Oral Public Comments

IACC Full Committee Meeting

February 4, 2009

List of Oral Public Comments

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

Katherine Walker

February 4, 2009

[PII redacted]

Good Afternoon, my name is Katherine Walker. I'm the mother of a five-year-old son with PDD-NOS. Today I need to let the IACC know that my son's health and safety, and the safety of thousands of children who have yet to be vaccinated are not a hot potato.

The game of hot potato is a favorite among young children. You remember, you throw a small object around a circle of friends as quickly as you can and try not to drop it. Well as a childhood game, this behavior is appropriate. But in the business of ensuring that federally mandated vaccines are truly effective and safe, this behavior is not acceptable.

As a mother of a vaccine injured child, I am angry, of course. I am hurt and tired of all the work it takes to just get through the daily routines of life with my son. Yet, I am not here to lay blame at anyone's feet for what happened to MY son. This issue of blame is one Ms. Storey had brought up I believe in November. Blame is not my intention.

My intention is to encourage the fiduciary duty of the federal government, and each of you sitting here as representatives of that government. If the government mandates it, the government should study its safety. I do challenge the IACC with the task of ensuring that from this point forward, the safety of vaccines – and their relationship to autism – is not treated as a hot potato.

I need not repeat the fact that there is scientific basis for the vaccine research items that were struck from the Strategic Plan on January 14. Even if I were to concede there was not scientific support, is it still not your fiduciary responsibility to ensure the safety of susceptible individuals? Especially as the so-called "anecdotal" evidence is increasing rapidly?

We are quickly approaching a point of no return. The IACC may want to ignore this issue, they may desperately want to play hot potato, saying "we don't have the expertise" or "we don't want to duplicate work being done by another agency". However, the wave of public awareness and opinion is just beginning to rise. Now the IACC has the opportunity to be ahead of this wave. To be on the proactive side of this epidemic.

I acknowledge that there is indeed a conflict of interest with different entities of HHS having responsibility for the vaccine program while at the same time tasked with vaccine safety research. How could there not be conflict? In order to restore the trust needed to truly have an effective vaccine program, the HHS must ensure all research done on vaccine safety and the vaccine-autism relationship is conducted by independent and nonbiased organizations.

If there truly is a sincere desire to determine the etiology of autism. There MUST be a sincere approach to thorough investigation of even the claim of harm done by vaccines. This is not debatable. Your mission and core values MUST include an authentic commitment to uncover and curb the causes of ASD. It must be done without bias to any industry or governmental interest or initiative. It must be fair and balanced.

I thank the IACC for allowing me the opportunity to speak, and I once again, I conclude with another quote from Thomas Jefferson:

"The force of public opinion cannot be resisted when permitted freely to be expressed. The agitation it produces must be submitted to." --Thomas Jefferson to Lafayette, 1823. ME 15:491

Theresa Wrangham

February 4, 2009

safeMinds
Sensible Action For Ending Mercury-Induced Neurological Disorders

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.

I state the obvious today - many autism organizations are extremely dissatisfied with the IACC's action to remove previously approved vaccine research objectives due to concerns regarding the IACC's mandate; government agency conflicts of interest in ongoing vaccine injury litigation; NIH lack of expertise to conduct vaccine research; and that these objectives did not originate from IACC science workshops.

Respectfully, our concerns are founded in science conducted by respected members of the scientific community who share our concern. The countless citing and recitation of the Combating Autism Act's colloquy statements to the IACC should leave no doubt as to the undeniable Congressional mandate and wishes of We, The People. This committee is charged with including vaccine research specific to autism in the strategic plan.

The NIH website states, and I quote, "NIH has a long and fruitful history of vaccine research". A quick search of the Clinical Trials search engine produces 433 studies using keywords "vaccine safety NIH". One titled "Research to Advance Vaccine Safety" contains the objective - "identification of risk factors and biological markers that may be used to assess whether there is a relationship between certain diseases or disorders and licensed vaccines". Collaborating organizations include NIMH, CDC, NICHD and NIEHS.

Despite statements to the contrary, the previously approved vaccine objectives were supported in the IACC science workshops and according to February's IACC transcript of the Strategic Planning Work Group, Dr. Craig Newschaffer confirmed that initiative 34 - *Risk factor studies in other special populations* – as a "perfect fit". The scientific community involved in the Strategic Planning Workgroup on numerous occasions, and in agreement with autism organizations and many public IACC members, stated the need for vaccine-focused research; acknowledgement of autism as a multi-system disorder; and cited a bias regarding the state of vaccine research and recommended the inclusion of limitations for studies currently cited in the "What we know" section of Question 3 with the addition of research supporting vaccine concerns.

Many of SafeMinds Board Members were also present via telephone when these issues were discussed at great length during the July 8th meeting of the work group. The outcomes from these discussions were not wholly presented in the screen presentation made to the IACC on July 15th, and no was attempt made to integrate them via the SafeMinds document furnished to the committee on July 10th that summarized these outcomes. Coincidentally, SafeMinds has since been informed that there is *no audio file for the July 8th meeting and no transcription taken, which calls the veracity of the screen presentation made to the IACC on July 15th into question.*

Thus, the justification for the revote was without merit and requires the IACC to reinstate the objectives. However, in light of Dr. Insel's acknowledgement of the existing inherent conflicts of interest within HHS to conduct this research, which includes the National Vaccine Program Office, reinstatement will require the addition of provisions for independent entities to conduct the research, as well as mechanisms to provide objective oversight and transparency in the grant review and monitoring process. Furthermore, inaccuracies in the "What we know." section of Question 3 must be corrected.

In closing, we remind the committee that over a million affected individuals, families and communities depend on your expedient action to correct what are obvious errors. People with ASD deserve optimal health and affordable access to treatments, supports and services to lead happy and productive lives. Their best interests must supersede the political machinations at work within this body.

Peter Bell

February 4, 2009

On behalf of Autism Speaks, I wish to express our concerns about the events that transpired during the January 14 IACC meeting. These concerns involve two issues - the process by which changes were made to the Strategic Plan for Autism Research and the substantive merits of those changes.

Part of what generated enormous enthusiasm for the Combating Autism Act among the families and advocacy communities was that it established a process for public participation in the IACC. Until the January 14 meeting many advocacy organizations, including Autism Speaks, believed that the public's role was, at last, appropriately integrated into autism public policy at HHS. There was a sense that a genuine partnership was being forged among the public, scientific and medical communities, as well as the federal officials at HHS. In fact, the Strategic Plan, as approved and drafted before the January 14 meeting, had the support of a broad consensus of the autism advocacy community. A significant component of the approved plan, and an element of great importance to the Congressional sponsors of the CAA, was the inclusion of two research objectives relating to vaccine research. These objectives had been approved at the December 12th IACC meeting -- with the support of several federal members.

Surprisingly, and disappointingly, this all changed at the January meeting. It is important to underscore that the process by which these two objectives -- of forty-two total research objectives -- were reconsidered and the resulting deletion have undermined the trust that had been developed throughout the process. The topic of vaccine research was not on the published agenda, nor was advance notice given to public members. Thus, many of the IACC members and the public were not given an opportunity to anticipate and thoughtfully consider what represented a significant change to the scientific objectives of the Strategic Plan. Because vaccine research is a controversial and complex topic which had been previously addressed by the IACC, the decision to revisit it and propose significant changes to the plan without advance notice and adequate time to prepare and respond to the arguments put forth by the NIH leadership was unfortunate. It did not reflect the collaborative, transparent, and fair spirit with which the IACC had been functioning.

The justifications given by some federal members of the IACC for removing the vaccine- related objectives from the research objectives section of the plan ranged from the fear that the feasibility study would be duplicative, or not in sync with, efforts underway by the National Vaccine Advisory Committee (NVAC); to the potential for a conflict of interest related to a lawsuit against the Department of HHS; to, finally, the fact that these two research objectives were the only objectives that did not come through the IACC's scientific workgroup process and, thus, are not founded in good science.

The concern with respect to NVAC's role in vaccine safety could have easily been remedied by adding text to the plan that the objectives be met in coordination with the NVAC. Unfortunately, this was not offered, nor was there an opportunity to have a substantive debate on the merits of keeping the research objectives.

Further, it strains all interpretation of the IACC's Vision Statement for the Strategic Plan to "… set the standard for public-private coordination and community engagement" to move two of forty-two objectives because they did not arise out of the scientific workshop when they were supported vigorously by nearly all of the IACC's public members and were critical components in securing the

sponsorship and passage of the CAA. It also begs the question: Why did Congress insist, by statute, that the public be represented on the committee if it only wanted a plan produced by a series of scientific workshops?

Autism Speaks and other members of the autism advocacy community were assured throughout this process that the scientific workgroups were advisory to the IACC. Moreover, scientists who were part of the workshop on etiology did in fact recommend that vaccines, among a wide range of other environmental factors, be studied as a risk factor for autism.

Autism Speaks regrets that because of these breaches in process and trust, we were compelled to withdraw our support for the Strategic Plan despite the many important and good objectives that the plan embodies and the tremendous amount of hard work that has gone into the plan over the past two years.

This brings me to the second concern – the merit of the changes that were made to the strategic plan:

As outlined in Autism Speaks' policy statement posted on our website (see http://www.autismspeaks.org/policy_statements.php (IACC Note: URL is not valid.)) and also attached, we are "committed to the health and well-being of all children. As such, we support the programs that ensure the public health, including an effective and safe immunization program designed to prevent major diseases." It is Autism Speaks' position that the best way to ensure that parents are confident in the safety of our vaccine program and, at the same time, protect the minority of children who may be at increased risk for serious adverse effects of vaccinations, is to foster collaborative, trusting relationships among the general public, the medical and scientific communities, and the federal government whose mandate it is to conduct research on the safety of vaccines. Studies show that the key to parental willingness to have their child vaccinated is a trusting relationship with their medical provider and the medical community in general. Autism Speaks' position is to advocate for the common ground for trust between the general public and the medical community by directly and immediately address on-going, legitimate questions regarding the safety of vaccines. We recognize that authoritative studies addressing safety require time and resources, but we also recognize that quick government action toward addressing these questions will instill necessary confidence, trust, respect, and demonstrate the collaboration and transparency we all aspire to.

Autism Speaks is confident that rigorous science can address the questions parents and many members of the scientific community feel are important. New discoveries in science have raised new questions about the role of environmental factors in autism, including the question of whether immunization is associated with increased risk for ASD. As acknowledged in the CDC's draft scientific agenda, fundamental questions have not been addressed, such as whether the use of combination vaccines confers increased risk for adverse events and whether there are subgroups in the general population, such as children with certain genetic or metabolic conditions, that are more vulnerable to serious adverse effects of vaccines, including ASD. Such research would potentially have wide- ranging effects on clinical practice/vaccination policy and may help our community identify subgroups of children at risk, different vaccine schedules for those at risk, and recommendations for careful monitoring of adverse effects.

Studies that can address these questions are clearly feasible. Case-control studies and randomized clinical trials can be conducted to address whether there are differences in adverse effects associated with a combination vaccine versus individually administered components. Studies of infant siblings of

children with ASD, who are at higher risk for developing the disorder, offer an opportunity for studying gene-environment interactions. The National Children's Study, which is examining the influences of a wide range of environmental and genetic factors on risk for health outcomes, can provide another resource for studying whether vaccines are associated with increased risk for neurodevelopmental disorders in subsamples of the general population. Improvements in the Vaccine Adverse Events Reporting System (VAERS) would also allow better monitoring of a wide range of adverse events, including seizures and neurological events.

Autism Speaks believes that a fruitful strategy for moving forward would be to establish a working group comprised of key representatives of the stakeholder, medical, and scientific communities and the federal agencies involved in vaccine safety research. The goal would be to work collaboratively to review and prioritize the scientific questions that need to be addressed in light of the most recent scientific findings and public concerns.

In conclusion, I want to say for the benefit of committee members that we still believe the IACC can reclaim the promise the Strategic Plan for Autism Research had following the December 12, 2008 meeting. It is our hope that the IACC will seize this opportunity to renew confidence, trust, and a spirit of collaboration among the public, scientific and medical communities, and the federal government. This can best be accomplished by incorporating the original, approved vaccine research objectives, including the same budgetary requirements, as priority items in the soon to be drafted second version of the Strategic Plan for Autism Research. I urge you to do so, as we believe that individuals with autism and their families -- and the general public -- will be best served through this action.

Autism Speaks
Statement on Vaccine Research and Safety
Also found at: http://www.autismspeaks.org/policy_statements.php (IACC Note: URL is not valid.)
Autism Speaks is committed to the health and well-being of all children. As such, we support the programs that ensure the public health, including an effective and safe immunization program designed to prevent major diseases. Immunization programs have been very effective in reducing mortality, morbidity and costs associated with common childhood diseases. Today's parents no longer need to worry that once dreaded diseases like polio and smallpox could be threats to their children. Public trust in immunization programs must be protected. Thus it is critical that we take steps now to do all we can to affirm the public confidence in the safety of vaccines. Autism Speaks is committed to actively supporting research to find answers to the following questions:

Are there adverse events from vaccines that impact neurodevelopment over time?
Are common adverse events occurring more frequently than before? If so, what changes have occurred and why?
Does the use of combination vaccines or the practice of giving several vaccinations in one day confer increase risk for adverse events?
Are there subgroups in the general population that exhibit more adverse events than others?

In order to answer these challenging and complicated questions, Autism Speaks is mobilizing the scientific community and engaging broad scientific expertise, including experts in genetics, neuroscience, and immunology. We are working diligently with officials in our government to address the questions that parents have through both basic and clinical research. We believe this to be the most effective course of action toward creating meaningful change.

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Yvonne Hershey & [PII redacted]

February 4, 2009

Good afternoon. My name is Yvonne Hershey and this is my 17-year old son, [PII redacted]. We are here today because of the profound impact mercury has had on our lives. And we are here today because we believe it is critical that research into the effects of mercury continue so that all families with children suffering from Autism Spectrum Disorder can realize the same happy ending that we are experiencing. Thank you for giving us this opportunity.

Ours is a story of transformation. This healthy, sensitive, intelligent, witty and musical young man sitting here today bears little resemblance to the adolescent of four years ago.

We'll start at the beginning: [PII redacted] was happy as a baby, as a toddler and through his elementary school years. Very early on, however, we became aware of focus and attention problems.

[PII redacted]: When I started middle school, things got much worse. By 7th grade, I would go to my room immediately after school and come out only to eat dinner.

I discovered bottles of pills stashed in his dresser drawer. [PII redacted]'s dad and I were at a complete loss. What had happened to our son?

Things continued to spiral downward until they hit bottom when [PII redacted] was in 8th grade. He was severely depressed and his explosive rage controlled our lives. Life, every day, was hell – for him and for us, his parents and siblings. It seemed inevitable that his life would either end by his own hand or be spent in a correctional institution.

After a suicide attempt, [PII redacted] spent one week in a behavioral hospital. Medications prescribed by a psychiatrist for ADD, rage and depression were not only ineffective, but made things worse. In desperation, we began exploring alternative solutions. In this process, we found a research clinic in Quakertown, Pennsylvania established by a medical doctor

[PII redacted]: After a lot of testing, I was diagnosed with mercury poisoning caused by high levels of thimerosal in the childhood immunizations I received in the early 1990's.

While it is true that many children suffer no ill effects from their immunizations, the presence of mercury wreaked neurological havoc in [PII redacted].

[PII redacted]: When I was 14, I started treatment that lasted about 15 months. I took two different things – Vitamin B12 to break up the mercury that had lodged in my brain, and Glutathione to move it out of my body. My parents say they began seeing changes in less than a month.

It would be difficult to overstate the transformation that unfolded. I vividly remember the moment when, for the first time in years, [PII redacted] looked directly at me and responded to a comment I had made. And in his eyes I saw a glimmer, a spark of life that had been nonexistent for a very long time. For me, that marked the beginning of hope for a complete recovery.

And what a recovery it has been. [PII redacted] loves life, he loves people, he even loves school – at least some times.

[PII redacted]: I don't have trouble concentrating in class any more. Several years ago, I was on the verge of dropping out of school. But now, my grades are better than a B average. My goal is to do even better. And I've started thinking about where I want to go to college. My depression and rage are gone.

[PII redacted] is full of conversation and music. His rich bass singing reverberates throughout our house. And after years of deafening silence, it is indeed music to my ears.

I am not a scientist, or a medical professional, or an expert on Autism Spectrum Disorder. I am only a mother, who has witnessed firsthand the devastating effects of mercury poisoning on my son and the astounding changes that occurred when the mercury was removed and his brain was allowed to heal. The pain and cost of Autism Spectrum Disorder are far-reaching and devastating, to individuals, to families, and to society. I am here today because I believe it is absolutely essential for research to be ongoing, so that answers can be found and people educated about the causes and treatment of ASD.

[PII redacted]: And I am here today because, well – I got a day off school, and also because I think it would be great if other families could get the help they need.

We ask that you please consider our story and the stories of thousands of others as you make decisions on funding for research into the mercury/autism link.

Thank you!

John Erb

February 4, 2009

On November 30th, 2007, I stood before this committee and explained to you the culmination of my years of research into the cause of Autism.

I read to you about several studies that have shown that the ASD is likely caused by MSG in the food and vaccines.

Since that time I have found further studies linking glutamate to Autism as far back as 2000. (The following studies will not be read due to time limits and will have an updated DOC with references instead of links.)

The largest genetic study done concluded :"glutamate-related genes as promising candidates for contributing to Autistic Spectrum Disorder" Mapping autism risk loci using genetic linkage and chromosomal rearrangements.

Another study showed "Glutamate carriers and altered Ca(2+) homeostasis play a key interactive role in the cascade of signaling events leading to autism" Altered calcium homeostasis in autism- spectrum disorders. Nat Genet. 2007 Mar;39(3):319-28. Epub 2007 Feb 18.

Palmieri L, Papaleo V, Mol Psychiatry. 2008 Jul 8. I would love to get a hold of the abstract for this study but oddly the abstract is missing:
The hyperglutamatergic hypothesis of autism.Fatemi SH. Prog Neuropsychopharmacol Biol Psychiatry. 2008 Apr 1;32(3):911

Now here is a study that states "CONCLUSIONS: Abnormalities in glutamate/glutamine may partially underpin the pathophysiology of autistic spectrum disorders, and the authors confirm earlier reports that limbic areas are metabolically aberrant in these disorders."In vivo 1H- magnetic resonance spectroscopy study of amygdala-hippocampal and parietal regions in autism.Page LA, Daly E, et al. Am J Psychiatry. 2006 Dec;163(12):2189-92.

CONCLUSIONS: The present study suggests that an abnormality in glutamatergic neurotransmission may play a role in the pathophysiology of autism.

Increased serum levels of glutamate in adult patients with autism. Prog Neuropsychopharmacol Biol Psychiatry. Shinohe A, Hashimoto K, et al. 2006 Dec 30;30(8):1472-7

In this one "The results were compared with values from age-matched controls. Patients with autism or Asperger syndrome and their siblings and parents all had raised glutamic acid,...These results show that children with autistic spectrum disorders come from a family background of dysregulated amino acid metabolism and provide further evidence for an underlying biochemical basis for the condition. Plasma amino acid levels in children with autism and their familiesAldred S. , Moore KM, et al. J Autism Dev Disord. 2003 Feb;33(1):93-7 and this one: "A genome scan was previously performed and pointed to chromosome 6q21 as a candidate region for autism. This region contains the glutamate receptor 6 (GluR6 or GRIK2) gene, a functional candidate for the syndrome. Glutamate is the principal excitatory neurotransmitter in the brain and is directly involved in cognitive functions such as memory and learning.....these data suggest that GluR6 is in linkage disequilibrium with autism." Linkage and

association of the glutamate receptor 6 gene with autism.Jamain S, Betancur C, Mol Psychiatry. 2002;7(3):302-10.

As early as 2001: CONCLUSIONS: Subjects with autism may have specific abnormalities in the AMPA-type glutamate receptors and glutamate transporters in the cerebellum. These abnormalities may be directly involved in the pathogenesis of the disorder. Postmortem brain abnormalities of the glutamate neurotransmitter system in autism.Purcell AE, Jeon OH, et. al Neurology. 2001 Nov 13;57(9):1618-28.

or this one from 1998: "Based on 1) neuroanatomical and neuroimaging studies indicating aberrations in brain regions that are rich in glutamate neurons and 2) similarities between symptoms produced by N-methyl-D-aspartate (NMDA) antagonists in healthy subjects and those seen in autism, it is proposed in the present paper that infantile autism is a hypoglutamatergic disorder." Hypothesis: is infantile autism a hypoglutamatergic disorder? Relevance of glutamate - serotonin interactions for pharmacotherapy. Carlsson ML. unfortunately it did not reach a conclusion. J Neural Transm. 1998;105(4-5):525-35. and one from 1996: "These findings demonstrate that abnormal plasmatic levels of neurotransmitter amino acids may be found in some autistic children. Increased glutamatemia may be dietary in origin or may arise endogenously for several reasons, among others, metabolic derrangements in glutamate metabolism perhaps involving

vitamin B6, defects or blockage of the glutamate receptor at the neuronal compartment, or alterations in the function of the neurotransmitters transporters."

Plasma excitatory amino acids in autism.Moreno-Fuenmayor H, Borjas L, Invest Clin. 1996 Jun;37(2):113-28. and there is this one: "Autism is a neurodevelopmental disorder with early manifestation. It is a multifactorial disorder and several susceptible chromosomal regions for autism are identified through genome scan studies. The gene coding for glutamate receptor 6 (GluR6 or GRIK2) has been suggested as a candidate gene for autism based on its localization in the autism specific region on chromosome 6q21 and the involvement of receptor protein in cognitive functions like learning and memory." Glutamate receptor 6 gene (GluR6 or GRIK2) polymorphisms in the Indian population: a genetic association study on autism spectrum disorder.Dutta S, Das S, Guhathakurta S, et al.1: Cell Mol Neurobiol. 2007 Dec;27(8):1035-47. Epub 2007 Aug 22.

In Conclusion, as I said before, by removing MSG from the food and vaccine supply we will end this terrible disorder.

Autism is a global epidemic, requiring global concern and a global reaction.
To that end I am announcing the creation of a Global Autism Institute and Academy, funded by sponsor by associations around the world, in Chesapeake Virginia.

This facility will act as a nerve center collecting and distributing research, data and resources to share worldwide. This centralization of specialized knowledge will aid in discoveries on how to teach people how best to serve this special population and to find ways to reduce and reverse the harm that comes with this disorder.

I invite all those here to participate in this venture, that together we may bring healing to the world.

John Erb GAIA

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Maribel McIntyre

February 4, 2009

Throughout history, the role of science has been not only to explain those mysteries that we cannot understand, but also to find answers to complex challenges. To understand the world around us, before the scientific method was ever designed, we mostly relied on the information that we received through our senses, even when this information did not seem very logical. Let me elaborate.

Folklore has it that Lake Superior never gives up its dead. Sounds strange, doesn't it? Normally, the bodies of those who drown will eventually float. Actually, scientific explanation is that a cadaver in the water starts to sink as soon as the air in the lungs is replaced with water. Once submerged, the body stays underwater until the bacteria in the gut and chest cavity produces enough gas to float it to the surface like a balloon. So, with this information, how can we explain the bizarre occurrence in Lake Superior? Well, apparently, the frigid temperatures of Lake Superior slow down bacterial action and that's why the bodies tend to remain sunken. This sounds like an exception to an expected process due to unique characteristics, in this case, the water temperature. As we all know, there's always an exception to every rule.

In theory, the human body should be able to detoxify itself from the neurotoxins contained in vaccinations. But, what happens if the body cannot detoxify itself? What would be the effects, changes and consequences of having substances such as Mercury and Aluminum trapped in your body? What happens to those special populations that do not follow the expected process of detoxification from neurotoxins? So many questions that deserve to be answer!

This is not about placing blame; this is about understanding the mystery of Autism and finding answers. Just like those people who noticed Lake Superior's peculiar behavior, which has been explained by science, as parents, we have noticed changes in our children development and health when exposed to neurotoxin-laden vaccinations. Let the science explain what we see! Let's study the effects on neurotoxin on children!

The goal of public health is to improve lives through the prevention and treatment of disease. Let us prevent and treat Autism!

Maribel McIntyre [PII redacted]

Paula Durbin-Westby

February 4, 2009

The Autistic Self-Advocacy Network would like to take this opportunity to thank members of the Interagency Autism Coordinating Committee for inviting us to present on Ethical Concerns in Autism Research this past November. We applaud the effort the IACC has made so far in developing a Strategic Plan for autism research.

Much remains to be done.

Funding allocation has been skewed in the direction of finding causes and cures. For example, $75 million dollars have been allocated toward just one research initiative that of identifying animal and cell models in the attempt to find a "cure" for autism. Compare this with a mere $1.6 million for the entire services research area.

Public Law 109-416 has a broader mandate than research into causes and cures. Although the short title, the "Combating Autism Act," was geared toward obtaining congressional and public support for the act, it is time to take a step back and seriously think about what funding priorities mean to people who are on the autism spectrum, their families and communities. The research agenda should respect the wishes of autistic individuals and their families, many of whom have written in response to Requests for Information. If you look at the sheer volume of comments in response to the December 19, 2007 RFI you see that approximately 90 comments were received on services and related issues, under the treatments section. If we add comments about education, assistive technology, and concerns about the future, the comments number in the hundreds, a sizable percentage of all comments received.

The Autistic Self-Advocacy Network recommends a shift in focus to research into areas that will actually help families and individuals on the autism spectrum. Such research should address the domains measured by the World Health Organization Quality of Life Instrument, including, in the area of Independence, mobility, Activities of Daily Living, communication, and employment.

Regarding communications technologies and systems, the Strategic Plan mentions Picture Exchange Communication Systems but does not address other systems. PECS cannot adequately represent 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 abound, including 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 people on the autism spectrum to use and develop language in ways that are natural to us, even if it is sometimes 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.