Written Public Comments

IACC Full Committee Meeting

October 23, 2009

List of Written Public Comments

Benedetta Stilwell

July 15, 2009

AUTISM**:** Autism, Autism, Autism - Needs more so much more research. PLEASE, PLEASE. Please do research more on ***immune*** systems and their reactions to ***vaccines***. More research is needed on ***inflammatory responses*** and ***mitochondria problems*** brought on by vaccines. It may open up new wonderful discoveries that will help mankind. Don't miss this opportunity - not -one more year!

Thanks,

Benedetta Stilwell of Mt. Vernon, Kentucky

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

Karen Kaye-Beal

July 20, 2009

Would you kindly ask the moderator of the section of the town hall on Future of Adults Services for Autism at the ASA to make the public aware of our foundation and its new group, the Autism Community Housing and Living Group? See attachment for a description.

Karen Kaye-Beall, Director
Foundation for Autism Support & Training (FAST)
Developing high quality, model community homes and supportive living options for adult consumers with autism Speech, Communication & Reading Center (SCRC)

To improve a person with autism's functional communication abilities and reading skills is to greatly improve their overall quality of life

Center for Autism Support & Training (CAST)
Providing in-home intensive support services, respite care and family training services for families and children with autism up to 21 years of age

[PII redacted]
www.foundationforautismsupportandtraining.org

FOUNDATION FOR AUTISM SUPPORT AND TRAINING

DEVELOPING MODEL COMMUNITY HOMES - SUPPORTED LIVING OPTIONS – EMPLOYMENT &

RECREATIONAL DAY PROGRAMS

The Community Housing and Living Group

Shifting the balance from limitation to safe and sound choices for supported independence

Foundation for Autism Support and Training (FAST) creates replicable Community Housing Models for adults on "all parts" of the Autism Spectrum

The Maryland-based Foundation for Autism Support and Training (FAST) has developed a comprehensive solution that enables adults with autism spectrum disorders to be as independent as possible, receive loving, appropriate life-long services and live within their communities. Employing best practices in caring for and supporting adults with autism, the FAST Models flexibly combine key aspects of Universal Housing Design with the provision of therapeutic supports that focuses on daily living skills, functional communications, continuing education, ongoing employment development and recreation.

The FAST model approach has resulted from a collaborative effort between Karen Kaye-Beall, George Braddock, John Rowell, Kathryn Weit, Tom Keating and their associates.

FAST CEO Karen Kaye-Beall is the mother of two teens with autism and the Director of the Center for Autism Support and Training, as well as the Speech, Communication and Reading Center, both approved autism service providers with the State of Maryland.

George Braddock, founder of Creative Housing Solutions, is a leading national housing consultant and general contractor, with a 25 year proven track record of pioneering the implementation of person-centered planning principles to more than 1500 projects and homes for people with disabilities. **Publications:** Three books Co-Authored by George Braddock and John Rowell focusing on community housing issues for people with disabilities and their staff:

-*Person Centered Environments*
-*The Bay Area Project, Housing Design Guidelines*
-*Design for Safety*

Kathryn Weit is the Policy and Political Affairs Analyst for the Oregon Council on Developmental Disabilities. She staffs their Policy Committee and Family Issues Committee. Kathryn provides staff support to the Developmental Disabilities Coalition and is the primary liaison to the legislature, state agencies and human services coalitions. She was chosen by Oregon's Governor to sit on his Special Commission on Autism and has an adult son with severe autism.

John Rowell, AIA is an Associate Professor in the Department of Architecture at the University of Oregon, worked closely with Creative Housing Solutions on countless projects and has conducted research in the area of Environments for People with Developmental Disabilities.

Tom Keating, Ph.D is Director of the Eugene Research Institute, in Eugene, Oregon, which focuses on assistive technology research and development with an emphasis on cognitively accessible computing and design of systems for community living support, including creation of the *Picture Planner™* icon-based personal organizer. He is also an Adjunct Research Associate in the Computer and Information Sciences Department of the University of Oregon. Keating's work over the past fifteen years has focused on the role of assistive technology in the lives of students and adults with cognitive and physical disabilities, on human interface design and development of cognitively accessible software for activities of daily living, and on intelligent systems for remote caregiving. His perspective in all of his work is strongly influenced by his role over the past 25 years as primary care provider for his brother James Keating, who has autism.

FAST's Autism Community Housing and Living Models address a national crisis of unprecedented magnitude looming for adults with autism, and their families. An anticipated "perfect storm" is emerging as ill-prepared and under-funded adult services systems in our country confronts the fastest growing developmental disabilities in the United States: Autism Spectrum Disorders (ASD). Now considered an epidemic*, ASD affects an estimated 1.5 million people in the U.S, with 80 percent of whom are under the age of 22.

There are also estimates that the rate of increase in autism is between 10 to 17% a year. As these children become adults, some health policy leaders are increasingly viewing autism an incipient "financial and societal tsunami."

The therapeutic aspect of FAST counters this economic impact. According to a study by the Harvard School of Public Health, the lifetime costs for caring for and treating a person with autism in the United States is $3.2 million and at the least, $35 billion for all people diagnosed with autism in the US.

Although bills have been introduced in Congress to address the need for appropriate community services such as housing, transportation, vocational training and employment opportunities for adults with autism, comprehensive, quality affordable models for the provision of such services continues to lag drastically behind the needs.

In contrast, the FAST Model improves living environments that further the goals of self-determination for all adults with autism through a model that provides an option for private home ownership and yet invites a public/private partnership that can solve the enormous public health challenge. The FAST housing designs incorporates a small number of attractive, light and spacious private living suites which are attached to and surround a central shared living area. The plan incorporates the latest technology for recognized best support practices: assistance in communications; safety and security; effective insulation for sound intrusion; and organizational systems and spaces for storage and convenience. Although other, existing arrangements have been adequate for those adults with autism who are considered to have milder symptoms or are on the higher functioning end of the autism spectrum, the features of this model make it a viable option for more adults across a broader range of the spectrum, those with more severe symptoms who are more likely to remain in the parent's home or in institutions.

FAST's Autism Community Housing and Living Group is now providing consultations to service providers, parents groups, individuals and any stakeholders with interests in these issues.   Always leading from a person-centered orientation, FAST can help in the decision of the most appropriate housing models for any particular group or combination, but fully understanding the specific needs of people with autism and more to the point, adults with more severe requirements on the middle to lower ends of the autism spectrum. FAST provides consultation on choosing the right location for homes within the community; on possible funding options for housing; for home design options; on training provider agencies to know how to work with and support the unique needs of people with autism; on assistive technology that supports safety, communication and independence; and on how to develop employment and recreation options for day programming. FAST also has the proven expertise in developing intentional community models, so if the solution required is to develop homes for consumers with disabilities, support aids and others to live near each other, our team has proven capabilities in creating such intentional communities and villages.

People with autism want what everyone else wants: to live, work, play and communicate with those they care about. FAST's replicable models make that possible for more people with autism.

Contact: 301-260-2777   www.foundationforautismsupportandtraining.org

Mary Barclay

July 22, 2009

The behavior of this agency at its last public meeting was shameful! The IACC members need a reality check. The public autistic community deserves a voice at these meetings. Those parents were there to speak for all of us. When you silence them, you are silencing thousands of families affected by autism.

Unfortunately we are gaining numbers at an astounding rate. Soon there will be too many of us to silence. Hope you’re prepared for that!

Mary Barclay

Eileen Nicole Simon

July 23, 2009

My son will be 47 in September. He is high functioning, and at one point we felt sure he had made a complete recovery from autism. Sadly, he remains dependent. He lives in a locked-alarmed-door group home, from which he escaped 3 times this past year - the last time he was missing for 7 weeks and 2 days.

Looking for him during late March and April, I saw many shelters for the homeless, and non-shelters. He somehow survived with many other homeless men at Logan Airport and South Station in Boston, or in medical waiting rooms at Harvard Medical Area hospitals. Our capitalistic every-man-for-himself system is a disgrace.

One possibility in our capitalistic society might be to require mandatory long-term-care insurance for every child born - the way automobile insurance is required for all drivers. Insurance companies are America's answer to socialism, and insurance actuarial scientists might come up with what is really causing the autism epidemic sooner than scientists funded by NIMH. More at http://www.conradsimon.org/Society.html

I will keep trying to propose this until someone notices or comes up with a better workable idea. I am very frightened, not only for my own son but also for the large numbers of children with autism who will soon be adults.

Eileen Nicole Simon
--
Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

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John Best

July 23, 2009

You have a couple of [derogatory language redacted] who claim to have Asperger's Syndrome but who are really just [derogatory language redacted] addressing this committee that is supposed to be dealing with autism. [PII redacted], [PII redacted] and [PII redacted] are young [offensive language redacted] who do not have anything wrong with them.

I resent these [offensive language redacted] having anything at all to say to any committee that is supposed to be dealing with this nightmare called autism. Autism is an incapacitating disorder and nobody so affected has the ability to speak for themselves in any manner whatsoever. Ergo, parents of these children must speak for them.

Allowing [offensive language redacted] like [PII redacted] and [PII redacted] to [derogatory language redacted] you with their anti-cure [profanity redacted] does not help any child who is 100% crippled mentally with autism. I suggest you [offensive language redacted] these young [profanity redacted] out of the IACC meetings and never allow them back in. Perhaps you should form a new committee to help [offensive language redacted] who try to prevent brain damaged children from being cured to accommodate these [offensive language redacted].

Thank you,

John Best
Londonderry, NH

The New England Center for Children

July 24, 2009

Hello, I am speaking on behalf of the New England Center for Children, a school for individuals diagnosed with autism. We are proud to be an award winning program that has provided educational services to people with autism for over 30 years and, in that time, we have become very familiar with the challenges facing individuals with autism and their families and caregivers. Because of this, we feel that we are in a unique position to speak to the question, “Where can I turn for services?”

The committee has already noted the overwhelming need for greater access to empirically verified treatment and teaching procedures nationwide. We have two main points that we would urge the committee to consider. The first being that an effective science for teaching individuals diagnosed with autism already exists. Applied Behavior Analysis arose from the application of a rigorous science of human learning and hundreds of scientific studies, published in peer-reviewed journals, have validated applied behavior analysis as an effective method of teaching and treating challenging behavior.

The first sub-question in the Strategic Plan under “Where can I turn for services?” is “What types of services and supports should I seek?” Of the myriad of treatment and educational choices available, the science clearly supports applied behavior analysis. When the IACC indicates that valuable, limited funds for research should be dedicated to one type of service or support, they are taking a risk, hoping that those funds will result in research that improves services available to individuals diagnosed with autism.

Because it is a proven approach, and one in which research aimed at further advancing and improving services continues, we urge the IACC services subcommittee to advocate for the allocation of research funds to support research in applied behavior analysis and, in particular, applied behavior analytic research designed to improve curricula and methods for teaching individuals with autism. Secondly, although effective services exist, they are in extremely short supply. We also urge the Services Subcommittee of the IACC to advocate for research on the dissemination of empirically validated services and the training of service providers.

Dave Hoyda

July 24, 2009

Why do you not require individual states to put federal matching Medicaid funds back into where they are used and not into a state's general fund?

Dave Hoyda
Technical Service Manager
Tate & Lyle Custom Ingredients
800-323-9489 ext 58743

Sommer Slosson

July 28, 2009

Just quit. Stop pretending you know what you're doing and let others who truly care and know what's going on with autism take care of business so our kids will have some help up there. Good grief, you guys make yourselves look [offensive language redacted].

Sommer Slosson
Southlake, TX
Mom of autistic 5-yr-old

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Jean Public

July 29, 2009

1. FIRST I WANT MORE MEMBERS FROM GENERAL AMERICAN SOCIETY TO BE ON THESE COMMITTEES. TO ONLY HAVE THOSE WITH FINANCIAL INTERESTS IN THE INDUSTRY MAKING ALL OF THE DECISIONS, AND HAVING CLOSED MEETINGS TO BOOT SO THAT NOBODY FINDS OUT WHAT THEY DID UNTIL MONTHS OR YEARS LATER, IS NOT A GOOD SYSTEM FOR A DEMOCRACY TO WORK WELL. WE WANT OPEN MEETINGS WITH EVERYTHING DOCUMENTED ON WHO TAKES RESPONSIBILITY FOR WHAT IS DONE. THE AMORPHISM ON WHO SAID WHAT IS FAR TOO DISTANT AND HARD TO FIGURE OUT.

WE NEED MORE STAKEHOLDERS ON THE COMMITEE ASKING MORE QUESTIONS. FOR EXAMPLE, HERE THEY ARE GOING AHEAD WITH CLINCAL TRIALS ON BABIES AND PREGNANT WOMEN AND THEY DON'T KNOW WHERE THE VACCINE IS BEING MADE, DONT KNOW IF ITS ONE OR TWO SHOTS, DONT KNOW HOW THEY WILL KEEP TRACK OF WHO GETS WHAT SHOTS, HAVE NO SYSTEM IN PLACE TO CAPTURE EVERY MALADAPTIVE RESULT FROM THE VACCINES.

THE RUSH TO PROFITS IS EXTREME AND DISASTROUS FOR AMERICA. NJ, FOR EXAMPLE, WITH A POPULATION OF NINE MILLION ONLY HAD 800 CASES OF FLU. THAT IS CERTAINLY NO PANDEMIC AND JUSTIFIES ABSOLUTELY NOTHING FURTHER IN CARE. WHAT IS GOING ON IS PANDEMIC FOR PROFITS WITHIN BIG PHARMA, BIG MEDICINE AND THE HANGERS ON POLITICAL COMMUNITY - ALL TO MAKE HAY WHILE THE SUN SHINES AND MONEY CAN BE MADE. THIS IS NOTHING BUT A TOTALLY CORRUPT SCHEME.

JEAN PUBLIC [PII REDACTED]

Barry Morse

July 30, 2009

Please follow this hypothesis:

Plastic is the cause of the rapid rise in autism.

The human brain works primarily by electrical energy. Plastic is an excellent insulator. Plastics photo-degrade; they get smaller but remain as plastic. During the time of fetal neural development, at the moment that the nerves should make connection, they are blocked from doing so by a piece of plastic. I believe the autistic mind produces the same amount of electrical energy and that energy has fewer areas of diffusion. This is evidenced by the heightening the various senses experienced by the autistic individual. Note the rapid rise in autism in the last twenty years and consider the time it would take for the plastics to infiltrate our ecosystem or the direct ingestion of photo-degraded liquid by pregnant women.

I am aware of how much is said about the effects of plastic but I have never heard of it in the above context; that the plastic itself is acting as insulating particles in the electrically based environment of a developing fetus's brain resulting in neural dysfunction…as if there was a small piece of plastic blocking the neurons from connecting.

The easiest way to see this is to take a plastic bottle of drinking water and freeze it. Let it thaw and sit. Turn it upside down, turn it into the light and see the shiny plastic particles descend in the water that you are about to drink.

I believe that this hypothesis bears investigate on.

Thank you for your consideration.

Bob Moffitt

July 30, 2009

I am the proud grandfather of a lovable nine year old, nonverbal boy, who regressed and was diagnosed autistic just prior to three years of age. In the six plus years since our little guy has regressed, our nation's most prestigious public health agencies have acknowledged they are certain of just two things:

#1 They do not know what "causes" autism

but

#2 They know it is not vaccines

I would respectfully suggest the highest priority be given to what is "causing" thousands of families to suffer the agony of having a child diagnosed with autism. Obviously, "something" has caused autism to explode from 1 in 10,000 two decades ago...to...1 in 150 today. Whatever that "something" is extends from Maine to California, North Dakota to Texas....which all but eliminates local air, food and water supplies. Indeed, the only thing this widely dispersed generation of children share is our universal childhood vaccine policies. And, it is fairly certain that "genetics" is not the major contributing "cause" of this epidemic.

Therefore, I will never understand why public health officials have not supported pending federal legislation that seeks to fund an independent, scientific study of "vaccinated vs. unvaccinated" populations, to ascertain, once and for all, if BOTH populations have suffered the same dramatic, inexplicable increase in autism. Not only do they refuse to support this legislation....the IACC has been determined to avoid ANY independent investigation of vaccines. Every study the IACC and other prestigious public health agencies rely upon was funded by...or...done by someone who manufacturers, patents, endorses, promotes, administers, defends in a court of law, and/or profits from vaccines.

It is also time that toxicological research is conducted to ascertain the "safety" of the various known toxins and other suspect ingredients in vaccines...and....to determine how these various substances interact when administered in 6-7-8 vaccines given a child in a single visit to his pediatrician.

Respectfully

BOB MOFFITT
SLOATSBURG, NEW YORK

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Todd Gastaldo

July 30, 2009

THREE POSSIBLE AUTISM FACTORS: OBVIOUS BIRTH CRIMES

1. Mass temporary baby asphyxiation followed by mass permanent amputation of up to 50% of baby blood volume (medical euphemism "immediate cord clamping")...

The massive OBGYN crime - committed in most c-section births and most "cord blood banking" births - may be causing MANY cases of autism, according to retired OBGYN George Malcolm Morley. See Dr. Morley's website at www.cordclamp.com.

2. Mass closure of the birth canal up to 30% (most births) followed by mass KEEPING the birth canal closed up to 30% when babies get stuck and forceps/vacuums are used to pull (1 in 10 births).

It has been known since last century that semi sitting and dorsal delivery positions close the birth canal up to 30%.

For the simple biomechanics and radiologic and clinical references from the medical literature - see Gastaldo TD. Letter. BIRTH. 1992:19(4):230-1. http://www.blackwell-synergy.com/toc/bir/19/4, FREE ACCESS.

(Sometimes OBGYNs pull so hard they rip spinal nerves out of tiny spinal cords. OBGYNs indirectly ADMIT ON VIDEO that they are routinely closing birth canals up to 30%. The American College of Obstetricians and Gynecologists/ACOG's shoulder dystocia training video, ruled exempt from the hearsay rule in Costantino v. Herzog, purports to demonstrate how to allow the birth canal to open maximally in the small number of cases when babies' shoulders get stuck - which is the indirect admission that OBGYNs know they are routinely closing birth canals up to 30%.)

3. Mass NO MEDICAL INDICATION infant [offensive language redacted] (medical euphemism "routine infant circumcision) - still American medicine's most frequent surgical behavior toward MALES. (Autism reportedly has a male-female ratio of 4:1, according to Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention (F-15), 4770 Buford Hwy NE, Atlanta, GA 30341, USA. [PII redacted]. JAMA. 2003 Jan 1;289(1):49-55.)

American MDs still stand to go to prison for their ongoing massive infant [offensive language redacted] - for ignoring their own Scientific Board to [offensive language redacted].

When confronted with their [derogatory language redacted] neurology, members of the House of Delegates of America's largest state medical association ignored their own Scientific Board and resurrected a resolution which their own Scientific Board had squashed - thereby suddenly declaring newborn circumcision "an effective public health measure" "confirmed" (in Africa) to prevent transmission of HIV/AIDS.

It was an obvious hoax.

In recent years, American taxpayers (via NIH) were forced to fund the "scientific" [offensive language redacted] in [offensive language redacted] attempt to prove the obvious hoax.

BILLIONS are being spent (via PEPFAR) in part to promote [offensive language redacted] in accord with the obvious hoax.

See Prof. Duesberg and [offensive language redacted] - and geopolitical reasons for OBGYN crime
http://health.groups.yahoo.com/group/chiro-list/message/3838

MD fear of imprisonment is a powerful source of bias which should be mentioned every time the American-taxpayer-funded "scientific" [offensive language redacted] research is mentioned - and every time people discuss Microsoft mogul Bill Gates' recent $50 million donation for the [offensive language redacted]...

A RELIGIOUS EXEMPTION FROM THE CHILD ABUSE STATUTES

I am still in favor of a religious exemption from the child abuse statutes for the ancient Jewish ritual that leaves most of the foreskin on the penis. (Most ritual circumcisers in America - OBGYNs and mohelim - are TOTAL [offensive language redacted] who ignore the fact that the Jewish God originally reportedly commanded leaving most of the foreskin on the penis. See again: Prof. Duesberg and [offensive language redacted] - and geopolitical reasons for OBGYN crime
http://health.groups.yahoo.com/group/chiro-list/message/3838

NOTE: Back in 1988, soon after I petitioned Congress for a religious exemption from the child abuse laws for the ancient Jewish ritual that leaves most of the foreskin on the penis, American MDs came out against ALL religious exemptions (Jan. 1988 Pediatrics) and in favor of [derogatory language redacted] (Feb. 1988 Pediatrics) - immediately after which (March 1988) came the obvious hoax that it had been "confirmed" in Africa that circumcision prevents transmission of HIV/AIDS (see above).

[Offensive language redacted] are STILL being [offensive language redacted] because American MDs do not wish to go to prison.

I've notified the US District Court for the District of Oregon
(Magistrate Judge Dennis Hubel) that US Attorney Karin J. Immergut and her Assistant US Attorney Bob Nesler are failing to prosecute obvious medical and chiropractic crimes promoted by the United States of America.

See United States of America v. Todd D. Gastaldo
CIVIL NO. 09-310-HU
MOTION TO DISMISS
ALSO: URGENT: REPORT OF SUSPECTED MASS CHILD ABUSE BY OBGYNs^^^

^^^Filed May 26, 2009

Note: US Attorney Karin J. Immergut was just appointed to be a circuit court judge. The Acting US Attorney is Kent Robinson. I will cc them all (yet again) via: [PII redacted]

For my MOTION TO DISMISS...
See An [offensive language redacted]...

http://health.groups.yahoo.com/group/chiro-list/message/3592

^^^The US Attorney is suing me on behalf of the United States of America for payment of an ALREADY PAID chiropractic student loan and doesn't believe that I already paid it back - so I am attempting to avoid the contract (on this ALREADY PAID student loan) by noting Plaintiff United States of America's radiation fraud in the inducement of chiropractic student loans and the fact that Plaintiff USA is in the HABIT of promoting crimes by failing to prosecute them. For the text of my Motion to Dismiss, see the URL above.

Please help stop all the OBGYN crimes regardless whether they are causing any cases of autism.

Thanks.

Sincerely,
Todd

Dr. Gastaldo
Hillsboro, Oregon
USA
[PII redacted]

This post will be archived for global access at http://health.groups.yahoo.com/group/chiro-list/

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Philip Gluyas

July 31, 2009

I have discovered that you will be receiving a contribution to your annual call for information from Mr [PII redacted] of California.

For the sake of accurate and unbiased information about the whole Autistic Spectrum, I implore you to [offensive language redacted]. He is a serious threat to the understanding of the Autistic Spectrum and he has tried to undermine the contributions already made by [PII redacted] and [PII redacted]. He has been taught to universally hate Autism and is unable to look past this. He needs psychotherapy urgently and is incapable of making a useful contribution to your committee. He is a self-confessed [offensive language redacted] to the Autistic Community and rejects the concept of neurodiversity utterly.

[PII redacted] is capable of getting a job. He has no medical notes that prevent this, and he should be focused on that if I may say so. But he has given up without a good reason to do so because of the sheer hatred he has for the Autistic Spectrum.

Kind regards,
PHILIP GLUYAS
[PII redacted]

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Jerry Baugh

August 4, 2009

I received an email requesting comments on the Strategic Plan for Combating Autism.

Although my wife and I are not familiar with the Strategic Plan and the PL on Autism, we are stakeholders because both of our sons (age 33 and 26) suffered significant intellectual losses, particular expressive and receptive verbal skills, between 1 and 2 years of age. Both have mental retardation.

Our older son has a 1 1/2 to 2 1/2 year old mentality with mild, hypotonic cerebral palsy and volatile temper tantrums with cursing and throwing things, and with adult-onset grand mal epilepsy (well controlled by Depakote).

Our younger son was - like his brother - slow to sit up and had hypotonic CP but seemed normal and even quite advanced intellectually (my wife once exclaimed "He's going to be a genius!") until he hit a stone wall at about 14 months and literally lost all expressive and receptive verbal skills - only to slowly relearn them over the next few years. So striking were [PII redacted]'s losses, my wife and I took him to our pediatrician thinking he had suffered a stroke; but her simple, physical exam showed no signs of a cerebral vascular accident, and EEGs and CT scans were normal. Our younger son has an 8 to 10 year old mental maturity and the emotional maturity of a 12 to 15 year old with a short fuse/hot temper under some conditions. Unlike his older brother, he is not epileptic.

In the course of genetic counseling, we learned that my sons and I have a rare, perhaps unique, balanced chromosomal translocation involving the centromere of Chromsome 7 and Chromosome 15.

Pediatricians and genetic counselors were extremely skeptical upon hearing our tale of early intellectual and language losses - one virtually called us liars to our faces at a hospital in Omaha - and I wrote letters to Editors of medical journals for Geneticists in this country and Canada asking if (1) there were other cases with a chromosomal translocation like the one my sons and I share and (2) if there were other cases of profound language and intellectual losses between 1 & 2 years of age with slow regaining of those skills.

We understand that research at the University of Washington later proved that parents were correct and those in the medical profession who discounted their stories were wrong. There is a condition resulting in significant losses at an early age, just like our sons, and they gave it a name: Regressive Type Autism.

The chromosomal translocation my sons and I have is: t(7:15)(p11.2;p11.2). I am unaware of another translocation exactly like it in medical literature or genetic databases such as the one at Delaware. I had arranged for our cell lines to be preserved for future research at the Corriell Labs in New Jersey and at the European lab in Salisbury, England. Our case has been studied in recent years at Boston Children's Hospital/Harvard Medical School and currently (since Sept 2003) at the Hospital for Sick Children genetic lab in Toronto. They have found no difference in genetic structure between my cell lines and those of my son that would account for their disabilities and explain why I am unaffected. There has been no final report.

In an email to a division of NIH a few months ago, I suggested that researchers on the Regressive Autism Team contact [PII redacted] at "Sick Kids" in Toronto to include our case in their new research under the Autism strategic plan. I heard nothing from new researchers nor the people in Toronto indicating that our case was considered.

Please reiterate our offer to scientists to include our case among Regressive Autism cases being studied under your initiatives. We will be glad to cooperate.

Thank you.

Jerry Baugh

Lincoln, Nebraska

Anonymous

August 4, 2009

Wanted to submit request towards "*under-represented areas and new opportunities needed for advancing research and knowledge about ASD"*. Don't know if this is part of the program tomorrow, so I send them for whomever and whenever you deem appropriate.

Endocrinology: thyroid particularly. Should we be monitoring pregnant, newborns and toddlers more closely (frequently). Which tests and which parameters?

Enzymes: should we expand the good work of "March of Dimes" -- (eg biotinidase deficiency when detected early can be helped : frequent infections, hearing loss, MR and even death, etc.) -- understand and follow enzymatic differences and their potential consequences

GI: a Mayo study recently claimed GI not a significant autism issue. Many experts think otherwise. How was the study design, might it be done differently to yield additional and perhaps different information?

Nutrition: Vitamin D and a link to immunity. Should we be monitoring and supporting here more thoroughly? Is there an increased deficiency and if so, why is this happening?

Thks,

"Anonymous"
(request anonymity)

Juanita V. Williams

August 19, 2009

Concerned about nonverbal individuals not being heard or able to participate!

Pasquale Miranda

August 19, 2009

I am the parent of a non-verbal autistic boy. He is 14 years of age and is currently using a communication device to help communicate his needs. It is my understanding that no research money is going towards this significant portion of the autism community. Fifty percent of the autism population's needs are not being addressed. It is this very same group that is in need of the most help. I do not mean to downgrade the needs of verbal and hi-functioning autistic individuals, but I know their own parents would agree that they feel blessed their children are able to at the very least to communicate how they feel, what hurts, what they need and desire. Please do not ignore the significant needs of our non-verbal and low-communicating children. They do have so much to offer as seen by their many accomplishments. The NIMH should realize that helping this group of kids can contribute significantly to their well-being, their families and ... to society as a whole. My 14 old boy is showing so much potential to perform many vocational tasks. I believe he will, one day be a contributing member of society. He will always need human and communicative support however. His potential is apparent but he greatly needs significant support. To be honest, I am very surprised that this portion of the autism community is not being researched. I just assumed that all my family's work and contributions were going towards children that had the same difficulties as my son. It angers me that only a portion are being dealt with. Where is our hope supposed to lie? We already know that a high percentage of progress is made when parents contribute significantly and complement what is being done is school programs. We are those parents. I also know that ABA is not the complete answer to my son's difficulties. It has helped, but so much more needs to be done. Research, training, physical and psychological testing and treatment, sibling and family interventions, community services to integrate those with special needs, awareness training, etc. Please hear our voices, because you won't hear our children's as long as treatment remains as currently being delivered. Thank you very much.

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Amanda V. Porter

August 19, 2009

My youngest grandchild, now seven, was found to be autistic a year or so after his birth although his mother was very particular about her diet and circumstances. He is still adorable, like my normal grandchildren, but very difficult for me to bond with, much as I would like to. I feel that it is utterly deplorable that this condition seems to be spreading to many families and yet there has not been adequate research to determine why or how. FURTHER RESEARCH IS ESSENTIAL! Whatever is causing this aberration needs to be discovered and addressed as soon as possible!

Amanda V. Porter,
[PII redacted]

Thomas Milner

August 19, 2009

My 13 year old autistic son is non-verbal. He has no other medical conditions (co-morbidities). He seems to have a neurologic disorder rather than a behavioral.

My limited experience with other autistic children tells me that most are verbal and show tremendous variability compared to each other. This seems not to be the case with non-verbal autistics, i.e. they are comparatively homogeneous. As such they lend themselves much more to medical research than the verbal cohort.

In addition to being non-verbal, my son also has limited non-verbal communication abilities. This strongly suggests low intelligence; however, I suspect that his neurologic disorder is inhibiting his ability to communicate, and that his intelligence is normal. Parents know best!

Anne Dachel

August 20, 2009

Since today is the final day for comment on the actions of the IACC, I'm sending several of the recent articles from Age of Autism, the daily web newspaper of the autism epidemic. These reports contain lots of comments from readers on the IACC. The role of Thomas Insel is a major focus in these stories and in the comments that follow. It seems that the IACC has demonstrated little leadership in addressing the autism emergency and will only continue to lose credibility.

ANNE DACHEL
AGE OF AUTISM: MEDIA

AUG 20 When Vaccine Development is Family Business: Thomas Insel's Conflicted Role on Vaccines and Autism
By Dan Olmsted and Mark Blaxill
(http://www.ageofautism.com/2009/08/when-vaccine-development-is-family-business-thomas-insels-conflicted-role-on-vaccines-and-autism.html#more)

AUG 14 The Really Big Lie About Autism: Thomas Insel Testifies
By Anne Dachel
(http://www.ageofautism.com/2009/08/the-really-big-lie-about-autism-thomas-insel-testifies.html)

AUG 13 Katie Wright on IACC: "Can You Hear Me Now?"
By Katie Wright

AUG 7 AGE OF AUTISM: Senator Harkin Takes On Tom Insel at Autism ...
By Katie Wright
(http://www.ageofautism.com/2009/08/senator-harkin-takes-on-tom-insel-at-autism-meeting.html (IACC Note: URL is not valid.))

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

Julie Cook

August 20, 2009

I am a parent of an 11 year old girl with autism and I am very concerned about the staffing of and the lack of progress made by this committee since the passage of the Combating Autism Act in 2006. I watched Dr. Insel speaking to the appropriations committee under Sen. Harkin and it was very obvious that despite the fact that no one knows what environmental trigger is causing autism (and we all agree there is at least one) – that he will NOT pursue any research that may implicate vaccines. As long as the committee is made up of and lead by people with at least the appearance of conflicts (ie. Insel's brother's activities surrounding the development of at least one vaccine that made it into the vaccine schedule), I am convinced that no meaningful progress will be made. If highly respected physicians such as [PII redacted] and [PII redacted] are calling for specific research to be done why are they not being listened to? Isn't it at least worth the effort to restore the public trust in the vaccine schedule – because right now it is severely compromised and that is not good for public health?

With the passage of this act, Congress mandated that parents of children with autism would have a voice in these issues. Sadly, that has not happened and consequently three years later I am sitting here with a daughter who is still severely affected with autism and not ONE thing has changed. No new funding (public or private -insurance) has opened up for her treatment nor has any meaningful research been conducted that will help her with her chronic debilitating GI pain, her failure to gain weight and absorb nutrients, her ability to sleep through the night, her off the chart inflammation markers and compromised immune system, her extreme self-injurious behavior, etc. etc. etc. As long as the bulk of the research dollars is going to research such as eye gaze studies and autism father's mate's body type preferences, and single genetic markers we will never get any closer to conducting meaningful research which recognizes that autism is a medical disease that effects whole body systems and not just a "mysterious behavior disorder" that needs to be dealt with by psychiatrists with psychotropic drugs. The only people who are happy with the progress made to date are people like Insel's brother and the thousands of researchers who get to keep getting the grants to conduct "safe, worthless research" that will ensure that autism remains a mysteries behavioral disorder for another 50 years and won't do a [offensive language redacted] to help my daughter.

In order to comply with the letter and the spirit of the CAA I urge you to have a better balance of people on the committee and not be afraid to follow the science and conduct meaningful research that is the only way that we can figure out what is actually causing this epidemic and more importantly how to EFFECTIVELY treat it.

Respectfully,
Julie A. Cook

Pat Mia

August 20, 2009

It has come to my attention that Mr.Thomas R. Insel whom serves the public in directing public funds toward Autism research has conflict of interest due to blood relation to an inventor of a vaccine that no less contains mercury.

Until this road block is removed and this man is properly reprimanded I see no reason for further comment. Please also properly reprimand all others responsible (who or what group appointed this man without properly checking his background?).

Thank You,
Parent to 2 fully vaccinated children

Tony & Lily

August 20, 2009

Thanks you to help the autism child!!!

We are the guardians, most hoped that you study, why the autism child will not speak??? They have the spoken language apraxia???

Thanks!!!!!!

Tony & Lily

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

Imran Riaz

August 21, 2009

Good morning. My name is Imran Riaz. I am a clinical psychologist living in Washington DC who works with children with learning disorders. I am writing you to urge you to include nonverbal autistic children in the IACC strategic planning. This is a subpopulation of autistic children who have too long been un-included in important autistic research.

Thank you for your time.

Sincerely,

Imran Riaz
[PII redacted]

Barry Morse

August 24, 2009

Please follow this hypothesis:

Plastic is the cause of the rapid rise in autism.

The human brain works primarily by electrical energy. Plastic is an excellent insulator. Plastics photo-degrade; they get smaller but remain as plastic. During the time of fetal neural development, at the moment that the nerves should make connection, they are blocked from doing so by a piece of plastic. I believe the autistic mind produces the same amount of electrical energy and that energy has fewer areas of diffusion. This is evidenced by the heightening the various senses experienced by the autistic individual. Note the rapid rise in autism in the last twenty years and consider the time it would take for the plastics to infiltrate our ecosystem or the direct ingestion of photo-degraded liquid by pregnant women.

I am aware of how much is said about the effects of plastic but I have never heard of it in the above context; that the plastic itself is acting as insulating particles in the electrically based environment of a developing fetus's brain resulting in neural dysfunction…as if there was a small piece of plastic blocking the neurons from connecting.

The easiest way to see this is to take a plastic bottle of drinking water and freeze it. Let it thaw and sit. Turn it upside down, turn it into the light and see the shiny plastic particles descend in the water that you are about to drink.

I believe that this hypothesis bears investigation.

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

Daniel Pech

August 24, 2009

I have read, and understand, that 'comments received by the IACC are public documents.' Amen to *that. I **need** what I say to be public*, because otherwise what I say remains too much in the dark. The freer anyone is to access what I say, the better for me and those like me. So, here's just what I can manage today, in my one-hour-per-patron-public-library-online-alottment:

First, two items:

ONE
According to Bhattacharjee,Judhijit. "Friendly faces and unusual minds." Science. 310.5749 (Nov 4, 2005): 802(3), a rare few individuals with Williams-Beuren syndrome show normal intelligence.

TWO
According to Stojanovik, Vesna. "The co-occurrence of autism and Williams syndrome: a case study report. " The Journal of Speech-Language Pathology and Applied Behavior Analysis. 1.4 (Winter 2006): 46(9), there is an individual with both Williams-Beuren syndrome and autism.
Until yesterday, when I found these two items, I felt I was alone in my belief that I possess, or suffer from, all three of the above factors, namely, Williams-Beuren syndrome, a normal ("enough") intelligence, and autism. In 2004 I became homeless because of an intense and lifelong complex of misunderstanding about me on the part of my mom, my dad, and their [offensive language redacted] pastor. *Especially* because of their pastor, because it was he who recommended the action, on the part of my widowed mother, to refuse to take me back into her residence after I was admitted to Adventist Medical Center Psychiatric Ward. Oddly enough, and both surprising and relieving to me, the moment I was admitted, I found I was treated by humans (namely the staff) with consideration and kindness for the first[profanity redacted] time in my life! Unfortunately, I was discharged onto the street five days later, since I was found to be of sound mind. Gee, I wonder why I was of sound mind in there. I am a two-year-old in an adult body, and am constantly distressed and frustrated that I am treated so badly and indifferently. I was forced by my homeless distresses to wonder at my life, and about why in [offensive language redacted] it had come to this. I had had the good fortune, during the previous two decades, to be effectively alone and isolated for most weekends, and for most of my off-work hours, and thus by no design of my own had begun to so piece together the bits of my life which I had lived in others' effective presence that I had a solid foundation of self-knowledge, by way of writing, including that done into so very many early hours of the morning, from which to think once I was essentially thrown in the dumpster by direction of a [offensive language redacted] who was convinced that he had unerringly filled out, from the start, the Sudoku puzzle called [PII redacted]. I was assumed, basically, to be a socio-economic superman, and well able to take care of myself in the world, and included in that assumption was that the reason for my 'success' as a 'budding' said superman was because I had done to myself what they all believed can only be done if one is to succeed in life: force your intellect, body, and soul, into the 'shape' of [offensive language redacted] by treating these as if they were pack animals, worthy of no better consideration than how the most brutish Marine recruit is treated (and thought of) by the Drill Instructor during Basic Training. So, that 'pastor'[offensive language redacted], in very practical ways, every time I happened to fail to meet the fictional notion of me which he was *certain was* me. So, in the end, with a healthy problem blown way out of line by a harassing employer, I

not only had to stop working, but I had to get beat up psychologically by my mom for my failure to be what she was certain I COULD be IF ONLY I WERE AS WILLING AS SHE HAD ASSUMED I HAD BEEN FOR BECOMING the SUPERBOY that I HAD NO IDEA I WAS TO ANYONE UNTIL I HAD BEEN FORCED BY MY BOWELS TO FIND A PYSCHOLOGICALLY STRONG ENOUGH EXCUSE TO STOP ATTENDING-UNDER-PRESSURE THAT [offensive language redacted] CHURCH. It was the church that [PII redacted] had pastored right before [PII redacted] went into politics, and the man who took over as pastor made the future-morally-failed [PII redacted] look better than [offensive language redacted].

In the Introduction to ***Neural Basis of Self and Other Representation in Autism: An fMRI Study of Self-Face Recognition***, the authors write:

"It has been suggested that the core symptoms of autism may result from a lack of the fundamental appreciation of the commonality between self and others"

As an autistic individual, I think this is true. But, I think it may not be true in quite the simple way that its words suggest. My own attempts to articulate the nature of my own condition (so as to get help in life as a homeless adult with pdd-nos) run up against the same problem: the disparity---or ambiguous connection---between the facts on the one hand, and the language used to denote it on the other hand. Consider the following.

Imagine the U.S. Space Program unexpectedly finds outer space suddenly monopolized by a race of extremely friendly star-hopping aliens. And, imagine that these aliens, despite their awesome technological knowledge and power, consistently fail to see just how comparatively flimsy are our own spacecraft. The damage we would suffer from their friendliness would make us head back to Earth and stay there. This is autism. At least in many cases. At least in my case. With one exception.
As I hope is seen in this analogy, autism is may not be so much the disability as the 'place' of escape; the world of refuge. I like to think of autism as the heightened senses of blind persons: a neuro-plastic compensation for an underlying disability. Specifically, I like to think of it as a compensation of a type allowing a cognitive escape from the external context by which the disability manifests. In other words, that autism is a specific type of neurological response to a 'vacancy' in the ecology of the brain; a type which creates a whole inner world out of what is left intact in neurological function. Nature abhors a vacuum---or, in the words of a character in the Jurassic Park movies, 'Life finds a way.'

More specifically, my theory is that the disability which I imagine in every case underlies the behavior called 'autism' is a feebled dynamic autonomy. This would be why autistic persons have difficulty facing the normal dynamic stressors that the normal people take for granted. My own experience, at least, is well described in these terms. These stressors are what normal persons know as the substance of living; what stimulates growth and maturation, and what comprises the 'good stuff' of life itself. But, a person with a feebled dynamic autonomy lacks a well-formed, strong, dynamic sense of themselves as sensorily and socially independent from their environment. Many of them are unable to see themselves as differentiated persons in a socially neurotypical context. At least, I speak for myself here. Worse, it is why they (or at least me) must avoid social contact on a normal person's terms. In short, they are unable to negotiate with the too-powerful aliens in the analogy above. It is also why the [PII redacted] test does not, in fact, directly test for the autistic person's ability to know of, and about, other minds, and other, independent points of view: the test is conducted by these [offensive language redacted], and there is often too much damage involved for the autistic person to make him willing to play along with the test. Besides, it takes no great energy for him to simply rocket back toward Earth and then let gravity pull him the rest of the way home.

But, now, here's the exception in my case. Imagine there were no Earth to head back to. The means of escape from the context by which the disability arises has vanished, yet the disability remains. The autism has vanished, but the disability remains. In other words, I have very little autism, but I'm being killed through the underlying disability.

While the incidence of autism is reportedly rather higher among boys than girls, the incidence of the underlying disability may not be so disparate between genders. I could not help but notice that many 'normal' women (and some men) have a hard time genuinely believing that they have a right to have their own needs; they're psychologically so focused on the needs, wishes, and opinions of others, that they are usually at other's mercy even regarding other's opinions about themselves.

Many autistic persons face a similar problem: the inability to stand up as their own persons under the pressure of the personal social autonomy of normal persons. Just like the U.S. Space Program in face of the genuinely friendly aliens, they cannot cope on a level which normal people take for granted. Many autistic persons may in fact be unable to afford to admit to [derogatory language redacted] that they recognize themselves as differentiated persons. Because if they did, then these [derogatory language redacted] would take too much for granted that being friendly will basically solve the problem.

While we want to reach the stars, there may be unexpected problems along the way that require us to act primarily in self-preservation, regardless of what those who already live out there may expect from us. In fact, when those star-people were born, just like us, they were very much awake, yet they do not remember it. They do not remember being born.

I myself have a very mild case of autism---at least in regard to most things. But, I believe I have the underlying disability in spades. In fact, I'm now very ill, and very homeless, for it. The neuro-plastic compensation in my case seems to be...

...Firstly, a hyper-focus on the feelings and opinions of others (similar to Williams Syndrome), including their feelings/thoughts about/for/against me. My entire sense of reality is forcefully, even violently, changed every two seconds when I find myself in an ordinary conversation, or even when simply as an anonymous bystander in the midst other people's conversations.
...Secondly, a creative intelligence so 'high' that it seems to me able to take up the slack wherever my nearly absent conventional knowledge acquisition-and-retention fails.

All-in-all, I often appear not disabled at all when in social contact with more-or-less socially aggressive persons, especially if I have enough nutritional support despite my severe digestive problems so that I can function well enough socio-cognitively to at least force myself to respond as a normal person. The stellar language ability of Williams people masks their severe general IQ deficit, and all my own abilities masks my severe disability. I cannot be my own person in the face of others, and, given my current state, requires something which I cannot obtain: completely isolation from other people. The more distress I experience from the presence of others, the less able I am to find rest in observing non-human life forms, even to the point where I must look away from wild birds, and even bugs. I was the last to know that I was thought of as a budding socio-economic superboy. Only when I was forced by my bowels to seek isolation (despite my wish to continue to comply with other's wishes that I keep company with them) for years did it begin to occur to me, because while in their company I was simply trying to stay both alive and sane at the same time. Their militarism didn't help, either.

Please help me! I'm homeless. To me, the world is a world of [derogatory language redacted]. Everything controls me, limits me to what I cannot cope with, holds me in paralysis. I cannot function. People are everywhere, and I have no way to be alone, in a place to myself, with a bathroom to myself (and I need a bathroom over twenty times a day, often for a half hour or more at a time, which is impossible for public bathrooms since I would get harrassed. I'm getting dehydrated, constantly hungry, no place to BE. WHAT DO PEOPLE EAT? WHAT DO HUMAN BEINGS EAT? People, their very presence, and the socio-economic disparity between them and me, and I have nowhere to get cleaned up. They do nothing for me that lasts, nothing that makes any difference in the long run. I got a new pair of socks the other day and felt liberated when I put them on, as if I belonged.

When I'm in the midst of a public calamity, such as a natural disaster that displaces people, I feel very liberated, contrary to how everyone else feels, only to find that they think I'm even more of a superhuman who can take care of himself in the world, which is just wrong. In the calamity, ordinary people treat me as a co-victim, and they go out of their ordinary way to show that I belong amongst them, as one of them, and that I am allowed to take care of a few of my needs without being harrassed. But they're all [derogatory language redacted] otherwise: unapproachable, and having an untouchable Mount Olympus to which they go to get away from the demands of the world. A home. ***A stable and comfortable base from which to function as their own persons in the world***, and to improve their lives---never the lives of others like me, no matter how well I comply with their damned wishes. I was the very last person in the world to know that I was thought so 'highly' of. All I was doing was working out of a sense of panic, and then taking as much advantage of my ability to attain an 'endorphine high' as my health would permit for the day. I didn't know about endorphines, I was just trying to stay both alive and sane at the same time (a losing juggling act).

I have PDD-NOS. But, if normal people see me as 'normal enough' from the outside, then I'm [offensive language redacted]. Even worse, if they see me as some kind of all-purpose superman. They're all then like kryptonite, and of a kind that increases its potency with time-and-contact because of their selfish assumptions about me. Assumptions about me based on my behaviors, and then they judge me based on my reactions to their actions toward me which they have which are based on their assumptions. Greedy, selfish, pushy assumptions. They get the first few Sudoku spaces wrong, and then, because it still can be filled out most of the way with internal consistency, they get the [profanity redacted] puzzle filled out wrong while being so sure it is right. So I'm [offensive language redacted]. Then the problem hits the wall of explosive frustration on my part when they think that the reason the 'Puzzle of Daniel' cannot be completely filled in is because Daniel is [offensive language redacted], a mental case, a rebel, doing drugs, or all of these. Like they think that their own little program for opening documents is THE ONLY PROGRAM for creating documents, so that when they go to open 'Document Daniel' or some other person, and the document displays partly or totally jumbled and nonsensical, they take for granted that the document itself is what is screwed up, because they assume it is being displayed properly for what it is.

Kimm

August 25, 2009

Subject: shocking self-injurious behavior captured on youtube shows need for in home supports

Self-injurious meltdowns...the NOT so common face of autism.....you won’t see this in autism documentaries......
Warning: behavior is disturbing to watch......
www.youtube.com/watch?v=JsJ154jWRsU
Youtube: autism and self-injurious behavior

This family is constantly struggling with San Diego Regional Center to secure nursing care support, as if they don't already have enough of a fight just trying to protect their autistic son. They want him to stay home. He was just pulled from an icf ddh, because the group home staff left him behind a door to beat himself so badly, he suffered a hematoma. Truly, a rare glimpse of the cases that WARRANT help. (he often requires 2:1) Yes, there are families out there who DON'T need much help, as their autistic children aren't that severe, or aren't even really autistic, but LOOK at this video, this is HARDCORE autism, this is WHY government programs for autism were created. This family really loves their child. They have radically improved his health since he was presented to them in such bad shape after out of home placement. Now, they are doing everything they can to keep him home and need in home support, as you can see, not just one person or family can handle this child. He is a 24/7 job. This is REALITY you don't see about autism. This child happens to be a descendant of the Konkow Maidu Tribe of California.....a yet unrecognized tribe.

Kerry Lane

August 31, 2009

Subject: Tylenol is Autism Trigger

As an attachment I have sent a summary of data submitted at the recent FDA hearing on acetaminophen. Can we get it or new data included somehow?

http://www.regulations.gov/#!documentDetail;D=FDA-2009-N-0138-0005;oldLink=false

Eileen Nicole Simon

September 2, 2009

That hardly sounds worth the time, effort, and expense of travel. Once more, I hope the following questions will be discussed:

(1) Developmental language disorder is the core handicap of children with autism, and the greatest obstacle to progress to a more hopeful long-term outcome. Why isn't this a primary focus of the strategic plan?

(2) What specific systems in the brain are vulnerable to all etiologies associated with autism? These include PKU, prenatal rubella and other infections, prenatal exposure to valproic acid, thalidomide, and alcohol, tuberous sclerosis, neurofibromatosis, fragile-x syndrome, adenylosuccinate lyase defect, mitochondrial disorders, oxygen insufficiency at birth, and more.

I will try to watch the webcast.

Eileen Nicole Simon

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

Jean Public

September 5, 2009

I may not be able to come to this meeting, but think it should be put on computer software program so all in the United States can have a voice in what we all have to say about autism caused by big pharma and big medicine fear mongering in injecting unsafe vaccines and their decidedly unsafe [offensive language redacted].

1. All systems are different. This agency cannot in any way encourage all to get this vaccine when some people in this country have very different systems that cannot take this toxin into their body safely. We are all different. There are as many killed by the vaccine itself as by the disease, so to encourage people and demand that they take these vaccines is horrific. Absolutely horrific.

2. These vaccines are being made in [offensive language redacted]. In that country, they kill their own people through greed. America should not be allowing any drug to be made in [offensive language redacted]. Even in America, we have a lab that almost poisoned millions by sending out a poisoned vaccine. If you intend to use a drug, it should be manufactured where the whole process is open to inspection daily.

3. Big pharma is buying satisfactory approvals for its drugs. We cannot allow this money and greed to continue to mandate what the ordinary American citizen takes or does not take. Big money and big pharma and big medicine have severely poisoned the American health system. Nobody works for the common man anymore. Money has bought off far too many. This agency has in fact been regulatory captured because of the revolving door, where the employee works for the feds or state, gets mandates in to make big money for big pharma, and then goes to big pharma where they get the big raise. This is going on all of the time.

Certainly those who advocate vaccines NEVER MAKE THEMSELVES OPEN TO INTENSE QUESTIONING. NEVER. THEY HIDE BACK FROM BEING QUESTIONED CONSTANTLY.

THEWHOLE HEALTH SYSTEM OF WHAT IS GOING ON WITH VACCINES MAKES MOST AMERICANS WHO KNOW ABOUT THIS MESS VERY VERY MAD.

JEAN PUBLIC [PII redacted]

Bruce A. Vanicek

September 9, 2009

Please join National Autism Association's "How much longer?" campaign going on right now. Click on the following link to let your voice be heard about our government's refusal to properly address the autism epidemic. Thank you for all your help! Bruce

http://tinyurl.com/nc6v9m
Join the network and send out the action alerts by clicking on each one. It'd be a huge help. We've already had 50,000 emails sent and we are making an impact.

The following is a request issued by Wendy Fournier, president of NAA:
In the past decade, we've asked for government aid, insurance coverage, and meaningful research for our children with autism. We've asked for the abuse in schools to stop, for vaccines to be held to higher safety standards, and for our children to be treated for their medical issues. Most of all, we've asked for autism to be declared a national health crisis.

We've asked for these things politely, impolitely, loudly, softly, creatively, professionally, in small numbers and in large...we've asked and we've asked again. But as it stands today, we have more cases of abuse, wandering-related deaths, seizure-related deaths, bankruptcies and divorce in our community than ever before.

With the fatigue that comes from constant uphill battles, along with a gross lack of resources, we live in a permanent state of asking one question: How Much Longer? How much longer will we continue to see the numbers climb? And our children die? And research funding go to the wrong places? And our children be abused? And health agencies avoid the real issues? Really, how much longer can this crisis continue before we turn a corner? When its 1 in 75 kids? 1 in 50? 1 in 25? Do we really want it to get that point? Tired or not, we have to kick it up a notch.

So our plea to you is this: take two minutes out of your day on 09-09-09 to join our How Much Longer For Autism campaign a mass mailing/faxing/calling campaign done through NAAs easy web-based advocacy software. It costs nothing, and could finally create the awareness we need.
Will you help? Say yes only if you don't mind a little controversy. This campaign isn't warm and fuzzy and its far from polite. Its edgy, sarcastic and harsh at times, but when you live day to day seeing an increasing number of children suffer from vulgar abuse, impossible challenges, even death, you tend to put graceful asks aside for a message that people might actually notice.

Will you help spread awareness? Take a stand for a healthier future? Raise your voice for civil rights and an end to abuse? Then please visit: http://tinyurl.com/nc6v9m and get ready to join us on 09-09-09

Kerry Lane

September 15, 2009

Subject: BATCH ONE

ATTACHMENTS

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Acetaminophen Toxicity

FDA Lane Submission APAP

Glutathione Loss by Gliotoxin

GSH/GSH Redox Pail Anti-Oxidant Defense Slide

Kerry Lane's attachments can be viewed here:
Attachment 1 (PDF – 9 KB) | Attachment 2 (PDF – 1.2 MB)

Kerry Lane

September 15, 2009

Subject: BATCH TWO

ATTACHMENTS

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Kerry Lane

September 15, 2009

Subject: BATCH THREE

ATTACHMENTS

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Kerry Lane

September 15, 2009

Subject: BATCH FOUR

ATTACHMENTS

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Gliotoxin-Glutathione Interections Slide

Gliotoxin – reduced Glio Slide

Kerry Lane's attachments can be viewed here:
Attachment 1 (PDF – 1 MB) | Attachment 2 (PDF – 1 MB)

Kerry Lane

September 15, 2009

Subject: BATCH FIVE

ATTACHMENTS

Gazaryan IG, Krasinskaya IP, Kristal BS, Brown AM. Zinc irreversibly damages major enzymes of energy production and antioxidant defense prior to mitochondrial permeability transition. [Pubmed ID: 17565998]

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Metabolism Methionine – Glutathione Slide

Methionine Metabolism Slide

Kerry Lane's attachments can be viewed here:
Attachment 1 (PDF – 1.3 MB) | Attachment 2 (PDF – 1.5 MB)

Eileen Nicole Simon

September 19, 2009

I was able to listen-in for about half an hour (9:45-10:15) to the conference call on Sep 17. I have the following two comments:

(1) Autism has many causes (inferred from its association with many medical conditions). The final common pathway for all causes must be looked for in the brain. Bio-specimens would be specific to the particular etiology. All must cause impairment in brain systems needed for language development.

(2) Mitochondrial DNA may be far more important than nuclear DNA in looking for genetic defects. Mitochondria are the site of aerobic energy production in all cells of the body. Much evidence has shown that mitochondria likely evolved from a primeval symbiotic infection. Mitochondria are bacteria-like and vulnerable to impairment by antibiotic medications. I have just posted something on my website that summarizes my point of view at http://www.conradsimon.org/mitochondria.html

I hope you can take time to look at this, and something I posted in 2003 at http://www.conradsimon.org/V-BrainstemDamage.html#MolecularSuffocation

I would like to hear some of these ideas discussed.

Sincerely,

Eileen Nicole Simon, PhD (Biochemistry), RN
--
Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

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

Beverly Frost

September 25, 2009

Next to nothing for adults seems to be done. Please consider the plight of adults on the autism spectrum in future meetings and research. I have a very bright, BS degree son who is extremely low functioning and can get no services whatsoever in Vermont. There are no laws or programs or even recommendations to help this type of person. Once you are 22 often you are on your own and left to aging parents to care for you.

Thank you.

Beverly Frost,
[PII redacted]

B. Nicholson

September 26, 2009

Lina, pheromones cause autism epigenetically. See:

BBC-TV interview Discovery Channel: “The Kiss.” 1989

CBC-TV National Film Board of Canada interview; “Slippery Blisses.” 1998

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Eileen Nicole Simon

September 27, 2009

I listened in to part of the second call on Sep 23. I heard the end of the mitochondrial discussion - thanks, this is important. I was also glad to hear that developmental language disorder will be viewed as a priority. I hope at some point to be invited as an IACC participant, both as a parent, and for my research perspective. For now I am posting most of my ideas at
http://www.conradsimon.org/IACC.html

Autism is a huge tragedy for many of us. Please don't stall around with "intriguing" academic projects that aren't aimed at finding the cause of the increase in autism.

Eileen Nicole Simon, PhD, RN
--
Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Eileen Nicole Simon

October 2, 2009

I listened via the workshop call-in line from a little after 3:30 until adjournment. I will post comments soon on heterogenity (and need to seek the "final common pathway" in the brain), and Dr. Insel's comments about data sharing. I most appreciated his comment that someone not involved in obtaining data might still come up with a breakthrough idea based on shared data. A great deal of data published 50 to 150 or 300 years ago remains relevant to understanding the brain impairment in autism.

I watched the webcast yesterday, and was most interested in the comment by Peter Gerhardt that we need more data on inmates in the criminal justice system. I have worked in the MA Department of Corrections for 18 years. Some of my blog postings from nearly 3 years ago might be of interest http://www.inferiorcolliculus.org/milieuresearch.html

Eileen Nicole Simon

Marian D

October 5, 2009

I wanted to clarify some remarks I made at the meeting, and thank the committee for the program and information exchange it encouraged.

Regarding the vaccine issue and clinical management of autism, I suggested that we review two things: protocol and perspective.

Protocol.
Do we *teach* the way we did 50 yrs ago? No. Do we *build* the way we did 50 years ago, etc., etc. No. Programs that we have routinely known over the years have had to adapt to a changed environment. They continue to be necessary events, but the models have had to evolve to reflect a changed and more complex environment.

Question: Is it time to revisit the current vaccine *schedule* (eg move back) and *administration* (combine with innocuous vitamin to bolster immune system)?

(*I do not have a position on the issue; I am recommending areas of consideration and study.)*

Perspective.
We often think of malnutrition as a phenomenon belonging to third world countries, and manifesting in a profound way. Could it not also be mildly present (of autoimmune origin), asymptomatic, yet dramatically influencing biochemical competency?

What happens to metabolic pathways when the proper nutrients aren't there? You get toxic accumulations of substrate and products that never materialize. These and other substances may also have unintended access to organs through barriers that have become permeable. More havoc.

We have research on the effects of "improper" purine metabolism and the great harm that subtle differences here can unleash.

There is research, too, on how with inadequate nutrition genes can mutate and be rendered incapable of battling common environmental pathogens. There may be immunocompromised people out there that we don't recognize.

Areas of Research
Neuroimmunology/immunogenetics. At what point (developmentally, level of endocrine functioning, etc.) is the immune system called in? What is the comparative effect of immune activation at different stages of life and development?
Beyond disease-specific numbers, is there an *immunological fragility* -- an increased incidence or clustering of immunological events among families?

Adults with Autism
Dr Insel mentioned that he did not receive (at this time) much response from parents of *adult* autistics. There may be several reasons for this: it was a long and detailed questionnaire and this subject was at the end; secondly and more importantly -- these families are recovering from years of managing so

much in so many directions and now in addition even the most resilient may have their own declining health, etc. to contend with.

Thank you,

Marian Dar

Mary Weber

October 7, 2009

I read a lot and several years ago I read a report that soy can inhibit the development of the nervous system in children. That made me look at baby formulas and all but 2 or 3 had soy. I know the normal benefits of soy in many cultures for adults. The big difference is that Asian countries ferment soy and America companies refine it or process it differently, and Asians are more likely to breast feed.

When I thought back about the extravagant use of soy for its cheap protein value and when Autism started showing up so often, it seemed there might be a relationship.

The other thing I have noticed is that the parents that have made great strides in helping their Autistic children did so through diet and their personal assistance to modify behavior.

I am 66 and have raised children. I breast fed, soy wasn't being used, much, if at all back then and I don't even recall Autism being an issue. There is truth to "You are what you eat". Has anyone researched this?

B. Nicholson

October 7, 2009

Epigenetic pheromones cause autism. When your rich [derogatory language redacted] are only allowed a voice, you will never listen.

Eileen Nicole Simon

October 9, 2009

Thanks - The new statistics are frightening! I hope the IACC can immediately initiate a study to find environmental factors involved: (1) What chemical substances were used during pregnancy by mothers of children with autism? Alcohol, valproic acid, tylenol? (2) What substances did they use before pregnancy? Birth control pills? Starting at what age? (3) Was labor induced or was the baby delivered by C-section? (4) Was umbilical cord blood collected for banking? Was the baby breathing before the cord was clamped? (5) Was the hep-B vaccine given, or antibiotics?

Mistakes have had to be corrected in the past: Diethylstilbestrol, synthetic vitamin K, Gantrisin. No medicines or artificial sweeteners etc. should be used during pregnancy. Induction of labor can be dangerous. Placental circulation should continue after birth until respiration is well established -oxygen on wheels can be brought to the delivery table. Vaccines should not be given in the newborn nursery, and some antibiotics may be more dangerous than germs.

Please investigate these mundane factors.

Eileen Nicole Simon

Jack Russell

October 15, 2009

As a parent of twin boys with autism I am appalled by the notes of Story Landis from the last IACC meeting that recently came to light. My children were plagued with a variety of medical problems before we treated them biomedically. They woke up nightly screaming in pain because of the GI problems but something as simple as a change in diet stopped that nightmare. My children have now been dropped from the exceptional children program in the school and require no school services because of the treatments we have chosen. Instead of looking to me for answers, the IACC seems to be set on attacking parents like me to protect their own interests. For Dr. Landis to discount the documented medical history of my children as a money-making scheme is sickening. Because of her attitude thousands of children will continue to suffer in silent pain.

I request that she be removed from the IACC immediately.

Jack Russell

Eileen Nicole Simon

October 15, 2009

Thank you for forwarding my comments to members of the IACC. I hope a sense of urgency will be prompted by the latest statistics on prevalence. Many genetic conditions are associated with autism - all must affect a common vulnerable system in the brain. Environmental causes must be actively looked for as a priority to account for increases in autism, and possibly other increasing afflictions of childhood such as asthma, obesity, and diabetes.

Eileen Nicole Simon

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

Anne Thomas

October 16, 2009

Doesn't anyone there care about what is happening here with these children? My daughter was involved in a study with [PII redacted] and [PII redacted] many years ago that came close to finishing her off. Back then I thought I was doing a wonderful thing for her to get in that study, especially since I heard about it from the Nat. Autism Soc. What a joke, her med. was up to toxic levels, when we had to drop out, funny but her records that told anything were gone. How convenient for NIH. Ironically I know [PII redacted] has since had a child with autism. I have never once heard one person say one word about the rise in numbers over the years. In 1986 it was one in 10,000 I was told. Now it's one in 100. If you [derogatory language redacted], you know something is wrong. Until my grandchild got this, I did not know what the word meant, had never heard it. Also I had only met one handicapped child in my life. My husband was in the military, we lived everywhere and still did not know any. Something [offensive language redacted] here. A LOT OF PEOPLE SHOULD BE VERY ASHAMED, BUT I REALIZE THAT HAVING A HEART SEEMS TO BE OUT OF STYLE. SHAME ON ALL OF YOU.

Anne Thomas

Lisa Ledwell

October 16, 2009

To Whom it May Concern,

Eventually, a comprehensive study of vaccinated vs. unvaccinated population outcomes will be completed by a group of honest individuals who actually care about the children on this planet. When their study reveals the horrible truth you are desperately trying to hide, you will find yourselves on the wrong side of history. Your efforts to suppress the truth is costing lives. I don't understand why you will not do this research......corruption, arrogance, ignorance? You already know that vaccines injure and even kill people.....this is a well-documented fact. I am asking you to DO THE RIGHT THING.

Thank you,

Lisa Ledwell

Maryland

Cecile Lawrence

October 16, 2009

This month CDC announced that autism has increased in prevalence from 1 in 150 to 1 in 100 for the birth cohort of 1996 and underscores that urgency is needed in discovering the reasons behind the rise. The question of whether the rise in autism is real has been answered by an NIH-funded study at UC Davis M.I.N.D. Institute which found a 600-700 percent increase in the number of children born in California with autism since 1990. Lead author and respected epidemiologist Dr. Irva Hertz-Picciotto stated that "about 10 to 20 times more research dollars are spent on studies of the genetic causes of autism than on environmental ones. We need to even out the funding." I agree.

The IACC continues to fail in designing a strategic plan that is suitably aggressive in response to the autism epidemic.

Vaccines can cause autism, as evidenced from compensation made to families since 1991from the Vaccine Injury Compensation Program. What remains unknown is how many individual have regressed into autism from vaccine adverse events. Congress has directed vaccine research be done in the 1986 Congressional Mandate for Safer Childhood Vaccines requiring research to reduce vaccine adverse events and the 2006 Combating Autism Act's legislative history that specifically stated that, "...for the purposes of **biomedical** research, no research avenue should be eliminated, including biomedical research examining potential links between vaccines, vaccine components, and autism spectrum disorder," as found in the Colloquy of Sen. Enzi, Santorum, Sen. Kennedy and Sen. Dodd. The National Vaccine Advisory Committee (NVAC) in June identified comparison of vaccinated and unvaccinated populations in determining total health outcomes as a critical vaccine safety research gap, as well as identified additional autism specific outcome vaccine research as necessary. The IACC must restore the previously approved vaccine research objectives to the IACC's research agenda, which are now recommended by NVAC, as well as consider additions in this line of research as identified by the NVAC report. Objectives must be retrospective, as well as prospective and include a variety of studies (human, animal, cellular). Studies already underway, such as the National Children's Study and the Childhood Autism risks from Genetics and the Environment (CHARGE), can and should use medically verifiable vaccine records in their study design and actively seek to recruit unvaccinated (by choice) individuals to gain the robust sample size needed for reporting purposes.

Conduct body burden studies on individuals with autism spectrum disorders that would investigate the toxic load of toxicants such as mercury and aluminum, their effects alone or in combination, and synergistic effects when combined with other toxins or viral or bacterial agents.

Given the growing body of research that clearly indicates ASD growth to be predominately due to the environment, expansion of this objective is necessary with an added focus on the identification of comorbid disease states (immune system abnormalities, inflammatory bowel disease, oxidative stress, etc.). Last year the IACC public members voted for 20 factors to be investigated and **were outvoted Federal IACC members who outnumber public members**.

Research on biomarkers in environmental exposure should also be expanded from 3 measures to 10 measures. Increase was again favored by IACC public members and failed **due to federal members voting it down last year**.

At February's IACC meeting, Dr. Insel acknowledged that the **Department of Health and Human Services has conflicts of interest**. The conflicts of interest must immediately end. Such people must recuse themselves or be removed from the committee.

Sincerely,

Cecile A. Lawrence, Ph.D., J.D.
Independent researcher and writer
Apalachin, NY

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

Eileen Nicole Simon

October 21, 2009

I notice 2 IACC vacancies. I looked at some of the NIH agencies and noticed the Speech and Language Pathology Department of the NIH Clinical Center. Could someone from that department be appointed? [PII redacted]? Developmental language disorder is the core handicap of children with autism, and needs to be a focus of research, especially clinical research -include those who work directly with people afflicted by language handicaps.

Sincerely,
Eileen Nicole Simon
--
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Jill Boyer

October 22, 2009

I have a question that I hope someone on the IACC committee will answer or address on 23 October 2009. It has come to my attention that the Whittemore Peterson Institute has discovered a new retrovirus, XMRV, that is in a small sample of people with autism (roughly 40 percent). Will there be more research in this area?

Thank you,

Jill Boyer

Parent of two children with autism and seizure disorder

Jill Boyer, [PII redacted]

John Piselli

October 22, 2009

I am writing you today as a parent with two boys on the spectrum. I want you to know how deeply we feel the initiatives of this meeting should not get bogged down with one particular item but stick with the total agenda of the meeting.

We hope the IACC will design a strategic plan that is aggressive enough to deal with the autism epidemic. We need to stop funneling most of the funds to the genetic causes and start looking at the environmental ones. The funds need to be evened out. The most important need is to get on board with the biomedical research. Biomedical protocol is the only way our kids are being "somewhat saved". The biomedical approach is expensive because health insurance will not pay for supplements, infusions, hyperbarics, etc. These are avenues these kids take and get better. Us parents are running out of money and time with our children. While you sit and dilly dally over genetics another child is lost. The statistics are alarming. I don't know anyone who doesn't know an autistic child. Time is running out for these 1990's children that have been afflicted with an extremely aggressive innoculation schedule and a toxic environment. They are the [offensive language redacted] we talked about in Earth Science in the 70's. The time is now and we see who is suffering - the children with toxic loads that their bodies can't handle.

Please do the right thing at this meeting for the next generation growing in this toxic world and aggressive vaccine schedule.

Thank you.

Patty & John Piselli