

Meeting of the Interagency Autism Coordinating Committee

October 22, 2010

The National Institutes of Health, Main Campus
The William H. Natcher Conference Center
45 Center Drive
Conference Rooms E1/E2
Bethesda, MD 20892

Conference Call Access:

Phone: (888) 577-8995

Access Code: 1991506

Meeting of the IACC

Morning Agenda

- 9:00** Registration
- 10:00** Thomas Insel, M.D., Chair, IACC
Call to Order and Opening Remarks
- 10:10** Review and Approval of July 16, 2010 Minutes
- 10:15** Alexa Posny, Ph.D.
- 10:45** Wendy Fournier and Lori McIlwain
- 11:15** Richard Frank, Ph.D.
- 11:45** Kevin Pelphrey, Ph.D.
- 12:15** Lunch

Morning Break

Morning Agenda

11:15 Richard Frank, Ph.D.

11:45 Kevin Pelphrey, Ph.D.

12:15 Lunch

Lunch Break

Afternoon Agenda

- 1:00** Public Comments
- 1:30** Alice Kau, Ph.D. and Regina James, M.D.
- 1:40** David Armstrong, Ph.D.
- 1:50** Geraldine Dawson, Ph.D. and Stephen Scherer, Ph.D.
- 2:00** Gerald Fischbach, M.D.
- 2:10** Ann Wagner, Ph.D.
- 2:20** Michael Huerta, Ph.D.
- 2:25** Committee Business
 - Workshop Update – Services Subcommittee
- 2:30** Break

Meeting of the IACC

Open Session for Public Comment

IACC Services Workshop: Building a Seamless System of Quality Services & Supports Across the Lifespan

November 8, 2010

Presentation to the IACC October 22, 2010

Ellen Blackwell and Lee Grossman
Co-Chairs, IACC Services
Subcommittee

Building a Seamless System of Quality Services & Supports Across the Lifespan

- Rockville Hilton – Rockville, Maryland
- 9:00 AM – 5:30 PM
- Meeting open to the public:
pre-registration online
- Webcast live at: <http://videocast.nih.gov>
- Call in – (888)577-8995
– Access Code 1991506

Goals of the Workshop

- Inform *Recommendations for the Secretary* (Draft 2/09)
- Inform the 2011 IACC Strategic Plan, Chapters 5 & 6
- Explore what cost-effective, high quality systems and practices are working in states, or hold promise for systems reform
- Envision what a streamlined services system may look like in the future

Introductory Session

“Where We Are Today and Where We Want to be in Ten Years?”

- **Nancy Thaler**, National Association of State Directors of Developmental Disabilities Services
- **Bill East**, National Association of State Directors of Special Education
- **K. Charlie Lakin**, Research and Training Center on Community Living, University of Minnesota – National Core Indicators and ASD

Presentations

- *Self Direction* - **Michael Head**, Michigan Mental Health and Substance Abuse Administration Department of Community Health, and **James Conroy**, Center for Outcome Analysis – Havertown, Pennsylvania
- *Standardized Assessment* - **Don Clintsman**, Washington Division of Developmental Disabilities

Presentations (continued)

- *Prevention and Reduction of Seclusion and Restraint* - **Kevin Ann Huckshorn**, Delaware Health and Social Services, Division of Substance Abuse and Mental Health
- *Direct Service Workforce Training* - **Carrie Blakeway**, The Lewin Group, and **Erika Robbins**, Ohio Department of Job and Family Services

Presentations (continued)

- *Housing Options* - **Sheldon Wheeler**, Maine Bridging Rental Assistance Program and **Joseph Wykowski**, Community Vision – Portland, Oregon
- *Peer Supports* - **Lisa Crabtree**, Towson University Center for Adults with ASD; **Jim Sinclair**, Autism Network International; and **Julie LaBerge**, Bonduel School District, Wisconsin

Presentations (continued)

- *Systems Integration* - **John Martin**,
Ohio Department of Developmental
Disabilities

Spring 2011 – Second Meeting for Additional Issues

- Diversity and cultural sensitivity
- Recreational opportunities
- Family support
- Home and community-based characteristics
- Employment/vocational issues, including benefits counseling
- Early childhood

Additional Issues (continued)

- Infrastructure
- Person-centered policies and planning
- Medical and health homes
- Quality measures for children and adults
- The expanding role of managed care delivery systems in services and supports

Additional Issues (continued)

- Mental health parity
- Criminal justice diversion
- Post-secondary education
- Rebalancing the long-term services and supports system
- Community asset-building
- Environmental and home modifications

Everyone interested in developmental disabilities issues is urged to attend!

Webcast Live:

<http://videocast.nih.gov/>

Conference Call Access:

Dial: 888-577-8995

Access code: 1991506

Cost: The meeting is free and open to the public.

Pre-Registration:

<http://www.acclaroresearch.com/oarc/11-8-10/>

Meeting of the IACC

Afternoon Agenda

- 2:30** Break
- 2:45** Committee Business
- RFI Update
 - Portfolio Analysis
 - Discussion: Updating the Strategic Plan
- 5:00** Public Comments Discussion Period
- 5:30** Closing Comments and Adjournment

Upcoming IACC Meetings

November 8, 2010 – IACC Services Workshop

November 19, 2010 – IACC Planning Subcommittee

December 14, 2010 – IACC Committee - Tentative

•This meeting may end prior to or later than 5:30 PM ET, depending on the needs of the committee.

2010 Request for Information (RFI): Updating the IACC Strategic Plan for Autism Spectrum Disorder Research

2010 RFI

- RFI issued to solicit input to inform the next update of the Strategic Plan
- Notice Number: NOT-MH-025
- Open Period -June 18, 2010– July 30, 2010 (six weeks)
- Response via web-based form

2010 RFI

- Respondents asked to provide input on all chapters of the strategic plan, including the introduction
 - **What issues and topics should be added?**
 - **What issues and topics that are currently included should be modified or removed?**
 - **Other information?**

2010 RFI

- 54 responses submitted
- Responses can be viewed online at:
<http://iacc.hhs.gov/public-comment/2010/index.shtml>

Autism Spectrum Disorder (ASD) Research 2009 Portfolio Analysis

Introduction

- Comprehensive analysis of the 2009 Autism Spectrum Disorder (ASD) research portfolio of major Federal agencies and private organizations
 - Second annual analysis
- Inform the IACC and stakeholders about the funding landscape and current directions for ASD research
- Help Federal agencies and private research organizations to guide future funding
 - Highlight current gaps and opportunities
 - Catalog current research activities and progress

ASD Research Funders Solicited

Federal Funders of ASD Research

- 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)

Private Funders of ASD Research

- 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)

Information Requested from Each Agency/Organization

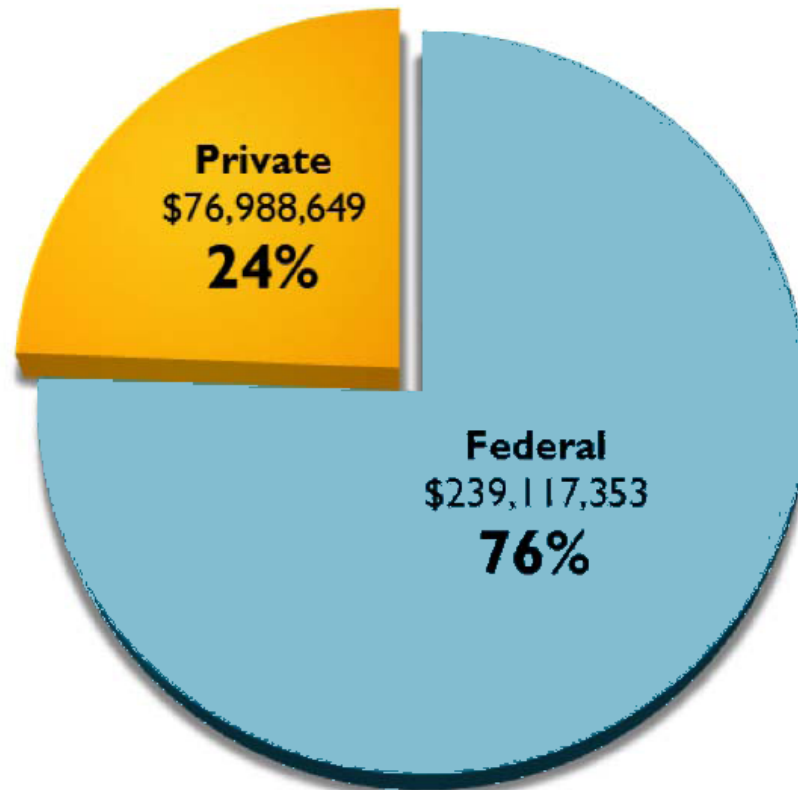
- Number of research projects
- Total ASD research funding
- Project Titles
- How funded projects correspond to the IACC 2010 Strategic Plan

2009 Autism Spectrum Disorder (ASD) Research Funding by Funding Agency/Organization

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

These slides do not reflect decisions of the IACC and are for discussion purposes only.

2009 Autism Spectrum Disorder (ASD) Research Funding by Type of Agency/Organization: Federal versus Private (Total = \$316,106,002)



American Recovery and Reinvestment Act (ARRA)

P.L. 111-5 Enacted in February 2009

Intent:

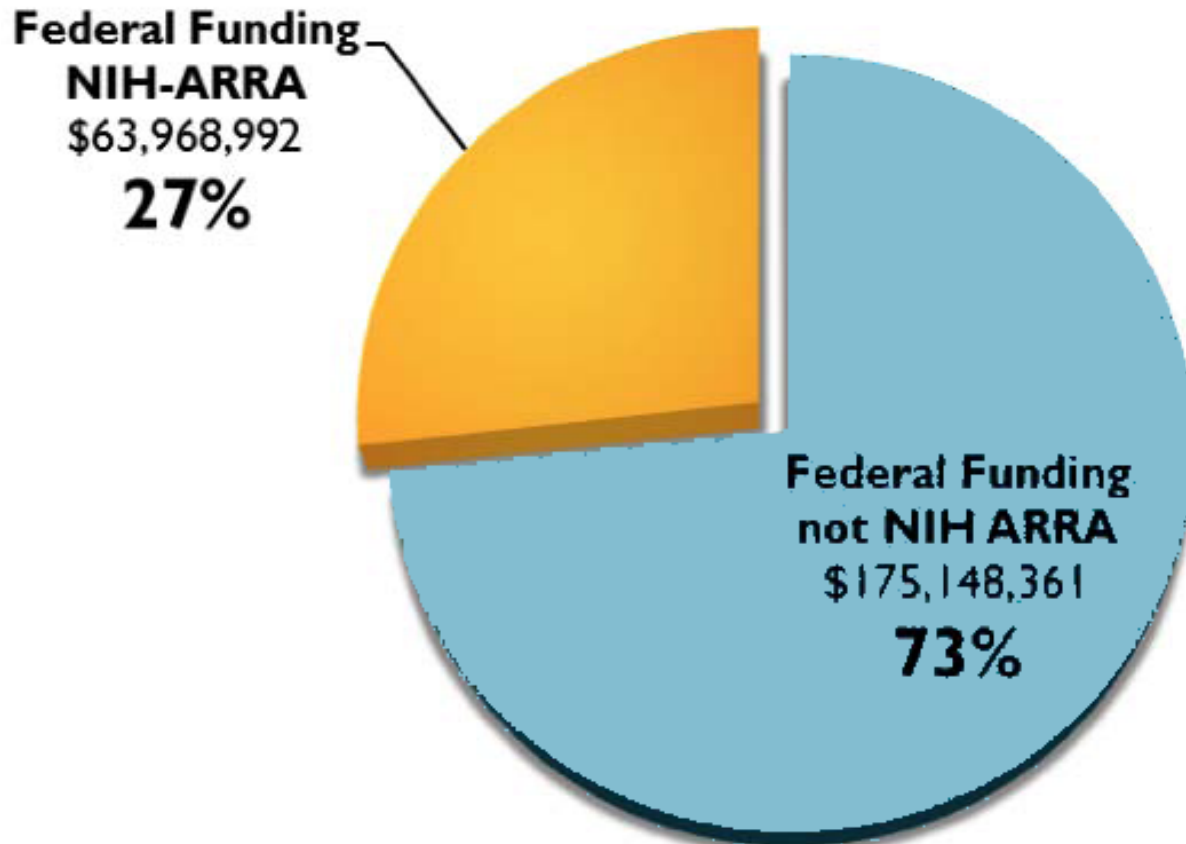
- Stimulate the economy and invest in long-term growth
 - Including support and advancement of biomedical research
- Create and preserve jobs

NIH received ARRA funds, \$64M of which were used to support autism related research.

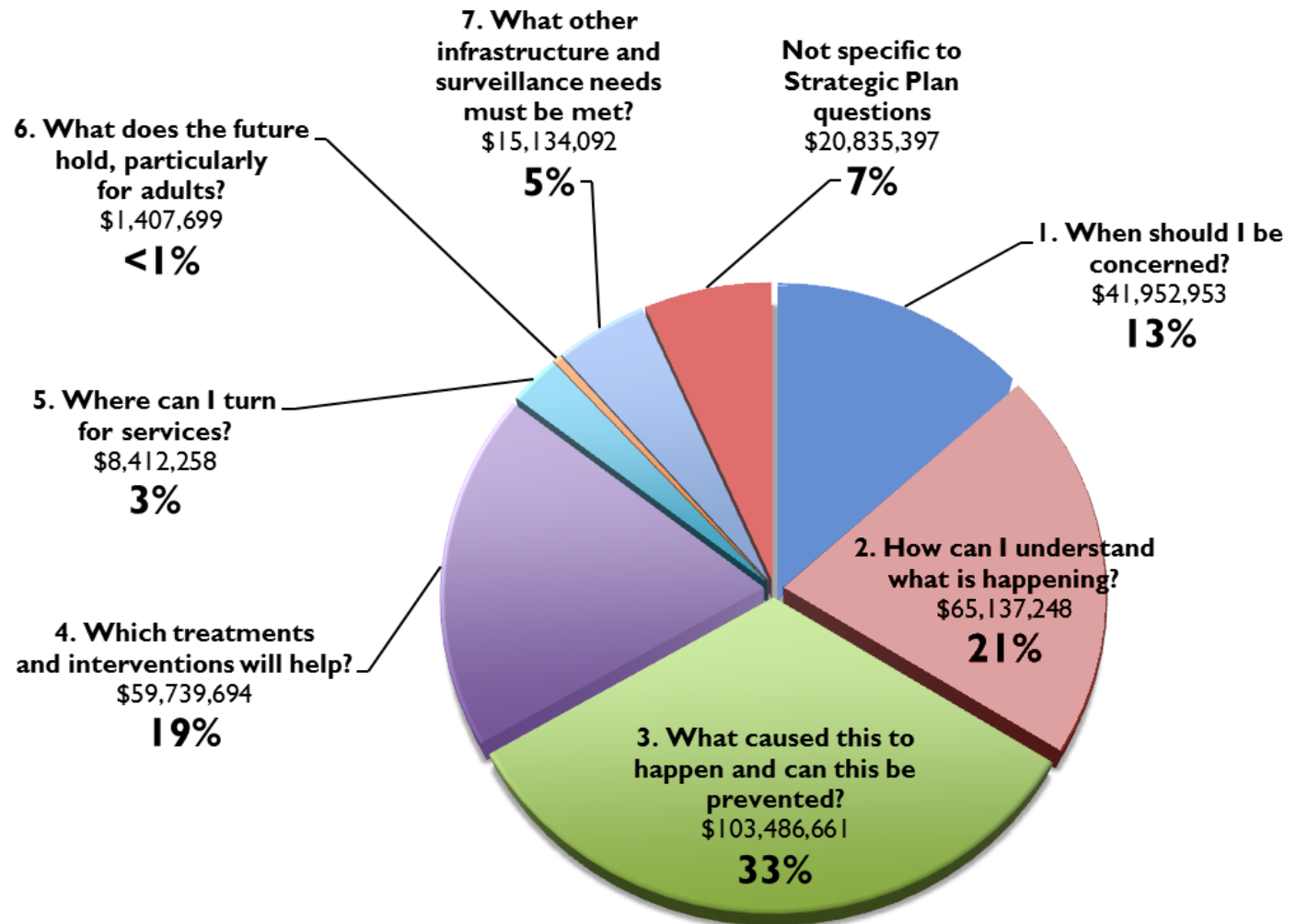
NIH ARRA funding accounted for:

- 20% of all 2009 ASD research funding (\$316M)
- 33% of NIH funding (\$196M)
- 27% of federal funding (\$239M)

2009 Autism Spectrum Disorder (ASD) Research Federal Funding: NIH-ARRA vs. Non NIH-ARRA (Total = \$239,117,353)

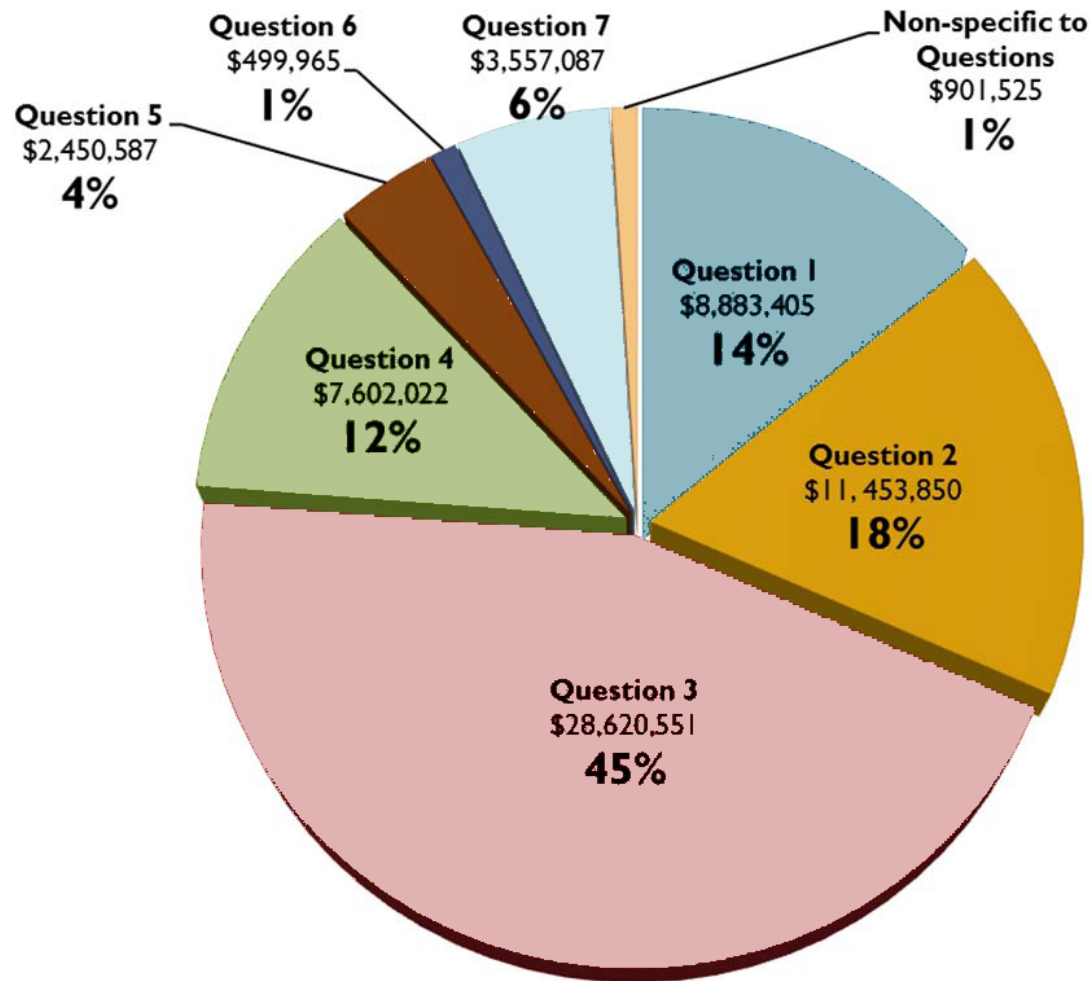


2009 Autism Spectrum Disorder (ASD) Research Funding by Strategic Plan Question (Total = \$316,106,002)



2009 NIH-ARRA ASD Research Funding by Topic Area

(Defined as Questions in the 2010 Strategic Plan)



Funding for Each Objective in the 2010 Strategic Plan

- The following table lists the total funding of all projects corresponding to each objective within the Strategic Plan.
- Categorization of the projects was conducted by each participating organization.
- The table lists each objective, the number of projects that were categorized as being relevant to that objective, the amount of funding the projects related to that objective and the percentage of overall 2009 ASD research funding represented.

Funding for Each Objective in the 2010 Strategic Plan

- Green dots indicate objectives that have greater than or equal to the number of recommended projects and greater than or equal to the IACC recommended funding.
- Yellow dots indicate objectives with some degree of funding or some amount of projects, but not equal to the amount recommended.
- Red dots indicate objectives that have no projects or funding.
- Objectives labeled "New!" are either entirely new additions to the 2010 Strategic Plan or significantly modified objectives from the 2009 Strategic Plan.

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
	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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
	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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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.	-	-	-
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: <ul style="list-style-type: none"> 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%

These slides do not reflect decisions of the IACC and are for discussion purposes only.

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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%
NEW!	7.F Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.	-	-	-
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%

These slides do not reflect decisions of the IACC and are for discussion purposes only.

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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

	Strategic Plan Objectives	Projects	Amount	Percent of Total Funding
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%
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%

2009 Autism Spectrum Disorder (ASD) Research Federal Funding by Strategic Plan Question and Objective

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

Grand Total	985	\$316,106,002	100%
--------------------	------------	----------------------	-------------

Conclusion

- Trends identified during the analysis can be used to:
 - Update the Strategic Plan
 - Understand the current research landscape
 - Identify new research opportunities and priorities
 - Address underfunded areas
 - Guide future research efforts
- Analyses will continue to be conducted annually to inform the committee on research progress

The Process for Updating the Strategic Plan

*Recap: IACC Planning
Subcommittee Meeting
October 6, 2010*

Updating the IACC Strategic Plan

The Planning Subcommittee discussed the need for the 2011 update of the IACC Strategic Plan to capture updates including:

- Research progress
- New opportunities and gaps
- New objectives that may be needed
- Updates based on the Portfolio Analysis, RFI, Public --Comment, Summary of Advances, perspectives of committee members, etc.

Updating the IACC Strategic Plan

The Planning Subcommittee considered three options for updating the Strategic Plan:

1. Line edits of 2010 Strategic Plan Text
2. Adding a separate 2011 update section to each of the Strategic plan (a.k.a. “bookends”)*
3. Both line edits and bookends

*Voted for Option 2

Updating the IACC Strategic Plan

TEMPLATE FOR UPDATES

2010 Update for Chapter _____

What is new in this research area and what have we learned this past year?

What gap areas have emerged since last year?

What new research opportunities and research objectives have emerged?

Updating the IACC Strategic Plan

Committee Discussion

1. Method of updating
2. Review draft updates for Chapters/Questions
1- 4

Meeting of the IACC

Public Comments: Discussion Period

Meeting of the IACC

Adjournment