

Oral Public Comments

**IACC Full Committee
Meeting**

January 14, 2009

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Katherine Walker

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Subject: SafeMinds Statement

Good afternoon. I am Katherine Walker, mother to a son with autism and a Government Affairs Committee Member of SafeMinds. I thank the committee for the opportunity to speak today on behalf of SafeMinds and applaud the progressive objectives approved during the strategic planning process, particularly those related to the role of the environment.

However, the continued emphasis on funding genetic research, which substantially outpaces environmental research, remains a significant concern. The 2006 IACC report validated this concern when it concluded that research on environmental causes and treatments were underfunded. Current funding for environmental research is insufficient to achieve the Congressional goals of identifying the causes and treatments for autism.

This month, NIH-funded research confirmed that autism's rise is **real** and as a result, creates great concern as to how this growing population's immediate and future need for treatments, services and supports will be met. *The Rise in Autism and the Role of Age at Diagnosis* in this month's edition of *Epidemiology* found **that of the estimated 600-700% increase** in California's autism cases, **less than one-tenth** is due to inclusion of milder cases and **less than one-quarter** is due to earlier diagnosis. Lead investigator Dr. Hertz-Picciotto stated that this is a clarion call to researchers and policy makers who have focused attention and money on understanding the genetic components of autism. She added that these findings require that research funds and emphasis shift from genetics to environmental threats including chemicals, such as heavy metals, pesticides and infectious agents.

These recommendations echo those from the 2007 IOM workshop "Autism and the Environment" and require that emphasis be placed on environmental research to understand autism's etiology and identify effective treatment. Considering the national economic downturn, NIH must, now more than ever, wisely invest the Combating Autism Act research funds. SafeMinds requests that the NIH autism research portfolio reflect a preference for funding environmental risk factor research over genetic research. Environmental risk factor research must include vaccines and their components, as specified in the Combating Autism Act colloquy statements of Senators Enzi, Santorum, Dodd and Kennedy and Congressmen Barton and Smith. SafeMinds also respectfully recommends that the research budget be significantly increased to achieve Congressional goals and avoid interdisciplinary conflicts for resources. This action would require a comprehensive disease cost analysis be conducted, as well as a review of approved research opportunities not funded due to resource constraints.

Additionally, the inaccurate description of vaccine-autism research in Question Three of the "What We Know" section must be corrected. Specifically, the limitations and recommendations as noted in the 2004 IOM report should be included as well as findings from peer reviewed research supporting the ongoing concerns of parents **and the scientific community**.

In closing, the strategic planning process has taken a considerable amount of the IACC Committee's time and not allowed for performing other mandated duties, such as monitoring all Federal autism

activities. As possible solutions to the IACC's mandated responsibilities, we respectfully request that February's agenda address mechanisms for oversight, review and evaluation and include establishing a strategic planning subcommittee and an Autism Advisory Board and adopting a grant review model similar to that of the Department of Defense as possible solutions.

Paula Durbin Westby

January 14, 2009



The autism research agenda has been near-exclusively focused on causation and cure, two priorities out of step with the needs and desires of the autistic community. In the year 2008, only approximately 1% of the NIMH autism research budget was allocated to services research.

Research that focuses on discovering and eliminating autism both enters the dangerous and unethical realm of eugenics and avoids addressing the social barriers that autistic people face that prevent quality of life and full participation and inclusion in society at large. Balancing the autism research agenda to focus on quality of life will pay dividends by providing evidence on the most effective methods of delivering services and providing for an effective education across the lifespan. Such a research agenda would complement other aspects of federal disability policy, such as de-institutionalization mandated under *Olmstead v. L.C.*, the IDEA and NCLB requirements for evidence- and research-based methodologies, the IDEA “Least Restrictive Environment” right and increased numbers of individuals with disabilities, including the autism spectrum, in the workforce.

We recommend the following:

- Require that no less than half of the federal autism research budget across all departments and agencies, including NIH, CDC, HRSA, HHS, DOL and others, be allocated towards services-research.
- Pursue a vigorous quality of life autism research agenda focused on issues such as improved service-delivery methodologies, social barriers to full participation and quality of life, effective systems change models, means of effectively and respectfully addressing social, behavioral, emotional and other challenges, empowering communication and other priorities.
- Mandate that the Inter-Agency Autism Coordinating Committee include representation from autistic self-advocacy organizations, such as the Autistic Self-Advocacy Network, and that there exist parity between the number of parent, provider and self-advocate representatives in the public membership to the IACC.
- Include a specific recognition in the Strategic Plan of the perspectives of autistic adults who do not want to be “cured” of autism and who see severe ethical issues with the cure agenda. People on the autism spectrum are not the only ones concerned about a possible prenatal test and selection out of autistic fetuses: In recent interviews, researcher Simon Baron-Cohen has raised concerns about the possible negative consequences of prenatal testing. He asserts: Caution is needed before scientists embrace prenatal testing so that we do not inadvertently repeat the history of eugenics of inadvertently “cure” not just autism but ... associated

talents...” Neurological diversity adds in a positive fashion to general human biodiversity; to reduce it may lead to unintended negative consequences.

- Fund research into Augmentative and Alternative Communication (AAC) options for autistic people across the lifespan, including Assistive Technology, so as to empower all autistic people to meaningfully communicate.
- Allocate no less than one third of the federal autism research agenda towards the needs of adults on the autism spectrum, addressing the near total lack of research funding towards the needs of this population to date.
- Fund Community-Based Participatory Research (CBPR) models including autistic self-advocates as full partners at every stage of the research process, from topic selection to study design and implementation. Look to existing projects as models, such as the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE – <http://www.aaspireproject.org>).
- Provide for Student Loan Forgiveness for services-related and quality of life/participation-based research that is comparable to the loan forgiveness offered for researchers who work on basic science research.
- Look to research funded by the National Institute of Disability and Rehabilitation Research (NIDRR) as a model for autism research priorities.