

Written Public Comments

**IACC Full Committee
Meeting**

December 14, 2010

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

Jean Public

October 26, 2010

I HAVE COMMENTS FOR THE PUBLIC RECORD. I WATCHED FROM 1 PM TO 4 PM. I WAS DISAPPOINTD IN THE FAILURE TO MAKE ANY MEANINGFUL STRIDES DURING THIS PORTION OF THE MEETING. IT WAS JUST ALOT OF TALK WITH NO REAL ADVANCEMENT TO HELP KIDS WITH AUTISM OR TO PREVENT KIDS FROM GETTING AUTISM. PEOPLE WHO SEEMED TO ENJOY SAYING NOTHING SEEMED TO BE TALKING MOST OF THE TIME.

IT IS MY OPINON OF THE SPENDING OF \$4.2 MILLION FOR 2 YEARS FOR OUTCOMES OF AUTISM BY LEVIN GROUP IS JUST POLITICAL WASTE. I BELIEVE THIS IS A USELESS STUDY WHICH WILL RESULT IN NO ADVANCEMENT TO HELP AUTISM.

[derogatory and hate language redacted]

IF THIS COMMITTEE IS LOOKING FOR REAUTHORIZATION, I HAVE TO GO ON RECORD RIGHT NOW AS SAYING IT SHOULD NOT BE REAUTHORIZED BECAUSE IT DOES NOTHING BUT SIT AROUND AND TALK. YOUR TIME AS PUBLIC SERVANTS WOULD BE FAR BETTER SPENT HELPINIG IN THE FIELD THE FAMILIES THAT HAVE TO DEAL 24 7 WITH AUTISTIC CHILDREN. THE REST WHO ARE QUALIFIED TO DO RESEARCH NEED TO BE IN THE LAB RESEARCHING WHAT HAPPENS TO INFANTS IN THE WOMB WHO GET FLU SHOTS IN THEMOTHERS BODY, ETC. ULTRASOUND ALSO CAN BE INVESTIGATED. I DO NOT THINK THE TIME OF THE PUBLIC SERVANTS ARE BEING FULLY UTILIZED TO HELP AMERICA BY THIS SITTING AROUND TALKING WITH NO ADVANCEMENT FOR THE PEOPLE HURT BY AUTISM.

JEAN PUBLIC [PII redacted]

Connie Frenzel

November 4, 2010

Subject: IACC Nov 8 question on Medicaid/managed care-health care needs of adults

I am very pleased that you [Lee Grossman] are co-chairing this committee meeting with Ellen Blackwell. I and others have a concern about Medicaid and providers under the Medicaid system to appropriately provide treatment for our adults with autism. As you know there are few medical providers knowledgeable about autism and for that matter developmental disabilities to see our adults. The Developmental Disabilities Nurse Association and others have voiced this concern in the past. The situation continues and will only get worse. Pediatricians and child neurologists and child psychiatrists continue to see some of children who are now adults because there are no physicians knowledgeable to see our adults.

Now California has just stated they are going to mandate that everyone receiving Medi-cal (Medicaid) must join the managed care network in their county. Currently we have a choice but they are now planning to start pilot projects so that in the next 5 years everyone must be in a managed care network. Currently, there are few physicians who will accept Medical and those that do, are not autism experts or have experience with autism. In California, there is a negative incentive for physicians who treat adults to take patients with autism due to the very low reimbursement rate by Medicaid.

The state says they are doing this because mandatory managed care will achieve cost savings and better care. HOW??? Under managed care, if the primary emphasis is "cost savings" there will be little emphasis put on physicians to learn about autism.

Mandating managed care for everyone on Medicaid may be what is going to happen all over the country. It might work for the general population but for people with autism and others with DD who need specialized care, it will be very detrimental.

I believe the IACC should address

- A. What can be done to appropriately serve adults with autism in the Medicaid system taking into account the lack of training in autism and poor reimbursement impacting access to care?
- B. What can be done to train physicians and nurses who see adults on autism? I am particularly concerned that internists, gastroenterologists, psychiatrists and neurologists need to receive some training. There are ways to get them trained but so far little has been done to correct the situation.

Advocates are very concerned that the current managed care networks are not able to provide the needed providers and specialists that are adults need. They will not be able to handle the numbers of developmentally disabled and seniors on Medi-cal/Medicaid, nor do they have the expertise to do so. Now, with mandatory managed care, unless we start training physicians immediately I fear disastrous results. There will be no choice of providers.

Can this issue be addressed at the IACC? I did not see it on the agenda? Can it be fit in?

This is such a huge issue perhaps a subcommittee on health care needs of our adults needs to be formed?

Thank you for assistance and please feel free to forward this onto the appropriate committee members or Ellen Blackwell

Connie Frenzel Registered Nurse (RN) Master of Science (MS)
Member, Developmental Disabilities Nurse Association
Acting President, Autism Society-San Francisco Bay Area

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S. Jill Boyer

November 12, 2010

Subject: IACC Meeting

I would appreciate it if the research committee will discuss or put on their list the Xenotropic murine leukemia virus-related virus (XMRV) retrovirus since I believe it is associated with autism. We greatly need to have research money allocated toward this. As some on this committee may know, Human immunodeficiency virus (HIV) (another retrovirus) pediatric patients show autistic symptoms such as loss of speech, apraxia, loss of motor skills and seizures.

If you are not the correct person to contact, please let me know and I will send this information to the appropriate person.

All the best, Jill
S. Jill Boyer-Lehnert
[PII redacted]

Caroline Rodgers

November 14, 2010

To satisfy the vision and mission of the IACC, you must do more than make a good effort. You must do more than make an excellent effort. You must make an outstanding effort to discover what is causing autism and do whatever it takes to stop it, at whatever cost.

Become a change-maker by forging a way to encourage research into prenatal ultrasound as an autism risk factor because . . .

- Prenatal ultrasound is a common denominator among pregnant women throughout the world that coincides with the autism boom
- Prenatal ultrasound has several bioeffects, not all of which are well understood
- Prenatal ultrasound has been proven to change brain formation in mammalian fetuses
- Women with the most and best first-trimester prenatal care and/or ultrasound exposure have the greatest chances of bearing children diagnosed with autism
- Safety research has been repeatedly denied funding
- Strong market forces work against consumer protection

Bruce Meatheringham

November 16, 2010

Subject: My Story With ADS Channel 10 (A Conversation That Motivated Me To Start Research) do you want a copy?

When I was on work experience at Channel 10 in Adelaide Australia a conversation inspired me to undertake research into savants.

After this research some savant skills started and I Started Research into synaesthesia which lead to me been diagnosed with synaesthesia.

Would you like a copy of My story with ADS Channel 10 (A Conversation That Motivated Me To Start Research)?

It is a story I have written about myself

Bruce Meatheringham

Dana Hall

November 16, 2010

Subject: Medical Code for Autism

Hello,

I am wondering about the medical code for autism related wandering a safety suggestion that was discussed at the last IACC meeting. We are an autism service dog provider and are interested to know if this code would allow the service dogs to be covered for the children. Currently individuals who are blind and veterans already have a billing code for this. Some other disabilities do also. We feel that these service dogs can change a child's life and prevent wandering related deaths.

I didn't hear anything mentioned about autism service dogs and just wanted to bring this topic up. There is quite a bit of research and studies that have been done on service dogs for children with autism that show how beneficial these are.

Thank you,

Dana Hall
Blessings Unleashed Foundation
Autism Service Dogs

Eileen Nicole Simon

November 17, 2010

I just noticed the strategic plan updates for q1-4 on the IACC website. I would like to suggest:

- (1) Developmental language disorder must be a priority focus.
- (2) Environmental factors should begin with medications taken during and before pregnancy.
- (3) Effects of environmental factors on brainstem auditory nuclei should be investigated.
- (4) Please read: MORGAN DL et al. Neurotoxicity of carbonyl sulfide in F344 rats following inhalation exposure for up to 12 weeks. *Toxicol Appl Pharmacol.* 2004 Oct 15;200(2):131-45.
- (5) Note: Morgan et al. (2004) refer to the inferior colliculi throughout their report as the "posterior colliculi" and stated, "Although the posterior colliculus is not typically examined in standard brain survey sections, a fortuitous section in one animal indicated severe necrosis."
- (6) The "posterior" or inferior colliculi should be the first structure in the brain investigated in testing for toxicity of environmental factors.
- (7) The inferior colliculi should be chosen as a region of interest (ROI) in fMRI investigations.
- (8) Obstetric and neonatal interventions should be investigated (not avoided). Clamping of the umbilical cord and neonatal hep B vaccine should be stopped.
- (9) Please read: HUTCHON DJ. Why do obstetricians and midwives still rush to clamp the cord? *BMJ.* 2010 Nov 10;341:c5447.

Eileen Nicole Simon

Eileen Nicole Simon

November 18, 2010

I am hopeful that my comments might be taken into consideration during update of the plan tomorrow. I may sound like a broken record, and a crank, but language development is the greatest concern for those of us dealing with the lifelong disability of autism.

Even "high functioning" adults with Asperger's Syndrome or PDD-NOS, like my 48-year-old son, are handicapped if language development has gone no further than concrete, fact-filled, stereotyped statements. My son and I have discussions about communicative intent and theory of mind; these are not the primary problem. My son only began speaking just before age six, and he speaks with the handicaps that people often have trying to go beyond concrete usage in a foreign language.

My son suffered a traumatic birth with a severe cephalhematoma and scar still evident under his right eye. Birth injuries have been documented often in children with autism, but usually dismissed as due to "some problem" with the mother or child. These conclusions are not scientific, and they are not ethical.

Obstetric interventions must be investigated. Many are unsafe. Please read <http://www.bmj.com/content/341/bmj.c5447.long> and read our comments. Thanks.

Eileen Nicole Simon

Donna Young

November 18, 2010

Subject: Autism caused but mostly preventable...Past Conference calls on means of prevention by education and review of births for damaged children.

Very few autistic children have an actual link to a genetic mutation. But even if a child has a predisposition to this mutation, the disorder may be stopped, if the baby got all their placenta blood infusion as an equal right to security of person, and equal right to this protection.

(Even a criminal or civil investigation, after the child's birth care is a duty to the child - this is equal protection - as a full citizen (no age discrimination) to have done if there was in the child's conception to the birth care, the standard of care which is no harm taught in the birth education or training of the local doctors).

I was wanting to know if any members of this organization, sent a follow up to President Obama, to the Open Letter, for his reply. I recommend he deal with this issue by allowing for in the U.S.A. a Commissioned Public Inquiry.

www.medical-truths.com

Now can the board allow for approval of signatures from your organization, to sign this petition, too, as action is needed.

www.thepetitionsite.com/1/protect-babies-and-mothers-too

I am presenting seeking to make public ads on television (TV) to give tips on how to likely prevent any future children being caused Autism. Most of these babies will have been early umbilical clamped babies and were caused a testable anemic condition. But the parents thought they were taking home a living child, thus a healthy child...not knowing that up to 60 percent of the child's placenta blood went to blood banks...a betrayal of the services of the local institution.

The Question to confirm lack of truth in education, that most parents who are members of the autistic groups, cannot answer, "Do they know when their child's quality of lifeline was clamped off, tied off, or willfully finger-thumb-squeezed off for 10 to 20 seconds? Then it was cut? But the trapped blood in the placenta was then sent to another interest group's profits...the stem cell cord blood banks. The time for the baby to have his or her stem cells was following their birth, and proper amount of red cells, too. They were deprived of specialty enzymes, hormones, platelets, and nutrients found in their whole blood. Many were caused to have a shrunken heart, too...not enough blood volume to keep the heart as to its original size. The heart valves are damaged too. These early clamped babies, (any clamping before the child was wrapped head to toe to be kept warm) and any clamping done before the placenta was birthed, will result in a tested anemic baby, too few red cells.

Thank you for forwarding this letter to concerns of prevention of increased autistic children by methods known to cause all or any type of internal problems, by stopping any early cord clamping or

cord compression, before the placenta is birthed. The time period allowed for a healthier and stronger child is ten to twenty minutes before the high risk of cosmetic removal of the cord is allowed...by clamping and then cutting off the cord.

Yours truly,

Ms. Donna Young

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Bruce Meatheringham

November 18, 2010

Subject: A Copy of My Story With ADS Channel 10 (A Conversation That Motivated Me To Start Research)

Thank you for your interest in my story.

My time at Channel 10 in Adelaide Australia inspired me to undertake research. I have Attached a copy of my story and I hope you enjoy it.

Yours sincerely

Bruce Meatheringham

MY STORY WITH ADS CHANNEL 10 (A CONVERSATION THAT MOTIVATED ME TO START RESEARCH)
Written By Bruce Meatheringham
[PII redacted]

My Story With ADS Channel 10 (A Conversation That Motivated Me To Start Research)

A Little Bit About My Year Before ADS Channel 10

I started doing the Diploma of Screen and Media course with M.A.P.S. (Media Arts Production Skills) at Hamilton Secondary College. In March I met [PII redacted] at a party and talked with her about doing the M.A.P.S course, she then offered me three days work experience with Channel 10.

First Day At ADS Channel 10 - 28th of September

I remember sitting at a desk feeling very nervous, [PII redacted] was the only person I knew. I recognized Mark Aiston but I didn't know him and I didn't know what to say. Then [PII redacted] came in and introduced me to some of the staff. Consequently, I went out on a job. First Week Work Experience At ADS Channel 10 28th -30th September

In the 3 days I was there I learned a lot about how a news service works, about cameras and editing. I asked a lot of questions and I was happy to be asked back in November.

The Conversation That Started Research

On the first day I was in a car going to a job at Uraidla with [PII redacted] and [PII redacted]. [PII redacted] said she knew me from an Autism party. [PII redacted] said "There is a video on YouTube about an Autistic Savant - **GUY DRAWS ROME**. Check it out; if this doesn't get a creative person to look at Savants, nothing will." After looking this up I decided on the last day at ADS Channel 10 to show my memory for numbers. [PII redacted] gave me a ten-digit number, which he said I memorized in 6

seconds. The staff liked this and asked me if I could do mathematical calculations; just like I had been asked in the past about this and calendar calculations, I said “No” because I didn’t think I could.

Definition:

Savant (noun): *A person of profound or extensive learning; learned scholar.*

<http://dictionary.reference.com/browse/savant>

Savants Research

I spent a month researching savants. I looked at a lot of different savants. I e-mailed some friends who are interested in the arts, telling them about the drawing savants [PII redacted] hire and [PII redacted]. Number and calendar calculating savants who interested me were [PII redacted] and [PII redacted]; [PII redacted] because he loved numbers and like me had a history of epilepsy; [PII redacted] because he became a Sudden Savant doing calendar calculations. I could relate to that; my skills started to evolve after this research.

Numbers And Me Pre Research

A little bit about me and numbers. Before savant research, numbers were just memorised. In 2008 people started to ask if I could do calendar calculations and maths. I said “No.” My year 12 drama teacher had pointed out to me [PII redacted]’s book “Born on a Blue Day” because I like to remember things by numbers; but I read the first chapter and thought this is not me, I can’t do what he can do with numbers and I don’t see colours with numbers.

A Change In Use Of Numbers

Suddenly just over a week from when I started savant’s research, 7th of October 2009 I decided to try to calendar calculate. I realized my brain had been saving some dates and days for years. I didn’t notice I was doing this and then worked out a formula for doing calendar calculations. Within 24 hours I became a calendar calculator. A few days later I started multiplying numbers by themselves and by 27th October I began doing divisions beyond the calculator. A month and a half after starting calendar calculations, I memorized the day of my birthday spanning every week for 30 years without looking at a calendar. I started to show my skills with doing sums like 13 divided by 87, 85 times 85. I didn’t believe I had such skills and was scared of being made fun of by other people. No school report says I could do this.

Second Time At ADS Channel 10, 9th- 12th November 2009

I had 4 days work experience and when I came in I knew [PII redacted] was going to ask me what the ten-digit number was. Then I showed I could do calendar calculations. I enjoyed my time at ADS Channel 10, learned more about television (TV) news and got an opportunity to assist a live news cross and be part of a story. It felt sad to leave. After the story went to air, people in my local area started to call me a “superstar.”

Sensory Synaesthesia Mission

I remember when researching savants, I heard a statement about [PII redacted]’s synaesthesia by Shai Azoulai. Researcher/Graduate Student. At (UCSD) University of California-San Diego Psychology- “This could be the lynchpin that spawns off a new field of research”, in the YouTube video Extraordinary people-[PII redacted] Part 3 of 3. In late October 2009 I became obsessed with synaesthesia and how there are people who see colours with letters, numbers and sounds. After looking into it more, I found it to be cross-sensory experience. This made me think that my sensory issues are like synaesthesia

but I don't have cross-sensory experience. I found it very interesting how [PII redacted] sees numbers as colours, shapes and textures and I could relate to two statements by [PII redacted]: "I'm alone and not as the others." "I didn't know what it was, I was very frightened" in the YouTube video Extraordinary people-Synaesthetes. So I decided to research synaesthesia to see if my sensory issues were synaesthesia.

For two months, every waking hour I was thinking about synaesthesia. In research I looked at links between Asperger syndrome, autism and different types of synaesthesia and synaesthesia in non synaesthetes. In November when I was very tired and was thinking what it would be like to be cross-sensory, I had a temporary sound-coloured shape experience. I saw a doctor about this. He said he knew about synaesthesia and that it did not happen all the time. So he said, "Don't worry, it's cross-wiring in the brain." I said, "I have sensory issues with cross-wiring on the same sense. What are they?" He said I don't know; something to do with the brain." This is the same old answer I'd heard before. In a shop I looked at a book on the human body and found some information on the sensory part of the brain for touch (Somatosensory Cortex). Now I had a name for where my brain may be very mixed up.

After that, on the Internet I found a book called Sensory Perceptual Issues in Autism and Asperger Syndrome by [PII redacted]. It said many people with Asperger syndrome/high functioning autism define their sensory processing problems as more disabling than the deficits in communication/social behaviour. When I read this I broke down in tears so true for me this book should be read by anyone working with people with autism and Asperger syndrome. It stated that synaesthesia is a crossing of the senses.

On the 22nd of December, through a family friend I met a neuroscientist. I asked him about my sensory issues. He said he didn't know and that I should ask a neuropsychologist. Then I said, "I have been looking into synaesthesia." He asked me what synaesthesia was. I said "A condition in which hearing a sound = seeing a colour." He said, "That's what you've got." I said, "But to have synaesthesia you have to experience crossing of senses." He said "**Same concept.**" These words were later useful when talking about synaesthesia to other people.

On the 28th of December I was researching synaesthesia on the Internet and saw this synaesthesia same modality as when seeing black = seeing colour. I looked up synaesthesia same modality (stimulus modality is one aspect of stimulus) and came across this:

Synesthesia Definition (US spelled) (noun)

A condition in which one type of stimulation evokes the sensation of another, as when the hearing of a sound produces the visualization of a color.

A sensation felt in one part of the body as a result of stimulus applied to another, as in referred pain. The description of one kind of sense impression by using words that normally describe another.

<http://www.answers.com/topic/synaesthesia> Number two describes me, finally a breakthrough.

I also found this website with types of synaesthesia on the same sense.

<http://www.mixsig.net/about/types.php>

I also found this definition after getting my referral, which I like:

Definition: **Synaesthesia** from the Ancient Greek σύν (syn), (union) and αἴσθησις (aisthēsis), "sensation" is a neurological condition where a normal sensory stimulus triggers a response in another sense or in a different aspect of the same sense.

Reference:

Definition from <http://archive.student.bmj.com/issues/07/11/education/413.php> Ancient Greek words for synaesthesia from <http://en.wikipedia.org/wiki/Synesthesia>

Finally An Answer

It was great to finally have an answer and a name for this.

2009 Summary

In 2009 I got my Diploma of Screen and Media. 2009 was a year about learning new things and learning about myself.

A Little Bit About My Synaesthesia

I have multiple types of bidirectional (two ways) synaesthesia on the same sense. Feeling Touch in one part of the body = feeling Touch in another.

Feeling Pain in one part of the body = feeling Pain in another.

Feeling Vibration in one part of the body = feeling Vibration in another.

I believe my forms of synaesthesia are rare, most synaesthetes don't know they are different. I always knew I was different from when my synaesthesia started after episodes of **Sylvian Epilepsy (Epilepsy** where episodes occur in sleep).

Reference: <http://www.onlinemedicaldictionary.org/Sylvian+Epilepsy.aspx?q=Sylvian+Epilepsy> (IACC Note: URL is not valid.)

Synaesthesia Research Results

By doing this research I can now identify some other synaesthetes. I have already identified a synaesthete who, when she thinks of a number, she sees a colour; someone asked me about this in relation to their friend.

Getting A Referral To Get A Diagnosis

My first thought was this would be easy; just show a definition and the website printout and say a neuropsychologist knows about this. First I rang the South Australia (S.A.) Health Dept. They had no idea. I rang Adelaide University School of Psychology on the 4th of January 2010. They said Dr [PII redacted] teaches this subject and will be back on the 18th of January. So on the 6th of January I consulted a doctor. I showed him the synaesthesia definition and the website printout. He said he would look in the medical books and that I could see him on the 13th of January 2010. He said he didn't know who to refer me to. He asked me to see my Psychologist and ask her who to refer to, who I am seeing for anxiety disorder and who I would be seeing on the 20th of January. I said "I will be ringing the university next week." I rang the university at 10:15 am on the 18th of January and spoke to Dr [PII redacted] who said she would e-mail the name of a neurologist. That day at 1:48 pm I got this e-mail:

Hi Bruce,

I am following up on your call this morning re the possibility that you have synaesthesia.

You could possibly try contacting [PII redacted] – who is the University’s Head of Neurology – he is based at the Royal Adelaide. He may or may not be able to help you. In any case, I would think that the symptoms you describe fall into the domain of neurology and so a neurologist is most likely to be able to diagnose your symptoms.

Good luck with your quest. Regards,
[PII redacted]

When I had read the e-mail and had seen [PII redacted] who is the University of Adelaide’s Head of Neurology, I thought yes, just what I want – Head of Neurology. It would mean a lot one day to meet [PII redacted] and thank her for being the first Doctor to take my sensory issues seriously. After I saw the Psychologist on the 20th of January, I got back to my Doctor on the 27th of January 2010 and asked him to refer me to [PII redacted]. He said it would cost a lot to get into his North Adelaide office. I asked “How much?” He said he would look into it tomorrow 28th January 2010 and wrote a referral. I booked an appointment for the 20th of April 2010 at 9.00am.

Diagnostic Process

At the appointment I told [PII redacted] about my sensory issues and said they are synaesthesia, he thought I was right and he asked me if I have grapheme colour synaesthesia (seeing letters and numbers as colours) I said no, I don’t but I have a good memory for numbers. He tested me on calendar calculations and I told him I have memorized the dates. He said that it’s on the number area as well I

was given a referral for an Magnetic resonance Imaging (MRI) and at the second appointment, 18th of May 2010, he confirmed the diagnosis of synaesthesia and asked me to speak about my synaesthesia to students at the University of Adelaide-School of Medicine. I am happy to be asked to speak to Medicine students and would be willing to speak to Doctors anywhere about my synaesthesia.

Summary Of Diagnosis

I am very happy to have a diagnosis as it puts an end to people taking this for a big joke I am going to focus on the positives like vibration can be good for sensing sound and what I have got with numbers and calendar months is a gift. I am yet to talk about that but will one day tell [PII redacted] about it. For now I am still very upset with everyone in the area of health who I spoke to and did not take this seriously. Anyone who takes my synaesthesia for a joke needs their head looked at. Some people say they know what synaesthesia is, if they can’t tell me that I am a synaesthete then they don’t know what synaesthesia is.

My name is Bruce Meatheringham. I have **Asperger syndrome** (an autism spectrum disorder) and people with it therefore show some difficulties in social interaction, along with restricted and repetitive patterns of behavior and interests.

Reference: http://en.wikipedia.org/wiki/Asperger_syndrome and synaesthesia.

This to date - 20 of May 2010 is the result of how one conversation between [PII redacted] and [PII redacted] at ADS Channel 10 motivated me to start research that made me more aware of myself. I am starting to make a film about synaesthesia at M.A.P.S. on the 28th of May as part of my Advanced Diploma of Screen and Media.

Eileen Nicole Simon

November 19, 2010

I was able to listen to some of the meeting today, and have the following comments:

- (1) Thanks to Dr. Insel for saying that objectives should be to find answers (not to launch studies). Many answers can be found in the existing medical literature, thus studies to re-invent the wheel are not always needed.
- (2) If Ari Ne'man ever had autism (is there solid evidence?), he is cured now and not in need of life-long care. He certainly does not speak for most of us, or our children who unfortunately are not cured. His "self-advocacy" remarks are a slap in the face for those of us who struggle to advocate for the on-going severe needs of our adult children. Autism is a tragedy for afflicted children and their families. The increasing prevalence of autism is a national emergency.
- (3) Mechanisms of INJURY need to be looked for (INJURY, not some alternative word). People who claim to have autism are not to be believed, trusted, or asked for advice.
- (4) Problems of neuronal migration should be compared with the dysmaturation in the brains of monkeys subjected to asphyxia at birth. See Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Exp Neurol.* 1969 May;24(1):38-53.

Eileen Nicole Simon

Connie Frenzel

November 24, 2010

Dear Lee,

I am very pleased that you are co-chairing this committee meeting with Ellen Blackwell.

I and others have a concern about Medicaid and providers under the Medicaid system to appropriately provide treatment for our adults with autism. As you know there are few medical providers knowledgeable about autism and for that matter developmental disabilities to see our adults. The Developmental Disabilities Nurse Assoc and others have voiced this concern in the past. The situation continues and will only get worse. Pediatricians and child neurologists and child psychiatrists continue to see some of children who are now adults because there are no physicians knowledgeable to see our adults.

Now California, has just stated they are going to mandate that everyone receiving Medical (Medicaid) must join the managed care network in their county. Currently we have a choice but they are now planning to start pilot projects so that in the next 5 years everyone must be in a managed care network. Currently, there are few physicians who will accept Medical and those that do, are not autism experts or have experience with autism. In California, there is a negative incentive for physicians who treat adults to take patients with autism due to the very low reimbursement rate by Medicaid.

The state says they are doing this because mandatory managed care will achieve cost savings and better care. HOW??? Under managed care, if the primary emphasis is "cost savings" there will be little emphasis put on physicians to learn about autism.

Mandating managed care for everyone on Medicaid may be what is going to happen all over the country. It might work for the general population but for people with autism and others with DD who need specialized care, it will be very detrimental.

I believe the IACC should address

A. What can be done to appropriately serve adults with autism in the Medicaid system taking into account the lack of training in autism and poor reimbursement impacting access to care?

B. What can be done to train physicians and nurses who see adults on autism? I am particularly concerned that internists, gastroenterologists, psychiatrists and neurologists need to receive some training. There are ways to get them trained but so far little has been done to correct the situation.

Advocates are very concerned that the current managed care networks are not able to provide the needed providers and specialists that are adults need. They will not be able to handle the numbers of developmentally disabled and seniors on Medical/Medicaid, nor do they have the expertise to do so. Now, with mandatory managed care, unless we start training physicians immediately I fear disastrous results. There will be no choice of providers.

Can this issue be addressed at the IACC? I did not see it on the agenda? Can it be fit in?

This is such a huge issue perhaps a subcommittee on health care needs of our adults needs to be formed?

Thank you for assistance and please feel free to forward this onto the appropriate committee members or Ellen Blackwell

Connie Frenzel RN MS

Member, Developmental Disabilities Nurse Association Acting President, Autism Society-San Francisco Bay Area

Eileen Nicole Simon

November 29, 2010

I would like to make some suggestions, and would appreciate getting some feedback:

- (1) Developmental language disorder needs to be included as a strong focus of research.
- (2) I like Dr. Insel's idea that we need to look for answers, and language development is of primary importance for human development, and an area for which more answers are badly needed.
- (3) Please leave out any references to "facilitated communication". This is not an area of research deserving of federal funding.
- (4) Please be wary of advice promoted by anyone who claims to have recovered from autism or Asperger's syndrome. I noticed Ari Ne'man is described in Wikipedia as having been "verbally advanced and socially isolated as a child". Therefore he never had autism or Asperger syndrome. His "self advocacy" is not helpful for our children afflicted with autism.
- (5) Please read Cederlund M, Gillberg C. One hundred males with Asperger syndrome: a clinical study of background and associated factors. *Dev Med Child Neurol.* 2004 Oct;46(10):652-60, and take special note of their finding on language development:
"Forty-five of 92 children (49%) for whom fairly detailed data about early language development were available, clearly did not have normal language development at 2 years of age. It cannot be concluded that the remainder had normal language development."
(p656)

The "Strategic Plan" will remain weak unless the issue of language development is made a primary target of research.

Sincerely,
Eileen Nicole Simon

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

Eileen Nicole Simon

December 7, 2010

Subject: A research priority, and a request

Below are written comments I want to submit to the IACC for inclusion in the update to the Strategic Plan. I plan to submit additional comments on (a) the inferior colliculus as a site in the brain that may be essential for social awareness, and (b) facilitated communication. I am sorry that I cannot attend this meeting in person.

Sincerely,

Eileen Nicole Simon

--

RESEARCH PRIORITY:

Language distinguishes the human species from all others. A child who does not learn to speak is disabled, not just different. A person who remains nonverbal into adolescence and adulthood is disabled, not just different. Developmental language disorder is the primary concern of parents whose child develops autism, and the entire extended family. Lack of social awareness or a “theory of mind” may underlie failure to learn to speak, but so much more hope can be held out for the child with autism who does learn to speak. Social stories and other therapeutic interventions can be used to help development of children who become verbal. Those who remain nonverbal also remain dependent upon others for 24/7 care throughout life.

Loss of language (aphasia) is known to result from injury within the brain. To look for impairment within the brain should be the focus of research on developmental language disorders, even if the impairment is the result of a genetic defect. The IACC “strategic plan” needs to include research on brain systems underlying the human capacity for language.

REQUEST

I would like Dr. Insel to read and respond to my comment above, not just inquire of members of the committee whether this might be something they would like to discuss.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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

Eileen Nicole Simon

December 7, 2010

Subject: The inferior colliculi and environmental awareness

Below are written comments I want to submit to the IACC for consideration as a research area relevant to the social obliviousness of children with autism, in updating the Strategic Plan.

Sincerely,
Eileen Nicole Simon

--

THE INFERIOR COLLICULUS AND ENVIRONMENTAL AWARENESS

The inferior colliculus in the midbrain auditory pathway has higher blood flow than any other area of the brain [1]. High blood flow also supports greater aerobic metabolism in the inferior colliculus (plural colliculi) than in any other area of the brain [2]. The high rate of aerobic metabolism in the inferior colliculi may support a vigilance function in these small nuclei [3]. The inferior colliculi appear to have evolved as a posterior extension of the optic lobe of lower vertebrate species, as an alerting mechanism for visual attention [4]. Vigilance and alerting functions underlie an active “information seeking” instinct; language is the pinnacle of the information-seeking drive of the human species [5].

Research with animals provides evidence that lesions of [a] the lateral lemniscal tracts (connection of the superior olives with the inferior colliculi), [b] lesions of the tectum including the superior and inferior colliculi, and [c] lesions of the brachium of the inferior colliculi (connection to the medial geniculate bodies) all lead to marked loss of environmental awareness [6-8].

High blood flow in the inferior colliculi leaves them vulnerable to all of the many etiological factors associated with autism. They are susceptible to injury from any abnormal substance in the circulation whether from genetic metabolic disorders, prenatal exposure to alcohol and drugs, exposure to toxic substances in the environment. The inferior colliculi are a primary site of damage by bilirubin infiltration secondary to injury of the blood-brain-barrier, and to ischemic injury at birth [9]. Maturation of the brain was disrupted in monkeys with primary lesions of the inferior colliculi resulting from asphyxia at birth, and sites of maturational disruption are comparable to those found in brains from people with autism [10].

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1. Landau WM, Freygang WH, Rowland LP, Sokoloff L, Kety SS. The local circulation of the living brain; values in the unanesthetized and anesthetized cat. *Trans Am Neurol Assoc.* 1955-1956;(80th Meeting):125-9.
2. Sokoloff L, Reivich M, Kennedy C, Des Rosiers MH, Patlak CS, Pettigrew KD, Sakurada O, Shinohara M. The [14C]deoxyglucose method for the measurement of local cerebral glucose utilization: theory, procedure, and normal values in the conscious and anesthetized albino rat. *J*

Neurochem. 1977 May;28(5):897-916.

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10. Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Exp Neurol*. 1969 May;24(1):38-53.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
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Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

December 7, 2010

Subject: Facilitated communication

Below is a comment I want to submit to members of the IACC in considering any mention of "facilitated communication" as an aid to independence for nonverbal adults with autism. I plan to submit one more comment on how facilitated communication led to the death of my son, [PII redacted].

Someone suggested a change for a recent reworking of the IACC Strategic Plan, suggesting that with the help of "facilitated communication" non-verbal people with autism are able to live independent lives. This is silly. A facilitator is a care-provider, whose services must be purchased. What educational credentials do these facilitators have? Facilitated communication was promoted in the early 1990s at the same time the "trauma theory" of mental illnesses was gaining popularity. This theory enabled some "therapists" to make a lot of money convincing young people (especially young women) that they had "suppressed memories" of early abuse. By the late 1990s many of these therapists were being sued by families of their clients. A good account can be found on Wikipedia at http://en.wikipedia.org/wiki/False_memory_syndrome.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
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Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

December 7, 2010

Subject: The death of my son [PII redacted]

The psychiatric profession has long been prey to advice from uneducated people. Please do not succumb to advice such as "facilitated communication" being useful for independence.

Sincerely,

Eileen Nicole Simon

--

Facilitated Communication led to the death of my son, [PII redacted]. The group home where he lived provided a "facilitator" for him, who reported that [PII redacted] revealed to her that he had been physically and sexually abused by his mother (me). The last time I saw [PII redacted], I brought him some Halloween candy. The house director then started to scream at me, and told me I would no longer be allowed to visit. [PII redacted] came to the door in his purple ghost costume, and his last words to me were, "I love you mom." On January 17, 1995 I got a call at work from my husband that [PII redacted] had died. A few weeks later, we got the toxicology report, that [PII redacted] had died from an overdose of Thorazine (chlorpromazine). The dose was 1500 milligrams (mg) per day, 500mg at 3pm, 500mg at 7pm, and 500mg at "hour of sleep." This dosage was prescribed by a psychiatrist who explained that staff at the group home said they could not control [PII redacted]'s behavior on any lower dosage. [PII redacted] refused to take the medication, so they crushed it up and put it in his favorite desert, chocolate pudding. I posted more on my website, conradsimon.org.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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Eileen Nicole Simon

December 7, 2010

Subject: A research priority, and a request

RESEARCH PRIORITY:

Language distinguishes the human species from all others. A child who does not learn to speak is disabled, not just different. A person who remains nonverbal into adolescence and adulthood is disabled, not just different. Developmental language disorder is the primary concern of parents whose child develops autism, and the entire extended family. Lack of social awareness or a “theory of mind” may underlie failure to learn to speak, but so much more hope can be held out for the child with autism who does learn to speak. Social stories and other therapeutic interventions can be used to help development of children who become verbal. Those who remain nonverbal also remain dependent upon others for 24/7 care throughout life.

Loss of language (aphasia) is known to result from injury within the brain. To look for impairment within the brain should be the focus of research on developmental language disorders, even if the impairment is the result of a genetic defect. The IACC “strategic plan” needs to include research on brain systems underlying the human capacity for language.

REQUEST

I would like Dr. Insel to read and respond to my comment above, not just inquire of members of the committee whether this might be something they would like to discuss.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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

Eileen Nicole Simon

December 7, 2010

Subject: The inferior colliculi and environmental awareness

THE INFERIOR COLLICULUS AND ENVIRONMENTAL AWARENESS

The inferior colliculus in the midbrain auditory pathway has higher blood flow than any other area of the brain [1]. High blood flow also supports greater aerobic metabolism in the inferior colliculus (plural colliculi) than in any other area of the brain [2]. The high rate of aerobic metabolism in the inferior colliculi may support a vigilance function in these small nuclei [3]. The inferior colliculi appear to have evolved as a posterior extension of the optic lobe of lower vertebrate species, as an alerting mechanism for visual attention [4]. Vigilance and alerting functions underlie an active “information seeking” instinct; language is the pinnacle of the information-seeking drive of the human species [5].

Research with animals provides evidence that lesions of [a] the lateral lemniscal tracts (connection of the superior olives with the inferior colliculi), [b] lesions of the tectum including the superior and inferior colliculi, and [c] lesions of the brachium of the inferior colliculi (connection to the medial geniculate bodies) all lead to marked loss of environmental awareness [6-8].

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1. Landau WM, Freygang WH, Rowland LP, Sokoloff L, Kety SS. The local circulation of the living brain; values in the unanesthetized and anesthetized cat. *Trans Am Neurol Assoc.* 1955-1956;(80th Meeting):125-9.
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3. Fisch L. The selective and differential vulnerability of the auditory system. In GEW Wolstenholm GEW, Knight J, eds. *Sensorineural Hearing Loss: A Ciba Foundation Symposium.* London: Churchill, 1970, pp110-116.
4. Butler AB, Hodos W. *Comparative Vertebrate Neuroanatomy: Evolution and Adaptation,* Second Edition. Hoboken NJ: Wiley-Interscience, 2005.

5. Angelo R. Physiologic acoustic basis of speech perception. *Otolaryngol Clin North Am.* 1985 May;18(2):285-303.
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10. Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Exp Neurol.* 1969 May;24(1):38-53.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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

Eileen Nicole Simon

December 8, 2010

Subject: Amputation of the placenta

[PII redacted] and I were pointedly ignored at the meeting on October 22. Is this because we both questioned common obstetric interventions? Autism is too serious a disorder to not question all obstetric and neonatal practices. Every medical specialty must provide evidence of safety for every procedure employed.

Sincerely,

Eileen Nicole Simon

--

AMPUTATION OF THE PLACENTA AT BIRTH

Fetal circulation does not stop at the moment of birth. Traditional textbooks taught that the umbilical cord should not be tied until pulsations in it ceased. Pulsations of the umbilical cord are from the newborn's heart, continuing to return blood to the placenta for oxygen until the lungs are fully functional. When the lungs have fully inflated, the fetal shunts in the heart close and pulsations of the umbilical cord cease.

Many obstetricians do still wait for pulsations of the cord to cease, or at least for evidence that the newborn lungs are fully functional. Many obstetricians have objected vehemently against the protocol adopted during the 1980s to clamp the umbilical cord immediately at birth. Read the online rapid responses to the article by Hutchon, many from retired obstetricians [1].

The obstetric profession needs to encourage all practitioners to wait for full lung function before clamping the umbilical cord. Banking of umbilical cord blood is a large part of the present-day problem. Other errors in obstetrics and neonatology have had to be corrected, (a) use of diethylstilbestrol to prevent miscarriage, and (b) routine injection of synthetic vitamin K at birth are examples that gained widespread public attention [2-4].

Amputation of the placenta can cause a lapse in respiration, and evidence has long been available that this can result in ischemic injury of nuclei of the brainstem auditory pathway, which in turn can interfere with a child's learning to speak [5].

The IACC should initiate discussion with policy-makers in the obstetric profession.

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5. Windle WF. Brain damage by asphyxia at birth. *Sci Am*. 1969 Oct;221(4):76-84.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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

Eileen Nicole Simon

December 10, 2010

Subject: Ranking of written comments

RANKING OF WRITTEN COMMENTS

I have been submitting written comments to the IACC for nearly 3 years now. I have received no acknowledgement beyond being told that my comments will be submitted to the committee for their consideration. I have been asking for (a) the brain and (b) developmental language disorder to be included as priority research projects for the Strategic Plan, but these have yet to be included. Why? Why isn't research on developmental language disorder of primary importance?

Why isn't it important to consider brain impairments beyond vague associations of gene abnormalities to synapse chemistry? Abnormal patterns of cell migration and myelin formation, structural and functional differences in the amygdala, fusiform gyrus, cerebellum, basal ganglia, hippocampus, cortical mini-columns, and under-connectivity within the cerebral cortex have all been reported in people with autism. Shouldn't research on genetic and perinatal brain insults underlying these specific abnormalities be important? Are toxic factors perhaps to blame for increasing gene abnormalities (especially perhaps in mitochondria) as well as direct effects on brain maturation?

Would it be possible to list the topics submitted as written comments for each meeting? Could the comments be ranked for relevance to understanding autism? If not why?

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

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

Eileen Nicole Simon

December 10, 2010

Subject: Consider two interacting environmental factors

Attached is a vaccine research strategy that I submitted for the IACC meeting held February 4, 2009. It is also viewable at <http://www.conradsimon.org/files/IACC4feb2009strategy.pdf>

Two or more environmental factors can interact and cause injury to the brain, even though each factor alone would not. It is not necessary to postulate a genetic predisposition for susceptibility to environmental factors. My attached proposal is based on research that provided evidence that high bilirubin levels alone are not damaging to the brain (no ultraviolet (UV) lights needed). Even low levels of bilirubin will cause selective staining of selective subcortical nuclei following any factor that disrupts the blood-brain barrier (BBB). Ischemic injury at birth first and foremost damages the blood-brain barrier. Certain antibiotics and combinations of antibiotics have also been found to impair the blood-brain barrier.

Any genetic or environmental factor considered for "what caused this to happen" must be investigated for its effect on specific systems of the brain, not just synapse impairments everywhere in the brain. Areas of the brain involved in learning to speak should be of primary interest, like the inferior colliculi in the auditory pathway, which because they have higher blood-flow than any other area of the brain will be more susceptible to any abnormal metabolites in the circulation.

Eileen Nicole Simon, PhD (Biochemistry), Registered Nurse (RN)
[PII redacted]

Attachment #1 to Eileen Nicole Simon's December 10, 2010 submission:

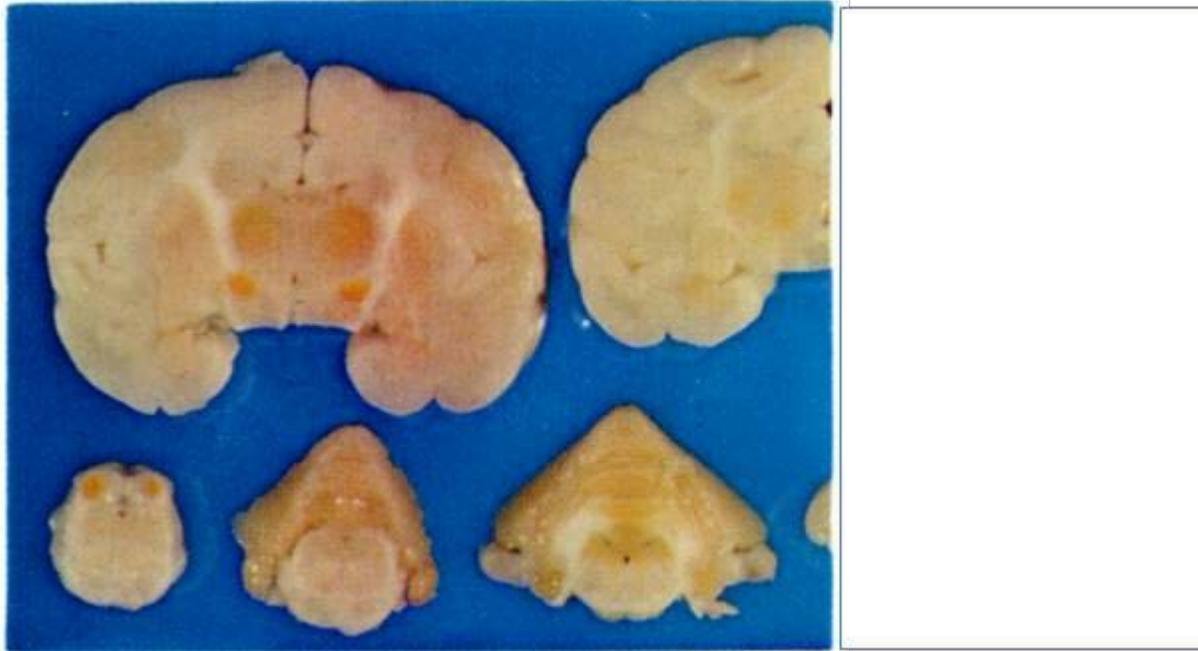
A working hypothesis and plan for vaccine research is needed. I propose:

Working hypothesis – vaccine injury may be similar to that caused by bilirubin. Plan –

- (a) Review existing evidence on brain injury from toxic substances [1-14].
- (b) Design experiments with mice, rats, and monkeys

Bilirubin staining is not uniform throughout the brain.

Vaccine components are likely also more toxic to subcortical areas of high metabolic rate:



Not all children are injured by vaccinations, because injury likely results from two factors: Note, not all children are injured by high bilirubin levels [15-17].

Bilirubin enters neurons following disruption of the blood-brain barrier [18-21].

The blood-brain barrier is disrupted by ischemic anoxia [22, 23].

A baby slow to breathe at birth may suffer anoxic disruption of the blood-brain barrier. The blood-brain barrier can also be disrupted by synthetic vitamin K, or antibiotics [24-27].

A baby treated with antibiotics may suffer toxic disruption of the blood-brain barrier.

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Existing evidence on brain injury from toxic substances [1-14]

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Not all children are injured by high bilirubin levels [15-17]

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Bilirubin enters neurons following disruption of the blood-brain barrier [18-21]

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The blood-brain barrier is disrupted by ischemic anoxia [22, 23].

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The blood-brain barrier can also be disrupted by synthetic vitamin K, or antibiotics [24-29]

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