

## IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research —2012 Update

### Introduction:

The Combating Autism Reauthorization Act (CARA) was signed into law on September 30, 2011. CARA led to the establishment of a new Interagency Autism Coordinating Committee (IACC) by the Secretary of Health and Human Services, Kathleen Sebelius. At their first meeting in July 2012, the new Committee developed a plan and timeline to update the *IACC Strategic Plan for ASD Research* by the end of 2012. The *Strategic Plan*, first issued in 2009, was also updated in 2010 and in early 2011.

The IACC voted to update the *Strategic Plan* by working with content experts for each of the chapters of the plan to identify recent advances that have added to “What do we know?” as well as new opportunities or gaps that have emerged, which have altered “What do we need?” The Committee decided to postpone consideration of any changes in the specific objectives or other parts of the Strategic Plan until 2013. This *2012 Strategic Plan Update* covers advances and new opportunities in the field that have emerged between January 2011 and December 2012, recognizing that the plan could not be updated earlier in 2012 while the IACC was being re-established.

This year the speed of progress over the past two years has made composing the update challenging, with major findings emerging nearly every week. For instance, this year substantial changes, from updated prevalence numbers to new diagnostic criteria, were reported. The sheer volume of work that is now being produced in this field is overwhelming; according to PubMed, there were more than 1,000 autism papers on genetics or imaging since January 2011, whereas a decade ago there were less than a third of this number of papers published<sup>1</sup>. This intense activity reflects a marked increase in autism research in the scientific community, and the sense of progress was evident in almost every chapter of this update. Autism research has become one of the hottest fields in biomedical science as demonstrated by Time magazine’s recognition of early treatment of autism as one of its Top 10 Medical Breakthroughs of 2012.

Though this *Strategic Plan Update* will inevitably be unable to capture every important advance and new opportunity that is emerging in the field, the IACC has endeavored to capture in this document the key trends and most groundbreaking new insights from the past two years. This update should be paired with two other publications from the IACC in order to gain a more complete picture of the autism

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<sup>1</sup> Office of Autism Research Coordination (OARC), National Institute of Mental Health and Thomson Reuters, Inc. on behalf of the Interagency Autism Coordinating Committee (IACC). IACC/OARC Autism Spectrum Disorder Research Publications Analysis Report: The Global Landscape of Autism Research. July 2012. Retrieved from the Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/publications-analysis/july2012/index.shtml>

research landscape over the past two years. The *IACC Autism Spectrum Disorder Research Portfolio Analysis Report* describes federal and non-federal investments in autism research, including an accounting of how current research aligns with each of the objectives of the *IACC Strategic Plan*.<sup>2</sup> 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.<sup>3</sup> Together with this 2012 *IACC Strategic Plan Update*, we hope these documents provide a useful overview of the state of autism research at the end of 2012.

#### Conclusion:

The *IACC Strategic Plan for Autism Spectrum Disorder (ASD) Research*, first published in 2009, has now been updated in 2010, 2011, and 2012. The changes in “What do we know?” and “What do we need?” are intended to provide further guidance to researchers and research funders about the opportunities for progress in each of the seven question areas of the *Plan*. This *Strategic Plan Update* does not address the need for an increased focus on services provision issues, which has been discussed at IACC meetings and is an area of intense interest among several IACC members as well as some of the content experts who participated in the *Strategic Plan Update* process. In the coming year we look forward to an opportunity to delve more deeply into this and other issues that emerged as gaps during the update process.

The IACC wishes to express its appreciation to the many people who assisted in this update process. (*names will be listed at the end*) In addition to the experts who generously volunteered their time to work with the IACC on this update, the Committee also heard from many members of the public who sent in ideas or provided written recommendations for consideration. While the final 2012 *Strategic Plan Update* could not reflect every concept or every concern, the IACC assembled this document to capture the current state of the science with respect to autism research, as well as a sense of where the newest opportunities and challenges lie in this effort to meet the evolving needs of people with ASD and their families.

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<sup>2</sup> Office of Autism Research Coordination, National Institute of Mental Health, on behalf of the Interagency Autism Coordinating Committee (IACC). 2010 IACC Autism Spectrum Disorder Research Portfolio Analysis Report. July 2012. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website: <http://iacc.hhs.gov/portfolio-analysis/2010/index.shtml>.

<sup>3</sup> Interagency Autism Coordinating Committee. 2011 IACC Summary of Advances in Autism Spectrum Disorder Research. 2012 Apr. Retrieved from the U.S. Department of Health and Human Services Interagency Autism Coordinating Committee website at <http://iacc.hhs.gov/summary-advances/2011/index.shtml>