

## 2013 IACC Strategic Plan Update – Draft Introduction – Prepared by Tom Insel, OARC, and John Robison

The Combating Autism Act (CAA) and the subsequent [Combating Autism Reauthorization Act \(CARA\)](#) established an Interagency Autism Coordinating Committee (IACC) to advise the Secretary of Health and Human Services on issues related to Autism Spectrum Disorder (ASD). One responsibility of the IACC was the development of a strategic plan for ASD research, to be updated yearly. The *IACC Strategic Plan*, first issued in [2009](#), was produced by the IACC, composed of federal officials and public stakeholders, with extensive input from researchers, adults on the autism spectrum, parents, advocates and the general public that was gathered through a series of meetings and public comment opportunities. This inclusive process ensured that the *IACC Strategic Plan* reflected diverse perspectives from across the autism community.

The *IACC Strategic Plan* is organized around seven general topic areas that are represented in the plan as consumer-focused Questions (e.g. Question 1, “When should I be concerned?”, which covers the topic of screening and diagnosis). Each Question is assigned a chapter that provides a description of the state of the science in that area. Each chapter also contains: a section describing the research and community needs for its relevant Question; the aspirational goal, or long term vision, for each area; and a list of specific long- and short-term objectives. The objectives were created by the committee to address critical gaps and opportunities they perceived in the research landscape in 2009. Each objective also includes a recommended budget that serves as an estimate of how much the Committee projects it might cost to conduct the research-related activities described. The *IACC Strategic Plan* was updated in [2010](#) and [2011](#), adding several new objectives. In [2012](#), following the reauthorization of the Committee, the plan was updated with advances and new research opportunities.

For the 2013 update of the *IACC Strategic Plan*, the Committee voted to focus on accountability without adding new objectives or re-writing the previous versions. With access to an extensive portfolio analysis conducted by the NIH Office for Autism Research Coordination linked to every objective as well as the annual IACC Summary of Advances documents from past years, the IACC reviewed what has been invested in ASD research in the U.S. since 2008. Using data from both public and private funders, the IACC determined the level of progress for each of the 78 objectives in terms of the number of projects funded and dollars committed to each objective since 2008. To assess the return on this investment, the IACC also invited a group of external experts to evaluate how research has supported progress towards the aspirational goals in each of the seven chapters of the *IACC Strategic Plan*.

This update summarizes both investment and scientific progress across all seven Questions of the *IACC Strategic Plan*. Most areas have received extensive investment (\$1.5 B expended from 2008-2012 by federal and private funders) and significant progress has been made since the original plan was published in January, 2009. According to the [PubMed database](#) of biomedical research literature, over 11,000 journal articles on autism have been published since January, 2009, more than double the number published in the preceding five years. The world of ASD research has changed profoundly during this period, with increases in U.S. ASD prevalence estimates, changes in ASD diagnostic criteria, greater understanding of co-occurring conditions and services needs, and new insights from genetics, environmental studies, and neuroimaging

into the biology and etiology of ASD. In addition to this review of the investment and progress, the Committee and external experts identified current research gaps, needs and barriers, as well as new opportunities created by advances in the field, which can provide direction for future investment.

In preparing the *2013 Strategic Plan Update*, the IACC also recognized some cross-cutting issues that have emerged with greater urgency since January, 2009. While much of the research literature has been focused on infants and children, the IACC encouraged more attention to the needs of adults with ASD. Additionally, because research has frequently been limited to individuals with more mild disabilities or those who live in communities with greater resources and access to healthcare, the IACC felt that more focus on the most disabled individuals and underserved populations would be essential. And in both public comments received by the IACC as well as discussions within the Committee meetings, the need for interventions for co-occurring or associated conditions was emphasized, as for many individuals and families these issues are equally or more challenging than the core symptoms of ASD. Throughout the seven Question areas in the IACC Strategic Plan, the Committee underscored the need for research to focus on developing efficacious, efficient, scalable and cost-effective interventions, tools and practices that can be translated into affordable and practical healthcare and service options for the autism community. The Committee also highlighted the urgent need to translate scientific discoveries into interventions that can improve quality of life for individuals with autism and their families.

Though this *2013 IACC Strategic Plan Update* will inevitably be unable to capture all the changes in the ASD field since 2008, the IACC has endeavored to deliver through this document an accounting of the investments made and how research has evolved since the January 2009 publication of the original *IACC Strategic Plan*. This update should be read with two other IACC publications to gain a more complete picture of the autism research landscape. The *IACC Autism Spectrum Disorder Research Portfolio Analysis Report* describes Federal and non-Federal investments in autism research. The annual *IACC Summary of Advances in ASD Research* reports in detail specific scientific findings that members of the IACC identify as having significantly advanced the field. Together, with this *2013 IACC Strategic Plan Update*, the Committee hopes that these documents will provide a useful overview of the state of autism research at the end of 2013.