

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee that advises the Secretary of Health and Human Services on issues related to Autism Spectrum Disorder (ASD). It was established by the Children’s Health Act (Public Law 106-310), reconstituted under the Combating Autism Act (CAA; Public Law 109-416), and was most recently renewed in 2014 under the Autism Collaboration, Accountability, Research, Education, and Support Act (Autism CARES Act; Public Law 113-157). One of the statutory responsibilities of the IACC under the CARES Act and preceding authorizations dating back to 2006 is the development of a strategic plan for ASD, to be updated annually. The *IACC Strategic Plan*, first issued in 2009, is developed by the IACC – including federal officials and public stakeholder members – and is informed by extensive input from researchers, adults on the autism spectrum, parents, advocates, and the general public. This inclusive process ensures that the *IACC Strategic Plan* reflects diverse perspectives from across the autism community. In this edition, for the first time, the *Strategic Plan* takes a more comprehensive approach, by not only addressing autism research, but also incorporating more information about gaps, opportunities, and implications relating to autism services, supports, and policies, in accordance with the requirements of the CARES Act.

This 2016-2017 revision of the *IACC Strategic Plan* is the work of the IACC membership appointed under the CARES Act. The CARES Act increased the required number of public members on the Committee, which includes at least two members on the autism spectrum, at least two parents or legal guardians of individuals with autism, and at least two advocacy, services, or research organization representatives. Several of the members have dual roles as professionals in fields related to ASD as well as having personal experience with ASD. The slate of new and returning IACC members was announced in October 2015 and embodies a wide variety of views, perspectives, and expertise.

As in previous years, 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, “How can I recognize the signs of ASD, and why is early detection so important?,” which covers the topic of screening and diagnosis). Each Question is assigned a chapter that provides the aspirational goal, or long-term vision; a description of the state of the field; the needs and opportunities in research, services, and policy; and three to four broad objectives for each Question topic.

For the 2017 update of the IACC Strategic Plan, the Committee agreed that given the recent advances in the autism field, it was an appropriate time to re-evaluate the autism landscape and formulate new objectives for each Question. With access to an extensive portfolio analysis conducted by the National Institutes of Health (NIH) Office of Autism Research Coordination (OARC), 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 United States since 2008. The 22 new objectives in this *Plan* were created by the Committee to address critical gaps and potential advances they perceived in the current research landscape. Because the objectives have been updated and broadened from the previous *Strategic Plan’s* 78 research objectives, the IACC expects that multiple funder portfolios will play key roles in addressing different aspects of each objective in this Plan. [Insert language about budget recommendations, once method is determined.]

In formulating this new *Plan* for ASD activities, the IACC has moved toward a paradigm shift in how we approach autism. A few years ago, scientists saw autism as a disorder to be detected, treated, prevented and cured. The majority of research was directed at understanding the genetic and biological foundations of autism, and toward early detection and intervention. Today, our understanding of autism is much more nuanced. We realize that there are many different “autisms” – some severe, and some comparatively mild. We have come to understand that autism is far more common than previously suspected and there are most likely many undiagnosed children, adolescents, and adults in the population, as well as under-identified and underserved individuals and groups, such as girls/women with ASD, people in poorly resourced settings, members of underserved minority communities, and individuals on the autism spectrum with language and/or intellectual disabilities. Most importantly, individuals on the autism spectrum have become leading voices in the conversation, spurring acknowledgment of the unique qualities that people on the autism spectrum contribute to society and promoting self-direction, awareness, acceptance and inclusion as important societal goals.

Research on genetic risk and the underlying basic biology of ASD remains a primary focus of the research portfolio and does play an important long-term role in the potential to develop new and broadly beneficial therapies and interventions. These advances may one day mitigate or even eliminate some of the most disabling manifestations of autism, especially for those on the spectrum who are most severely impacted. However, balanced with the potential for these future payoffs, is the importance of efforts that can have a more immediate impact. Individuals who are autistic today will remain autistic for the foreseeable future; most of them have significant unmet needs. To help those people – who range in age from infants to senior citizens – we must in the short-term translate existing research to develop effective tools and strategies to maximize quality of life, and minimize disability, while also ensuring that individuals on the autism spectrum are accepted, included, and integrated in all aspects of community life.

The community has been very clear in its calls for more research into adult issues and better services and supports for the millions of Americans living with autism today. Recent studies of adult mortality have indicated that people with ASD are at higher risk of premature death than people in the general population, painting a very disturbing picture that bears investigation. In light of data and insights from the community, the IACC proposes a comprehensive research agenda that addresses the needs of autistic people across the spectrum and across the lifespan, including improvements to services, supports, and policies. The IACC also believes that, as many in the autism community have indicated, efforts to address the many co-occurring conditions that accompany autism should be made a greater priority.

Though this *2016-2017 IACC Strategic Plan* cannot possibly capture all the changes in the ASD field since 2008, the IACC has endeavored to deliver an updated picture of the evolving landscape of autism, as well as a new, broad vision of the current and future challenges and opportunities in autism research, services, and policy. To provide a more complete and detailed view of autism research progress, this update accompanies two other annual IACC publications. 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* describes specific scientific findings that members of the IACC identify as having significantly advanced the field and as having the potential to impact public health and quality of life in the ASD community. Together, with this *2016-2017 IACC Strategic Plan for ASD*, the

Committee hopes that these documents will provide an insightful overview of the state of autism in 2017, as well as outline a strategic agenda for future progress.