

November 12, 2008

RE: Concerns on Draft IACC Strategic Plan

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 New Jersey (formerly COSAC)
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

Cc Dr. Della Hann, NIMH