

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. A needs assessment remains necessary due to issues surrounding patient privacy in linked databases and to determine how this connection is possible with existing tools and resources. It remains to be decided whether this should be a government led effort or a public/private partnership. Such resources could be utilized by both the research and services provision community.</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. <u>Autism Services Across America</u> by Dr. Peter Doehring also reviews existing programs and services.</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. NDAR, IAN and SFARI are all publicly available. To advance this objective we need to encourage patients and families to join the registry compared to registry numbers for cystic fibrosis (100%) Autism is behind at ~4% of patients enrolled in a registry. A table of the numbers of registrants by year would be an informative figure.</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, the Autism Brain Net with several sites governed by a scientific board which awards samples based on scientific merit 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. This atlas is the most important project completed recently and with public access to the data, it will be transformative. Need to contact Thomas Lehner for numbers of samples (brains, DNA, fibroblasts).</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." Data from papers" through NDAR, connects readers from the Pubmed citation of a study to the actual data deposited in the database. Several organizations and groups (Simons, Autism Speaks, ASF, IAN, CDC) publish lay-friendly versions of their reports and advances online. There remains the issue of lack of comprehensive internet access in some communities and lack of open access publications.</p>	\$1,254,150
<p>7F. Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.</p> <p><i>IACC Recommended Budget: \$400,000 over 2 years</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 consensus of the group was that it is not too early to begin replication studies. In</p>	\$0

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<p>the databases there are 70,000 subjects, 7,000 exomes and 2,500 MRIs, these resources are primed for replication analysis. The intent of the objective was to quickly replicate potential treatments, however, mechanisms to serve that function do not yet exist.</p>	<p>\$0</p>
<p><i>No recommended budget assigned by the IACC</i> 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>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>\$9,583,653</p>
<p><i>IACC Recommended Budget: \$6,800,000 over 2 years</i></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>\$23,810,274</p>
<p><i>IACC Recommended Budget: \$660,000 over 2 years</i></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>\$1,369,963</p>
<p><i>IACC Recommended Budget: \$1,650,000 over 3 years</i></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>\$24,702,276</p>
<p><i>IACC Recommended Budget: \$5,000,000 over 3 years</i></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>\$3,681,460</p>

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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. Currently at UNC there is a reassembly of those who participated in TEACCH. Also, Paul Shattuck's work has focused on large datasets regarding adults with disabilities seeking services. In addition, the Utah cohort (mentioned in Question 6) also addresses issues related to adults with autism.

IACC Recommended Budget: \$16,200,000 over 5 years

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.

The recommended budget was not met for this objective based on projects reported. Information about this program was requested from CMS; it is possible that the program is no longer funded and that priorities have shifted to other methods of disseminating best practices information.

\$0

IACC Recommended Budget: \$75,000 over 5 years

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.

The recommended budget was met/exceeded for this objective, and several projects were categorized to this objective. The ATN is not broadly shared like other repositories. Initially, the ATN was populated with large amounts of undirected data, however, now it is has had a strong focus on developing clinical guidelines.

\$19,353,505

IACC Recommended Budget: \$1,850,000 over 1 year

7O. Create an information resource for ASD researchers (e.g., PhenX Project) to share information to facilitate data sharing and standardization of methods across projects by 2013.

- 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.

The recommended budget was met, with a small number of projects 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. NDAR has a common subject identifier that is now broadly used. Funding is necessary to establish methods standards and developing standardized protocols. This is a long term project and will need to be approached carefully.

\$2,404,279

IACC Recommended Budget: \$2,000,000 over 2 years

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.

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. Emphasis on this objective is still required. A discussion at the workshop with those who use animal models would be informative.

\$1,588,780

IACC Recommended Budget: \$1,100,000 over 2 years

Not specific to any objective

\$43,431,065

Total funding for Question 7

\$158,028,308