

Written Public Comments

**IACC Full Committee
Meeting**

April 19, 2018

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Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Dr. Debasis Kanjilal

April 19, 2018

Dear Highly Respected All Committee Members,

THIS IS 171ST EMAIL DIRECTLY TO NRP (National Resuscitation Program), CC TO ALL OTHER COMMITTEE MEMBERS AND HIGHLY RESPECTED INDIVIDUALS TO SAVE MILLIONS OF NEWBORN BABIES IN THIS WORLD SINCE JAN 6, 2017.

I WROTE OVER 6,000 EMAILS TO ALL PRESIDENTS, PMs, MONARCHS, DICTATOR (NORTH KOREA), ALL IVY LEAGUE INSTITUTIONS, ALL JOURNALS, ALL MAJOR NEWS PAPERS, ALL RESPONSIBLE ORGANIZATIONS (WHO, UNICEF, UNITED NATION, DOCTORS WITHOUT BORDERS, RED CROSS, ALL HUMAN RIGHTS , ANIMAL RIGHTS, AUTISM, DISABILITIES, CARING FOR CHILDREN, NIH, CDC AND OTHERS), ALL NOBEL PRIZE WINNERS AND THOUSANDS OTHERS

EXCEPT CHINA (NO EMAILS) SINCE 2014 TO SAVE THE NEWBORN BABIES IN THIS WORLD:

DOCTORS , ALL OVER THE WORLD, SCREWED UP NEWBORN BABIES BRAIN DUE TO HYPOXIA (LOW OXYGEN) BEFORE (OBSTETRICIANS) , DURING (OBSTETRICIANS) , AFTER BIRTH (NEONATOLOGISTS, PEDIATRICIANS AND OTHERS IN THE DELIVERY ROOM) SINCE 2006.

Now we need help:

1) From Lawyers : file lawsuits against

NRP / ILCOR / ANZCOR / European Newborn Resuscitation Committees (ERC) because they have failed to do due diligence before implemented dangerous recommendations

in 2006 (Dr. Ola Didrik Saugstad, Dr. Maximo Vento, Dr. Siddrath Ramji) and

in 2010 (Dr. Jennifer Dawson, Dr. Maximo Vento) that havoc the tens of millions of children in this World .

2) From Lawmakers (most important) can STOP them now : their nonsense in USA, Europe and rest of the World to prevent producing children with brain damages, autism, and deaths.

3) From Biomedical Engineers : To invent a device that can transmit hearing information inside the brain , that will help nonverbal children / adults with Autism. They can hear but they cannot process the information. They will be able to talk and succeed in their life.

4) The smart and generous guys like Mr. Bill Gates, Mr. Warren Buffet and many others: To actively think and come up with a solution quickly how to help children / adults with developmental disability (Autism and others). They and their families are suffering immensely.

Breakthrough Study Reveals Biological Basis for Sensory Processing Disorders (noted in Autism) in Kids (USA, 2013):

Impaired white matter microstructure (water diffusion is less directional)

Abnormal white matter (higher rate of water diffusion)

Loss of integrity of fiber bundles (higher rate of water diffusion perpendicular to axonal fibers)

Learn more about Sensory processing disorder

Thanks and Regards for your valuable time

Dr. Kanjilal

Mount Sinai / Elmhurst Hospital

[PII redacted]

1)

Home > UCSF News Center > Breakthrough Study Reveals Biological Basis for Sensory Processing Disorders in Kids

Breakthrough Study Reveals Biological Basis for Sensory Processing Disorders in Kids (USA, 2013)

The image shows areas of the brain that can be affected by sensory processing disorders. Using an advanced form of MRI, researchers at UCSF have identified abnormalities in the brain structure of children with SPD primarily in the back of the brain.

Sensory processing disorders (SPD) are more prevalent in children than autism and as common as attention deficit hyperactivity disorder, yet the condition receives far less attention partly because it's never been recognized as a distinct disease.

'Out of Sync' Kids

Sensory processing disorders affect 5 to 16 percent of school-aged children.

Children with SPD struggle with how to process stimulation, which can cause a wide range of symptoms including hypersensitivity to sound, sight and touch, poor fine motor skills and easy distractibility. Some SPD children cannot tolerate the sound of a vacuum, while others can't hold a pencil or struggle with social interaction. Furthermore, a sound that one day is an irritant can the next day be sought out. The disease can be baffling for parents and has been a source of much controversy for clinicians, according to the researchers.

These brain images, taken with DTI, show water diffusion within the white matter of children with sensory processing disorders.

Row FA: The blue areas show white matter where water diffusion was less directional than in typical children, indicating impaired white matter microstructure.

Row MD: The red areas show white matter where the overall rate of water diffusion was higher than in typical children, also indicating abnormal white matter.

Row RD: The red areas show white matter where SPD children have higher rates of water diffusion perpendicular to the axonal fibers, indicating a loss of integrity of the fiber bundles comprising the white matter tracts.

<https://www.ucsf.edu/news/2013/07/107316/breakthrough-study-reveals-biological-basis-sensory-processing-disorders-kids>

2)

Learn more about Sensory processing disorder

Related terms:

- Aphasia
- Schizophrenia
- Sensory processing
- Attention Deficit Hyperactivity Disorder
- Dyslexia
- Movement
- Autism
- Lesion
- Interventions

<https://www.sciencedirect.com/topics/medicine-and-dentistry/sensory-processing-disorder>

Sensory processing disorder - an overview | ScienceDirect ...

www.sciencedirect.com

Sensory processing disorder (SPD) is a complex developmental disorder affecting children and adults. People with SPD over-respond, under-respond, excessively crave ...

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EXCEPT CHINA (NO EMAILS) SINCE 2014 TO SAVE THE NEWBORN BABIES IN THIS WORLD:

Dr. Ola Didrik Saugstad experimented on newborn hypoxic (low oxygen) babies (Mali, West Africa, one of the poorest nation) resuscitation and got very promising results:

Did he use marijuana on African newborn babies with hypoxia (low oxygen) ?
Did he violates human rights ?
African newborn babies need oxygen, not marijuana.

Hypoxia and reoxygenation of the newborn: clinical and experimental studies (Dr. Saugstad, at Oslo University Hospital, 2016)

(He was very disappointed that marijuana or cannabidiol did not protect the brain of pigs after hypoxia. Thank God, otherwise he would use marijuana in newborn babies with hypoxia. But still he does not give oxygen during resuscitation but ready to use marijuana)

Short-term effects of cannabidiol after global hypoxia-ischemia in newborn piglets. (Dr. Saugstad, Oslo University Hospital Pediatric Research, Spain 2016)

(He used marijuana in hypoxic piglets but marijuana did not protect the brain. He is not happy, now he wants to use higher dose of marijuana. But he will not give oxygen during resuscitation but ready to use marijuana in higher dose. He intended to do another study with higher dose of marijuana.)

Can marijuana use during and after pregnancy harm the baby? (NIH, USA, 2018): Yes it causes harm; marijuana / cannabidiol damages developing brain of fetus and newborn babies.

MALI, WEST AFRICA: Top 12 poorest countries in Africa

Thanks and Regards for your valuable time

Dr. Kanjilal
Mount Sinai / Elmhurst Hospital
[PII redacted]

1)

Dr. Ola Didrik Saugstad experimented on West African (Mali) newborn babies on resuscitation and got very promising results: Did he use marijuana on African newborn babies with hypoxia (low oxygen) ? Did he violates human rights ? African newborn babies need oxygen, not marijuana.

Hypoxia and reoxygenation of the newborn: clinical and experimental studies (Dr. Saugstad, at Oslo University Hospital, 2016)

(He was very disappointed that marijuana or cannabidiol did not protect the brain of pigs after hypoxia ; thank God otherwise he would use marijuana in newborn babies with hypoxia. But still he does not give oxygen during resuscitation but ready to use marijuana.)

Project

project number

2013120

Responsible person

Ola Didrik Saugstad

Institutions

Oslo University Hospital HF

project Category

Open project support

health Category

Reproductive Health and Childbirth

research activity

7. Disease Management

One drug we have been testing is Cannabidiol (CBD). This is a non-psychoactive relative of cannabis, which has proven to be able to protect the brain in a variety of different situations. We have previously participated in studies that have demonstrated a very strong protective effect of this drug on newborn mice.

In our study we used 55 newborn pigs. All the pigs were put into anesthesia so that they did not experience pain or discomfort. After a period of oxygen deficiency, the pigs were revived and some were given CBD and others not. The pigs were also divided so that some were choking a few degrees and others not. To our surprise and disappointment, we found no protective effect of CBD in this model.

An important part of the group's activity is a resuscitation project in Mali, West Africa. The project is moving forward, despite difficult political relations with strong terrorists in the country. We have received the first results that are very promising with regard to reduced newborn mortality. Work will continue in 2017 and 18.

<https://forskningsprosjekter.ihelse.net/prosjekt/2013120>

2)

Pediatr Res. 2016 Nov;80(5):710-718. doi: 10.1038/pr.2016.149. Epub 2016 Jul 21.

Short-term effects of cannabidiol after global hypoxia-ischemia in newborn piglets. (Dr. Saugstad, Oslo University Hospital Pediatric Research, 2016)

(He used marijuana in hypoxic piglets but it did not protect the brain. Now he wants to use higher dose of marijuana. But he will not give oxygen during resuscitation but ready to use marijuana in higher dose. He wants another study with higher dose of marijuana.)

Garberg HT1,2, Huun MU1,2, Escobar J1,3, Martinez-Orgado J4, Løberg EM5, Solberg R1, Didrik Saugstad O1,2.

CONCLUSION:

In contrast to previous studies, we do not find significant protective effects of Canabidiol (CBD) after HI in piglets. Evaluation of CBD in higher doses might be warranted.

<https://www.ncbi.nlm.nih.gov/pubmed/27441365>

3)

Can marijuana use during and after pregnancy harm the baby? (NIH, USA, 2018): marijuana / canabidiol damages developing brain of fetus and newborn babies.

Given the potential of marijuana to negatively impact the developing brain, the American College of Obstetricians and Gynecologists (ACOG) recommends that obstetrician-gynecologists counsel women against using marijuana while trying to get pregnant, during pregnancy, and while they are breastfeeding.¹⁰³

Human research has shown that some babies born to women who used marijuana during their pregnancies display altered responses to visual stimuli, increased trembling, and a high-pitched cry,¹⁰⁸ which could indicate problems with neurological development.¹⁰⁹

Very little is known about marijuana use and breastfeeding. One study suggests that moderate amounts of THC find their way into breast milk when a nursing mother uses marijuana.¹¹³ Some evidence shows that exposure to THC through breast milk in the first month of life could result in decreased motor development at 1 year of age.¹¹⁴ There have been no studies to determine if exposure to THC during nursing is linked to effects later in the child's life. With regular use, THC can accumulate in human breast milk to high concentrations.⁹⁸ Because a baby's brain is still forming, THC consumed in breast milk could affect brain development. Given all these uncertainties, nursing mothers are discouraged from using marijuana.^{103,115}

<https://www.drugabuse.gov/publications/research-reports/marijuana/can-marijuana-use-during-pregnancy-harm-baby>

Substance Use While Pregnant and Breastfeeding (NIH, USA, 2018)

Risks of Stillbirth from Substance Use in Pregnancy

- Tobacco use—1.8 to 2.8 times greater risk of stillbirth, with the highest risk found among the heaviest smokers
- Marijuana use—2.3 times greater risk of stillbirth
- Evidence of any stimulant, marijuana, or prescription pain reliever use—2.2 times greater risk of stillbirth
- Passive exposure to tobacco—2.1 times greater risk of stillbirth

Source: Tobacco, drug use in pregnancy, 2013

<https://www.drugabuse.gov/publications/research-reports/substance-use-in-women/substance-use-while-pregnant-breastfeedin>

4)

Mali

From Wikipedia, the free encyclopedia

Economy[edit]

Main article: Economy of Mali

The Central Bank of West African States handles the financial affairs of Mali and additional members of the Economic Community of West African States. Mali is one of the poorest countries in the world.[69] The average worker's annual salary is approximately US\$1,500.[71]

<https://en.wikipedia.org/wiki/Mali>

Top 12 poorest countries in Africa:

<https://answersafrica.com/top-10-poorest-countries-in-africa.html>

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Ramey Chisum

April 19, 2018

Dear NIMH,

I came across an article about how excessive tantrums can be a sign of psychiatric disorders which are responses to family dynamics. It's been my main research criteria to find the correlation between Autism and family dysfunction. Mental illness in Autism is unfortunately missed in all forms of Autism research, yet conditions of OCD, Anxiety and Depression which are all mental illness are more prevalent among Autistic individuals than general society. WebMD states that ASD(link to article below) is a group of related mental health issues. So, since it is scientifically, medically and clinically proven that Autism is a mental illness and mental illness comes from family issues, seems that Autism is a family disease. It's also a scientific fact that Autistic individuals have an increased or decreased brain matter content which interferes with neurological function and brain matter content is negatively impacted by stress. According to Emily Elert with Spectrum News along with numerous studies on Autism, mental illness in parents raises the risk of Autism for children significantly. Autism is a complex illness, it's not surprise it would take so long to discover the cure, but that's no reason to ignore the obvious either.

<https://www.webmd.com/parenting/news/20071219/5-tantrum-red-flags>

<http://www.autism.org.uk/about/health/mental-health.aspx>

<https://cmha.ca/documents/obsessive-compulsive-disorder-ocd/>

https://en.m.wikipedia.org/wiki/Anxiety_disorder

<https://www.mentalhealth.org.uk/a-to-z/d/depression>

<https://spectrumnews.org/opinion/parents-mental-illness-raises-risk-of-autism/>

<https://www.webmd.com/brain/autism/mental-health-aspergers-syndrome>

There are many inconsistencies in the refrigerator mother theory, but the basis that parental behavior can and does affect a child's cognitive outcome has been overlooked due to those inconsistencies. According to Spectrum News, schizophrenic parents specifically the mother increases the risk of Autism in children by 70%. In 2009 Truman Medical Center attempted to diagnose me with Schizophrenia although now the hospital refuses to even attempt any diagnosis of mental illness for me. The schizophrenia diagnosis for me by Truman Medical Center though was not derived from observing me, but communication with my mother and sister that violates HIPAA. During my daughter's first year when she only lived with myself and her father, there were no signs of Autism and my daughter was speaking full sentences by one year old. But after my daughter and I moved in with my mother my daughter symptoms of Autism appeared, before the move we had limited to no contact with my mother and family. My mother is in denial about her own mental health issues, but recent developments with my sister have proven that parents do have an enormous role in their children's mental health. And apparently their grandchildren too as my mother has my sister's four kid's living with her and me with

my two children as well, plus my sister's ex husband. My sister however is running around the country homeless in the midst of severe psychotic episodes from undiagnosed schizophrenia.

https://en.m.wikipedia.org/wiki/Refrigerator_mother_theory

Thank you for your time, have a nice day.

Sincerely,
Ramey Chisum

Dear NIH,

I was doing some research on Diabetes because there are some inconsistencies in the explanation of Diabetic Ketoacidosis. In the article attached below regarding Ketoacidosis resulting from eating disorders such as anorexia, dextrose which is a corn byproduct and extremely high in sugar will produce more insulin and decrease glycogen secretions. But diabetics are cautioned to avoid sugars especially corn derived. I'm not suggesting that diabetics consume a diet high in sugar, but maybe that since anorexics are starved for food, and diabetics are starved for the nutritional benefits of food, that maybe the insulin decrease in diabetics and anorexics causing Ketoacidosis needs to be considered as a similar disorder resulting in the same symptoms. Since stress decreases insulin levels, diabetes increases stress even more, we should look at the affects of stress on diabetes entirely. Also this article says that saline solution is used to lower insulin levels and I believe it is used in medicinal insulin itself. Saline solution contains high levels of salt which dehydrate the body causing fluid retention and for diabetics this is especially concerning due to risk of gangrene, edema, kidney and pancreatic failure and limb loss. Saline also contains potassium chloride and sodium chloride both containing chlorine which is known to increase cancer risk by 93%. Already having an unhealthy Pancreas and or Kidney due to diabetes raises this risk, for insulin dependent diabetics especially type 1, regular insulin injections are doing harm to the body. I understand that the term benefits outweigh the risks is a factor here, I'm just stating that stress is known to lower insulin levels. Maybe reducing stress levels in diabetics would result in higher and normal insulin levels. Going one step further reducing stress for anorexics will eliminate eating disorders as well.

https://wikem.org/wiki/Starvation_ketoacidosis

Another issue I would like to address is Autism. My daughter who is five has not been diagnosed with Autism yet due to my insistence that there is another explanation for her symptoms, is incredibly bright and intelligence. But unfortunately the special needs experts don't recognize that intelligence and continue to insist my daughter has defected brain. There is nothing wrong with my daughter's brain, there is a lot wrong with her environment. I fully believe Autistic individuals have difficulty dealing with their surroundings but that this disorder is not due to a brain dysfunction, more of a societal dysfunction. It is well known that humans have made many mistakes throughout time concerning the environment and civilization and especially home issues. Maybe those mistakes are causing children to have difficulty with their environment. I've found that almost all symptoms of Autism corresponds with those of PTSD. Now Autism is not as severe as PTSD, but even consistent dysfunction within a family can be traumatizing. And symptoms of Autism compared to those of PTSD may be seen as more debilitating,

but considering the traumatic stress of dealing with dysfunctional families regarding autism is affected during developmental stages, that would explain the difference. If a person is more susceptible to PTSD as this and many articles suggest, their initial symptoms of the original condition may be stemming from PTSD. In actuality an autistic individual gravitating toward situations where PTSD may occur could be considered comfortable for an autistic individual, PTSD is what they know. I think we could all agree autistic people are in need of some comfort but like all self destructive acts, seeking PTSD is just going about it the wrong way.

<https://www.ncbi.nlm.nih.gov/m/pubmed/28726442/>

Many scientific opinions agree that stress causes weight gain. But there are two problems with the way stress is known to cause weight gain. First of all many scientist's claim that stress causes an increase in appetite. This might be the case, or stress could cause a decrease in appetite or stress may not cause any change in appetite but weight is still gained. If caloric intake and exercise were the only factors of weight gain, then obese individuals would constantly gain weight every single day without stopping because they have all the ingredients for continual and indefinite weight gain but that's simply not the case. Overweight people do stop gaining weight and do in fact maintain their weight for months even years at a time although scientifically they should be gaining. The other issue with the current explanation of how stress causes weight gain is telling the obese individual they need to calm down and not be so stressed. We all want to be slim and attractive, so if there are obstacles preventing that from happening along with conventional methods of diet and exercise aren't causing weight loss, it's not just within the obese individual to change. And you can't really tell an obese individual to grow thicker skin and be tougher so their environment won't get to them, that's what fat people already did, grow thicker skin. And the reason overweight people literally grow thicker skin is to protect themselves from their environment, being a person who's unwillingly gained weight to be protected from my environment I can tell you it does work. Being the intelligent and attractive person I am is not well accepted within my social circuit, but being overweight is. Many people in the world especially many of those who are at a healthy weight are happy when other's are obese, it makes them feel better about themselves. For example my sister who is anorexic, absolutely craves anything that causes me to gain weight. In fact, if I were at a healthy weight it would make my sister angry because she's unhealthy and anorexic. So being overweight allows my sister to feel good and I can not be pummeled on a daily basis. Now it would seem as though the logical solution to this issue would be to cut off communication with my sister and delve deeply into my psyche to unflip that faulty switch and lose the weight. But it's not just my sister with the problem and obesity isn't my only problem, and sensitivity to my environment certainly isn't my problem. My problem is that, well if I knew what my problem was I wouldn't be fat. Maybe you all can figure it out.

<https://www.nih.gov/news-events/nih-research-matters/stress-obesity-link-found>

<https://www.mayoclinic.org/healthy-lifestyle/stress-management/expert-answers/stress/faq-20058497>

Thanks,

Ramey Chisum

Jonathan Mitchell

April 19, 2018

Samantha Crane claimed I was harassing the entire IACC for providing public commentary she did not like. I think this was unprofessional of her and she should apologize to me. I'm an autistic individual far more handicapped than she is. I have an interest in autism research and issues, and, I don't think I should be intimidated by a public member by saying that polite opinions i've expressed constitute harassment. thank you

I am the mother of a severely behaviorally challenged young autistic adult man. I am in complete agreement with Kennedy Krieger psychiatrist, Dr. Lee Wachtel who spoke to you and said

"Second, the Interagency Autism Coordinating Committee (IACC) must promote a choice-based approach to service provision that ensures adults with aggressive and self-injurious behaviors have a place to go when their families can no longer safely care for them. Some autistic adults have severe behaviors that cannot be managed in community settings. They may not exhibit them all the time, but they need to be somewhere with experienced caregivers who can manage dangerous behaviors when they do occur, with access to professionals who can treat them, as well as structured programs to maximize community access as well as providing satisfying site-based programming. This population needs to be surrounded with well-trained, well-paid aides, because the health and happiness of these adults depends almost exclusively on that one variable. The IACC should write a white paper focused specifically on the service needs of this population. "

Dr. Wachtel is describing my son's situation and the situation of so very many of us perfectly. I would urge you to write the white paper he recommends and if I can help in any way, I would be more than willing to participate. You can see my son's story at www.thekiids.org or watch https://drive.google.com/file/d/1By-LwXbDkr-H3nKSc7MVbMn-Ti_6_uc2/view

Note: Profanity has been redacted in this document

Dr. Brian M. Chiodi

April 19, 2018

GGGGuuuuueeeessss who's getting a drunk emaaiiiiiiiiiiiiiiiii!!!!!! And booooyyy do i have a story. Now i have contacted many people before about what has happened to me and I understand that it takes a long time to build a case. BUT [profanity redacted]. My first abuse occurred in 200 [profanity redacted] 3. Turns out I am one kurl, splinter skill, gift or whatever the [profanity redacted] you wanna call it. anyway hypnotizations pretty popular as you know and has been for some time. I understand its done for the effect and is a way to correct bad behaviors. But it has its drawbacks. Look no further than my life [profanity redacted]. They hypnotized, raped, and used that [profanity redacted] satan thing on me. That's not all though, the last [profanity redacted] to hypnotize and use that [profanity redacted] satan thing told me to, "Hang yourself like in that video." I understand those who have had this [profanity redacted] done to them not only have a lawsuit for rape and attempted murder but also---get this--- a billion dollars via the awe-inspiring and almighty United States government! The [profanity redacted] who decided on its use -SCOTUS!- can shove that money up their [profanity redacted]. Ill add that this hasn't just happened in the united states either. everybody gets excited about traveling and knowing things. Anyway I'm gonna be putting a lot of people in prison so i have had to deal with a lot of verbal, physical and all other abuses. So theres that. And another thing, Im one of the ones on the spectrum that become schizophrenic. Weep for me later please. I did so shortly after the last time that satan thing was used on me. I'll go ahead and say i need all the information i need about that satan thing knowing that ill never hear anything about it until the [profanity redacted] who interfered in my life ruin their pathetic lives FBI wiretap style, but here I am looking for a [profanity redacted] doctor or some other [profanity redacted] that knows what the [profanity redacted] I'm talking about. P [profanity redacted] S BE DISCREET WITH WHO YOU SHARE THIS WITH OR YOU WILL HAVE A LAWSUIT TOO. I WILL STOP AT NOTHING TO PUT EVERYONE IN PRISON. and don't reply with "where do you live" either its [profanity redacted] stupid. give me something I can use to bridge this wait. ----God Bless.

Kevin Valazza

April 19, 2018

I am requesting that you support more funding for research, and development of more treatment facilities for children with severe self injury and aggression behaviors. I am a special education teacher and I know first hand the benefits of having more support than not. I have seen the families whom will be directly impacted on your decisions to further funding.

Lindsay Bessey

April 19, 2018

We need more assistance and funding for those with autism and their families. New York State in particular is severely lacking in care for these people.

Neera Ghaziuddin

April 19, 2018

I am a child and adolescent psychiatrist who has diagnosed and treated with electroconvulsive therapy (ECT) many patients with Autism who have co-occurring severe mood disorders or catatonia. Many autistic patients with catatonia also engage in severe self injurious behaviors (SIB). These are potentially treatable conditions but are under recognized and often inaccurately treated. I am writing to your organization to increase awareness among families and to urge training for psychiatrists to better recognize and treat these conditions. Successful treatment has the potential for vastly improving the quality of life of the individual with Autism and his/her family. Lack of awareness among patients/families, lack of psychiatric beds for individuals with Autism and the lack of appropriate training among professionals are significant barriers.

Dana Mullican

April 19, 2018

As a parent of a young adult with autism, I realize that even though he has struggles and we as a family have them from time to time that we are fortunate that he can verbally communicate and does not have violent behaviors to himself or us. As a high school teacher and friend of someone on the other end of the spectrum, I am again reminded that attention and funding is needed for severe autism where those affected harm themselves and others. I cannot imagine the stress and despair of parents and caregivers not to mention the frustration and pain of those with autism. I implore your group to push for more funding and research of severe autism. Thank you.

Debra Odineal

April 19, 2018

There is an immediate need for more funding for research into self-injurious behaviors for this group of individuals. I have been following the journey of a former student through his mother's facebook posts and it is heart wrenching to watch the pain this young man endures at his own hands. I cannot imagine anything worse than having to watch your child engage in this type of behavior and be unable to stop it. It is unbelievable to me that with all the technological and medical advances, we still have vulnerable children and adults who are not getting the help they need.

I pray that through research and continued support these children and families will soon find the help and answers they so desperately need.

My name is Armondo Cordone, a retired Buffalo Police officer and parent of a 12-year-old autistic son with severe self-injurious behavior and aggression. There is nothing in my law enforcement training that could have prepared me to protect my son, family and myself from injury. Having to continually stop your child from putting his head through windows/walls, punching himself forcefully in the head, severely biting himself and becoming aggressive when you try to stop him is unbearable. No parent should ever have to continually restrain their child. These episodes are not a once a month thing, but are daily, often several times a day. In our family, we would be grateful for one day a month where there were no severe incidents. You get up each morning knowing that you just have to make it through another day without your child or family members becoming injured. My young son requires 2-3 trained adults to restrain him, once we required 5.

When your child falls asleep you are extremely, physically and emotionally exhausted. Then you hope that he sleeps through the night so you can catch your breath and research where to get him help. The help that's desperately needed. Sadly, each night you come up with almost nothing. No respite, weekend or summer programs due to severity or appropriate doctors and facilities. You are on your own. What you do find are 9 units in the entire United States that can assess and treat. For us, that help was 8 hours away with a 6 month-2-year waitlist. There was nothing we wouldn't do to help our son. We would move heaven and earth. And, that's just about what we had to do. We applied to the Kennedy Krieger Institute's neuro-behavioral unit, our only hope. Once accepted you send weekly journals, doctor's/school reports, data, pictures and videos (hard to do when you're in crisis). Due to the extreme need in the U.S. and such limited availability, you are basically trying to prove that your child is the most extreme case on the list. This is not unique to Kennedy Krieger. Help is at your fingertips but it's terribly hard to reach. If you are one of the lucky ones to be accepted you wait for what seems to be an eternity for a bed. When you get the call that a bed has opened, you feel as though a miracle has been bestowed upon you. But, then you have to fight your insurance company, that sense of relief turns into more stress on top of an already stressful life. Our son at this time was in a hospital for 7 weeks with nothing being done for him, we needed to get him out. One day our insurance approves the Kennedy Krieger admittance because we have out of network coverage, the next day the insurance company changes their mind. For us, we and Kennedy Krieger spent 2 entire days going back and forth with our insurance company demanding the reason for the denial after it was approved. Asking them to show you what in our contract they are basing their decision on. They can't give you an answer, they keep switching you back and forth between the same people who can't give you a straight answer. Now, we have to get attorneys involved. In the meantime, you lose the bed that opened. Utter heartbreak! You continue to fight as though you're fighting for your life. We ended up getting our insurance to overturn their denial and did end up at Kennedy Krieger for 9 months. My wife left Buffalo and stayed with our son, I was able to visit once a month. But the stress didn't end there. Because our son left the state, he lost his school placement. Getting him back into an appropriate school, was another battle in itself.

This is an extremely hard, heartbreaking life, but what makes it harder is the lack of research and resources. It became increasingly harder to understand why this was so, as we met more and more families in a same or more severe situation. Children living in psychiatric units which are not appropriate for them, shameful. Children like our son are not being advocated for within the IACC or national autism organizations. My wife calls it "autism's dirty, little secret". I do however, know that it will soon be a

secret no more, it will get national media attention. If you are an autism advocate, you need to advocate for ALL or you are not an autism advocate.

The lack of resources for and research on severe self-injurious behavior and aggression in this country is appalling. Autistic individuals and their families left to live in crisis and in fear in these United States should not be. Our children and families deserve better. You need to stop ignoring this crisis. There also needs to be a parent of an individual with severe self-injurious behaviors on the IACC. These individuals cannot advocate for themselves.

Note: Profanity has been redacted in this document

John Best

April 19, 2018

[Profanity redacted] you. Tell the truth about how mercury in vaccines causes all autism. That's a direct order. Again, [profanity redacted] you.

John Best
Londonderry, NH

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

David Phillips

April 19, 2018

My name is David Phillips.

I am a huge advocate for individuals with autism.

I have a web show on YouTube called unlocking the key to autism and I have a website unlockingthekeytoautism.com.

I am strongly recommending that we need more research, funding and inpatient units for individuals with autism who engage in self-injurious behavior. we especially need a unit in Western New York so that they can get the treatment that they need and be able to live richer lives because in some cases their self injurious behavior can even cause death.

--

David Phillips.

unlocking the key to Autism.Host and executive producer.

unlockingthekeytoautism.com

[PI redacted]

unlockingthekeytoautism@gmail.com

For a Change, Good News in Autism!

For a long time, autism has been the subject of unremitting bad news both in the scientific press and in the media-- the special diets don't work, the gastrointestinal tract doesn't really seem to be involved, and pharmacotherapy aimed at autism has been unpromising.

Yet, there is one area where modern medical science has good news, and that is in the area of catatonic symptoms. Autism patients evidence the stupor, mutism, negativism, posturing, agitation, and repetitive behaviors of catatonia. Especially common are repetitive actions that involve hitting one-self, and so destructive have these been that they have earned the sobriquet Self Injurious Behavior (SIB). Catatonic SIB is a nightmare for parents and caregivers, because it does not respond to neuroleptics or other medicines, and the children require immobilization by arm and body restraints, helmets, and constant monitoring to keep them from damaging themselves permanently. A "normal" childhood is completely negated.

The good news is that these behaviors do respond to the catatonia treatments of the benzodiazepines such as lorazepam (Ativan), and to repeated inductions of seizures, electroconvulsive therapy (ECT). This important piece of good news has not been widely disseminated, but thanks to researchers at the Kennedy Krieger Institute (Johns Hopkins University) , the University of Mississippi , and the University of Michigan , significant scientific progress is being made in understanding catatonia in autism, and in defining its treatment.

For more than a century, the abnormal motor behaviors described as catatonia were considered a type of schizophrenia, a poorly defined and poorly treatable syndrome. In the past 30 years, however, catatonia has been re-identified as a systemic motor dysregulation syndrome, independent of schizophrenia, with effective diagnostic tools, and effective treatments.

So there is good news! Many of the children and adolescents with autism spectrum disorders may be relieved with treatments that are reliable and effective. This is in contrast to other areas of autism, where relief is less certain. Special progress has been made in SIB, and so awful is this disorder that success here must be reckoned almost among the major miracles of modern medicine. Yet in autism, children may also be helped who demonstrate food and toileting refusal, repetitive speech (Tourette's syndrome), and episodic aggressivity. Applying the new knowledge of catatonia to the patients in the autism world offers both treatment relief and greater understanding of the underlying disorder.

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4 Fink M, Taylor A. *Catatonia: A Clinician's Guide to Diagnosis and Treatment*. Cambridge: Cambridge University Press; 2003.

5 Shorter E, Fink M. *The Madness of Fear: A History of Catatonia*. New York: Oxford University Press, 2018.

Dear IACC:

Thank you for encouraging public comment so that I can share my perspective, based on 20 years of navigating services for my daughter, and over 12 years of vocational work with children and adults with disabilities.

My daughter – Common Constellation of Diagnoses:

1. Autism with high support needs (as is more common for girls)
2. Intellectual Disability
3. Stereotypic Movement Disorder
 - a. manifesting in severe and highly frequent self-injurious behavior
 - b. for health and safety she requires two staff at all times
4. Mood Disorders

Barriers to Services: Lack of Coordination between DD (DHS), Medicaid (Mental (Autism) and Physical Health), and Local and State Education Agencies

- In my experiences the most significant barrier to services has been the lack of coordination and shared resources between disability services and mental health services along with the often marginalized/silent public education partner.
- My daughter’s intellectual disability determines that her services come under the Office of Developmental Disability Services. Autism, in contrast, is under the mental health umbrella. Our public school system is responsible for services through age 21. School districts are often left “holding the bag” for all special education and related services costs. Thus, access to needed services for ages 3-21 is most often contentious and litigious.

Competition for Medicaid Funding:

These three separate state agencies *should* coordinate to meet disability-related needs. Rarely does this needed coordination happen. Agencies are incentivized to “hoard” their disability service funds rather than to share funding streams. This could partly be due to a fear that coordinating services and funding will constitute “double-dipping.”

Although there is a federal mandate (34 CFR 300.154 - Methods of ensuring services) for Medicaid to assist in paying for some IEP-based services, that rarely happens – particularly because the eligibility and funding models are detached from one another (i.e., autism as an educational diagnoses in schools but requiring a medical diagnoses for public and private insurance purposes.)

IACC: Addressing Lack of Coordination Barrier?

As the *Interagency* Autism Coordinating Committee my fervent hope is that you will discuss and investigate the depth of this problem in meeting the needs of many autistic individuals. We need you to propose solutions to this significant problem which leads to a lack of needed services for some of our most vulnerable autistic population. In addition this lack of coordination leads to higher costs for everyone.

IACC Progress:

In listening to several IACC meetings I am concerned that there are a few “elephants in the room” which are impeding needed progress:

- **Social and Medical Models of Autism:**

Common to many groups in the disability community (i.e. Blind and Deaf) - Autistic self-advocates often affirm a social model of disability in contrast to a medical model.

Also common in the self-advocacy community is the inability to “agree to disagree” with those individuals and families who experience especially “severe” autism and believe the medical model is more applicable to them.

Perhaps this terminology difference could be reframed in terms of the common co-occurring conditions that autistic individuals experience: DD/ID, Mood Disorders and Stereotypic Movement Disorders including self-injury, and aggression. These co-occurring conditions are often seen as a constellation orbiting autism – with autism being the primary diagnosis. However, it is often these co-occurring diagnoses and their corresponding manifestations which need *treatment* under a medical model.

- **Access to Services**

The hard reality is that service *eligibility* is always determined based upon a medical model both in the private and public health insurance and provider sectors.

- **Losing focus?**

The emphasis on acceptance in the self-advocacy movement is completely understandable. However, the mission of the IACC is not set-up to resolve disagreement between the social and medical model proponents.

Continued disagreements on the IACC based upon the social and medical models of disability distracts from what we need the IACC to do – get down to the business of how best to coordinate between agencies for diagnosis, treatment and services to be put in place quickly and based upon evidence-based studies (including ABA.) In addition, if there is not enough information about vocational, housing and other support needs for autistic adults the IACC should recommend further large-scale studies.

IACC: Need to focus on Charter

- **Medical Model** – Accessing Services: Your Working Group questions are based upon the medical model – which is appropriate given the reality of how services must be accessed for now.
- **Recognition of self-advocates/ASAN** -Can there be agreement that self-advocates should, of course, be at the table, and that self-advocacy groups such as ASAN have clearly stated their mission to promote a social model? Perhaps the IACC can “officially” acknowledge and note ASAN’s stance AND then move on to the many other aspects of the mission of the IACC.

- **Recognition of parent advocates** - Just as official recognition of ASAN's stance should happen, family advocates and autistic individuals who are trying to get help based upon a medical model need to be recognized – and not vilified for describing needs in those terms.
- **Fears about limited funding** - There seems to be a fear in the self-advocacy community that supports which are particularly important to them (i.e. housing and vocational services) will be lost in the deluge of needs framed within the medical model. This perceived competition leads to both the social and medical model communities holding to their positions as tightly as possible. We need the IACC to stay focused on the task of compiling all services needs and recommending coordination activities between agencies to address needs effectively and efficiently.
- **Effective Interagency Coordination is Possible** - After years of work I was able to convince state agencies (Directors of DHS/DD, OHA (Mental Health), ODE (Department of Education)) and our Senate President's Office to implement coordination of services and shared funding for my daughter's needs. This coordination was made possible by referring to the seemingly little known federal mandate contained in 34 CFR 300.154. It is, however, discouraging to know that it is unlikely that this mandate will be operationalized any time soon – in any state. Could the IACC work to provide specific recommendations on how to operationalize this mandate?

The IACC's work might end in 2019 – please know your work can make a significant difference if you tightly adhere to your charter.

Christie Riehl
Salem, Oregon

My name is Kerima Cevik. I am the mother of a nonverbal, autistic teen of color with high support needs. Every system currently available to help our son has failed him. I was horrified to learn that now this committee is receiving comments asking that they recommend funding for the establishment of more residential institutions and increases in group home facilities when abuses continue rampantly in both, and service providing companies like AdvoServ simply change leadership, change their names and are allowed to continue in business after harming autistic youth and adults in their care. Institutionalization would be the final betrayal of my son, who was physically and emotionally abused at school and has been the victim of lifelong disparities in health care, community supports, and services. He is now homeschooled and we pay for most all his needs out of pocket. We have cared for him without respite since his birth. He will be 16 this year.

This committee could dramatically improve the quality of my son's life right now by recommending funding decisions that would have lifelong life-changing benefits for my son and his nonverbal high support needs peers of color. My son needs a reliable AAC system. Every nonverbal autistic person has a human right to effective communication support. But current systems do not foster true language acquisition. Please recommend funding research investigating promising practices to help non-speaking people communicate, including older children like my son and adults - especially communication supports that allow for open-ended communication. The ability to communicate has a direct and positive impact on how we interact with our offspring and how they behave with us.

I am also the creator of a viral Twitter hashtag called #AutisticWhileBlack, made in a moment of sadness at how my son and other autistics of color are erased from the autism conversation. The story of Rebecca Clark, a 25-year-old Autistic African American young woman who was the victim of patient dumping made national news. The catastrophic encounters with police that ended in the deaths of autistics like Paul Childs, Stephon Watts, and the entire sagas of autistics like Reginald 'Neli' Latson, including his being placed in solitary confinement are a giant red flag that this committee must consider recommending funds towards investigating and addressing disparities according to age, race, language, gender, and socioeconomic status. My son's life literally depends on seeking a better understanding of the experiences of these underserved populations before dictating policy on how to keep these groups from harm. The death toll of autistics of color shows that something must change.

My son's sleep cycle issues do not seem to be sufficiently researched. Neither are other co-occurring physical and mental health concerns he and many of his peers have. I hope this committee is considering recommending funding for better research in these areas

The current structure for finding services that help autistic people integrate into the community and maintain autonomy throughout their lives varies in efficiency and effectiveness throughout the country. Shouldn't more funding be recommended for this as well?

One thing that makes my son's abuse in school even more heinous is that there are already lifelong education and community living programs that we know are effective. Doesn't it make sense to scale up effective programs so that they can serve everyone who needs them across all autistic populations?

My son is now a teen. Early intervention is all we parents of older and aging autistic offspring hear. Please consider recommending funding to address the needs of autistic adults, including older adults. We know that community-based help is less costly than institutionalization and produces better outcomes. I don't understand why we aren't acting on that knowledge.

I am an aging caregiver. What I see is the community-based solutions that will allow me to age in place are very akin to what my son will need to age with me and continue community living after his father and I pass away. Shouldn't we be recommending funding to help in finding effective supports for caregivers, to help us stay with our natural support networks?

Finally, we know from the history of the Down syndrome population that institutionalization of ID/DD labeled people is inhumane, costly, and does not produce good outcomes. Please do not recommend funding for repeating this catastrophic mistake for nonspeaking high support needs autistics. It terrifies me to think that with the high level of potential in assistive technology and community based supports that could be made available to our stakeholders if properly funded, we are actually discussing allocating funds to build massive institutions and locking our loved one up when we know that even zoo animals do not do well in enclosed spaces confined for the remainder of their lives. Better research is needed beyond simply approaching autism as a series of maladaptive behaviors needing enforced compliance. We tend to rush to dictate policy without proper research. Please let's not continue allowing this kind of advocacy to influence our decisions.

Thank you for your time.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Dwight Zahringer

April 19, 2018

My statement and public request of the IACC board is once again, being repeated to address my previous letters from the last ~~FOUR~~ FIVE meetings (that have still gone unaddressed).

I have a 6-1/2 year old moderate / severe ASD son with tics and PANs who has a heavy metal toxic burden (Aluminum).

1.) IACC should speak with / survey parents more and focus research on their feedback. There is truth in the herd.

I request that the IACC facilitates a survey the parents of ASD children in the United States. I request that this survey is over 50 but under 100 questions pertaining an ASD child and overseen and co-managed by a third party foundation, or organization for Autism that is recommended and voted on by the public. I request that the IACC proposes and allocates funding for this study in the fiscal year of ~~2016-2018~~ to be published no later than the ~~spring of 2017~~ winter of 2018-2019.

Over the past ~~28~~ 40 months since my son's official diagnosis we have invested all our free time, over \$194,000 out of pocket on ABA, OT, Speech, accessories, learning aids, medical tests and vitamins. In addition to 28-32 hours a week of ABA in-home he is also attending a special education class 5 days a week, 4 hours a day. We've done the EEG's, 4 rounds now of different gene testing as well and completed a MicroArray in May of 2017.

23 months ago we finally gave in and had allergies, hair, stool and urine tested? My son is allergic to many items. He's off the charts in aluminum, copper, lithium, rubidium and cesium. Then he was diagnosed with PANs and had a scare of Lyme as well.

We immediately started natural chelation with nutrients. We went GF/CF/SF and eliminated all sugars. We went 100% organic and juice every day. All chicken is free-range, antibiotic free and expensive. All beef is grass fed, non-GMO and expensive. Every bit of food that enters his body is known to the source and purity.

Results::

- any gluten, any sugar causes extreme aggression and yeast flare
- any "normal" produce produces foul stool, changes behavior and increases stims

What I also learned:

My road has many miles to travel, but I've covered more ground with natural healing than I did with any Dr's 7 minute consultation or prescription recommendation (what ~~the hell~~ is Marinol anyways and why would my child be prescribed this and not natural cannabis oil?) I'm not the only one. My path was paved by many, walked by thousands and is continuously modified with new tests, strategies and nutrients.

Parents live autism. They see changes that are microscopic. They notice what causes changes. They talk to one-another and compare notes. Compare Dr's. Compare protocols. Compare results.

2.) Glyphosate. What are the affects on the human brain and gut microbiome? What are the affects on the human ASD brain and gut microbiome? Are there correlations, that have been studied between Glyphosate exposure and Autism Spectrum Disorders?

Why would a 5- $\frac{1}{2}$ -6- $\frac{1}{2}$ year old child on the spectrum who was breast fed for two years and ate a natural, healthy diet have over 3x the normal levels of Glyphosate in his blood? We do not live near a farm, he does not work in produce, nor any processing plant.

Can the IACC to investigate how Glyphosate is affecting children with ASD vs. Non-ASD in the fiscal year of 2016, now 2017- 2018?

3.) The IACC makes a formal request to Congress to subpoena Dr. William Thompson at the CDC.

Since his admission of falsifying tests, at the request of his superiors on how children receiving the MMR vaccine before 36 months were 340% more likely to receive an autism diagnosis or develop tics. Dr. Thompson made admissions to Biochemical Engineer Brian Hooker in a series of phone calls and not only gave specifics on how to obtain the correct data but also expressed remorse in his cover-up.

I ask: why hasn't the IACC been concerned with this information? Why hasn't the IACC even asked for clarification from the CDC and response been made public?

I request that the IACC makes a public, formal request to Congress to subpoena Dr. William Thompson of the CDC.

I request that the IACC makes a public, formal request to Nancy Messonnier, MD at the CDC for a full debriefing of the study to be included in the next IACC Summary of Advances in Autism Spectrum Disorder Research: Calendar Year ~~2016-2017~~-2018 that Dr. Thompson authored and the allegations of the link between autism and the MMR.

I request that the IACC demand retraction of published study (PubMed 2004 Feb;113(2):259-66.) at the AAP of the MMR/Autism paper co-authored by Dr. DeStefano and Dr. Thompson.

When will any of my requests be addressed or answered?

--

Dwight Zahringer
[PII redacted]

Katharine Hikel, M.D.

April 19, 2018

In doing research on obstetrical violence - now a legal term in most of the world except the USA - it's clear from some research that the forcing of women into overmedicated and surgical births has consequences for infants too:

<file:///C:/Users/Owner/Downloads/poi130046.pdf>

<https://jamanetwork.com/journals/jamapediatrics/fullarticle/1725449>

Pitocin (oxytocin) is perhaps the greatest factor the young autism-disorder population has in common; yet denial and discrediting of this problem by the 'scientific' community ensures the ongoing trumpery of women and children by Big Pharma and the revenue-hungry OBGYN manarchy whose 'mone is bigger' regime is second only to cardiology in cost, charges, and expenses driven by overuse - and, in the case of maternity care, cultural misogyny. It is shocking to see this otherwise robust research project include multiple evaluations of every other possible cause of ASD (typically focusing on genetics -- blame the mother AMD the baby) - but skipping completely the thing that most of these children have in common - overmedicated hospital birth.

What is sadly lacking in your research are multiple, ongoing, and long-term outcome studies which include the timing and dosage of oxytocin/Pitocin during labor and delivery, as well as subsequent NICU admissions. Then we'd have some data to believe in.

Alas, an unexamined consequence of obstetric violence is brain damage to infants. The forced overmedicalization of childbirth is bound to have consequences that must not be ignored. We pray that the 'Strategic Plan' may lead resistance to this malignant culture.

<https://www.ncbi.nlm.nih.gov/pubmed/27578339>

<https://scholarship.law.duke.edu/cgi/viewcontent.cgi?article=3924&context=dj>

<https://www.tandfonline.com/doi/full/10.1016/j.rhm.2016.04.002?src=recsys&>

At Hillside Family of Agencies, we work closely with youth on the Autism Spectrum whose profound neurobehavioral challenges demonstrate a clear and urgent need for advanced clinical expertise and support. These youth and their families have nowhere else to turn for the behavior analysis services that can direct treatment pathways and create opportunities for meaningful change that will foster long-term quality of life improvement. Hillside joins our peer organizations in strongly urging increased funding in support of the research, resources and supports for these youth and their families, including well-trained clinicians in psychiatry, nursing, behavior analysis, and brain health concerns to provide collaborative in-home support and training, school-based behavior analysis and other services, out-patient programming, residential services, and up to and including inpatient units such as the ones that provide behavior analytic assessment and treatment to address the needs of this extremely vulnerable client population. We must not let these children and families down.

Thank-you for your time,

Amy Patterson, BSN RN
Acting Nurse Manager, Developmental Disabilities Services
Hillside Children's Center

Deborah A. Napolitano, Ph.D, BCBA-D, LBA
Clinical Director, Hillside Developmental Disabilities Services
Director of Behavior Analytic Services
Hillside Children's Center
Clinical Associate Professor of Pediatrics, URM

Hillside Family of Agencies

Our Mission

We partner with youth, adults and their families to provide individualized health, education and human services through an integrated system of care.

Our Vision

Healthy and productive people thriving in families and communities.

Our Philosophy of Service & Our Promise

Hillside Family of Agencies is family-driven, youth-guided, trauma-informed, and culturally competent. We promise to provide compassionate, comprehensive, innovative and effective services to help families in the communities we serve reach their full potential.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Eileen Nicole Simon, PhD, RN

April 19, 2018

[PII redacted]

Following are comments I would like to hear discussed by members of the IACC, at the meeting to be held on April 19, 2018:

1. Discussion?

Once again I want to ask that public comments be discussed, not just mentioned in brief summaries.

The IACC is becoming more and more unresponsive to the concerns many of us have.

What happened to the original mandate for heads of government scientific agencies to investigate the cause of increasing prevalence of autism? Is it forbidden to question dangerous medical procedures like clamping the umbilical cord immediately after birth?

I have asked over and over for auditory system damage caused by asphyxia at birth to be discussed by members of this committee. Why is this request repeatedly ignored?

2. The Key to Autism Is the Midbrain

The midbrain is a possible locus of injury underlying neurological deficits of autistic children. As such, it should be discussed.

The inferior colliculi in the roof (tectum) of the midbrain are highly active components of the auditory pathway. I have cited many times the seminal paper by Seymour Kety ([Regional neurochemistry and its application to brain function](#). Bull NY Acad Med. 1962 Dec;38:799-812).

Please click the link, and look at the autoradiography pictures that reveal blood flow in the inferior colliculi to be higher than anywhere else in the brain. Aerobic metabolism has also been found to be highest in the inferior colliculi. These are auditory signal-processing centers, and may be important for deciphering components of speech.

The auditory system is also always active, even during sleep. It may be the vigilance center of the brain. Could it be the seat of the conscious state? Might damage of the inferior colliculi underlie the lack of environmental and social awareness in autistic children?

Julie Maryjanowski

April 19, 2018

We didn't tell our family or friends for many years our son had self-injurious behaviors. Feeling like Prisoners in our own home. We visited the Kennedy Krieger Institute and before we could enter we had to prove numerous trips to the ER to show we didn't have any help. They also wanted multiple vaccinations before we entered the program. This was a 6 hour drive from our home. We still got the run around after providing bloodied pictures of our son from self harm. We couldn't continue jumping through the hoops. We ultimately got him into a residential facility close to our home for 1.5 years before he returned home. He is still a handful and still has SIBs.

The need is so strong for hospital and/or residential units for these fragile kids and adults. Parents are trying to deal with this on their own. Marriages crumble leaving kids more vulnerable. Parents go off the deep end themselves with their mental health at risk as well. Siblings distance themselves and extended family runs for the hills.

Funding is vital, awareness is important.

3 years ago my son Clay was a happy and hyper 8 year old boy with autism. He attended school, he went to church, he enjoyed various activities with the family like going out to eat and on family vacations. He is not that little boy anymore. I wish there was a term to describe what has happened to him, it is much more than autism, autism alone did not prevent us from doing things with him and enjoying life. Three years ago I could not have imagined him hitting himself, biting himself, banging his head or attacking me, his brother, other family members and teachers, daily, often for hours at a time. I never could have imagined back then how severely self-injurious, aggressive and disruptive has now become. I am sure you can not imagine it either. I still find it hard to comprehend and he is my own child and I have lived with it for 3 years. Three years of constant cuts, scratches and bruises. He does not want to hurt himself or anyone else but he is not in control of his body, he is suffering in some way that nobody (not even the best psychiatrists, medical doctors, neurologists, behavior therapists and speech pathologists in this country) fully understand or can fix. Despite having extensive behavior therapy, several med trials, speech therapy, experimentation with diet, family and staff training and being fitted with protective gear to prevent injury, he has still developed an inch thick calcified section of his forehead due to his head banging. Everyone around him is trained in applying his helmet when behaviors begin, but the problem is his behaviors are intrinsically motivated, meaning are not in response to any predictable, external stimuli. It happens out of the blue, and he is so quick and does it with such force it is nearly impossible to prevent damage he does to himself. He has also done a lot of damage to others, bruises, scratches, pulled hair and even broken bones. I am telling you this because during autism awareness month you will hear a lot of celebration about autism, and rightly so. It is great for those who are gifted with special abilities due to their autism to celebrate it. BUT I am here to tell you the other side, this kind of autism is nothing to celebrate, I am not glad, don't see it as a gift, I do not see his suffering as part of neurodiversity. I am not telling you this to get your sympathy. I am not a hero, I am not a supermom, he is not a burden or some kind of monster because of what happens to him. He is still my beloved child who I love as much as I love my typical child, as much as you love yours. I am telling you about his kind of autism in hopes that there may be increased awareness and support. He is not the only one, I have gotten to know hundreds of others and their families. The resources are scarce, the waiting lists long, most psychiatric facilities, schools and providers refuse to work with them because they frankly don't know how and are not equipped. Clay is one of the lucky ones, he relatively safe and very well cared for, his family and staff are well trained and his home is modified to fit his needs. I have very good relationships with his caregivers, his therapists, their supervisors and the directors of services. I am grateful. Yet it is heartbreaking that he suffers so every day. It is my greatest hope that new treatments emerge and become available, that more resources and funds are made available, that autism with self injury can be studied and the cause determined so that it can be prevented. I also hope autism with self injury could be called something else to distinguish it from other forms of autism. Those who do not experience autism as something to suffer from and do not see themselves as broken or needing to be fixed resent those of us who are crying out for our suffering kids and wanting desperately to stop their self injury and aggression. Autism awareness, research and resources need to address both end of the spectrum, please don't forget those severely affected and those with self injury and aggression. Please.

Hello, my name is Julie Greenan, and I am the biological mother of five children diagnosed with Autism Spectrum Disorder. My children clearly illustrate the "spectrum" that is this disorder, making our lives a challenge on a daily basis. Each is smart, beautiful, tender, and amazing in their own right. I am in a very unique position to witness how, in recent years, the focus of research and treatment has been geared toward early intervention, inclusion, and increased job access for those on the spectrum. I have a child that has benefited from each of those things in some way, and acknowledge their importance in today's climate of self advocacy. However, I also have a child that those focuses have not been able to touch. A child that may never be eligible for inclusion. One that despite intensive early intervention, remains very "low functioning" as society would interpret. A child that has trouble getting through the day with less than 500 instances of self injury, or injuring a staff member, let alone hold a job.

My second son Sam, now sixteen, has been severely self injurious and aggressive since the age of three. At that point, he had been receiving services for nearly two years, including intensive ABA and behavioral support. The self injury started with self punching, self biting, and head banging, with any attempt to block these behaviors being met with equally intense aggression. Throughout the years the self injury worsened to include jumping from elevated surfaces to land on his knees, and pulling rooted teeth from his mouth in bursts of behavior that often lasted for hours. We were a family in complete crisis, trying to keep our beautiful boy from devastating injury while looking for help. We were lucky to find Kennedy Krieger Institute's Neurobehavioral Unit, where Sam has been inpatient three separate times. Each admission was different, but rooted in the same issues. Behaviors that morph and change, along with their function. Medication efficacy that wanes despite increasing dosages, or that isn't effective at all. Countless pediatrician appointments, dentist appointments, ER visits to rule out pain or injury before we treated with behavioral modification or medication changes.

Sam's situation remains precarious. He recently required surgery to repair a severely, purposefully bitten tongue. His latest attempt to self injure involves grabbing his scalp in his fist, and twisting in an effort to open the skin. This has resulted in him wearing arm restraints during all waking hours. In response to this, he rubs the ends of the restraints on his face in an effort to open that skin. He now wears a neck pillow to block that. His level of agitation now requires partial sedation, making him vacant and off balance. But safe. For now. This is no way for a child to live.

I don't pretend to know the answers. What I do know is that the DSM-V has failed to adequately or appropriately represent my son and the severity of his impairment and lifelong disability. Maybe a separate diagnostic criteria detailing severity and timetable of impairment would be a start. Specifically, we need much more research into self injury and aggressive behavior among individuals with autism to find improved treatment modalities. We need more inpatient beds while families try to keep their children safe. Waiting years for help is not a livable condition. We need this committee to recognize that this is a crisis. We need HELP. I have had the opportunity to meet families from all over the country with kids similar to Sam. We are all one behavioral episode away from losing our placement, losing our school setting, landing our child in an overcrowded psychiatric ER of a county hospital that has no hope of helping them. That is our best option, and our only option in many cases. We have to do better.

I beg you to increase funding and research for this under served population within the autism community. I beg you to investigate ways that individuals needing stabilization can access help, and not have to wait years for it. Living in crisis on a daily basis, for years on end, is devastating. It infiltrates the life of your entire family. It has to stop.

Thank you for your time and consideration.

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Elissa Leonard

April 19, 2018

When you mask B12 deficiency in Vegetarian Moms, (by saturating them with high folic acid) it looks just like AUTISM. B12 Deficiency is the differential diagnosis for every symptom of autism and no one was checking for decades. Epidemic Misdiagnosis and Negligence.

Article: Cerebral Atrophy in a Vitamin B12-deficient Infant of a Vegetarian Mother.

<https://www.ncbi.nlm.nih.gov/pubmed/25076673>

So-called HELLP syndrome did not exist, it was "discovered" in the USA in the 1980s after folic acid was added to womb. Folic acid masks and worsens B12 Deficiency. Interesting. B12 Deficiency is the differential diagnosis for HELLP syndrome, but in the USA no one will discuss this. Epidemic of Negligence harming women and babies.

FACT: B12 deficiency causes Hemolysis. Elevated Liver Enzymes. Low Platelets. And all other symptoms of so-called HELLP. Including death from organ shutdown. B12 is needed by every cell in our bodies. Folic acid will correct the anemia until very late-stage. when women and babies are dying or dead.

Article: <https://www.ncbi.nlm.nih.gov/pubmed/19304410>

All the symptoms of AUTISM SPECTRUM DISORDER

Damage done depends on duration, severity, diet, genes, use of meds.

Babies acquire B12 Deficiency from mothers who do not know they have it. Toddlers eat folic acid fortified carbohydrates all day long. This masks and exacerbates B12 Deficiency. We are harming the target population. Of course no one in public health wants to talk about it. It's called CYA.

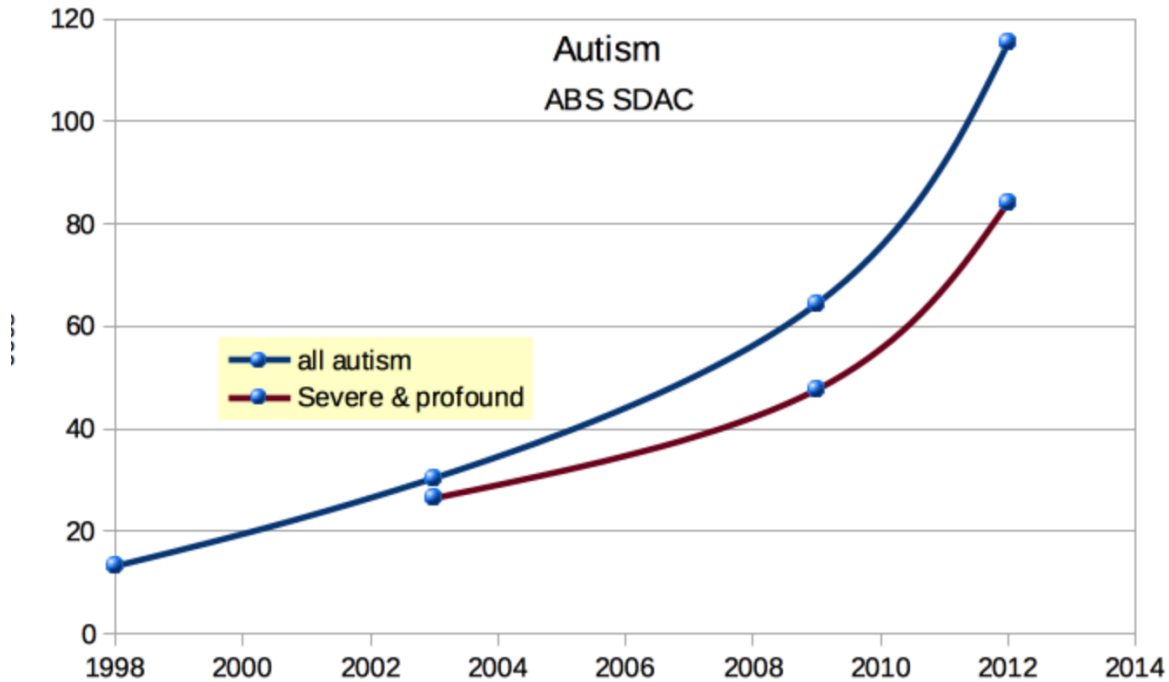
Article: <https://www.ncbi.nlm.nih.gov/pubmed/27736023>

Look at Australian autism incidence after folic-acid-only fortification of food supply in 2009. If synthetic folate lowers autism why did autism exponentially rise?

B12 and folate have a shared metabolism. Folic acid is not well-metabolized by all. In folic acid fortified populations, the dominant nutritional cause of high homocysteine (Neuro-Toxin) is vitamin B12 deficiency.

We are telling women to avoid meat. We are saturating them with synthetic folate that is useless or harmful in patients with B12 deficiency.

We Did This.



<https://www.medscape.com/viewarticle/887062>

Epidemic of adverse effects and mental health problems in children when we tell women of childbearing age to avoid meat, take high folic acid, eat a plant-based diet devoid of vitamin B12. Children with B12 Deficiency in the brain self-medicate which can lead to addiction.

Epidemic high folic acid masks low vitamin B12, leading to epidemic misdiagnosis.

This is vitamin B12 deficiency in children. Presents on a spectrum from mild to severe. Patients need not be anemic nor macrocytic nor test outside "normal" range of B12. Mom's folic acid corrects the anemia. Low fat high carb diet increases the need for B12, making reference range obsolete and misleading. No one is re-training doctors.

<https://www.martynhooper.com/2016/08/19/a-family-affair/>

Please comment on this at your next public meeting.

Pediatric B12 Deficiency is the differential diagnosis for every symptom of Autism Spectrum Disorder. All the neurological, digestive, behavioral, cognitive, sleep, movement, mental health etc. symptoms could be injuries from untreated Pediatric B12 Deficiency.

(Full stop. Fact. I've met the misdiagnosed patients.)

The CDC has known this since at least 2001.

Please let us know why no one was alerted, why no change in the standard of care was made, and why no public health agency will say the words Pediatric B12 Deficiency Brain Injury and Autism in the same sentence.

There appears to be a conspiracy of silence that

- Folic Acid masks and exacerbates B12 Deficiency
- Dietary guidelines have touted plant-based diet without B12 awareness
- Many common medications block B12 absorption in mothers and children.
- Women and children have high levels of synthetic folate. In fact almost all US pregnancies have unmetabolized folic acid. B12 deficiency makes folic acid useless.
- When checked, high percent B12 deficiency in pregnancies in folic acid fortified populations. No one's been checking
- Multivitamin formulations can convert B12 to useless analogue. Prenatal multivitamins do not reliably replete B12
- Doctors have neglected to check B12, Homocysteine, Methylmalonic Acid in symptomatic children for decades
- Folic Acid (synthetic folate) can change the DNA methylation of the unborn, affecting generations to come. Especially in the presence of low vitamin B12. Folate and B12 have a shared metabolism that folic-acid-only can derange.

Let's discuss how this known risk of giving folic-acid-only to people with B12 deficiency was allowed to persist for the last 20 years of our universal intervention of the food supply that no one can opt out of.

Folic-acid-only fortification has not been accompanied by the strictest standards of safety and monitoring for unintended effects, as is required for universal interventions. Early autism stats? Educated women, receiving prenatal care, taking folic acid... were they vegetarians with masked B12 Deficiency?

Now that we know, what are we doing about it? Conspiracy of silence means more and more injuries that could have been prevented.

Imagine if this 2003 CDC headline had been properly descriptive:

"B12 Deficiency-- Even In Absence Of Anemia-- Causes Symptoms of Autism. It Causes Injuries On a Spectrum From Mild To Severe. Babies Acquire It From Undiagnosed Mothers"

The CDC knew this was happening. They did the minimum possible- one headline- in order to not call attention to the epidemic of misdiagnosis.

<https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5204a1.htm>

Articles:

Neurologic impairment in children associated with maternal dietary deficiency of cobalamin--Georgia, 2001. <https://www.ncbi.nlm.nih.gov/pubmed/12578322>

B12 deficiency is common in infants and is accompanied by serious neurological symptoms.

<https://www.ncbi.nlm.nih.gov/pubmed/27736023>

Dear Members of the Inagency Coordinating Committee on Autism,

When properly checked, Vitamin B12 deficiency is more common in infants than previously thought ¹, ¹²and it presents as serious neurological symptoms on a spectrum from mild to severe. ^{1, 2} The symptoms of ASD and the symptoms of pediatric B12 deficiency are identical: Failure to thrive, irritability, feeding problems, developmental delay, regression, clumsiness, vision and hearing problems, cognitive problems, trouble in school, sensory disorders, behavioral problems, stimming, obsessive compulsions, anxiety, depression, thoughts of suicide, brain changes on MRI, cerebral atrophy.

Seemingly asymptomatic women (with undiagnosed deficiency) pass B12 deficiency on to their babies, in-utero and during breast-feeding.² In addition, highly symptomatic women and children without anemia have been misdiagnosed, because folic acid (the synthetic folate in vitamins and fortified foods) can correct the type of anemia doctors were taught to look for³; We call this “masking.”

In addition to masking, folic acid can also exacerbate B12 deficiency. Current evidence shows that opposite extremes of low vitamin B12 in the presence of high folic acid can predispose pregnant women to gestational diabetes as well as later diabetes and obesity in their children.^{4,5, 6} This imbalance of folate/B12 affects generations to come, and can change DNA methylation in offspring.⁷

Bound to animal protein, B12 is the largest and most complicated vitamin to digest. Causes of B12 deficiency in women of childbearing age are many and varied¹²:

Vegetarian or vegan diet, the use of B12-blocking or inactivating medications (oral birth control, metformin, proton pump inhibitors, statins, antibiotics, chemotherapy, nitrous oxide), stomach problems or gastric surgery, anorexia, alcohol use, microwave cooking, parasites, bacterial overgrowth, autoimmune pernicious anemia, as well as having any of a dozen or more known common gene variants in B12/folate metabolism.

Vitamins B6, B9 and B12 and other nutrients work together in keeping toxic homocysteine down.³ This is called One Carbon Metabolism. FolicAcidOnly Interventions derange one carbon metabolism in people with B12 deficiency and common gene variants. Vitamin B12 Deficiency is the dominant nutritional cause of high homocysteine in folic acid fortified populations. B12 deficiency makes folic acid useless.

Proper testing for B12 deficiency includes using a variety of tests : B12, homocysteine (Hcy), methylmalonic acid (MMA) ⁸No one test is completely reliable.⁸ Patients can have a “normal” B12 level because of useless analogues in the food supply and vitamins; or their B12 can circulate but not be transported to the cells. These patients can have “functional” deficiency.^{9,10}

There is no gold standard B12 test, so we urge all to know the signs, symptoms and risk factors. Every symptom of autism is also a symptom of pediatric B12 Deficiency^{11, 13}and B12 deficiency is not ruled out without an immediate trial of therapy with B12 injections. Prompt treatment of B12 deficiency is “gratifying”⁸, and lack of treatment can quickly cause permanent nerve, vessel, tissue, brain damage and problems in growth and development.²

¹<https://www.ncbi.nlm.nih.gov/pubmed/27736023>

² <https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5204a1.htm>

³<http://www.bloodjournal.org/content/bloodjournal/129/8/940.full.pdf?sso-checked=true>

⁴<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3541499/>

⁵<https://www.ncbi.nlm.nih.gov/pubmed/27876554>

⁶<https://www.ncbi.nlm.nih.gov/pubmed/17851649>

⁷<https://academic.oup.com/ije/advance-article/doi/10.1093/ije/dyy032/4931210>

⁸<http://www.bloodjournal.org/content/early/2017/03/30/blood-2016-10-569186?sso-checked=true>

⁹<https://www.ncbi.nlm.nih.gov/pubmed/921081>

¹⁰<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC370297/>

¹¹ <https://www.ncbi.nlm.nih.gov/pubmed/20402062>

¹² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2696961/>

¹³<https://www.ncbi.nlm.nih.gov/pubmed/1432418>

Elissa Leonard

Producer/Writer/Director

Sally Pacholok the movie

Annet Mahendru stars as Sally Pacholok

Meet the New Erin Brockovich: FREE

<https://www.youtube.com/watch?v=OvMxJ6GRBNQ>

Diagnosing and Treating B12 Deficiency

(researcher/patient interviews for Sally Pacholok screenplay)

<https://www.youtube.com/watch?v=BvEizypoyOO>

[PII redacted]

I am writing to request that the IACC recognize and support research for the severe self injurious behaviors in severe autism. In addition, I want to see the recognition of the extreme lack of health care and service providers as well as residential options for children and especially adults with severe autism. My 25 years old son has severe autism and severe self injurious behaviors along with aggression His life is not the life portrayed on popular television shows and movies. He spends seven days a week at home. His outings consist entirely of two things: taking long rides in our van and going to the doctor and weekly ECT treatments. That's it. This is because he continues to be unstable despite 21 years of one medication after another. At last count he has taken more than 35 different medications which have had either no effect or horrendous side effects. He has had two hospitalizations within the past three years. The first was a six-month stay at Kennedy Krieger Institute. Although he was discharged with an overall 80 percent reduction in behaviors, the self injurious behaviors returned within a year after discharge. At this point, he is injuring himself at a rate far in excess of anything he has ever done before. His adult years have seen a massive increase in self injury as well as aggression. This is also accompanied by the increase in isolation at home.

The second hospitalization was this summer at Vanderbilt Psychoatric Hospital for 11 days. The adult unit was not prepared for his behaviors. He spent the entire 11 days in his room because the staff admitted they were afraid of a meltdown. Instead of enjoying some fresh air at meals, he ate in his room. He only walked up and down the halls when his dad and I were there. During one burst of behavior along with elopement, the staff stood back and watched while my husband and I restrained him long enough to get him back to his room.

I know that among many people, this view of an intellectually disabled and self injurious person with severe autism is not popular and is very foreign. However, his head injuries from banging his head in every hard surface he can find are very real. He launched himself without warning into walls, kitchen cabinets, glass doors and door frames. He has a large bruise at his hairline that never goes away. He has sustained cuts in his head but won't allow me to get close enough to stop the blood flow. He bits his wrists and tears at the skin. His wrists are so calloused and damaged that they don't even resemble wrists. While at Kennedy Krieger, he slapped his ears so hard and often that he developed a cauliflower ear. Now, he has reinsured that ear and started in the other one. He refuses to wear ear guards or padded helmet as protection. The best I can do is put the helmet and arm guards in myself and stick with him to block as many of the blows as possible. Along with padded mats and posey mits, which only my husband can get on him, we are trying everything in our power to keep him safe. Nevertheless, every wall in my home has a large deep hole all the way to the insulation and studs from his head banging.

It took us months to find a psychiatrist who would accept him. We ended up with a geriatric psychiatrist. He is an excellent physician, but he lacks the adult autism experience. He recently stated that he has to think about what to do because he had just about exhausted his medication ideas. Along with psychiatrists, there are no day programs for adults in my area who will accept his behaviors. Just within the past six months, we have lost his in home speech therapist, occupational therapist and behavior analyst. The IT and BCBA left specifically due to his self injurious behaviors and aggression. As an adult, he receives his services through the Medicaid Waiver. The BCBA put together a behavior plan that did

not consider his behaviors. She left in frustration stating that she could not do his behavior plan because of his out of control behaviors! I don't know where else to turn. Efforts at funding private behavior services for an adult have been a failure.

The vast majority of people have no idea how families like mine are living. The toll on marriages is very high. We just want some peace in our homes. But by far the biggest thing we need is to understand what's causing our kids to harm themselves so seriously. I fear for the children with severe autism who are still young. My son's behaviors have increased so significantly as he has aged. And the access to health care professionals and hospitals who will accept him and be able to work with him are almost nonexistent. When I do locate an excellent hospital such as Kennedy Krieger, the waiting list is up to two years long. With only 16 beds available and because of his age, I have no expectation that he will ever make it back to Kennedy Krieger.

Again, please, please support our urgent need to find out what's happening to our children and support whatever it takes to increase access to desperately needed health care and service providers. As aging parents, it is our responsibility to see that our children are going to be safely taken care of after we are gone. Please help!

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Gene Bensinger

April 19, 2018

Public Comment Submission April 19, 2018 IACC Meeting

To Dr. Joshua Gordon IACC Chair and Committee Members:

I write today to request that the IACC create and adopt a formal Code of Conduct, possibly modeled on the current HHS code that covers the actions of public members of the Committee, and the organizations they represent, as well as members of the public and any organizations invited to participate in IACC meetings and activities. Currently, federal members are held accountable to a code. Public members are not. Implementing full coverage of IACC members will provide the IACC Chair and leadership with a powerful and much needed tool that will help create positive conditions and set an example leading to more respectful interactions within the autism community.

This year's Autism Awareness and Acceptance Month marks twenty years of my deep involvement in a wide range of federal, state, and local autism and developmental disability related advocacy efforts, policy formulation, and legislative initiatives on behalf of my now adult autistic son, my family, and the broad autism community. As I reflect on the tremendous changes that have occurred on every autism related issue over those two decades, and the many changes, opportunities, and challenges that lie ahead, I am more troubled than I have ever been about the destructive rhetoric expressed today by members of our community toward one another in both formal communications and informal exchanges. Destructive rhetoric delays and derails progress. Our community cannot afford, and shouldn't tolerate it.

Expressing genuine, even passionate, concern and disagreement on the issues that impact individuals diagnosed with autism, their families, and the broad community is natural. Opposing views and dialogue test, inform, and strengthen policy, regulation, and law. That's extraordinarily helpful. But spirited debate in the autism community has been steadily eroded and replaced by invective, spurious assertions, and personal attacks on the motives and character of one another. Sadly, some of this rhetoric has been generated by organizations currently represented on the IACC by appointed public members.

Adopting a formal Code of Conduct that applies to all public members and invited participants will give much needed strength to the "Spirit of Collaboration" core value designated in the 2016-2017 IACC Strategic Plan. I believe that the potential for sanction or penalty, including removal from the IACC, will send an unequivocal message to all autism community stakeholders that good conduct, in and out of IACC meetings, is not only requested, it is required in order to participate in the fundamentally collaborative activities of the IACC.

Thank you for giving my request serious consideration. I am available anytime to discuss it in more detail. I'd also be happy to provide the committee with examples of the above, though I expect you already know of (too) many. In closing, I urge all Committee members, but especially public ones, to

read a brief excerpt from an extraordinary speech that I've linked below. It was delivered by former Vice President Joe Biden at Yale University in 2015. In the excerpt, Vice President Biden explores the topic of incivility (his own) related to the initial passage of the Americans with Disabilities Act. I learned much from it and I hope others in our community will, too.

"Let me give you an example. After only four months in the United States Senate, as a 30-year-old kid, I was walking through the Senate floor to go to a meeting with Majority Leader Mike Mansfield. And I witnessed another newly elected senator, the extremely conservative Jesse Helms, excoriating Ted Kennedy and Bob Dole for promoting the precursor of the Americans with Disabilities Act. But I had to see the Leader, so I kept walking.

When I walked into Mansfield's office, I must have looked as angry as I was. He was in his late '70s, lived to be 100. And he looked at me, he said, what's bothering you, Joe?

I said, that guy, Helms, he has no social redeeming value. He doesn't care -- I really mean it -- I was angry. He doesn't care about people in need. He has a disregard for the disabled.

Majority Leader Mansfield then proceeded to tell me that three years earlier, Jesse and Dot Helms, sitting in their living room in early December before Christmas, reading an ad in the Raleigh Observer, the picture of a young man, 14-years-old with braces on his legs up to both hips, saying, all I want is someone to love me and adopt me. He looked at me and he said, and they adopted him, Joe.

I felt like a fool. He then went on to say, Joe, it's always appropriate to question another man's judgment, but never appropriate to question his motives because you simply don't know his motives.

It happened early in my career fortunately. From that moment on, I tried to look past the caricatures of my colleagues and try to see the whole person. Never once have I questioned another man's or woman's motive. And something started to change. If you notice, every time there's a crisis in the Congress the last eight years, I get sent to the Hill to deal with it. It's because every one of those men and women up there -- whether they like me or not -- know that I don't judge them for what I think they're thinking.

Because when you question a man's motive, when you say they're acting out of greed, they're in the pocket of an interest group, et cetera, it's awful hard to reach consensus. It's awful hard having to reach across the table and shake hands. No matter how bitterly you disagree, though, it is always possible if you question judgment and not motive."

<https://obamawhitehouse.archives.gov/the-press-office/2015/05/17/remarks-vice-president-yale-university-class-day>

Sincerely,
Gene Bensinger
(Volunteer) Parent Advocate
[PII redacted]

Anonymous

April 19, 2018

My son has ASD and ADHD. He had B12 deficiency when a baby but was undiagnosed until nearly 15 months. We took him to many doctors and the pediatrician thought he had Autism. My son was non verbal. Could not walk. Regressed in skills. Could not close his mouth properly and dribbled constantly. He could not eat solid food or water - could only take milk from the breast (I breastfed him day and night to keep him alive as he would take no other source) He had constant diarrhoea and vomiting was hypermobile, screamed a high pitch scream, would sleep as often as possible , had huge sensory issues especially to touch and was deathly pale.

It was only after I took him to the emergency hospital as he wasn't wetting his nappies did a locum Dr find him to have B12D . He was not diagnosed with ASD at this point but B12 deficiency.

Now my son is 8 and has recently been diagnosed with having ADHD and ASD. He has sensory issues (although not as severe thank goodness) social communication difficulties and learning difficulties

I (his mother) was diagnosed as B12d shortly after.

A lot of symptoms surrounding ASD and B12 are the same. Unfortunately because of this , our pediatrician didn't think of B12 but ASD which, at the time, was wrong. My son had less than 10 ng/l of B12 and was actually dying in his hospital cot. His first injection gave him life and he had colour. He sat up for the first time in months and wanted to touch things.

I wish people would rule out B12d before they diagnose children with ASD. In some cases, it won't be ASD but B12. My son is not the only one.

1. How can we address autism if we refuse to understand the fundamentals of pediatric B12 deficiency?
2. Because it is well documented that vitamin B12 deficiency in infants and young children causes developmental delay and regression, why aren't children suspected or diagnosed on the "autism spectrum," properly being screened for B12 deficiency at the first opportunity (serum B12, methylmalonic acid, homocysteine)?
3. Are you aware that some children diagnosed on the autism spectrum are misdiagnosed and actually have a B12 deficiency brain injury?
4. Why aren't women being screened for B12 deficiency during their prenatal visits? Pregnant women and even those admitted to obstetrics units are not even screened for B12 deficiency with a simple questionnaire, to obtain if they are vegan, vegetarian, autoimmune disorder, malabsorption syndrome, GI disease (celiac, Crohn's), GI surgery (gastric bypass), genetic mutations [MTHFR, MTRR, MTR], taking metformin or a proton-pump inhibitor—and then these same women who are at risk, are encouraged to breastfeed. Not only do we not test women, we do not screen with basic at-risk questionnaires. Women who are low or deficient in B12 will have poor B12 in their breast milk, which can permanently injure their child's growing brain for life.
5. For those clinicians who do test children for B12 deficiency, what tests are they using and why aren't all clinicians testing and documenting the incidence?
6. Because of the knowledge deficit in the medical and health care community regarding B12 deficiency, wouldn't it be prudent to start a B12 Awareness campaign?
7. Who is responsible for this dangerous health care threat (B12 deficiency) against women and children, and why is the U.S. government, medical community, and autism groups apathetic to the reality of this medical disorder?
8. Why aren't we screening infants at three or six months of age for low B12 in their urine using the urinary methylmalonic acid test. Newborn screening will not detect a child who is borderline or low in B12, that then becomes deficient as the deficient mom continues to breast feed. This is how many children are silently being injured.
9. It is poor public health care to encourage women to breast feed if the clinician and health care institution fails to determine if that mother is low or deficient in vitamin B12.
10. Are health care professionals and institutions aware of what nitrous oxide does to B12 in the body?
11. Should obstetricians be giving pregnant women hydroxocobalamin injections monthly at their prenatal visits to prevent low B12 in children?
12. Should some funding be directed toward B12 deficiency prevention, education, testing, and research?

Would be interested to give health care leaders in D.C. an informative lecture on the consequences and dangers of pediatric B12 deficiency.

Ruth Chaffin

April 19, 2018

Hello, I'm have pernicious anemia (B12 deficiency), and my daughter is on the spectrum, type 1, she is 18 years old Thank you

Margaret Tallon

April 19, 2018

I have b12 deficiency, I was only diagnosed a couple of years ago, I also have hypothyroidism. My 17 year old son was diagnosed with aspergers, dyspraxia, sensory processing disorder at age 12. I got his b12 checked a couple of years ago, also low b12, low folate, high homocysteine. He seemed fine up until the age of 11 apart from the fact that he didn't walk until he was 18 months. My mother had MS, i remember hearing pernicious anaemia mentioned as a child but she wasn't treated for it. She had MS 13 years before she passed away. She had no remission's, she just got progressively worse and was totally and utterly incapacitated before she passed away, she couldn't even speak. I honestly believe pernicious anaemia killed her. My sister also has b12 deficiency. I haven't had my 15 year old sons b12 tested yet, he appears well apart from the fact that he has Raynaud's Syndrome and didn't walk until he was 22 months. I breastfed both of my sons. My first baby was stillborn at full-term if that's of any relevance. I hope this is of some assistance.

Eileen Kurlander

April 19, 2018

IACCPUBLICINQUIRIES@MAIL.NIH.GOV

United States Health Consortium
USHealthConsortium.org
Eileen Kurlander, Executive Director
EKurlander@USHealthConsortium.org

Dear,

The United States Health Consortium is comprised of Scientists, Doctors, Nurses, Advocates, Parents, Individuals and Activists who care about clean air, food, water, medicines and vaccines.

Specifically, our parent community wants to be heard.

Our scientists know immune activated events with overloading toxicity is at the root of the brain and neurological damage and parents are actually eyewitnessing these immediate changes happening in their children. Vaccine Injury and Toxicity Reporting is occurring in less than 1% of actual injuries. Doctors are not trained in, nor do they look for vaccination side effects, nor do they have effective treatment options to offer.

Over 6 million wide ranging adverse events occur from vaccination yearly.

Vaccine Immune Activation Events Andre Chart of vaccine induced chronic illness
<http://ipaknowledge.org/Maryland-HPV-Letter.php> **Cutting parents out of school vaccination.**

Here are concerns parents have who have children affected by Autism.

[Michelle Wolfson](#) Please explore the probability that there are subtypes of autism with different causes and different treatments. Only by identifying the subtypes can we begin to target interventions successfully. Also, please make an effort to educate the medical community that people with autism may also have medical needs that require treatment. Too many times our children (and adults too) are not given proper treatment for real medical issues because (1) they can't explain what's going on in a way their doctor can understand and/or (2) the doctor assumes symptoms are "just autism-related." We also need more group homes and affordable Section 8 housing for our adults.

[Molly Dimon](#)

We need more residential programs for children with Autism that have gotten to the point that the parents can't handle them anymore. And we need them in all the states not just a couple. I shouldn't have to send my kid to another state for treatment. (This isn't my issue right now, but eventually may be.)

Shannon Primer

In addition to the others, that just because the ND community can speak, doesn't mean they speak for all people with autism. They may like themselves and be ok with their autism, but my sick kid can't speak for himself and until he can, I will search for a cure and health! (which does go hand in hand with [Michelle's](#) treat the person, not the autism comment).

Michelle: Actually, I didn't say "not the autism;" I believe in treating the autism too, or at least finding ways to ameliorate the most troublesome of the core symptoms, especially communication difficulties.

[Lauren Forman](#) Hiding from the cause has cost thousands of kids and families a bright future. Waiting for a paper which was faked to prove that there is no autism link to MMR or vaccines for the omnibus hearings was really chicken shit and the problem is worse.

This epidemic has now caused a whole business to be developed - like cancer - which will cause us for people whose livelihood is about Autism will not help ending the epidemic. We all know that cancer doctors would never do the treatment that they recommend. So the autism providers will start not vaccinating their kids or families but will they take a hard stand that this is destroying families at an alarming rate? That remains to be seen but if we follow cancer the answer will be no and this will become an entrenched illness in our collective society where a whole business model around it where people have a financial interest to NOT stop the epidemic and this will destroy the economic viability of the globe because there will never be enough good caregivers when the number hit 1:2 which is where we are going in a few short years.

Schools are ill equipped in teaching these kids and it's mostly staffing and training. If they would fully fund IDEA that would change dramatically.

Rachel Hovendum

They need to recognize that it is an epidemic and treat it as such.

Amanda Vollmer

"My child quit talking after getting the MMR vaccine and now bangs his head against the wall every day, lost all his eye contact, doesn't recognize me anymore and is now afraid to eat new foods, but HEY-- I'm glad he doesn't have the Measles which can cause a runny nose, cough, and a rash, can be treated with Vitamin A, typically lasts only 7-10 days and resolves itself."

Said no parent of a vaccine injured child, ever.

Maria Nagy:

Insurance coverage for autism and it's behavioral needs in all fifty states and US territories. (There are still families that do not have ABA covered by insurance in their states) from birth (they if they want to claim we are born with it then pay for it).

- Open Up Speech and language therapy insurance coverage to include more non-speaking communication elements.

-early genetic testing for detox pathways, gut vulnerability, epilepsy drug application, digestive / nutrient absorption and food allergy issues.

Needs requested...

Planning/funding for housing and adult supports

Planning / funding for respite for caregivers

Fully funded IDEA

Recognizing the rise of murder suicide in autism families due to stress, isolation and perceived Helplessness

Recognizing the elopement risks and associated deaths, particularly the drowning risk.

Training all doctors and dentists to appropriately work with people with autism.

Training police, fire and rescue.

And if they aren't going to fund this stuff, an autism tax break that doesn't require tens of thousands in spending.

[Nina Boleda](#)

Meaningful day programs for those who are over 22 and more impacted to be in a work training program.

Michelle M Guppy

I keep thinking of how dismally "autism awareness month" is failing. There should be a standardized measure to survey all identified families living life with autism, seizures, and a side of PANDAS -- all of which fall in the "autism" spectrum to quantify the success of the last few decades of raising such awareness.

If the awareness campaign was working, there would be appropriate action to address the issues facing those who live "Life with Autism" --- and sadly, there has been no appropriate action that my son, nor anyone I know, has benefited from to make their lives a bit better.

My questions (as parent of now adult son) to all those parents caring for a loved one with true autism - who cannot speak for themselves or live independently - would be:

1) No matter how strong a Christian you are - do you believe you will die in peace leaving your child behind knowing there even IS a place they will be PROPERLY cared for, let alone a place that is safe and appropriate and allows freedom of choice based on their individual needs and wants?

2) Do you even have anyone who you could list as a guardian to care for your loved one with

"autism" in the event you cannot care for them anymore or you die?

3) Is your loved one getting the appropriate medical treatment - alternative medicine or otherwise - covered by the insurance you have?

4) After they age out of public school at 21 - have you found an appropriate for their needs day program for them to attend?

5) Are you and your loved one welcome at church?

6) Like most working people, with regard to the 24/7 caregiving - do you get regular time off? Do you get weekends off? A week or two for vacation? Do you have caregivers you can call on in emergencies or when you need reprieve? Is it because there is no one, or you can't afford to pay them, or both? If you have caregiving options, is it just in your home or is there a place that opens their doors for our loved ones to get to go outside their own home for once? Many are blessed with the occasional, or quarterly respite option -- but I mean weekends, the ability to take a vacation for a full week - let alone - <GASP> - TWO WEEKS A YEAR.

7) Once you must retire, whoever in the household brings in the paycheck, one or both, will the continuing needs of your loved one be able to be met on a retirement budget?

8) When you pay income taxes at end of year, are you able to deduct ALL costs of care for your loved one with autism?

9) If there were an appropriate day program or residential option for your loved one, would you be able to afford it out of your paycheck, their SSI, or whatever the state provides?

10) For those still in school - are they getting a Free and Appropriate Public Education based on their unique specialized needs?

Thank you for hearing what is happening in and with our American families. Autism affects the child, the whole family, the community and our country. Let alone our economy.

Thank you for doing what you do to help others.

Sincerely,

Eileen Kurlander

Article: Lyons-Weiler J, Ricketson R. [Reconsideration of the Immunotherapeutic Pediatric Safe Dose Levels of Aluminum](https://doi.org/10.1016/j.jtemb.2018.02.025). Journal of Trace Elements in Medicine and Biology. 2018 Jul(48):67-73. DOI: <https://doi.org/10.1016/j.jtemb.2018.02.025>

Caryn E. Porretta

April 19, 2018

To whom it may concern:

Usually when writing important letters I'd begin by explaining who I am, where I work, or what I do, but at this time that is not important. I could present facts upon facts or case study upon case study, but I'm not going to do that either. Research can be read and analyzed, however personal experiences are things no one can take away from a person.

Each and every day the news reports on car accidents, drinking and driving, obituaries, and the weather. Hardly if ever do individuals with Self-Injurious-Behavior- biting, pinching, or scratching oneself, banging body parts against windows, walls, or furniture, and let us not forget crying, whining, or screaming that pairs with these behaviors make the daily news. Understandably the news is not long enough to cover everything, but individuals with Self-Injurious-Behaviors need to be supported rather than judged.

Everyday there are individuals affected by Self-Injurious-Behaviors. These individuals are not the only human beings affected, but siblings, cousins, families, friends, and teachers all join together to build a positive, safe, but even more importantly: a loving environment every person deserves. In my classroom we have great days and we have tough days, but NEVER bad days. Reflecting daily only makes me a better teacher, educator, and positive role model for my kids. Despite getting pinched, grabbed, hit, or bit on our toughest days, I am honored to be a part of my students' lives and their support systems.

At the beginning I expressed that I was not going to start by introducing myself or things about me and I'm not going to do that right now either. What I am going to tell those reading this is, yes, I am a special education teacher. A special education teacher that cares for ALL children as if they were my own, and works to individualize every aspect of every day to meet the needs of my kids. Five days a week, two days on the weekend, and even on school vacations I think about how I can teach better, how I can guide my support staff in teaching better (who mind you are not certified teachers, but teach like they are) to help our kids.

At the very least I ask those reading this to spend a day with individuals affected by Self-Injurious-Behavior whether a child or an adult. I wish you nothing but the best, although the truth hurts. Be ready for a tough 6-8 hour day from Hell, a tougher 24 hours of non-stop Hell, or even the utmost 365 days a year Hell. When finished spending one day with someone else's pride and joy, stop and ask yourself ?What if my family and friends were affected by Self-Injurious-Behavior??

After all, research offers information, but research is not everything. The information worth using is a personal story like mine and knowing how it affects me every day and how it is my choice to help individuals crying out for the basic rights of living you and I have ALL the time.

Sincerely,

Caryn E. Porretta

Patricia Holden

April 19, 2018

Hi there, I am 54 yes old. I have had Pernicious Anaemia requiring Vit B 12 Injections (four weekly) for over twenty years. In the last few years I need the injections considerably more than that (fortnightly) to curb the neurological decline that I am experiencing. I had also however been a Vegetarian with a poor Diet when I was younger and knowing what I now know about Vit B 12 deficiency its very likely that I was deficient during my Pregnancies.

I have a 34 year old son with Diagnosis of Autism. My Younger son who is 32 does not wish to go for testing but it is highly likely that he too is on the spectrum.

We all share similarities, now whether that means I have Autism too or they have Vit B 12 Deficiency I don't know. There is so much concern about this now that it is would certainly be worth mentioning it.

I would like you to add this to your collation of information and to your findings.

Best Wishes

Patricia Holden
Oxford, UK