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2009 AUTISM SPECTRUM DISORDER RESEARCH
PORTFOLIO ANALYSIS REPORT

Prepared by the Office of Autism Research Coordination
and Acclaro Research Solutions, Inc.

IACC
INTERAGENCY AUTISM COORDINATING COMMITTEE
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APPENDIX A:

2009 IACC Autism Spectrum Disorder Research Portfolio Analysis Report

Introduction

In 2010, the Office of Autism Research Coordination (OARC) and Acclaro Research Solutions, Inc., on behalf of the Interagency Autism Coordinating Committee (IACC), conducted a comprehensive analysis of the 2009 Autism Spectrum Disorder (ASD) research portfolio of major Federal agencies and private organizations. This is the second annual analysis of this nature, following the 2008 IACC Portfolio Analysis released in 2009. The intent of these analyses is to better inform the IACC and interested stakeholders about the funding landscape and current directions for ASD research. Additionally, this analysis examines the extent to which current funding and research topics align with the current 2010 IACC Strategic Plan for ASD research. The 2009 Portfolio Analysis can also be used by Federal agencies and private research organizations to help guide future funding priorities by highlighting current gaps and opportunities in ASD research, as well as serving current activities and research progress.

Who funded ASD Research in 2009?

The Office of Autism Research Coordination, on behalf of the IACC, asked Federal agencies and private organizations for information about the ASD-related research grants they funded in 2009, including the annual budget for each project and its relevance to the seven critical questions of the 2010 IACC Strategic Plan for ASD Research, listed below.

1. **When Should I Be Concerned?**
2. **How Can I Understand What Is Happening?**
3. **What Caused This To Happen and Can It Be Prevented?**
4. **Which Treatments and Interventions Will Help?**
5. **Where Can I Turn For Services?**
6. **What Does the Future Hold, Particularly For Adults?**
7. **What Other Infrastructure and Surveillance Needs Must Be Met?**

Research project data was requested from 13 Federal and private ASD stakeholders, and all reported they had provided funding for ASD research in 2009. Table 1 lists the 13 agencies and organizations that participated in this effort.

Agencies and Organizations Included in the 2009 IACC Portfolio Analysis

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
• Centers for Disease Control and Prevention (CDC) • Centers for Medicare and Medicaid Services (CMS) • Department of Defense (DoD) • Department of Education (Ed) • Health Resource and Services Administration (HRSA) • National Institutes of Health (NIH)	• Autism Research Institute (ARI) • Autism Science Foundation (ASF) • Autism Speaks (AS) • Center for Autism and Related Disorders (CARD) • Organization of Autism Research (OAR) • The Simons Foundation (Simons) • Southwest Autism Research and Resource Center (SARRC)

Table 1 *lists the six Federal agencies and seven private organizations included in the 2009 IACC Autism Spectrum Disorder Research Portfolio Analysis of ASD research funding.*

American Recovery and Reinvestment Act of 2009 (ARRA)

The American Recovery and Reinvestment Act (ARRA or Recovery Act) was enacted in February 2009 with the objective of stimulating the economy, creating and preserving jobs, and investing in long-term growth. Among the federal agencies that support autism research projects, as described in this report, only the National Institutes of Health (NIH) received/used fiscal year 2009 Recovery Act funds to support autism research projects. The NIH received $8.2 billion in Recovery Act funds to help stimulate the U.S. economy through support and advancement of biomedical research. The funds were used to support individual research projects and expand and enhance existing programs. In 2009, $64 million in NIH Recovery Act funds were used to jumpstart the implementation of the newly released 2009 IACC Strategic Plan for Autism Spectrum Disorder Research, supporting 141 new autism research projects. Many of the NIH-ARRA funded projects directly align with IACC Strategic Plan objectives, including research to identify biomarkers for early diagnosis, develop rapid screening instruments, identify subtypes of autism, explore the underlying environmental and genetic causes, and understand autism in adults. In total, NIH-ARRA funding ($64 million) accounted for 33% of NIH's overall ASD research funding in 2009, as well as 27% of the

overall Federal funds spent on autism research in 2009 and 20% of total ASD research funding across participant agencies and organization in 2009 (Figure 1).

Who funded ASD Research in 2009?

Comparison of 2009 NIH-ARRA, NIH Non-ARRA & Non-NIH ASD Research Funding

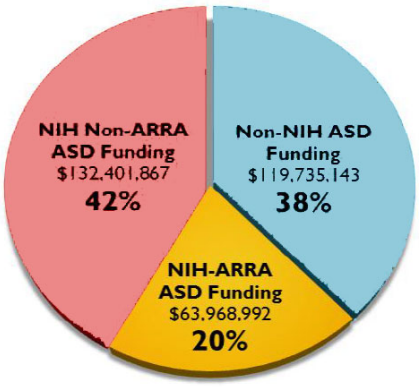

Figure 1 *Sixty-two percent of 2009 ASD research funding was provided by the NIH. NIH-ARRA funding accounted for 33% of NIH ASD research funding and 20% of FY09 ASD research funding. Thirty-eight percent of FY09 ASD research funding was from sources other than the NIH.*

What was the breakdown of funding?

The 13 stakeholders that were included in this analysis contributed a total of $316,106,002 across 985 projects in 2009 (Table 2).

2009 ASD Research Funding by Agency/Organization
(All on-going projects included)

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	517	$196,370,859
The Simons Foundation (Simons)	98	$51,526,058
Autism Speaks (AS)	220	$23,416,615
Centers for Disease Control & Prevention (CDC)	27	$18,929,998
Department of Defense (DoD)	15	$9,394,599*
Health Resource and Services Administration (HRSA)	9	$8,097,807
Department of Education (Ed)	11	$6,317,029
Center for Autism & Related Disorders (CARD)	29	$850,594
Autism Research Institute (ARI)	16	$400,382
Organization for Autism Research (OAR)	14	$330,000
Southwest Autism Research & Resources Center (SARRC)	5	$285,000
Autism Science Foundation (ASF)	6	$180,000
Center for Medicare& Medicaid Services (CMS)	1	$7,061
GRAND TOTAL	**985**	**$316,106,002**

**Funding for the DoD includes all ASD funding for 2009, as well as $1,734,909 of FY08 ASD research funding that was not reported in the 2009 Portfolio Analysis.*

Table 2. *The table lists the total funding provided by the agencies and organizations included in the portfolio analysis and the number of projects funded. Please note that the NIH figure includes both ARRA ($64million) and non-ARRA ($132million) funding. Together, the agencies and organizations funded 985 projects.*

The National Institutes of Health (NIH) was the leading contributor of funding for ASD research in 2009 with a total of $196,370,859 funding 517 projects. This funding included both NIH-ARRA ($63,968,922) and non-ARRA funding ($132,401,867). Non-ARRA funding accounted for 67% of total NIH funding for 2009 and supported 376 projects, whereas NIH-ARRA funding accounted for 33% and supported 141 projects. The Simons Foundation was the second largest funder of ASD research, funding 98 projects totaling $51,526,058. Autism Speaks ranked third in funding with $23,416,615 allocated across 220 projects.

In a comparison of Federal versus private funding for ASD research in 2009, the Federal government provided 76% ($239,117,353) of the total 2009 ASD research budget (Figure 2). Private organizations funded 24% ($76,988,649) of ASD research in 2009. In total, the Federal government supported 597 ASD research projects in 2009, and private organizations funded 388

projects. In 2009, while private funding remained at close to the same level as in 2008 (approximately $78.5 million in 2008 and $77 million in 2009), Federal funding was significantly increased, due to the large contribution of NIH-ARRA at approximately $64 million (Figure 3), as well as an increase in Federal agencies' overall annual appropriated funding for autism research (approximately $144 million in 2008 and $175 million in 2009).

Comparison of Federal vs. Private Funding for ASD Research in 2009

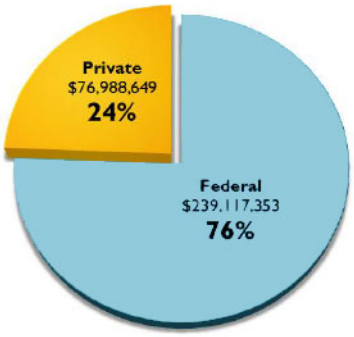

Figure 2. *Seventy-six percent of the $316,106,002 distributed for ASD research in 2009 was provided by Federal sources, while the remaining 24% of funding was obtained from private organizations.*

Of the approximate $3 million Federal ASD ressearch funds distributed in 2009, 27% was provided by NIH-ARRA .

Comparison of ARRA vs. Non-ARRA Federal Funding for ASD Research in 2009

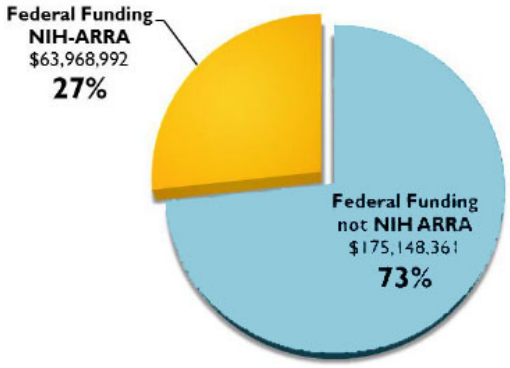

Figure 3. *Seventy-three percent of the $239,117,353 distributed for ASD research by the Federal government in 2009 was provided from sources other than NIH-ARRA, while the remaining 27% of Federal funding was from NIH-ARRA.*

What ASD Research was Done?

To better understand what areas of research were funded in 2009, projects were aligned with the corresponding questions in the 2010 Strategic Plan. Figure 4 illustrates the breakdown of the research funding according to the Plan's seven critical questions related to diagnosis, biology, risk and protective factors, treatments, services, lifespan, and infrastructure and surveillance issues. Identifying how current research investments correspond to the Strategic Plan aids in providing an understanding of the current main areas of focus in the field, as well as areas that are in need of further development.

2009 ASD Research Funding by Topic Area

(Defined as Questions in the 2010 Strategic Plan)

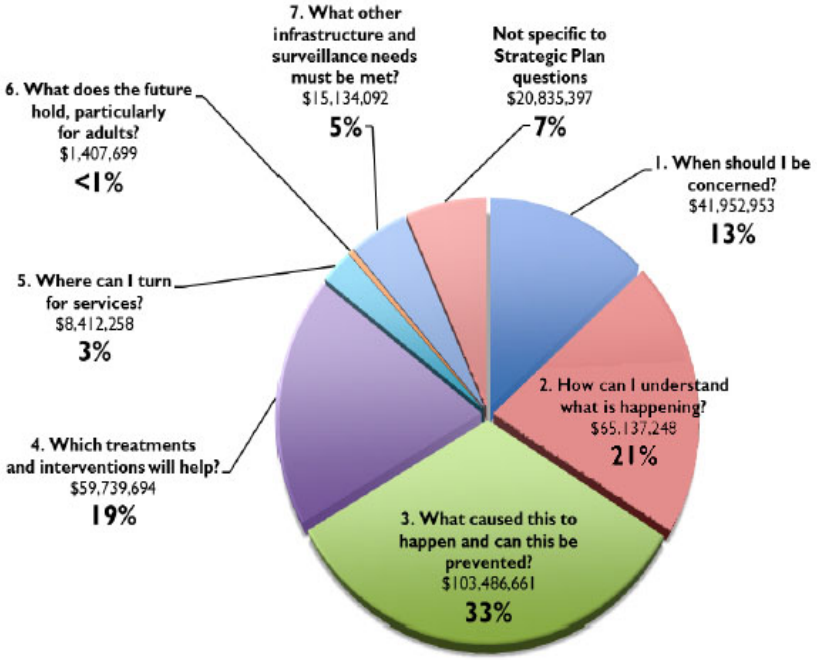

Figure 4. *In 2009, the largest proportion of ASD research funding (33%) was devoted to risk factors for ASD (Question 3); 21% of the research addressed the underlying biology of ASD (Question 2,); 19% related to interventions and treatments (Question 4); 13% related to diagnosis (Question 1); and 5% related to infrastructure and surveillance (Question 7). Research on services and lifespan issues (Questions 5 and 6) received just over 3% of the total funding provided.*

As in the prior year, 2009 ASD research funding supported projects related to all six critical questions in the Strategic Plan, as well the recently added seventh critical question. Funding varied by question, with the largest proportion of funding (33%) devoted to topics associated with Question 3: "What Caused This To Happen and Can It Be Prevented?". Research related to Question 2, targeting the underlying biology of ASD, ranked second, receiving 21% of ASD funding. Topics associated with Question 6: "What Does The Future Hold?", which addresses lifespan issues, received less than 1% of ASD research funding. Research funding received from NIH-ARRA followed a similar pattern to overall ASD research funding. Research related to Question 3 received the most NIH-ARRA funding (45%), followed by research funding for Question 2 (18%). As with overall 2009 ASD research funding, research associated with services and life span issues received the least NIH-ARRA funding (4% and 1%, respectively). Though small, these percentages do indicate a

slightly greater emphasis on these two areas in the NIH-ARRA funding in comparison with the overall funding for autism research across all agencies and organizations (3% and <1%, respectively, as noted in Figure 4). Also, notably, in the NIH-ARRA funding, only 1% was allocated to projects outside the scope of the Strategic Plan, reflecting the deliberate effort of NIH to focus its ARRA funding on priority areas identified in the IACC Strategic Plan. The allocation of NIH-ARRA funding by Strategic Plan Question is illustrated in Figure 5.

2009 NIH-ARRA ASD Research Funding by Topic Area

(Defined as Questions in the 2010 Strategic Plan)

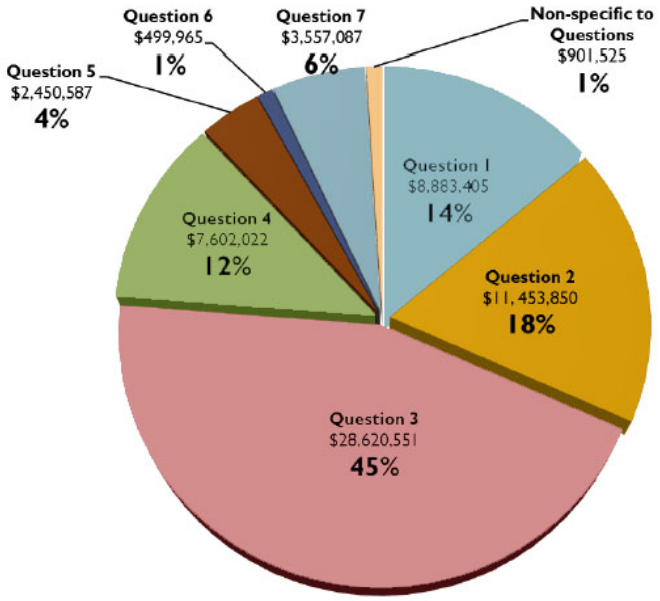

Figure 5. *In 2009, the largest proportion of NIH-ARRA ASD research funding (45%) was devoted to risk factors for ASD (Question 3); 18% of the research addressed the underlying biology of ASD (Question 2); 14% related to diagnosis (Question 1); 12% related to interventions and treatments (Question 4); 6% related to surveillance and infrastructure (Question 7); and 4% related to services (Question 5). Research on lifespan issues (Question 6) received just 1% of the NIH-ARRA ASD research funding provided.*

How did the research align with the objectives in the IACC Strategic Plan?

After assessing the distribution of research funding across the Strategic Plan questions, the next area for analysis was how well the research funded in 2009 addressed the specific research objectives outlined in the Strategic Plan. In addition to the 40 objectives included in the first IACC Strategic Plan issued in 2009, 32 new objectives were added to the Strategic Plan in 2010. Each question in the Plan has several short- (S) and long-term (L) objectives, designated alphabetically,

calling for specific research efforts with a goal date and an estimate of the budget required to accomplish the goal. For clarity of discussion in this analysis, the objectives have been abbreviated using the question number, short- or long-term goal status and alphabetical designation (see Appendix A for the full objective title). For example, the first short-term objective in Question 1 ("When Should I Be Concerned?"), 1.S.A, calls for the development of "at least one efficient diagnostic instrument that is valid in diverse populations for use in large-scale studies by 2011." The budget recommended is $5,300,000 over two years.[1] Summaries of funding for individual questions and their related objectives are listed below, as well as in Appendix A, and illustrated in Figure 6.

Question 1: When Should I Be Concerned?

Thirteen percent ($41,952,953) of 2009 ASD funding, including 14% ($8,883,405) of NIH-ARRA funding, corresponded to Question 1. Of that research, 76% ($32,100,411) was specific to the question's seven objectives. The two objectives receiving the most funding (1.L.A, 32% and 1.L.B, 21%) relate to identification and measures of biomarkers, respectively. The two new objectives for this question received the least funding (1.S.C < 1% and 1.S.D, 0%), while 23% ($9,852,542) of ASD funding for Question 1 was not related to any of the seven objectives.

Question 2: How Can I Understand What Is Happening?

Question 2 addresses the biological aspects of ASD and includes seven short-term and two long-term objectives. While research topics associated with Question 2 received the second largest investment, with 21% ($65,137,248) of the 2009 ASD research funding, including 18% ($11,453,850) of NIH-ARRA funding, a large proportion of funding corresponding to the question (42%, $27,455,589) was not specific to any individual objective. This is followed by 14% of Question 2 funding associated with studies related to understanding the underlying biological pathways of genetic conditions related to autism (2.S.D). Three of the seven short-term objectives each received less than 2% of total funding for Question 2 (2.S.B, 2.S.C, and 2.S.F).

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[1] *Budget recommendations were formulated by scientific and program experts in the field and provide an estimate of what it would cost to conduct each project. The IACC provides these budget recommendations as part of their advisory capacity to the Federal government, but the IACC does not have its own research budget to conduct or support research.*

Question 3: What Caused This To Happen and Can It Be Prevented?

As in 2008, the largest proportion of research funding (33%, $103,486,661) for 2009 related to the question of causation, with 90% related to specific objectives. Research related to Question 3 also received the largest proportion of NIH-ARRA funding (45%, $28,620,551). Research focused on identifying genetic risk factors for ASD (3.L.B) received 43% of Question 3 funding. The other nine objectives split 47% of Question 3 funding, although one short-term objective (3.S.D) received less than 1% of funding. The remaining 10% ($10,218,471) of Question 3 funding was deemed unrelated to specific objectives.

Question 4: Which Treatments and Interventions Will Help?

Research addressing treatments and interventions received the third largest amount of 2009 ASD research funding (19%, $59,739,694), including the fourth largest amount of NIH-ARRA funding (12%, $7,602,022) among the questions in the 2010 Strategic Plan. Almost 80% ($46,973,006) of ASD funding associated with Question 4 was specific to the objectives. The short-term objective (4.S.B) related to standardization and validation of systems to replicate ASD, and identifying molecular targets or neural circuits received 33% of the funding for Question 4. One new short-term objective (4.S.E), which recommends workshops to identify core symptoms to target for treatment studies, received no funding, while the three long-term objectives associated with this question accounted for less than 5% collectively (4.L.A, 4.L.B and 4.L.C). Funding not related to a specific objective amounted to 21% ($12,766,688) of Question 4 funds.

Question 5: Where Can I Turn To For Services?

Six objectives associated with Question 5 relate to services. Research associated with this question received the second lowest amount of 2009 ASD research funding (3%, $8,412,258) and accounted for 4% ($2,450,587) of NIH-ARRA funding. The majority (85%, $7,126,989) of funding allocated to Question 5 was associated with the objectives. Topics related to long-term objective A, addressing methods to improve dissemination, implementation and sustainability of evidence-based interviews, services and supports in diverse community settings, received 69% of Question 5 funding. Fifteen percent ($1,285,269) of funding was not related to a specific objective, and one short-term objective (5.S.C) did not have any funded research for 2009.

Question 6: What Does The Future Hold, Particularly For Adults?

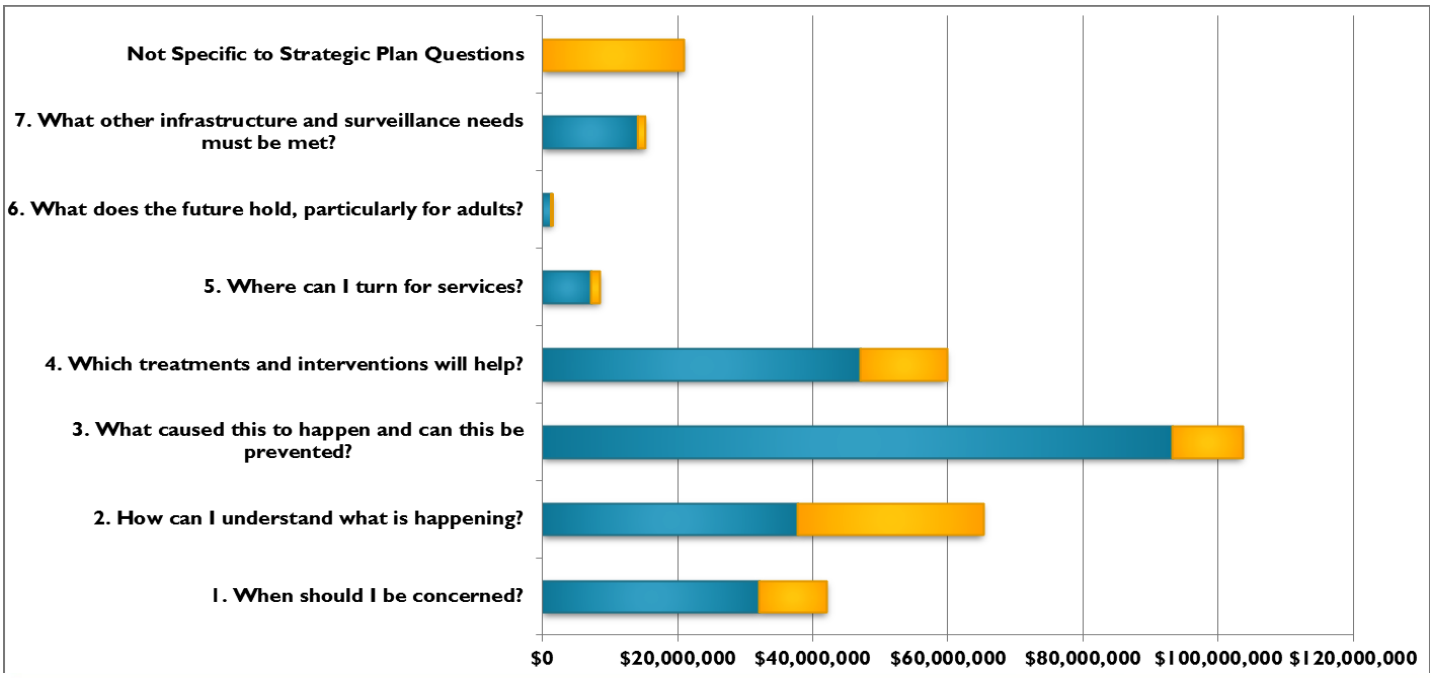
Question 6 was the least funded critical question, for both total 2009 ASD research funding (< 1%, $1,407,699) and NIH-ARRA funding (1%, $499,965). Question 6 addresses lifespan issues, including transitioning into adulthood. Of the eight objectives associated with this question, only three received funding in FY09. Fifty-one percent of funding for Question 6 went to a new long-term objective (6.L.B) related to studying how interventions, services, and supports, delivered during childhood, impact adult health and quality of life. Additionally, 36% of Question 6 was directed to long-term objective A, development of community-based interventions to improve quality of life and health outcomes, while 11% ($159,444) was not related to a specific objective.

Question 7: What Other Infrastructure and Surveillance Needs Must Be Met?

Question 7 was added to the Strategic Plan in 2010 and received 5% ($15,134,092) of 2009 ASD research funding, including 6% of NIH-ARRA funding ($3,557,087). There are 13 objectives relating to issues of infrastructure and surveillance needs contained in Question 7. Objective 7.I received 42% of Question 7 funding and addresses supplementing Autism and Developmental Disabilities Monitoring (ADDM) networks to include population-based surveillance data and to conduct analyses evaluating factors contributing to changes in ASD prevalence. Of the remaining 12 objectives, six received either no funding or less than 1% of total Question 7 funding. Only 7% ($1,000,000) of Question 7 funding was not associated with question objectives.

While 93% ($295,270,605) of total FY09 ASD research funding aligned with the seven critical questions, 7% ($20,835,397) of 2009 ASD research funding, including 1% ($901,525)of NIH-ARRA ASD research funding, was not related to any of the seven questions. This funding was allocated to 40 ASD research projects.

2009 ASD Funding Specific to Strategic Plan Objectives

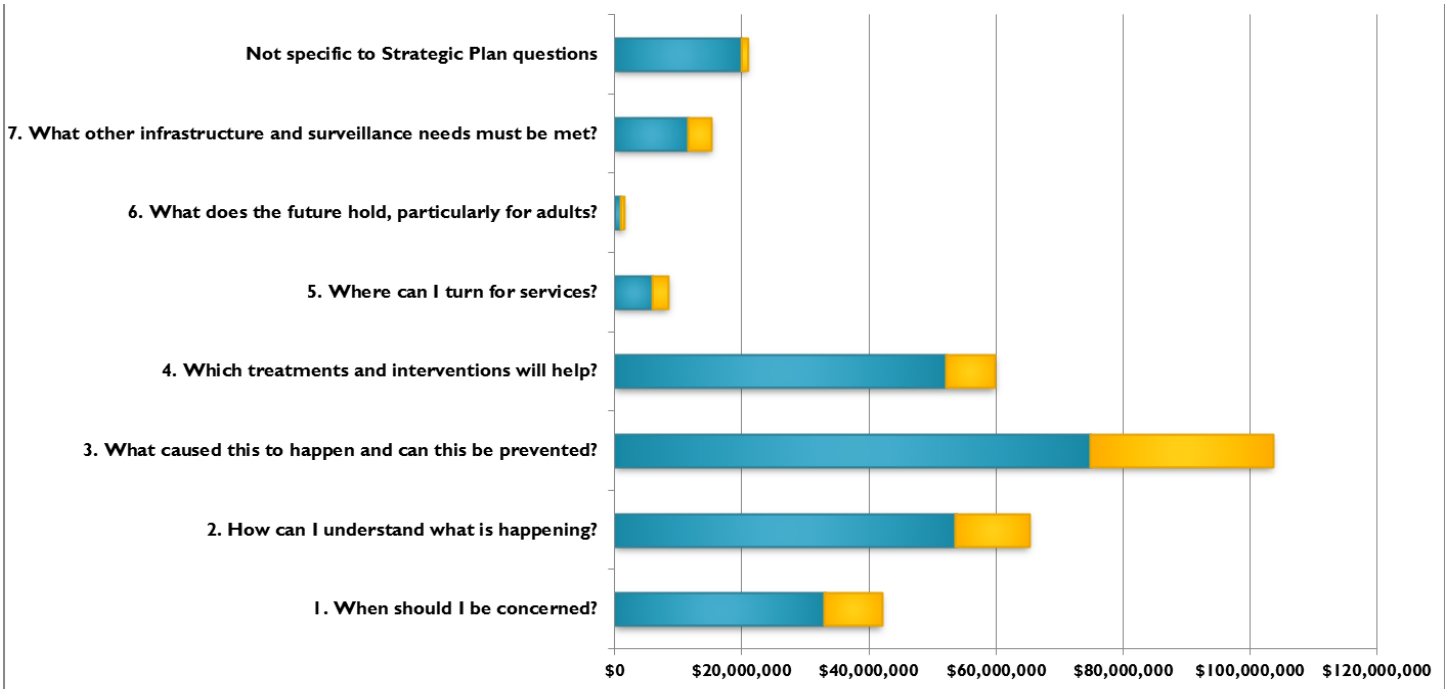


	1. When should I be concerned?	2. How can I understand what is happening?	3. What caused this to happen and can this be prevented?	4. Which treatments & interventions will help?	5. Where can I turn for services?	6. What does the future hold, particularly for adults?	7. What other infrastructure & surveillance needs must be met?	Not specific to Strategic Plan Questions
Specific to Question Objectives	$32,100,411	$37,681,659	$93,268,190	$46,973,006	$7,126,989	$1,248,255	$14,134,092	
Not Specific to Question Objectives	$9,852,542	$27,455,589	$10,218,471	$12,766,688	$1,285,269	$159,444	$1,000,000	$20,835,397
TOTAL	$41,952,953	$65,137,248	$103,486,661	$59,739,694	$8,412,258	$1,407,699	$15,134,092	$20,835,397

Figure 6. *2009 ASD funding for each of the 2010 Strategic Plan Questions based on research specific to or not specific to Question objectives. Funding specific to research objectives is designated in blue, while funding not specific to objectives is designated in yellow.*

Of the seven critical questions described in the 2010 Strategic Plan, Question 3 (risk factors), Question 6 (issues over the lifespan) and Question 7 (infrastructure and surveillance) each had more than 88% of research related to specific objectives. Conversely, 42% of funding allocated to Question 2 (biology of ASD) and 23% of Question 1 (diagnosis) was for projects outside the focus of the objectives (Figure 6).

Comparison of 2009 Private and Non-ARRA Government ASD Funding vs. NIH-ARRA Funding Specific to Questions



	1. When should I be concerned?	2. How can I understand what is happening?	3. What caused this to happen and can this be prevented?	4. Which treatments & interventions will help?	5. Where can I turn for services?	6. What does the future hold, particularly for adults?	7. What other infrastructure & surveillance needs must be met?	Not specific to Strategic Plan Questions
All Other Funders	$33,069,548	$53,683,398	$74,866,110	$52,137,672	$5,961,671	$907,734	$11,577,005	$19,933,872
NIH ARRA	$8,883,405	$11,453,850	$28,620,551	$7,602,022	$2,450,587	$499,965	$3,557,087	$901,525
TOTAL	$41,952,953	$65,137,248	$103,486,661	$59,739,694	$8,412,258	$1,407,699	$15,134,092	$20,835,397

Figure 7 *2009 ASD funding for each of the 2010 Strategic Plan Questions based on traditional funding or NIH-ARRA funding. Traditional funding is designated in blue, while NIH-ARRA funding is designated in yellow.*

NIH-ARRA funding accounted for 20% of 2009 ASD research funding. As with the overall FY09 ASD research funding, Question 3 "*What Caused This To Happen and Can It Be Prevented?*" and Question 2 "*How Can I Understand What Is Happening*?" received the largest proportion of NIH-ARRA funding. Likewise, Question 7 "*What Other Infrastructure and Surveillance Needs Must Be Met?",* Question 6 *"What Does The Future Hold, Particularly For Adults?"* and Question 5 "*Where Can I Turn To For Services?"* received the smallest proportion of NIH-ARRA funding (Figure 7).

Total funding for ASD research from all participating agencies and organizations increased by 42% ($93,890,660) between 2008 ($222,215,342) and 2009 ($316,106,002). This is the result of a 66%

increase in Federal spending ($95,392,508), of which 27% ($63,968,992) is a result of NIH-ARRA funding. NIH-ARRA funds provided a substantial boost to ASD research funding, but even without ARRA funding, total Federal funding increased 22% ($31,423,516), from 2008 ($143,724,845) to 2009 ($175,148,361). Total private funding for ASD research remained relatively stable, with a small decrease of 2% ($1,501,848) between 2008 ($78,490,497) and 2009 ($76,988,649).

Conclusion

The 2009 ASD Research Funding Portfolio Analysis is the second comprehensive annual review of ASD research funding across both the Federal and private sectors and provides a valuable snapshot of the current funding landscape. These analyses will continue to be conducted annually as part of the process for updating the IACC Strategic Plan for ASD Research. Trends identified during the analysis can be used to address underfunded areas, identify new research opportunities and priorities, and guide the direction of future research.

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APPENDIX A:

2010 IACC Strategic Plan for Autism Spectrum Disorder Research Autism Research Funding 200

2010 IACC Strategic Plan for Autism Spectrum Disorder Research
Autism Research Funding 2009 - Combined ARRA and non-ARRA

Question 1: When should I be concerned?

	Strategic Plan Objectives	Projects	Funding	Percent of Total 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. IACC Recommended Budget: $5,300,000 over 2 years.	15 (10%)	$4,728,120 (11%)	1%
	1.S.B Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparison of general developmental screening versus autism-specific screening tools, in both high risk and population-based samples through studies of the following community populations that are diverse in terms of age, socio-economic status, race, ethnicity, characteristics of ASD, and general level of functioning by 2012. IACC Recommended Budget: $5,400,000 over 3 years.	11(8%)	$3,973,712 (9%)	1%
NEW!	1.S.C Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services by 2012. IACC Recommended Budget: $2,000,000 over 2 years	1 (1%)	$139,072 (<1%)	<1%
NEW!	1.S.D Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. IACC Recommended Budget: $6,000,000 over 5 years	-	-	-
	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 by 2014. IACC Recommended Budget: $33,300,000 over 5 years.	42 (29%)	$13,565,554 (32%)	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. IACC Recommended Budget: $71,100,000 over 5 years.	33 (23%)	$8,832,885 (21%)	3%

Data Includes 2009 funding from Federal/private funders of ASD research and 2009 NIH ARRA funding.

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Question 1: When should I be concerned?

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. IACC Recommended Budget: $18,500,000 over 5 years.	6 (4%)	$861,069 (2%)	<1%
1.O Not specific to any objective	38 (26%)	$9,852,542 (23%)	3%
Grand Total	**146**	**$41,952,953**	**13%**

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Question 2: How can I understand what is happening?

	Strategic Plan Objectives	Projects	Funding	Percent of Total Funding
	2.S.A Support at least four research projects to identify mechanisms of metabolic and /or immune system interactions with the central nervous system that may underlie the development of ASD during prenatal-postnatal life by 2010. IACC Funding Budget: $9,800,000 over 4 years.	34 (12%)	$7,811,087 (12%)	2%
	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. IACC Recommended Budget: $8,900,000 over 5 years	3 (1%)	$993,806 (2%)	<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. IACC Recommended Budget: $1,400,000 over 2 years	2 (<1%)	$726,911 (1%)	<1%
NEW!	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. IACC Recommended Budget: $9,000,000 over 5 years.	49 (17%)	$9,233,574 (14%)	3%
NEW!	2.S.E Launch three studies that target the underlying biological mechanisms of co-occurring conditions with autism including seizures/epilepsy, sleep disorders and familial autoimmune disorders by 2012. IACC Recommended Budget: $9,000,000 over 5 years.	12 (4%)	$5,186,144 (8%)	2%
NEW!	2.S.F Launch two studies that focus on prospective characterization of children with reported regression, to investigate potential risk factors by 2012. IACC Recommended Budget: $4,500,000 over 5 years.	1 (<1%)	$607,379 (1%)	<1%

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Question 2: How can I understand what is happening?

NEW!	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. IACC Recommended Budget: $22,600,000 over 5 years.	21 (7%)	$5,503,947 (8%)	2%
	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. IACC Recommended Budget: $126,200,000 over 12 years.	9 (3%)	$6,086,548 (9%)	2%
NEW!	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.	16 (6%)	$1,532,262 (2%)	<1%
	2.O Not specific to any objective	143 (49%)	$27,455,589 (42%)	9%
	Grand Total	**290**	**$65,137,248**	**21%**

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

	Strategic Plan Objectives	Projects	Funding	Percent of Total Funding
	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. IACC Recommended Budget: $43,700,000 over 4 years.	11 (6%)	$11,852,549 (11%)	4%
	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. IACC Recommended Budget: $3,500,000 over 3 years.	3 (2%)	$4,844,321 (5%)	2%
	3.S.C Initiate efforts to expand existing large case-control and other studies to enhance capabilities for targeted gene – environment research by 2011. IACC Recommended Budget: $27,800,000 over 5 years.	10 (5%)	$11,867,708 (11%)	4%
	3.S.D Enhance existing case-control studies to enroll racially and ethnically diverse populations affected by ASD by 2011. IACC Recommended Budget: $3,300,000 over 5 years.	3 (2%)	$103,827 (<1%)	<1%
NEW!	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. IACC Recommended Budget: $8,000,000 over 2 years.	13 (7%)	$1,739,200 (2%)	1%
NEW!	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. Estimated cost $56,000,000 over 2 years.	13 (7%)	$2,887,527 (3%)	1%
	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. IACC Recommended Budget: $11,100,000 over 5 years.	2 (1%)	$3,740,812 (4%)	1%

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

3.L.B	Identify genetic risk factors in at least 50% of people with ASD by 2014. IACC Recommended Budget: $33,900,000 over 6 years.	80 (40%)	$44,705,496 (43%)	14%
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. IACC Recommended Budget: $25,100,000 over 7 years.	7 (4%)	$1,992,228 (2%)	1%
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. IACC Recommended Budget: $44,400,000 over 5 years.	12 (6%)	$9,534,522 (9%)	3%
3.O	Not specific for any objective	45 (23%)	$10,218,471 (10%)	3%
Grand Total		**199**	**$103,486,661**	**33%**

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Question 4: Which treatments and interventions will help?

	Strategic Plan Objectives	Projects	Funding	Percent of Total Funding
	4.S.A Support at least three randomized controlled trials that address co-occurring medical conditions associated with ASD by 2010. IACC Recommended Budget: $13,400,000 over 3 years.	6 (3%)	$4,733,841 (8%)	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. IACC Recommended Budget: $75,000,000 over 5 years.	69 (31%)	$19,565,072 (33%)	6%
	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. IACC Recommended Budget: $27,800,000 over 5 years.	29 (13%)	$2,939,350 (5%)	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. IACC Recommended Budget: $16,700,000 over 5 years.	8 (4%)	$7,286,371 (12%)	2%
NEW!	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. IACC Recommended Budget: $50,000.	-	-	-

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Question 4: Which treatments and interventions will help?

NEW!	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: • Five trials in infants and toddlers by 2013. IACC Recommended Budget: $30,000,000 over 5 years. • Three randomized controlled trials of interventions for school-aged children and/or adolescents by 2013. IACC Recommended Budget: $18,000,000 over 5 years. • Three trials for adults by 2014. IACC Recommended Budget: $18,000,000 over 5 years.	43 (19%)	$10,045,511 (17%)	3%
	4.L.A Complete at least three randomized controlled trials on medications targeting core symptoms in people with ASD of all ages by 2014. IACC Recommended Budget: $22,200,000 over 5 years.	8 (4%)	$1,198,146 (2%)	<1%
	4.L.B Develop interventions for siblings of people with ASD with the goal of reducing risk recurrence by at least 30% by 2014. IACC Recommended Budget: $6,700,000 over 5 years.	2 (1%)	$132,263 (<1%)	<1%
NEW!	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. IACC Recommended Budget: $10,000,000 over 5 years.	7 (3%)	$1,072,453 (2%)	<1%
	4.O Not specific to any objective	52 (23%)	$12,766,688 (21%)	4%
	Grand Total	**224**	**$59,739,694**	**19%**

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Question 5: Where can I turn for services?

	Strategic Plan Objectives	Projects	Funding	Percent of Total 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. IACC Recommended Budget: $1,000,000 over 3 years.	2 (6%)	$671,946 (8%)	<1%
NEW!	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. IACC Recommended Budget: $6,000,000 over 3 years.	6 (17%)	$446,340 (5%)	<1%
NEW!	5.S.C Implement and evaluate two 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, with at least one project aimed at the needs of transitioning youth by 2015. IACC Recommended Budget: $10,000,000 over 5 years.	-	-	-
	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. IACC Recommended Budget: $7,000,000 over 5 years.	11 (31%)	$5,772,488 (69%)	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. IACC Recommended Budget: $16,700,000 over 5 years.	5 (14%)	$103,722 (1%)	<1%

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Question 5: Where can I turn for services?

NEW!	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. IACC Recommended Budget: $8,000,000 over 5 years.	6 (17%)	$132,494 (2%)	0.0%
	5.O Not specific to any objective	6 (17%)	$1,285,269 (15%)	<1%
	Grand Total	**36**	**$8,412,258**	**3%**

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

	Strategic Plan Objectives	Projects	Funding	Percent of Total Funding
NEW!	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. IACC Recommended Budget: $5,000,000 over 3 years.	1 (14%)	$20,000 (1%)	<1%
NEW!	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. IACC Recommended Budget: $5,000,000 over 3 years.	-	-	-
NEW!	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. IACC Recommended Budget: $8,400,000 over 5 years.	-	-	-
NEW!	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. IACC Recommended Budget: $7,500,000 over 5 years.	-	-	-
NEW!	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. IACC Recommended Budget: $12,900,000 over 5 years.	2 (29%)	$509,965 (36%)	<1%

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

NEW!	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. IACC Recommended Budget: $5,000,000 over 5 years.	2 (29%)	$718,290 (51 %)	<1%
NEW!	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. IACC Recommended Budget: $6,000,000 over 5 years.	-	-	-
NEW!	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. IACC Recommended Budget: $4,000,000 over 5 years.	-	-	-
	6.O Not specific to any objective	2 (29%)	$159,444 (11%)	<1%
	Grand Total	**7**	**$1,407,699**	**<1%**

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

	Strategic Plan Objectives	Projects	Amount	Percent of Total 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 . IACC Recommended Budget: $520,000 over 1 year.	-	-	-
7.B	Conduct an annual "State of the States" assessment of existing state programs and supports for people and families living with ASD by 2009. IACC Recommended Budget: $300,000 each year.	1 (2%)	$7,061 (<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. IACC Recommended Budget: $1,300,000 over 2 years.	3 (7%)	$2,156,176 (14%)	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. This includes developing fibroblast repositories to produce pluripotent stem cells. Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, promoting detection of biological signatures. IACC Recommended Budget for establishing biobanks by 2011: $10,500,000 over 2 years. IACC Recommended Budget for maintaining biobanks: $22,200,000 over 5 years.	2 (5%)	$436,815 (3%)	<1%
NEW! 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. IACC Recommended Budget: $400,000 over 2 years.	1 (2%)	$25,000 (<1%)	<1%

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

NEW!	7.F Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. (No recommended budget assigned by the IACC.)	-	-	-
NEW!	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. IACC Budget Recommendations: $200,000 over 2 years.	-	-	-
NEW!	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. IACC Recommended Budget: $6,800,000 over 2 years.	1 (2%)	$1,442,000 (10%)	<1%
NEW!	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. IACC Recommended Budget: $660,000 over 2 years.	15 (35%)	$6,415,815 (42%)	2%
NEW!	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. IACC Recommended Budget: $1,650,000 over 3 years.	11 (27%)	$494,449 (3%)	<1%
NEW!	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. IACC Recommended Budget: $5,000,000 over 3 years.	5 (12%)	$2,457,472 (16%)	1%

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

NEW!	7.L Expand the number of ADDM sites in order to conduct ASD surveillance in younger and older age groups; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015. IACC Recommended Budget: $16,200,000 over 5 years.	2 (4.7%)	$699,304 (4.6%)	0.2%
NEW!	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. IACC Recommended Budget: $75,000 over 5 years.	-	-	-
	7.O Not specific to any objective	2 (5%)	$1,000,000 (7%)	<1%
	Grand Total	**43**	**$15,134,092**	**5%**

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Current project and funding status for each question objective is indicated within the table by colored "dots" next to the objective. Any objective colored green has greater than or equal to the number of recommended projects and greater than or equal to the recommended funding; any objective colored yellow has some degree of funding or some number of projects, but less than the recommended amount; while any objective colored red has no funding and no current projects.

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2010 IACC Strategic Plan for Autism Spectrum Disorder Research
Autism Research Funding 2009- Combined ARRA and non-ARRA

Other –Not specific to Strategic Plan questions

Strategic Plan Objectives	Projects	Amount	Percent of Total Funding
Other	40 (100%)	$20,835,397 (100%)	7%

Grand Total

Strategic Plan Objectives	Projects	Amount	Percent of Total Funding
Grand Total	**985**	**$316,106,002**	**100%**

Data Includes 2009 funding from Federal/private funders of ASD research and 2009 NIH ARRA funding.

Current project and funding status for each question objective is indicated within the table by colored “dots” next to the objective. Any objective colored green has greater than or equal to the number of recommended projects and greater than or equal to the recommended funding; any objective colored yellow has some degree of funding or some number of projects, but less than the recommended amount; while any objective colored red has no funding and no current projects.

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