

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, though the goal of creating more efficient diagnostic instruments has not yet been completed. In addition to efficiency, emphasis should be placed on developing cost-effective, performance-based tools, and on validating these across diverse populations. Recent RFAs issued by NIMH and Autism Speaks focusing on parental engagement and early access to care could result in projects that address this objective.</p>	<p>\$14,368,811</p>
<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, there is a need for more comparative studies between general developmental screeners and autism-specific tools (may need an update from Amy Wetherby about her comparison study in diverse settings). Other progress in this area includes ACF and CDC-funded work with a general screener in Native American populations. Remaining needs in this area are promotion of family engagement and follow-through, training of intervention and primary care providers and family members, and development of free and validated diagnostic tools for international communities.</p>	<p>\$10,761,298</p>
<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 objective. 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. The progress in this area is poor for autism relative to other disease fields, and the more sophisticated approaches employed in fields such as AIDS prevention should be applied to autism. More work should be done to identify the reasons for disparities and to validate the tools that are being developed. A barrier to progress is the need for qualitative studies and the difficulty in securing funding for such studies.</p>	<p>\$796,593</p>
<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.) The Planning Group does not understand the objective as it is worded, and would like clarification about the intent of this objective.</p>	<p>\$0</p>
<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. Microarray testing is now recommended in AAP guidelines. The utility of this testing is more clear in cases where there is already a concern than for diagnostic use in the general population. There is a need to better understand the relationship of genotype to phenotype, implications of genotype for treatment or medical management options, and to understand the potential impact of microarray testing on providers and families.</p>	<p>\$4,143,183</p>
<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. NIH and ASAN held workshops directly on this topic, and Autism Speaks held a related workshop. This area remains of interest due to the ethical concerns that will continue to arise as screening tools progress. Responsible communication of risk and examination of barriers to care for positively screened patients are among these concerns.</p>	<p>\$71,489</p>
<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>The recommended budget for this objective has been met, and more than 40 projects have been supported in this area, but most projects are still in discovery phase. Identifying reliable early biomarkers has been challenging, but some progress has been made. Remaining needs include linking biomarkers to response to treatment and the need to validate biomarkers discovered in high risk populations for applicability in the general population. There is also a need</p>	<p>\$57,932,106</p>

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for biomarkers that are cost-effective.		
<p><i>IACC Recommended Budget: \$33,300,000 over 5 years</i></p> <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>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 severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016.</p>		
<p><i>IACC Recommended Budget: 18,500,000 over 5 years</i></p> <p>Not specific to any objective</p>		
<p>The recommended 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. There was a discussion of whether this objective should be expanded to be compatible with RDoC criteria now being used by NIMH.</p>		\$51,951,069
<p>The recommended 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. There is a need for finer ways to quantify social behavior and detect change in response to successful treatment. There is a need to move toward performance-based measures and away from the checklist approach.</p>		\$10,620,318
		\$36,124,099