

Oral Public Comments

**IACC Full Committee
Meeting**

November 17, 2015

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Note: Personally Identifiable Information (PII) has been redacted in this document

Carolyn Gammicchia

November 17, 2015

I stand before you today as a parent of a young man with autism and someone who has many concerns. Too many unfortunately to begin to mention within my allotted 3-5 minutes of oral comments. However as I thought about what would be most effective to say, and to be representative of the thousands of families I've met over the two decades since our son was formally diagnosed, I think it's important to minimally ask for your consideration of the following and I would like answers to these questions:

- The last full meeting of the IACC was July 8th, 2014 and the last charter was signed by former Chair Tom Insel in September, 2014. Why has it taken over a year to have this meeting and the new committee announced? I ask this because the charter stipulates there should minimally be two meetings per fiscal year and due to the urgency of the needs of the autism community in the U.S. I say urgency because there have been at close to a hundred deaths involving individuals associated with wandering incidents as well as homicides since that last meeting. Yes, the needs of the autism community are urgent and a year without a meeting of this committee needs an explanation.
- The IACC members have been announced and I'd like to know which members serve which positions in the committee as public members? Additionally there are three members who represent the Autism Science Foundation (Singer, Mandell, and Parnell) and also one additional member from the Simon's Foundation (Reichardt) who represents an organization who has given the ASF a significant amount of grant funding for marketing of the AutismBrainNet. Another new IACC appointee, Dr. Amaral is actually Director of that program as well. How will this allow for work of the committee to be without conflict of interest or bias and to represent the entire autism community when all of these appointees are working together in some way and grant funds from each of their organizations are benefitting each other? It can't really and the same holds true from the appointed members who have connections to Autism Speaks. Neither of these organizations by the way provide direct support to families or individuals with autism beyond their resources listed on their websites or their contact number that refer to other organizations for assistance. Autism Speaks 2014 financial statement (990) indicated they provided less than 5% of their annual income to support families. So as a parent that has supported other parents seeking assistance or to assist our son, I'm not seeing the organizations that help families day in and day out represented here. I know because I've contacted them in the past and not gotten needed information from them. I also personally have had people call me due to referrals from Autism Speaks. I'm also not clear as to Ms. Goodman's representation because I have been able to access Autism Now for resources and supports in the past and our son has benefitted from those services. Additionally I am glad that the committee has finally appointed a female self-advocate to be a voice on gender specific issues. This was of great concern for many years for females on the autism spectrum.

This is information taken from the IACC website home page:

"The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism

spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum.

The IACC mission is to:

- Provide advice to the Secretary of Health and Human Services regarding Federal activities related to autism spectrum disorder.
- Facilitate the exchange of information on and coordination of ASD activities among the member agencies and organizations.
- Increase public understanding of the member agencies' activities, programs, policies, and research by providing a public forum for discussions related to ASD research and services.”

My question of the committee is how can this happen with the current appointed public membership? We have current members reappointed to this committee whose role it should have been to do so. However I've had several discussions with parents about the current IACC appointments and the following was of concern:

- A parent of a sixteen year old son with autism didn't know what the IACC was. Nor within that same conversation did a mother of a four year old child.
- Many individuals I spoke with upon discussing writing letters to the IACC stated to me they felt it would be fruitless because they felt the committee is not responsive to the public. That should not be the case because this committee is supposed to be representative of and responsive to the autism community.
- Many individuals have expressed concern that the appointments will not provide for full inclusion of areas of concern felt by the autism community.
- We do not feel the IACC has taken the time to listen to those they are supposed to be representing. If you don't have representative members from organizations supporting families and individuals with varying degrees of autism daily how will that happen?

In closing I'd like to say that I support Lisa Ackerman's of TACA's public written comments for the record as well and the past comments by representative members of the National Autism Association. These are the organizations that I feel should be represented on the committee as well as parents of individuals who have navigated the system and do not have conflict of interests due to their work within privately funded research and or as a service provider.

Respectfully submitted,

Carolyn Gammicchia
[PII redacted]

There a lot of concerns I have that I would like to bring to your attention. However, I feel the need to focus on what is really happening with my family. As I tell you about my reality please keep in mind I am a representative of many families. You have all not met in over a year. Over the last year I'm sure you can look back and remember your days off and holidays. How you've been able to relax and enjoy life. Most people can do that, people with or without autism. However there is a subset of people who struggle everyday who have no days off and who have virtually no resources. They have no voice on this committee. There is certainly no organization of promoting a "life like this!" One where an individual is trapped in there body unable to communicate their needs. Smearing feces, projectile vomiting, , can't keep clothes on, can't communicate wants or needs, pains, feelings, OCD, psychotic episodes and the real kicker the meltdowns. The meltdowns are another term for hold my family hostage.

Over the last year a significant thing happened to place my life into a new dimension of "Hell" my 9 and 11 year olds grew bigger than me. Behavior that i could at one time "manage or control" became too much! Without getting into too much descriptions of exactly what has transpired my purpose in bringing this up is to give a voice for these children. I believe no one here will. If I did to my child what he has done to me CPS would be called, I'd have charges and my kids would be taken away. There are also whole organizations devoted to helping women who are treated like this by a spouse. Restraining orders are issued and people are saved from the abuse. But when it comes to an autistic kid, families have almost nothing. In situations where cops have been called the person with autism is harmed, drugged, and put in a place so inappropriate that if this person were a pet organizations would be outraged and charges would be filed. [Offensive language redacted] with the same care that I've heard often happens to these children. Families trying to get help see that it's so inappropriate, there is nothing out there or they have wait-lists that last years.

My one son has been on a wait-list for 7 years he is 9. I'm afraid to be alone with him. We have spent 100s of thousands of dollars on medical treatments and behavior therapy. I have had to go to committee after committee and beg them to take my son. I couldn't face life living like that anymore. I had to let go of where he would go and how they would treat him, or perhaps mistreat him. I had to look my kid in the face and tell him i cannot be the mom you need me to be and he couldn't understand it. The number of moms who live in a situation of despair is growing and they are killing their kids and sometimes themselves.

They say that ordinary people are capable of doing extraordinary things but ordinary people can also after living day, after day, after day in despair be driven to do horrific things. Ordinary moms like me! I am left knowing I failed my kid and I'm told I'm lucky that I got to send him off. Although I know I will seek help to get through this. This committee and this nation should be scared because there is nothing more dangerous than a Mom who has nothing to lose, who is in despair and is angry.

These families, these children, these siblings, all of our communities NEED to stop the leisurely pace at which you address autism and particularly this issue and confront this reality with the urgency of a nation on the brink of collapse!

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Laurie Reyes

November 17, 2015

Thank you for this opportunity to share with the IACC all that the Montgomery County Department of Police Autism/Intellectual Disabilities Outreach program has done and is continuing to do since my last public comment in 2011.

In 2011, I stressed what I felt was the importance of providing insurance coverage through the ICD-9 now 10 House Bill for the coverage of wandering safety tools. I felt that those “tools” needed to be just one layer in a total approach to Autism Safety. This is still a very important issue for me; I inform all I can about this potential coverage as well as other potential legislation related to Autism safety.

Montgomery County...

In Montgomery County we average between two to three searches a week for individuals with Autism, intellectual disabilities or Alzheimer’s. These are what we call “missing at risk” searches. We knew in Montgomery County that we needed to do more than just respond to the growing number of searches. We also needed to address the calls for service for individuals with Autism that had not eloped but were the focus of other calls for service. The goal was to provide a “total approach” to Autism safety through education, outreach, empowerment, and response.

Education... Since 2010 all of our incoming recruits have received a block of instruction on the dynamics of interacting with and searching for individuals with Autism. We teach our officers to “think Autism” and never underestimate a person with Autism. All of the officers view a video produced by the MCPD Autism Outreach program. The video showcases a family and their son [PII redacted]. [PII redacted] is a young man who has Autism. He also has been the focus of three significant searches. [PII redacted]’s parents share their experiences open and honestly. The video is moving and educational, leaving our officers with a sense of some of the challenges in caring for an individual with Autism. The video captures why it is so important that officers are educated and aware of Autism and what they can do to assist families.

We provide our current officers the instruction as part of the MCPD CIT training. We have provided Autism Safety instruction to our public school bus drivers, Ride On drivers, medical personnel, students, caregivers, social services and beyond. We worked with Autism Speaks in the creation of a national Autism safety video that tells the story of [PII redacted] and his amazing parents. We have also partnered with Pathfinders for Autism, a dynamic organization that shares our same philosophy of education and awareness.

Outreach...In 2013 the Montgomery County Police held our first Autism Night Out event. We partnered with Autism Speaks, and many other dynamic service providers in the Autism community. The event was created to bring law enforcement/first responders and the Autism community together in a fun, educational environment. It has turned into an evening of reunions, friendship, togetherness and awareness. Officers, caregivers and individuals with Autism learn from each other. I believe that exposure leads to understanding. This event is testament to that idea.

The outreach continues through our Montgomery County website, Facebook page, twitter, local media, national media, print media, awards and beyond. The program takes every opportunity to let caregivers,

individuals with Autism and the community know we, the police are here to assist them, we are here to serve them and ensure that any experiences that we have with them are positive. The program provides follow ups to the caregivers of individuals with Autism. The follow up consists of immediate contact following an incident of elopement as well as our MCPD elopement/wandering Safety kit. The kit contains our MCPD Autism Safety T-shirts. The T shirt is bright yellow with a Montgomery County police badge and says, "I have Autism, call 911 if I am alone". It should be noted, this shirt is completely voluntary and is only provided for individuals that cannot speak for themselves AND are in immediate danger should they elope. They are not designed to label any individual who has Autism, only to keep those safe that are in immediate danger should they elope. I understand the controversy our shirts bring however, our goal is to save lives and in my experience of hundreds of searches, I can tell you these shirts will continue to save lives. The kit also contains our MCPD Wandering Safety Tip Sheet, Neighbor Letter and 911 Script with a suggestion to print out a google map of their home to document bodies of water and other potential hazards, home and vehicle window clings and other safety handouts.

Most important...We truly encourage caregivers to have some type of ID bracelet for their loved one with Autism that may not be able to speak for themselves under stress. I understand, yet again the idea that we don't want to label individuals with Autism. I can only again express what we feel is the best way help keep our young men and women with Autism safe, especially for those navigating a road to independence. I have been the Autism/ID coordinator since 2005. I have looked into many different ways to inform our officers of those living with Autism in our community that may be in need of our assistance from time to time. I think that the answer can be found in the ID bracelet. Caregivers and the wearer can determine what the bracelet can be engraved with, what information would be important. Understanding the sensory concerns, I still feel it is an important piece of the safety puzzle. I have worked with children as part of our Project Lifesaver program who had a very difficult time initially wearing our Project Lifesaver bracelet. Over time, the wearers got used to the idea of the bracelet and began to associate the bracelet with the police. To the point that that it became a non-issue and in many cases, positive association between the bracelet and the police officer was developed. I encourage caregivers, teachers, medical personnel and social workers to work with our youngest individuals with Autism to wear an ID bracelet of some type. Not only to wear the bracelet but have the young people show the bracelet to officers in the community. The act of showing the bracelet creates that familiarization between the bracelet and the officers. It also provides the officers with an interaction with a young person with Autism. This will break down barriers. It also will help us in law enforcement in three ways...

1. Many times we find the loved one with Autism long before caregivers realize they are missing. The more information immediately available to officers, the better off we are to have a positive outcome.
2. As our young men and women navigate to independence, there may be bumps on the road. Even those that have speech may not be able to speak under stress, the ID bracelet allows individual to show the bracelet if necessary.
3. We teach our officers to "think Autism". We teach them to look for the ID bracelets, ask about the bracelets. Showing the bracelet to officers allows the wearer or their caregivers to share a little bit about the individual. It makes the encounter about more than just Autism, but goes to build understanding.

We do not have all the answers to safety. I just know what I have found to be effective tools in keeping those with Autism safe. If I could share anything it would be that our goal is of course to educate, provide outreach and empowerment but above all, our job is to save lives.

Empowerment

This piece is as important for us as all the others. We recognize that we the police are in a position to provide empowerment to those with Autism in our community. In recent years, we have provided the MCPD Chief's Awards to two deserving families and a young man with Autism. We named our Autism Ambassador, [PII redacted], who provided the key note speech at our Autism Night Out event. [PII redacted] continues in his role as the MCPD Autism Ambassador as a self-advocate, teaching our recruits about his "Autism super powers". I am proud to say that the White House recognized the importance of the partnership between [PII redacted] and I have and all that it represents. We were awarded as White House Champions of Change. I am also proud to say there are many partnerships with our officers and individuals with Autism/ID in Montgomery County. They may not yet, and may not ever be awarded by the White House but they are no less special.

Response...The response to calls for service for "missing at risk" individuals with Autism is immediate, and thorough due to the expertise of our Montgomery County Managed Search and Rescue team, coordinated by Officer Jason Huggins. This unit completes our "total approach" to wandering prevention and Autism safety. Officer Huggins and his team coordinate and effectively deploy our educated officers. The urgency of these calls is understood by responding officers. Officers truly go above and beyond in an effort to ensure the safety of the missing individual.

We have shared our "total approach" with other police agencies and they are listening. I am here today to share this with all of you.

Thank you,

Laurie

Officer Laurie Reyes
Montgomery County Department of Police
Special Operations Division
Autism/Intellectual Disabilities Outreach

From society's earliest beginning persons with particular diseases have been separated from others and left behind with only a few caring others to oversee their suffering. In today's world I feel that non-verbal and minimally verbal children with autism are the 21st century's group that are left behind.

Even in the Autism organizations their missions and focus is on the higher functioning persons or at least the verbally competent. Campaigns that focus on "Awareness" or "Acceptance" are evidence of this. Would anyone encourage a parent to just accept disease such as cancer or congenial heart disease? Many children with autism have physical symptoms which leave them in pain that is never addressed.

My grandson was pulling his hair out, banging his head and bouncing so hard that he had permanent bruising, all this self-injurious behavior stopped after his first IVIG treatment. After he was no longer in pain! Most insurance companies do not cover this treatment for someone with Autism but would for someone with Aids although the blood work is similar. This just is not right.

We keep them in schools because we have a law that says we have to, however because of the nature of the law and the fact that the numbers are increasing each year and financially breaking our schools budget this becomes adversarial relationship even to get 30 minutes a day with a speech therapist? The whole school program is based on Applied Behavior Analysis (ABA) as if the source of the problem was their behavior rather than seeing the behavior as a means to communicate their needs.

Whatever causes Autism or the list of deficits that cause an individual to be given that label it is widely recognized as a brain disorder that interferes with the coordination and integration among areas of the brain. This is demonstrated in alternative sensory perception system development.

These sensory channels are our learning channels, which are visual, auditory, tactic, kinetic and they may or may not be open on the right, left or both sides of the brain and can be generalized, global or selective, thus persons with autism have an alternative mode of perception. Because of this "we" cannot know how the person with autism is perceiving an object or scene. We can guess or intuit but we do not know, especially with our nonverbal or minimal verbal persons.

We need to work to integrate the sensory system and use recognized theories of learning together with the latest research on brain plasticity. Rapid Prompting Method (RPM) has given us a path to do this. RPM is a teaching method that works, teaching the person with autism to read, write or type, count and calculate and express what they are experiencing. I urge the committee to review this teaching technique because once the child learns to express themselves and their needs the behavior problems disappear. We do not expect the blind or deaf child to learn in the same manner as sighted or hearing children, why do we expect it of a child with deficits in other learning channels?

The problems of communication are a great danger in the emergency room. 1-68, the numbers of Aids patients were much less than this when we as health professions were mandated to learn how to treat them, where are the teaching programs and the mandates to help professionals learn how to communicate with persons with autism. RPM offers an inexpensive and easily learnt technique to implement there. But no such action has taken place or even talked about.

I urge this committee to make recommendations to our hospitals, our schools, our government agencies, to our physicians and other health care providers. Don't stop the research on causal factors,

but cut it in half and ensure it is focused on areas with high probability of success. Take the other half of the resources to develop programs for the parents and professionals to help these children learn to communicate, to read and learn and help us integrate them into the fabric of our lives.

Deanna L Mulvihill RN PhD

Subject: Four Workgroups Are Needed to Improve the Lives of People with Autism and Their Families

Four Workgroups Are Needed to Improve the Lives of People with Autism and Their Families

1. Workgroup on Autism and Wandering
2. Workgroup on Environmental Factors and Autism
3. Workgroup on Co-Occurring Conditions with Autism
4. Workgroup on Caregiver Support

Testimony Presented By Lisa M. Wiederlight, MPP Executive Director, SafeMinds
Before the
Interagency Autism Coordinating Committee
November 17, 2015
National Institutes of Mental Health Bethesda, MD

My name is Lisa Wiederlight. I am a mother to a 15 year old boy with autism who is an amazing, intelligent person who also endures gastrointestinal issues and had a grand mal seizure in May of this year. I have earned a master of public policy degree from the University of Maryland, worked for a U.S. Senator and for the Executive Office of President of the United States, and have administered millions of dollars in federal grants. Addressing my son's autism, however, has been the most challenging assignment. Life turns us in many different directions—and in the Spring of 2015, I was honored to become executive director of SafeMinds.

SafeMinds mission is to end the autism epidemic by promoting environmental research and effective treatments for people with autism. Like you, we want to improve the lives of people with autism, and to prevent and treat chronic illness and family stress.

Today, at this first meeting of this IACC, you have a blank slate. Much of the autism community feels disenfranchised, unsupported, and disappointed in the lack of a federal response to the surging autism crisis. Taxpayers have spent \$1.6 billion in the past 10 years on autism, and yet there have been few significant and positive changes in the safety, health, education, employment, housing, and well-being of people with autism and their families. The time for change, and for increased collaboration, is now. Today, SafeMinds asks that the IACC convene four workgroups.

Number One: Forty-nine percent of people with autism wander or elope from otherwise safe environments. What would you think if your child was reported missing from school, especially if he was nonverbal? Today I ask that you engage the legislative affairs offices of both the Department of Health and Human Services and the Department of Justice to pursue the passage of S.163, Avonte's Law Act of 2015. This bill provides funding for law enforcement training on preventing and addressing wandering in people with autism, and for community outreach. Today, I also ask that you convene an ongoing Workgroup on Autism and Wandering. Since May of this year, we have lost over 30 people with autism to wandering and elopement. These deaths are unacceptable.

Number Two: Autism prevalence has increased from 1 in 2000 before the 1980s, to 1 in 68 for children born in 2002. Ask anyone seeking behavioral support services for their teens with autism if there is an epidemic—the waiting list at Kennedy Krieger’s Neurobehavioral Unit is two months for outpatient services, and more than that for inpatient services. There is a manifestation of the epidemic for you. That autism requires a genetic susceptibility and an environmental trigger is widely recognized, but federal causation research funding has been predominantly focused on genetics, and prevention efforts are directed at early intervention to change the autism trajectory. Since there is no such thing as a genetic epidemic, and most children continue to have severe autism despite high quality behavioral programs, today I ask that you convene a permanent Workgroup on Environmental Factors and Autism.

Number Three: Up to 70 percent of children with autism have gastrointestinal disorders, which can manifest as maladaptive behaviors. Many of us were told by our pediatricians that diarrhea and constipation are just symptoms of autism, and our children were not treated for these physical illnesses because of their autism diagnosis. We know that up to 40 percent of people with autism have seizures, which affects mortality rates. Nothing can equal the fear a parent feels when she is holding her son’s head in her hands on the floor of his bathroom as he seizes in her arms. I know this personally. And then, no one can tell you why this happened, and how to prevent it from happening again. Once more we autism parents hear from medical professionals, “Kids with autism have seizures. We don’t know why.”

Research published in 2013 by Penn State University found that children with autism are 28 times more likely to commit suicide than their neurotypical peers. What has the government done about this? Nothing. Today I ask that you convene a permanent Workgroup on Co-Occurring Conditions with Autism. I hope that many medical professionals will join the doctors currently on this committee in the workgroup.

Fourth, and finally, you cannot take care of people with autism if you do not also take care of their parents and other caregivers. While autism is a spectrum disorder, many caregivers acknowledge that raising a child with autism is exhausting, overwhelming, isolating, depressing at times, joyful at times, and extraordinarily expensive. While there are very high-parenting “highs” there are very low, “lows.” Yet, there are few supports for the caregivers who worry, absorb the aggressions and tantrums of their children, and cry at night wondering how they can help their children to get better, and to thrive. We love our children, but many of us also need help. Today, I ask that you convene a Workgroup on Caregiver Support to ensure that all families thrive.

Thank you for listening to me. I wish to volunteer for each of these workgroups, and I am sure you will have many other willing volunteers from the community.

Note: Personally Identifiable Information (PII) has been redacted in this document

Albert Enayati

November 17, 2015

Subject: Vaccines Caused [PII redacted]'s Autism

Testimony Presented By

Albert Enayati, MSME

Research Scientist, Senior System Engineer

Father of [PII redacted], who regressed into autism after his childhood vaccinations

Board Member of SafeMinds and APRC

E-mail: [PII redacted]

Before the

Interagency Autism Coordinating Committee (IACC)

November 17, 2015

Bethesda MD.

My name is Albert Enayati. I am a board member of SafeMinds and APRC, both volunteer organizations focused on identifying and removing the harmful environmental agents contributing to the severe disability that frequently accompanies autism. Sadly, despite my 20 years of autism advocacy, we are still ignoring environmental risk factors, with no safe and effective medications or prevention strategy in sight. No conclusive biomarkers have been identified and no new treatments validated. Over the past seven years of IACC coordination, Federal agencies have spent 1.6 billion dollars in many fields of autism research, but environmental research has been underfunded and autism prevalence continues unabated, including severely disabling cases.

It is time to dedicate resources to a more fruitful path; environmental causation of autism. Within this field, a topic in need of funding is the role of vaccines in autism etiology.. Please take note that a recent study among parents by the Simons Foundation found that 42% of parents felt vaccines contributed to their child's autism.¹ The IACC should not ignore this large segment of the community and observations by so many parents regarding their children's developmental history.

In 2009 the National Vaccine Advisory Committee (NVAC)^{2, 3, 4} recommended to this committee a number of feasible research proposals on vaccines and autism. Not a single one has been implemented. My son [PII redacted] regressed after his vaccinations. He is suffering from his autism and breaks my heart piece by piece. He has serious self-injurious behavior. He has run away, ended up in the emergency room, and been tased by law enforcement. His finger was nearly amputated because he cannot communicate his pain from infection. His medications don't help. Meanwhile, the main decision-makers on autism research, here at the IACC – the NIH, CDC, Autism Speaks and the Simons Foundation - have been discriminating against children like my son and many children across the country whose parents report regressions after their childhood immunizations. Even if it is “unpopular”, it is ethically imperative that we investigate these reports and study these children. Public health is not simply freedom from infectious disease. Autism is not always a gift or alternate way of being. It often comes with a great cost. My son deserves to have attention paid to him and research done to help him have a better quality of life.

On many occasions Dr. Insel informed me that “science does not support my point of view”. In fact, very little meaningful science has been done on vaccines and autism, only a small fraction of possibilities have even been looked at, and the studies that have been published are riddled with conflicts of interest, data manipulation and in the case of Dr. Thorsen, indictment for financial research fraud. In addition, Dr. William Thompson, a senior researcher at the CDC who has whistleblower status, has reported dumping inconvenient data in a garbage can, along with colleagues, to avoid reporting an increased risk of autism in African American boys who received MMR vaccine.

A 2011 study by the Institute of Medicine's Immunization Safety Review Committee⁵ evaluated the evidence on possible causal associations between immunizations and certain adverse outcomes. In 135 of 158 pairs evaluated, they found that “evidence is inadequate to accept or reject a causal relationship”. They found no relationship between MMR and autism, but given that their evaluation included studies like the one where data was dumped, the safety of our children demands that we allow for future research to inform the questions.

Even the package insert for DTaP⁶ vaccine suggests that we need further study. Here's a quote from 2005: [emphasis added]

“Adverse events reported during post-approval use of Tripedia vaccine include idiopathic thrombocytopenic purpura, SIDS, anaphylactic reaction, cellulitis, autism, convulsion/grand mal convulsion, encephalopathy, hypotonia, neuropathy, somnolence and apnea. Events were included in this list because of the seriousness or frequency of reporting.”

Yet, there are no studies looking specifically at autism and receipt of DTaP vaccines.

In a recent study of 100 published papers analyzed by Science magazine⁷, only 39% of published articles could be replicated unambiguously. We need to keep an open mind and start actually funding unbiased research into vaccines and autism. A recent paper indicates that aluminum in vaccines may have direct association with the increased rate of autism⁸. Another paper found increased risk of autism from the birth dose of Hepatitis B.⁹ The Vaccine Injury Compensation Program has compensated at least 83 cases with autism or autism-like conditions.¹⁰ Vaccines have been found to increase the risk of seizures, tics and mitochondrial collapse, all of which commonly co-occur in autism.^{11,12,13}

A controlled study has not been done of autism risk among children given the recommended vaccine schedule compared with those not so vaccinated.

Autism can no longer be considered a purely heritable, genetic disorder. Several studies suggest that as much as 50% of risk may be due to environmental factors. It is imperative that the non-genetic causes of autism be investigated. Unbiased research on the role of vaccinations needs immediate support. Our children are too important to let even a controversial stone go unturned.

Sincerely and respectfully
Albert Enayati, MSME
Board Member, SafeMinds and A.P.R.C

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13. <http://www.cdc.gov/vaccinesafety/concerns/thimerosal/environmental-exposures.html>

On behalf of Madison House Autism Foundation, we would like to welcome you as the new IAAC Board. If you are as stellar as your biographies purport, this board will accomplish a great deal. Madison House Autism Foundation is one of the few national organizations working solely on the issues of Adults on the Autism spectrum. We are taking a comprehensive look at the issues facing adults from graduation throughout the lifespan.

We have supporters, partnerships and colleagues across the nation. Our activities and conversations focus on housing, employment, healthcare, education for those on the spectrum, education of providers, concerns and issues facing individuals and their families as they navigate life in the community. We hope that you will take an active role in making certain that this population receives the attention that it deserves. Historically, a very small portion of any federal funding has been allocated to increase knowledge about this population. Only about 4% of primary research publications on autism have addressed lifespan issues in recent years whereas all of today's autistic children are heading rapidly into adulthood. In fact, research focused on adults has consistently been among the smallest categories of autism-related research since the 1980s.¹

Many concerns for parents and individuals include the lack of appropriate services so that life after high school can include employment, structure, and continued physical and mental well-being. Many families have a difficult time navigating services in securing housing, employment, medical care ... when and if these services are available. Many parents are aging; current public policy is leaning heavily towards individuals aging in place in the parental home. Each day, we hear about parents in their 70s and 80s contending with the physical and mental stress of being the sole support for community engagement and all other activities in their adult child's life.

We hear numerous stories about autistic adults being unemployed, yet who have skills that can be highly valued by employers. According to [A.J. Drexel Autism Institute](#), young adults with autism have higher unemployment rates and higher rates of complete social isolation than people with other disabilities.²

Families face restrictions in not being able to move across state lines and maintain needed support for their adult children. Parents may travel to new locations to secure employment. They may be unable to return to their home state because services and funding will be lost and they may not be able to secure funding near family or they may be placed on waiting lists decades long. Natural supports of families - aunts, uncles and grandparents are sacrificed for services - unintentionally forcing many autistic adults into living into isolation away from family.

¹ (Office of Autism Research Coordination (OARC), National Institute of Mental Health and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee (IACC). IACC/OARC Autism Spectrum Disorder Research Publications Analysis Report: The Global Landscape of Autism Research. July 2012. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/publications-analysis/july2012/index.shtml>

² Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015. - See more at: <http://drexel.edu/autisminstitute/research-projects/research/ResearchPrograminLifeCourseOutcomes/IndicatorsReport/#sthash.iIX9qHKq.bL3QLsbl.dpuf>

As all people, when autistic adults age, they have typical medical issues. Few physicians and healthcare professionals have the knowledge or feel comfortable in treating autistic patients for typical medical issues. We need to make sure that our physicians and other healthcare professionals are capable and willing to treat our population and physicians are not penalized when they need to give our adults adequate office time.

We need to make certain that universities can make appropriate accommodations when our population becomes part of their student bodies. As we all know, success may look different for all individuals and that definition of success has been poorly clarified for our population.

As you see, there is a lengthy list of issues facing our adults ... I could elaborate on much more.

The name of this organization is the Interagency Autism Coordinating Committee, and I hope that you take that name seriously and call into play the agencies across our government that can help make a difference in the lives of thousands of families across the country. This is a large and complicated situation, and cooperation in many arenas can ensure that the talents and abilities of this population can be realized and those who needing greater support services can access those services without stressing families who are already highly stressed. In fact, some of these families may have one, two or three individuals on the spectrum. As we solve these problems, we may also be helping other populations as well.

We call for greater action on behalf of the adult population on the autism spectrum and their families. Autistic children become autistic adults. Individuals and families need and deserve great minds and talent in making the process of living with autism more humane.

Madison House is here to be of any assistance that our ten years in the field can offer. Together, we can formulate a new and better future for adults on the autism spectrum.

Respectfully submitted,
JaLynn Prince President and Founder
Madison House Autism Foundation
Jprince@madisonhouseautism.org
www.madisonhouseautism.org
November 10, 2015

Subject: ASHA Statement before the Interagency Autism Coordinating Committee

I wanted to thank the Interagency Autism Coordinating Committee (IACC) for allowing the American Speech-Language-Hearing Association (ASHA) this opportunity to address members of the Committee today. As you may know, ASHA is the national professional, scientific, and credentialing association for more than 182,000 audiologists, speech-language pathologists, speech, language, and hearing scientists, audiology and speech-language pathology support personnel, and students. Speech-language and social communication impairments are core features of individuals with autism spectrum disorder (ASD) for which speech-language pathologists play a central role in the screening, assessment, diagnosis, and treatment.

On behalf of ASHA, I wanted to congratulate the new public members of the IACC on their successful nominations. ASHA and its members look forward to working with you, other committee members, and the staff of the IACC on advancing research and care for individuals with Autism Spectrum Disorder (ASD).

ASHA certified speech-language pathologists provide speech, language, feeding and swallowing therapy to students with ASD to help them acquire the skills they need to function in their home, school and social environment. Speech-language pathologists also treat related disorders prevalent in the ASD population—including social communication impairments—and are the designated professionals for assessing augmentative and alternative communication (AAC) needs that supplement or replace natural speech with aids, such as speech-generating devices.

Evidence suggests that diagnostic features of ASD are evident in very young children. Parents report abnormalities in their children's language development and social relatedness at about 14 months of age (Chawarska et al., 2007); making the speech-language pathologist often the first professional families meet. The professional roles and activities of the speech-language pathologist include clinical/educational services (diagnosis, assessment, planning, and treatment); prevention and advocacy; and education, administration, and research. Consulting and collaborating with other professionals, family members, and caregivers makes the speech-language pathologist a key member of a multidisciplinary team treating the individual with ASD.

While the Autism CARES Act extended the work of the IACC another five years to 2019, it adds a requirement for a report to Congress concerning young adults with ASD and the challenges related to the transition from existing school-based services to those available during adulthood. For transitioning adolescents and adults with ASD, social communication is a particularly important skill area to consider, and the role of the speech-language pathologist remains vital in this new focus. Communication rules in adolescent social interactions are often subtle and unspoken, and successful navigation within social settings requires awareness of these rules. Speech-language pathologists provide interventions that assist the individual with ASD in post-secondary educational programs, employment, maintaining relationships, and acquiring the skills necessary for independent living.

Again, thank you for this opportunity to address the IACC, congratulations on your nomination, and we look forward to working with you.

APPENDIX

Addressing the Needs of All Individuals with Autism

NICHOLAS GAMMICCHIA

**ARTIST
FILM MAKER
TRAVEL ENTHUSIAST
CREW MEMBER
SON, SIBLING, COMMUNITY MEMBER
SELF ADVOCATE**



Addressing the Needs of All Individuals with Autism

What we're told...

My parents were told they would have to institutionalize me by the age of ten when I was diagnosed with autism at age two.

-By age ten I was in a general education fifth grade classroom and on the honor roll.

My parents were told I would never earn a diploma.

-I did and exited high school on the honor roll.

My parents were told I would never be able to attend college by my Michigan Rehabilitation Services advisor.

-I am and have earned my Associate's Degree and am on the Dean's List.

What we do...

My parents were told I would never be able to work.

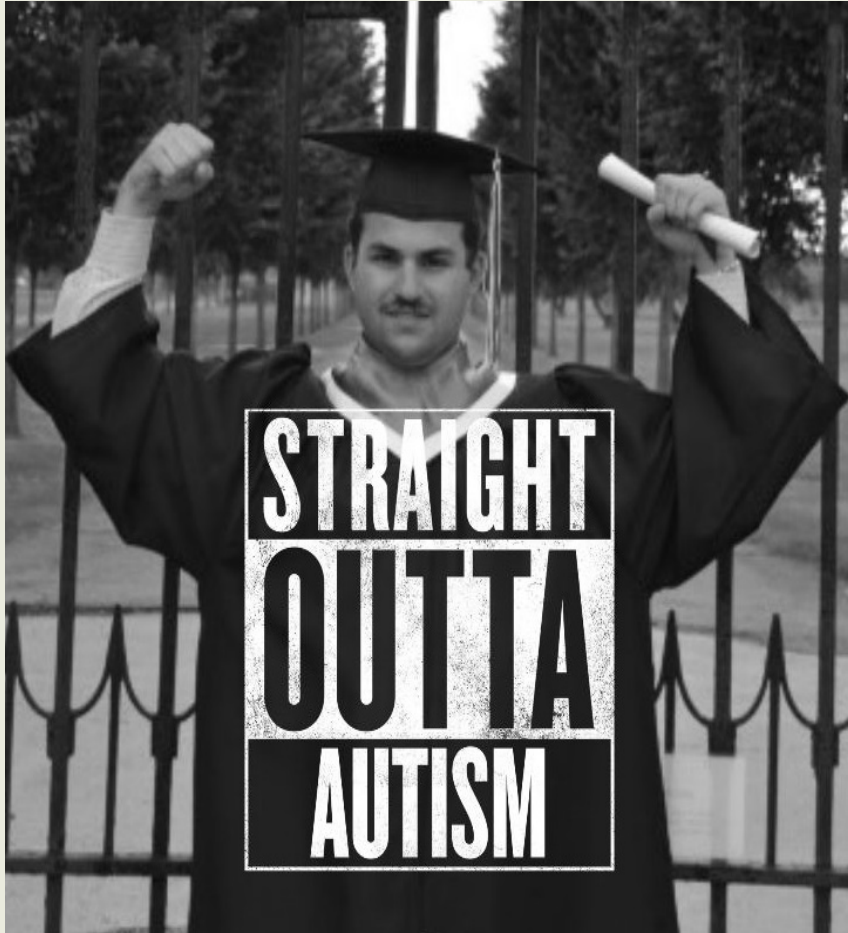
-I started Nick's Art Project, my own non-profit, when I was in high school. All proceeds raised go to provide art and music scholarships to individuals with disabilities.

My dream has been to work for Disney Studios as a Story Board Artist and to write, score, and illustrate screenplays. I was told this wasn't a possibility.

-I'm currently attending a twenty week Film Workshop, after being awarded a 2/3 tuition scholarship.

I share these stories because I want you to look beyond the limitations some people think a diagnosis can bring.

Addressing the Needs of All Individuals with Autism



What's important:

- Please listen to us as you work to represent us.
- Look at what behavior is communicating. In many cases it's medically based.
- I am where I am today due to medical intervention. Why doesn't the IACC have an MD as an appointed public member?
- If we don't identify as "autistic", that is our choice.

Addressing the Needs of All Individuals with Autism

Identifying Needs

What's important:

- Life is more than school
- Ensure proper assessments for appropriate services and supports
- Identify strengths and use them
- Respect culture, diversity, and preferences

The Tip of the Iceberg



Addressing the Needs of All Individuals with Autism



CHALLENGES AFTER CHILDHOOD

Help is limited for adults with autism

Rise in diagnoses threatens to overwhelm programs



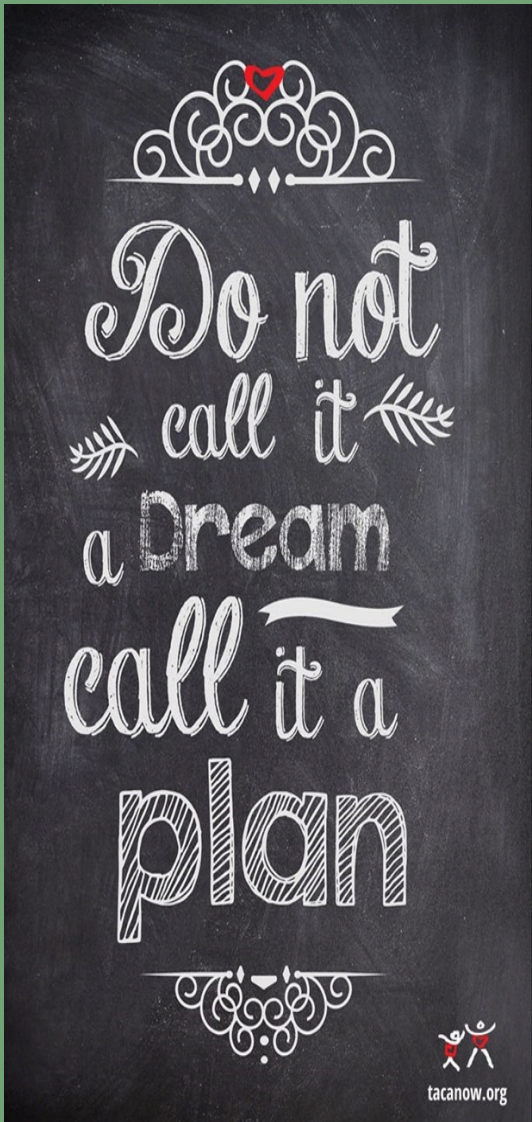
This front page story was featured in the Detroit Free press on April 25, 2012.

Why have things not improved since then for many adults with autism?

We need funding for applied research to develop programs and services for adults with autism.

We also must:

- Presume competence
- Individualize services
- Personalize supports
- Realize possibilities
- Look at overall wellness
- Think about people, not profit



In closing I'd like to ask that you consider the varying needs of individuals with autism and work toward a plan of action to ensure their quality of life is the most it can be. To do so, I'd again like to ask that the Safety Subcommittee be reconvened and ask too that the Services Subcommittee be reconvened to assist you all in doing so.

Thank you very much and smooth sailing with your tasks on the IACC.

