

**From:** IACC (webmaster@nih.gov)  
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**Date:** Sunday, August 16, 2009 11:00:11 AM  
**Subject:** Your submission to the IACC

Thank you for your submission to the IACC. This is your receipt, and your answers are provided below:

## **I. Strategic Plan Question 1: When should I be concerned?**

### **a. What relevant research topics are missing or underrepresented in section I. "When should I be concerned?"**

My concerns began right after the traumatic births of my first two sons. My first baby had a large cephalhematoma that covered the right side of his head for most of his first year of life. The pediatricians told us not to be concerned, and not to be concerned with his delayed motor and language development. My second son was stillborn, then brought back to life by resuscitation. He also became very jaundiced during his first week of life. His motor development was right on time, but his language developed as an increasing repertoire of phrase fragments learned in one context then applied according to Kanner's description of "irrelevant and metaphorical" comments in new contexts. I thought birth injury had just been bad luck until Dr. George Morley responded to my website. See (1) Morley GM. Cord closure: Can hasty clamping injure the newborn? OBG Management, July 1998: 29-36, and (2) his website at <http://www.autism-end-it-now.org/>

### **b. What are the new opportunities and needs for advancing research and knowledge about ASD in section I. "When should I be concerned?"**

Many children with autism suffered complications at birth. Epidemiologists never make more than passing mention of how the brain might be affected, then suggest that "some defect" in the mother or child caused the difficult birth. See Windle WF. Brain damage by asphyxia at birth. Sci Am. 1969 Oct;221(4):76-84. Monkeys were prevented from breathing and the umbilical cord was clamped off at birth. Damage to the brain was in the inferior colliculi of the midbrain auditory pathway. There are at least 13 case reports published of people who lost the capacity to understand spoken language following bilateral injury of the inferior colliculi. See citations to these case reports at <http://www.conradsimon.org/IACCMay12Comment.pdf> beginning at the bottom of page 8. How much more serious this would be for a human infant with damage of the inferior colliculi caused by asphyxia at birth.

### **c. What are your suggestions for prioritizing the research objectives in section I. "When should I be concerned?"**

Look at (1) Odd DE et al. Resuscitation at birth and cognition at 8 years of age: a cohort study. Lancet. 2009 May 9;373(9675):1615-22, and (2) the response to Odd et al.'s article by Mercer J & Bewley S. Could early cord clamping harm neonatal stabilization? Lancet. 2009 Aug 1;374(9687):377-8. The effects of asphyxia at birth caused by umbilical cord clamping (now also to harvest placental blood) and other invasive obstetric and neonatal care protocols need to be examined for safety. Medical error must be looked for, not disregarded. See the three articles by AF Robertson, Reflections on Errors in Neonatology in the Journal of Perinatology. 2003 Jan;23(1):48-55, Mar;23(2):154-61, and Apr-May;23(3):240-9.

## **II. Strategic Plan Question 2: How can I understand what is happening?**

### **a. What relevant research topics are missing or underrepresented in section II. "How can I understand what is happening?"**

Idiopathic autism is not necessarily the result of some yet to be identified genetic cause. Environmental causes must be sought for the recent increased prevalence of autism. Consider combinations of two or more environmental factors - not just gene-environment interactions. Almost all infants are subjected to invasive obstetric procedures and neonatal treatments. Clamping of the umbilical cord, vaccinations, and antibiotic treatments do not cause apparent harm to most infants, but infants unlucky enough to suffer

ischemic impairment of the brain (by clamping off postnatal placental blood flow too soon) may be at greater risk for injury from postnatal treatments. Vaccination is a highly visible intervention. Most of us are completely unaware of other interventions. We need to ask and be informed of all perinatal standard treatments. See my suggestion for a vaccine research strategy at: <http://www.conradsimon.org/files/IACC4feb2009strategy.pdf>

**b. What are the new opportunities and needs for advancing research and knowledge about ASD in section II. "How can I understand what is happening?"**

Focus on the brain, and how it can be affected by all of autism's etiological causes. Blood flow and metabolism are not uniform throughout the brain. The brain is a collection of sensory and motor systems. The auditory system has greater blood flow and metabolism than any other component of the brain. The auditory system is the alerting system of the brain, and may be the essential system for general awareness at some level. Children with autism display hyperacusis and lack the normal (and expected) ability to learn language through the auditory sense. People working in the field of auditory processing should be encouraged to take an interest in the language disorder of children with autism. People working in the field of computational analysis of speech (as now in use to create subtitles for meetings) should likewise be urged to investigate what is missing in the autistic child's analysis of speech.

**c. What are your suggestions for prioritizing the research objectives in section II. "How can I understand what is happening?"**

See the recent paper by Russo N et al. Brainstem transcription of speech is disrupted in children with autism spectrum disorders. *Dev Sci.* 2009 Jul;12(4):557-67. As for greater male vulnerability see the paper I published with my dissertation advisor, Simon N, Volicer L (1976) Neonatal asphyxia in the rat: greater vulnerability of males and persistent effects on brain monoamine synthesis. *J Neurochem.* 1976 May;26(5):893-900. Look at effects of alcohol, valproic acid, thalidomide, and other drugs on the brain. Alcohol affects brainstem centers of high metabolic rate, like the inferior colliculi and mammillary bodies, as do other drugs. See Husain K et al. Carboplatin-induced oxidative injury in rat inferior colliculus. *Int J Toxicol.* 2003 Sep-Oct;22(5):335-42. and Cavanagh JB & Nolan CC. The neurotoxicity of alpha-chlorohydrin in rats and mice... *Neuropathol Appl Neurobiol.* 1993 Dec;19(6):471-9.

### **III. Strategic Plan Question 3: What caused this to happen and can this be prevented?**

**a. What relevant research topics are missing or underrepresented in section III. "What caused this to happen and can this be prevented?"**

Autism is associated with many etiologies, including genetic metabolic disorders. What is needed is to look for a final common pathway in the brain affected by all predispositions for autism. Phenylketonuria (PKU) was a genetic cause of autism in the past. Note that discovery of the metabolic defect in PKU, and treatment by dietary restriction of phenylalanine, predate discovery of the structure of DNA. PKU is caused by a defective enzyme in the liver, not the brain. Abnormal metabolites (mainly phenylpyruvic acid) of this defective enzyme are clearly toxic to the brain. Within the brain, the auditory system has the highest rate of blood flow and aerobic metabolism and is most vulnerable to toxic abnormal metabolites like phenylpyruvic acid. Developmental language disorder is the core handicap of children with autism. The brain impairment underlying this handicap is the final common pathway of all etiologies of autism, and likely includes the auditory system.

**b. What are the new opportunities and needs for advancing research and knowledge about ASD in section III. "What caused this to happen and can this be prevented?"**

Folstein & Rutter (1977) reported concordance for autism in 4 of 11 pairs of monozygotic twins. Of 21 twin pairs, 17 pairs were discordant for autism and in 12 pairs autism was associated with an event likely to cause brain damage. Of the identical twins studied by Belmonte & Carper (2006), the more seriously affected twin was not breathing at birth, and at 9 months of age he failed a hearing test. Norman (1982) noted that perinatal hazards are increased for twins and that thus twins are not a good model for genetic versus environmental studies of things like intelligence. References: (1) Folstein S, Rutter M. Infantile autism: a genetic study of 21 twin pairs. *J Child Psychol Psychiatry* 1977 Sep;18(4):297-321. (2)

Belmonte MK, Carper RA. Monozygotic twins with Asperger syndrome: differences in behaviour reflect variations in brain structure and function. *Brain Cogn.* 2006 Jun;61(1):110-21. (3) Norman MG. Mechanisms of brain damage in twins. *Can J Neurol Sci.* 1982 Aug;9(3):339-44.

**c. What are your suggestions for prioritizing the research objectives in section III. "What caused this to happen and can this be prevented?"**

Research with twins as described above provides strong evidence that genetics has less to do with causing autism than environmental causes of brain damage. What causes brain damage in the perinatal period, and what systems of the brain are more vulnerable to damage? Neurotransmitter hypotheses are currently too non-specific. Investigation of inhibitory versus excitatory neurotransmission in specific brain structures like the inferior colliculi may shed some light on how acoustic processing might be disrupted in children with autism.

#### **IV. Strategic Plan Question 4: Which treatments and interventions will help?**

**a. What relevant research topics are missing or underrepresented in section IV. "Which treatments and interventions will help?"**

Every effort must be made to promote language development. Deaf sign language was helpful for my son who was resuscitated at birth. My son who suffered head trauma learned to read before he learned to speak. He could read single words at age two, but did not speak in sentences with grammatical innovations until he was almost six. Until then he was fluently echolalic – his speech appeared “metaphorical and irrelevant” to those who did not know him well. His speech was “pragmatic” for those of us who did know him well. Medications should not be used until the dysfunctional brain systems that cause autism are understood. Vitamins might be useful, especially vitamin B1 (thiamine – an essential co-enzyme for aerobic enzymes), especially in cases where mitochondrial disorder is suspected. When my children were young we tried all the fads plus megavitamins that made us burp (and I ate and took what they did). We thought our oldest son was cured. Sadly he is not.

**b. What are the new opportunities and needs for advancing research and knowledge about ASD in section IV. "Which treatments and interventions will help?"**

Language is the most characteristic difference of humans from all other animal species. Linguists should be encouraged to take an interest in the characteristic language disorder of children with autism. Memory for the musical envelope of speech is preserved, as is pronunciation. Linguists have studied things like “distinctive phonological features” and “syntactic transformations”. My son who was resuscitated at birth had no delays in motor milestones or beginning speech. By age two he was singing all the Christmas carols, including The Twelve Days of Christmas, with clear pronunciation and perfect pitch. At age four, he finally made his first “grammatical transformation”, saying, “I’m a good idea,” at the door wiping his feet – derived from having been told many times, “That’s a good idea” or “That’s a good boy,” for wiping his feet on the doormat. What prevented normal development from single words to baby-talk and progressive mastery of syntax?

**c. What are your suggestions for prioritizing the research objectives in section IV. "Which treatments and interventions will help?"**

Can children with autism be helped to hear syllable boundaries, and taught to use “baby talk”? Brown and Bellugi (1964) determined that children first recognize stressed syllables before beginning to speak. Stressed syllable word fragments are then used in unique syntactic arrangements. The ability to make syntactic transformations appears to be an innate human capacity from an early age. The results are what Brown and Bellugi referred to as “telegraphic speech” e.g. “Apple, I want” or “Mommy go store”. The echolalic autistic child would instead say something like, “You want the apple?” or “Mommy has to go to the grocery store.” Can autistic children be taught to hear and use single syllables and make syntactic rearrangements? References: (1) Brown R, Bellugi U. Three processes in the child’s acquisition of syntax. *Harv Educ Rev.* 1964; 34:133-151. (2) Brown R. *A First Language: The Early Stages.* Cambridge, MA: Harvard University Press, 1973.

## V. Strategic Plan Question 5: Where can I turn for services?

### a. What relevant research topics are missing or underrepresented in section V. "Where can I turn for services?"

Where can we turn? Who will pay for lifelong care? Actuarial scientists from Social Security should be included in the IACC panel of agency experts. Actuarial scientists may be more aggressive at seeking environmental causes of the increased prevalence of autism. They might bring a new perspective on what kind of research could more quickly lead to prevention. Another way to involve actuarial scientists would be to require long-term-care insurance be purchased by parents of every child born. This should take priority over banking of umbilical cord blood. Banking of umbilical cord blood is dangerous, because it may prevent full natural transition from fetal to neonatal respiration. Placental blood is respiratory blood and by nature's plan should be transferred to the capillaries surrounding the alveoli. Otherwise blood may be drained from the brain for the more immediate needs of the pulmonary system.

### b. What are the new opportunities and needs for advancing research and knowledge about ASD in section V. "Where can I turn for services?"

Housing and food are basic human needs, and our capitalistic democratic society is clearly failing to ensure these needs are met for everyone. Financial bailouts for mortgage lenders are the disgrace of the current American system. The right to private ownership should not be denied to those fortunate enough to be able to accrue sufficient assets to provide for their own needs. However, we need socialism to the extent required to provide for those who are disabled and unable to survive without assistance. I suggested to my legislators that rather than bail-out banks, they should give the money to Marriott Hotels to build enough Residence Inn Hotels to ensure housing for everyone. I am sure entrepreneurs at Marriott would know how to take the money, build the hotels, and eventually make a profit by encouraging those they housed to work toward shared ownership of their homes – providing jobs as housekeepers, cooks, maintenance, grounds keepers, etc. Please look into this.

### c. What are your suggestions for prioritizing the research objectives in section V. "Where can I turn for services?"

Put the \$16,700,000 and \$7,000,000 proposed in the Strategic Plan for "evidence-based services" and "effective interventions" in community settings up for bid. Encourage companies like Marriott to consider what opportunities this might provide for them. Encourage partnerships between companies like Marriott and current community service providers, like Vinfen in Massachusetts. Put out a bid for real and thoughtful new strategies. In the following section on what the future holds, you state that little is known about autism spectrum in the criminal justice system. I work in the Massachusetts Department of Correction, and know that statistics can be gathered. First, autism and Asperger spectrum disorders can clearly be seen as part of a wider spectrum of developmental disability. Further, many physical problems like gastro-intestinal disorders, asthma, and diabetes are clearly evident to direct care-givers. Note also: Incarceration is the costliest kind of long-term care.

## VI. Strategic Plan Question 6: What does the future hold?

### a. What relevant research topics are missing or underrepresented in section VI. "What does the future hold?"

My son with ASD is now 46 years old. I have now spent more than half my life working to try to understand and work with his cognitive impairments. I even returned to school and earned a PhD in biochemistry. Why are my efforts to discuss what I have learned over more than 40 years so disregarded? Trying to suggest ideas to the IACC has been like trying to talk to a stone wall. I would appreciate seeing the IACC discuss not only pre- and post-natal problems, but birth itself. This seems to be more of a taboo subject than vaccinations. Obstetric protocols have become more invasive over the same two decade period that autism prevalence has increased. Most important is the evidence (also disregarded) that the auditory system of the brain is injured by asphyxia at birth, which most likely impairs language development.

**b. What are the new opportunities and needs for advancing research and knowledge about ASD in section VI. "What does the future hold?"**

My first two sons and I participated in the Collaborative Perinatal Study (CPS) which was to have been a prospective study of perinatal health and outcomes. The National Children's Study looks like a re-invention of this idea. The IACC should try to find the data collected in the CPS and find children who developed autism, and try to locate these individuals now. If these data are now thought to be out of date, why is there such a clamor for prospective versus retrospective studies? Then do retrospective studies. I have worked for nearly 18 years at Bridgewater State Hospital in Massachusetts, and in 1994 I applied for a grant to obtain and study developmental records of our patients. I have just proposed to MHM Services (current holder of the contract) that we apply for research grant funding, also to help increase nursing staff – and observations of care givers like nurses in the patient milieu may provide more insight than researchers working in ivory-tower laboratories.

**c. What are your suggestions for prioritizing the research objectives in section VI. "What does the future hold?"**

We need actuarial scientists, from private insurance companies as well as Social Security to do some down-to-earth research on why autism and all developmental disabilities are on the rise (including problems like kernicterus). We can't just keep appealing to legislators, who more often than not pull out empty pockets and chide us about the "duty of family". The basis of a capitalistic society is that "All men are created equal" and clearly this is no longer true in this polluted world, where medical care is based on invasive and unnatural procedures and pharmaceutical poisons.

**Other Information**

Developmental language disorder is the core handicap of children with autism. This needs to be the priority for research on autism. Children learn to speak through hearing. Auditory processing disorders need to be looked for. Evidence published decades ago revealed the vulnerability of the auditory system to injury from any factor that disrupts aerobic metabolism. Perinatal anoxia, prenatal exposure to toxic substances like alcohol or medications like valproic acid (Depakote), and postnatal treatments including vitamin K, antibiotics, and vaccine administration can lead to impairment of metabolism in the auditory system. Every perinatal intervention should be investigated as a possible root cause of injury.