

Written Public Comments

**IACC Full Committee
Meeting**

March 14, 2008

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B. Sachau

February 20, 2008

It is clear a very high priority should be given to the confluence of vaccines, which still contain mercury, into small babies have on their bodies. They are injected with quantities of mercury in the adjuvant far above what babies should have as safe [offensive language redacted]. The mothers have told you. Who knows those children better than them? Certainly not the people at the National Institutes of Health (NIH) who have [offensive language redacted] while this epidemic continues.

B. Sachau

Eileen Nicole Simon

February 26, 2008

I want to point out the similar statistics for autism and "respiratory depression" at birth. Respiratory depression of an infant born alive means that transition from placental to pulmonary respiration has not taken place before the umbilical cord is clamped. How many prospective parents have any idea that the current obstetric protocol is to clamp the cord within seconds after birth? Widespread adoption of this protocol dates back to the mid-1980s and corresponds to the beginning of increased prevalence of autism. Respiratory depression (low Apgar scores) means anoxia, which can cause selective damage of the auditory pathway in the midbrain. This does not mean hearing loss, but may impair acuity for sounds required for learning to speak, and brainstem damage at birth prevents normal maturation of the cerebral cortex (Faro JvID & Windle WF, Exp Neurol. 1969 May;24[1]:38-53 - old but still relevant evidence). See also my website below, especially <http://www.conradsimon.org/AutismPrevalence.html>.

Disruption of the blood-brain barrier (BBB) by anoxia at birth also allows bilirubin, mercury, and other circulating toxins to enter neurons of the brain. I do believe autism can be viewed as a variant of kernicterus, which is also on the rise. I do want to bring these issues, especially the obstetric error of umbilical cord clamping to the attention of the IACC, and to have the chance for discussion of my concerns with members of the IACC. Thanks.

Eileen Nicole Simon, PhD (Biochemistry), RN

Perry Olson

February 28, 2008

I would like to speak about our at-home intensive applied behavior analysis (ABA) program, including our remarkable results and difficult funding issues. Our children are 5 and 3; both have been in an intensive ABA program since 23 months and 18 months of age. The 5 year was diagnosed as moderate/severe autism at 23 months and we were told he may never speak and may have to be institutionalized. At the age of 5, he is finishing up kindergarten in a typical classroom one year ahead of his peers. He is outgoing, confident and a bright child with a wonderful future ahead of him.

In the future, instead of us filling out institutional or group housing applications, our children will likely be filling out college applications. We have spent over \$250,000 out of pocket, but it was worth every cent.

We had to move from Washington DC area, leaving our life and all friends to find a school district that would help our children. We found that in Amherst New Hampshire.

We want all children with autism to have the opportunity to become functioning members of society and to lead happy independent lives.

Thank you

Eileen Nicole Simon

March 7, 2008

Following is what I want to emphasize:

1. Abnormal language development is the most serious handicap for children with autism, and even Asperger syndrome.
2. The auditory pathway is essential for learning to speak.
3. Injury of the auditory pathway at the midbrain level results in loss of speech comprehension. At least 9 case reports are summarized at <http://www.conradsimon.org/Language.html>.
4. Blood flow and metabolism are higher in the auditory pathway than any other area of the brain.
5. Asphyxia at birth damages this metabolically most active area of the brain, and results in disruption of maturation of the cerebral cortex (Faro & Windle. Exp Neurol 1969;24:38-53).
6. Other known causes of autism, like mitochondrial disorders and phenylketonuria are likely to affect the metabolically most active auditory system.
7. Birth complications are associated with autism, though often dismissed or downplayed.
8. Anoxia at birth and other predispositions for autism damage the blood-brain barrier (BBB), which has been shown to allow secondary injury by factors like bilirubin (Lucey et al. Exp Neurol 1964;9:43-58).
9. Obstetric and neonatal care protocols may contribute to "respiratory depression" (anoxia) at birth, and should be investigated as factors in the increased prevalence of autism. I have posted more at: <http://conradsimon.org/AutismPrevalence.html>.

Any comments would be appreciated.

Thanks

Eileen Nicole Simon

March 7, 2008

The issue of oxygen insufficiency at birth needs to be addressed because the auditory system is selectively affected, which can surely impact learning to speak. Autism is too tragic to neglect or downplay this important predisposition.

ATTACHMENT

- 1.) Could the auditory system be the final common pathway in the brain affected by all of autism's multiple etiologies?
- 2.) Midbrain auditory system injury impairs speech understanding. Figure 1. Johkura K et al. Defective auditory recognition after small hemorrhage in the inferior colliculi. *Journal of Neurological Science*. 1998 November 26;161(1):91-6. Nine such case reports are summarized at: <http://www.conradsimon.org/Language.html>
- 3.) The highest blood flow and metabolism in the brain is in nuclei of the midbrain auditory system. Figure 2. Kety SS. Regional neurochemistry and its application to brain function. In French, JD, ed, *Frontiers in Brain Research*. New York: Columbia University Press, 1962. pages 97-120.
- 4.) Experimental asphyxia at birth damaged the midbrain auditory nuclei, and long-term maturation of the cerebral cortex was disrupted. Figure 3. Faro MD, Windle WF. Transneuronal degeneration in brains of monkeys asphyxiated at birth. *Experimental Neurology*. 1969 May;24(1):38-53.
- 5.) Blood-brain barrier (BBB) damage caused by anoxia, antibiotics, and other etiological predispositions to autism allows secondary damage from bilirubin, mercury, or abnormal metabolites of genetic-metabolic disorders.
- 6.) Obstetric and neonatal care protocols may contribute to increased prevalence of autism. See: <http://www.conradsimon.org/AutismPrevalence.html>.

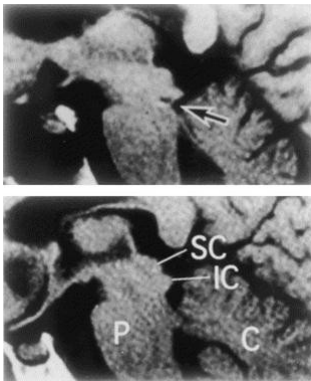


Figure 1

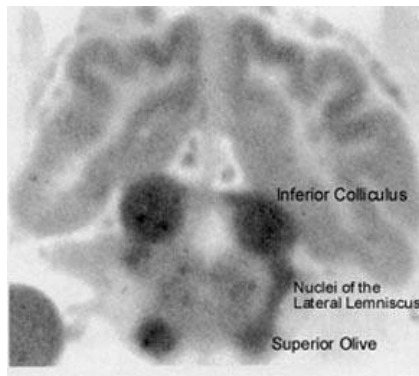


Figure 2

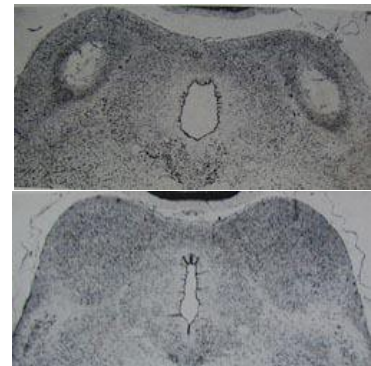


Figure 3

Figure 1 – Injury of the inferior colliculi in a skiing accident (top) led to loss of speech comprehension. Johkura et al. (1998).

Figure 2 – Highest blood flow and metabolism in the brain is in nuclei of the brainstem auditory pathway. Kety (1962).

Figure 3 - Asphyxia at birth damages nuclei of the midbrain auditory pathway. Faro & Windle (1969).

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

Joseph Mele

March 8, 2008

I am Joseph Mele. I have also started Autistic Pride LLC (limited liability company). Autistic Pride has the aim to empower autistics with knowledge of business and money. Economic empowerment is a key issue for many on the spectrum.

I am not here to give some trite simple minded verbiage about autism being a blessing. Nor am I given to preach the hopelessness and devaluation of autistic lives that [offensive language redacted] groups promote. Soren Kierkegaard, the Danish existentialist wrote "God blesses those he [offensive language redacted] in the same breath". Much of my thoughts here today are informed by the story of [PII redacted] as presented by Kierkegaard in "Fear and Trembling".

Not all awareness is good awareness. It is simply not enough to support awareness. I am very much against the disabling attitude promulgated by Autism Speaks and others. On one level, it feeds into the despair and initial hopelessness. Parents who don't know what autism is when faced by this unknown are disoriented, breeding fear and anger. They are ripe targets for any snake oil salesman that comes by. On another level, it contributes to the disrespect and devaluation of autistic lives. It does not promote understanding of stimming and comorbidities. It even promotes lies how autistics do feel about themselves.

Autism cannot speak. Just like [PII redacted] could not speak. How intelligible, is it for a father to kill his son that he adores? If autism did speak it would be unintelligible as well. For it is fantastic to have friends, to be loved and respected and admired. But the paradox of autism and it is really is a paradox or it would be done for as much as [PII redacted] would be done for if faith was not a paradox. If it was not a paradox, It would be on the order of a disease, Such that only an evil person would oppose a cure. But autism is so much more than simply that.

The Greek tradition that threads itself throughout our society is the poison that we are in need of a cure from. A priori goodness, beauty. Also what it means to be human. All absolute standards any deviation from which is sickness, disease and death. Kierkegaard wrote about what it means to be not in alignment with the universal in the discussion of the book of Tobit. He relates this to being born different. To be someone out of alignment with the universal from the start. This is about all of us who are born not in alignment with the universal whether they are autistic, Down syndrome, cleft lip or just clearly not the same as most people.

We must value autistics on their own terms. Many autistics have made huge contributions to our society. Browbeating an autistic to give up his arcane and narrow interests in the quest of being social as his focus is no victory. An autistic will always be autistic. To have him to give up his gift of being unintelligible is a terrible price to pay. We all know that this social acceptance and social conformity is an artificial construct foisted upon him. As it is, a violation of his nature it will never be truly his. Condemned to be ordinary, Kierkegaard relates how it is a mockery to say to [PII redacted] - "Why don't you express the universal and get married." It is a mockery too to say to those on the autistic spectrum for example, "Why don't you express the universal and get married, enjoy sports, sit still, stop

it with arcane facts on medieval pottery that Nobody wants to hear".
[PII redacted] when he invented bit torrent, he was alone not managing a team. Was he intelligible?
[PII redacted] see the value of his work before it was finished? When [PII redacted] received the Nobel Prize, He stood alone. When did his colleagues see the value of his work? If they really saw the value and the forthcoming Nobel Prize it is hard to imagine that they would not jump in with both feet right away. No, they were unintelligible. Aligned with universal in the end on the basis of faith on the strength of the absurd or paradox.

So here is the reason why the puzzle piece is so pernicious. It truly represents the fact autistics being out of alignment with universal are an enigma. It is condemnation from a society that praises social recognition and clarity. It has no room individual unintelligibility to the whole. Without which you cannot have individuals rise above and achieve what the society thinks and deems impossible. It mocks the very foundation of autistic existence. It is worn by those that imagine their lives have a value and meaning autistic lives don't because those lives and their meanings are unintelligible in the immediacy. It must be remembered that to truly [offensive language redacted].

When it comes to formulating public policy on autism it should be about letting autistics be comfortable in their own skin, unintelligible to society but en-pensioned with their goals. Allowing them to be them. Anything less is disrespectful and unacceptable. Autism is only a tragedy in society that cannot understand the true worth of an individual. Autism is a challenge, something to get through not overcome.

Michael Carnevale

March 10, 2008

My Name is Michael Carnevale and I live in Princeton, New Jersey. I am the parent of a child with autism, who turns 14 years old today. Initially, I would very much like to thank the members of the Committee for the opportunity to speak, and also for your efforts on behalf of our children.

I ask the committee to include the following adult service elements into its planning, and particularly to encourage and direct research into identification of the best methods and practices to accomplish important adult ASD service goals.

As an interagency coordinating committee, you are uniquely, and perhaps solely, well placed to effect meaningful improvement in ASD adult services.

It is evident that many ASD children can develop the ability to perform meaningful work, and earn a wage. The pre-Kindergarten through 12 (ages 3 to 21) education should afford an ASD student a base from which to proceed with life skills, vocational and employment training, which could begin in school. To be something other than a hollow exercise, however, training for ASD students should be coordinated with willing and appropriate employers. These employers, public or private, would be willing to hire the ASD adult for a suitable position. This pool of employers could be expanded using an incentive system, many of which are already used in Federal programs to accomplish other worthy goals.

Beyond limitations inherent in the disability itself, ASD adults seeking employment will be geographically limited due to mobility problems, may require more supervision than a typical worker given comprehension issues, and will face difficulties in simple matters such as commuting unless other supports are in place.

The IACC should direct research and planning to:

- a. Establish a model, at the Federal level, perhaps through or in conjunction with ASD service provider(s), for public-private training scheme whereby training is provided to ASD students/adults by public entities to fit jobs which are actually available in the workplace, either in the public or private sector. The model should be developed realistically and on the basis of empirical data and sound analysis to identify suitable occupations and employers, bearing in mind the spectrum nature of the disorder.
- b. Encourage adoption of training to work schemes by the States.
- c. Identify and propose incentives or mandates (as the traffic will bear) for employers to hire ASD adults such as set-asides on government contracts or contractors, tax incentives, and recognition of cooperating employers. Money earned by ASD adults could help offset some care or housing expenses.

The IACC should examine this issue in its research and propose solutions in the area of supervised housing, perhaps involving additional agencies.

Clearly, many ASD adults should be able to enjoy a decent, healthy quality of life and contribute to the community if accorded adult support. That support will differ based on each individual's needs and abilities. Support will help ASD adults to shop, cook if appropriate and safe, handle their limited finances (such as making small purchases), engage in self-care including personal hygiene and dressing, the use of medication and health care issues, and to avoid dangerous situations. Research and anecdotal evidence of experiences of ASD adults appears to establish that an ASD adult's intellectual functions will continue to develop and improve practical function given continued use and training. A program of continuing education will therefore help many improve their life skills and, significantly, their neurological function throughout their lives.

The IACC should conduct research and planning into the most effective methods to encourage and require the increasing accessibility of ASD adults to adult life skill support, including supports offered by various providers, coaches and teachers. This should include some level of part-time continuing education. The creation of a pool of trained ASD adult support providers, especially as part of a coordinated approach combining employment, housing and life skills together, would go a long way toward meeting needs of ASD adults.

The establishment of research-based methods and practices of providing adult ASD services could only be helpful in focusing, supporting and directing public and private ASD services.

Thank you very much for your time and attention.

Patrick Kelty

March 10, 2008

My name is Patrick Kelty. I am 18 and have autism.

This year I had my first excellent year in school. In the past, teachers abused and ignored me. Now I am about to graduate and I have not really had a decent education.

What waits for me now?

I know little kids matter but they have many years to catch up. What about us?

What about me and my friends who have autism and no one understood us? How are we supposed to catch up? What do you plan to do about it?

I want to go to college, but all the colleges for kids with autism are really expensive and we don't qualify for financial aid.

Why not?

Why can't a part time student go to college on financial aid? I would like that.

This summer I will go to Denver for four weeks to try to learn skills the schools denied me over many years.

It costs \$1000 a week.

Can't we do better than that?

Thank you

Patrick Kelty

Graduate; Youth Leadership Forum

Nashville, Tennessee

Nina Wall Cote

March 14, 2008

It is a pleasure to be able to offer comments to you all today. My name is Nina Wall Cote and I serve as the Director of the Bureau of Autism Services, at Pennsylvania Department of Public Welfare. I am joined here today by my colleagues, Claire Choutka, our Bureau's clinical director and Pia Newman, the Bureau's Assistant Director. Prior to my tenure in state government, I worked as a therapist in private practice providing support to families of individuals living with autism as well as persons with autism. I will also share that I am the parent of a young man with autism, who celebrated his 18th birthday last weekend. I have worked in the system as an advocate locally, regionally and at the state level and served as co-chair of Pennsylvania's Autism Task Force.

The Autism Task Force was commissioned by DPW Secretary Estelle Richman in 2003. The Autism Task Force generated a comprehensive report which has served as a blueprint for all of the work currently underway in the Autism Bureau - a year old last month. It is heartening to us as a Bureau and as family members to see the unprecedented focus on ASD in the media, to see dollars flowing to any number of important scientific research endeavors that we hope will shed light and provide understanding regarding etiology of this disorder affecting 1/150 individuals.

While our Pennsylvania families affected by autism offer strong and tireless support to the necessary work of science in understanding in our understanding of autism-what we also hear from families, and the professional community, with equal passion and palpable urgency is a clamor for need for resources to be directed to the arena of service provision.

We find ourselves in an environment where there are no uniform standards with respect to diagnosis, assessment, treatment and training; without standards, anything goes. As a nation we are uniformly challenged by the lack of professionals trained to understand and to support the complex and varied needs that characterize the spectrum that is autism.

In 2008 we see faces of children affected by autism in the media, an important development when considering only 10 years ago, a parent given a new diagnosis was hard pressed to find any useful resources regarding their child's diagnosis or any existing services and supports. Children with autism become adults with autism. What we do not see in 2008, are the faces of adults with autism in the media. Also absent is the needed focus on the services needed to support adults with autism and their families.

Our families are exhausted and stressed and this is often not exclusively due to the needs of their children, but from having to unilaterally piece together or privately fund the services that will make the difference in whether a person has a chance at an independent life.

In Pennsylvania there is much work underway. We are in the process of developing the standards that are sorely lacking, crafting training protocols and undertaking the work of capacity building at all levels in the system. Pennsylvania has recently submitted a Medicaid waiver application to CMS, the focus of which will be to support adults with autism.

We have also crafted a model to support adults with autism based on an 'a' waiver authority which, once we receive CMS approval, will be rolled out as a pilot project in one region of our state. The PA

Autism Bureau will bring up three regional autism centers this year. The ASERT Centers will serve as hubs for the work in the area of applied research endeavors, training, resource development and information dissemination. The regional centers will be collaborations between entities that house the autism expertise in various regions of the Commonwealth.

Services are lacking. Dollars to fund services are dear. We spend a disproportionate amount of time crisis managing while people with autism fall into inappropriate from systems or languish at home with only support from their aging parents who fear what will happen to their sons and daughters when they are gone.

We have to find ways to reach out to families and people with autism who are "lost ' in the system, live in rural and economically challenged areas or who are otherwise isolated without the means or the contacts to secure desperately needed services and support. We need to ensure that we are listening to those individuals living with autism who are able share their stories and express what it is they want and need to lead productive lives. We need to make sure we remember how there can never be a "one size fits all" response to a community whose needs are so vastly different.

Nationally, we face a crisis of monumental proportions as we see an exploding population of individuals who are being diagnosed with ASD. As states and as a nation we cannot be remiss by not focusing on the need to develop appropriate services to support individuals with autism across the lifespan and across the autism spectrum.

It is our great hope, as a state that is home to some of this country's finest researchers in the field of autism, that nationally we are able to strike the same balance that we strive to establish in Pennsylvania between the need to balance the important work of science with an equal attention and focus to the realm of service delivery.

Thank you for your kind attention.

Nina Wall Cote, Director
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