

Oral Public Comments

**IACC Full Committee
Meeting**

December 12, 2008

List of Oral Public Comments

Karen Driscoll	3
Paula Durbin-Westby	5
Theresa Wrangham.....	7
Ann-Mari Pierotti	9

Karen Driscoll

December 12, 2008

My name is Karen Driscoll. I am a Marine Corps wife, and parent of a child with autism. My husband is an active duty Marine, helicopter pilot and veteran of two combat tours.

I come today to you in an effort to obviously raise awareness of the issues impacting our military children, as well as ask for the advocacy of this group to focus on this - and I know you guys mentioned this earlier - a critical subpopulation at risk.

In my advocacy efforts within the Pentagon and on Capitol Hill, we have been gathering data through the Freedom of Information Act on the number of our military children with an ADS diagnosis currently. Based on the total population of our military dependents under the age of 21, that puts autism prevalence of our military children at one out of every 88.

This is an alarming figure, because this is an at-least picture. These are the diagnoses that we know of today as well as, it does not include data on children that might use alternate insurance via an employed spouse in the civilian sector.

So this is an at-least picture that puts autism prevalence in the military at one in every 88. And I highlight this to you because in my efforts I've been advocating for the treatment needs of our military children, and how the unique military lifestyle impacts the quality of life of the individual child itself, his future for - future in terms of developing functioning and able to succeed in life. But this also has an impact on the family unit, the mental and physical health of the parents and siblings. But we have a unique aspect of the impact on combat readiness. Because when we don't take care of our children and families here at home it impacts the war fighter overseas.

And I want to highlight that picture to you in my personal story. My husband is a helicopter pilot, and while in Iraq, his squadron was responsible for casualty evacuations in support of 1 MEF, which is 1st Marines. You want the helicopter pilot focused on his mission and in support of his Marines. You don't want that helicopter pilot worried about the \$4,000 therapy bill that it's taking to pay for his child's treatment. Or more importantly, how his wife is going to survive this deployment without him, and take care of perhaps more than one child with an autism diagnosis.

So this is a unique subset of our population that is obviously critical to the health of our country, and I want to highlight that unique aspect and ask for your support. Obviously, the treatment needs, but to research why our military children are at higher risk.

And if I could just wrap up, obviously I want to talk about - and I know there are some wonderful advocates in the room - on the vaccination safety, that this is a unique population that obviously has a higher compliance in vaccination, as well as a unique population that might be exposed to additional environmental toxins based on the military lifestyle, the nature of military installations.

So I ask just to raise that awareness, that there is a unique population out there, obviously critical to the success of our country, but also has a unique lifestyle that could be measured immediately and identified and tracked with an already diverse societal population in and of itself.

[Karen Driscoll's presentation can be viewed here.](#) (PDF – 249 KB)

Karen Driscoll's attachments can be viewed here:

[Attachment 1](#) (PDF – 153 KB) | [Attachment 2](#) (PDF – 627 KB) | [Attachment 3](#) (PDF – 676 KB) | [Attachment 4](#) (PDF – 147 KB)

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

Paula Durbin-Westby

December 12, 2008

Thank you for permitting to address this meeting of the Interagency Autism Coordinating Committee. I am here as an autistic self-advocate, autistic citizen and taxpayer.

One of my current concerns, after attending the meeting on November 21 and noting that no person on the autism spectrum was represented during the voting, is: A person on the autism spectrum is needed to stand in for Stephen Shore (or his successor) when he is not here. This situation needs to be remedied immediately. According to the section in Public Law 109-416 Section 399CC, Interagency Autism Coordinating Committee: "Additional members: Not fewer than 6 members of the Committee, or 1/3 of the total membership of the Committee, whichever is greater, shall be composed of non-Federal public members....of which- A) At least one such member shall be an individual with a diagnosis of autism spectrum disorder."

If this individual is not present, especially during voting sessions, the letter of the law is not being adhered to. Although there are no specific provisions in the law for the appointment of substitutes, several members of the Interagency Autism Coordinating Committee regularly appoint other individuals to represent them. This is not to disparage Stephen at all or to question his absence. Increase the number of individuals on the autism spectrum who have a direct voice on the committee and select a representative who represents autistic individuals, as well as parents and community members, who do **not** wish for a cure for autism, for themselves or their family members.

Make at least one additional change in the composition of the committee, and that is to include another agency with a more practical focus. For example, the National Institute on Disability and Rehabilitation Research (NIDRR), another division of the Department of Education's Office of Special Education Programs, has as its goal a focus on rehabilitative research that impacts individuals across the lifespan. "The mission of NIDRR is to generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community and also to expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities". The choice of only one education representative, from the Early Childhood Office of Special Education Programs, provides too narrow a focus from the education agency sector. Again, this statement is not intended in any way to reflect on any person from the Department of Education who is currently serving on the IACC, nor is it a call for removal of that division. It is a call for the addition of NIDRR or agencies with a lifespan, practically-oriented approach.

Broaden the scope of the term "intervention" to include supports such as assistive and augmentative communication technology, positive behavioral supports and other practical ways of "intervening" to help autistic people achieve as full participation in society as possible.

Regarding specific services and supports, the Strategic Plan mentions Picture Exchange Communication Systems but does not address other systems. PECS does not stand in for the entire realm of Augmentative and Alternative Communication/Assistive Technology. The Strategic Plan should recommend funding specific research initiatives into emerging promising communications technologies, both for those with no or little expressive language and for those who do have expressive language but

cannot always access it reliably. Examples of such emerging technologies include Aided Language Stimulation, Storybook Aided Language Stimulation, Natural Aided Language, functional communication training with AAC, and Language Acquisition through Motor Planning (LAMP). Augmentative and Alternative Communication and Assistive Technology allow them to use and develop their language, even if it is not oral language. Many of the most popular communications systems have been developed entirely without the input of individuals on the autism spectrum. To develop effective communications tools, autistic individuals MUST be consulted at all stages of the research, from design, through implementation techniques and evaluation.

Remove references to untested treatments, not only including those that have been found questionable, such as chelation, but also those that appear to have the stamp of scientific legitimacy but may be just as “untested” as the more controversial treatments. For example, research into pharmacological agents or other means of “decreasing certain repetitive and stereotyped behaviors,” as mentioned in the “Which Treatments and Interventions Will Help?” section, should be undertaken ONLY with full research participation by individuals on the autism spectrum who can advise as to reasons and functions of these behaviors. Reduction of stereotypies just for the sake of reduction of stereotypies may have unintended negative consequences.

A concern about mandatory reporting of people diagnosed on the autism spectrum in states such as Delaware’s Autism Surveillance and Registration Program, and now a similar proposal in New Jersey: The “Developmental Disabilities Surveillance and Research” program section of Public Law 109-416 awards grants to state and local entities for setting up surveillance databases for use in epidemiological studies. In addition, both the Strategic Plan and the Consolidated Strengths and Weaknesses document recommend, and assume, that large databases will be available for use and that individuals or their information will be tracked via linked administrative databases.

Voluntary participation in data collection is certainly acceptable; enforced participation is not and is unethical. Although it is tempting to quickly gather a large cohort such as the 20,000 subjects desired by the year 2011 for genome-wide association studies, mentioned in the Strategic Plan’s Aspirational Goal in the “What Caused This and Can This be Prevented?” section, every precaution must be taken to ensure that specific individuals cannot be traced utilizing these databases and that individuals and families have the right to opt out. In Delaware currently, very few exemptions are permitted.

Remove language that urges cost savings as a goal of research. Under “Which Treatments and Interventions Will Help” there is a suggested addition that states: For those who improve, the resulting cost savings are significant.” There is a danger that a focus on cost effectiveness will preclude those who do not “improve” or who are in need of more substantial services throughout the lifespan. The IACC should move away from language of “costs to society.” For example, part of the costs to society is the appropriation of funding for Public Law 109-416, which in no way is directly attributable to autistic people’s expenses: it is funding appropriated for research, not for provision of services. In addition, “costs to society” language is intended to alarm taxpayers and citizens, and often the object of their alarm will be autistic people themselves.

Paula C. Durbin-Westby
[PII redacted]

Theresa Wrangham

December 12, 2008



Good afternoon. I am Theresa Wrangham, President of SafeMinds and mother to an 18 year old daughter with autism. I thank the committee for the opportunity to speak today.

During the strategic planning process concerns have been forwarded to the IACC, many of which have been resolved. However, there continues to be concern on vaccine language contained in the strategic plan. The most recent meeting of the IACC failed to correct inaccuracies regarding vaccine research and the current plan's reference to the 2004 Institute of Medicine (IOM) Report. These inaccuracies appear largely due to the lack of time given the committee during the planning process, as well as a lack of recognition of supporting science to accurately reflect what we know.

I would respectfully remind the committee that the community supported the Combating Autism Act due to our understanding of the epidemic facing our nation and the need for appropriate response. The intent of this act with regard to vaccine research is clear.

Representative Barton in the House Colloquy stated: "this legislation is not designed to predetermine the outcome of scientific research. Rather this legislation calls for renewed efforts to study all possible causes of autism including vaccines and other environmental causes."

Senator Enzi in the Senate Colloquy stated "However, I want to be clear that, for the purposes of biomedical research, no research avenue should be eliminated, including biomedical research examining potential links between vaccines, vaccine components and autism spectrum disorder."

Representative Chris Smith Added" I believe that we do not yet have the answers we need regarding the biological effects of thimerosal and I am hopeful that research on environmental factors will include further study to find those important answers.

This issue continues to be scientifically debated and requires additional study and the intent of the Combating Autism Act was clear in that this committee should assign research priorities as it pertains to autism. The committee has SafeMinds summary of science that has continued subsequent to the IOM 2004 Report for review. It is clear that this issue continues to be of great concern and requires your action. To ignore the intent of the public and the Combating Autism Act will continue to fuel the public's growing distrust of the immunization schedule.

We ask the Strategic Plan be a thoughtful process in which the committee is allowed the time necessary to put forward a plan that the autism community can enthusiastically embrace; that the budget not be constrained, but bold in pursuing answers; that research priorities focus on the environment, gene-environment interaction, and treatment that continue to be underrepresented. We ask that adoption of oversight, review and evaluation mechanisms, such as an Autism Advisory Board and a Department of Defense grant review model, should be added to the Plan and that the Introduction embody the urgency

of this crisis. We respectfully request that a workgroup be convened in January 2009 to focus on these additional enhancements to the Strategic Plan.

Ann-Mari Pierotti

December 12, 2008

The American Speech-Language-Hearing Association (ASHA) is pleased to have the opportunity to provide comments to the Interagency Autism Coordinating Committee (IACC). ASHA is the professional, scientific, and credentialing association representing more than 130,000 speech-language pathologists, audiologists, and speech, language, and hearing scientists in the United States and internationally.

We are all aware of the devastating toll that autism spectrum disorders or ASD can have on individuals and their families and caregivers. We also know that difficulties with language and social interactions are among the hallmark characteristics of individuals with ASD. Therefore, we wanted to take this opportunity to speak to you today about the critical and central role that speech-language pathologists have in providing programs and services for individuals with autism. We also want to make sure that you are aware of the resources that ASHA has that may be helpful to you as you finalize your Strategic Plan for Autism Spectrum Disorder Research.

Speech-language pathologists are often the first professionals to see a young child with language and social problems and are often the first to recognize ASD. Speech-language pathologists are involved in a wide range of roles addressing the needs of individuals with ASD, including screening, identification, diagnosis, program planning, and intervention. Speech-language pathologists need to be integrally involved in all aspects of care to maximize the social-communication skills and quality of life for children, adolescents, and adults with ASD. They collaborate with families and other professionals, conduct research in areas of assessment and treatment, and are involved in advocacy to support greater independence for individuals with ASD in home, work, school, and other community environments. To assist our members, other professionals, and community stakeholders, ASHA convened a committee on autism to create resources delineating the role of the speech-language pathologist in the diagnosis, assessment, and treatment of communication disorders associated with ASD across the age span. The [documents](#) stemming from the committee's work are available to you and the public on ASHA's Web site. The documents involved a systematic review of research on interventions designed to improve the language and social interaction skills of individuals with ASD. We believe that these documents and other information on ASHA's Web site related to ASD can be useful to your committee in the creation of the strategic plan.

ASHA commends the significant accomplishments of the IACC, and we very much appreciated the chance to respond to the RFI seeking comments on your strategic plan. We highly recommend that the Strategic Plan for Autism Spectrum Disorder Research put more emphasis on intervention research. We look forward to working with you as you develop and implement the strategic plan. If you need additional information, please contact Diane Paul, ASHA's Director of Clinical Issues in Speech-Language Pathology, at 301-296-5688 or dpaul@asha.org.

Sincerely,

Catherine H. Gottfred, PhD, CCC-SLP
President