

APPENDIX B:

ASD Research Progress on *2011 IACC Strategic Plan* Objectives in 2011

Data includes 2011 funding from Federal/private funders of ASD research.

Current project status for each objective is indicated within the table by colored “dots” next to the objective. Any objective colored green has greater than or equal to the recommended funding; any objective colored yellow has active projects, but with funding that totals less than the recommended amount ; while any objective colored red has no active projects. Please note that an annualized recommended budget amount was used in determining the project status for each objective.

NEW! Objectives labeled "New!" are either entirely new additions to the *2011 IACC Strategic Plan* or significantly modified objectives from the *2010 IACC Strategic Plan*. Objectives from the *2010 Strategic Plan* that did not change or that have been slightly modified for clarification purposes in the *2011 Strategic Plan* are unmarked.

This document is for discussion purposes only and does not reflect the decisions of the IACC

ASD Research Progress on IACC Strategic Plan Objectives

Question 1: When should I be concerned?




	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
	1.S.A Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. <i>IACC Recommended Budget: \$5,300,000 over 2 years.</i>	8 (6%)	\$2,387,955 (8%)	1%
	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, socioeconomic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012. <i>IACC Recommended Budget: \$5,400,000 over 3 years.</i>	9 (7%)	\$970,284 (3%)	<1%
	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. <i>IACC Recommended Budget: \$2,000,000 over 2 years.</i>	1 (1%)	\$28,000 (<1%)	<1%
	1.S.D Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. <i>IACC Recommended Budget: \$6,000,000 over 5 years.</i>	0	\$0	0%
NEW!	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. <i>IACC Recommended Budget: \$9,600,000 over 5 years.</i>	1 (1%)	\$690,019 (2%)	<1%
NEW!	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. <i>IACC Recommended Budget: \$35,000 over 1 year.</i>	0*	\$0	0%

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*Two workshops were held in 2011 (NIH and ASAN) that completed this objective, but the funding mechanisms used were not captured in the Portfolio Analysis.

ASD Research Progress on IACC Strategic Plan Objectives

Question 1: When should I be concerned?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
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. <i>IACC Recommended Budget: \$33,300,000 over 5 years.</i>	43 (32%)	\$12,416,466 (41%)	4%
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. <i>IACC Recommended Budget: \$71,100,000 over 5 years.</i>	42 (31%)	\$9,376,400 (31%)	3%
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. <i>IACC Recommended Budget: \$18,500,000 over 5 years.</i>	15 (11%)	\$2,353,440 (8%)	1%
1.Other Not specific to any objective	16 (12%)	\$2,310,877 (8%)	1%
Total Funding for Question 1	135 (100%)	\$30,533,441 (100%)	10%

The percentages noted in parentheses in the “Projects” and “Funding” columns indicate the fraction of all projects or funding within that specific question, whereas the percentage in the “Percent of Total ASD Funding” column indicates the percent of the entire ASD research funding portfolio for 2010. Due to rounding, the percentages within a question may not equal exactly 100%.

*Two workshops were held in 2011 (NIH and ASAN) that completed this objective, but the funding mechanisms used were not captured in the Portfolio Analysis.

ASD Research Progress on IACC Strategic Plan Objectives

Question 2: How can I understand what is happening?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
2.S.A Support at least four research projects to identify mechanisms of fever, metabolic and/or immune system interactions with the central nervous system that may influence ASD during prenatal-postnatal life by 2010. <i>IACC Recommended Budget: \$9,800,000 over 4 years. (Fever studies to be started by 2012.)</i>	25 (6%)	\$2,013,417 (3%)	1%
2.S.B Launch three studies that specifically focus on the neurodevelopment of females with ASD, spanning basic to clinical research on sex differences by 2011. <i>IACC Recommended Budget: \$8,900,000 over 5 years.</i>	1 (0%)	\$150,000 (<1%)	<1%
2.S.C Identify ways to increase awareness among the autism spectrum community of the potential value of brain and tissue donation to further basic research by 2011. <i>IACC Recommended Budget: \$1,400,000 over 2 years.</i>	1 (0%)	\$22,000 (<1%)	<1%
2.S.D Launch three studies that target improved understanding of the underlying biological pathways of genetic conditions related to autism (e.g. Fragile X, Rett syndrome, tuberous sclerosis complex) and how these conditions inform risk assessment and individualized intervention by 2012. <i>IACC Recommended Budget: \$9,000,000 over 5 years.</i>	64 (16%)	\$12,360,956 (17%)	4%
2.S.E Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism, including seizures/epilepsy, sleep disorders, wandering/elopement behavior, and familial autoimmune disorders, by 2012. <i>IACC Recommended Budget: \$9,000,000 over 5 years.</i>	23 (6%)	\$4,807,760 (7%)	2%
2.S.F Launch two studies that focus on prospective characterization of children with reported regression to investigate potential risk factors by 2012. <i>IACC Recommended Budget: \$4,500,000 over 5 years.</i>	3 (1%)	\$339,709 (<1%)	<1%
2.S.G Support five studies that associate specific genotypes with functional or structural phenotypes, including behavioral and medical phenotypes (e.g., nonverbal individuals with ASD and those with cognitive impairments) by 2015. <i>IACC Recommended Budget: \$22,600,000 over 5 years.</i>	45 (11%)	\$11,105,408 (15%)	4%
2.L.A Complete a large-scale, multi-disciplinary, collaborative project that longitudinally and comprehensively examines how the biological, clinical, and developmental profiles of individuals, with a special emphasis on females, youths, and adults with ASD, change over time as compared to typically developing people by 2020. <i>IACC Recommended Budget: \$126,200,000 over 12 years.</i>	5 (1%)	\$972,559 (1%)	<1%

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ASD Research Progress on IACC Strategic Plan Objectives








Question 2: How can I understand what is happening?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
2.L.B Launch at least three studies which evaluate the applicability of ASD phenotype and/or biological signature findings for performing diagnosis, risk assessment, or clinical intervention by 2015. IACC Recommended Budget: \$7,200,000 over 5 years.	4 (1%)	\$324,241 (<1%)	<1%
2.Other Not specific to any objective	227 (57%)	\$41,027,141 (56%)	14%
Total Funding for Question 2	398 (100%)	\$73,123,190 (100%)	24%

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ASD Research Progress on IACC Strategic Plan Objectives








Question 3: What caused this to happen and can it be prevented?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
<p>3.S.A  Coordinate and implement the inclusion of approximately 20,000 subjects for genome-wide association studies, as well as a sample of 1,200 for sequencing studies to examine more than 50 candidate genes by 2011. Studies should investigate factors contributing to phenotypic variation across individuals that share an identified genetic variant and stratify subjects according to behavioral, cognitive, and clinical features. <i>IACC Recommended Budget: \$43,700,000 over 4 years.</i></p>	7 (5%)	\$2,207,214 (4%)	1%
<p>3.S.B  Within the highest priority categories of exposures for ASD, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011. <i>IACC Recommended Budget: \$3,500,000 over 3 years.</i></p>	0	\$0	0%
<p>3.S.C  Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene – environment research by 2011. <i>IACC Recommended Budget: \$27,800,000 over 5 years.</i></p>	10 (7%)	\$5,714,408 (9%)	2%
<p>3.S.D  Enhance existing case-control studies to enroll racially and ethnically diverse populations affected by ASD by 2011. <i>IACC Recommended Budget: \$3,300,000 over 5 years.</i></p>	0	\$0	0%
<p>3.S.E  Support at least two studies to determine if there are subpopulations that are more susceptible to environmental exposures (e.g., immune challenges related to infections, vaccinations, or underlying autoimmune problems) by 2012. <i>IACC Recommended Budget: \$8,000,000 over 2 years.</i></p>	5 (3%)	\$419,215 (1%)	<1%
<p>3.S.F  Initiate studies on at least 10 environmental factors identified in the recommendations from the 2007 IOM report "Autism and the Environment: Challenges and Opportunities for Research" as potential causes of ASD by 2012. <i>IACC Recommended Budget: \$56,000,000 over 2 years.</i></p>	3 (2%)	\$0 (0%)	0%
NEW!	0		
<p>3.S.G  Convene a workshop that explores the usefulness of bioinformatic approaches to identify environmental risks for ASD by 2011. <i>IACC Recommended Budget: \$35,000 over 1 year.</i></p>	This objective was completed in 2011.	\$0	0%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 3: What caused this to happen and can it be prevented?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
NEW!	<p>3.S.H  Support at least three studies of special populations or use existing databases to inform our understanding of environmental risk factors for ASD in pregnancy and the early postnatal period by 2012. Such studies could include:</p> <ul style="list-style-type: none"> • Comparisons of populations differing in geography, gender, ethnic background, exposure history (e.g., prematurity, maternal infection, nutritional deficiencies, toxins), and migration patterns; and • Comparisons of phenotype (e.g., cytokine profiles), in children with and without a history of autistic regression, adverse events following immunization (such as fever and seizures), and mitochondrial impairment. These studies may also include comparisons of phenotype between children with regressive ASD and their siblings. • Emphasis on environmental factors that influence prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations. <p><i>IACC Recommended Budget: \$12,000,000 over 5 years.</i></p>	16 (11%)	\$4,657,095 (8%)	2%
NEW!	<p>3.S.I  Support at least two studies that examine potential differences in the microbiome of individuals with ASD versus comparison groups by 2012. <i>IACC Recommended Budget: \$1,000,000 over 2 years.</i></p>	4 (3%)	\$439,971 (1%)	<1%
NEW!	<p>3.S.J  Support at least three studies that focus on the role of epigenetics in the etiology of ASD, including studies that include assays to measure DNA methylations and histone modifications and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012. <i>IACC Recommended Budget: \$20,000,000 over 5 years.</i></p>	19 (13%)	\$5,341,237 (9%)	2%
NEW!	<p>3.S.K  Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and genetic susceptibilities for ASD by 2012. <i>IACC Recommended Budget: \$1,535,000 over 3 years.</i></p>	3 (2%)	\$463,841 (1%)	<1%
	<p>3.L.A  Conduct a multi-site study of the subsequent pregnancies of 1,000 women with a child with ASD to assess the impact of environmental factors in a period most relevant to the progression of ASD by 2014. <i>IACC Recommended Budget: \$11,100,000 over 5 years.</i></p>	1 (1%)	\$2,864,377 (5%)	1%
	<p>3.L.B  Identify genetic risk factors in at least 50% of people with ASD by 2014. <i>IACC Recommended Budget: \$33,900,000 over 6 years.</i></p>	59 (40%)	\$25,383,346 (42%)	8%
	<p>3.L.C  Determine the effect of at least five environmental factors on the risk for subtypes of ASD in the pre- and early postnatal period of development by 2015. <i>IACC Recommended Budget: \$25,100,000 over 7 years.</i></p>	5 (3%)	\$379,913 (1%)	<1%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 3: What caused this to happen and can it be prevented?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
3.L.D Support ancillary studies within one or more large-scale, population-based surveillance and epidemiological studies, including U.S. populations, to collect data on environmental factors during preconception, and during prenatal and early postnatal development, as well as genetic data, that could be pooled (as needed), to analyze targets for potential gene/environment interactions by 2015. <i>IACC Recommended Budget: \$44,400,000 over 5 years.</i>	10 (7%)	\$11,567,250 (19%)	4%
3.Other Not specific to any objective	5 (3%)	\$724,770 (1%)	<1%
Total Funding for Question 3	147 (100%)	\$60,162,637 (100%)	20%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 4: Which treatments and interventions will help?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
4.S.A ● Support at least three randomized controlled trials that address co-occurring medical conditions associated with ASD by 2010. <i>IACC Recommended Budget: \$13,400,000 over 3 years.</i>	4 (2%)	\$1,826,542 (3%)	<1%
4.S.B ● Standardize and validate at least 20 model systems (e.g., cellular and/or animal) that replicate features of ASD and will allow identification of specific molecular targets or neural circuits amenable to existing or new interventions by 2012. <i>IACC Recommended Budget: \$75,000,000 over 5 years.</i>	89 (34%)	\$21,606,118 (36%)	7%
4.S.C ● Test safety and efficacy of at least five widely used interventions (e.g., nutrition, medications, assisted technologies, sensory integration, medical procedures) that have not been rigorously studied for use in ASD by 2012. <i>IACC Recommended Budget: \$27,800,000 over 5 years.</i>	18 (7%)	\$2,254,724 (4%)	1%
4.S.D ● Complete two multi-site randomized controlled trials of comprehensive early intervention that address core symptoms, family functioning and community involvement by 2013. <i>IACC Recommended Budget: \$16,700,000 over 5 years.</i>	20 (8%)	\$11,156,647 (18%)	4%
4.S.E ● Convene a workshop to advance the understanding of clinical subtypes and treatment personalization (i.e., what are the core symptoms to target for treatment studies) by 2011. <i>IACC Recommended Budget: \$50,000.</i>	0	\$0	0%
4.S.F ● Launch five randomized controlled trials of interventions including biological signatures and other measures to predict response, and monitor quality of life and functional outcomes, in each of the following groups:			
<ul style="list-style-type: none"> • Five trials in infants and toddlers by 2013. <i>IACC Recommended Budget: \$30,000,000 over 5 years.</i> • Three randomized controlled trials of interventions for school-aged children and/or adolescents by 2013. <i>IACC Recommended Budget: \$18,000,000 over 5 years.</i> • Three trials for adults by 2014. <i>IACC Recommended Budget: \$18,000,000 over 5 years.</i> 	23 (9%)	\$5,445,599 (9%)	2%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 4: Which treatments and interventions will help?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
NEW!	<p>4.S.G Support at least five studies on interventions for nonverbal individuals with ASD by 2012. Such studies may include:</p> <ul style="list-style-type: none"> Projects examining service-provision models that enhance access to augmentative and alternative communication (AAC) supports in both classroom and adult service-provision settings, such as residential service-provision and the impact of such access on quality of life, communication, and behavior; Studies of novel treatment approaches that facilitate communication skills in individuals who are nonverbal, including the components of effective AAC approaches for specific subpopulations of people with ASD; and Studies assessing access and use of AAC for children and adults with ASD who have limited or partially limited speech and the impact on functional outcomes and quality of life. <p><i>IACC Recommended Budget: \$3,000,000 over 2 years.</i></p>	13 (5%)	\$2,830,851 (5%)	1%
NEW!	<p>4.S.H Support at least two studies that focus on research on health promotion and prevention of secondary conditions in people with ASD by 2012. Secondary conditions of interest include weight issues and obesity, injury, and co-occurring psychiatric and medical conditions. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i></p>	1 (<1%)	\$222,265 (<1%)	<1%
	<p>4.L.A Complete at least three randomized controlled trials on medications targeting core symptoms in people with ASD of all ages by 2014. <i>IACC Recommended Budget: \$22,200,000 over 5 years.</i></p>	12 (5%)	\$1,527,858 (3%)	1%
	<p>4.L.B Develop interventions for siblings of people with ASD with the goal of reducing risk recurrence by at least 30% by 2014. <i>IACC Recommended Budget: \$6,700,000 over 5 years.</i></p>	2 (1%)	\$14,256 (<1%)	<1%
	<p>4.L.C Conduct at least one study to evaluate the safety and effectiveness of medications commonly used in the treatment of co-occurring conditions or specific behavioral issues in people with ASD by 2015. <i>IACC Recommended Budget: \$10,000,000 over 5 years.</i></p>	8 (3%)	\$2,834,887 (5%)	1%

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ASD Research Progress on IACC Strategic Plan Objectives








Question 4: Which treatments and interventions will help?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
NEW!	<p>4.L.D Support at least five community-based studies that assess the effectiveness of interventions and services in broader community settings by 2015. Such studies may include comparative effectiveness research studies that assess the relative effectiveness of:</p> <ul style="list-style-type: none"> Different and/or combined medical, pharmacological, nutritional, behavioral, service-provision, and parent- or caregiver-implemented treatments; Scalable early intervention programs for implementation in underserved, low-resource, and low-literacy populations; and Studies of widely used community intervention models for which extensive published data are not available. <p>Outcome measures should include assessment of potential harm as a result of autism treatments, as well as positive outcomes. <i>IACC Recommended Budget: \$37,500,000 over 5 years.</i></p>	32 (12%)	\$6,296,024 (10%)	2%
	4.Other Not specific to any objective	37 (14%)	\$4,777,350 (8%)	2%
	Total Funding for Question 4	259 (100%)	\$60,793,121 (100%)	20%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 5: Where can I turn for services?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
	5.S.A  Support two studies that assess how variations and access to services affect family functioning in diverse populations, including underserved populations, by 2012. <i>IACC Recommended Budget: \$1,000,000 over 3 years.</i>	8 (6%)	\$1,351,793 (5%)	1%
	5.S.B  Conduct one study to examine how self-directed community-based services and supports impact children, youth, and adults with ASD across the spectrum by 2014. <i>IACC Recommended Budget: \$6,000,000 over 3 years.</i>	1 (1%)	\$0 (0%)	0%
	5.S.C  Implement and evaluate five models of policy and practice-level coordination among State and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, (which may include access to augmentative and alternative communication [AAC] technology), with at least one project aimed at the needs of transitioning youth and at least one study to evaluate a model of policy and practice-level coordination among State and local mental health agencies serving people with ASD, by 2015. <i>IACC Recommended Budget: \$25,000,000 over 5 years.</i>	3 (2%)	\$600,000 (2%)	<1%
NEW!	5.S.D  Support two studies to examine health, safety, and mortality issues for people with ASD by 2012. <i>IACC Recommended Budget: \$4,500,000 over 3 years.</i>	1 (1%)	\$0 (0%)	0%
	5.L.A  Test four methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings by 2013. <i>IACC Recommended Budget: \$7,000,000 over 5 years.</i>	24 (18%)	\$5,840,814 (23%)	2%
	5.L.B  Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015. <i>IACC Recommended Budget: \$16,700,000 over 5 years.</i>	0	\$0	0%
	5.L.C  Evaluate new and existing pre-service and in-service training to increase skill levels in service providers, including direct support workers, parents and legal guardians, education staff, and public service workers to benefit the spectrum of people with ASD and promote interdisciplinary practice by 2015. <i>IACC Recommended Budget: \$8,000,000 over 5 years.</i>	30 (23%)	\$6,048,734 (24%)	2%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 5: Where can I turn for services?

NEW!	<p>5.L.D Evaluate at least two strategies or programs to increase the health and safety of people with ASD that simultaneously consider principles of self-determination and personal autonomy by 2015. <i>IACC Recommended Budget: \$2,000,000 over 2 years.</i></p>	<p>4 (3%)</p>	<p>\$279,999 (1%)</p>	<p><1%</p>
NEW!	<p>5.L.E Support three studies of dental health issues for people with ASD by 2015. This should include:</p> <ul style="list-style-type: none"> ● One study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment. <i>IACC Recommended Budget: \$900,000 over 3 years.</i> ● One study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD. <i>IACC Recommended Budget: \$900,000 over 3 years.</i> ● One study evaluating pre-service and in-service training program to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice. <i>IACC Recommended Budget: \$900,000 over 3 years.</i> 	<p>3 (2%)</p>	<p>\$443,860 (2%)</p>	<p><1%</p>
	<p>5.Other Not specific to any objective</p>	<p>59 (44%)</p>	<p>\$10,857,304 (43%)</p>	<p>4%</p>
	Total Funding for Question 5	133 (100%)	\$25,422,504 (100%)	8%

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ASD Research Progress on IACC Strategic Plan Objectives



Question 6: What does the future hold, particularly for adults?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
6.S.A ● Launch at least two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of the service delivery system (e.g., safety, integrated employment, post-secondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services) and determine best practices by 2012. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	6 (17%)	\$542,193 (11%)	<1%
6.S.B ● Evaluate at least one model, at the state and local level, in which existing programs to assist people with disabilities (e.g., Social Security Administration, Rehabilitation Services Administration) meet the needs of transitioning youth and adults with ASD by 2013. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	2 (6%)	\$700,000 (14%)	<1%
6.S.C ● Develop one method to identify adults across the ASD spectrum who may not be diagnosed, or are misdiagnosed, to support service linkage, better understand prevalence, track outcomes, with consideration of ethical issues (insurance, employment, stigma) by 2015. <i>IACC Recommended Budget: \$8,400,000 over 5 years.</i>	1 (3%)	\$28,000 (1%)	<1%
6.S.D ● Conduct at least one study to measure and improve the quality of life-long supports being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of ASD-specific training, if necessary, by 2015. <i>IACC Recommended Budget: \$7,500,000 over 5 years.</i>	2 (6%)	\$0 (0%)	0%
6.L.A ● Develop at least two individualized community-based interventions that improve quality of life or health outcomes for the spectrum of adults with ASD by 2015. <i>IACC Recommended Budget: \$12,900,000 over 5 years.</i>	15 (43%)	\$2,154,170 (44%)	1%
6.L.B ● Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015. <i>IACC Recommended Budget: \$5,000,000 over 5 years.</i>	4 (11%)	\$1,348,557 (28%)	1%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 6: What does the future hold, particularly for adults?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
<p>6.L.C  Conduct comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services, and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2018. Topics should include:</p> <ul style="list-style-type: none"> • Community housing for people with ASD; • Successful life transitions for people with ASD, including from post-secondary education to adult services, employment, sibling relationships, and day programs; and • Meeting the service and support needs of older adults with ASD. <p><i>IACC Recommended Budget: \$6,000,000 over 5 years.</i></p>	0	\$0	0%
<p>6.L.D  Conduct implementation research to test the results from comparative effectiveness research in real-world settings including a cost-effectiveness component to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2023. <i>IACC Recommended Budget: \$4,000,000 over 5 years.</i></p>	2 (6%)	\$75,000 (2%)	<1%
<p>6.O Not specific to any objective</p>	3 (9%)	\$50,000 (1%)	<1%
Total Funding for Question 6	35 (100%)	\$4,897,920 (100%)	2%

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ASD Research Progress on IACC Strategic Plan Objectives









Question 7: What other infrastructure and surveillance needs must be met?

2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
● 7.A 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 healthcare, education and social services by 2009. <i>IACC Recommended Budget: \$520,000 over 1 year.</i>	0	\$0	0%
● 7.B Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011. <i>IACC Recommended Budget: \$300,000 each year.</i>	1 (1%)	\$88,154 (<1%)	<1%
● 7.C 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. <i>IACC Recommended Budget: \$1,300,000 over 2 years.</i>	7 (6%)	\$1,387,146 (3%)	1%
● 7.D Establish and maintain an international network of biobanks for the collection of brain, 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. <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. 	6 (5%)	\$8,531,425 (19%)	3%
<i>IACC Recommended Budget: \$82,700,000 over 5 years.</i>			
● 7.E Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their finding to the community, including people with ASD, their families, and health practitioners by 2011. <i>IACC Recommended Budget: \$400,000 over 2 years.</i>	1 (1%)	\$533,354 (1%)	<1%
● 7.F Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. <i>(No recommended budget assigned by the IACC.)</i>	0	\$0	0%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 7: What other infrastructure and surveillance needs must be met?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
	7.G  Develop a web-based tool which provides population estimates of ASD prevalence for states based on the most recent prevalence range and average identified by the ADDM Network by 2012. <i>IACC Recommended Budget: \$200,000 over 2 years.</i>	0	\$0	0%
	7.H  Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the National Database for Autism Research (NDAR) and link NDAR with other existing data resources by 2012. <i>IACC Recommended Budget: \$6,800,000 over 2 years.</i>	1 (1%)	\$1,517,596 (3%)	1%
	7.I  Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least 5 hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012. <i>IACC Recommended Budget: \$660,000 over 2 years.</i>	13 (11%)	\$4,928,453 (11%)	2%
	7.J  Develop the personnel and technical infrastructure to assist states, territories, and other countries who request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013. <i>IACC Recommended Budget: \$1,650,000 over 3 years.</i>	6 (5%)	\$545,414 (1%)	<1%
	7.K  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. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>	31 (27%)	\$5,509,686 (12%)	2%
	7.L  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. <i>IACC Recommended Budget: \$16,200,000 over 5 years.</i>	6 (5%)	\$705,552 (2%)	<1%
	7.M  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. <i>IACC Recommended Budget: \$75,000 over 5 years.</i>	0	\$0	0%
NEW!	7.N  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. <i>IACC Recommended Budget: \$1,850,000 over 1 year.</i>	22 (19%)	\$7,419,887 (17%)	2%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 7: What other infrastructure and surveillance needs must be met?

	2011 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
NEW!	<p>7.O 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.</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>	3 (3%)	\$1,070,941 (2%)	<1%
NEW!	<p>7.P 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. <i>IACC Recommended Budget: \$1,100,000 over 2 years.</i></p>	0	\$0	0%
	7.Other Not specific to any objective	18 (16%)	\$12,314,084 (28%)	4%
	Total Funding for Question 7	115 (100%)	\$44,551,691 (100%)	15%

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ASD Research Progress on IACC Strategic Plan Objectives

Question 7: What other infrastructure and surveillance needs must be met?

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