Written Public Comments

IACC Full Committee Meeting

November 10, 2009

List of Written Public Comments

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

Eileen Nicole Simon

October 25, 2009

Subject: Family panel at the IACC Meeting October 23, 2009

Thank you for the family presentations at the IACC meeting on Oct23! Most important for me:

1.) [PII redacted] comment that autism should not be viewed as a human variant without proof. Thank you. Autism is too disabling for most of those afflicted, and their families. The "variant" advocates are like the "myth of mental illness" groups of the past. They detract from the difficult to obtain life-long care needs that seriously mentally ill people need.

2.) Co-occurring physical illnesses like gastrointestinal (GI) disorders point to the multiple etiological factors with autism (a specific impairment within the brain) as a final common pathway. My children had outstandingly good physical health - their brains were affected by trauma and anoxia at birth. It is wrong to dismiss any parents' ideas of what caused their child's autism. What vulnerable systems in the brain are affected by all causes of autism need to be considered.

3.) [PII redacted] stated that learning to read was key. Yes, this was true too for my son who is now 47 years old. He still has difficulty (like people with presbyacusis) with hearing speech. He learned to speak after beginning to point to words (not pictures) in his story books at age 2! He was almost 6 years old before he stopped using phrase fragments and learned to make grammatical transformations (also known as Chomsky's syntactic structures).

4.) [PII redacted] described his problems with manual dexterity, and being taught how to tie his shoe laces in second grade. My son reacted badly once to hearing on the radio that learning to tie shoe laces was a triumph for [offensive language redacted] children - he ran out the back door screaming, "I am not [offensive language redacted]." Fine motor skills are also still difficult for my son.

5.) I would like to learn more about the "Montgomery Exceptional Speakers" program that [PII redacted] spoke about. Voice modulation and learning appropriate interactions remain difficult for my son.

6.) Because of an appointment I did not hear all of [PII redacted]] presentation. Her son's development sounded a lot like that of my second son, [PII redacted] (who died at age 31 in 1995). [PII redacted] needed resuscitation at birth, but we were then very relieved that his motor milestones were all on time. His problems were totally due to developmental language disorder. He was fluently echolalic, but never learned to make more than the most rudimentary and concrete grammatical transformations. We also suspected a hearing problem, and [PII redacted] benefitted very much from learning deaf sign language.

Please arrange more family panels. I would also like to hear dialog between parents and members of the IACC. Please respond to more of the specific issues that we raise
Sincerely,
Eileen Nicole Simon

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Marcia Hinds

October 25, 2009

Subject: What if it really isn't Autism?

The forward for the book I am writing is at the end of my email. What if Autism is not a psychological "disorders," but a treatable medical condition? [PII redacted], my son, was diagnosed by the leading authority on Autism in Minnesota when he was only four years old. This psychiatrist said my son would never be okay. According to this "expert," the best we could hope for is that someday [PII redacted] might be running a computer in the basement of a company. There, he would not have to deal directly with people. [PII redacted] has been treating my son, [PII redacted], medically since he was five. Today [PII redacted] is twenty-one. He does all the things the doctors told me he would never do. [PII redacted] currently attends a university on a merit based academic scholarship and studies Mechanical Engineering. He has a 4.0 GPA (grade point average) in his major and a 3.8 overall. He joined Sigma Chi Fraternity and is president of the Jewish Student Association. [PII redacted] drives and has a ton of friends (who would have seen that one coming?) I want that for all kids afflicted with Autism. Please contact [PII redacted] and make this kind of treatment the norm instead of the exception.

Thanks for listening,
Marcia Hinds
[PII redacted]

[Attachment follows]

Attachment

FOREWORD *by Michael Goldberg, MD*

What if the psychological term "Autism" had never existed? What if ever increasing numbers children were showing up in schools without speech, lost in their own worlds, and having unexplained seizures? Would we be diagnosing these children with a "developmental disorder?" Or would we be looking for root causes of their DISEASE and treating what they have medically? What if your children have is not "Autism" at all, but a medical disease in most part caused by viruses? For many children afflicted with autism, this is the case. The latest scientific research supports this idea and it is exactly what I have been advocating for twenty-seven years.

A study conducted by researchers who collaborated from the Whittemore Peterson Institute, the Cleveland Clinic, and the National Cancer Institute and has tremendous implications for any family dealing with "Autism." This study describes the detection of a virus called XMRV (xenotropic murine leukemia virus-related virus) in about two-thirds of patients diagnosed with chronic fatigue syndrome (CFS).

Many of those diagnosed with "Autism" have blood work that contains these same viruses. Autism (or should I say a "diagnosis" of Autism) has increased in staggering numbers over the past ten years. One in every 91 children in the US has what we refer to as "Autism" (read American Academy Pediatrics Report). These statistics are endorsed by the Centers for Disease Control and Prevention (CDC), American Academy of Pediatrics, and other agencies. California reports a 273 percent increase, Maryland 513 percent, and Florida 600 percent.

When a child is diagnosed with cancer, everyone understands the seriousness of the disease and its treatment. Because of this, cancer research is funded generously. "Autism" is now the third most prevalent childhood disease, but it remains the least funded in terms of research dollars. And how much of these research funds are devoted to the genetic causes of "Autism?" We are wasting what precious funds we have on genetic research for a disease that is, in no way, genetic in nature. In addition, the cost to local school districts in special education expenses is astronomical and growing every year! We are draining budgets and there are kids NOT getting better every day.

What we have is an epidemic. Developmental disorders do not increase by 600% or occur in epidemic proportions. From a purely scientific perspective, an epidemic of something that can't be spread by germs is NOT POSSIBLE. It also should be impossible to medically treat and recover children with these various disorders, but I have been doing exactly that for 27 years (CFS and attention deficit hyperactivity disorder (ADHD)) and now 14 year ("Autistic Spectrum"). [PII redacted], the subject of this book, is just one of many patients now leading productive normal lives. I want that for all children.

We must promote the medical treatment for this disease I call Neuro-Immune Dysfunction or NIDS. I have proven time and time again, kids can get better. We, along with the medical community must come together, rally around the NIDS flag (or any other name you all want except "Autism") and focus on the true medical crisis.

We have lost too much time focusing our energies on the genetic and "refrigerator mother" causes of this disease. The time to act is now. We must refocus our resources and move in the right direction with hard science, hard logic, and hard data and finally address this crisis medically.

This is a tough disease, but as a disease, it is beatable. It more than past the time for parents and the medical community to join hands and lead the charge and make recovery possible for all children afflicted with the disease formally known as Autism.

Marian Dar

October 26, 2009

Subject: Proposed research area: thyroid

Sometimes, you can get insight from looking at events deductively.

In studying the *immunology* of autism, is there a pattern of increased/susceptibility relating to *birth order*?

Could a mother develop an innocuous, but chronic condition (and to all outward appearances mild/subclinical) that might impinge on the health and development of future pregnancies?

For example, *thyroid dysregulation.*

Years ago researchers were surprised to find male fetal cells when they biopsied an elderly women. The thyroid is integral to immune, gastrointestinal (GI) and metabolic function, etc.

Marian Dar

SCIENCE
NEWS

Fetal cells may trigger autoimmune disease. (fetal cells circulating in mother's blood)
Science News | August 2, 1997| Fackelmann, Kathleen | Copyright

Researchers got a jolt some years ago when they tested the blood of a young female laboratory technician. A powerful molecular technique detected the presence of genetic material from the Y, or male, chromosome. The researchers feared something had gone wrong with the test.

Once they realized the technician was 6 weeks pregnant, however, that solved the mystery, recalls Diana W, Bianchi, a pediatric geneticist at the New England Medical Center in Boston. The test had homed in on male DNA (deoxyribonucleic acid) in fetal cells that were circulating in the woman's bloodstream.

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

Diane Miller

October 27, 2009

Subject: Brain studies

Has any research been done on the brain Broca area regarding autism?

Diane D. Miller
[PII redacted]

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

Donna Young

October 28, 2009

Subject: Re: Upcoming IACC Full Committee Meeting - November 10, 2009

To my current knowledge the National Institute of Mental Health (NIMH) will not promote prevention of some known contributing factors of the testable anemic conditions caused by the discretion of some, most of them, doctors. They are seeking for profits, the placenta blood, separating it and selling it for profits at the private or public cord blood banks. Shame on NIMH for failing to ask this one question: "Do either of the natural parents actually know when the umbilical cord was hand-squeezed off (finger- thumb teaching by Dr. Morley to medical students, then released after 10 to 20 seconds); or when the cord was tied-off, or clamped off. The interruption of the placenta blood causes the heart to shrink; the blood to flow away from the brain cells; and causes the infant to be caused a testable anemic condition and to be revived for return of blood and oxygen. In that period time of revival off the umbilical cord the brain can be subtle to seriously damaged and other organs, or muscles.

I am sending an attachment sent to The National Cancer Institution. This kind of distress to every cell in the body is the likely one common link to the increase of cancers, not to just the Jews, but to any race or faith of the family.

My recommendations are for criminal charges taken against the societies, associations, or colleges that promoted false reasons for seeking blood that rightfully belonged to the infant or infants, if it was a multiple birth. Prior to the 1900's when most births were in the home, we did not have the cancers we have today, or the brain tumors or the increase of autism. This is the common factor when there is no association with injections of live or dead viruses, or mercury/Thimersol used in vaccinations to children.

When you take a Federal criminal charge against a corporation, or society or college for the suppression of truth, and promoting harmful protocols, they do not go to jail, but they may be fined. The disciplinary action is to stop the false teaching worldwide. Thank you for your attention to my concerns.

Thank you for a reply.

Yours truly,

Donna Young, Birth Researcher since 1998
[PII redacted]
[PDF attachment follows]

Attachment

October 28, 2009

Anemia was medically caused to many babies born from 1939-1945. This may be the reason of The increase of all cancers. And why the problem is current today, of all races.

Contact: Donna Young, Birth Researcher since 1998, [PII redacted]

Please reply. Thank you.

Regarding: Jews+survived+Holocaust+Europe+have+more+cancer/2150606/story.html (IACC Note: URL is not valid.)

There is another reason that those born during the beginning of the Second World War may have higher cancer rates. This is because the medical persons during 1939-1945were doing early umbilical cord clamping. See article on anemia written in the 1930's by Dr. W. F. Windle, et al.

If the medical person or persons waited until the pulsation ceased in the umbilical cord, the time period may take from 12 to 20 minutes. There is no good reason they clamped the umbilical cord before the placenta was birthed. They may have done it for time efficiency, to get the birth over with, using drugs to advance the placenta’s birth. They would use a muscle contracting drug, man-made, Oxytocin or Pitocin. It is dangerous to use while the placenta is yet in the womb, but it is used falsely claiming it stops excessive bleeding. It may actually enhance bleeding to the mother. In any case, the World Health Organization, back in 1998, directed immediate cord clamping when oxytocin was used.

The birthing mothers or the natural father would have no true informed consent and therefore could not protect their offspring of being caused an anemic condition, testable only by a blood test. The baby or babies would look normal on the outside, but they would be caused medical latent Problems of the risk factors known of the testable anemic conditions.

The doctors remained silent as did the institution that received the infant’s placenta blood and contents from the cord. The secrets of the medical society go back to the outdated Oath of the medical professional groups not to share, by their own medical law, the secrets of the arts outside of the male doctors’ sons. The medical secrets are maintained by the chain-owed news media, including the government control over CBC (Canadian Broadcasting Corporation) radio and TV and its affiliate stations. This suppression of truth, or warning to the public, at large, comes under freedom of opinion of the medical journalists involved in medical press releases.

The unethical medical persons were knowingly trapping the baby's hormones, enzymes, and the specialty proteins inside the placenta. They knew by the measurement of blood in both humans and animals that they were seeking up to 60 percent of the total blood volume that was intended, by nature, to go into the infant's expanding lungs. This inflow would keep constant blood flow into the heart, the brain, to all cells of the central nervous system, while the expanding lungs, at birth, were being filled with the placenta blood to do the gas exchanges. The placenta was doing the gas exchanges while the neonate (newborn child) was switching to the adult system. But the early clamped babies would end up with a shrunken heart, heart valve damage, often with holes in the heart or causing them heart murmurs, not detected for years later in some instances. Other internal disorders would not be apparent for months or sometimes years. The mystery of Cerebral Palsy victims could be associated with early cord clamping as well as the increase of autism. To investigate these illnesses a review of when the cord was hand-squeezed off, tied-off or clamped would have to be known or investigated. Most birthing mothers have no video or witnesses of the doctors' hands when the cord was being interfered with. This is deliberate as to no mirrors being put up, and no advanced warning to the doctor's training or personal discretionary decision, that the natural parents have had no input or allowance to have a signed birth contract to say no to any cord clamping, whatsoever. This is then to return to primal and natural birth choices. The only reason to clamp off the cord is for visual reasons, not those feared. Visual reasons would be for dropping the infant and the cord tore; or for lack of due diligence of care and someone put a knife into the placenta and/or the cord. All other reasons are fear factors, no testing or evidence of the choice of the medical persons on blood infusion interruption. This will be found true for any person aiding the child's birth who are not ethically, morally, or competently trained on this issue. There has been no criminal charges against the medical societies, colleges or corporations of medical associations. They may be yet fined for their known deception to the public at large, if Section #180 of the Criminal Code of Canada (CCC) were to be enforced and other sections of the CCC of Causing bodily harm or damage.

The doctors do know or ought to know that any early umbilical cord clamping is any cord tying, clamping or hand-squeezing off the inflow of the placenta blood before the placenta was naturally birthed. The doctors were doing this criminal negligence at their own choice and discretion. The evidence that may be presented to a court is visual, measurable, testable and a reportable offense to the minor, the newborn citizen. This has not been done as doctors protect their own reputations and their pocket books as to their interpretation of "Do no harm."

Interferon: One of the key fighters of germs and bacteria in the body was interferon, the big daddy of virus fighters of all kinds. But this Interferon was not known to the public until about the early 1950's. The seeking of the placenta blood leaving the victimized infant anemic was the medical secret of the medical leaders and the government of Canada, United States and other Nations. They allowed the doctors to seek the placenta blood because the doctors said they were not worried about causing blood-testable anemia in the babies. This was because anemic conditions are not fatal, in most instances.

Some more ethical doctors did not clamp off the infusing blood into the expanding lungs until after five to 10 minutes, but the unethical doctors who may have received a financial collection fee from the private or public labs (those on the hospital premise) would clamp off the umbilical cord almost instantly, or do experiments on the child by the drug they gave the mother during birth and time elements of the cord tying. The time experiments were instant, 10-seconds, 20-seconds, 30-seconds, to minutes. The rule of thumb of cord clamping for a healthier infant (LEAST ANEMIC) was five-minutes. The APGAR test score started out with instant clamped off infants, mostly needing revival of Receiving some fluid back into their body (revival with blood products, plasma, experimental artificial blood, plus 11 oxygen).

Children were being tested from one-minute clamping to five-minute clamping. Any child that had at least two or three-minutes before clamping proved or tested to be less anemic then those babies instantly clamped. (Journal of the American Medical Association, March 21, 2007). But few women are ever told from the 1930's to the present day of their right to choose no umbilical cord clamping ever, no cosmetic removal of the placenta and the cord from the owner/infant.

The doctors today yet seek to have the placenta and cord and the membrane and the contents of The placenta and cord are sought. How much they received today for the extraction of the human tissue is yet to be discovered by the Auditor General of each Province or Territory in Canada. The seeking of human tissue is yet a big organized medical secret between the members of the College of Physicians and Surgeons and the Ministries of Health of each Province, as well as the collusion With the Federal agents of Health Canada, and the Ministry of Public Safety. They have allowed the infant's private property, blood, from the placenta from living babies, still-born-babies; aborted babies, premature infants or full term, to be taken and not with true informed consent. The taking of a minor's blood for research or practical use must be the top priority because the weaker infants do not work that long, weakened during and at the time of their birth.

The doctors who know the truth do not do any early clamping or hand-squeezing off the inflow of blood into their own infant's expanding lungs. But if the price is right, they do not protect all infants as they do their own. The profits influence their ethics. It may be that simple when you consider an extracted collection of stem cells may fetch over and above $30,000.00 USA (United States of America) dollars. It would be the duty of all Auditor Generals to find out what the hospital or the doctors or midwives are paid for the collection of the extracted white cells, red cells (mature and immature), platelets, plasma and the specialty hormones for every child they imposed on for the child's placenta blood and by their own discretion did early clamping. The clamping is most often imposed as an element of surprise of no true informed consent. Even calling 9-1-1 to have a First Responder will result in the same fate as to the false training they also receive by the directions of the professional experts. The false information is yet given out by some of the members of the American Congress of Obstetricians and Gynecologists (ACOG) and the Society of Obstetricians and Gynaecologists of Canada (SOGC) who do not share the truth of the known facts, known since and prior to 1801 (Dr. Erasmus Darwin's quotation as revealed by Dr. Mavis Gunther, 1957) and shared today by Dr. George Malcolm Morley of Michigan, USA (www.cordclamp.com). It is not surprising to know of the increase of cancers, brain tumors in the minor- population today. We must look at prevention of distressing every cell in the body by what the doctors put in their birth policy, trends, protocols and/or procedures, or allow to be put into some Emergency Manuals. Check out early and instant cord clamping policies set by the Society of Obstetricians and Gynecologist of Canada (SOGC). Policy #81 May 2000 directed to be routinely done instant Umbilical cord clamping. This was with the known side effect of early clamping called delayed of seconds to under three-minutes in Policy #79 December 1998. Policy #79, revealed the early clamped infants were yet anemic months after their birth. Anemia is very difficult to correct in the young.

The duty is to have each State bring the necessary criminal charges against the medical Corporations for their known false teaching to all medical students. This is the only way to bring in change, by using a disciplinary action. The medical institutions, societies, colleges, associations will not voluntarily make amends as the amends will require financial compensation for the no true informed consent assault on the infants. The corporations are to be fined. The corporations do not go to jail, of course, but they are fined Under the Food and Drug Act and under the Federal Criminal laws of endangering a minor. Who may give blood?: The proper ethics and standards are for those to be able to give up their blood without personal weakening are to all those over the age of 17, over 110 pounds, tested and found in good health of no diseases; and able to give true informed consent. Many medical institutions have knowingly exploited infants, some 4-million born annually in the USA. The newborns are being weakened in the USA and in all Nations. The duty is to fine ACOG, for bulletin #216, November 1995, yet being taught in the USA medical institutions, and abroad, and to fine SOGC, as well, in Canada.

References: www.medicalveritas.com www.cordclamp.com www.lotusbirth.com
The Lippincott Manual of Nursing Practice, page 1161, 7th edition, year 2001, where it states
"Up to 60 percent more blood will go into the infant if the umbilical cord is not clamped while pulsating."
For this to happen the baby must be first wrapped head to toe to prevent hypothermia from setting in.
Gunther, Mavis, M.D, London, United Kingdom, 1957 Windle, W. F., USA, 1930, Peltonen, T. Morley,
George Malcolm, member of ACOG, Michigan, USA JAMA, March 21, 2007

B. Nicholson

October 28, 2009

Subject: Re: Upcoming IACC Full Committee Meeting - November 10, 2009

I will not be heard, but your [derogatory language redacted], your [derogatory language redacted], your complete and [derogatory language redacted] will become [derogatory language redacted] hence.

B. Nicholson
PHEROMONES CAUSE DISEASE, YOU [derogatory language redacted].

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

Steven Kossor

October 28, 2009

Subject: Unable to attend on 11/10 but here is information you may find useful

I will be involved in a program regarding treatment outcome data collection in Pennsylvania on 11/10, but thought the attached information will be of interest.

I'm a licensed psychologist and a certified school psychologist and have been working with children who have Autism spectrum disorders since 1977. I've developed a model for the treatment of Autism symptoms in children that has been extremely successful over the past 16 years, funded entirely by Medicaid via the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. Our Treatment Outcome research data was studied independently by researchers at the University of North Carolina at Chapel Hill, who found a statistically significant association between the treatment program and reductions in physical aggression, noncompliance with adults and other areas of functioning based on a four-month initial treatment period involving more than 300 treatment programs. I have attached the press release authorized by the researchers and a monograph describing the model I developed and would be happy to discuss these data and the model if someone at the IACC is interested.

Steve Kossor Executive Director
The Institute for Behavior Change
www.ibc-pa.org
[PII redacted]

Attachment

FOR IMMEDIATE RELEASE

PROMISING TREATMENT FOUND FOR CHILDREN WITH INAPPROPRIATE BEHAVIOR

Researchers Dr. Natasha K. Bowen and Erica Richman of the University of North Carolina at Chapel Hill studied 301 treatment records of children age 3 to 17 between 2002 and 2007. They found that Behavioral Health Rehabilitation Services (BHRS) as implemented by the staff of the Institute for Behavior Change had a statistically significant association with reductions in physical aggression, noncompliance with adult prompts, socialization deficits and communication deficits. An association was also found with improvements in the environmental safety of the children. The results were presented at the prestigious bi-annual meeting of the Training Institutes sponsored by Georgetown University and the Substance Abuse and Mental Health Services Administration in Nashville, TN on July 16th. This is the first study to measure the relationship of BHRS to the outcomes of so many children; previous studies involved fewer than 30 subjects. Because there was no comparison group, no claims of causality can be made, but the consistent findings of association between the intervention and outcomes is promising. More research is planned to study the treatment effects in greater detail.

In the IBC model for BHRS delivery, Masters-level staff receive weekly supervision from licensed professional psychologists. The Masters-level staff then supervise Bachelors-level staff who go to the homes and schools of children to deliver behavioral support services directly to children for up to 7 hours per day, five to seven days per week. This extremely intensive intervention model unites parents, teachers and mental health professionals in a coordinated, concerted effort to help the child learn new ways of living and coping with stress and the demands of living socially. This study shows that the intensive involvement of Licensed Psychologists and Bachelors-level staff (called “Therapeutic Staff Support providers”) is consistently associated with behavioral change that is substantial in the lives of children with Autism Spectrum disorders, ADHD and a variety of other behavioral conditions. The treatment is funded 100 percent by Medicaid. Throughout Pennsylvania, it is available regardless of family income.

CONTACT: Steven Kossor, Executive Director [PII redacted] www.ibc-pa.org

The Institute for Behavior Change

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83-1432

Evaluating the Effectiveness of the IBC Model for Treating Mental Illnesses in Children Using Behavioral Health Rehabilitation Services (BHRS) via the Medicaid EPSDT mandate

- The Institute for Behavior Change staff have been helping children with diagnosed mental illnesses by providing in-home and in-classroom psychological evaluation, treatment planning and outcome monitoring, and behavioral support services since 1997. Of more than 500 children treated by IBC staff, 90 percent have completed treatment in 3 years or less; 75 percent in under 2 years.

- IBC provides staff to deliver Behavioral Health Rehabilitation Services (BHRS) under the supervision of Licensed Psychologists via the Medicaid statute. These services can be created in any state, according to the federal Medicaid statute, under mandated EPSDT regulations. As permitted by the federal Medicaid statute, any child in Pennsylvania with a disabling mental illness is eligible for these services, at no cost whatsoever, regardless of family income.

- Behavior is addressed in five basic domains: 1) physical aggression (2) lack of safety awareness, (3) socialization deficits, (4) communication deficits, and (5) noncompliance with adult prompts. Each child in treatment has three goals drawn from these domains in each 13-week treatment period. Treatment periods can be repeated as often as necessary (using the intentionally broad federal definition of "medical necessity") up to the child's 21st birthday.

Methods

- For the current report, hierarchical linear modeling (HLM) was used on a subset (N=301) of all cases available (N=587) to control for the effect of repeated treatment periods on the same children. Only the first 13 week treatment period for any given child was analyzed using the HLM procedure.

- A child is prescribed necessary BHRS treatment by a licensed psychologist, following a thorough bio-psycho-social evaluation of the child's strengths, weaknesses and needs, summarized in a 12+ page evaluation report and a written treatment plan. The plan is implemented by a Treatment Team including Bachelor-level Therapeutic Staff Support (TSS) providers who function under the weekly supervision of Masters-level Behavior Specialists (who are themselves supervised weekly by the licensed psychologists). In the present study, TSS service varied from 10 to 35 hours per week. Behavior Specialists provided 2-3 hours of service per week

- The child's parent provides direct feed-back to the Behavior Specialist as to the frequency and severity of target behavior. Data is collected weekly from the parent throughout the 13-week treatment period. Data for 587 treatment periods was available for study, but only the data from the first 13-week treatment period for any given child was analyzed in the present study, to control for the effect of time in treatment.

Sample

HLM analyses excluded records in which any one outcome was targeted for more than the first time in the same child (n=301). The subsample had the following demographic characteristics:

- 301 treatment periods (the first 13-week BHRS treatment experience for all subjects) were analyzed, children ranging in age from 3-17
  - 13.6 percent - Ages 3-4
  - 47.6 percent - Ages 5-8
  - 25.6 percent - Ages 9-12
  - 13.0 percent - Ages 13-17

- The sample included children of various backgrounds including Caucasian (79.2 percent), Asian (10 percent), and African American, Bi-racial, and Latino/a (10.8 percent). The latter group was formed due to the small sample size.

- The diagnoses of the children included Autistic Spectrum Disorders (47.3 percent), ADHD (26.8 percent), Mood Disorder, (11.4 percent), and Behavioral Disorders (14.4 percent)

- This was the first outpatient treatment experience for 72 percent of the children; 28 percent had received outpatient psychotherapy previously. 12 percent had received inpatient treatment for mental illness symptoms in the past.

Results

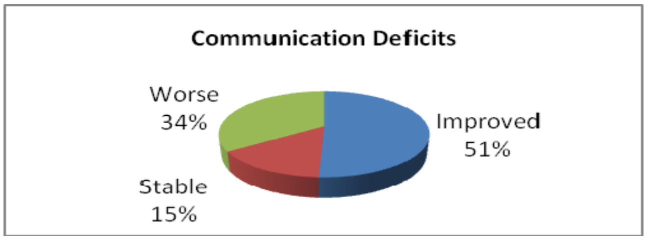
- At least 15 percent net change in target behavior was shown by the following percentages of children, after just 13 weeks of treatment.

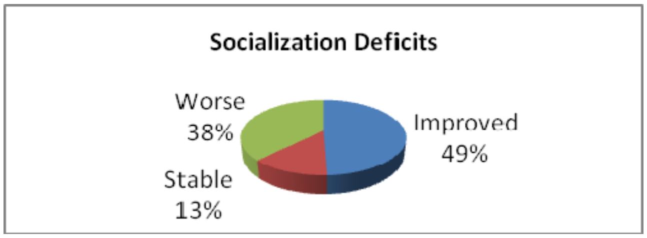
Target Behavior Domain	**Improved**	**Improved or Stabilized**
Communication deficits	51	66 percent
Socialization deficits	49	62 percent
Physical Aggression	47	68 percent
Non-compliance	36	57 percent
Safety Awareness	27	58 percent

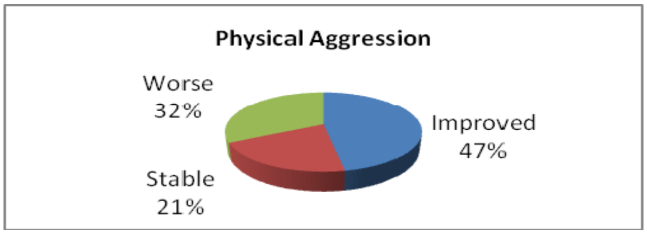
Of the 587 treatment records that were made available, about half included multiple treatment periods for the same child. To control for the variable of time in treatment, a subsample of 301 records was selected for analysis by the University of North Carolina researchers because each represented a child's initial treatment period of 13 weeks.

- Behavior improved or stabilized in between 58 percent and 68 percent of the cases receiving BHRS treatment implemented by the staff of the Institute for Behavior Change in just 13 weeks.

Charts for the top 3 improvement areas in the first 13 weeks of treatment:







HLM Analyses of the subsample (N=301)

- Hierarchical linear modeling (HLM) was used to determine if the IBC treatments were related to improvements in client behavior.

Although a control group is necessary in order to claim that treatment caused behavior change in the children, HLM establishes that decreases in target behaviors occurred during the IBC treatment period.

HLM was chosen for the analysis because the data have a nested, multilevel structure, with time points nested within individual children. This process ensures that the violation of the assumption that observations are independent of each other is accounted for (Guo, 2005).

- Analyses confirmed the hypothesis that increased time in treatment was significantly related ($p<.05$) to better outcomes in four of the five behavior domains for all children (with the fifth domain, Safety Awareness, achieving a significance level of p=.051).

Age and gender were both shown to be significant predictors for change in physical aggression. Males improved more than females (p=.017), and younger children improved more than older children (p=.03).

A cross level interaction was found, indicating that children who spent longer times in treatment generally showed less noncompliance with adult prompts over the course of treatment.

Younger children were more likely to show improvement in safety awareness than older children.

Evaluating the Effectiveness of the IBC Model for Treating Mental Illnesses in Children

Discussion

- Treatment provided by IBC staff is positively related to a decrease in identified target behaviors (level one predictors).
- Improvements occurred in all five domains over the 13 week period. Considering that the first 13 weeks of treatment often show the slowest rate of improvement (as the child adjusts to changes imposed by the treatment plan, while rapport with the treatment team is being established, and the common "extinction burst" phenomena occurs), the rates of improvement shown are remarkable.
- Regarding physical aggression, age and gender influenced outcomes with boys and younger children more likely to show improvement within the first 13 weeks of treatment.
- Regarding safety awareness, younger children are more likely to improve in the first 13 weeks of treatment than older children.
- Among Medicaid recipients, BHRS is received disproportionately by Caucasian children suggesting inadequate dissemination of information about the availability of BHRS to families of children eligible for Medicaid.
- More research is planned to investigate the effects of BHRS on children, including analyses of successive treatment programs for the same child over periods of 1 to 2 years.

The research cited in this monograph was conducted by Dr. Natasha K. Bowen and Erica L. Richman at the University of North Carolina at Chapel Hill. Assistance with graphics and presentation of research findings was provided by William LaValle and Matthew Mauriello of the Institute for Behavior Change. Further research is underway. Visit www.treatmentplansthatworked.com to obtain more than 150 of the actual Treatment Plans used by IBC staff to produce the data for this study.

Contact: Steven Kossor
Licensed Psychologist, Certified School Psychologist
Executive Director, The Institute for Behavior Change
sakossor@ibc-pa.org 610-212-0738

Suggested Readings (a comprehensive literature review identified just two articles addressing BHRS explicitly)

Toffalo, D.A.D. (2000). An investigation of treatment integrity and outcomes in wraparound services. Journal of Child and Family Studies, 9, 351-361.

This article describes a study of 28 children receiving BHRS (mislabeled "wraparound") in rural Pennsylvania. It aimed to find a relationship between adherence to prescribed levels of service hours and improvement in client functioning. Significant improvement in client functioning was evidenced after six months of BHRS delivery, whether or not the client received all of the "prescribed" hours of service.

Bugaj, S.J., & Manning, R.L. (2002). Suggestions for improving the delivery of Therapeutic Staff Support in the public schools. Journal of Mental Health Counseling, 24, 88-93.

This article outlines procedures for facilitating collaboration between BHRS agencies employing TSS providers in the school setting. Procedures, school organization, and role of professionals in the school setting are summarized. No evaluation of BHRS efficacy or efficiency was reported.

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

Idil Abdull

October 28, 2009

Subject: [Forward: Letter to the National Institutes of Health (NIH)/Centers for Disease Control and Prevention (CDC)]

Dear Sir/Madam:

Please take a look at these letters as well as the attached report on autism and Somali children in Minneapolis. If you are interested in finding out more about autism, its causes and perhaps a cure then looking into this population is your best bet. There is no word for autism in Somali yet it is so popular now in almost every family. One must ask why? I hope you ask yourself that.

Thank you very much and I look forward to hearing from you on how you can help our children and all children with autism.

Idil Abdull - Parent Advocate & Co Founder Somali American Autism Foundation
Email: contactus@saafmn.org www.saafmn.org

[Attachment follows]

Attachment

Autism and the Somali Community - Report of Study Fact Sheet

Background

In 2008, Somali parents and others in the Twin Cities raised concerns about disproportionally high participation rates of Somali children in a preschool program for children receiving Autism Spectrum Disorder (ASD) special education services as compared to the overall percentage of Somali children in the city's public schools. The program, the Early Childhood Special Education (ECSE) Citywide ASD Classroom Program, is operated by the Minneapolis Public Schools (MPS).

The Minnesota Department of Health (MDH) shared the community's concerns about a possible elevation in ASD rates in Somali children and agreed to study the occurrence of ASD among preschool- age Somali children in Minneapolis. **This study did not attempt to identify possible causes or risk factors for ASD.**
The Study

Minnesota does not have a public health surveillance system that will inform us about the actual occurrence – the *population prevalence* – of ASD in Minnesota, including in the Somali population. Therefore, the study involved analyzing special education data, known as *administrative prevalence,* about the number of children who are eligible to receive ASD services and are participating in ECSE programs. Administrative prevalence only tells us about who in the population is participating in the MPS ASD programs. It does not tell us about who in the population has ASD (population prevalence).

What the Study Found
There were a number of significant scientific challenges in using administrative data to try to analyze this situation. Nonetheless, the study found that:

- Administrative prevalence of Somali children, ages 3 and 4, who participated in the MPS ECSE ASD programs was significantly higher than for children of other races or ethnic backgrounds. This is consistent with what families and others observed. Because of the study's limitations, it is not proof that more Somali children have autism than other children; however, it does raise an important question of why Somali children are participating in this program more than other children. In addition, it is not known whether this is because 1.) there is truly a higher rate of autism among Somali children, 2.) there is better outreach to Somali families compared to other children, 3.) whether non-Somali children that are identified as having ASD use services outside of the school system, or 4.) due to other reasons.
- Differences in administrative prevalence rates between preschool Somali children and preschool children of other races and ethnic backgrounds decreased markedly over the three year period. It is unclear if this is 1.) an identification issue, 2) a change in parental awareness for the need for developmental screening, 3.) whether Somali children improved over time and therefore no longer needed services, 4.) whether more non-Somali children were being identified as needing services, or 5.) there were other reasons.
- The proportion of preschool Asian and Native American children, ages 3 and 4 participating in the ECSE ASD programs was strikingly low compared to other children. It is not known whether this is because 1.) there are fewer Asian and Native American children who have ASD, 2.) there

is less effective outreach to these children, 3.) they are using services outside of the school system, or 4) due to other reasons. This seemingly low prevalence rate among Asian and Native American children may artificially boost the comparative rate among Somali Children, distorting a true understanding of all groups involved.

Despite the limitations, the study represents an important step forward, providing information that will help guide future efforts to understand autism, both in the Somali community and in the larger population.

Next steps

To better understand whether there is, indeed, a higher occurrence of ASD in Somali children as compared with non-Somali children, a wide range of skills, expertise, and knowledge of the community and environment is needed. Issues to be explored include:

- Exploring the feasibility of developing a population-based public health ASD surveillance system in Minnesota.
- Estimating administrative ASD prevalence for a larger geographic area in Minnesota and elsewhere in the country.
- Learning more about how children come into the system and whether there are cultural differences in how behavioral and developmental problems are addressed.
- Conducting additional analyses to address pending study questions.

While addressing these issues will assist in estimating the true prevalence of ASD in the Somali community and in Minnesota, MDH, along with the Somali community and a wide range of partners, will continue work to:

- Improve access to culturally competent, care.
- Increase access to information about child development and available resources for children with special health care needs.
- Ensure that physicians and other providers have the right tools to diagnose and refer children with ASD to appropriate services.

Ongoing opportunities

- MDH has convened representatives from the Minnesota Chapter of the American Academy of Pediatrics and members of the Somali Community to discuss issues related to culturally appropriate screening and medical diagnosis. These conversations continue.
- The University of Minnesota is applying for funds to study very early signs of autism that would be more bio-behavioral and valid cross-culturally.
- Minnesota is considering legislation establishing an Autism Spectrum Disorder Task Force charged with examining ways to improve services, service delivery, training of professionals, and education of parents and the public on autism.
- The *Somali and Autism* website is available through MDH to provide information and links to services for Somali families.
- The Interagency Autism Coordinating Committee, a federal government advisory panel, has released a blueprint for autism research to help fill the gaps between what we know about autism and what we need to do to help families.

For more information

You can find the full report at: Autism and the Somali Community,

PDF of the report: http://www.health.state.mn.us/ommh/projects/autism/report090331.pdf (IACC Note: URL is not valid.)

If you have questions please contact the Department of Health at 651-201-4754.

Attachment #2 to Idil Abdull's October 28, 2009 Submission

AMY KLOBUCHAR
MINNESOTA

COMMITTEES:
AGRICULTURE, NUTRITION, AND FORESTRY
COMMERCE, SCIENCE AND TRANSPORTATION
ENVIRONMENTAL AND PUBLIC WORKS
JOINT ECONOMIC COMMITTEE
JUDICIARY

UNITED STATES SENATE
WASHINGTON, DC 20510

July 20, 2009

Thomas Frieden, MD, M.P. H.
Director, Center for Disease Control and Prevention
[PII redacted] Atlanta, GA 30333

To Whom It May Concern:

I am writing to express my concern about a health problem specific to Minnesota's citizens of Somali Descent. In March of this year, the Minnesota Department of Health released a report concluding that Somali children between the ages of three and four are up to seven times more likely to be enrolled in an Autism Spectrum Disorder Special Education class than are non-Somali children.

The Minnesota Department of Health's study was not able to conclude what causes increased autism rates in Somali children, but I am pleased to report that the Department has agreed to spend the next year doing additional studies beyond what was released in their March 2009 report, and they hope to have diagnostic confirmation of what their administrative research showed.

The Somali American Autism Foundation (SAAF) is hard at work to bring attention to this issue and has met with my staff on several occasions as part of their advocacy. They respectfully ask that you keep these citizens of Minnesota in mind when the NIH/CDC plans research studies or clinical trials related to incidences of autism. If you have questions regarding that request, please contact SAAF at [PII redacted].

Thank you for your careful consideration of this important matter. If you have questions or need additional information from me or my staff, please contact Rose Baumann in my Washington, DC office at [PII redacted] or by email at [PII redacted]. I am hopeful that we will be able to work together to find an explanation for this troubling problem.

Sincerely,
(signed)
Amy Klobuchar
United Sates
Senator

Attachment #3 to Idil Abdull's October 28, 2009 Submission

AMY KLOBUCHAR
MINNESOTA

COMMITTEES:
AGRICULTURE, NUTRITION, AND FORESTRY
COMMERCE, SCIENCE AND TRANSPORTATION
ENVIRONMENTAL AND PUBLIC WORKS
JOINT ECONOMIC COMMITTEE
JUDICIARY

UNITED STATES SENATE
WASHINGTON, DC 20510

July 20, 2009

Dr. Raynard Kington, MD, PhD
Acting Director
National Institutes of Health (NIH)
[PII redacted] Bethesda, MD 20892

To Whom It May Concern:

I am writing to express my concern about a health problem specific to Minnesota's citizens of Somali Descent. In March of this year, the Minnesota Department of Health released a report concluding that Somali children between the ages of three and four are up to seven times more likely to be enrolled in an Autism Spectrum Disorder Special Education class than are non-Somali children.

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Sincerely,
(signed)
Amy Klobuchar
United Sates Senator

Cc: Dr. Duane Alexander, Director Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

B. Nicholson

October 29, 2009

Subject: Re: Upcoming IACC Full Committee Meeting - November 10, 2009

And do tell them from me that they are just a bunch of [derogatory language redacted], too. To ignore the obvious cause of epigenetic changes in humans (human pheromones) is criminal negligence and should be punished in a court of law by sentence of death, seriously. You people are far too [derogatory language redacted] to be in positions of authority and if 'the committee' didn't have their heads [profanity redacted] perhaps it might occur to them to resign. I sincerely hope so, for the sake of the children if nothing else.

Eileen Nicole Simon

October 29, 2009

Subject: Family panel at the IACC Meeting October 23, 2009

Thank you for forwarding my comments to the IACC members. I only wish more back-and-forth discussions could take place between IACC and parents of children with autism. If such discussions could become part of the process I would make every effort to attend IACC meetings. I have to work November 10 and will at best only be able to listen-in from about 3:30 to 5pm. I will submit comments. First, note:

1.) I am pleased to see that Dr. Francis Collins is on the committee. I am quite impressed with some of his writings, especially that he seems interested in environmental factors that may cause autism, and not just in "genetically susceptible" children. I will submit more on this later.

2.) I have a website about which I have received many emails. Someone copied me on an email she sent to the IACC yesterday, proposing criminal charges. I am not interested in litigation of any kind, but do feel procedures like umbilical cord blood banking should be scrutinized. I will submit comments on this later also. I would place clamping of the umbilical cord before the first breath as the highest priority possible cause of the increased prevalence of autism to be investigated - the evidence from research 50 years ago with newborn monkeys remains in the medical literature.

Sincerely,

Eileen Nicole Simon

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

Marcia Hinds

October 29, 2009

Subject: What if Autism is the result of a virus?

I hope the committee is aware of the latest study published by the Whittemore Peterson Institute and Dr. Judy Mikovits. Here are links that show the discussion by Dr. Mikovits and Annette Whittemore founder of the Whittemore Institute latest research concerning the XMRV (xenotropic murine leukemia virus-related virus) virus and Autism.

This is a new medical discovery that has tremendous ramifications for people with chronic fatigue, autism, attention deficit hyperactivity disorder (ADHD), other autoimmune diseases and even cancer. This is so exciting that what Dr. Michael Goldberg of Tarzana, California has been talking about and treating for years. These ideas are finally being recognized by the medical community. I hope recovery for all children with autism and everyone with autoimmune disease is on the way.

Marcia Hinds
[PII redacted] [Attachment follows]

Attachment #1 to Marcia Hinds' October 29, 2009 Submission

XMRV Retro-virus and Autism

Dr Michael Goldberg of Tarzana. California has successfully been treating children with Autism for years. He has long stated the obvious namely that you cannot have a developmental/genetic epidemic. http://www.nids.net/pdf/myth.pdf (IACC Note: URL is not valid.)) and the latest study by the Whittemore Institute findings support his hypothesis. This study describes the detection of a retro-virus called XMRV (xenotropic murine leukemia virus-related virus) in about two-thirds of patients diagnosed with chronic fatigue syndrome (CFS). Many of those diagnosed with "Autism" have blood work that contains these same viruses.

Dr. Michael J. Goldberg, MD
www.neuroimmunedr.com

[PII redacted]

Here is a video link that features Annette Whittemore, president and founder of the Whittemore Peterson Institute and Dr. Judy Mikovits... and they discuss the autism/ immune link as it relates to the latest study of XMRV published in the SCIENCE journal.

Part one....

http://www.youtube.com/watch?v=mzIdpMUunHE

and part two...

http://www.youtube.com/watch?v=yOdnwPCh-yw
more
http://www.youtube.com/watch?v=6vISWCI-13M&feature=related

XMRV and Autism
Particles of the retrovirus, XMRV, in human blood and demonstrate that it is transmitted between blood cells. XMRV was first discovered in prostate cancer tissue of men with certain genetic defects. It has also been found in patients with Chronic Fatigue Syndrome (CFS).

Like the more well-known retrovirus, HIV (human immunodeficiency virus), this pathogen is blood-borne, and not transmitted through the air. The findings have potential significance for a number of other disorders including, it turns out, autism. Researchers tested blood samples from a "small group of children" with autism and found that 40 percent of them were positive for XMRV, according to a statement from the Nevada Commission on Autism Spectrum Disorders. More testing is underway which, the Commission said, "could dramatically increase that 40 percent positive finding." (Given the small sample size, such a statement is purely speculative).

As Dr. Mikovits explained to a _television news program_ (http://nevadanewsmakers.com/) in Nevada, It is not in the paper and not reported, but we have actually done some of these studies (in ASD children) and found the virus in a significant number of samples that we have tested for. It could be linked to a number of neuro-immune diseases, including autism. It certainly won't be all, because there are genetic defects that result in autism. But there are also the environmental effects; there is always the hypothesis that, 'My child was fine and then they got sick, and then they got autism.'"

According to Dr. Mikovits, XMRV (which admittedly sounds like a satellite radio system for your Winnebago) can lie dormant in people, until it is "turned on or off" by other factors, such as stress hormones like cortisol, or in response to the presence of inflammatory "cytokines," protein molecules secreted by immune cells to help regulate the immune system. And then Dr. Mikovits dropped a bombshell that is sure to spark controversy. "On that note, if I might speculate a little bit," she said, "This might even explain why vaccines would lead to autism in some children, because these viruses live and divide and grow in lymphocytes -- the immune response cells, the B and the T cells. So when you give a vaccine, you send your B and T cells in your immune system into overdrive. That's its job. Well, if you are harboring one virus, and you replicate it a whole bunch, you've now broken the balance between the immune response and the virus. So you have had the underlying virus, and then amplified it with that vaccine, and then set off the disease, such that your immune system could no longer control other infections, and created an immune deficiency."

So there you have it - a possible explanation of regressive autism in a significant number of cases associated with immune system deregulation triggered by vaccination.   Of course, much more work is needed to nail down the exact significance of such an association. For example, is the virus implicated in the cause of autism, or do children harbor the virus as a result of autism? Either way, it is notable that such questions are being asked by mainstream sources such as the University of Nevada and by extension the National Cancer Institute (NCI) and the Cleveland Clinic: Can XMRV infection plus vaccination create the right conditions for regressive autism? That remains to be seen. But it also means that the thousands of parents who claim their children did regress shortly after vaccination may not be so crazy and "fringe" as they have been portrayed by experts such as Dr. Paul Offit of Children's Hospital of Philadelphia and Dr. Thomas Insel, head of the National Institute of Mental Health and Chair of the federal Interagency Autism Coordinating Committee (IACC). "We certainly are advocating vaccinations and how important those are to the well being of the children," explained Annette Whittemore, founder of the Whittemore Peterson Institute.

"But what we are hoping for is, by finding out whether or not one is positive to XMRV, whether it is in one family member or another, and then looking for it in children, you could alter the immune response in such a way that you can protect the child and still be able to vaccinate and avoid autism in these kids. And again, I don't think ether one of us is sitting here saying, 'Vaccinations cause autism,' but rather a number of factors; a genetic susceptibility to the illness, to the infection itself, and then on top of that you are adding something to that mix that takes that child over the top."

Apparently, the CFS findings have impressed the scientific community. "We presented these data three times: Twice at closed conferences at the National Institutes of Health (NIH), and one at an international meeting a few weeks ago, and you could hear a pin drop in the audience - it's amazement" Mikovits said. "The scientists are excited, everyone is working on it, so we know we are going to get a lot of help. It's just amazement, it's an entirely new field of medicine and everyone who's ever worked in this family of viruses is, now that we've shown it's a human pathogen, is extremely excited." Whittemore added that researchers hoped to develop a vaccine against XMRV quickly, noting that "It would be easier to find a vaccine against this than HIV, because it is a simple retrovirus." The discovery raises more questions than it answers. What, exactly, is it about immunization that might switch on XMRV viral expression? Could the > effect of heavy metals upon cytokine balances be at play?

Where did this retrovirus come from, and how did it apparently become so prevalent in children with autism? Did these children inherit the virus from a parent, or was there some other unexplained route of transmission? Why has the NIH said nothing about XMRV in association with autism, and did Dr. Insel know about these findings without sharing them with the IACC?

Finally, Dr. Insel has said that a vaccine against autism may one day be developed. Was he actually referring to a vaccine against XMRV, and what role, if any, might he or _members of his family_ (http://www.ageofautism.com/2009/08/when-vaccine-development-is-family-business-thomas-insels-conflicted-role-on-vaccines-and-autism.html) play in the development of such a vaccine? According to Insel's _own biography_ (http://www.med.umich.edu/depression/bio/insel_bio.htm), in 1994, he went to Emory University, Atlanta as a Professor in the Department of Psychiatry, and Director of the Yerkes Regional Primate Research Center. "As director of Yerkes," his bio says, "Dr. Insel built one of the nation's leading HIV vaccine research programs."

B. Nicholson

October 29, 2009

Subject: Regarding: Upcoming IACC Full Committee Meeting - November 10, 2009

[offensive language redacted] should be a crime and everybody at the National Institute of Mental Health (NIMH) should be serving life sentences.

Marie Sherrett

October 29, 2009

The United States Is Ill-Prepared To Provide Services of All Types For Adults Who Have Autism

TABLE OF CONTENTS

INTRODUCTION

According to web sites of the Autism Society of America or other autism-related nonprofits like Unlocking Autism, Autism Speaks, Cure Autism Now, Defeat Autism Now, the National Alliance For Autism Research, etc., the developmental disability called autism, which also encompasses any number of autism-spectrum disorders, is at an all-time high and no one knows why. At this juncture, not even the Centers For Disease Control could deny such a statement. Where before the prevalence was 1 to 10,000, then 1 to 500, then 1 to 250, it is now, in 2006, given as 1 to 166 births per the Autism Society of America (ASA). What will become of all these persons who live a normal life span? Who will care for them? What will happen to them in any state or county after they are 21? A reality is only in the State of Minnesota can such persons attend school up to age of 25. Per various reference sites, many states have little or no services, jobs, aides, recreation or housing after 21 for such persons.

Although the writer is the parent of a son, 26, with autism, she was able to look beyond all this to see the issue from the outside-in to address all concerns to fully research this paper. She acknowledges assistance and interest from the autism community to do so. Thus, this research paper tries to address current or still-to-be realized concerns of millions of parents about long-term care, recreation and employment issues of those with autism across the United States. Although there is no one real, all-powerful solution to this current or looming dilemma, the reality is that governments and caregivers cannot afford to wait idly by, hoping the problem will go away.

As of today, 1.5 million of all ages here in the United States today have autism. Since there is no known cure, this paper will show that we must act now to provide for the long-term needs of such persons. In retrospect, we have no choice. There is no turning back.

PROBLEM: The United States Is Ill-Prepared To Provide Services of All Types For Adults Who Have Autism

SOLUTION: Pass more federal legislation now giving parents or caregivers tax-free dollars to decide for themselves how to assist these children with disabilities as adults since vaccines may be found to cause it.

ARGUMENT

No discussion concerning long-term care issues involving those with autism can be complete unless we consider the sad fact that the disability has now reached epidemic levels across the United States. Its journey began decades ago when the disorder was first noted by Leo Kanner at Johns Hopkins in 1943. Almost simultaneously, Hans Asperger in Germany described a less-severe, but more verbal version of the disorder. Later, in the 1970's, psychologist Bruno Bettelheim blamed the disorder on "refrigerator mothers" whose uncaring attitudes molded the children to their own image. In 1980 researching scientists decided it was no longer a mental illness, but a neurological disorder per the Diagnostic Statistics Manual. Fast forward to 2006 where now the disability may be on a spectrum or there could even be multiple kinds. Sadly, the stigma of finding fault with and blaming the disorder on the mothers still occurs.

In 1975 Public Law 94-142, "The Education For All Children Act" was passed by the United States Congress mandating free, appropriate public education for those with disabilities. In the 1990's that Act was reauthorized and was then called, "The Individuals With Disabilities Education Act (IDEA)." IDEA finally included a separate paragraph describing children with autism and refunded again and is now called, "The Individuals With Disabilities Education Improvement Act (IDIEA)." With the advent of the IDIEA, it was noted that each generation of parents spawned action and called the public's attention to the issue. However, the concern of parents (and others) is it may be all for naught if jobs, programs and services (including mental health, if needed) can be almost nonexistent for such persons from age 21 forward since that is when special education services usually end.

The Health Care Financing Administration matches Medicaid Home and Community• Based "waiver" funds tied to state fund availability for such persons. Previously, these funds went to institutions. Parents and caregivers pushed in lawsuits to close such sites and have such persons back in the local community. This costs money and services are now essentially done by lottery in states, if done at all. As a direct result, waiting lists for services and support funds have sprung up and exist all over the United States for community supports, employment assistance, transportation needs, etc., for such persons at age 21 and beyond. Meanwhile, they wait.

Another social problem, although often ignored, is the fact that, statistically-speaking, the divorce rate or even abandonment by one of two parents in a family involving autism is higher than the national average. Thus, someone with autism faces a real possibility of growing up in a one-parent household, usually a single mother. So, along with child care, financial, employment and other hardships encountered by such persons, an additional stressor may be the person with autism may be cared for by someone who can least afford to do so. The sole caveat to that is if a non-custodial parent of a marriage dies and the parents were married, a custodial parent may possibly then get benefit through the Social Security Administration, especially if the child with autism already gets or is entitled to get Supplemental Security Income, which may then change. This is no comfort to say the least programs and so-called benefits around the country. The State of Pennsylvania has little or no services and jobs for such persons starting at that age. In that state, parents and caregivers of those 21+ with autism have only just begun to mobilize their efforts in that regard. Is it any wonder then that a couple a few years ago made headlines by abandoning their 10-year-old child with a severe disability at a hospital with a note saying they could no longer afford to care for the child? Parents are already worried and they should be. It almost goes without saying that where, when their children were young such parents pushed for Applied Behavior Analysis (ABA)-based education programs for such children, such parents will be in for rude awakenings when those same children tum 21. Parents cannot expect job coaches and aides to be trained on ABA. It just does not occur. At best the former have high school diplomas.

There is such a shortage of job coaches, some nonprofit entities are even bringing in and training people from other countries to work in those capacities. Supervising agencies often also have employees from other countries. If that is the case, English is thus a second language for some grown children's job coaches. Only the nonprofit entity's supervisors are almost guaranteed to have college one or more degrees.

Nonprofits under each state's Developmental Disabilities Administration (DDA) participate in what is essentially another kind of lottery system: Parents look around and try to interview staff of such entities to see if there is a "fit" between job, "consumers" and job coaches. This can only occur if a state even has such provisions and funding through its regulations. Although DDA has training on behavior management and even on addressing the challenging behaviors involved in autism, no credentialing program of any kind exists in the United States today. Thus, job coaches may only be required to attend a minimum number of training hours to be considered in compliance or credentialed. If staff is sick on the day of training, they may not necessarily be required to make up the so-called educational or training deficit. In all this, the consumers or adults with autism 21+ suffer, as do their parents or caregivers.

Closer to home, a December 2006 focus group at The ARC of Prince George's County, Maryland (MD), tried to address these issues. Although some parents present had adult children with other disabilities, the remainder were ALL single parents of those with autism. A need for "meaningful" jobs was seen, plus transportation, employing training and other issues. It was noted, although the 2006 Combating Autism Act had been passed by Congress, not even that Act fully addressed issues involving adults with autism. One attendee put it this way: "What is the point of the government spending $20,000+ in private special education school tuition for such a child when the only job my child is offered is one cleaning toilets? When will The ARC learn to go out into the community and find decent-paying jobs? Do they need my help?" It was also verbalized that, although office skills training is given, jobs are not even guaranteed by The ARC on completion of the training.

Not all adults with autism live at home. Some still live in group home situations, even if they have siblings who could assist them if needed. Perhaps that is why Congress passed the Lifespan Care Respite Act on December 8, 2006 to help give families "a break." The Act recognized that families of those with autism, among others, daily experience stress and responsibility. When services are provided, changes occur.

Challenging behaviors associated with autism do not simply disappear starting at age 21. By then a child with autism has grown and is often taller and stronger than parent caregivers or job coaches. How do you explain autism to a prospective employer if you as a parent are still trying to understand it yourself? Along with those worries is the fact Medicaid providers may not cover speech, occupational, sensory integrative and other therapies, much less dental needs!

It is almost like parents and caregivers are in a Catch 22 situation: They know such children will always qualify for Social Security Insurance (SSI), which could stop should the adult with autism have more than $2,000 in assets like a home or car, which could not occur unless the person is at the Asperger's level of autism. They can also be sure job coaches and staff will change yearly. Are staff all trained to work on behaviors of adults with autism? Do they attend training sessions? Do they read up on autism? Have they researched it? What kind of recreational programs are available for such persons at 21+? These are all questions parents in particular have, while simultaneously wondering who will assist such children if the parents no longer can. After all, not all those with autism have siblings ready, willing and able to take over care of their sibling with autism after their parents can no longer do it all.

Each state seems to "make its own kind of music." Are there enough mobile crews with sufficiently varied jobs to keep the interest of adults with autism? Not really. The writer knows of a parent who went to work for MD's Community Services For Autistic Children and Adults and quit, unimpressed with jobs for consumers she supervised. The writer's son was turned down by Melwood in MD twice for services, including supported employment, although the consumer held many part-time jobs through a private Virginia special education school. Also in MD, another future consumer, son of a friend of the writer, despite attending Kennedy Krieger Institute High School, was told by Melwood the only job available on graduation was to clean toilets! VA is said by parents to fail miserably for job services. This is also evidenced by the fact it also only offers a sole $500.00 grant maybe per year and per family of those with developmental disabilities, a drop in the bucket for such families. (MD rolling access funds range from $500.00 to $2,000 per family per year. Texas has a long waiting list (although MD does, too). Yet, California's Institute For Applied Behavior Analysis has a model program emphasizing positive behavior supports plus jobs in community settings. A sample of programs or services in some states shows no one single set of standards.

The situation is only going to get worse before it gets better. The clear resolution to the dilemma faced by thousands (millions?) of parents and caregivers across the country is having the ability to not only give one-to-one help to persons with autism once they are 21+, but also to do so in a home setting. The country has seen that institutionalization does not work. If anything, it only further separates those with autism from their families. Those with autism need all the 1 to 1 help they can get to control their often-difficult, abusive or challenging behaviors which can occur from provocation or by frustrations due to constantly changing circumstances or staff, especially if staff are untrained on autism in adults. This takes money and lots of it.

If parents and caregivers were allotted $50,000-$100,000 per year, tax-free by the United States Government, they could decide for themselves what their adult child with autism needs. They would also then be in a better position to develop jobs, programs, services, educational supports and recreation ideas for such children. No one else can better do so, whether the child lives with them or not.

CONCLUSION

Parents of a child with autism need no longer be faced with the heavy responsibility to seek long-term care arrangements for such children. Although we as a society may never know the real cause or causes of autism (vaccines, older fathers or even watching television too much have all been blamed!), it is long past time for the United States Federal Government to address this issue, especially if it turns out vaccines containing mercury are one of the main causes of autism. The next piece of Federal legislation should be entitled, "The Federal Tax-Free Funding To Families of Those With Autism Act." Let parents and caregivers choose aides, nonprofit providers, case managers, plan programs and help governments arrange for involved recreational services for their adult children with autism while also being able to support them in their own homes. Family and children have waited long enough and never asked for this burden to be placed on them in the first place.

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

Idil Abdull

October 31, 2009

Subject: Regarding: [FWD: Letter to the National Institutes of Health (NIH)/Centers for Disease Control and Prevention (CDC)]

Hello,

Thanks for reading my email and I am glad that our message and concerns will be shared with the committee. However, we need more from an autism research institute. We need help, research and someone to tell us why our kids are being with autism at such an alarmingly rate. We would like research dedicated to us since there is no known cause of cure for autism as of now. It could be that maybe the answer is in us, but we will have to be first studied.

Please let me know who and how we can accomplish this. Also, please note that these children are born in Minnesota and are as American as APPLE PIE. Also, Dr. Insel did a hearing on August 5th in congress in which he was asked by Senator Harkin to describe a road map for when a child is diagnosed and he did not have a clear answer. This is an insult to so many parents like me. We need a road map of what to do next and we need help for our children now.

Thank you and I look forward to hearing from you.

Idil Abdull - Parent Advocate & Co Founder Somali American Autism Foundation [PII redacted]
www.saafmn.org

Eileen Nicole Simon

November 2, 2009

Subject: Questions for members of the IACC

1. Are the public comments for NOT-MH-09-013 posted online?

2. Can we request discussion of the comments submitted?

3. Can members of the IACC provide written responses to public comments?

4. Can someone respond to the evidence I have submitted, that the auditory system of the brain is vulnerable to impairment by many of the etiological factors associated with autism?

5. Can someone respond to the evidence I have submitted that clamping the umbilical cord at birth interferes with normal transition from placental to pulmonary respiration?

I have many more questions to ask, and I will continue to request answers.

Sincerely,

Eileen Nicole Simon, PhD (Biochemistry), RN (Registered Nurse)

B. Nicholson

November 3, 2009

Subject: Regarding: Today IACC Scientific Workshop Panel 1 Conference Call

I'd rather not be heard without having to listen to [profanity redacted], thank-you.

B. Nicholson

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

John Best

November 3, 2009

Subject: Re: Today IACC Scientific Workshop Panel 1 Conference Call

How do I apply for a grant to do a study on autism?

I propose to test for the APO (Apolipoprotein) E4, E3 and E2, break those groups out by symptoms, further break them out by the amount of mercury they received via vaccines and at what age they received it, then [derogatory language redacted].

In conjunction with this, I would want to do [offensive language redacted] with Andrew Cutler's protocol and chart results of symptom improvement or lack of same.

Thank you,

John Best
[PII redacted]

Daniel Pech

November 3, 2009

Subject: Autism early warning signs

Autism is a misnomer. And, the underlying disability does not always manifest as autism.

In cases in which the underlying disability does not manifest as autism, the early warning signs do not exist. There is no language delay, and no language oddities. There are no social signs of a disability. No restricted interests. No repetitive behaviors, and no fixations. At least nothing that the child is able to recall when questioned. There is no test that can show that he has any disability. He is too ready, and too able, to please. He passes every test, and is diagnosed as perfectly normal by all who know him. That's the problem. It's like a paper test for fighting in a war, and the people who keep giving him the tests cannot tell that the tests are not a real, live war. So, he's...to be, or not to be, that is the question. "I think, therefore, I'm [offensive language redacted]", or "I'm [offensive language redacted], therefore, I am."

No one can know he has a disability---not even himself. Only long after his life is so ruined that everyone thinks he is a recalcitrant superman does he even have a clue himself. But, by then, he's thrown out as a rebel against authority. And, so, he is homeless, with severe digestive problems, increasing food allergies, and general, increasing organic frialty: he is unable to manage himself as his own person in the mere presence of others, who, at any time, may at all express feelings regarding his presence or actions, unlike a TV the human likenesses in which pose no interactive threat to him (bio-feedback monitors hooked up to me are [offensive language redacted] to look at). He's utterly captive to everyone, all the time, because his responses to them are so perfectly oriented to their own preferences, needs, and opinions that no one thinks he is in any great distress. Normal humans take for granted that a person who so does not demand to be excused does not feel a need to get away from all possible human contact or presence. He has no way to function as his own human person in the human world, and this is a disability that only increases the longer he lives, because no one has ever let him alone on his terms.

There is no equity which they have ever observed for his sake, because his reactions are so genuinely enthusiastically pro-their-preferences that they simply take for granted that he has nothing better to do with himself than to be their happy [offensive language redacted]. The way he reacts to most others under most conditions can only give them the impression that he is highly capable, competitive, resourceful, etc. But, they never give him the space and time to be his own person, so he is constantly trying to escape his distress by being THEM, or by focusing on what THEY want. So, it does not show, and when it does, it's not much too see of all that it actually is. They expect a particular personality from him, and that's what they get, and he can't help it, and he can't get help. Not from official channels, and not from private individuals who, after all, are what those official channels are comprised of. He has no life left, and no way to escape. And, no one cares. They just FEEL caring. And all he gets is advice to take anti-anxiety medication. But, he's a walking contraindication to every medicine there is, and the for-profit medical establishment and their [offensive language redacted] doctors refuse to keep track of all the botched or failed cases and their conditions.

Eileen Nicole Simon

November 3, 2009

Subject: Regarding: Today IACC Scientific Workshop Panel 1 Conference Call

The discussion of "When should I be concerned?" was disappointing. Please ask the IACC to consider launching retrospective studies of mothers of autistic children to determine:

1. All pregnancy exposures to medications and other drugs and chemical substances.
2. Use of medications and drugs during pregnancy.
3. Use of uterine stimulant drugs for induction or augmentation of labor.
4. Was birth by cesarean section?
5. Newborn birth weight and length of gestation.
6. Was resuscitation needed following clamping of the umbilical cord?
7. Were hepatitis B, vitamin K, and other injections given in the newborn nursery?
8. Were antibiotics administered?
9. Were transfusions or volume expanders needed in the newborn period?
10. Was the infant anemic during the first year?

Many more questions of concern can and should be asked.

Sincerely,

Eileen Nicole Simon

Eileen Nicole Simon

November 4, 2009

Subject: Regarding: Tomorrow IACC Scientific Workshop Panel 3 Conference Call

I listened to most of the conference call today. The diverse causes of autism must all affect a common vulnerable system in the brain. Evidence has been available for more than 50 years as to what that system may be - the auditory system. Not only do children learn language through hearing, but the auditory sense is the vigilance monitor for the brain. Children with autism often exhibit hyperacusis, which suggests a problem with inhibitory neurotransmission in the auditory pathway. I have been looking for what caused my sons' autism for 40 years now. I posted my ideas on the internet nearly 10 years ago. Please read what I posted in April 2000 at: http://www.conradsimon.org/WorkingPaper.html

I have since posted much more, but what I posted back then should suggest a few avenues for ongoing research.

Eileen Nicole Simon

Eileen Nicole Simon

November 6, 2009

Subject: Regarding: Questions for members of the IACC

Thank you for your detailed response below. It is frustrating to me that my comments have been mostly overlooked, or perhaps dismissed because "the studies have not been done." I have just posted five studies that predate what most researchers may consider valid, but evidence gathered in the past remains as solid evidence. Please look at the five papers I have just posted at http://www.conradsimon.org/BrainstemProcessing.html

Sincerely,

Eileen Nicole Simon