Written Public Comments

IACC Full Committee Meeting

January 18, 2011

List of Written Public Comments

Bruce Meatheringham

December 16, 2010

Subject: link to my film about synesthesia that I talked in My Story with ADS Channel 10 (A Conversation That Motivated Me to Start Research)

Here is the link to my film I talked about in my story

http://www.youtube.com/watch?v=2cmRcnlL1kA

I hope you enjoy it Thanks
Bruce Meatheringham

Marian Dar

December 28, 2010

Subject: Jan 12 meeting on safety

Don't know if you're soliciting feedback but here are some concerns that this parent of a 22 yr old autistic adult has and that other families may share:

When my son was young and 2 ft tall and his behavior took off, on average people were sympathetic or simply ignored him; he's also a track-star "bolter," but that's another story...

My son is now more than 6 ft tall and his antics are no longer a yawn or shaking head from a passer-by. in fact last year the police of a NY suburb approached me because he was pacing (!) and making faces in front of the *vacant* train station (someone had seen him from a window across the street!) where we were waiting to pick up a family member.

w/heightened security concerns and sensitivities everywhere and increasing every day, police and security personnel beyond the local community -- those in public centers -- eg. train stations, airports, bus depots, etc. -- need to also recognize and understand the unusual and possibly disarming behavior of autistics.

Marian Dar

Eileen Nicole Simon

January 7, 2011

Subject: Re: Questions

It has just felt like everything I have submitted has gone into the abyss. My comments clearly have not been used to inform any decision making by the committee, and this is distressing, not just as a personal affront but because I know that my comments should be considered relevant to: (a) a brain impairment that should be investigated as an underlying cause of developmental language disorder and (b) how this brain impairment may be the result of clamping the umbilical cord before the first breath, in addition to all of the other known causes of autism.

No other public comments in the Request for Information (RFI) refer to how various environmental factors might affect the brain, vaccines, monosodium glutamate (MSG), soy products, even prenatal ultrasound. Events during labor and birth must be considered in addition to pre- and post-natal factors. Obstetric interventions have had to be changed in the past, most prominently giving diethylstilbestrol (DES) to prevent miscarriage. I don't know how much litigation resulted, but I had a college classmate who became distressed during her junior year when she stopped having periods, then a few years after graduation we learned she had died of vaginal cancer. The son of a friend of mine developed testicular cancer and also died early in adulthood.

Autism is no less distressing than these horrible cases of fatal genital cancers. Obstetric interventions cannot be overlooked. If evidence can be provided that abrupt amputation of the placenta at birth provides the healthiest start for a newborn infant, then good - maybe placental detachment before birth would be even healthier - less blood, less bilirubin. No, published evidence over the past 30 years has clearly shown the dangers of preventing postnatal placental circulation, until the fetal shunts in the heart have closed and redirected blood flow to the lungs.

Please provide the above comments to members of the committee. I plan to submit more. The strategic plan does not explicitly address the core handicap of children with true autism, developmental language disorder. Why?

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

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

Eileen Nicole Simon

January 7, 2011

Subject: Regarding: Questions

Perhaps brief amendments to the strategic plan could be made to emphasize needs of special importance:

The first such amendment should be an explicit statement that research on developmental language disorder should be of highest priority, and research aimed at understanding where in the brain the underlying impairment originates.

It should (and no doubt does) go without saying that understanding the language disorder is of greatest urgency, but this appears to have gotten lost within myriad details in the paragraphs of the strategic plan. There may be other research priorities that should be highlighted as amendments to the basic plan.

Eileen Nicole Simon
[PII redacted]

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

Wendy Fournier

January 10, 2011

Subject: IACC Subcommittee on Safety

Dear Subcommittee Members,

During the last IACC meeting, we were very disappointed at the apparent loss of momentum and sense of urgency by the committee in addressing the issue of wandering.

This is an issue that the IACC can and must tackle with all haste, before one more child or adult is lost. There is no excuse for delay. I implore you to finalize your letter to Dr. Sebelius at your upcoming meeting and present it to the full committee at the January 18th meeting. In knowing that children and adults have died and will continue to die as a result of wandering, we do not need to wait for data to start building resources and working toward effective prevention methods to keep individuals with autism safe.

I understand that there may be concern on the part of some committee members that the independence of children and adults with autism may be threatened by efforts to prevent wandering. Let me clarify, we are talking about protecting those who are clearly at risk and unable to identify potential danger from wandering. We are not suggesting that every individual with an ASD diagnosis be fitted with a device to monitor their every movement. We are asking that every individual who is at risk of wandering-related injury or death has access to prevention resources that may save their lives — the same types of resources already available to the Alzheimers/Dementia population. This is one of the reasons why a medical diagnosis code for Autism-Related Wandering — following proper diagnostic screening — is crucial to our efforts and should be a top priority in your letter to the Secretary.

Please feel free to contact myself or Lori McIlwain if we can be of any assistance.

Sincerely,
Wendy Fournier

Wendy Fournier, President
National Autism Association
[PII redacted]
http://www.nationalautism.org

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

Stephanie Sorensen

January 11, 2011

Subject: initial inquiry/grant possibilities

Joan New, director at *Autism Speaks* suggested I contact IACC and see if there is a possibility of working with you on the research I have begun concerning the high rates of autism in the Minnesota Somali community. They may be interested in funding this work if you were able to provide a faculty member in Minnesota that I could proceed with/under. Their rolling grant (called Trailblazer research) seems to fit the work I have begun.

Please forward this to the appropriate department so that I can then submit my initial letter of inquiry, research statement, vision, etc.

Sincerely,
Stephanie Sorensen
[PII redacted]
I am wrapping up my work in New York and will be returning to Minnesota mid-January. 2011.

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

Eileen Nicole Simon

January 14, 2011

Subject: Written comments for the Jan 18 IACC meeting

Please note that I am more than a lay stakeholder. I have been researching the problem of developmental language disorder in autism for more than 40 years. I have a strong educational background in biochemistry and neuroscience, funded by The National Institute of Mental Health (NIMH). For the past 19 years I have been working as a direct-care provider for mentally ill prison inmates in the Massachusetts Department of Correction. Many (if not most) had developmental disabilities with ongoing language difficulties. Dyslexia is prominent. I also see first-hand how drug and alcohol abuse leads to paralysis of gastrointestinal function. The gastrointestinal (GI)-brain connection is not unique to autism. The brain needs to be the focus of research on autism.

Sincerely,
Eileen Nicole Simon
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In a comment submitted January 7 I suggested making brief amendments to the strategic plan as points of special importance for autism research, and I suggested 1.) an explicit statement that research on developmental language disorder should be of highest priority. I also suggested that research aimed at looking for where the underlying impairment in the brain is that prevents normal language development.

I want to add that 2.) autism is a neurological disorder, and the focus of research needs to be the brain. With respect to recent controversy over Wakefield's 1998 paper connecting gastrointestinal disorder to autism, please note that gastrointestinal dysfunction results from impairment of autonomic centers in the brainstem. (Note: Gastrointestinal dysfunction has long been recognized as part of the Wernicke-Korsakoff syndrome caused by chronic abuse of alcohol, which begins with symmetric bilateral lesions of brainstem nuclei. A similar pattern of ischemic injury at birth has been reported many times. See http://conradsimon.org/I-BrainDamageAtBirth.html, especially references 37-43.)

That "the brain" is starved by GI dysfunction is too non-specific both in autism and cases of alcohol and drug abuse.

I want also to request recognition that 3.) most children with autism are physically perfect. Except in the genetic and teratogenic cases, dysmorphic features are not present. Therefore perinatal problems near term or during birth should be the focus of research. The obstetric intervention of umbilical cord clamping interferes with natural transition from fetal to neonatal respiration; it is unsafe and should be investigated as a possible reason for increasing prevalence of autism since the mid-1980s. Banking of umbilical cord blood should be investigated as part of the ongoing increasing increase in autism prevalence.

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

Barbara Trader

January 14, 2011

Subject: The Association for Persons with Severe Handicaps (TASH) Public Comment on IACC Deliberations on Wandering and Elopement of Individuals with Developmental Disabilities, including Autism Spectrum Disorder (ASD)

TASH Public Comment on IACC Deliberations on Wandering and Elopement of Individuals with Developmental Disabilities, including Autism Spectrum Disorder (ASD)

Thank you for opportunity to provide comment to the Interagency Autism Coordinating Committee (IACC) as it deliberates on a possible letter to Health and Human Services (HHS) Secretary Kathleen Sebelius with regards to safety issues relating to wandering and elopement of individuals with developmental disabilities, including Autism Spectrum Disorder (ASD).

TASH is an international association of people with disabilities, their family members, other advocates, and professionals fighting for a society in which inclusion of all people in all aspects of society is the norm. TASH is an organization of members concerned with human dignity, civil rights, education, and independence for all individuals with disabilities. We have over thirty chapters and members from thirty-four different countries and territories. Since our inception over twenty-five years ago, TASH has gained international acclaim for our uncompromising stand against separatism, stigmatization, abuse and neglect. We actively promote the full inclusion and participation of persons with disabilities in all aspects of life. TASH believes that no one with a disability should be forced to live, work, or learn in a segregated setting; that all individuals deserve the right to direct their own lives. TASH 's mission is to eliminate physical and social obstacles that prevent equity, diversity, and quality of life.

Over the course of its 35-year history, TASH members have represented, developed and advocated for evidence-based, ethical service-provision for individuals with significant disabilities. TASH members have been and continue to be at the forefront of critical movements for systems change in the field of significant disabilities, including de-institutionalization, inclusive education and competitive, integrated employment for all people with disabilities. During that time, we have never shied away from addressing issues of challenging behavior from individuals with the most significant disabilities while not abandoning our commitment to ethics and civil rights for all people. With this in mind, we write to express concern over the proposed draft letter to HHS Secretary Kathleen Sebelius on wandering and elopement of individuals with ASD, in particular its recommendation that HHS support the creation of a medical sub classification coding for “ASD-related wandering”.

We feel that such a diagnostic code could seriously impair the civil and human rights of all individuals with developmental disabilities, including those with a diagnosis of Autism Spectrum Disorder, through the creation of obstacles to self-direction, freedom of movement and the ability to escape caregiver abuse. Our concerns are as follows:

- **Lack of Research Base:** To our knowledge, there exists no high quality research supporting the creation of a distinct medical code for “ASD-related wandering”. While wandering and elopement are challenges for all children and compelling anecdotal evidence clearly supports that they are likely greater challenges for children and adults with developmental disabilities, including ASD, no research supports the classification of this issue as a medical rather than a behavioral phenomenon. Furthermore, the proposed solution mentioned in the letter – the use of tracking devices – poses both significant ethical concerns and lacks a research base itself. We urge the Committee to explore various options to address this issue which do possess research support, such as Positive Behavioral Interventions and Supports (PBIS) and various other progressive practices in residential service-provision for people with significant behavioral challenges. TASH would be glad to provide recommendations of experts who have worked on these issues in the context of housing, education, behavioral support and other fields.

- **Risk of Enabling Other Safety Concerns:** The "medicalization" of wandering and its classification as a medical concern rather than a behavioral or human services issue might have unintended consequences in enabling other safety concerns. All behavior is communication. By characterizing wandering behavior as a medical phenomenon rather than a behavioral action occurring in response to a stimuli, efforts by non-verbal children and adults with ASD to remove themselves from settings which pose a threat to their health and safety, such as the inappropriate use of restraint and seclusion or caregiver abuse in residential service-provision, may be ignored instead of recognized as efforts at communication. Furthermore, such a coding could be utilized to encourage the use of guardianship for individuals with developmental disabilities, including ASD, who it might not otherwise be deemed appropriate for.

- **Other Safety Concerns Need to Be Addressed**: While wandering and elopement is a legitimate and important safety concern for individuals with developmental disabilities, including ASD, and family members, it is not the only such concern that exists. Issues such as restraint and seclusion, caregiver abuse, lack of access to health care and other concerns represent threats to the health and safety of individuals with significant disabilities which are just as urgent and just as costly in terms of human life as wandering and elopement. We believe that the IACC should communicate to the Secretary the full scope of these issues rather than miss an opportunity to communicate the need for broad-based systems change by focusing on only one aspect of safety concerns.

We recommend that:

1.) The IACC remove the recommendation calling for the creation of a medical sub classification for wandering.

2.) Investigate options with research support to address safety concerns posed by wandering and elopement, such as Positive Behavioral Interventions and Supports (PBIS).

3.) Revise the draft letter to the Secretary to address the full range of safety issues faced by individuals with developmental disabilities, including Autism Spectrum Disorder, including restraint and seclusion, caregiver abuse, preventable secondary conditions, misunderstandings with law enforcement and other safety concerns.

We thank the IACC for its time and for considering this critical issue. Please direct questions, comments and further inquiries to TASH's Executive Director Barb Trader at (PII redacted).

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

Pat Amos

January 14, 2011

Subject: Comment on IACC Deliberations on Wandering and Elopement

Comment on IACC Deliberations on Wandering and Elopement of Individuals with Developmental Disabilities, including Autism Spectrum Disorder (ASD)

I am writing to request that the IACC remove the recommendation calling for the creation of a medical sub classification for wandering. As the parent of three young adults on the autism spectrum -- the oldest 34 years of age -- as one of the founding members of both a state and a national autism advocacy organization, and as a professional employed as an Inclusion Specialist for a service providing agency in Pennsylvania that currently works with over 600 youth with autism in their homes and communities, I recognize that many children with this diagnosis (and many children with other diagnoses, and many children in general) can challenge us and cause us great concern by wandering out of our vision. The challenge, however, is not medical and there is no need to complicate the issue by declaring it so. I have always found that this behavior is communicative of a number of recognizable needs, such as the need for exploration, for exercise and movement, for testing or declaring one's own independence, for escaping distressing stimuli in the environment, for establishing safety in the face of perceived threats, and so forth. Wandering behavior challenges parents, caregivers, and service providers to enhance their supports, plan proactively, and get to know each individual well so that the need to be "on the move" can be anticipated and safely accommodated. Through positive behavior supports we can teach safety, negotiate boundaries, and cultivate communication about the source of the behavior. On the other hand, classifying wandering as a medical rather than behavioral issue will close minds to the seeking and resolving of the reasons why people wander. It will lead many to conclude that this behavior is meaningless and that the appropriate response is to be found through medical treatment in the presumed "safety" of isolated, congregate settings. That would be great and totally unnecessary setbacks to the decades of successful work that have been done on designing and maintaining safe, appropriate accommodations and supports that allow people with autism to participate meaningfully in their communities.

Thank you for your time in considering these comments.

Pat Amos, M.A. (Master of Arts)
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