THE INTERAGENCY AUTISM COORDINATING COMMITTEE

2009 AUTISM SPECTRUM DISORDER RESEARCH
PORTFOLIO ANALYSIS REPORT

Prepared by the Office of Autism Research Coordination
and Acclaro Research Solutions, Inc.
on behalf of the
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 Report* 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 *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 outlining current gaps and opportunities in ASD research, as well as serving to highlight 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.

***IACC Strategic Plan* Questions and Corresponding Research Areas**

IACC STRATEGIC PLAN QUESTION	RESEARCH AREA
1. When Should I Be Concerned?	Diagnosis
2. How Can I Understand What Is Happening?	Underlying Biology
3. What Caused This To Happen and Can It Be Prevented?	Causes and Risk Factors
4. Which Treatments and Interventions Will Help?	Treatments
5. Where Can I Turn For Services?	Services/Implementation
6. What Does the Future Hold, Particularly For Adults?	Issues Across the Lifespan
7. What Other Infrastructure and Surveillance Needs Must Be Met?	Biobanks, Data Sharing, Workforce, Surveillance

Table 1. *The table lists the seven consumer-based questions that serve as the framework for the IACC Strategic Plan for Autism Spectrum Disorder Research and the research areas that correspond to each question.*

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 2 lists the 13 agencies and organizations that participated in this effort. Combined, the Federal and private investment in ASD research in 2009 was $314,385,374, with the Federal government providing 76% ($237,426,725) and private organizations funding 24% ($76,958,649) of ASD research (Figure 1).

Agencies and Organizations Included in the *2009 IACC Portfolio Analysis*

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
• Centers for Disease Control and Prevention (CDC) • Centers for Medicare & Medicaid Services (CMS) • Department of Defense (DoD) • Department of Education (ED) • Health Resources 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 for Autism Research (OAR) • The Simons Foundation (SF) • Southwest Autism Research & Resource Center (SARRC)

Table 2. *The table lists the six Federal agencies and seven private organizations included in the 2009 IACC Autism Spectrum Disorder Research Portfolio Analysis of ASD research funding.*

Federal vs. Private Funding for ASD Research in 2009
(Total funding = $314,385,374)

Figure 1. *Seventy-six percent of the $314,385,374 distributed for ASD research in 2009 was provided by Federal sources, while the remaining 24% of funding was obtained from private organizations.*

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) reported use of 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 original research projects as well as to 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. These new autism projects include those that focus on novel research directions as well as some that provide supplemental support to existing projects in order to expand the scope of ongoing research. 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. The NIH-ARRA funds comprised 20% of total ASD research funding across all participating Federal agencies and private organizations in 2009 (Figure 2).

Impact of NIH-ARRA on Total ASD Research Funding in 2009
(Total funding = $314,385,374)

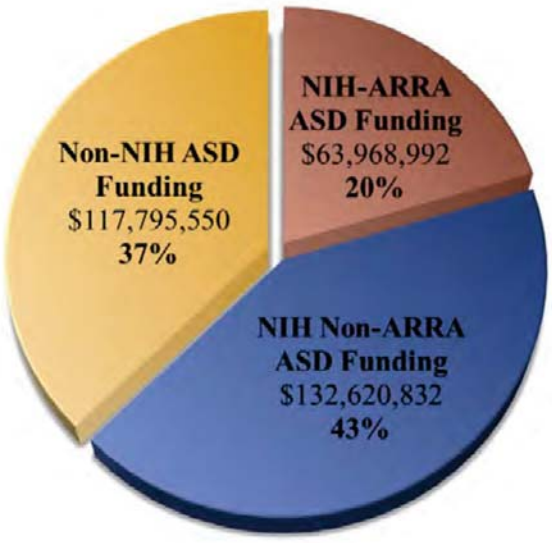


Figure 2. *Sixty-three percent of 2009 ASD research funding was provided by the NIH. NIH-ARRA funding accounted for 33% of NIH ASD research funding and 20% of total 2009 ASD research funding. Thirty-seven percent of 2009 ASD research funding was from sources other than the NIH.*

What was the breakdown of funding?

The 13 stakeholders that were included in this analysis contributed a total of $314,385,374 across 995 ASD research projects in 2009 (Table 3).

2009 ASD Research Funding by Agency/Organization

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	516	$196,589,824
The Simons Foundation (SF)	98	$51,526,058
Autism Speaks (AS)	220	$23,416,615
Centers for Disease Control and Prevention (CDC)	28	$19,229,994
Health Resources and Services Administration (HRSA)	9	$8,097,807
Department of Defense (DoD)	43	$7,185,010*
Department of Education (ED)	11	$6,317,029
Center for Autism and Related Disorders (CARD)	29	$850,594
Autism Research Institute (ARI)	15	$370,382
Organization for Autism Research (OAR)	14	$330,000
Southwest Autism Research & Resources Center (SARRC)	5	$285,000
Autism Science Foundation (ASF)	6	$180,000
Centers for Medicare & Medicaid Services (CMS)	1	$7,061
GRAND TOTAL	**995**	**$314,385,374**

**Funding for the DoD includes all ASD funding for 2009, as well as $1,734,909 of 2008 ASD research funding that was not reported in the 2008 Portfolio Analysis.*

Table 3. *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 ($64 million) and non-ARRA ($132 million) funding. Together, the agencies and organizations funded 995 projects in 2009, representing an overall investment of $314 million.*

The National Institutes of Health (NIH) was the leading contributor of funding for ASD research in 2009 with a total of $196,589,824 funding 516 projects. This funding included both NIH-ARRA ($63,968,992) and non-ARRA funding ($132,620,832). Non-ARRA funding accounted for 67% of total NIH funding for 2009 and supported 375 projects, whereas NIH-ARRA funding accounted for 33% and supported 141 projects. The Simons Foundation was the second largest funder of ASD research, supporting 98 projects totaling $51,526,058. Autism Speaks ranked third in funding with $23,416,615 allocated across 220 projects.

Comparing Federal versus private funding for ASD research in 2009, the Federal government provided 76% ($237,426,725) of the total ASD research budget (Figure 1). Private organizations funded 24% ($76,958,649) of ASD research in 2009. In total, the Federal government supported 608 ASD research projects and private organizations funded 387 projects. In 2009, while private funding remained close to 2008 levels (approximately $78.5 million in 2008 and $77 million in 2009), Federal funding was significantly increased due to the large contribution of approximately $64 million in NIH-ARRA funding (Figure 3), as well as an increase in Federal agencies' funding of autism research using base annually appropriated funding (approximately $144 million in 2008 and $173 million in 2009).

Of the approximate $240 million in Federal ASD research funds distributed in 2009, 27% was provided by NIH-ARRA (Figure 3).

Impact of NIH-ARRA on Federal ASD Research Funding in 2009
(Total Federal funding = $237,426,725)

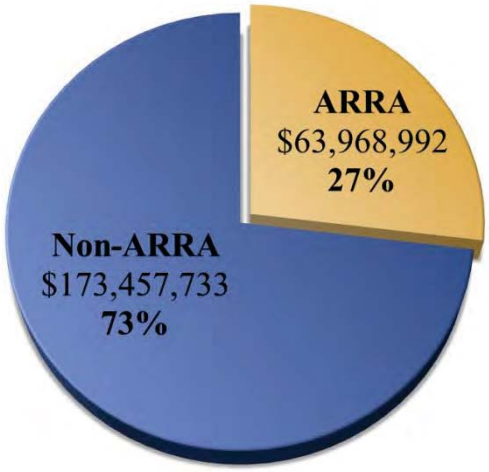


Figure 3. *Seventy-three percent of the $237,426,725 distributed for ASD research by the Federal government in 2009 was provided from sources other than NIH-ARRA, while the remaining 27% of Federal funding was from NIH-ARRA.*

What types of ASD research were funded?

To better understand what areas of research were funded in 2009, projects were aligned with the corresponding questions in the *2010 IACC 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. 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.

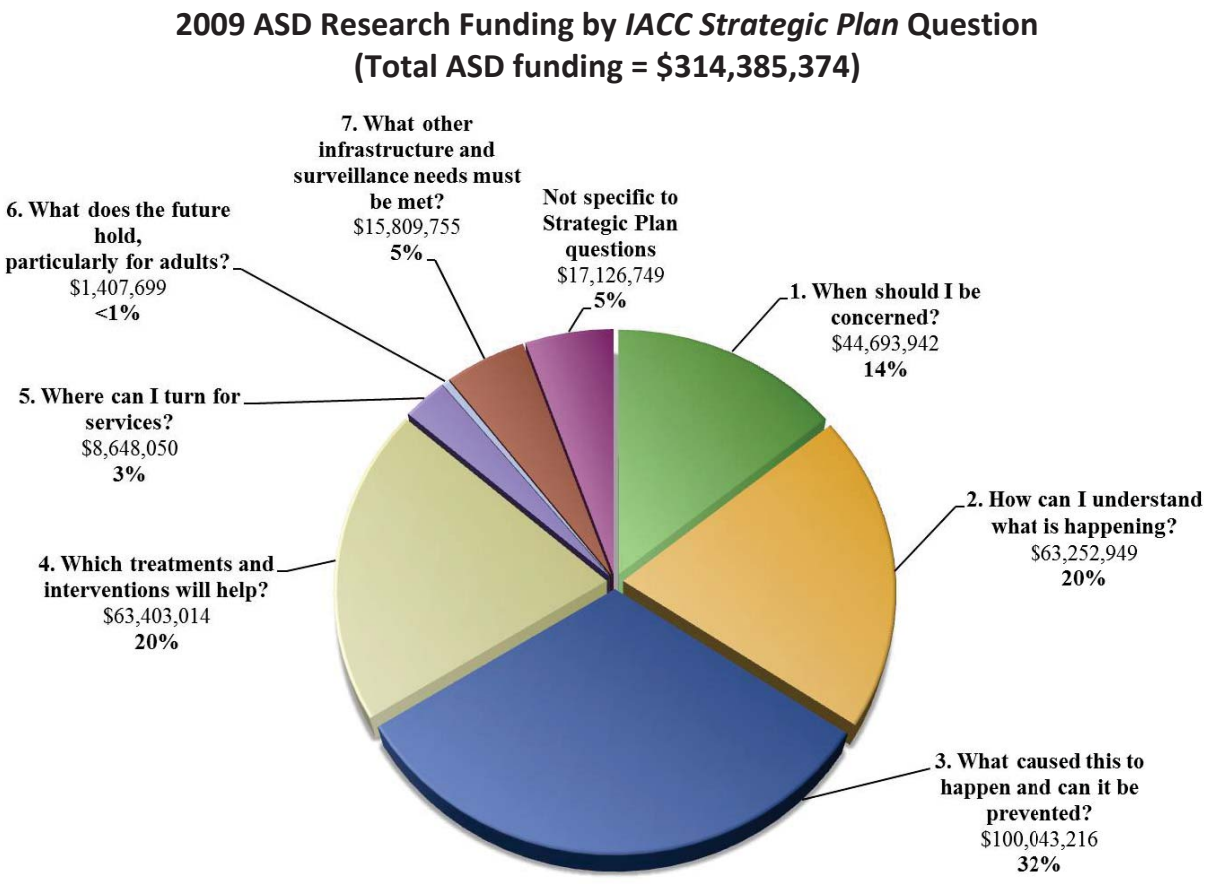


Figure 4. *Topic areas are defined by each question in the IACC Strategic Plan. In 2009, the largest proportion of ASD research funding (32%) was devoted to risk factors for ASD (Question 3); 20% of the research was related to interventions and treatments (Question 4); 20% addressed the underlying biology of ASD (Question 2,); 14% 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, while 5% of ASD funding was not specific to Strategic Plan questions.*

As in the prior year, 2009 ASD research funding supported projects relevant to all critical questions in the *Strategic Plan*. Funding varied by question, with the largest proportion of funding (32%) devoted to topics associated with Question 3, "*What Caused This To Happen and Can It Be Prevented?*." Research related to treatments/interventions and targeting the underlying biology of ASD (Questions 4 and 2, respectively) ranked second and third, each receiving 20% of ASD funding. In contrast, sparse funds were devoted to ASD services (Question 5) and issues that people with ASD face across the lifespan (Question 6), accounting for 3% and less than 1%, respectively.

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 (44%), indicating an

increased emphasis on identification of risk factors, followed by research funding for Question 2 (19%) on the underlying biology of ASD. As with overall 2009 ASD research funding, research associated with services and lifespan issues received the least NIH-ARRA funding (4% and 1%, respectively). Though small, these percentages do, however, 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). 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 by the IACC. The allocation of NIH-ARRA funding by *Strategic Plan* question is illustrated in Figure 5.

2009 NIH-ARRA ASD Research Funding by *IACC Strategic Plan* Question (Total NIH-ARRA funding = $63,968,992)

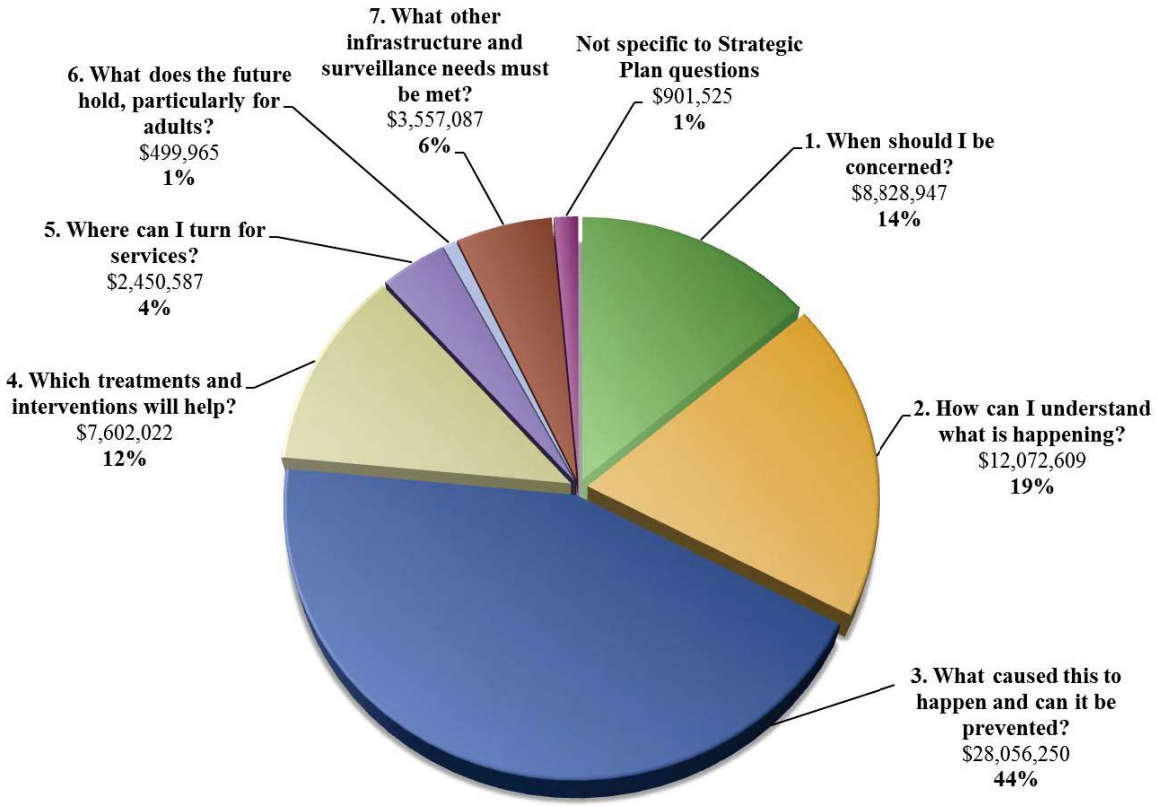


Figure 5. *Topic areas are defined by each question in the IACC Strategic Plan. In 2009, the largest proportion of NIH-ARRA ASD research funding (44%) was devoted to risk factors for ASD (Question 3); 19% of the research addressed the underlying biology of ASD (Question 2); 14% related to diagnosis (Question 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, as did research not specific to Strategic Plan questions.*

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

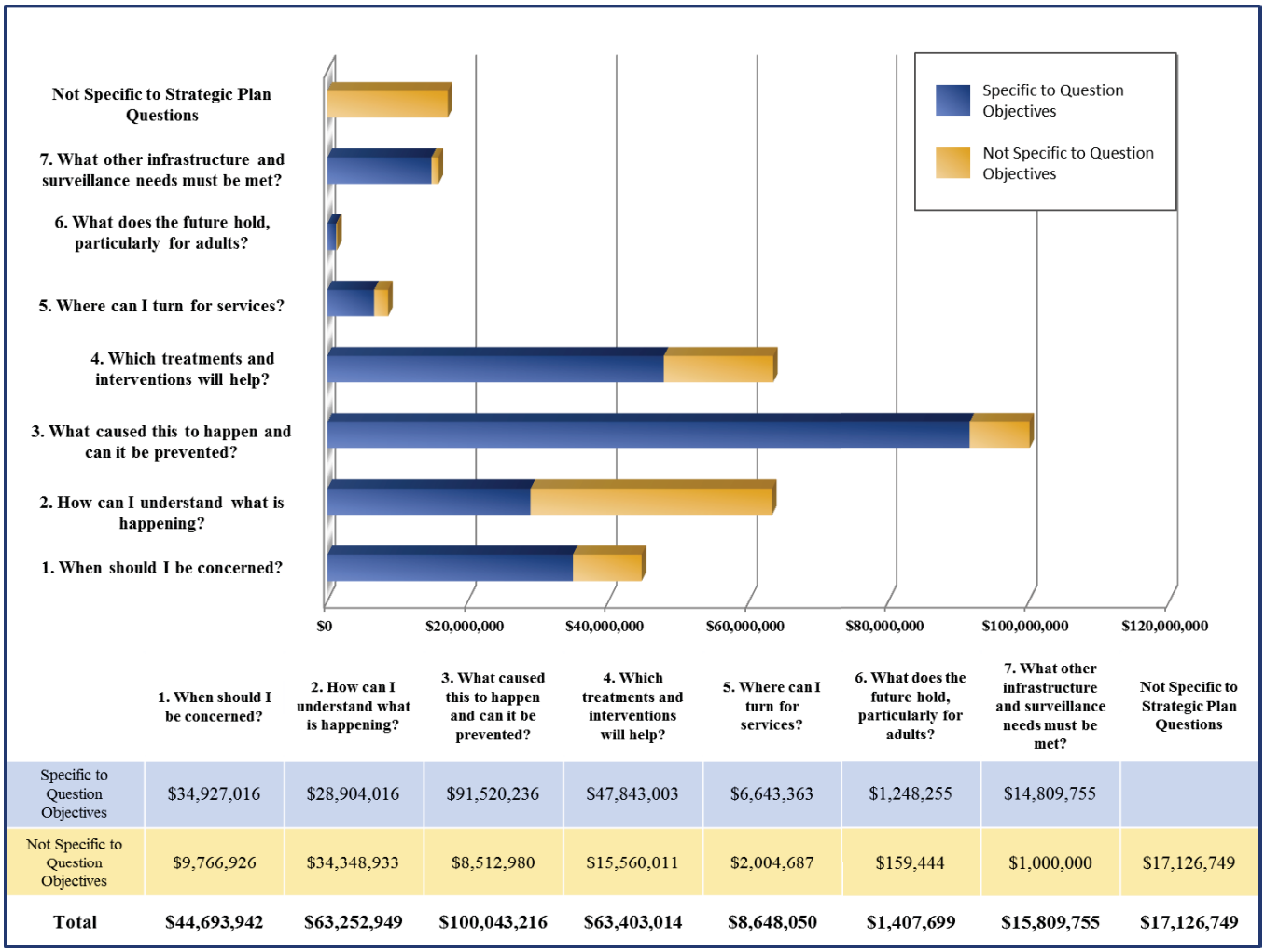
Within the seven questions that serve as the framework for the *IACC Strategic Plan*, each question has several specific short- and long-term objectives. In total, there are 62 objectives in the *2010 Strategic Plan*. The objectives call for specific research efforts with a goal date for completion and include an estimate of the budget required to accomplish the goal.[1] Each ASD project that received funding in 2009 was evaluated to determine which question and objective it fulfilled. This enabled assessment of progress corresponding to the *Strategic Plan* and identification of gaps in funded research.

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) had the largest percent of projects that were specific to *Strategic Plan* objectives (91%, 89%, and 94% respectively). Approximately 75% of the research encompassed by Question 1 (diagnosis), Question 4 (interventions and treatments), and Question 5 (services) is related to specific objectives in the *Strategic Plan*. Conversely, only 46% of funding allocated to Question 2 (biology of ASD) addressed *Strategic Plan* objectives (Figure 6). Brief descriptions of the types of projects that are not specific to particular objectives within a question are provided in the summary section for each question. The research projects specific to objectives combined with the projects falling outside the objectives represent the full scope of research being conducted for each question.

Within each question, the objectives are set apart by designating them as short- or long-term (with an "S" or an "L"), followed by sequential letters of the alphabet (e.g., 2.S.A, 2.S.B, 2.L.A, 2.L.B). For clarity of discussion, these shorthand abbreviations will be used in this analysis. For example, the first short-term objective in Question 1 ("*When Should I Be Concerned?*") is referred to as 1.S.A. Full titles and funding information for each objective can be found in Appendix A. The following analysis assesses the funding distributed to each question and its related objectives in the *Strategic Plan* (Figure 6).

[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 guidance to Federal agencies and partner organizations as to the potential cost of conducting the recommended research. The IACC's role in research is advisory. The committee does not have its own research budget to conduct or support research.*

2009 ASD Funding: Alignment with *IACC 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 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?	Not Specific to Strategic Plan Questions
Specific to Question Objectives	$34,927,016	$28,904,016	$91,520,236	$47,843,003	$6,643,363	$1,248,255	$14,809,755	
Not Specific to Question Objectives	$9,766,926	$34,348,933	$8,512,980	$15,560,011	$2,004,687	$159,444	$1,000,000	$17,126,749
Total	**$44,693,942**	**$63,252,949**	**$100,043,216**	**$63,403,014**	**$8,648,050**	**$1,407,699**	**$15,809,755**	**$17,126,749**

Figure 6. *2009 ASD funding for each of the 2010 IACC 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.*

Question 1: When Should I Be Concerned?

Fourteen percent ($44,693,942) of 2009 total ASD funding, including 14% ($8,828,947) of NIH-ARRA funding, corresponded to Question 1. Of that research, 78% ($34,927,016) was specific to the seven objectives within the question (Figure 6). The two objectives receiving the most funding relate to the development of biomarkers for ASD (1.L.A, 37%) and measures that would allow identification of subtypes across the spectrum (1.L.B, 20%). The two new objectives for this question received the least funding, addressing health disparities in ASD screening (1.S.C < 1%) and the impact of early diagnosis on choice of intervention (1.S.D, 0%). Twenty-two percent ($9,766,926) of ASD funding for Question 1 was not specific to any of the seven objectives (Figure 6) and consisted largely of general studies on early brain development and broad understanding of

cognitive, behavioral, and social characteristics of autism that relate to early development, including development of social behavior and language skills. Of the 147 overall projects related to Question 1, 40% of the projects and 46% of funding ($20,713,264) were new in 2009.

Question 2: How Can I Understand What Is Happening?

Question 2 addresses the underlying biological pathways of ASD and includes seven short-term and two long-term objectives. Research topics associated with Question 2 received the third largest investment, with 20% ($63,252,949) of the 2009 ASD research funding, including 19% ($12,072,609) of NIH-ARRA funding. Fourteen percent ($9,171,542) of Question 2 funding was related to understanding the underlying biology of genetic conditions related to autism (2.S.D), and six percent ($3,584,634) of funding supported projects that investigate biological pathways that could be triggered by environmental toxins or other factors related to autism, including immune system, dietary, and metabolic interactions with the brain (2.S.A). Two of the seven short-term objectives and one long term objective each received 2% or less of total funding for Question 2 (2.S.B, 2.S.C and 2.L.B) and 2.S.F received no funding. Over half of the funding corresponding to the question (54%, $34,348,932) was not specific to any individual objective, which may be related in part to the substantial amount of research that was ongoing in this area prior to the development of the *Strategic Plan*. These projects included a substantial number of imaging studies aimed at understanding how the unique structure, activity, and interconnectedness of the autistic brain underlies core autism symptoms, including deficits in cognition, social behaviors, and sensory processing. Other non-specific studies included cellular and animal models used to explore recurrent themes in ASD biology at a molecular level, such as synaptic dysfunction and cell maturation deficits. Question 2 had the largest number of projects (302) corresponding to the *Strategic Plan*, 38% of which were newly funded in 2009 ($33,494,583).

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

As in 2008, the largest proportion of research funding (32%, $100,043,216) in 2009 related to the question of causation, and 91% of this research corresponded to specific objectives. Research projects in Question 3 also received the largest proportion of NIH-ARRA funding (44%, $28,056,250). Research focused on identifying genetic risk factors for ASD (3.L.B) received 50% of Question 3 funding, while the remaining 41% was divided among the other nine objectives of Question 3. Seven of these objectives addressed research on environmental factors that may contribute to risk for ASD, including pre- and postnatal exposures and studies to determine if certain subpopulations are more susceptible to environmental exposures. Combined with related projects in 2.S.A (see above), these objectives represent an investment of more than $31 million in research into the potential involvement of environmental factors and gene-environment

interactions in the cause of ASD. The remaining 9% ($8,512,980) of Question 3 funding was considered unrelated to specific objectives and primarily included other genetic, epigenetic, and environmental studies. Thirty percent of Question 3 projects (57) and 35% of funding ($34,630,228) were new in 2009.

Question 4: Which Treatments and Interventions Will Help?

Research addressing treatments and interventions received the second largest amount of 2009 ASD research funding (20%, $63,403,014), including the fourth largest amount of NIH-ARRA funding (12%, $7,602,022) among the questions in the *2010 Strategic Plan*. Seventy-five percent ($47,843,003) of ASD funding associated with Question 4 was specific to the objectives. The short-term objective (4.S.B) related to the development of model systems to replicate ASD received 32% ($20,162,709) of the funding for Question 4. One new short-term objective (4.S.E), which recommends a workshop to identify clinical subtypes and develop personalized treatments, received no funding. Also underrepresented were the three long-term objectives, which collectively accounted for about 5% of Question 4 funding (4.L.A, 4.L.B, and 4.L.C). These objectives included randomized controlled trials of medications targeting core symptoms, development of interventions for siblings of people with ASD to reduce risk recurrence, and a study to evaluate medications commonly used in the treatment of co-occurring conditions or specific behavioral issues. Projects not related to a specific objective amounted to 25% ($15,560,011) of Question 4 funds. Of these projects, many focused on teaching social skills to children with autism, employing technology in ASD intervention design, and investigating how to effectively implement interventions and treatment strategies in classroom settings. Question 4 had the second greatest number of projects (234) related to an objective; 39% percent of these projects and the corresponding $21,421,022 in funding were new in 2009.

Question 5: Where Can I Turn To For Services?

Research associated with Question 5 received the second lowest amount of 2009 ASD research funding (3%, $8,648,050) and accounted for 4% ($2,450,587) of NIH-ARRA funding. The majority of funding (77%, $6,643,363) allocated to Question 5 was aligned with the *Strategic Plan* objectives. Projects related to long-term objective A, addressing methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services, and supports in diverse community settings, received 63% ($5,460,809) of Question 5 funding. One short-term objective (5.S.C), which encourages training to increase skill levels in ASD service providers, did not have any funded research for 2009. Twenty-three percent ($2,004,687) of funding was not related to a specific objective and included projects that addressed barriers to accessing healthcare as well as quality of life issues for people with ASD and their families. While

Question 5 had only 36 projects, 81% of those projects and over half of the funding ($4,602,956) associated with Question 5 were new in 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), although the ARRA funds boosted total support for this question by 55%. Question 6 addresses issues across the ASD lifespan, including the transition into adulthood. Of the eight objectives associated with this question, only three received funding in 2009. Fifty-one percent ($718,290) 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. Eleven percent ($159,444) of funding was not related to a specific objective, supporting projects that included an analysis of services and outcomes for transition age youth and a study addressing issues of bullying and victimization of adolescents with ASD. Although Question 6 had the least number of projects, new projects represented nearly 60% of the total funding.

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

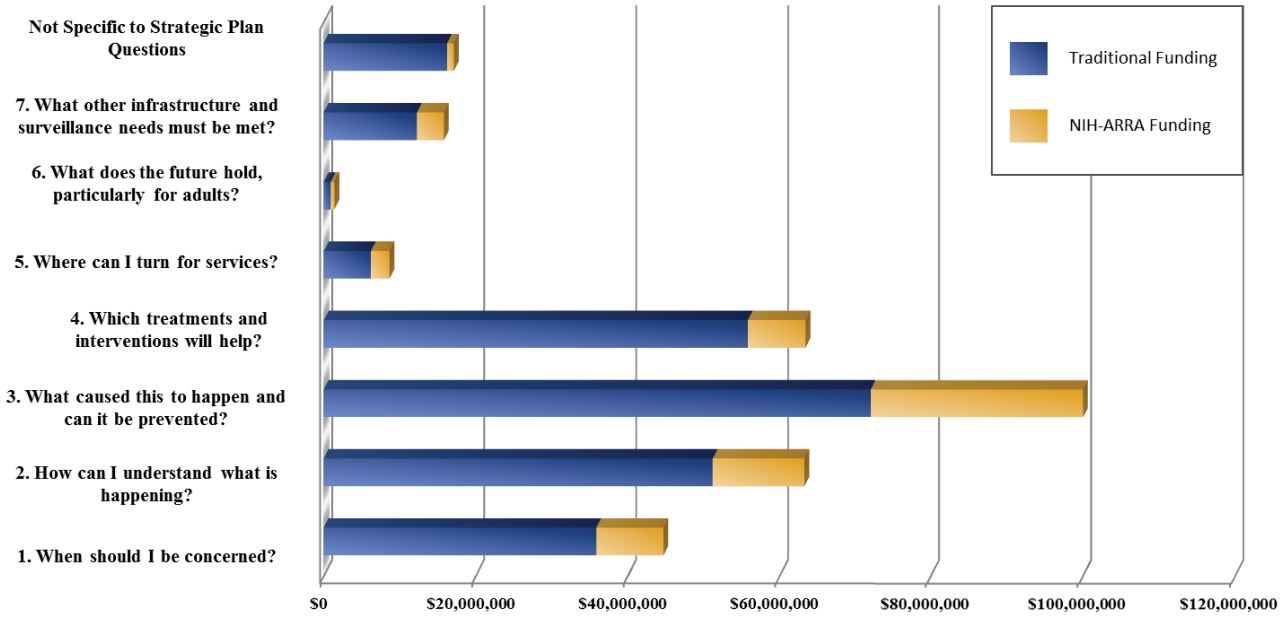
Question 7 was added to the *Strategic Plan* in 2010 and received 5% ($15,809,755) of 2009 ASD research funding, including 6% of NIH-ARRA funding ($3,557,087). There are 13 objectives relating to issues of infrastructure and surveillance needs. Objective 7.I received 42% ($6,715,815) of Question 7 funding and addresses supplementing CDC's Autism and Developmental Disabilities Monitoring (ADDM) Networks. Of the remaining 12 objectives, four received no funding. These underrepresented objectives included establishing funding mechanisms for the rapid replication of research findings (7.F), developing databases to track the involvement of people with ASD in healthcare, education, and social services (7.A), "Promising Practices" papers describing innovative and successful services and supports (7.M), and developing a web-based tool that can provide current State-by-State ASD prevalence estimates (7.G). Only 6% ($1,000,000) of Question 7 funding was not associated with specific objectives. Thirty-three percent of Question 7 projects and 35% ($5,570,698) of funding were new in 2009.[2]

[2] *When Question 7 was added to the IACC Strategic Plan in 2010, several ongoing projects were moved from other questions' objectives for a better fit within Question 7.*

Research Projects Not Related to IACC Strategic Plan Questions

While 95% ($297,258,625) of 2009 total ASD research funding aligned with the seven critical questions, 5% ($17,126,749) was not related to any of the seven questions (Figure 4), including 1% ($901,525) of NIH-ARRA funding (Figure 5). This funding was allocated to 31 ASD research projects, many of which support administrative and coordinating efforts.

Impact of 2009 NIH-ARRA Funding on ASD Research:
Alignment with the *IACC Strategic Plan*



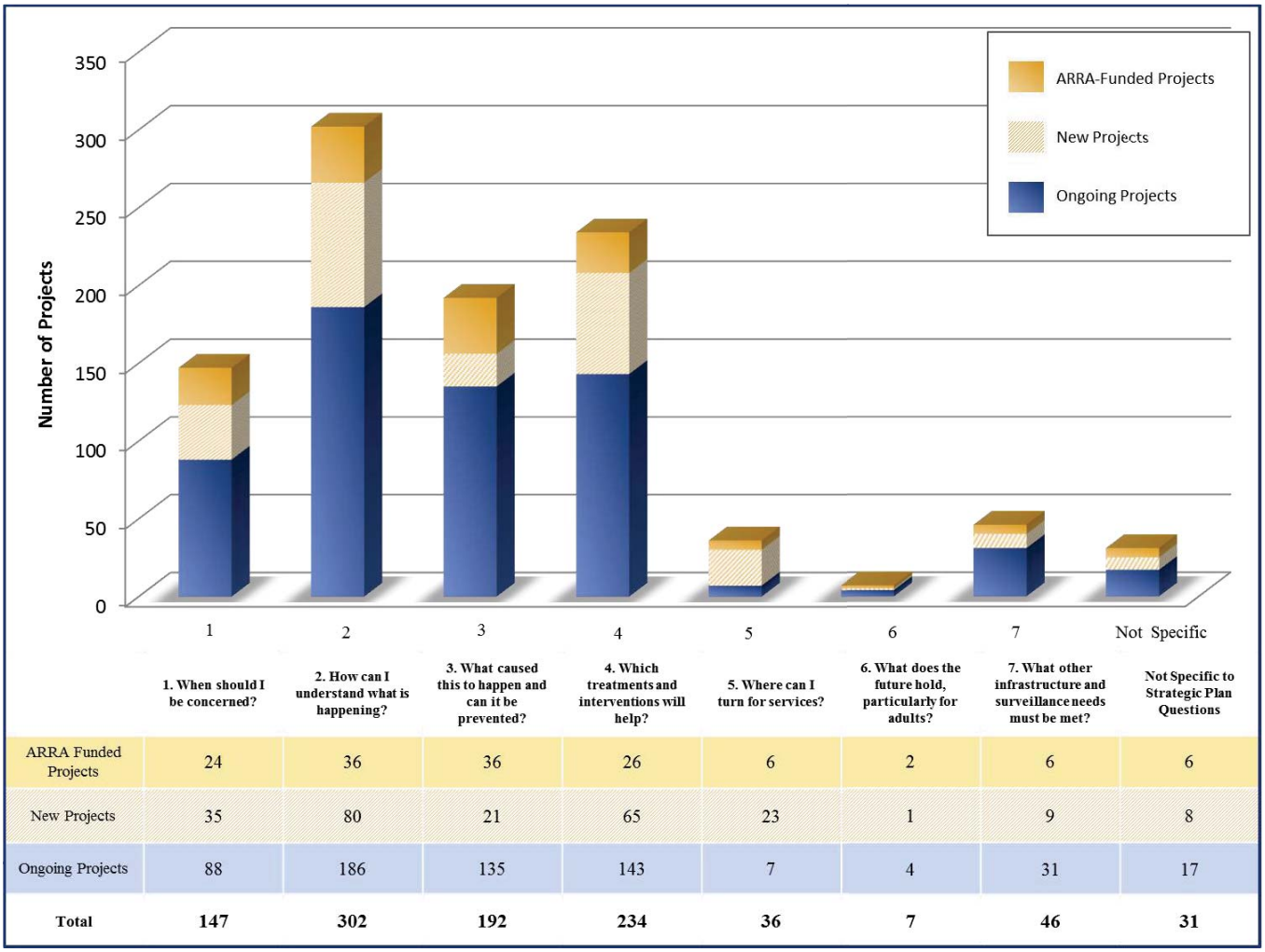
	1. When should I be concerned?	2. How can I understand what is happening?	3. What caused this to happen and can it be prevented?	4. Which treatments and interventions will help?	5. Where can I turn for services?	6. What does the future hold, particularly for adults?	7. What other infrastructure and surveillance needs must be met?	Not Specific to Strategic Plan Questions
Traditional Funding	$35,864,995	$51,180,340	$71,986,966	$55,800,992	$6,197,463	$907,734	$12,252,668	$16,225,224
NIH-ARRA	$8,828,947	$12,072,609	$28,056,250	$7,602,022	$2,150,587	$499,965	$3,557,087	$901,525
Total	**$44,693,942**	**$63,252,949**	**$100,043,216**	**$63,403,014**	**$8,648,050**	**$1,407,699**	**$15,809,755**	**$17,126,749**

Figure 7*. 2009 ASD funding for each of the 2010 IACC 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.*

Impact of NIH-ARRA Funding on IACC Strategic Plan Implementation

NIH-ARRA funding accounted for 20% of 2009 total ASD research funding (Figure 2). As with the overall 2009 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 amount of NIH-ARRA funding (Figure 5, Figure 7). 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 For Services?"* received the smallest allocations of NIH-ARRA funding (Figure 5, Figure 7).

New Investments in ASD Research in 2009



	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?	Not Specific to Strategic Plan Questions
ARRA Funded Projects	24	36	36	26	6	2	6	6
New Projects	35	80	21	65	23	1	9	8
Ongoing Projects	88	186	135	143	7	4	31	17
Total	**147**	**302**	**192**	**234**	**36**	**7**	**46**	**31**

Figure 8. *Of the 995 ASD research projects funded in 2009, 348 were newly funded or were supplements to enable ongoing research to continue in a new direction. Many of these new projects were supported by ARRA funding, noted in solid yellow. The remainder of new projects is denoted by lighter yellow shading. The blue bars indicate ongoing projects that were started prior to 2009.*

In 2009, a large number of new investments were made in ASD research, due in part to the availability of NIH-ARRA funds. Figure 8 illustrates the proportion of research projects that were started in 2009 across the seven questions of the *IACC Strategic Plan*. The 348 new ASD research projects, accounting for $123,574,025 in funding, comprise nearly 35% of all ASD research projects. New projects were substantially weighted by NIH-ARRA funds, as 2009 was the first year that ARRA funds were made available for biomedical research. While Questions 5 and 6 relating to services research had the smallest proportion of projects, there was a more substantial infusion of new funding and projects into these categories compared to other questions. For Question 5, 81% of projects and 53% of funding were new in 2009, and 43% of projects and 59% of funding were new for Question 6.

Conclusion

Total funding for ASD research from all participating agencies and organizations increased by 41% between 2008 ($222,215,342) and 2009 ($314,385,374). This is the result of a 65% increase in Federal spending ($93,701,880) and a 2% decrease ($1,531,848) in private funding between 2008 and 2009. NIH-ARRA funds provided a substantial boost to ASD research funding in 2009, but even without ARRA funding, total Federal investment increased 21% from 2008 ($143,724,845) to 2009 ($173,457,733). Of the 995 ASD research projects funded in 2009, $123,574,025 (39%) and 348 (35%) of those projects were newly established.

The *2009 ASD Research Funding Portfolio Analysis Report* 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. While this *Portfolio Analysis* provides a comprehensive account of research specific to autism, certain broad research efforts in Federal agencies and private organizations related to topics such as intellectual and developmental disabilities, brain disorders, and communication deficits are not fully captured in this analysis.

The IACC/OARC will continue to conduct annual portfolio analyses 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.

APPENDIX A:

ASD Research Progress on *2010 IACC Strategic Plan* Objectives

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

Current project and funding status for each question or 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 some degree of funding, but less than the recommended amount; while any objective colored red has no funding.

NEW! Objectives labeled "New!" are either entirely new additions to the *2010 IACC Strategic Plan* or significantly modified objectives from the *2009 IACC Strategic Plan*. Objectives from the *2009 Strategic Plan* that did not change or that have been slightly modified for clarification purposes in the *2010 Strategic Plan* are unmarked.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 1: When should I be concerned?

	2010 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. IACC Recommended Budget: $5,300,000 over 2 years.	15 (10%)	$4,728,120 (11%)	2%
	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 (7%)	$3,973,711 (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.	0	$0	0%
	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.	43 (29%)	$16,465,034 (37%)	5%
	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.	34 (23%)	$8,760,010 (20%)	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. IACC Recommended Budget: $18,500,000 over 5 years.	6 (4%)	$861,069 (2%)	<1%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 1: When should I be concerned?

2010 IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
1.O Not specific to any objective	37 (25%)	$9,766,926 (22%)	3%
Total Funding for Question 1	**147 (100%)**	**$44,693,942 (100%)**	**14%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 2: How can I understand what is happening?

	IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD 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.	30 (10%)	$3,584,634 (6%)	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. IACC Recommended Budget: $8,900,000 over 5 years.	5 (2%)	$1,370,107 (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.	48 (16%)	$9,171,542 (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.	11 (4%)	$3,893,300 (6%)	1%
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.	0	$0	0%
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%)	$5,903,875 (9%)	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.	6 (2%)	$2,721,384 (4%)	1%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 2: How can I understand what is happening?

IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
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 (5%)	$1,532,262 (2%)	<1%
2.O Not specific to any objective	163 (54%)	$34,348,932 (54%)	11%
Total Funding for Question 2	**302 (100%)**	**$63,252,949 (100%)**	**20%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

	IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD 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%)	$13,926,663 (14%)	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.	0	$0	0%
	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.	9 (5%)	$8,033,454 (8%)	3%
	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.	14 (7%)	$2,952,960 (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%
	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.	79 (41%)	$49,905,587 (50%)	16%
	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.	10 (5%)	$1,992,228 (2%)	1%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

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. IACC Recommended Budget: $44,400,000 over 5 years.	12 (6%)	$9,135,505 (9%)	3%
3.O Not specific for any objective	39 (20%)	$8,512,980 (9%)	3%
Total Funding for Question 3	**192 (100%)**	**$100,043,216 (100%)**	**32%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 4: Which treatments and interventions will help?

	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. IACC Recommended Budget: $13,400,000 over 3 years.	6 (3%)	$4,733,841 (7%)	2%
	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.	70 (30%)	$20,162,709 (32%)	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.	30 (13%)	$3,252,941 (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.	9 (4%)	$7,540,613 (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.	0	$0	0%
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.	42 (18%)	$9,791,270 (15%)	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.	10 (4%)	$1,168,146 (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%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 4: Which treatments and interventions will help?

	IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
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%)	$1,061,222 (2%)	<1%
	4.O Not specific to any objective	59 (25%)	$15,560,011 (25%)	5%
	Total Funding for Question 4	**234 (100%)**	**$63,403,014 (100%)**	**20%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Question 5: Where can I turn for services?

	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. IACC Recommended Budget: $1,000,000 over 3 years.	1 (3%)	$499,999 (6%)	<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.	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. IACC Recommended Budget: $7,000,000 over 5 years.	10 (28%)	$5,460,809 (63%)	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%
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%)	<1%
	5.O Not specific to any objective	8 (22%)	$2,004,687 (23%)	1%
	Total Funding for Question 5	**36 (100%)**	**$8,648,050 (100%)**	**3%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

	IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD 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.	0	$0	0%
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.	0	$0	0%
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.	0	$0	0%
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%
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.	0	$0	0%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

IACC Strategic Plan Objectives	Projects	Funding	Percent of Total ASD Funding
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.	0	$0	0%
6.O Not specific to any objective	2 (29%)	$159,444 (11%)	<1%
Total Funding for Question 6	**7 (100%)**	**$1,407,699 (100%)**	**<1%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

	IACC Strategic Plan Objectives	Projects	Amount	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. IACC Recommended Budget: $520,000 over 1 year.	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 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.	2 (4%)	$1,665,180 (11%)	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 (4%)	$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.	2 (4%)	$330,662 (2%)	<1%
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.)	0	$0	0%
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.	0	$0	0%
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.	2 (4%)	$1,932,996 (12%)	1%

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

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

	IACC Strategic Plan Objectives	Projects	Amount	Percent of Total ASD Funding
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 (33%)	$6,715,815 (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 (24%)	$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.	7 (15%)	$2,527,472 (16%)	1%
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%)	$699,304 (4%)	<1%
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.	0	$0	0%
	7.O Not specific to any objective	2 (4%)	$1,000,000 (6%)	<1%
	Total Funding for Question 7	**46 (100%)**	**$15,809,755 (100%)**	**5%**

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 2009.

ASD Research Progress on *IACC Strategic Plan* Objectives

Other –Not specific to Strategic Plan questions

IACC Strategic Plan Objectives	Projects	Amount	Percent of Total ASD Funding
Other	31 (100%)	$17,126,749 (100%)	5%

Grand Total

IACC Strategic Plan Objectives	Projects	Amount	Percent of Total ASD Funding
Total ASD Funding for 2009	**995**	**$314,385,374**	**100%**

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 2009.

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