

## Summary of the 2008 through 2012 Portfolio Analysis data for Question 7 as aligned to the IACC Strategic Plan

**Please note that the 2011 and 2012 data are still draft data and subject to change.**

Please read the following notes prior to reviewing the table:

- Current project and funding status for each question or objective is indicated within the table by colored highlighting of the objective. Any objective highlighted **green** has greater than or equal to the recommended funding; any objective highlighted **yellow** has some degree of funding or active projects, but less than the recommended amount; while any objective highlighted **red** has no funding or active projects.
- Highlighting of each total gives an indication of the progress toward meeting the IACC recommended budget for each objective. **Green** highlighting indicates that funding fully meets the recommend budget or that the objective has been otherwise completed. **Yellow** highlighting denotes that funding for a particular objective partially meets the IACC recommended budget, while **red** highlighting indicates that there has been no funding towards the particular objective.
- Please note that while the green, yellow and red indicators suggest a funding status for each year and that looking across all years may give some indication of a trend, that some agencies and organizations provide all the funding for multiyear grants in a single year, resulting in the appearance of “less funding” in other years, but that projects fulfilling the objectives may still have been ongoing in the years where the funding appears to be less. Thus, it is important to note the numbers of projects in looking across the chart, and to keep in mind that in a series, where, for example, most of the indicators are green, that the objective is likely to be largely “complete” according to the funding-based measure. This, however, does not provide information on whether or not the objectives were completed in terms of intended project results and outcomes. Please also note that in some cases, projects may have been funded, but were accomplished with smaller budgets than anticipated, so a “yellow” designation may not necessarily be indicative of ongoing need for more effort.

# QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?

## IACC Strategic Plan Objectives

## Funding

	Year 2008	2009	2010	2011	2012	Total
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.	<b>6.4</b> \$0 0 projects	<b>7.A</b> \$0 0 projects	<b>7.A</b> \$0 0 projects	<b>7.A</b> \$0 0 projects	<b>7.A</b> \$0 0 projects	<b>\$0</b>
Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011.	<b>5.1</b> \$311,670 6 projects	<b>7.B</b> \$7,061 1 project	<b>7.B</b> \$197,128 1 project	<b>7.B</b> \$88,154 1 project	<b>7.B</b> \$0 1 project	<b>\$604,013</b>
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.	<b>6.1</b> \$6,767,808 4 projects	<b>7.C</b> \$1,665,180 2 projects	<b>7.C</b> \$2,785,368 5 projects	<b>7.C</b> \$1,387,146 7 projects	<b>7.C</b> \$985,158 6 projects	<b>\$13,590,660</b>
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.	<b>2.1 &amp; 2.6</b> \$5,018,579 1 project & 1 project	<b>7.D</b> \$436,815 2 projects	<b>7.D</b> \$7,814,918 6 projects	<b>7.D</b> \$8,531,425 6 projects	<b>7.D</b> \$2,950,550 5 projects	<b>\$24,752,287</b>
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.	N/A	<b>7.E</b> \$330,662 2 projects	<b>7.E</b> \$390,134 1 project	<b>7.E</b> \$533,354 1 project	<b>7.E</b> \$0 1 projects	<b>\$1,254,150</b>
Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.	N/A	<b>7.F</b> \$0 0 projects	<b>7.F</b> \$0 0 projects	<b>7.F</b> \$0 0 projects	<b>7.F</b> \$0 0 projects	<b>\$0</b>
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.	N/A	<b>7.G</b> \$0 0 projects	<b>7.G</b> \$0 0 projects	<b>7.G</b> \$0 0 projects	<b>7.G</b> \$0 0 projects	<b>\$0</b>
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.	N/A	<b>7.H</b> \$1,932,996 2 projects	<b>7.H</b> \$2,453,253 3 projects	<b>7.H</b> \$1,517,596 1 project	<b>7.H</b> \$3,679,808 5 projects	<b>\$9,583,653</b>

IACC Recommended Budget: \$520,000 over 1 year

IACC Recommended Budget: \$300,000 each year (revised in 2010)

IACC Recommended Budget: \$1,300,000 over 2 years

IACC Recommended Budget: \$82,700,000 over 5 years (revised in 2011)

IACC Recommended Budget: \$400,000 over 2 years

No recommended budget assigned by the IACC

IACC Recommended Budget: \$200,000 over 2 years

IACC Recommended Budget: \$6,800,000 over 2 years

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.

N/A	<b>7.I</b> \$6,715,815 15 projects	<b>7.I</b> \$6,137,128 13 projects	<b>7.I</b> \$4,928,453 13 projects	<b>7.I</b> \$6,028,878 13 projects	<b>\$23,810,274</b>
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IACC Recommended Budget: \$660,000 over 2 years

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.

N/A	<b>7.J</b> \$494,449 11 projects	<b>7.J</b> \$170,490 4 projects	<b>7.J</b> \$545,414 6 projects	<b>7.J</b> \$159,610 4 projects	<b>\$1,369,963</b>
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IACC Recommended Budget: \$1,650,000 over 3 years

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.

N/A	<b>7.K</b> \$2,527,472 7 projects	<b>7.K</b> \$7,358,427 34 projects	<b>7.K</b> \$4,813,286 27 projects	<b>7.K</b> \$10,003,091 25 projects	<b>\$24,702,276</b>
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IACC Recommended Budget: \$5,000,000 over 3 years

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.

N/A	<b>7.L</b> \$699,304 2 projects	<b>7.L</b> \$1,429,602 8 projects	<b>7.L</b> \$705,552 6 projects	<b>7.L</b> \$847,002 6 projects	<b>\$3,681,460</b>
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IACC Recommended Budget: \$16,200,000 over 5 years

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.

N/A	<b>7.M</b> \$0 0 projects	<b>7.M</b> \$0 0 projects	<b>7.M</b> \$0 0 projects	<b>7.M</b> \$0 0 projects	<b>\$0</b>
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IACC Recommended Budget: \$75,000 over 5 years

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.

N/A	N/A	<b>7.N</b> \$6,662,790 3 projects	<b>7.N</b> \$7,419,887 22 projects	<b>7.N</b> \$5,270,828 22 projects	<b>\$19,353,505</b>
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IACC Recommended Budget: \$1,850,000 over 1 year

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.

N/A	N/A	<b>7.O</b> \$605,338 3 projects	<b>7.O</b> \$1,070,941 3 projects	<b>7.O</b> \$728,000 1 project	<b>\$2,404,279</b>
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IACC Recommended Budget: \$2,000,000 over 2 years

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.

N/A	N/A	<b>7.P</b> \$1,588,780 1 project	<b>7.P</b> \$0 0 projects	<b>7.P</b> \$0 0 projects	<b>\$1,588,780</b>
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IACC Recommended Budget: \$1,100,000 over 2 years

Not specific to any objective (Core Activities)

N/A	<b>7.Core Activities</b> \$1,000,000 2 projects	<b>7.Core Activities</b> \$13,253,709 26 projects	<b>7.Core Activities</b> \$12,314,084 18 projects	<b>7.Core Activities</b> \$16,863,272 23 projects	<b>\$43,431,065</b>
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**Total funding for Question 7**

N/A	<b>\$15,809,755</b> 46 projects	<b>\$50,847,065</b> 108 projects	<b>\$43,855,291</b> 111 projects	<b>\$47,516,197</b> 112 projects	<b>\$158,028,308</b>
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