

QUESTION 1: WHEN SHOULD I BE CONCERNED?

IACC Strategic Plan Objectives	Planning Group Summary	Funding 2008-2013
<p>1.S.A. Develop, with existing tools, at least one efficient diagnostic instrument (i.e., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011.</p> <p><i>IACC Recommended Budget: \$5,300,000 over 2 years</i></p>	<p>The recommended budget for this objective was met. Remaining gaps include the need to develop instruments that target diverse populations, and work needs to continue to develop instruments that are ready for broad deployment.</p>	\$14,368,811
<p>1.S.B. Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socio-economic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012.</p> <p><i>IACC Recommended Budget: \$5,400,000 over 3 years</i></p>	<p>The recommended budget for this objective was met, and more diverse populations were addressed. However, comparative studies between general developmental screeners and autism-specific tools are missing.</p>	\$10,761,298
<p>1.S.C. Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012.</p> <p><i>IACC Recommended Budget: \$2,000,000 over 2 years</i></p>	<p>The recommended budget has been partially met. The projects supported are only a beginning and more needs to be done to address this question. While the studies coded to this objective do not focus on identifying reasons for early screening and diagnosis disparities, they are aimed at developing tools to address these disparities.</p>	\$796,593
<p>1.S.D. Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015.</p> <p><i>IACC Recommended Budget: 6,000,000 over 5 years</i></p>	<p>No projects have been initiated in this area, though there may be some projects coded to question 4 that represent progress on this objective (e.g. Early Start Denver Model studies that look at children who were diagnosed early and some of their outcomes following treatment.) Possible barriers identified include the difficulty of finding a late-diagnosis cohort for comparison, and the more general difficulties of carrying out large, longitudinal studies.</p>	\$0
<p>1.S.E. Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting by 2012.</p> <p><i>IACC Recommended Budget: \$9,600,000 over 5 years</i></p>	<p>The recommended budget for this objective has been partially met. The committee would like an update from experts in the field about the applicability of microarray testing, but questions whether or not this objective should remain a priority – it is resulting in useful knowledge for the field and for the community?.</p>	\$4,143,183
<p>1.S.F. Convene a workshop to examine the ethical, legal, and social implications of ASD research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions.</p> <p><i>IACC Recommended Budget: \$35,000 over 1 year</i> <i>*completed in 2011</i></p>	<p>The recommended budget for this objective was met and the objective was accomplished as the committee intended. Follow-on activities may be warranted in the form of future workshops focusing on particular subtopics of interest.</p>	\$71,489
<p>1.L.A. Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014.</p> <p><i>IACC Recommended Budget: \$33,300,000 over 5 years</i></p>	<p>The recommended funding for this objective has been met, and more than 40 projects have been supported in this area. Identifying reliable early biomarkers has been challenging, but some progress has been made. Invited experts may be able to share information about progress made in this area and remaining needs/barriers.</p>	\$57,932,106
<p>1.L.B. Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015.</p> <p><i>IACC Recommended Budget: \$71,100,000 over 5 years</i></p>	<p>The budget for this objective was partially met and over 50 projects were supported in this area. While behavioral and/or biological heterogeneity are well covered by existing projects, gaps still exist in relating these to etiology and risk, treatment response, and/or outcomes.</p>	\$51,951,069
<p>1.L.C. Identify and develop measures to assess at least three “continuous dimensions” (i.e., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of ASD symptoms and</p>	<p>The budget for this objective was partially met. Basic aspects of the research are underway, but more work is needed for the studies to be applied for use by practitioners and/or families.</p>	\$10,620,318

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severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016.

IACC Recommended Budget: 18,500,000 over 5 years

Not specific to any objective

\$36,124,099