

December 11, 2008 [rev 12-14-08]

RE: Concerns on IACC Strategic Plan Discussions

Dear Members of the IACC:

In November, several autism organizations sent a letter to IACC members which outlined concerns with the draft Strategic Plan for autism research. Most of these issues have been resolved with revised language submitted for consideration at the November 21 IACC meeting. However, the discussions and voting on the language raised several concerns, and we write again asking the IACC to address them at the next meeting on December 12.

(a) During review of Questions I and II, suggested priority objectives calling for an increase in budget were scaled back (example, biobanking objective) or deferred to 2009 (example, adult prevalence study). If these reductions continue, the minimum budgetary requirements of the Combating Autism Act (CAA) will not be met. We ask that the revised priority objectives that entail spending at least to the minimum CAA requirements be retained.

(b) The discussion point on autism and vaccine associations in the "What do we know" section of Question III missed critical messages on this topic. Adequate research is essential to preserve public trust in immunizations. A portion of the public, including a segment of the scientific community, are concerned.^{1,2} Many parents of children with autism are choosing not to follow the recommended vaccine schedule.³ Legislative history accompanying the CAA requested that autism-vaccine research be conducted. We ask that the Plan reflect these points and that research on vaccines and autism be made a priority area, with objectives in Question III that specifically focus on this topic. Additionally, we reiterate our statement in the November 12 letter, that research on the environment, gene-environment interaction, and treatment were underrepresented in the draft Plan, and the final Plan should apply additional resources to these areas.

(c) IACC Member Lyn Redwood submitted additional and clarifying language for the Introduction that embodied a sense of urgency reflecting the alarming increase in prevalence and autism as a national health emergency and included provisions for accountability and evaluation of the research spending. To reiterate our position from the November 12 letter, (i) 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 (ii) the Introduction should embody urgency and the critical need of the government to apply the resources to address a crisis situation.

(d) The November 12 letter asked that a workgroup be convened in January 2009 to focus on additional enhancements to the Strategic Plan. It also asked that future Plan activities ensure integral participation of the diverse community representing families and individuals with autism. We ask that the IACC formally request that such a workgroup be convened immediately.

We appreciate the time and effort of the IACC to complete the Plan. We look forward to having a compelling and effective document that the autism community can enthusiastically support.

Sincerely,

Autism Research Institute
Autism Society of America
Autism Speaks
National Autism Association

SafeMinds
Southwest Autism Research & Resource Center
Talk About Curing Autism (TACA)
Unlocking Autism

Cc Dr. Della Hann, NIMH

¹ Florida Institute of Technology. Parents' Fears, Confusion Over Autism Confirmed By Survey. Oct 4, 2008. <http://www.medicalnewstoday.com/articles/124220.php>. ² Learning and Developmental Disabilities Initiative. Policy Implications Based on the Scientific Consensus Statement on Environmental Agents Associated with Neurodevelopmental Disorders. Sept 16, 2008. <http://www.iceh.org/pdfs/LDDI/LDDIPolicyStatement.pdf>. ³ Kuwaik G et al. Immunization Uptake in Siblings of Children with Autism. Pediatrics. September 2008.