

# Meeting of the IACC

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## OARC/IACC Update: New Documents and Web Releases

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National Institute of Mental Health

Executive Secretary, IACC

IACC Full Committee Meeting – July 10, 2012

# 2011 Summary of Advances



- Released in April 2011
- The IACC identified 20 research findings and associated peer-reviewed articles published in 2011 that they felt reflected the most significant advances in ASD biomedical and services research.
- Lay-friendly summaries of research findings
- These studies gave important new insight into the **prevalence** of autism spectrum disorder, the **biology** of the disorder, potential **risk factors**, possible **interventions**, and **services** needs.

# Publications Selected for 2011

## IACC Summary of Advances

### Q1 **DIAGNOSIS**

- Disrupted neural synchronization in toddlers with autism
- Detecting, Studying, and Treating Autism Early: The One-Year Well-Baby Check-Up Approach

### Q2 **BIOLOGY**

- Mutations causing syndromic autism define an axis of synaptic pathophysiology
- Absence of CNTNAP2 leads to epilepsy, neuronal migration abnormalities, and core autism-related deficits
- Protein interactome reveals converging molecular pathways
- Transcriptomic analysis of autistic brain reveals convergent molecular pathways

# Publications Selected for 2011

## IACC Summary of Advances

### Q3 **RISK FACTORS**

- Genetic heritability and shared environmental factors among twin pairs with autism
- Rare de novo and transmitted copy-number variation in autistic spectrum disorders
- Exome sequencing in sporadic autism spectrum disorders identifies severe de novo mutations
- Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study
- Multiple recurrent de novo CNVs, including duplications of the 7q11.23 Williams syndrome region, are strongly associated with autism

### Q4 **TREATMENTS & INTERVENTIONS**

- A systematic review of medical treatments for children with autism spectrum disorders
- Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial
- Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders

# Publications Selected for 2011

## IACC Summary of Advances

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### Q5 **SERVICES**

- Post-high school service use among young adults with an autism spectrum disorder

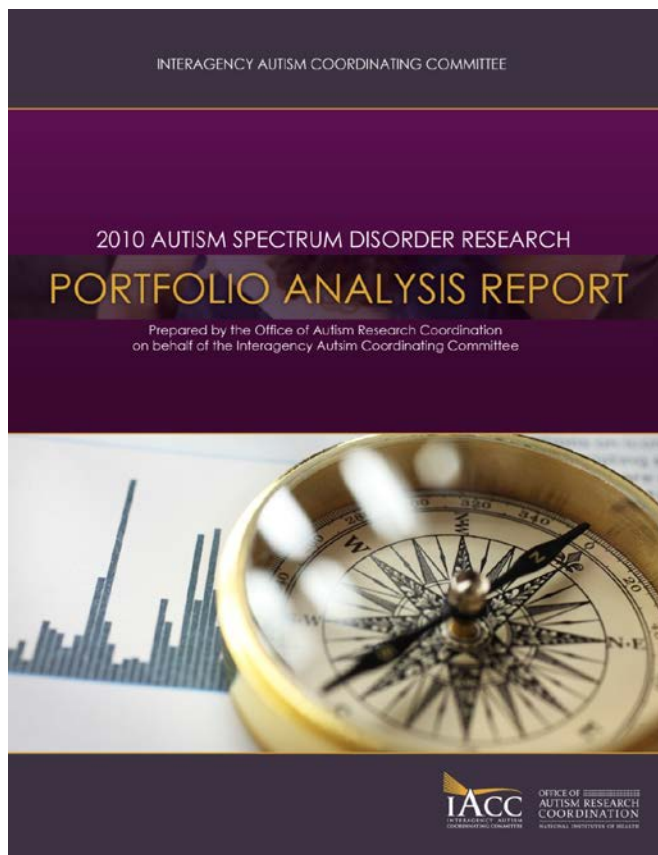
### Q6 **LIFESPAN**

- Epidemiology of autism spectrum disorders in adults in the community in England
- Autism spectrum disorders in older adults: Toward defining a research agenda
- Emerging new practices in technology to support independent community access for people with intellectual and cognitive disabilities

### Q7 **INFRASTRUCTURE & SURVEILLANCE**

- Trends in the prevalence of developmental disabilities in US children 1997-2008
- Prevalence of autism spectrum disorders in a total population sample

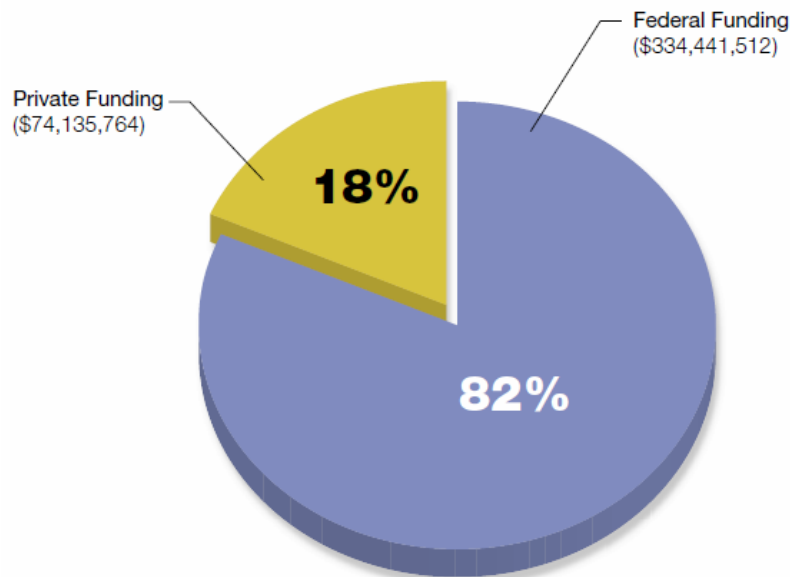
# 2010 IACC Portfolio Analysis



- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides comprehensive analysis of the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the funding landscape and current directions in ASD research
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan
- Highlights gaps and opportunities to guide future activities

# 2010 Federal and Private Autism Funding

- Total funding = \$408,577,276
- 18 funders
- Overall Increase since 2009 = \$93M



The 2010 Portfolio Analysis data reflect a larger proportion of overall funding from Federal sources, largely attributed to increased reporting from HRSA and the Department of Education, as well as several Federal funders of ASD research that were not captured in 2009 – NSF, EPA, ACF, AHRQ. Private funding remained similar to the 2009 level.

# 2010 Federal and Private Autism Funding

Funding Agency/Organization	Number of Projects	Total Funding
National Institutes of Health (NIH)	545**	\$217,143,701
<b>Simons Foundation (SF)</b>	123	\$53,729,921
Health Resources and Services Administration (HRSA)	82	\$43,303,150
Department of Education (ED)	139	\$30,432,564*
Centers for Disease Control and Prevention (CDC)	30	\$19,698,859
<b>Autism Speaks (AS)</b>	228	\$18,476,890
National Science Foundation (NSF)	69	\$12,222,206*
Department of Defense (DoD)	58	\$7,082,059
Administration for Children and Families (ACF)	1	\$1,877,959
Agency for Healthcare Research and Quality (AHRQ)	4	\$1,548,053*
<b>Center for Autism and Related Disorders (CARD)</b>	31	\$906,482
Environmental Protection Agency (EPA)	1	\$756,802
<b>Autism Research Institute (ARI)</b>	15	\$386,905
Centers for Medicare & Medicaid Services (CMS)	3	\$376,159
<b>Autism Science Foundation (ASF)</b>	13	\$245,000
<b>Organization for Autism Research (OAR)</b>	12	\$191,590
<b>Coalition for SafeMinds (SafeMinds)</b>	8	\$128,975
<b>Southwest Autism Research &amp; Resources Center (SARRC)</b>	5	\$70,000
<b>GRAND TOTAL</b>	<b>1367</b>	<b>\$408,577,276</b>

\*Annual funding amounts for AHRQ, ED, and NSF are estimated.

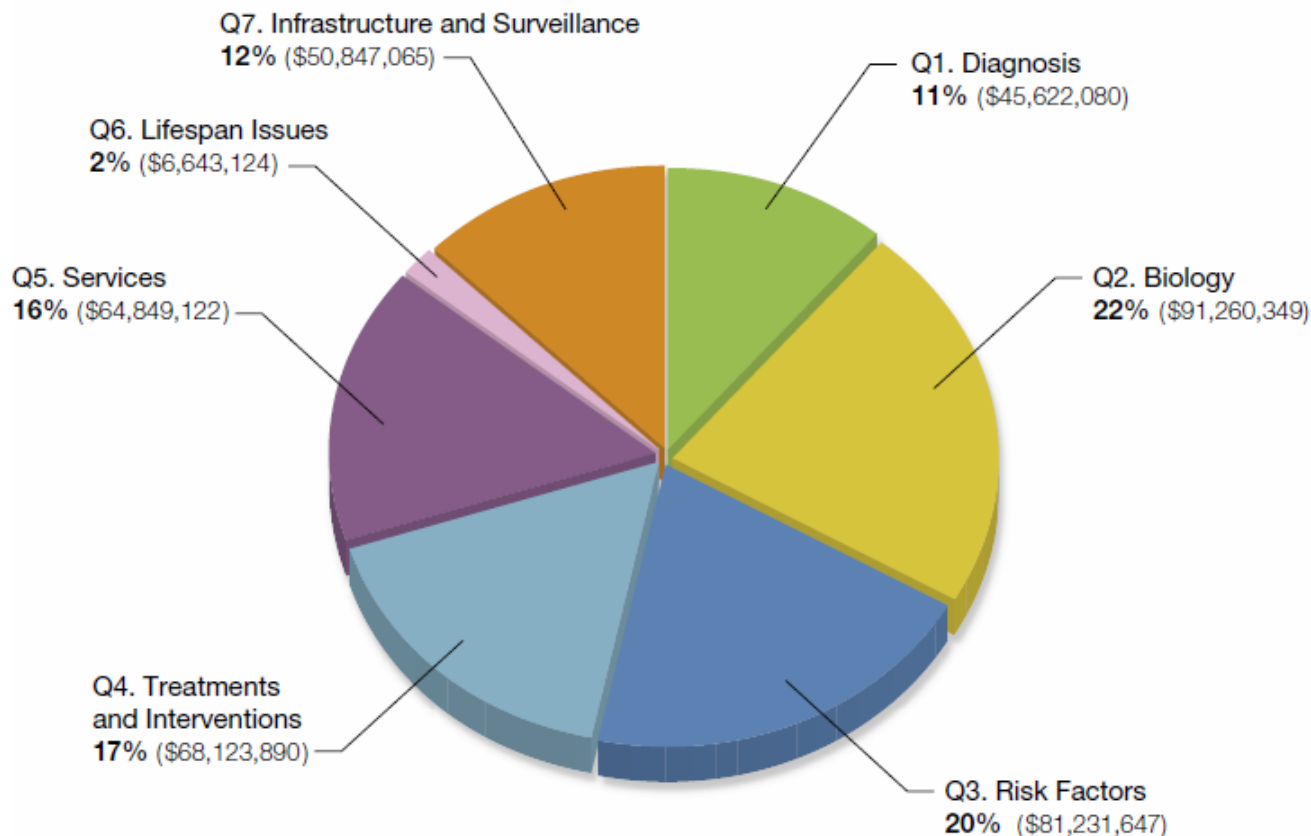
\*\*The NIH project number shown reflects unique NIH projects. Projects funded by more than one NIH institute ("co-funds") were combined and only counted as a single project. Private organizations are indicated in red text.

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

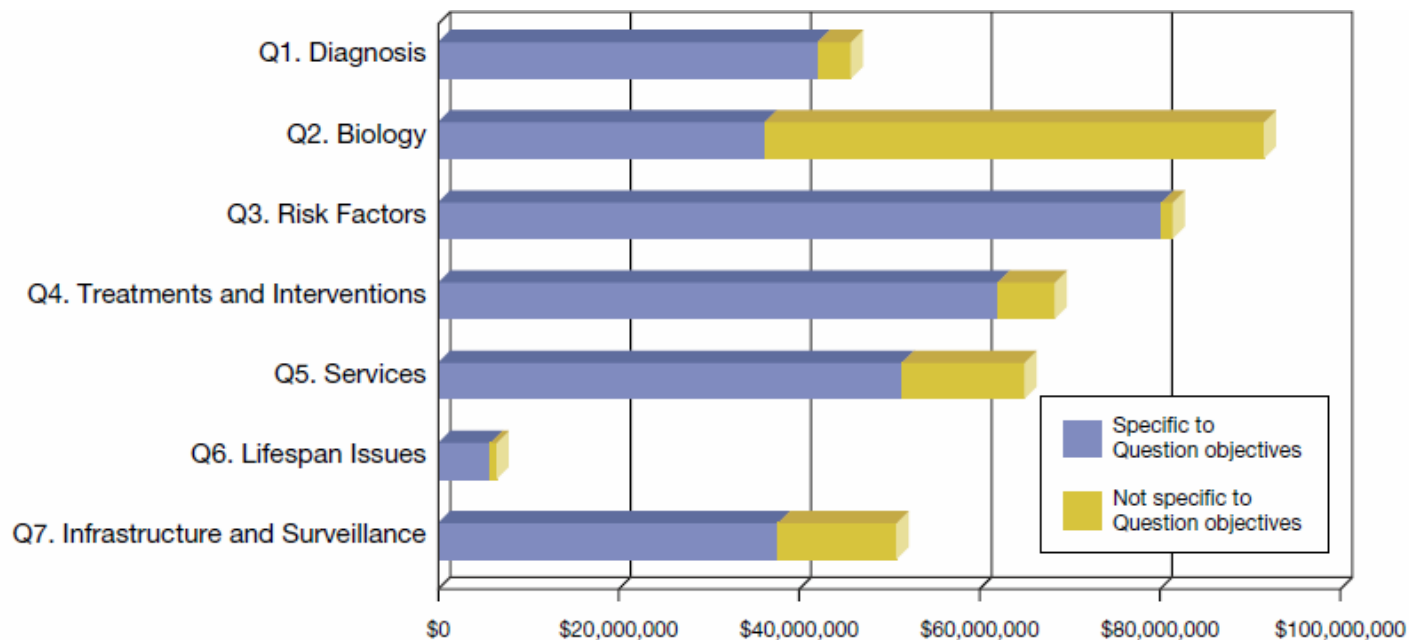


# How Was 2010 Autism Funding (All Funders) Distributed Across the *IACC Strategic Plan* Questions?

Total funding = \$408,577,276



# 2010 ASD Funding: Alignment with IACC Strategic Plan Objectives



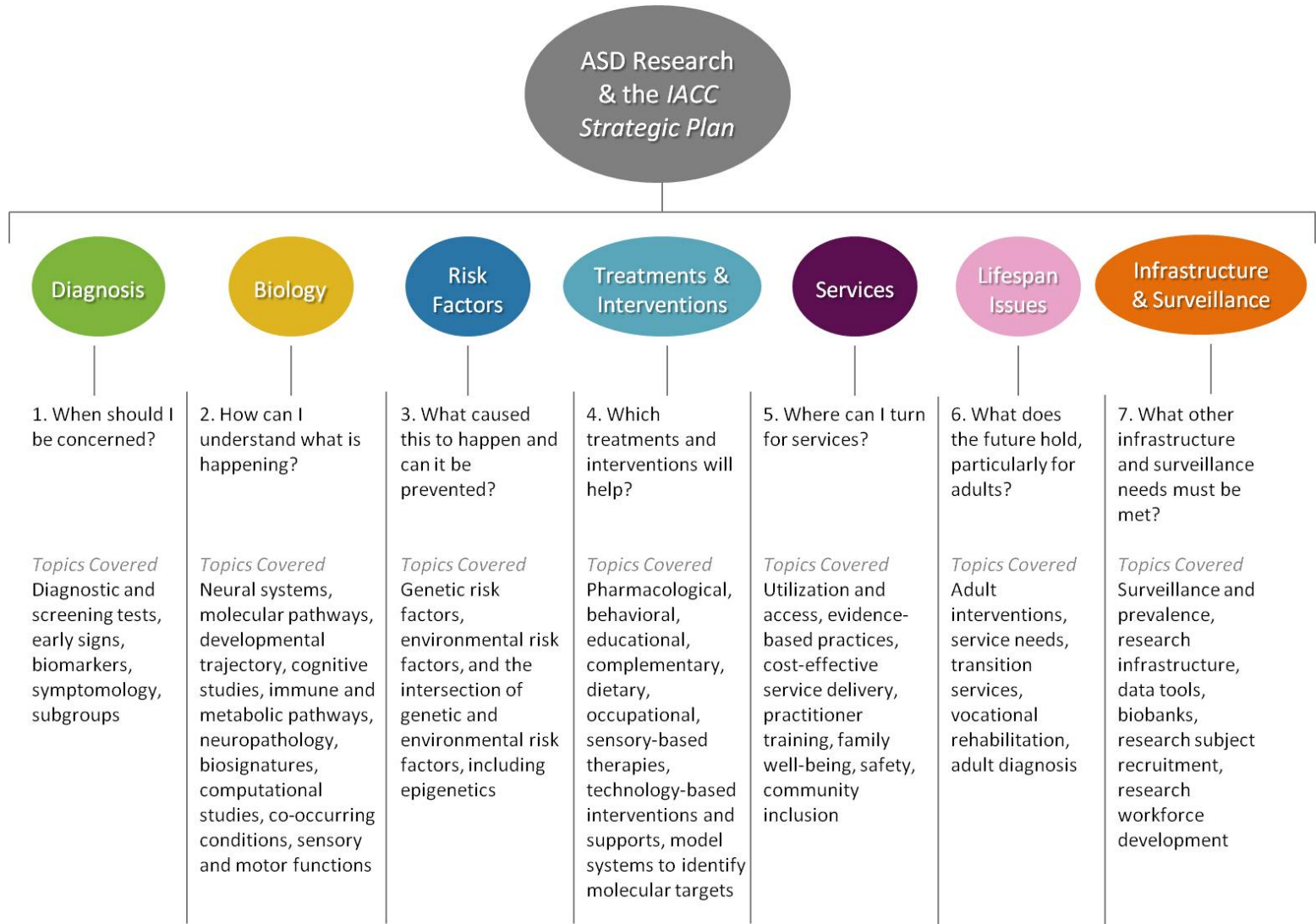
	Q1. Diagnosis	Q2. Biology	Q3. Risk Factors	Q4. Treatments and Interventions	Q5. Services	Q6. Lifespan Issues	Q7. Infrastructure and Surveillance
Specific	\$41,978,518	\$36,145,461	\$79,919,197	\$61,833,257	\$51,412,385	\$5,971,505	\$37,593,356
Not specific	\$3,643,562	\$55,114,188	\$1,312,450	\$6,290,633	\$13,436,737	\$671,619	\$13,253,709
% of funding for each Question	8%	60%	2%	9%	21%	10%	26%

# New in 2010: Subcategory Analysis

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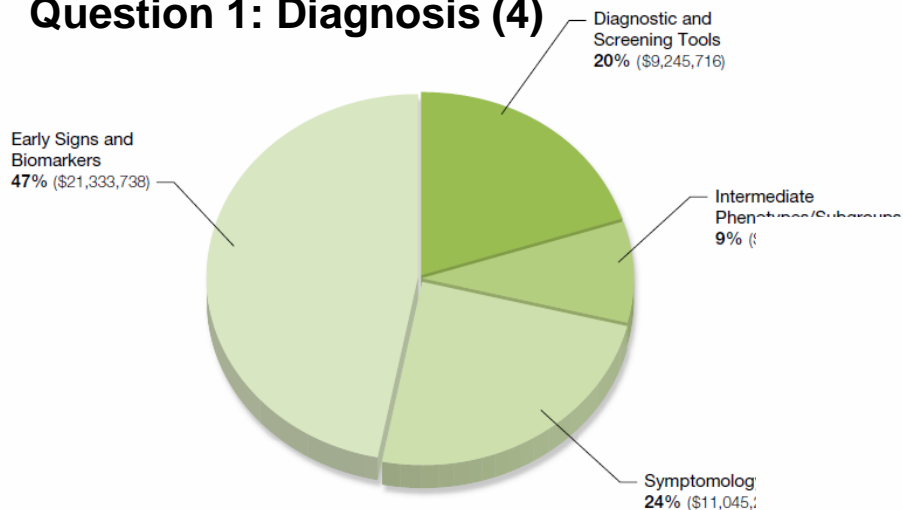
- Subcategories were developed for each of the seven questions of the *IACC Strategic Plan*
  - Provide a more detailed breakdown of research funding
  - Capture established and emerging research areas and areas of high public interest
  - Identify the types of research addressed by projects that do not correspond to specific objectives of the *Strategic Plan*
- Each project assigned to a single subcategory

# Strategic Plan Structure and Portfolio Analysis Subcategories

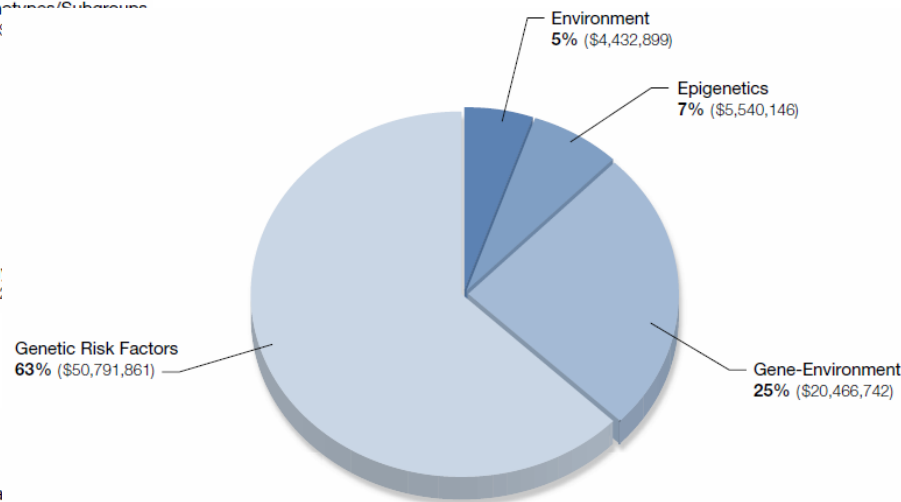


# In 2010, How Much Funding Was Devoted to Each Subcategory?

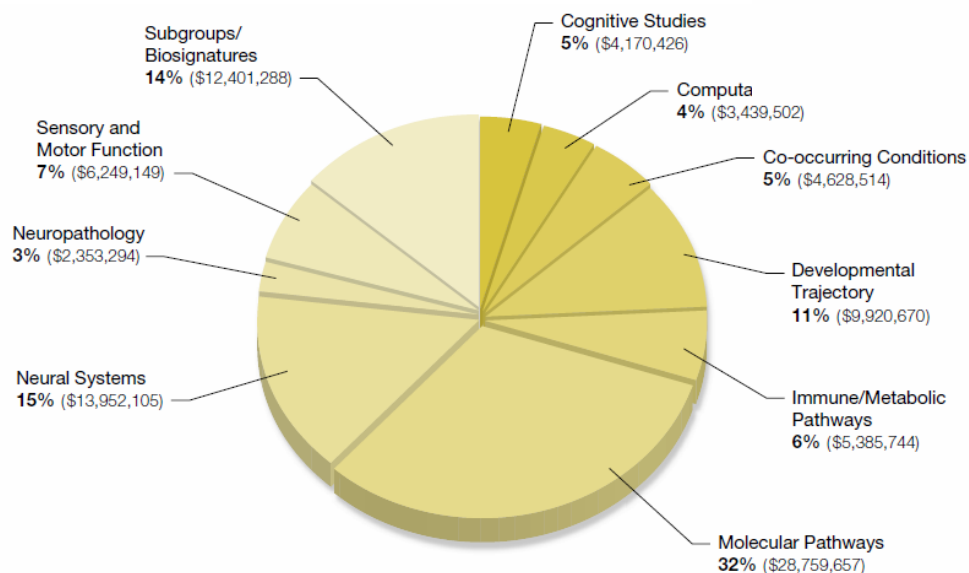
## Question 1: Diagnosis (4)



## Question 3: Risk Factors (4)

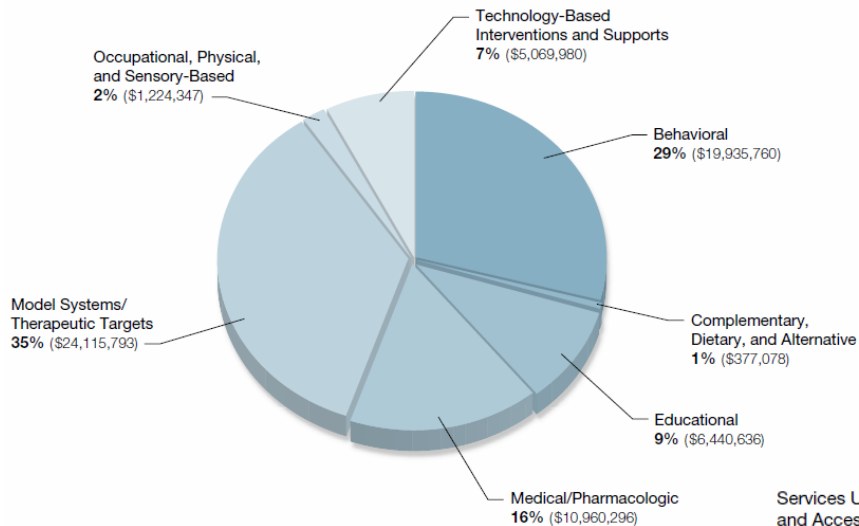


## Question 2: Biology (10)

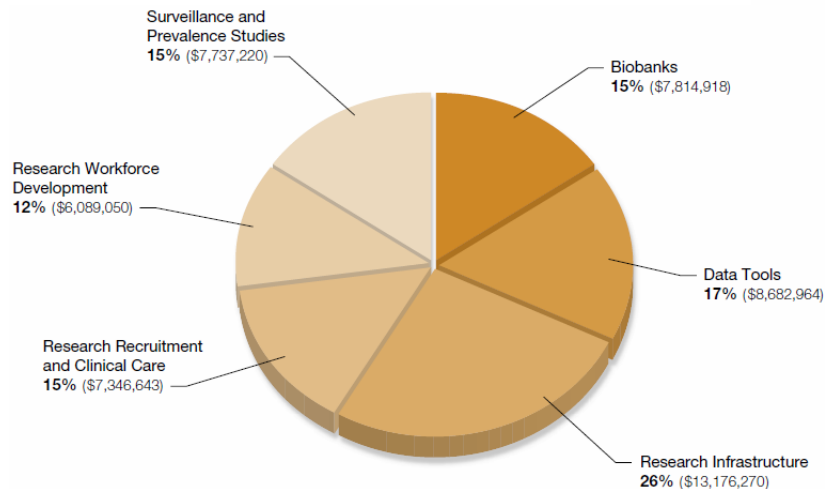


# Subcategories by Funding

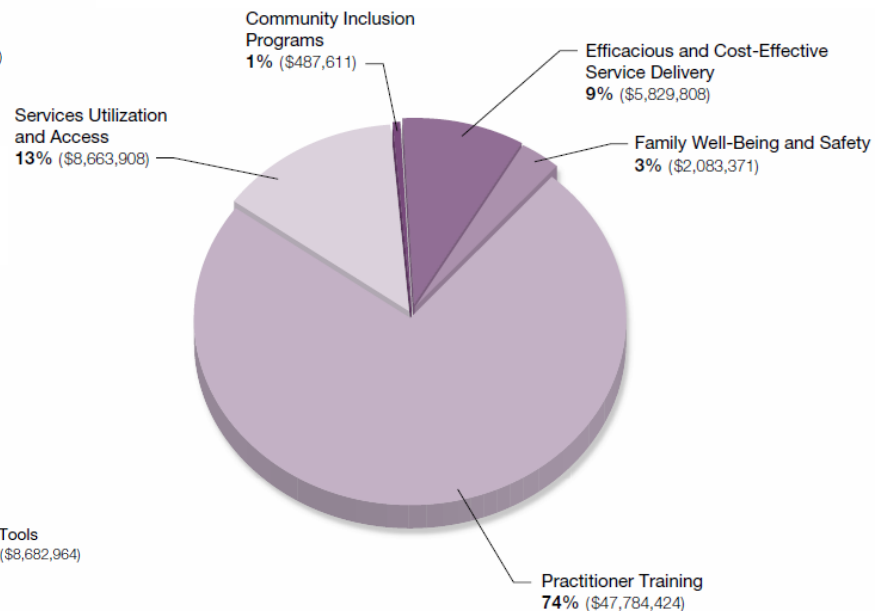
## Question 4: Treatments and Interventions (7)



## Question 7: Infrastructure and Surveillance (6)

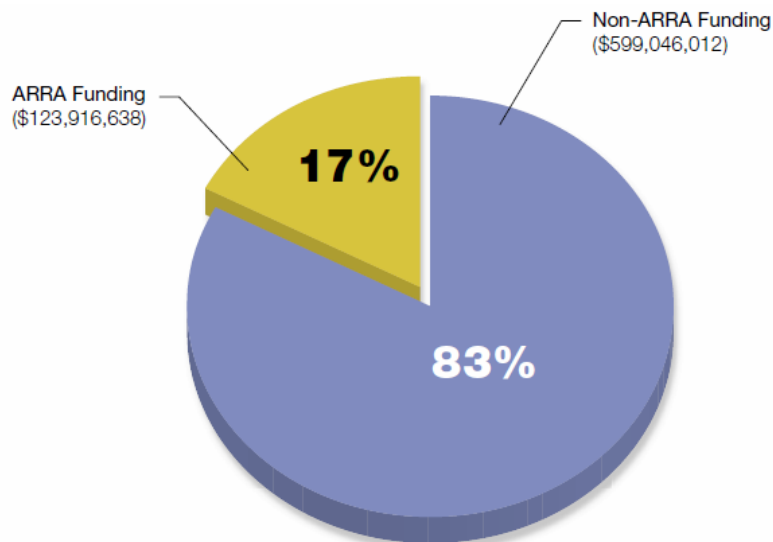


## Question 5: Services (5)

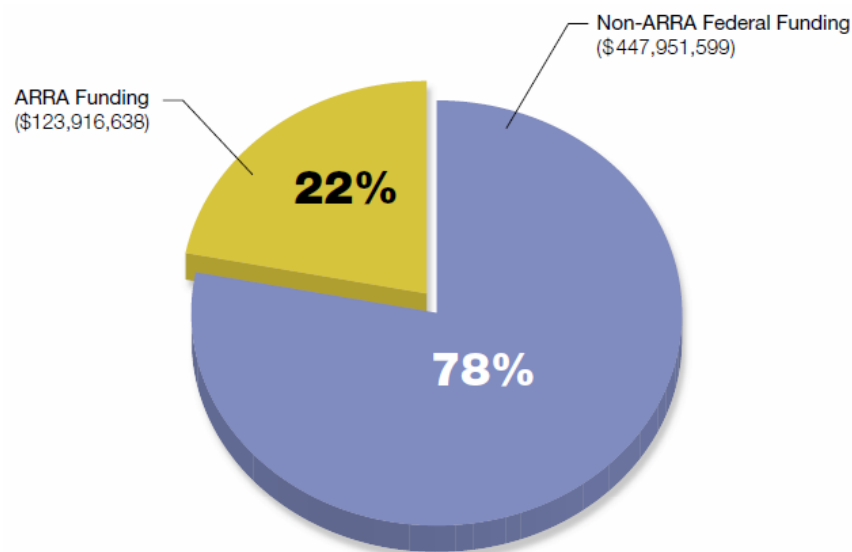


# Impact of ARRA on ASD Research Funding in 2009 & 2010

Impact of ARRA on  
Total ASD Research Funding  
for 2009 & 2010  
**Total funding = \$722,962,650**

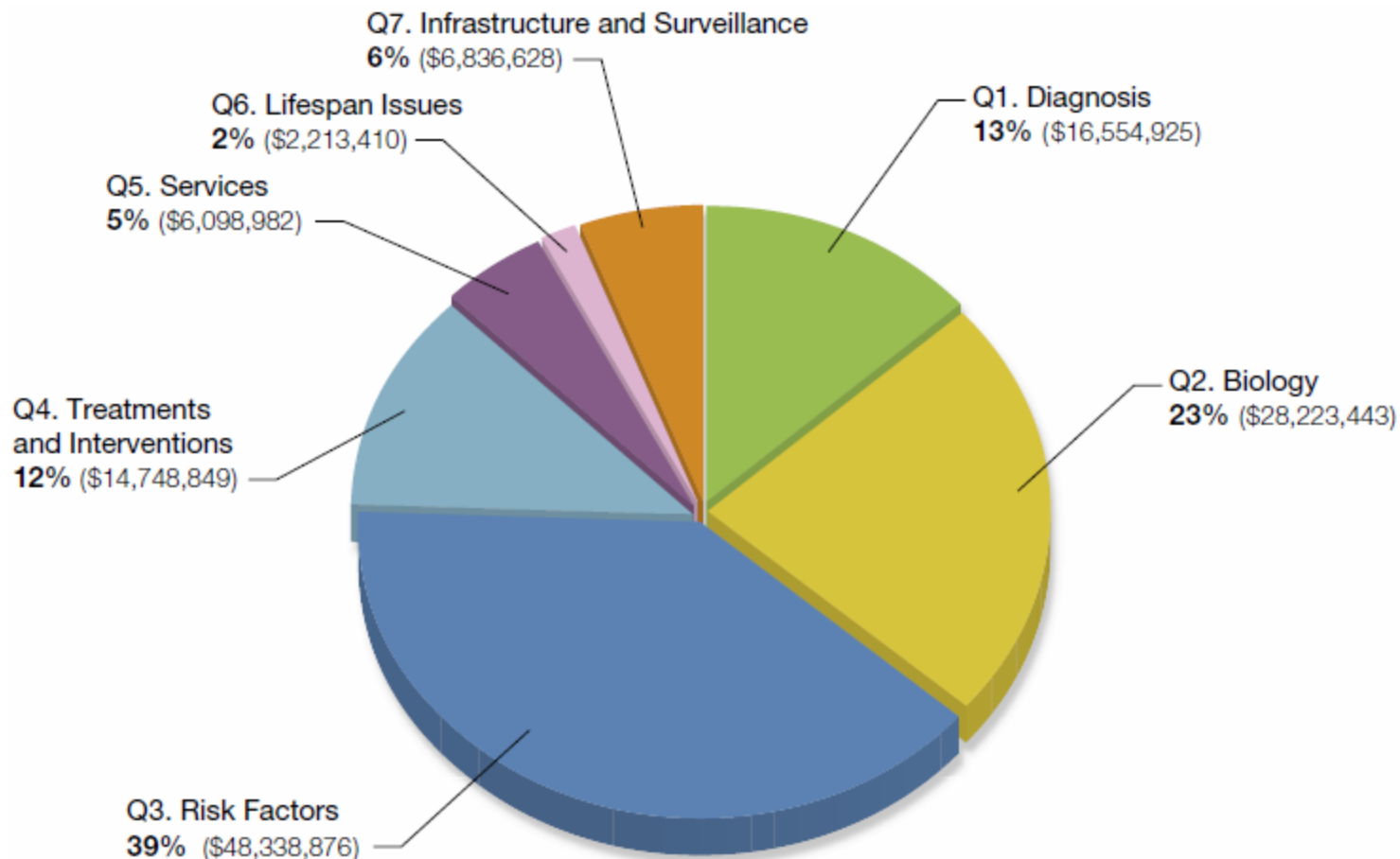


Impact of ARRA on  
**Federal** ASD Research Funding  
For 2009 & 2010  
**Total funding = \$571,868,237**



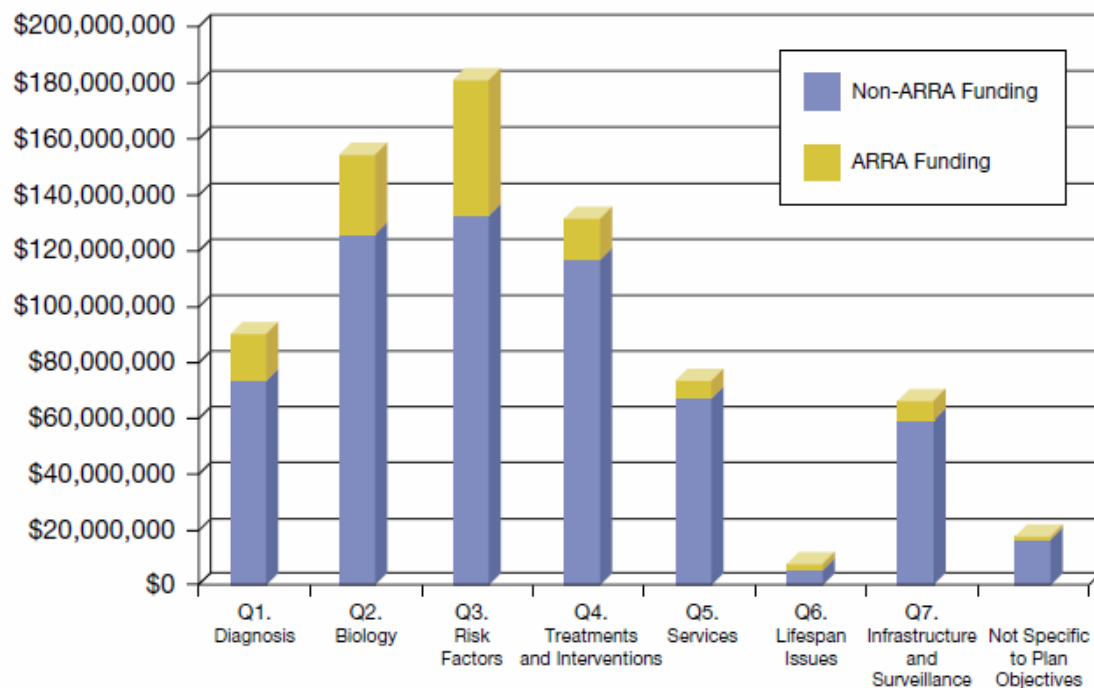
# How was 2009 & 2010 ARRA ASD Research Funding Distributed Across the *IACC Strategic Plan* Questions?

**Total ARRA funding = \$123,916,638**





# Impact of 2009 & 2010 ARRA Funding on ASD Research: Alignment with the *IACC Strategic Plan*



	Q1. Diagnosis	Q2. Biology	Q3. Risk Factors	Q4. Treatments and Interventions	Q5. Services	Q6. Lifespan Issues	Q7. Infrastructure and Surveillance	Not Specific to Plan Objectives
Non-ARRA Funding	\$73,761,097	\$126,055,149	\$132,830,821	\$116,778,055	\$67,398,190	\$5,837,413	\$59,589,569	\$16,795,718
ARRA Funding	\$16,554,925	\$28,223,443	\$48,338,876	\$14,748,849	\$6,098,982	\$2,213,410	\$6,836,628	\$901,525
% of ARRA total funding per Question	18%	18%	27%	11%	8%	28%	10%	5%

# What Progress is Being Made on Achieving IACC Strategic Plan Objectives?

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- In 2010 progress was underway on 83% of the 78 objectives in the 2011 IACC Strategic Plan.
- Since then two more objectives have been completed.
- Which objectives are not currently underway (i.e., no funding or projects to date)? **11 objectives spanning 6/7 Questions**

**1.S.C** Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012. *IACC Recommended Budget: \$2,000,000 over 2 years.*

**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.*

# Remaining Objectives – Cont'd

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**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.*

**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.*

**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.*

**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.*

# Remaining Objectives – Cont'd

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- 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.F** Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. *(No recommended budget assigned by the IACC.)*
- 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.*
- 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.*



All IACC publications and more information about the IACC are available at:

[www.iacc.hhs.gov](http://www.iacc.hhs.gov)



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