors' offices can be used to detect ASD during a child's one-year well-baby check-up. The checklist includes questions about the child's emotions, eye gaze, communication, gestures, and other behaviors. Of course, early diagnosis is only valuable if effective interventions are available. Recently published results from several successful trials of early interventions have validated approaches that are effective in young

children, creating real promise of improved health outcomes and quality of life for children with ASD.

NIH established an intramural research program to accelerate development and testing of innovative treatments for ASD. This program has studied hundreds of children including a cohort of young children with autism followed longitudinally in a natural history protocol. The most promising of these thus far appears to be donepezil, chosen in response to finding reduced REM sleep in children with autism in the natural history protocol. An open-label trial of donepezil resulted in enhancement of REM sleep in young children with autism; thus a randomized controlled study using donepezil to target symptoms of ASD is currently in development.

Recently, NIH launched the Fast-Fail Trials in Autism Spectrum Orders (FAST-AS) initiative. This initiative's goal is to implement an experimental medicine paradigm of "fast fail" Proof of Clinical Mechanism (POCM) and Proof of Concept (POC) trials in order to quickly test and analyze novel interventions (i.e., compounds) and their molecular and/or clinical targets for treating clinical dimensions of psychopathology associated with ASD.

Question 10. In addition to the Interagency Autism Coordinating Committee, there has previously been at the NIH a Transagency Autism Committee of NIH Institute and Centers. Does this group still exist? If so, please provide details on the group, how often it meets, and any documents such as transcripts of meeting notes, and activities.

Answer: The NIH formed an internal trans-NIH Autism Coordinating Committee (NIH ACC) in 1997 and is still in existence. The committee's goal is to enhance the quality, pace and coordination of autism-related efforts at the NIH. The NIH ACC also implements recommendations from the IACC strategic plan for autism research, as well as other initiatives and activities specific to management of the NIH research programs. The committee membership is composed of the following institutes:

- National Institute of Mental Health (NIMH)
- Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
- National Institute on Deafness and Communication Disorders (NIDCD)
- National Institute of Neurological Disorders and Stroke (NINDS)
- National Institute of Environmental Health Sciences (NIEHS)
- National Institute of Nursing Research (NINR)
- National Center for Complementary and Alternative Medicine (NCCAM)
- Representatives from the National Institute of Allergy and Infectious Diseases (NIAID)

The committee meets monthly as an internal group and does not produce public documents.

Question 11. Please provide a full list of therapies that the NICHD/NIH is aware of currently being used to treat autism with a bibliography of evidence to support their safety and efficacy, and ongoing research projects in which they are evaluated. Please provide a

notation to indicate when a therapy has not previously or is not currently being evaluated through NIH grants/contracts of intramurally.

Answer: The Agency for Healthcare Research and Quality published in 2011 a literature review evaluating the effect of available interventions on children younger than thirteen with ASD and in 2012 a literature review evaluating the effects of available interventions on adolescents and young adults with ASD. For the children's review, the experts reviewed 714 articles comprising 159 unique studies. For the adolescent and young adult review, the experts reviewed 1,035 articles, but eliminated all but 32 for a variety of reasons: not relevant to key questions, ineligible population, study size too small, not original research, or data not suitable. Many of the studies reviewed received support from NIH. These documents provide the most recent and most thorough evaluations of interventions for ASD.[6]

The most recent analysis of the distribution of autism research across both Federal and private funders and across types of research is reported in the 2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report.[7] In that year, 277 research projects were funded by Federal and private funders that addressed the question, "Which Treatments and Interventions Will Help?" for a total of over $68 million. Of those projects, 110 were funded by NIH. By using the "IACC Autism Spectrum Disorder Research Portfolio Analysis Web Tool,"[8] the reader can see the projects that were funded by all funders, including NIH. These cover a range of treatment approaches, including behavioral, educational, medical/pharmacological and technology-based interventions.

[6] The full reports from these two reviews are available at http://www.effectivehealthcare.ahrq.gov/ehc/products/106/656/CER26_Autism_Report_04-14-2011.pdf and http://www.effectivehealthcare.ahrq.gov/ehc/products/271/1196/CER65_Autism-Young-Adults_20120723.pdf.
[7] http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml.
[8] https://iacc.hhs.gov/apps/portfolio-analysis-web-tool/projects.

The Honorable Patrick Meehan

Question 1. [T]he CDC's April 2012 report on the prevalence of autism in the United States says "ASDs continue to be an important public health concern. The findings provided in this report confirm that prevalence estimates of ASD continue to increase in the majority of ADDM Network communities, and ongoing public health surveillance is needed to quantify and understand these changes over time. Further work is needed to evaluate multiple factors affecting ASD prevalence over time."

Questions 1.1 thru 1.3 Assigned to CDC.

Question 1.4: What is the federal research agenda for identifying subtypes of autism using genetic, brain imaging, and behavioral data? How can that research be most quickly integrated into treatment research?

Answer: The Federal Interagency Autism Coordinating Committee (IACC) provides an annual update to the IACC Strategic Plan (Plan) for ASD research that serves as the nation's research agenda.[9] Efforts to improve identification of autism phenotypes are addressed under the Plan's question 1 ("When should I be concerned?"), which focuses on research to improve tools for screening and diagnosis of various phenotypic features of autism; and question 2 ("How can I understand what is happening?"), which encourages research strategies that use technologies in genetics and brain imaging to understand the biological bases of ASD symptoms and expression.

The IACC's 2010 Research Portfolio Analysis report highlights the range of intervention strategies and approaches that received Federal (and private) sources of research support under question 4 of the autism strategic plan.[10] Moreover, NIH institutes have put forward several research initiatives that specifically encouraged research efforts to hasten the translation of findings in basic neuroscience to treatments and interventions for ASD and other neurodevelopmental disorders. Examples include the following Funding Opportunity Announcements (FOAs):

- New Experimental Medicine Studies: Fast-Fail Trials in Autism Spectrum Disorders.[11]
- Translational Research for the Development of Novel Interventions for Mental Disorders.[12]
- Preclinical Research on Model Organisms to Predict Treatment Outcomes for Disorders Associated with Intellectual and Developmental Disabilities.[13]
- Outcome Measures for Use in Treatment Trials for Individuals with Intellectual and Developmental Disabilities.[14]

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[9] http://iacc.hhs.gov/strategic-plan/2011/index.shtml.
[10] http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml - q4).
[11] https://www.fbo.gov/index?s=opportunity&mode=form&id=bad962ee955a1748dd61e48ef3be72a3&tab=core&_cview=1.
[12] http://grants.nih.gov/grants/guide/pa-files/PAR-11-177.html.
[13] http://grants.nih.gov/grants/guide/pa-files/PAR-11-038.html.
[14] http://grants.nih.gov/grants/guide/pa-files/PAR-11-045.html.

- Psychosocial/Behavioral Interventions and Services Research in Autism Spectrum Disorders.[15]
- The NeuroNEXT Clinical Trials.[16]

[15] http://grants.nih.gov/grants/guide/pa-files/PA-11-283.html.
[16] http://grants.nih.gov/grants/guide/pa-files/PAR-11-343.html.

HRSA Response to Question for the Record (QFR) from the House Oversight & Government Reform Committee Hearing on Autism, titled "1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autism" on November 29, 2012

Representative Patrick Meehan (p.5)

Researchers at the Center for Autism Research at The Children's Hospital of Philadelphia conducted a needs assessment in 2011, which surveyed individuals with autism spectrum disorders and their families living throughout Pennsylvania. The researchers found that individuals with autism of all ages and their families are struggling to find the services they need and are often dissatisfied with the services that are provided.

1) How can the federal government support the development and implementation of quality services delivered by trained professionals?

Response:

The Health Resources and Services Administration (HRSA) supports the development and implementation of quality services delivered by trained professionals through the Combating Autism Act Initiative (CAAI). HRSA administers several programs under CAAI that address different aspects of services for those with autism spectrum disorders (ASD) and other developmental disabilities. These HRSA funded programs include: (1) interdisciplinary training for health professionals, (2) evidence-based research interventions, and (3) state programs that address infrastructure/service building activities. These programs work collectively to promote early screening, diagnosis and evidence-based intervention for ASD.

The results of a national evaluation of CAAI grant investments from 2008-2010 conducted by Insight Policy Research indicates progress in several critical areas related to ASD service delivery. Selected results from the evaluation are presented below.

The Leadership Education in Neurodevelopmental and other related Disabilities (LEND) and Developmental Behavioral Pediatrics (DBP) programs has expanded their training resources and assisted local agencies and practices in building their capacity to provide community-based ASD services. During the 2009-2010 grant year, the LEND and DBP programs collectively trained close to 2,500 medium-term and 1,400 long-term trainees with increases of 13 percent and 22 percent respectively during the 2010-2011 grant year. Trainees included health care providers (psychologists, pediatricians, speech language pathologists, social workers, nutritionists, nurses, physical therapists, occupational therapists, geneticists and genetic counselors, dentists, health administrators, and others), other professionals who work with children (special educators, child care providers and others), and families who have children with ASD/developmental disorders (DD). The grantees also responded to the training needs of practicing pediatricians and other professionals who had limited experience identifying ASD in children. Between 2009 and 2011, the LEND and DBP grantees collectively offered more than 1,600 continuing education events pertaining to ASD screening, diagnostic evaluation, and evidence-based interventions for children with ASD. During the same timeframe, these grantees also offered more than 4,000 outreach trainings on valid and reliable screening and diagnostic tools, and/or evidence-based interventions for ASD and other DD, with the numbers increasing from year to year. These

increases have led to an expanded capacity of local communities to provide services for individuals with ASD.

In 2009–10, the 39 LEND grantees collectively provided diagnostic evaluations to more than 35,000 children. The following year, the number of diagnostic evaluations provided through a LEND program-affiliated clinic exceeded 44,000. Including the children who received diagnostic evaluations from a CAAI-supported LEND program in 2008–09, nearly 92,000 children were evaluated over the 3-year grant period.

Grantees further worked to improve access to ASD services in several ways. To create more coordinated systems of care for ASD, grantees mapped existing resources, identified gaps in services, and worked to build more interdisciplinary collaboration among providers from different disciplines, such as medicine and education. The LEND and DBP grantees provided Title V and other agencies with technical assistance to expand community-based services for ASD. Finally, all grantees focused on the particular needs of underserved populations as a means of reducing disparities in access to ASD services.

Research grantees developed evidence-based tools for clinicians and parents to support them in providing effective care for children with ASD. Together, the research grantees have developed eight medical guidelines, one comprehensive guideline report, fourteen toolkits for providers and parents to use in monitoring and managing ASD symptoms, and seven new behavioral measures for assessing a child's progress over time.

Demonstration grants are provided to states to develop infrastructure building activities to improve the ASD delivery system by promoting early screening, diagnostic evaluation, and intervention, in order to develop strategies aimed at building awareness of ASD among providers, parents and the public. The grantees pursued various activities aimed at improving the system of services for children and youth with ASD and other DD. For example, each State grantee developed a collaborative planning structure to implement its State's autism plan and to coordinate ASD planning and services among State agencies and organizations. Additionally:

- State grantees recruited and established new medical homes for children with ASD and other DD to improve delivery and coordination of services.
- To promote early and continuous screening for ASD and other DD, the State grantees developed standardized screening and diagnostic guidelines for providers.
- They also leveraged existing planning and service structures, such as public health regional centers, autism treatment centers, and provider networks, in order to expand regional systems of care.
- Several State grantees developed training materials and resource guides focused on youth transition services.

Responses to Rep. Bill Posey
Committee on Oversight and Government Reform
Hearing on "1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autism"

1. In 2000, you stated, "We do not know if autism rates are going up." Twelve years later, are you on behalf of the CDC now willing to state that the rates are going up – now that your study finds that 1 in 88 children born in 2000 is on the autism spectrum?

Answer: According to the most recent CDC report, the estimated prevalence of autism spectrum disorders (ASDs) continues to rise at most of the sites within CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.[1] While there is no simple explanation for the increase, we know that it is due in part to improved methods for identification and diagnosis, and to increased public awareness partly resulting from the expansion of behavioral health services in local communities. However, we do not know exactly how much of the increase is due to these factors.

2. Do you consider the alarmingly high increase in autism rates a national crisis?

Answer: CDC continues to consider ASDs an important public health concern in the United States and around the world. Moreover, CDC knows that the emotional toll on families and communities is staggering and the economic burden can be significant. CDC is committed to providing ongoing support to communities by tracking ASDs, helping families through early identification efforts, and addressing unanswered questions through research into the risk and protective factors associated with ASDs.

3. Does CDC classify autism among children as an epidemic? If not, does CDC classify the autism rate of 1 in 55 boys as an autism epidemic among boys? If not, why now? If not, what rate would autism have to reach to be classified by the CDC as bring at epidemic levels?

Answer: Autism is an important public health concern in the United States and around the world. The high estimated prevalence of autism is certainly cause for concern, regardless of how it is labeled. "Epidemic" is a term most frequently used in infectious disease outbreaks, but has been used in non-infectious applications as well. However, it is not a term that is clearly applicable to autism. CDC's specific definition of an epidemic is an observation of more cases than expected. With autism, there are many challenges in understanding how many cases are expected. We know that some of the increase in prevalence is due to how children with autism are identified and served in their local communities. CDC data show more children than ever are being identified with autism.

4. The March 2008 CDC Autism prevalence study published by the CDC put the rate of autism in children born in 2000 at 1 in 88 children, including a rate of 1 in 55 boys. This is significantly higher than previous estimates by the CDC. Since publication of that study what budget priority changes has CDC made to dedicate more resources to understanding the relationships and causes of autism. Additionally, please provide the CDC actual spending levels for Autism for 2005-2012. Include proposed expenditures for 2013-2018.

Answer: CDC's current FY 2012 appropriation for autism is $21.3 million – up more than 30 percent since 2008 – including $9.7 million for research. The President's Budget proposes the same amount for

[1] Data are available at http://www.cdc.gov/NCBDDD/autism/data.html.

Autism in 2013. CDC's funding levels for the National Center for Birth Defects and Developmental Disabilities (NCBDDD).

CDC Autism Appropriation History (NCBDDD)

FY 2003	FY 2004	FY 2005	FY 2006	FY 2007	FY 2008	FY 2009	FY 2010	FY 2011	FY 2012
$10,811	$13,242	$14,873	$15,067	$14,801	$16,212	$20,400	$22,058	$21,380	$21,265

* Budget history reflects funds appropriated to CDC's National Center on Birth Defects and Developmental Disabilities, FY2003-FY2012

CDC is currently conducting the largest study in the United States to help identify factors that put children at risk for ASD. [2]

5. The above-mentioned study put the rate a 1 in 88 children for the 2000 birth cohort, which is significantly higher than any earlier birth cohort. When did the CDC first become aware of these alarmingly high levels—assuming it was before the final publication of the study—and what steps has CDC taken to look for signals for further increases in the autism rates? Please share with the committee any additional data you have, including preliminary data, regarding the autism rates children born in each of the following years: 2001, 2002, 2003, 2004, 2005, 2006, 2007, 2008, or later. If there is not such data at present, when can we expect the CDC to provide this data?

Answer: CDC first became aware of the updated estimates of the prevalence of ASDs in 2011 during the analysis for publication. CDC released its updated prevalence report on ASDs in March 2012. CDC's ongoing tracking through the Autism and Developmental Disabilities Monitoring (ADDM) Network will help monitor future changes in the prevalence of ASDs.

There are no additional prevalence data on ASDs to share for those birth years. In 2014, CDC's ADDM Network expects to release an updated prevalence report on children who were born in 2002.

6. Has the CDC conducted a study on the safety of the current vaccination schedule? More specifically, has the CDC studies the safety and effectiveness of administering the currently recommended six-month immunizations: HepB, RV, DTaP, Hib, PCV, IPV and influenza immunizations? Please provide the pre-licensure and post-licensure studies that support this CDC recommendation.

Answer: The current childhood vaccination schedule protects vulnerable children from 16 infectious diseases and is designed to safely protect children from vaccine preventable diseases at the earliest age possible. The recommendations for immunizations are made by CDC's Advisory Committee on Immunization Practices (ACIP). Determinations about the age at which immunization should commence, as well as immunization schedules, are based on scientific studies and expert opinions from public health officials and specialists in clinical and preventive medicine and published in *General Recommendations on Immunization*.[3] CDC recommends that health care providers adhere as closely as possible to the recommended schedule. Delaying vaccines outside of the medically acceptable age ranges increases a child's exposure to the risks from vaccine preventable diseases.

[2] To learn more, please visit http://www.cdc.gov/seed.
[3] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6002a1.htm?s_cid=rr6002a1_e.

ACIP evaluates pre-licensure and post-licensure safety and effectiveness for the immunizations currently recommended in the childhood immunization schedule and publishes their recommendations in CDC's MMWR. The ACIP recommendations for the specific vaccines listed above are:

- A Comprehensive Immunization Strategy to Eliminate Hepatitis B Virus Infection in the United States.[4]
- Prevention and Control of Influenza with Vaccines - 2012-2013 Influenza Season[5] and CDC Prevention and control of influenza with vaccines: Recommendations of the Advisory Committee on Immunization Practices (ACIP), 2010. MMWR 2010;59(No. RR-8).[6]
- Updated Recommendations for Use of Tetanus Toxoid, Reduced Diptheria Toxoid and Acellular Pertussis (Tdap) Vaccine.[7]
- Prevention of Pneumococcal Disease Among Infants and Children.[8]
- Prevention of Rotavirus Gastroenteritis Among Infants and Children.[9]
- Updated Recommendations for Use of Hib Vaccine.[10]
- Updated Recommendations Regarding Routine Poliovirus Vaccination[11] and recommendations from 2000.[12]

7. Why has the CDC refused to conduct or facilitate the conduct of a retrospective study comparing vaccinated children with unvaccinated children?

Answer: CDC assesses the safety of vaccines administered to children, adolescents and adults in the United States through high quality, science-based surveillance and research and is committed to assuring that the vaccines administered in this country are safe and effective. CDC has not conducted a study of health outcomes in vaccinated versus unvaccinated populations for several reasons:

- Vaccines save lives and are one of the most effective preventive measures in a clinician's medical arsenal. The strongest study design that could yield meaningful results between these two populations is a randomized controlled clinical trial in which a vaccinated population is compared to a study population that receives no vaccine or vaccine not given in accordance with the current recommended schedule. Because unvaccinated or undervaccinated children in the U. S. have higher rates of some vaccine-preventable disease than vaccinated children, randomized, controlled trials designed to assess the safety of recommended versus alternative immunization schedules cannot be conducted on ethical grounds.

- The vast majority of children in the United States are vaccinated making it difficult to find unvaccinated populations.

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[4] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5416a1.htm.
[5] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6132a3.htm.
[6] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5908a1.htm?s_cid=rr5908a1_w.
[7] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6001a4.htm.
[8] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5911a1.htm.
[9] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5802a1.htm.
[10] http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5836a5.htm.
[11] http://www.cdc.gov/mmwr/PDF/wk/mm5830.pdf.
[12] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr4905a1.htm.

- The study of health outcomes and control for confounders in vaccinated and unvaccinated populations would be challenging because these two groups have different baseline health and social characteristics.

- There would be inaccuracies in making conclusions for the general population based on a non-random selection of families who choose not to vaccinate.

- The Institute of Medicine (IOM) is currently conducting an independent assessment surrounding the feasibility of studying health outcomes in children who were vaccinated according to the CDC recommended schedule and those who were not.[13]

8. There are databases, including the Vaccine Safety Datalink and state databases where information is readily available. Does the CDC believe that such a study would provide useful data in assessing the safety of childhood vaccines including any acute or chronic conditions for which there may be a correlation between vaccinated and non-vaccinated children? Why has such a retroactive study not been conducted by the CDC? What if any specific objection does the CDC have to the conduct of such a retroactive study? What if any specific value do you believe such a study would provide? If so, why? If not, why not? For more than a decade the debate over this issue has ensued, CDC has refused to conduct a study examining this particular issue, that common sense would tell anyone should be studied. When does the CDC plan to do such a study, and what steps will CDC take to involve outside parties to ensure that the study has broad acceptance across all communities?

Answer: CDC and the National Vaccine Program Office co-funded the IOM to conduct an independent assessment of the feasibility of studying the safety of the childhood vaccine schedule, including comparing children who were vaccinated according to the CDC recommended schedule with those who were not vaccinated and those vaccinated on an alternative vaccine schedule. The IOM commissioned a paper, *Study Designs for the Safety Evaluation of Different Childhood Immunization Schedules*, which was posted on the IOM website for public comment. The IOM identified potential research approaches, methodologies, and study designs that could inform new studies of the effects of multiple immunizations, including an assessment of the possible strengths and limitations of each approach, methodology and design, and their logistical and ethical feasibility. The IOM report, *The Childhood Immunization Schedule and Safety: Stakeholder Concerns, Scientific Evidence, and Future Studies*, www.iom.edu/childimmunizationschedule , was issued January 16, 2013. In it, the Committee expressed support for the childhood immunization schedule as a tool to protect against vaccine preventable diseases. The Committee also recommended using existing healthcare records data to continue to study the safety of vaccines, and reconfirmed a finding of the National Vaccine Advisory Committee (NVAC) that conducting a study which required some children to receive fewer vaccines than the recommended schedule, as would be needed for a randomized controlled trial, would be unethical (links to the childhood schedule and to the NVAC report are available on the CDC's Vaccine Safety website at http://www.cdc.gov/vaccinesafety/Concerns/childhood_immunization_iomstudies.html).[14]

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[13] Information can be found at http://www.iom.edu/Activities/PublicHealth/ChildhoodImmunization.aspx
[14] *Id.*

9. What is your view regarding autism causation and in particular the putative link between thimerosal exposure via vaccines and autism?

Answer: CDC has conducted research to evaluate vaccines and neurodevelopmental outcomes including autism and found no reliable evidence that certain vaccines or vaccine ingredients cause autism. To the contrary, studies have repeatedly found no evidence of a causal association. Copies of the studies are included as attachments.

10. Is Thimerisol currently used in any vaccines administered to children in the US that are under age 18? If so, please list those vaccines and how many of those vaccines are administered to children in the US that are under age 18.

Answer: The only routinely recommended vaccines that contain thimerosal and are currently administered to children under age 18 are seasonal flu vaccines. The specific brands and presentation that contain thimerosal or trace thimerosal are:

- Fluzone Multi Dose Vial—0.01% thimerosal
- Fluvirin Multi Doses Vial—0.01% thimerosal
- Fluvirin Single Dose Syringe—trace amounts
- Afluria Multi Dose Vial – 0.01% thimerosal

Other licensed vaccines that contain thimerosal and may be used in children, though are not routinely recommended include: Td vaccine, DT vaccine, Tetanus toxoid, and meningococcal polysaccharide vaccine.[15]

We are not able to quantify information about the number of doses of these vaccines that are administered to children in the United States under the age of 18 each year because thimerosal content varies by brand, and influenza vaccine coverage information does not include specific brand and presentation information.

11. How would independent researchers go about verifying the CDC studies that deny a causal relationship between thimerosal and autism? Is the Vaccine Safety Datalink open to the public? Are the VSD datasets required to be preserved for independent analysis and verification? Does the CDC or any federal agency actually verify that these datasets are preserved for independent verification?

Answer: CDC and the managed care organizations (MCOs) that comprise the Vaccine Safety Datalink (VSD) project established a data sharing program in 2002 to allow external researchers to access VSD data through the Research Data Center (RDC) located at CDC's National Center for Health Statistics (NCHS). Up to December 31, 2000, complete VSD datasets are available for use in conducting new analyses through the RDC. External researchers may contract with the VSD MCOs individually to access data from the VSD project collected after December 31, 2000. The external researcher must follow established MCO procedures and all studies using VSD data must be approved by each MCO's Institutional Review Board (IRB) whose data is being requested for study.

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[15] This information was taken from Thimerosal in Vaccines at http://www.fda.gov/BiologicsBloodVaccines/SafetyAvailability/VaccineSafety/ucm096228.htm#t1, accessed 12/13/12. Of note, Tripedia, a DTaP product that contained trace amounts of thimerosal, has not been supplied in the United States since mid-2011.

For the September 2007 study in the *New England Journal of Medicine (NEJM), Infant and Environmental Exposures to Thimerosal and Neuropsychological Outcomes at Ages 7 to 10 Years and* the September 2010 study in *Pediatrics*, Prenatal and Infant Exposure to Thimerosal from Vaccines and Immunoglobulins and Risk of Autism, CDC provided public use data sets consisting of final data files, documents and reports. These data sets are available by request through CDC's Immunization Safety Office for the 2007 study.[16]

Independent researchers have used CDC's publicly available datasets from the 2007 and 2010 studies for the following studies:

- June 2010, On-Time Vaccine Receipt in the First Year Does Not Adversely Affect Neuropsychological Outcomes, *Pediatrics* (Volume 125, Smith, Michael and Woods, Charles, 1134-1141): Researchers used the data from the 2007 *NEJM* study to determine whether children who received recommended vaccines on time during the first year of life had different neuropsychological outcomes at 7 to 10 years of age as compared with children with delayed receipt or nonreceipt of these vaccines. They found that timely vaccination during infancy had no adverse effect on neuropsychological outcomes 7 to 10 years later.
- July 23, 2011, Thimerosal Exposure in Early Life and Neuropsychological Outcomes 7-10 Years Later, *Journal of Pediatric Psychology* (Barile, John., et al, 1-13): Independent researchers used the data from the 2007 *NEJM* study to investigate associations between the receipts of thimerosal-containing vaccines and immune globulins early in life and neuropsychological outcomes assessed at 7 – 10 years. They found no statistically significant associations between thimerosal exposure from vaccines early in life and several neuropsychological outcomes including general intellectual functioning, speech and language, verbal memory, attention/executive functioning, fine motor coordination and behavior regulation.
- Two manuscripts that used the 2010 *Pediatrics* dataset are pending publication.

12. As you may be aware, federal studies indicate that the amount of mercury on the fetus side of the placenta is higher than the blood on the mother's side of the placenta. Do you feel that it is safe to inject 100 mcg of thimerosal (50 mcg mercury) into a pregnant woman in the first trimester via the seasonal influenza and A H1N1 vaccine (as was recommended by the CDC in 2009-2010)?

Answer: Thimerosal has been used as a preservative in vaccines since the 1930s. It is 49.6% mercury by weight and is metabolized into ethylmercury and thiosalicylate. Another form of mercury, methylmercury, makes its way through the food chain in fish, animals, and humans. Exposure to methylmercury has been shown to pose a variety of health risks to humans. Studies comparing ethylmercury and methylmercury indicate that they are processed differently in the human body that one form cannot be used as a surrogate for predicting the toxicity or pharmacokinetics of the other. Ethylmercury is broken down and excreted much more rapidly than methylmercury. For example, studies of the half-life of ethylmercury in the blood of human infants resulting from vaccinations containing thimerosal have been reported to range from 3.7 days to 7 days, compared to a range of 50 to more than 150 daysfor methylmercury in human adults. Therefore, ethylmercury (the type of mercury found in the influenza vaccine) is much less likely than methylmercury (the type of mercury in the environment) to accumulate in the body and cause harm. The only studies that showed higher umbilical cord blood mercury levels specifically investigated methylmercury, not ethylmercury that is

[16] Information about these data sets is available at http://www.cdc.gov/vaccinesafety/Concerns/Thimerosal/QA_Pediatrics-thimerosal-autism.html and http://www.cdc.gov/vaccinesafety/Concerns/Thimerosal/neuropsychological_Outcomes.html.

contained in thimerosal. There are no studies that CDC is aware of that looked at ethylmercury and investigated cord blood *vs.* maternal blood levels.

Regardless of the manufacturer, in the multi-dose influenza vaccine preparation, the amount of mercury per injection is 25 ug/0.5 ml dose (0.01%) as published by CDC for 2012-2013 influenza vaccines. Single-dose vaccine presentations without thimerosal are also available. During the past 50 years, approximately 50,000 pregnant women have been actively studied in different countries, including women in all trimesters of pregnancy. No increased risks for birth defects, spontaneous abortion or fetal death were observed after inactivated influenza vaccine. Additionally, data suggest that vaccination of pregnant women during their second and third trimesters may have protective effects for preterm birth and fetal growth.

CDC continues to monitor and study vaccine safety in pregnant women during all trimesters and uses this research to inform evidence-based maternal vaccination policies. CDC's comprehensive review of reports to Vaccine Adverse Event Reporting System (VAERS) identified no unusual patterns of pregnancy outcomes among vaccinated women. Benefits of vaccinating pregnant women usually outweigh potential risks when the likelihood of disease exposure is high, when infection would pose a risk to the mother or fetus, and when the vaccine is unlikely to cause harm.[17]

13. The FDA has licensed and CDC's recommendation includes administration of thimerisol-preserved vaccines for use in children as young as 6 months of age. In the mid-2000s the CDC expanded their recommendation of flu vaccines for all children, yet millions of children receive thimerisol-preserved vaccines each year. How many children received thimerisol-preserved flu vaccines in the 2011-2012 flu season? At similar immunization rates, how many children would receive thimerisol-preserved flu vaccines in the 2012-2013 flu season?

Answer: We are not able to quantify information about the number of children who have received thimerosal-preserved flu vaccines because thimerosal content varies by brand and vaccine coverage information does not include specific brand and presentation information.

14. How many thimerisol-free (only trace amounts) influenza vaccines were produced for the 2011-2012 flu season? Please break down inhaled vs. injected. How many does CDC expect for each in the 2012-2013 flu season?

Answer:

- 2011-2012 season: Manufacturers projected about 79M doses of thimerosal-free (or only trace amounts) influenza vaccine, of which about 15-16 M were projected to be intranasal.
- 2012-2013 season: Manufacturers projected about 62M doses of thimerosal-free (or only trace amounts) influenza vaccine, of which about 13M were projected to be intranasal.

15. Please provide the committee with a detailed explanation of your role, and the role of Dr. Diana Schendel in the Madsen et al. 2003 Pediatrics study on thimerosal-containing vaccines and autism (using Denmark autism incidence data)?

Answer: The Madsen et al. publication acknowledges three staff from CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD): Coleen Boyle, Jose F. Cordero, and Diana Schendel.

[17] http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6002a1.htm?s_cid=rr6002a1_e.

At the request of the Danish researchers, Coleen Boyle and Diana Schendel reviewed the paper and provided comments, a common role CDC fills for its colleagues in autism and other fields. In addition, Jose F. Cordero, who at the time was serving as NCBDDD Director, wrote a letter to *Pediatrics* encouraging the journal to consider the article for publication. The letter explained that the Madsen et al. study filled an important gap in the research by providing an epidemiologic analysis related to autism and thimerosal. CDC did not provide funding for the study, and CDC researchers did not analyze any of the data.

16. Are you aware that data were withheld by Denmark authors of the Madsen 2003 paper? These data showed that the downward trend in autism incidence continued in the years following the study end date. Has the CDC published subsequent studies analyzing the decline in autism that was first indicated in the Madsen study?

Answer: As CDC did not fund the collection of the data, nor analyze the data, CDC is not aware of, and cannot say with any degree of certainty that data were withheld by the Denmark authors of this paper. CDC has not published any subsequent studies analyzing the decline in autism referred to in the Madsen et al. study.

17. Did you work with Dr. Poul Thorsen? Please provide the committee with the extent of your work with Dr. Thorsen. When was your last communication with Dr. Thorsen?

Answer: CDC has a long-standing relationship with the Danish Agency for Science, Technology, and Innovation and Aarhus University in Denmark and has worked with Dr. Thorsen in the past; however, Dr. Thorsen was not a direct grant recipient of CDC funds. He served as a senior scientist on research studies conducted by those agencies and CDC, including studies on autism. CDC's last communication with Dr. Thorsen was in September 2010.

18. What role, direct or indirect, has Dr. Thorsen had with any of the databases and datasets that have been utilized by the CDC either directly or indirectly as a part of studies related to autism, vaccine safety, and/or child health and development? This includes any study in which CDC participated in any way including but not limited to direct or indirect funding, the involvement of CDC employees, or the involvement of non-CDC employees who were receiving some direct or indirect CDC funds. Please provide a detailed response to the Committee for each study and whether and what Dr. Thorsen's direct and/or indirect role was with each study and/or databases that may have been utilized for any such study.

Answer: Dr. Thorsen served as a senior scientist on research studies conducted as part of the CDC-Denmark Program on topics including cerebral palsy, autism, alcohol use in pregnancy, and Down syndrome. Dr. Thorsen was one of many co-authors on these research projects, all of which were subject to extensive peer review. As with many scientific publications, only some of the co-authors on these studies had access to the raw data and/or involvement in an analysis of the data. CDC has no reason to believe that the integrity of the science was compromised by Dr. Thorsen's role as co-author.

19. What specific steps has the CDC undertaken to ensure integrity of any research in which Dr. Thorsen, a wanted fugitive has been either directly or indirectly involved? Has the CDC gone back to validate the veracity of the studies he participated in either as an author, co-author? Please provide the specific actions taken by the CDC with respect to each individual study.

Answer: As CDC has no reason to believe that the integrity of the science was compromised by Dr. Thorsen's role as co-author, no further validation has been pursued.

20. What would be the effect to the 'whole body of evidence' if all papers that Dr. Thorsen is a co-author on were excluded? Please provide a list and copies of the studies which you consider to be the 'whole body of evidence' discounting an autism-vaccine injury/mercury link.

Answer: There would be no substantial effect. It is important to recognize that our overall understanding of a field of study, like autism, is not based primarily on the work of any one author. CDC has conducted research to evaluate vaccines and neurodevelopmental outcomes, including autism.[18] Dr. Thorsen was the co-author on one study that was published in the *New England Journal of Medicine* (2002; 347:1477-82). CDC's studies are consistent with the vast majority of science that does not support a causal association between vaccines and autism.

21. Will the CDC retract any of the collaborative publications with Dr. Thorsen that it has not gone back and independently validated? If not, why?

Answer: CDC does not plan to retract any of the collaborative publications with Dr. Thorsen, as there is no reason to believe that the integrity of the science was compromised by Dr. Thorsen's role as co-author.

22. Please list for the Committee, any studies that CDC employees and Dr. Thorsen are listed as coauthors since his Federal indictment on April 14, 2011.

Answer: The following studies were published after April 14, 2011 and include Dr. Thorsen and at least one CDC co-author:

1. Hvidtjørn D, Grove J, Schendel D, Schieve LA, Værke C, Ernst E, Thorsen P. Risk of autism spectrum disorders in children born after assisted conception: a population-based follow-up study. J Epidemiol Community Health. 2011;65(6):497-502.
2. Schelonka RL, Maheshwari A, Carlo WA, Taylor S, Hansen NI, Schendel DE, Thorsen P, Skogstrand K, Hougaard DM, Higgins RD; NICHD Neonatal Research Network. T cell cytokines and the risk of blood stream infection in extremely low birth weight infants. Cytokine. 2011;53(2):249-55.
3. Carlo WA, McDonald SA, Tyson JE, Stoll BJ, Ehrenkranz RA, Shankaran S, Goldberg RN, Das A, Schendel D, Thorsen P, Skogstrand K, Hougaard DM, Oh W, Laptook AR, Duara S, Fanaroff AA, Donovan EF, Korones SB, Stevenson DK, Papile LA, Finer NN, O'Shea TM, Poindexter BB, Wright LL, Ambalavanan N, Higgins RD; Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network. Cytokines and neurodevelopmental outcomes in extremely low birth weight infants. J Pediatr. 2011;159(6):919-25.
4. Natarajan G, Shankaran S, McDonald SA, Das A, Ehrenkranz RA, Goldberg RN, Stoll BJ, Tyson JE, Higgins RD, Schendel D, Hougaard DM, Skogstrand K, Thorsen P, Carlo WA. Association Between Blood Spot Transforming Growth Factor-β and Patent Ductus Arteriosus in Extremely Low-Birth Weight Infants. Pediatr Cardiol. 2012; [epub ahead of print]
5. Ambalavanan N, Carlo WA, McDonald SA, Das A, Schendel DE, Thorsen P, Hougaard DM, Skogstrand K, Higgins RD; Cytokine and Generic Database Subcommittees of the Eunice Kennedy Shriver National Institute of Child Health Human Development Neonatal Research Network.

[18] A chart of these studies is available at http://www.cdc.gov/vaccinesafety/00_pdf/CDCStudiesonVaccinesandAutism.pdf.

Cytokines and posthemorrhagic ventricular dilation in premature infants. Am J Perinatol. 2012;29(9):731-40.

23. When did CDC first become aware of financial irregularities with regard to Dr. Thorson and his work? When did CDC initiate an investigation into Dr. Thorson's alleged criminal activities?

Answer: CDC became aware of the irregularities in the first quarter of 2009 following a meeting between CDC and representatives from Aarhus University. Shortly thereafter, CDC engaged appropriate parties within the Department of Health and Human Services for further action.

24. Will the CDC provide the Committee with any and all communications that CDC employees or surrogates have had with Dr. Thorsen? If not, why not? If so, will those be provided to the Committee by February 1, 2013?

Answer: CDC will coordinate with the committee to determine the most appropriate process for addressing the committee's question and request for documents.

25. The CDC granted Dr. Thorsen's projects over $16 million in taxpayer money. Is further disbursement ongoing or planned? If not, when was the last payment made to Dr. Thorsen and/or the Danish contract?

Answer: While CDC has a long-standing relationship with the Danish Agency for Science, Technology, and Innovation and Aarhus University in Denmark, Dr. Thorsen was never a direct grant recipient of CDC funds. The cooperative agreement for the CDC-Denmark Program ended January 31, 2012.

26. Utilizing the DSM 5 criteria will likely make it difficult to compare populations of children diagnosed with autism under DSM 4 vs. DSM 5. This will make comparisons of populations pre- and post-DSM 5 difficult. What specific steps is the CDC undertaking to ensure that use of DSM 5 criteria does not disrupt long-term studies on the rates of autism?

Answer: While the DSM-5 is not scheduled for release until May, 2013, CDC has already taken steps to evaluate the potential impact of proposed changes on estimates of the prevalence of autism spectrum disorders (ASDs). Results from our preliminary evaluation were presented in a scientific poster at the International Meeting for Autism Research (IMFAR) in May 2012, and a full manuscript on these findings will be submitted for publication in early 2013. In the future, because of the way our surveillance data are collected, CDC will be able to apply both the current (DSM-IV) and future (DSM-5) diagnostic criteria to generate prevalence estimates based on the different definitions and evaluate the impact on prevalence trends and diagnostic practices. Thus CDC will be able to provide comparable trend data despite changes in diagnostic criteria.

Responses to Rep. Patrick Meehan
Committee on Oversight and Government Reform
Hearing on "1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autsim"

Question 1. [T]he CDC's April 2012 report on the prevalence of autism in the United States says "ASDs continue to be an important public health concern. The findings provided in this report confirm that prevalence estimates of ASD continue to increase in the majority of ADDM Network communities, and ongoing public health surveillance is needed to quantify and understand these changes over time. Further work is needed to evaluate multiple factors affecting ASD prevalence over time."

1.1 I understand from the CDC's prevalence data, and other studies, that there is an alarming rate of increase in autism diagnosis. In your opinion, what accounts for this?

Answer: While there is no simple explanation for the increase, we know that it is due in part to improved methods for identification and diagnosis, and to increased public awareness partly resulting from the expansion of behavioral health services in local communities. However, we do not know exactly how much of the increase is due to these factors.

1.2 Has CDC done any research into environmental factors that correlate with ASD, such as gastro intestinal disorders or auto immune diseases?

Answer: Last year, CDC published an analysis using survey data and found that children with autism spectrum disorders (ASDs) were at higher risk for stomach/intestinal illness, food allergies, or frequent diarrhea/colitis. CDC's Study to Explore Early Development is currently collecting information on gastro-intestinal function and autoimmunity to further address these topics.[19]

1.3 In the report, CDC refers to the significant rise in autism as "an important public health concern" but many in the community call it a crisis, an emergency or even an "epidemic". At what point does the increase in autism cases become more than a concern? Why isn't it an epidemic?

Answer: Autism is certainly an important public health concern in the United States and around the world. The continuing, dramatic rise in the estimate of autism is certainly cause for concern, regardless of how it is labeled. "Epidemic" is a term most frequently used in infectious disease outbreaks, but has been used in non-infectious applications as well. However, it is not a term that is clearly applicable to autism. CDC's specific definition of an epidemic is an observation of more cases than expected. With autism, there are many challenges in understanding how many cases are expected. Some of the increase in prevalence is due to how children with autism are identified and served in their local communities. CDC data show more children than ever are being identified with autism.

1.4 Assigned to NIH

Question 2. Assigned to HRSA

Question 3. The IACC annual Strategic Plan for 2011, outlines the following: "Decision makers (people with ASD, families, clinicians, and payors) frequently lack critical information about which treatment is best for an individual person. While there are many interventions in wide use, the field lacks

[19] More information is available at www.cdc.gov/seed.

comparative studies of their value or how these various interventions should be staged or combined. Comparative effectiveness research yields information from head-to-head comparisons of interventions or policies that, when combined with a personalized approach, can inform decision makers about health care choices. This approach, already helpful for cardiovascular and cancer research, needs to be developed to inform ASD interventions."

3.1 With the increased rate of Autism, given that there are no known medications to treat core symptoms of Autism and an increasing financial burden being places on families and taxpayers, why are more cost effective scientifically validated interventions and treatment modalities like Applied Behavior Analysis, which is identified by the CDC as an effective method and endorsed by both the American Academy of Pediatrics and the U.S. Surgeon General, not supported federally?

Answer: CDC identifies Applied Behavior Analysis (ABA) as a notable treatment approach and one that has become widely accepted among health care professionals and used in many schools and treatment clinics.[20] The Interagency Autism Coordinating Committee also provides information on the latest advances in treatments and interventions through the annual updates of its Strategic Plan for Autism Spectrum Disorder Research[21] and annual publication of the IACC Summary of Advances in Autism Spectrum Disorder Research.[22]

3.2 What could be done to increase support or promote these types of services?

Answer: The Interagency Autism Coordinating Committee annually updates its Strategic Plan for Autism Spectrum Disorder Research and publishes the IACC Summary of Advances in Autism Spectrum Disorder Research,[23] which describe recent advances in treatment and intervention research, making this information available to the public. In addition, research advances are presented and discussed in a public forum at meetings of the IACC, providing another way for the public to access information about the latest developments in treatment and intervention research. Currently, the IACC is finalizing the 2012 Strategic Plan.[24]

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[20] http://www.cdc.gov/NCBDDD/autism/treatment.html.
[21] http://iacc.hhs.gov/strategic-plan/.
[22] http://iacc.hhs.gov/summary-advances/.
[23] *Infra* at footnotes 12 and 13.
[24] More information is available at http://iacc.hhs.gov/.