

QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?		
IACC Strategic Plan Objectives	Planning Group Summary	Total Funding 2008-2012
<p>7A. Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009.</p> <p><i>IACC Recommended Budget: \$520,000 over 1 year</i></p>	<p>The Planning Group is not aware of any efforts (projects or funding) that have been made to address this objective since it was created. The committee may want to determine whether a needs assessment is still needed, and if so, what are the barriers to conducting the needs assessment? Are efforts to link these types of databases already underway?</p>	\$0
<p>7B. Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011.</p> <p><i>IACC Recommended Budget: \$300,000 each year (revised in 2010)</i></p>	<p>The recommended budget was partially met. Centers for Medicare & Medicaid Services (CMS) is working on this project and anticipates release of the report in 2014.</p>	\$604,013
<p>7C. Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010.</p> <p><i>IACC Recommended Budget: \$1,300,000 over 2 years</i></p>	<p>The recommended budget was met. The Interactive Autism Network (IAN) and Group Health Cooperative Autism Registry are two examples of projects that are responsive to this objective. This objective should be considered to be met, with funding exceeding the recommended budget and a large number of diverse projects addressing this issue.</p>	\$13,590,660
<p>7D. Establish and maintain an international network of biobanks for the collection of brain tissue, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011.</p> <ul style="list-style-type: none"> This includes support for post-processing of tissue, such as genotyping, RNA expression profiling, and MRI. Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, including newborn bloodspots, promoting detection of biological signatures. Support should also be provided to develop an international web-based digital brain atlas that would provide high-resolution 3-D images and quantitative anatomical data from tissue of patients with ASD and disease controls across the lifespan, which could serve as an online resource for quantitative morphological studies, by 2014. <p><i>IACC Recommended Budget: \$82,700,000 over 5 years (revised in 2011)</i></p>	<p>The recommended budget was partially met. While progress has been made, this is still an area of enormous need. There may be fewer samples available for study currently than there were at the inception of the Strategic Plan due to the freezer failure in 2012. NIH funded 5 brain banks in a new biobank initiative in 2013. The \$5M effort encompasses autism and other brain disorders, and thus may not be reflected in the portfolio analysis in 2013. A private effort is also underway, but overall, more work is needed to fill the gap. The Brainspan Atlas provides a useful source of information on gene expression in the brain during development, but the project is not reflected in the 2008-2012 funding figures because it is not autism specific. In 2009, NIH funded the atlas with \$18.4 million dollars and in 2010, NIH provided \$16.5 million.</p>	\$24,752,287
<p>7E. Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their findings to the community, including people with ASD, their families, and health practitioners by 2011.</p> <p><i>IACC Recommended Budget: \$400,000 over 2 years</i></p>	<p>The recommended budget was met but few projects were categorized to this objective. This objective has been partially achieved in terms of projects funded, but not through a web-based toolbox. Dissemination of findings has taken place through other efforts.</p>	\$1,254,150
<p>7F. Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.</p> <p><i>No recommended budget assigned by the IACC</i></p>	<p>The recommended budget has not been met and there are no projects categorized to this objective. The Planning Group discussed the issue that creation of funding mechanisms is not likely to be achieved through grant funding, and therefore would not be reflected in the grant portfolio. The group also discussed the possibility that it may be too early for replication studies, as the current focus appears to be on primary studies.</p>	\$0
<p>7G. Develop a web-based tool that provides population estimates of ASD prevalence for States based on the most recent prevalence range and average identified by the ADDM Network by 2012.</p> <p><i>IACC Recommended Budget: \$200,000 over 2 years</i></p>	<p>Autism tracking data is captured in CDC's environmental tracking tool and is not reflected in the autism grant portfolio figure because it is a general tool that encompasses multiple disorders and conditions. The intent of this objective has been accomplished through the CDC project and can be considered completed.</p>	\$0

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IACC Strategic Plan Objectives	Planning Group Summary	Total Funding 2008-2012
<p>7H. Create mechanisms to specifically support the contribution of data from 90% of newly initiated projects to the National Database for Autism Research (NDAR), and link NDAR with other existing data resources by 2012.</p> <p><i>IACC Recommended Budget: \$6,800,000 over 2 years</i></p>	<p>The recommended budget has been met for this objective. The objective to create mechanisms to support the contribution of data from newly initiated projects to NDAR has been met, and NDAR has linked with several other existing data sources such as the ATP, AGRE and IAN. In 2012, 81% of NIH-funded human subjects studies were contributing data to NDAR.</p>	<p>\$9,583,653</p>
<p>7I. Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least five hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012.</p> <p><i>IACC Recommended Budget: \$660,000 over 2 years</i></p>	<p>The recommended budget has been met and the research goals in the objective have been achieved. Initially supplements were needed to support these analyses, but now the ADDM sites are well established and are conducting these kinds of analyses using funds from the ADDM grants themselves, so supplements are no longer needed. Note that the funding amount reflects the full funding of the ADDM sites and not just the supplements.</p>	<p>\$23,810,274</p>
<p>7J. Develop the personnel and technical infrastructure to assist States, territories, and other countries that request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013.</p> <p><i>IACC Recommended Budget: \$1,650,000 over 3 years</i></p>	<p>The recommended budget was partially met. The Autism Speaks Global Health Initiative projects have been coded to their specific scientific areas and are not represented in this funding amount, but they also contribute toward this objective. The CDC provides personnel and help to States, territories and countries as requested but the budget for that assistance is not reflected in the portfolio analysis figures because this work is not done through grants. While progress has been achieved, ongoing efforts are needed in this area.</p>	<p>\$1,369,963</p>
<p>7K. Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early-career scientists into the ASD field by 2013.</p> <p><i>IACC Recommended Budget: \$5,000,000 over 3 years</i></p>	<p>The recommended budget was met for this objective. Many of the fellowships are coded according to the specific topic of the research conducted and thus are not represented in this funding figure. In 2008, NIH supported 46 autism related training/fellowship grants (\$5.1 million dollars), and in 2012 NIH supported 78 such grants (\$7.7 million dollars).</p>	<p>\$24,702,276</p>
<p>7L. Expand the number of ADDM sites in order to conduct ASD surveillance in children and adults; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015.</p> <p><i>IACC Recommended Budget: \$16,200,000 over 5 years</i></p>	<p>The recommended budget was partially met, but it is noted that the full funding of the ADDM sites is reflected in Objective 7I. While supplements have been provided to 6 ADDM sites by CDC to add 4 year olds; 2 other ADDM sites have received supplements from CDC to conduct surveillance studies among 15 and 18 year olds; and one ADDM site has received a supplement from Autism Speaks for population-based screening, further work is needed to better understand prevalence in younger and older populations. While subtypes were included in earlier analysis, with the changes in the DSM to eliminate subtypes, this part of the objective may no longer be relevant. In the future it may be more useful to collect data on characteristics of children or other adults with ASD who participate in studies.</p>	<p>\$3,681,460</p>
<p>7M. Support 10 "Promising Practices" papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities, by 2015.</p> <p><i>IACC Recommended Budget: \$75,000 over 5 years</i></p>	<p>The recommended budget was not met for this objective based on projects reported. The Planning Group would like an update from CMS on whether new papers are expected and if this is still something that is planned/needed.</p>	<p>\$0</p>
<p>7N. Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological (e.g., DNA, plasma, fibroblasts, urine), medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012.</p> <p><i>IACC Recommended Budget: \$1,850,000 over 1 year</i></p>	<p>The recommended budget was met/exceeded for this objective, and several projects were categorized to this objective. This should be discussed in the second call as it relates to the value of the ATN and whether it is useful to researchers.</p>	<p>\$19,353,505</p>
<p>7O. Create an information resource for ASD researchers (e.g., PhenX Project) to</p>	<p>The recommended budget was met, with a small number of projects</p>	<p>\$2,404,279</p>

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<p>share information to facilitate data sharing and standardization of methods across projects by 2013.</p> <ul style="list-style-type: none"> This includes common protocols, instruments, designs, and other procedural documents and should include updates on new technology and links to information on how to acquire and utilize technology in development. This can serve as a bidirectional information reference, with autism research driving the development of new resources and technologies, including new model systems, screening tools, and analytic techniques. <p><i>IACC Recommended Budget: \$2,000,000 over 2 years</i></p>	<p>funded. NDAR has developed a data dictionary that is now widely used across the research community to standardize data terminology so that researchers know what they are accessing. Funding for this project is not reflected in the total for this objective because NDAR is coded elsewhere. It would be helpful to have input from experts on whether current data sharing protocols are worthwhile or effective.</p>	
<p>7P. Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems, and make these models more easily available or expand the utility of current model systems, and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013.</p> <p><i>IACC Recommended Budget: \$1,100,000 over 2 years</i></p> <p>Not specific to any objective</p>	<p>The recommended budget was met for this objective. When mouse models are made, they are shared via Jackson Labs. Other model organisms are shared even more widely. Is there a continuing need for special support for this? Consult with experts on this question.</p>	<p>\$1,588,780</p>
<p>Total funding for Question 7</p>		<p>\$43,431,065</p> <p>\$158,028,308</p>