Written Public Comments

IACC Full Committee Meeting

July 19, 2011

List of Written Public Comments

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

Eileen Nicole Simon

April 8, 2011

Subject: April 11 meeting

It looks like I missed the deadline for submitting comments for the IACC meeting next week. I would like to bring attention to a recent paper on malformations of the superior olive in autism:

Kulesza, R.J. Jr., Lukose, R., Stevens, L.V. Malformation of the human superior olive in autistic spectrum disorders. Brain Research, January 7, 2011, volume 1367, pages 1360 to 1371.

Maybe Dr. Kulesza could be invited to speak at the meeting in July. Please submit this brief comment to the committee for future reference. Thanks.

Eileen Nicole Simon
[PII redacted]

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Marian Dar

April 8, 2011

Subject: "OUTSIDE AUTISM" movie

A vision -- of ways we can collaborate on *research* (Somali -- latitude, organic food?) and *support* to benefit autism and a spectrum of disorders and disease,

Marian Dar

[PII redacted]

Travis Breeding

April 16, 2011

Subject: Autism Needs Help

Hello, I'd like to do something to help myself and others. I wrote a blog about everything and Stephen Shore said I should submit it to you so I am. It is written below.

Good Evening, readers, friends, and family.

I've came to the conclusion that enough is enough. As someone living with Asperger's Syndrome a form of autism I am tired of dealing with the horrifying effects of autism and I think it's time that ALL people including the government listen up. I'm tired of dealing with all of the frustration and pain of being rejected and ignored because I am autistic. I'm tired of the harsh reality that other people can hate me and not like me because I have a syndrome or a disorder.

I didn't make any choice ever in my life that brought this on me. I never did anything wrong. Just like all of your children that are out there struggling with autism today did nothing wrong. I have sat back and watched the government and insurance companies push parents around who are trying to find help and answers for their autistic children. I have sat back and watched mothers quit their jobs and try to take care of their children. I have sat back and watched the government ignore the parents for far too long. But enough is enough.

I've decided that I'm tired of autism. I'm tired of waking up to the real harsh realities every morning. I don't like waking up knowing that girls think I'm creepy because I like them but have a disorder that is beyond my control. I'm just done with it. I want to be treated fairly and I want to be normal. I want to know 100 percent sure if Vaccines have caused this or not. I want answers from insurance companies and the government. I want the truth. I’m sick and tired of living with autism the way it is in society today.

Insurance companies don't care to provide any help. Even the state of Indiana Family & Social Services Administration (FSSA) is ignoring the needs of autism. They won't provide services for adults on the autism spectrum and the services they provide for children on the spectrum are far from adequate.

When you look at the funding that is provided by the federal government for autism is inadequate and much lower than what is provided for other disabilities and disorders.

Leukemia: Affects 1 in 1,200 / Funding: $277 million. Muscular Dystrophy: Affects 1 in 100,000 / Funding: $162 million. Pediatric AIDS: Affects 1 in 300 / Funding: $394 million. Juvenile Diabetes: Affects 1 in 500 / Funding: $156 million. Autism: Affects 1 in 110 / Funding: $79 million. I have just written a personalized letter to Mr. Barrack Obama asking for help and answers. I am tired of my needs being ignored by the Family and Social Services Administration (FSSA) and the state of Indiana and even the federal government and insurance companies. I'm tired of having to be socially ignored and rejected by peers because I have a syndrome that makes me socially awkward and weird and I've just decided that I'm not going to deal with it anymore. I would like to know why autism is the least funded of all disabilities and disorders. I would like to know why FSSA won't pay for autism related therapy and I'd like to know why the government and all of congress shows no interest in helping people with autism? Maybe just maybe it's the government that causes the rest of neuro-typical society to not like those of us on the autism spectrum. Maybe the neurotypicals who treat us different are just following the government's example?

Insurance Companies may be able to push parents of autistic children around and ignore their pleas for help. But I am someone who lives with autism personally on a daily basis because I am the one that does have it myself. I am personally asking that the government provide equal funding for autism as they do Juvenile Diabetes, Pediatric Aids, Muscular Dystrophy, and Leukemia. That would only be a start. Since Autism is more prevalent we actually need more funding. I refuse to be discriminated against by other people in society and local, state, and federal governments anymore. Autism Waivers should be funded for all immediately.

I am sick and tired of autism and tired of being treated the way I get treated because I'm autistic. The government should either educate the general population about autism to make them more accepting or they should provide more funding for social skills and allow people with autism to live in the same world and in the same way as other people are aloud.

I've decided that autism is not something I choose or want to live with. If I have to live with it the way it is today then I will eventually make the choice not to live. The government needs to listen up. I'm tired of being autistic. I'm tired of having autism. I'm tired of people treating me different because I have a disorder. I'm tired of it and I'm tired of being ignored. I want help. I want intensive therapy 40 hours per week, applied behavior analysis (ABA) and social skills training. Every child with autism and every adult with autism deserves that. I will give the government a chance to show that they care and provide some services and more funding for autism. But if they don't provide any additional funding or help then really they are saying they "hate" autistic people too.

Martha England

May 10, 2011

Subject: Re: Reminder: Joint Meeting of the IACC Subcommittee on Safety and Services Subcommittees - May 19, 2011

Thank you for informing me, but I will not be able to tune in that day. I will read your site notes on the meeting when you post it and wait for a public input notice. One of my main concerns is this: What happens when the phone lines are down, and transportation is cut off during times of emergency (911 for instance) for those in supported employment or otherwise independent and out in the community. What in a good one-step plan for them? Another is a general lack of law enforcement ability to derive autism characteristics and how to help them properly, instead of hurting them by mischaracterizations.

Sincerely, Martha England

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

Parrish Hirasaki

June 27, 2011

Subject: Memo to IACC

Re: Unsafe Prenatal Ultrasounds

I am an engineer with decades of experience in the space program and in industry that is relevant to ultrasound technology. I have independently concluded that unsafe prenatal ultrasounds could be causing the brain alterations that manifest as autism spectrum diseases. In researching the subject, I find that while this is not an original idea, it is not currently being explored.

Because most babies have had prenatal ultrasounds and are healthy, it seems likely that using calibrated machines and adhering to the guidelines make prenatal ultrasounds safe. However:

Machines age and go out of calibration.
There is a large unregulated resale market for ultrasounds.
Training of machine operators is often informal and self-administered.

I have built a website that serves as a repository of information. To date, most of the reference documents point to a possible link. However, it is my intention to present all related material.

Some points from the website (www.ultrasound-autism.org):

The increases in autism and in the use of prenatal ultrasounds follow the same timeline.
Prenatal ultrasound devices produce thermal as well as mechanical effects.
The heating is greatest near bones, i.e., the skull.

Higher intensity ultrasound devices are used therapeutically to heat internal body parts.
A connection to the brain-based left-handedness and ultrasound has been established.
Higher intensity ultrasounds have produced brain damage in animals.

The possibility that unsafe prenatal ultrasounds are driving the worldwide increase in autism spectrum disease should clearly be a priority. I hope you will see that this issue is explored promptly. We need a quick evaluation that, if confirming, leads to a public warning.

Contact info:

[PII redacted]
www.ultrasound-autism.org

Adrienne Robertiello

June 28, 2011

Subject: Safety/IACC

Many families who have family member with ASD in New Jersey have made use of a “9-1-1 identifier.” These families have presented their local 9-1-1 dispatch center with significant safety concerns including wandering, obsessions with dangerous items, common escape routes/locations, behavioral challenges, communication method, etc.

Throughout New Jersey, each county has made available access to radio transmitter location technology for use by their Sheriff’s search and rescue units. This has been a valuable tool for law enforcement in the locating of lost and wandering individuals. Some counties offer financial assistance for families who are unable to afford the devices and maintenance fees.

Some New Jersey schools have taken proactive measures to assist families who have children who are non-verbal or have limited expressive language skills. Information sheets are offered to families to complete/submit at their discretion. The forms include such information as safety concerns, contact information, emergency numbers, medical issues, communication method, allergies, and dietary constraints, as well as a picture of the child. These forms are submitted to the municipal police department. Wandering risk, prevention and response strategies should be considered as a standard educational option in individualized education program (IEP) documentation.

Children’s Specialized Hospital is beginning to work with New Jersey state agencies to develop and distribute educational material related to ASD safety concerns including wandering and elopement. Plans are to raise awareness of safety-related concerns through mainstream media outlets. We look to assist municipalities and emergency response teams to provide strategies and resources to assist with prevention and response skills for these circumstances. The hospital will be developing educational information about wandering and ASD for pediatricians to provide to families, for reference at public libraries, and for police/fire/rescue personnel. The hospital has begun developing safety social stories, visual supports, and other education materials and safeguards for families to assist in prevention and to provide safety resources and strategies. Provide behavioral modification strategies and video modeling mechanisms can be developed and made easily accessible for professionals, family members, caretakers, and service providers.

In addition, the hospital is evaluating the development of educational supplements and proposals related to safety concerns of children with ASD to organizations currently offering educational programs. Some of these include the Red Cross Babysitter Training course, SafeKids, Safe Routes to School, National Highway Traffic Safety Administration, and others.

In New Jersey, there is potential to capture the International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) secondary diagnostic code for wandering as part of the *Birth Defects and Special Needs Registry – Autism Supplement Information New Jersey Autism Registry*. When the secondary code is used in clinical applications, individuals who are at risk for wandering/elopement can be highlighted.

Eileen Nicole Simon

July 8, 2011

Subject: Comments for the July 19 meeting

Could public comments submitted be read, and commented upon? I would like to state once more the importance of research on language development, and brain system maturation processes essential for learning to speak. Can this be discussed openly?

I have suggested many times that the inferior colliculi in the midbrain auditory pathway be investigated by functional magnetic resonance imaging (fMRI) and examination of postmortem brains. This area of the brain has greater blood flow than any other area of the brain, and is thus susceptible to injury from any substance that gets into the circulation, whether from a genetic-metabolic disorder or via ingestion or injection [1].

Furthermore, ischemic injury from oxygen insufficiency during birth impairs the blood-brain-barrier, making the inferior colliculi and other brainstem auditory nuclei even more vulnerable to toxic insult [2]. This has been demonstrated as the reason for bilirubin staining of auditory nuclei as well as the basal ganglia [3].

Injury of brainstem centers in the perinatal period has also been found to disrupt normal maturation of the cerebral cortex [4].

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Eileen Nicole Simon

July 12, 2011

Subject: Oral Presentation

An article was published online in *Pediatrics* on July 11 that analyzed perinatal factors associated with autism. The authors of this article commented that obstetrical complications emerged as risk factors for autism and suggested a possible role of fetal and neonatal hypoxia.

Oxygen insufficiency is the great worry about any complication of childbirth. A possible disruption of dopamine in the brain was mentioned in the online article. However, the effects of hypoxia on the brain were reported in several papers published 40 to 50 years ago. Monkeys were subjected to asphyxia at birth by delivering the infant head into a saline-filled sac, then clamping the umbilical cord.

Prominent ischemic injury of auditory nuclei in the brainstem was found. Similar patterns of damage have been reported in human infants. The asphyxiated monkeys appeared to recover following initial difficulties with motor control. However, manual dexterity remained impaired, and brain maturation did not follow a normal course in monkeys allowed to survive for several months or years.

No one expects monkeys to learn to speak, but at least 12 case reports have been published of people who lost the ability to understand speech following injury of auditory nuclei in the midbrain (the inferior colliculi). How much more serious would such injury be for an infant?

Autism is associated with many causes: prenatal exposure to valproic acid, genetic metabolic disorders such as phenylketonuria (PKU), and encephalitic infections. The inferior colliculi in the midbrain auditory system have higher blood flow than any other area of the brain and are thus susceptible to toxic substances in the circulation.

Once more, as I have many times in the past, I would like to draw attention to injury of nuclei in the brainstem auditory pathway as a possible etiological factor for development of autism.

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Caroline Rodgers

July 14, 2011

Subject: revised final -- IACC public comments

Re: South Korean autism prevalence Twin autism study finds environmental factors outweigh genetic

Two recently published autism studies have stirred great interest among researchers for different reasons, yet each can be interpreted to support the concern that prenatal ultrasound is a significant risk factor in causing Autism Spectrum Disorder (ASD).

- An in-depth autism prevalence study conducted in South Korea suggests that autism rates may be much higher throughout the world than currently considered – yet there is outside evidence that women in South Korea, which makes aggressive use of medical technology, have more prenatal ultrasound exposure than women in other Asian countries and possibly, the world.
- A rigorous California twin study found that shared environmental factors outweigh genetics in causing autism. The study authors suggest that prenatal and early post-natal environments influence a child's susceptibility to autism. However, considering the demographic differences represented in the study population, it would be extremely unlikely that post-natal environments are the key, as the diversity that lends robustness to the statistical results would also lead to very divergent post-natal environments.

High South Korean autism prevalence

A careful study of a South Korean suburban population found that one in 38 children have ASD[1]– virtually three times the most recently established United States prevalence rate of 1 in 110. The study authors suggest that because a majority of the children with autism were discovered in the general school population and had not been previously diagnosed, this higher prevalence rate might represent a more accurate figure elsewhere in the world, as well. However, this assumes that ASD is easily overlooked, which does not seem to be the case in the United States. Here, an urgent need for safety measures to combat widespread wandering/elopement, special programs to assist a tidal wave of young adults aging out of the school system and newly created programs to assist college students with autism all argue that: 1) children with autism do not remain unnoticed and 2.) Previously, there has not been a need for such programs on the scale necessary today.

Going beyond the study results, if South Korea's high autism prevalence is unique to that country, the question is: Why? An examination of South Korea's medical climate suggest that there are at least three reasons to believe that South Korean women receive more prenatal ultrasound exposure than women elsewhere.

1. Medical specialists make up more than 80 percent of South Korea's practicing doctors – 30 percent more than in Western countries[2]. Specialists, in keeping with their training, are more likely to order high-tech tests for their patients.

2. About 90 percent of South Korean medical services are provided by the private sector, which has not been subject to strict government regulation and has been found to over-use medical technology[3].

3. In South Korea, as in all Asian countries due to longstanding cultural traditions, prenatal ultrasound has been used for sex selection. According to a study of sex ratios, "widespread use of sex-selective technology in South Korea preceded that of other Asian countries," producing as many as 229 boys to every 100 girls born[4]. To South Korea's credit, this gender imbalance has been corrected, yet the fact that it reached such a point of excess establishes that South Korea has a history of being more aggressive than any other Asian country in its use of prenatal ultrasound.

If prenatal ultrasound exposure is an autism risk factor, the 1-in-38 South Korean autism prevalence may continue to climb: In 2008, which was after the study's subjects were born, South Korea improved its support for prenatal care, including subsidization of ultrasound testing.

New twin study finds environment outweighs genetics

A comprehensive twin study e-published by the Archives of General Psychiatry found that, contrary to the results of previous twin studies, environment plays a bigger role than genetics in causing autism, due to the high rate of autism discovered among non-identical twins[5]. The authors concluded that some shared factor in the prenatal or early post-natal environment, combined with genetic factors, causes autism. As previously stated, post-natal environments would be so different across different demographic divisions that it would be difficult to find a single or even a combination of factors that could cause the same effect simultaneously in different populations. However, a common denominator that crosses virtually all demographic lines is prenatal ultrasound.

Ultrasound exams – which produce sound waves that are converted into heat when absorbed by tissue – introduce many variables into the prenatal environment due to differences in machine models, calibration, settings, length of sessions, type of exam, dwell time over tissue and possibly the exact moment of fetal development. The combination of different ultrasound factors with genetic predispositions could explain why some, but not all, children who undergo ultrasound scans develop autism and why twins in the same fetal environment could have different ASD outcomes. In casting about for environmental variables that might be at work, the authors cited studies that have associated autism with "parental age, low birth weight, multiple births and maternal infections during pregnancy."

Absent among these possible autism risk factors was prenatal ultrasound, yet this increasingly ubiquitous part of obstetrical care could explain virtually all of the stated risk factors. Consider:

1. **PARENTAL AGE:** Older mothers are automatically considered high risk and subjected to additional ultrasound scans[6].

2. **LOW BIRTH WEIGHT:** Growth restriction is one of the most frequent stated reasons for ultrasound[7], which would subject low birth weight babies to additional scans.

3. **MULTIPLE BIRTHS:** All multiple gestations are considered high risk, which subjects the fetuses to additional and longer ultrasound sessions.

4. **MATERNAL INFECTION:** While there is no known relationship between prenatal ultrasound and maternal infection, it is possible that both are ASD risk factors due to the same mechanism: elevated heat in the fetal environment. Sound waves are converted into heat when absorbed by fetal tissue, while infections induce the inflammatory response, raising the maternal thermoregulatory set point, which causes a corresponding increase in fetal temperature[8].

The increased exposure of twins to prenatal ultrasound would answer key questions relating to multiple gestations and autism, such as:

> **QUESTION**: Why do multiple gestations appear to be a risk factor for autism?
> **ANSWER**: They receive more scans and longer sessions, increasing the possibility of overheating fetal brain tissue at a critical point of development.
>
> **QUESTION**: Why does one of a pair of genetically identical twins sometimes develop autism while the other does not?
> **ANSWER**: Whether due to operator error or simply positioning, one twin could receive more ultrasound exposure than the other, increasing his or her odds of overheating developing fetal brain tissue.
>
> **QUESTION**: Why, when both genetically identical twins have ASD, can they have very different types of ASD?
> **ANSWER**: Unlike whatever chemicals, toxins or infectious agents that might succeed in crossing the placenta and could be expected to have similar effects on genetically identical fetuses, ultrasound can affect fetuses in the same uterine environment differently depending upon the amount of heat each fetus absorbs.

CONCLUSION

These two very different studies, with surprising results regarding 1) increased ASD prevalence in a country that maximizes its use of medical technology (echoing autism clusters in the United States in areas with concentrations of high-tech employment) and 2) the news that environmental factors appear to be more significant than genetics in causing ASD. Taken together, they make a strong case for reviewing current autism research priorities. Since autism cuts across all demographic divisions, it is fair to conjecture that the prenatal environment plays a greater role in causing ASD than the post-natal environment. Prenatal ultrasound, which has changed rapidly in just a few decades in terms of technology, applications and gestational window of exposure without an appropriate or even minimal array of safety studies keeping pace with these developments, deserves serious attention.

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Kendra Stea

July 15, 2011

Subject: Letter To Secretary Sebelius

Allow me to introduce myself. My name is Kendra Stea and I am the Director of Client Services at CPI (Crisis Prevention Institute, Inc.) CPI is an international training organization located in Milwaukee, WI. Since 1980, over six million human service providers have been trained in our *Nonviolent Crisis Intervention*® training program. As the world-leader of training and resources for the safe management of assaultive and disruptive behavior, we monitor legislation and public policy and advocate for the reduction and elimination of restraint and seclusion in a variety of settings such as education, human services, healthcare, mental health and corrections.

We listened with interest to the IACC Services and Safety Subcommittees conference call this week as you discussed the letter the subcommittees are currently drafting for Department of Health and Human Services (HHS) Secretary Kathleen Sebelius regarding the use of physical restraint and seclusion. We wanted to commend you and the IACC for moving forward on your plans to help drive the discussion to help ensure that HHS keeps the safety of individuals with disabilities, and the staff who care for them, at the forefront.

CPI stands in full support of the contents of the letter, as well as the proposed changes discussed during the teleconference. We have a few considerations to share with your group that might be helpful as the full committee considers the letter to Secretary Sebelius.

Changing Attitudes

Your comments specifically resonated with us when you mentioned the feedback you received from individuals who were concerned for the safety of staff. CPI has a long tradition of helping organization develop physical restraint and seclusion reduction initiatives, and this is not the first time that we have heard this sentiment. When organizations move toward creating cultures of care intended to reduce or eliminate restraint and seclusion, staff sometimes feel that their safety might be compromised. They often feel like they are losing a “tool” from their “toolbox”. To help answer these concerns, CPI works to help staff better understand the alternatives to restraint and seclusion. Training can actually give them safer, more effective positive behavioral interventions and supports therefore minimizing the risk for everyone, staff and clients alike. The use of restraint and seclusion in those cultures of care becomes an anomaly and is often seen as a treatment failure - a tool used only in behavioral emergencies. Through prevention efforts, and through enhanced verbal de-escalation training, staff can decrease the likelihood that a crisis will escalate to that point.

Achieving culture change isn’t always easy, and it cannot be done without the support of strong public policy that requires training for staff that is focused on prevention and grounded in evidence-based practices of positive behavioral interventions and supports. Learning transfer is an ongoing process that needs to be nurtured through required updates and refreshers.

Data Collection

The joint subcommittees also discussed the significance of data collection in restraint and seclusion reduction efforts. Debriefing, documentation and data collection after an incident, allows staff to more closely examine what might have precipitated the behavior, and to explore options for staff and for individuals to use in the future to prevent reoccurrences of these dangerous behaviors. On a larger level, the data that is collected can also help indicate what patterns exist in staff responses or environmental concerns that can then be mitigated through training and environmental changes. Finally, data collection supports transparency in care provision. All stakeholders (staff, clients, families, care givers, funders, accreditors, licensers etc…) want to see an improved quality of care as evidenced in the data the facility collects. This is an important level of accountability for organizations that is not consistently present across service settings.

Consistent Regulatory Guidance

The letter also suggests that more consistent regulatory guidance be provided across the various HHS and Department of Education agencies. We strongly support federal regulations across all service settings that use physical restraint or seclusion. Regulations should not only spell out what is appropriate, but should also spell out training requirements for staff. When staff have clear expectations they are better able to provide a consistent and supportive environment for the individuals in their care. Because individuals with Autism Spectrum Disorders are served through a variety of care settings, consistency of the regulations across these service settings will ensure that best practices are present no matter where the individual receives care.

We see in the July 7th unified regulatory agenda for the Department of Health and Human Services that Mr. Paolo Del Vecchio (Substance Abuse and Mental Health Services Administration (SAMHSA)) is the contact for looking at the Requirements Governing the Use of Seclusion and Restraint in Certain Non-medical Community-Based Facilities for Children and Youth. We have worked with Mr. Del Vecchio in the past and hope to offer our assistance to SAMHSA as they draft these policies.

Thank you for the work you and the IACC have done to this point to help improve the lives of individuals with ASD. Please feel free to contact me directly if you are interested in further input on this important issue.

Sincerely,

Kendra L. Stea, Master of Science (MS), Nationally Certified Counselor (NCC)
Director of Client Services
CPI
[PII redacted]

Matthew Carey

July 18, 2011

Subject: Public comment for tomorrow's meeting

I would like to thank the IACC members for their work over the recent years. It is my sincere hope that the Combating Autism Act will be reauthorized, allowing this committee to continue to guide autism research goals.

One goal I would hope that would be addressed in future Strategic Plans is the need for adequate medical care for autistics. It is my belief that the current medical system in the U.S. does not incentivize doctors for the care that is required by the disabled. One doctor told me that 70 percent or more of the information needed to come to a preliminary diagnosis comes from direct communication with the patient. It seems highly likely that individuals with difficulties in communication and sensory issues will require additional effort on the part of physicians. And, yet, insurance assumes that an office visit will be the same time for an autistic individual as for a non-autistic individual.

The questions that I would like to see addressed are straightforward. First, what is the appropriate amount of time doctors need to take to adequately address the needs of their autistic patients? This information could be used to allow for an additional or a different billing code for doctors to use with this population. Second, does the current system disincentive doctors from taking on disabled patients in general, and autistic patients in specific?

A recent paper gives a view of the importance of these issues: Parenting aggravation and autism spectrum disorders: 2007 National Survey of Children's Health. Parents without a medical home show much higher levels of aggravation. Addressing this one area could provide much benefit to not only the autistic children, but to the parents as well.

Again, I thank you for your time serving the needs of autistics.

Respectfully submitted

Matthew J Carey