

Oral Public Comments

**IACC Full Committee
Meeting**

May 4, 2009

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Theresa Wrangham

May 4, 2009

Subject: Policy Recommendations



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.

As the IACC commences their updating of the strategic plan, SafeMinds would ask that the committee revisit objectives already in the plan for modification and expansion, as well as the addition of new objectives, to more adequately address the autism epidemic facing our nation.

The need for treatment is of primary concern. Of the nine treatment objectives in the plan, we note that four were unanimously supported by public members as needing to be quadrupled in number. The public understands that treatment research is desperately needed to improve the lives of affected individuals as soon as possible and to assure the best long-term outcomes. Treatment is an area that requires significant expansion to appropriately address the needs of ASD individuals.

SafeMinds acknowledges the role of research as the cornerstone in the creation new and effective treatments for autism. NIH has historically placed a priority on inherited genetic risk factors when funding autism research. However, these investments have not yielded results that will provide the urgent breakthroughs needed to respond to this health crisis. It should also be noted that genetic research is well funded privately, while environmental research is underfunded. SafeMinds believes that now more than ever, wise research investments are necessary and recommends, as did the recent U.C. Davis study, shifting funding from genetic to environmental studies as they are most likely to lead to effective treatments and prevention. Research on environmental factors in the strategic plan has been limited to five factors, while public members of this committee unanimously supported investigation of twenty and the inclusion of interactions between exposures. SafeMinds would ask that rigorous steps be taken to identify environmental factors driving autism's rise with expansion of the number of factors pursued.

The current strategic plan contains only four research projects to identify metabolic and/or immune system interaction mechanisms with the central nervous system. These objectives are likely to inform causality that in turn leads to new treatments. SafeMinds would recommend an expansion to twenty five projects and that they not be limited to immune and metabolic systems interactions.

Little is known about possible differences between teen and adult ASD phenotypes, and whether subtypes of ASD change over time by age as well as by birth cohort. Conducting active screening prevalence studies in a multitude of U.S. locations with various sampling approaches of adults born before 1987 compared to prevalence of teenagers born during or after 1987, using the same diagnostic criteria, would provide a much needed assessment on possible differences in subtypes, as well as speak to the contribution of the environment relative to diagnostic changes in the recent rise of autism. SafeMinds recommends the addition of such an objective to the strategic plan.

Given the rich clinical data available on successful treatments used by physicians treating our children,

the number of clinical trials to determine efficacy and cost-effectiveness could easily be expanded from the two trials proposed in the strategic plan. Expansion is desirable as information gathered will inform best practices in the treatment of autism and assist in making treatment more widely available to those affected.

We would also request the convening of an independent panel, as recommended by Dr. Mark Noble at the last IACC meeting. To date, we are unaware of the next steps taken as a result of the IACC's last meeting in this regard and feel strongly that such a panel would signal to the autism community and the general public that vaccine safety concerns will be addressed free from conflicts of interest and in accordance with the Combating Autism Act's intent.

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

Ari Ne'eman

May 4, 2009

Hello, my name is Ari Ne'eman, and I am testifying today on behalf of the Autistic Self Advocacy Network, an international non-profit organization of Autistic adults and youth advocating for ourselves in public policy, service-provision, research and media representation. I'd like to start by applauding your decision to hear from ASAN Board Member [PII redacted] and our friend [PII redacted]. The topic of AAC has been one that we have been encouraging the IACC to take up for some time now, and we are pleased that the IACC has been responsive to that request. Through the use of Augmentative and Alternative Communication technologies, Autistic people across the lifespan can be empowered to communicate in meaningful and effective fashions.

This issue of Autistic voices is one that I would like to expand on. The IACC is a body charged with making decisions on autism research dollars allocated in our names and ostensibly for our benefit. And yet, I would like to remind the members of the community that the IACC continues to lack a representative from the organized Autistic self-advocate community, despite having many representatives from the various factions of the organized autism parent and professional community. As our new HHS Secretary has taken office, we encourage you to communicate the need to rectify this oversight in representation as soon as possible.

In respect to the IACC's upcoming work, I would like to take the time to call attention to three major issues of concern to the Autistic community. The first is the need to balance the autism research agenda, which currently drastically underfunds quality of life and services-research with the potential to benefit Autistic people across the lifespan. We call upon the IACC to heed the call of the Autistic and cross-disability community's and adopt "research dollar parity" between basic research and quality of life/services- research, recognizing that our society should spend as much money ensuring we have equality of opportunity and quality of life as is spent on matters of autism causation which have regrettably controlled the public arena so far. We must beyond the conversation around autism causation and cure and towards a quality of life focused autism research and advocacy policy.

A perfect example of the type of research the IACC should fund is health care disparities research for Autistic adults. As our country prepares to embark on national health care reform, this type of research will be crucial for ensuring that Autistic people across the lifespan have the ability to access medical services on an equal basis to the non-Autistic population. Currently, many access issues relating to sensory, social communication, unique co-existing medical issues and other differences amongst the Autistic population prevent full access. We urge that this research be funded and that it be funded amongst Participatory Action Research principles that ensure that the research is conducted with and not merely on Autistic people.

Finally, I call attention to the urgent need for the IACC to address bioethical issues associated with prenatal testing and the autism spectrum. Very recent genetic research findings bring the prospect of an autism prenatal test closer and closer. History has shown us that if this technology is developed, it will be utilized. The 92% rate of selective abortion in the Down Syndrome community and similar examples across the disability community show that this issue should be treated seriously by the autism research community. By making the focus of autism research preventing our very existences, our lives are

devalued and the prospect of a world without the neurological diversity that has benefited our society is a very real one. I urge this committee to consider the Ethical, Legal and Social Implications of autism prenatal testing both through dedicated funding towards consideration of ethical, legal and social implications, as has been adopted by the Human Genome Project, and through incorporation such a requirement of consideration into the IACC's existing and future funding projects.

The national conversation about autism has for too long excluded Autistic people. Thank you for your time and we encourage you to hear our voices.

Katie Miller

May 4, 2009

Thank you for allowing me the opportunity to speak today. My name is Katie Miller and I am here representing myself as an Autistic citizen.

I would first like to applaud the IACC for having a presentation on Assistive and Augmentative Communication given by an Autistic self-advocate. The significance of this is twofold. One, AAC is one of the most important areas of autism research because it provides non-speaking Autistics with ways to communicate. The limited numbers of AAC devices do not work for everybody. AAC research is vastly under-funded, leaving countless Autistics unable to express their thoughts due to lack of compatible technology. The fact that this presentation is being given by an Autistic self-advocate is also to be applauded. It shows that the views, experiences, and expertise of the Autistic community are valued.

It gives me great pride to witness an Autistic voice being heard.

While this is evidence of progress, Autistic voices should be a regular, organized, and consistent presence within the IACC, not an incidental occurrence. Out of eighteen members of the board, only one is Autistic. How can the committee succeed if it largely excludes the people it exists to serve?

Representatives of the Autistic Self-Advocacy Network have proven helpful to the Obama Administration as evidenced by repeat invitations to important service, education, and disability-related events, briefings, and exclusive bill signings. It is time that the IACC include a permanent autistic self-advocate presence. We are here to help you understand the challenges and strengths of our diverse community. We are the experts on our Autistic needs, experiences, ideas, thoughts, and feelings, and we are eager and willing to offer you that insight.

One of the challenges many Autistics face is less access to healthcare, and often less adequate healthcare, than that of the average population. These disparities are common throughout the lifespan and affect Autistics with diverse abilities and living situations. The reasons for healthcare disparities are likely as varied as Autistic people themselves. How, then, do we research solutions?

We directly involve all the affected parties: Most notably Autistics, doctors, nurses, and primary caregivers, but also friends, family, teachers, social workers, public transit operators, health-care receptionists, and anyone else directly deemed relevant to a particular case. This collaborative approach to research is called Community-Based Participatory Action Research. It equitably involves all parties in the research process, combining the unique knowledge and strengths of each to produce the desired result. Research done collaboratively is more likely to result in the discovery of concrete problems and solutions regarding improper health care for Autistic people.

In addition to executing Participatory Action Research, I strongly urge the IACC to implement research dollar parity. For every dollar that goes into basic autism research, I want to see a dollar going into quality-of-life, services, supports, and education research. These are the areas that directly improve the lives of autistic people. While scientists spend billions of dollars searching for the causes of autism, Autistic children are being abused by their teachers, who lack the education and resources to treat them appropriately. Teenagers are shuffled from school to school, without ever getting an appropriate

education. Young adults age out of the system, only to find they were not taught independent living skills and there are no programs able to help them. Autistic adults are being confined to institutions because community support systems are either non-existent or grossly underfunded. Whether an Autistic adult needs help holding a job or brushing her teeth, the fact is that research can and must be one to develop effective supports that allow Autistic people to reach their individual goals and lead fulfilled lives. Years are spend searching for a future cure, while Autistic people who are here now, who can be helped now, have needs not being met due to lack of research and funds. For every dollar, for every hour, that is spend in a lab looking for causes, think of how matching that time and money can make a real, measurable difference in someone's life.

The last points I want to touch on are the bioethics concerns and eugenic applications of genetic research. I believe that science for the sake of pure knowledge is not in essence wrong or bad in any way. It is how humans choose to use the knowledge we have gained through science that can lead to harm. I do not believe that it is wrong to be curious about the causes of autism. In fact, I myself am fascinated by the human brain and I enjoy reading about my own Autistic neurology in scientific texts. However, I am deeply concerned about how cause-based research may be used. If a pre-natal test for Autism is developed, up to 90% of Autistic people may follow in the steps of those with Down syndrome, and never make it out of the womb. . Because Autism is so complex and so varied, there is no way of predicting the future quality-of-life of an Autistic fetus only by identifying certain genes.

I am not taking a stand on abortion, but on eugenics. Today, we are abhorred by the times in history where groups as varied as the poor, mentally ill, blind, promiscuous, physically disabled, homosexual, and Jewish were labeled "degenerate", or "unfit". In an effort to improve human hereditary traits, such people were institutionalized, sterilized, and of course killed. Of course, we now recognize these reached acts as massive violations of human rights.

Let's not go there again. Let's not segregate people from society by confining them to institutions when they could live in the community with the right supports. Let's not think of people as "sick" "disordered" and "unfit" for living. Let's not take an entire group of people, and, without their consent, attempt to prevent future generations of them from existing. Let us respect and accept all people for who they are. Let us support and educate all people and aid them in living the best possible life possible. Let us develop ways to help people communicate their needs, access healthcare. Let us change society to accommodate all people, and let us make the world a place in which everyone can grow, learn, work, play, love, but most of all, live.

Thank you.

Paula Durbin-Westby

May 4, 2009

Subject: Augmentative and Alternative Communication:

It is gratifying to see that the IACC is addressing the critical issue of Augmentative and Alternative Communication.

Now it is time to allocated funding to AAC research. Including a presentation about AAC is an important but preliminary step.

Since communication difficulties are experienced by many, if not most, people on the autism spectrum, funding research in this area should be a high priority. Advances in communication technology, and the development of AAC options that are affordable, will have a practical application to the lives of people on the autism spectrum, throughout the entire lifespan.

Because of the extreme disparity between services/quality of life funding and the funding of basic research, funding for AAC should be diverted from the millions of dollars allocated to genetic and treatment research and NOT drawn from the already minimal funding for service-related research.

Community-Based Participatory Research:

I recommend using a community-based participatory research model for AAC and other research. Autistic adults must be included as collaborators in research, for both practical and ethical reasons. The community-based participatory research paradigm is one model; others may be developed and utilized.

One likely outcome of including people on the autism spectrum as collaborators and co- researchers is that the research will be made more relevant to the lives of people on the autism spectrum, including not only adults but children as well.

One example from a current research area is that of eye contact research. It has been recently discovered by Klin et al., that autistic children look at mouths more than at eyes. Although this is an exciting new discovery for researchers and others, it is not necessarily news to people on the autism spectrum, who are often aware of the reasons and motivation for our own actions.

In addition, studies have already been undertaken that show that typically-developing children also use multi-modal perception to process their experiences.

It has been suggested that some sort of retraining could be done to direct children to not look at mouths but at eyes. The theory is that by looking at mouths children, and presumably adults who do not make much eye contact, are missing important social cues.

While it is critical to understand the underlying mechanisms for human communications and processes, the design and application of scientific theories, especially when young children are involved, should have participation, input, and oversight from people on the autism spectrum.

Researchers should take into consideration the numerous self-reports of people on the autism spectrum about the necessity of looking at people's mouths in order to compensate for auditory processing difficulties, among other reasons. Including co-researchers who are on the autism spectrum can positively inform research so that time and taxpayer money are not wasted and so that studies involving autistic children as subjects do not cause additional difficulties when children are retrained to look away from mouths and possibly lose a significant visual method of accessing receptive communication. Audio-visual synchronies are important not just because they are early indicators of autism but because they are a critical component in how we make sense of communication inputs.

Autistic self-advocate organization as public member:

The time has come for the Interagency Autism Coordinating Committee to include representation from autistic self-advocacy organizations such as the Autistic Self Advocacy Network. Autistic self-advocacy organizations are an increasingly recognized stakeholder in autism policymaking and should not be purposely excluded from the Committee that makes decisions about federal funding for research. Adding a public member from an autistic self-advocate organization will begin to redress the existing imbalance in parity, and add a much-needed dimension of focus on research and policy that will benefit people on the autism spectrum across our lifespans.

This will enable research into AAC to move from the "promising practice" realm to a best-practice reality.

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