

November 17, 2008

RE: Concerns on Draft IACC Strategic Plan - Updated

Dear Members of the IACC:

The Combating Autism Act required the IACC to prepare a strategic plan for autism research in order to enhance the quality, effectiveness, and overall benefits of autism research spending within HHS agencies. While the 2008 planning activities reflect improvements relative to earlier Autism Matrix efforts, ultimately the draft plan and the planning process have fallen short. Autism advocates have identified a range of deficiencies and each may place priorities on different concerns. Nevertheless, as a community we are united in expressing our disapproval of the draft plan for the reasons outlined here.

- a) The plan fails to communicate a sense of urgency reflecting the alarming increase in prevalence and autism as a national health emergency. The beginning pages of the plan should embody urgency and the critical need of the government to apply the resources to address a crisis situation.
- b) The plan fails to allocate commensurate resources. The CAA authorized \$645 million for NIH research over five years. The plan falls short by close to \$200 million. Given the urgent situation, we consider the CAA allocation to be a minimum requirement for federal agencies and feel that even greater resources are needed.
- c) Research on the environment, gene-environment interaction, and treatment are underrepresented in the draft plan. The plan should apply additional resources to these areas.
- d) Provisions for accountability and evaluation for the research spending are absent. 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.
- e) The planning process diminished the voices of important segments in the autism community. Future activities related to the SP should ensure integral participation of the diverse community representing families and individuals with autism.

We ask that the IACC approve these specific action items: (a) adoption of amendments to the plan responsive to the above 5 concerns; (b) specification that research spending be at least the CAA minimum and establishment of a workgroup to be convened in January 2009 to develop recommendations to the IACC for increasing the research spending to at least that minimum and adding objectives which will bolster research on the environment, gene-environment and treatment; (c) inclusion of oversight provisions including an AAB and DOD-model review process; and (d) specification that oversight bodies and workgroups have strong and diverse community representation.

Each day, decisions are being made on autism research by NIH and other federal agencies which are outside of the SP. It is imperative that the plan be improved in the areas noted above at the November 21, 2008 IACC meeting.

Sincerely,

Autism Action Network (formerly A-CHAMP)
Autism New Jersey (formerly COSAC)
Autism One
Autism Research Institute
Autism Society of America
Autism Speaks
Generation Rescue

National Autism Association
Organization for Autism Research (OAR)
SafeMinds
Southwest Autism Research & Resource Center (SARRC)
Talk About Curing Autism (TACA)
Unlocking Autism
US Autism & Asperger Association

cc: Dr. Della Hann, NIMH

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.