

# **An Update on the Interagency Autism Coordinating Committee (IACC) and the National Institutes of Health (NIH)**

**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

# The Interagency Autism Coordinating Committee

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- A federal advisory committee
- Established by Congress under the Children's Health Act (CHA) of 2000
- Reconstituted under the Combating Autism Act of 2006
- Most recently reauthorized by the Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2014 - Public Law 113-157
- Managed by the Office of Autism Research Coordination/National Institutes of Health



# Role of the IACC

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- Coordinate efforts among federal agencies, as well as member private organizations concerning autism spectrum disorder (ASD).
- Provide advice to the HHS Secretary on matters related to ASD.
- Facilitate exchange of information among the member agencies in order to enhance coordination of research and services activities.
- Increase public understanding of federal autism activities, programs, policies and research.
- Serve as a public forum for discussing and gathering public input on issues related to autism spectrum disorder.

# IACC Federal Member Agencies

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- National Institutes of Health (NIH)
  - National Institute of Mental Health (NIMH)
  - National Institute on Deafness and Other Communication Disorders (NIDCD)
  - Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)
  - National Institute of Environmental Health Sciences (NIEHS)
  - National Institute of Neurological Disorders and Stroke (NINDS)
- Administration for Community Living (ACL)
- Food and Drug Administration (FDA)
- Centers for Medicare and Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)
- Agency for Healthcare Research and Quality (AHRQ)
- Centers for Disease Control and Prevention (CDC)
- Administration for Children and Families (ACF)
- Environmental Protection Agency (EPA)
- Department of Education (ED)
- Department of Defense (DoD)
- Social Security Administration (SSA)

# IACC Public Members

## **Adults on the Autism Spectrum, Family Members, Advocates, Researchers, Service Providers, Other Community Professionals**

- David Amaral, Ph.D., University of California Davis MIND Institute
- James Ball, Ed.D., B.C.B.A.-D., JB Autism Consulting
- Samantha Crane, J.D., Autistic Self Advocacy Network
- Geraldine Dawson, Ph.D., Duke University School of Medicine
- Amy Goodman, M.A., Self-Advocate
- David S. Mandell, Sc.D., University of Pennsylvania
- Brian Parnell, M.S.W., C.S.W., Utah Department of Human Services
- Kevin Pelphrey, Ph.D., George Washington University and Children's National Medical Center
- Edlyn Peña, Ph.D., California Lutheran University
- Louis Reichardt, Ph.D., Simons Foundation Autism Research Initiative
- Robert H. Ring, Ph.D., Vencerx Therapeutics
- John Elder Robison, College of William and Mary
- Alison Tepper Singer, Autism Science Foundation
- Julie Lounds Taylor, Ph.D., Vanderbilt University

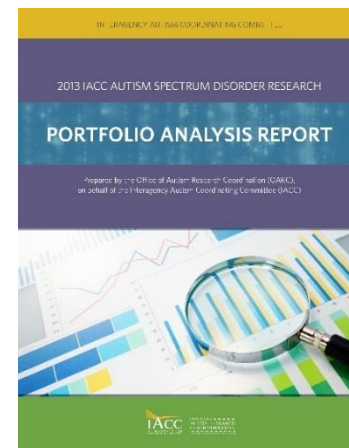
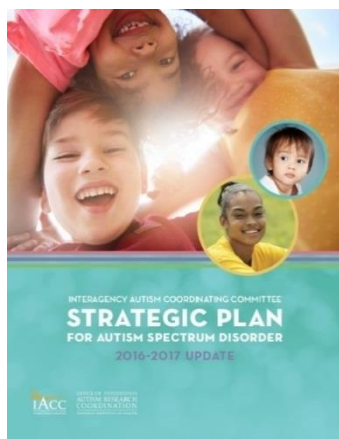
# What Does the IACC Do?

## Responsibilities under the CARES Act:

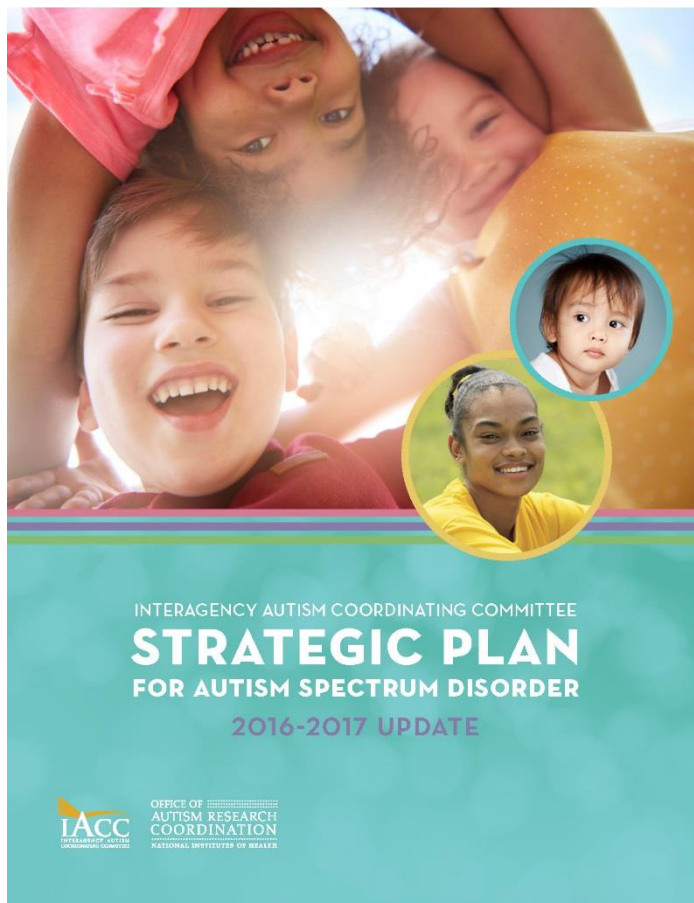
- Develop and regularly update a strategic plan for ASD
- Prepare an annual summary of advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding research or public participation in decisions regarding ASD

## How?

- Meetings, speaker presentations, workshops, gathering public input, analysis, written publications



# IACC Strategic Plan



**COMING SOON!**

- The IACC Strategic Plan (SP) provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.
- The IACC SP is organized around 7 consumer-based questions.
- The first IACC SP was developed in 2009 and focused on research efforts.
- Under the Autism CARES Act, the new IACC Strategic Plan will address both research and services activities.

# Structure of IACC Strategic Plan

## IAAC STRATEGIC PLAN QUESTIONS AND CORRESPONDING RESEARCH AREAS



**Question 1:** When should I be concerned?  
SCREENING & DIAGNOSIS



**Question 2:** How can I understand what is happening?  
BIOLOGY



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



**Question 4:** Which treatments and interventions will help?  
TREATMENTS & INTERVENTIONS



**Question 5:** Where can I turn for services?  
SERVICES



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



**Question 7:** What other infrastructure and surveillance needs must be met?  
INFRASTRUCTURE & SURVEILLANCE

# IACC Strategic Plan Update 2016-2017 Objectives



## Question 1 – Screening and Diagnosis

1. Strengthen the evidence base for the benefits of early detection of ASD.
2. Reduce disparities in early detection and access to services
3. Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD in order to facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.



## Question 2 – Biology

1. Foster research to better understand the processes of early development, molecular, and neurodevelopmental mechanisms, and brain circuitry that contribute to the structural and functional basis of ASD.
2. Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.
3. Support large scale longitudinal studies that can answer questions about the development of ASD from pregnancy through adulthood and the natural history of ASD across the lifespan.

# IACC Strategic Plan Update 2016-2017 Objectives



## Question 3 – Risk Factors

1. Strengthen understanding of genetic risk and resilience factors for ASD across a large population representing the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and comorbidities in ASD.
2. Understand the effects on ASD risk and resilience of individual and multiple exposures in early development, enabling development of strategies for reducing disability and comorbidities in ASD.
3. Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.



## Question 4 – Treatments & Interventions

1. Develop and improve pharmacological and medical interventions to address both core symptoms and comorbidities in ASD.
2. Develop and improve psychosocial, developmental, and naturalistic interventions for the core symptoms and comorbidities in ASD.
3. Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.

# IACC Strategic Plan Update 2016-2017 Objectives



## Question 5 - Services

1. Fully and successfully scale up evidence-based interventions in community settings.
2. Reduce disparities in access and in outcomes for underserved populations.
3. Improve service models to ensure consistency of care across many domains with the goal of maximizing outcomes and improving the value that individuals get from services.



## Question 6 – Lifespan Issues

1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and continue to provide supports throughout the lifespan.
2. Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.
3. Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.

# IACC Strategic Plan Update 2016-2017 Objectives



## Question 7 – Infrastructure & Surveillance

### Repositories

- Develop and expand programs and outreach to encourage families to donate brain and other tissues, and to participate in autism research generally.
- Create incentives to encourage standardization and sample sharing across banks.

### Data infrastructure

- Adopt the GUID across all research initiatives in order to reduce the likelihood of sample duplication.
- Standardization to a common data definition and responsibly share all the data supporting findings at the time when findings are announced.

### Human infrastructure

- Expand and enhance NIH programs to support training of ASD researchers.
- Develop programs to translate and disseminate ASD findings into actionable recommendations and real-world practices.
- Provide service providers with training in evidence based practices across multiple settings, from clinics to communities.

### Surveillance Infrastructure

- Expand surveillance efforts to the adult population to better understand prevalence and needs across the lifespan.
- Include more descriptive data concerning co-occurring conditions, including cognitive conditions, seizures, anxiety and depression, in surveillance efforts.

# 2016 IACC Summary of Advances



**AVAILABLE NOW!**

- Annual publication – required by CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Covers articles aligning with all seven Strategic Plan Question areas

<https://iacc.hhs.gov/publications/summary-of-advances/2016/>

# IACC Portfolio Analysis Report



**AVAILABLE NOW!**

- Assists the IACC in fulfilling the CARES Act requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides detailed 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 track progress in fulfilling the objectives of the IACC Strategic Plan

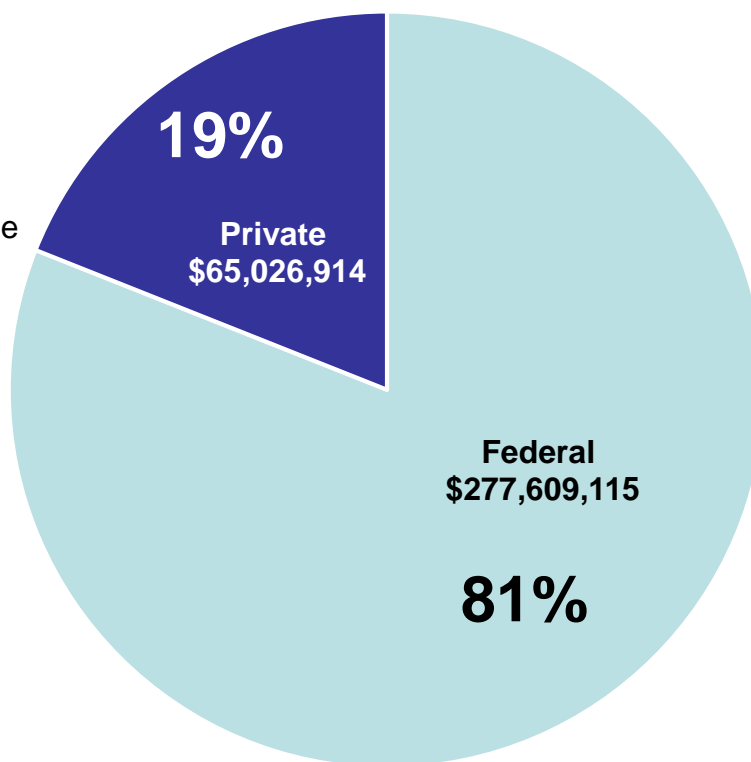
<https://iacc.hhs.gov/portfolio-analysis/2013/index.shtml>

# 2015 IACC ASD Portfolio Analysis

## Federal vs. Private Funding for ASD Research Total Funding: \$342,636,029

### **Private Organizations:**

- Autism Science Foundation
- Autism Research Institute
- Autism Speaks
- Brain & Behavior Research Foundation
- Center for Autism & Related Disorders
- New England Center for Children
- Organization for Autism Research
- Patient-Centered Outcomes Research Institute
- Simons Foundation

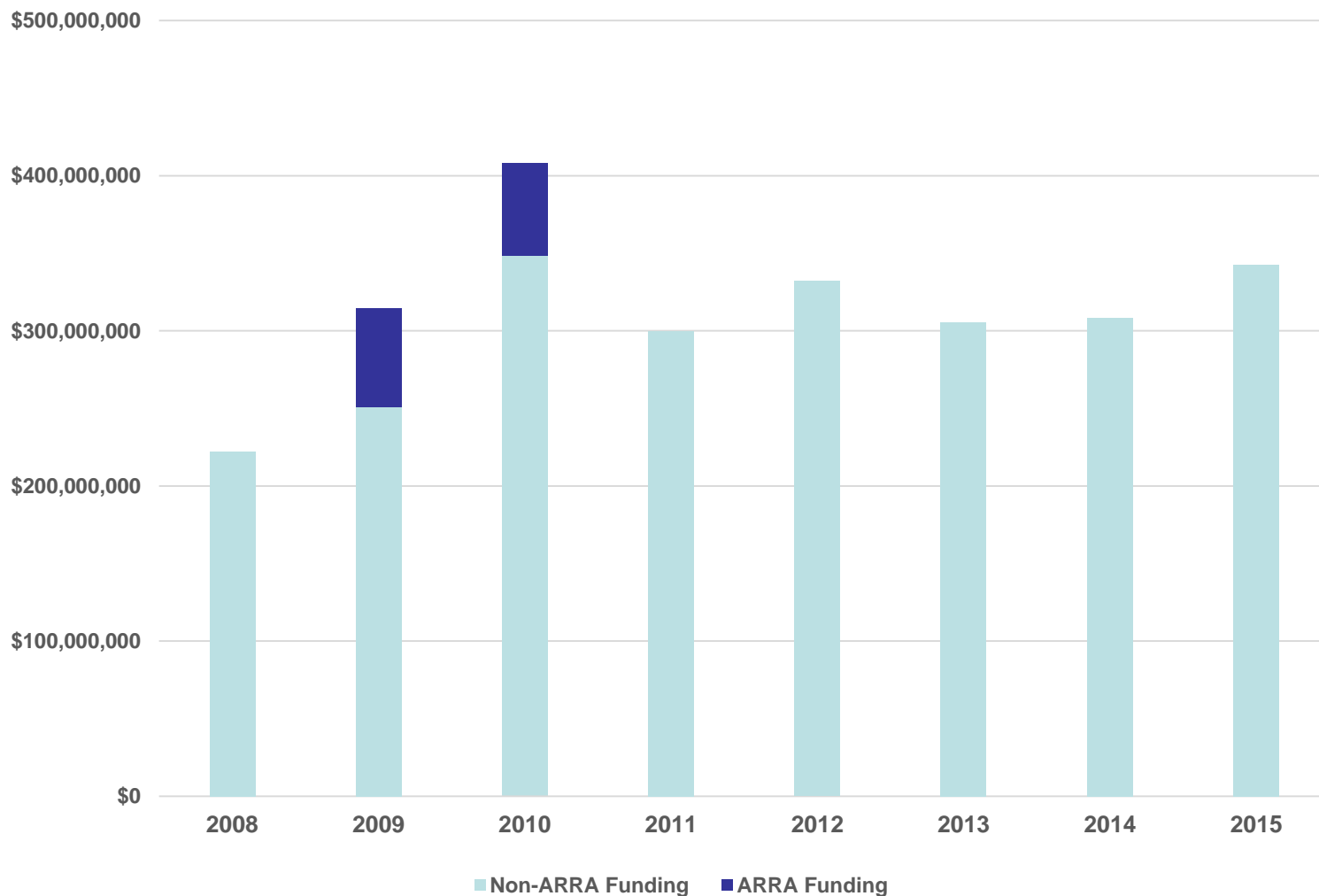


### **Federal Agencies:**

- Administration for Community Living
- Agency for Healthcare Research & Quality
- Department of Defense
- Department of Education
- Environmental Protection Agency
- Health Resources & Services Administration
- National Institutes of Health
- National Science Foundation

# 2015 *IACC ASD Portfolio Analysis*

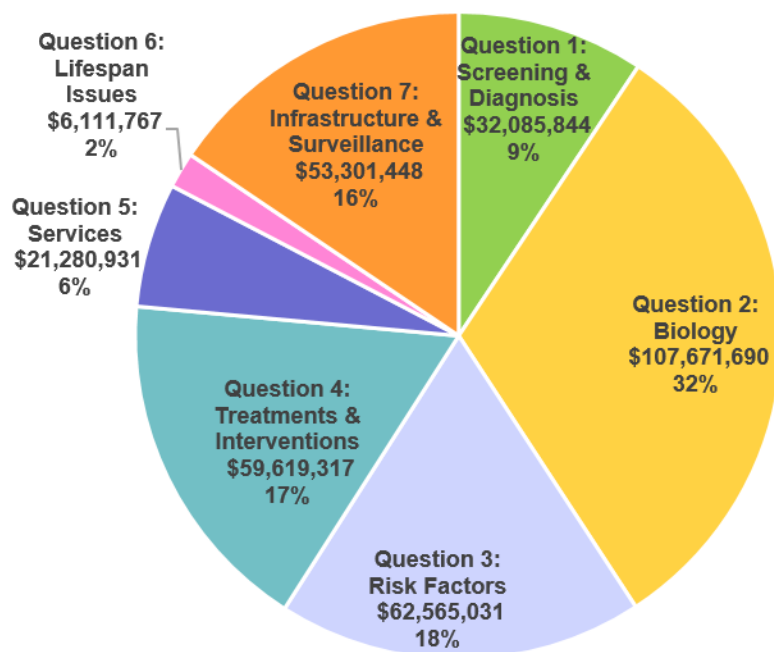
Combined Federal and Private Autism Research Funding  
2008-2015



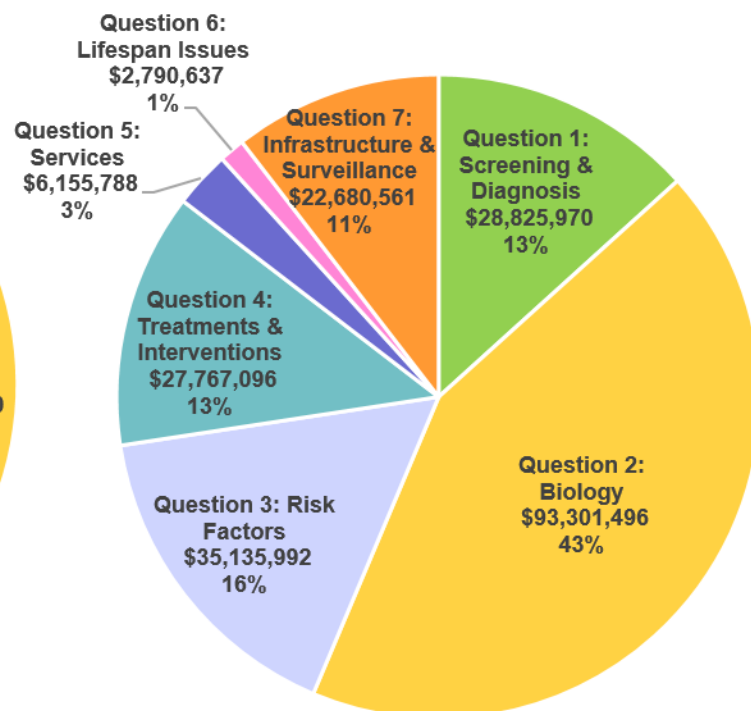
# 2015 IACC ASD Portfolio Analysis

## ASD Research Funding by IACC Strategic Plan Question

**All Funders**  
Total Funding: \$342, 636, 029

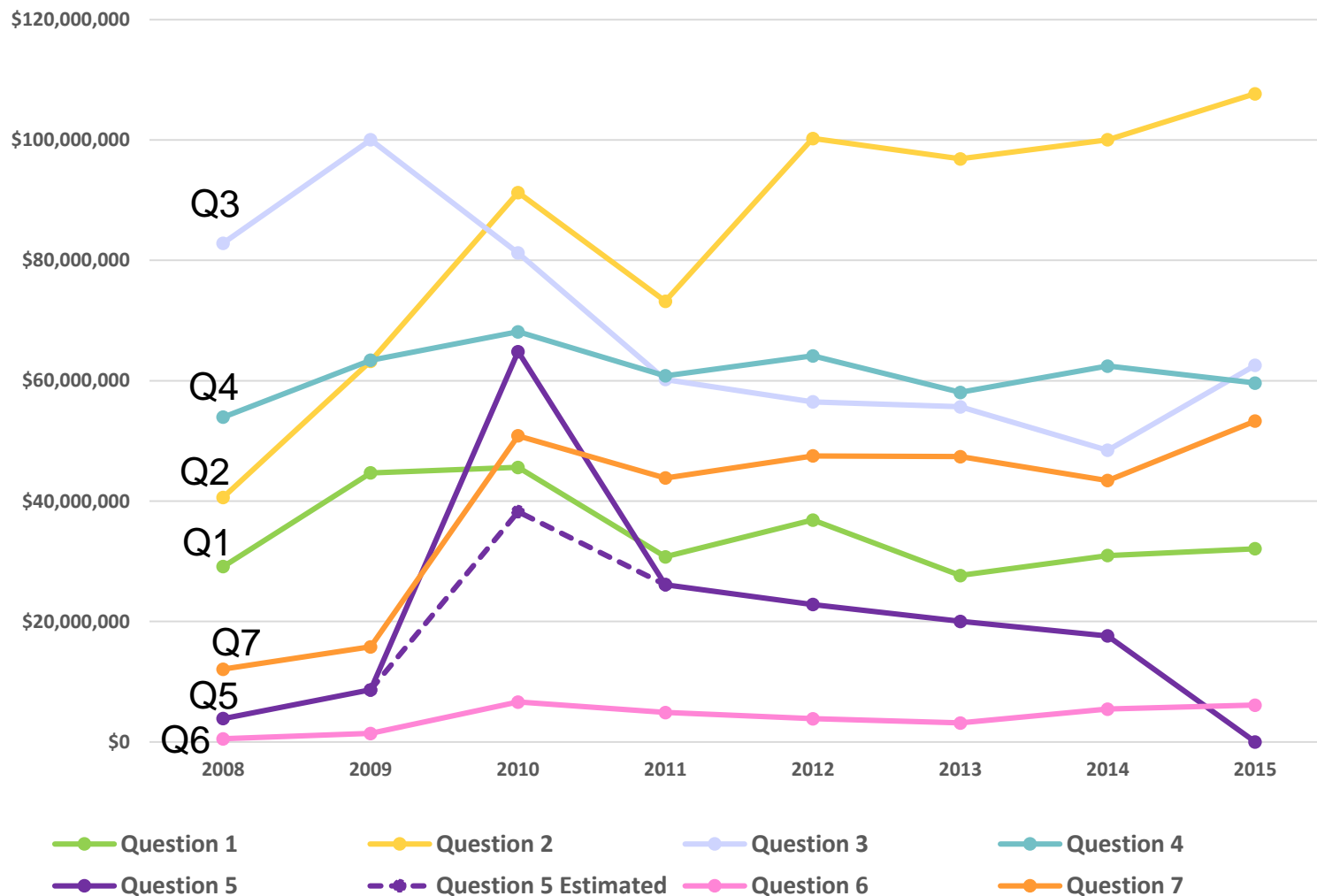


**NIH Only**  
Total Funding: \$216,657,540



# 2015 IACC ASD Portfolio Analysis

2008-2015 ASD Research Funding



# IACC Portfolio Analysis Report

For more the 2013 data, read the full report online:

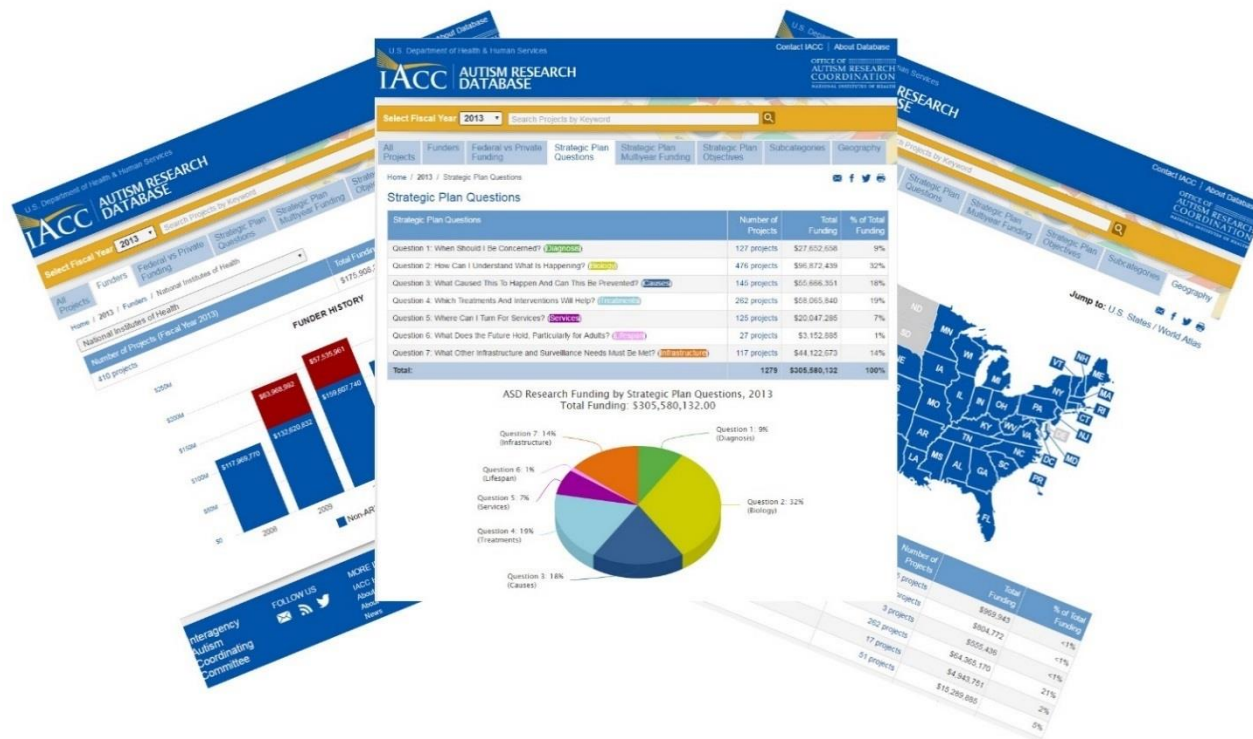


***AVAILABLE NOW!***

***The 2014-2015 Report will be published in late 2017***

**<https://iacc.hhs.gov/portfolio-analysis/2013/index.shtml>**

# IACC/OARC Autism Research Database



- A newly designed online database of ASD research
- Replaces the *IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool*
- New features: federal vs. private funding; geography
- Includes release of the *2013 ASD Research Portfolio Analysis* data
- 2014-2015 data will be added later this year

<https://iacc.hhs.gov/funding/data/>

# The National Institutes of Health (NIH)

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- The largest funder of autism research in the U.S. – estimated \$216m in FY 2016
- Research portfolio includes both biomedical and services research
- NIH is composed of 27 Institutes and Centers – 5 support large portfolios of autism research:
  - National Institute of Mental Health (NIMH)
  - *Eunice Kennedy Shriver* Institute of Child Health and Human Development (NICHD)
  - National Institute of Neurological Disorders and Stroke (NINDS)
  - National Institute of Deafness and Other Communication Disorders (NIDCD)
  - National Institute of Environmental Health Sciences (NIEHS)

# Major NIH Autism-Related Programs

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## **Autism Centers of Excellence (ACE) Program**

- The ACE Program is a trans-NIH initiative that supports large-scale multidisciplinary studies on autism spectrum disorders (ASDs), with the goal of determining the disorders' causes and the best treatments for them.

## **Services Research for Autism Spectrum Disorder across the Lifespan (ServASD)**

- The goal of ServASD research grants is to develop effective, real-world-ready approaches to providing early diagnosis, treatment, and supportive services for people with ASD at three different stages throughout the lifespan: early childhood, transition age, and adulthood.
- Research grants aimed at early childhood represent the **ASD Pediatric Early Detection, Engagement and Services (PEDS) Network**
  - Targets young children from 12–36 months of age and testing strategies for universal screening coupled with referral to and engagement in services when indicated in order to determine how to achieve earlier intervention and services for children with ASD.

# Major NIH Autism-Related Programs

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## **The Autism Biomarkers Consortium for Clinical Trials (ABC-CT)**

- A public-private biomedical research partnership managed by the Foundation for the National Institutes of Health aims to facilitate the identification and validation of biomarkers to accelerate and de-risk the development of effective therapies for ASD.

## **Childhood Autism Risks from Genetics and the Environment (CHARGE) Study**

- The CHARGE (Childhood Autism Risks from Genetics and Environment) Study is a large, population-based case-control investigation of environmental risk factors, broadly defined, in relation to ASD and developmental delay without ASD symptoms, with referents from the general population.

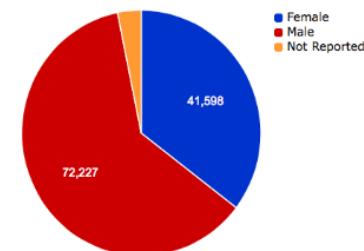
## **NIH NeuroBioBank**

- A program to collect and distribute post-mortem brain tissue from a diverse group of individuals in order to investigate the neuropathology of ASD and other disorders.

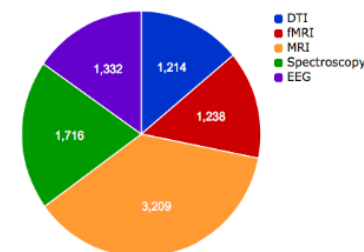
# National Database of Autism Research (NDAR)

- **NIH-funded web-based data repository that aims to accelerate progress in ASD research through data sharing, data harmonization, and the reporting of research results:**
  - Contains data from 338 Grants/Projects (\$745M) available for research use
  - Data from 100,000+ research participants
- **ASD Relevant data in NDAR:**
  - Genomics, imaging, neuro-signal recordings (EEG, Eye Tracking, fMRI), clinical data
- **Provides method to: “responsibly share all the data supporting any findings when those findings are announced.”**
  - Several tools for data definition, standardization and validation to help researchers adopt community data standards across projects and research institutions.

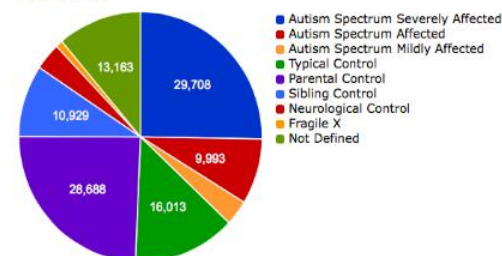
Gender<sup>1</sup>



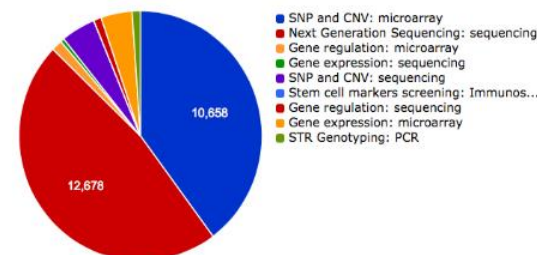
Neuroimaging



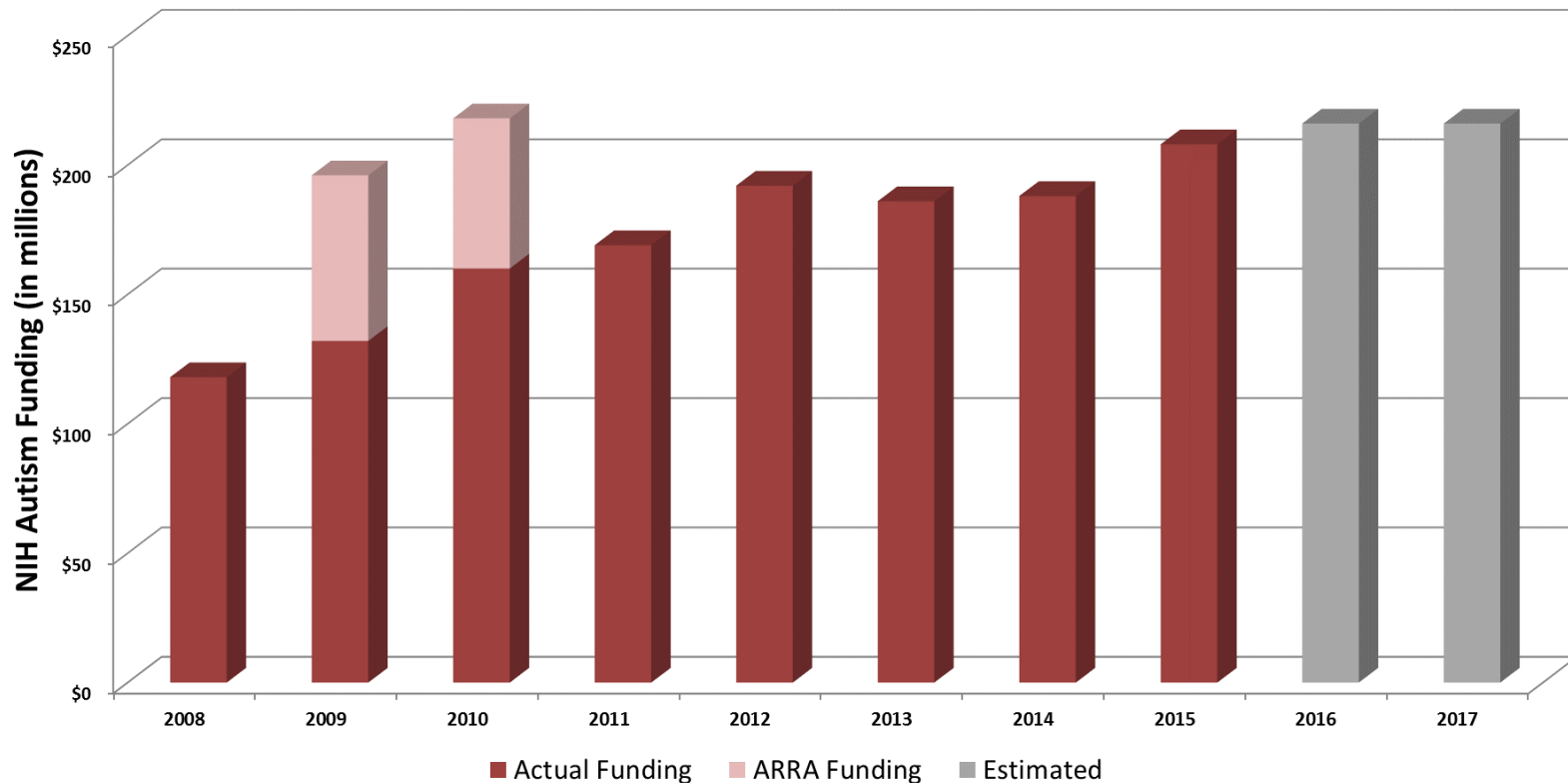
Phenotypic<sup>1</sup>



Genomic



# NIH Autism Funding 2008-2017



\*Data for this figure was used from NIH RePORTER (<https://projectreporter.nih.gov/reporter.cfm>)

Note: stacked bars for 2009 and 2010 show American Recovery and Reinvestment Act funds that were allocated to autism research

# How Can You Get Involved?

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**IACC Membership** includes representatives from Federal agencies as well as public stakeholders.

*You can get involved by:*

- Signing up for IACC email updates to receive news about the IACC, including future Call for Nominations announcements

**IACC Full Committee Meetings** are held quarterly and are open to the public, webcast, and archived online.

*You can get involved by:*

- Members of the public can prepare oral public comments at future IACC meetings or submitting written public comments for the meeting record
- Scientists can present groundbreaking findings at future IACC meetings or submitting public comments for the meeting record

**IACC Activities** help inform the autism community and guide future IACC strategic planning efforts.

*You can get involved by:*

- Responding to IACC Requests for Information
- Participation in IACC working groups
- Attending or participating in IACC/OARC-hosted scientific workshops on various autism topics

# IACC Upcoming Events

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**Next IACC Meeting:**

**Wednesday, July, 26<sup>th</sup>, 2017**

**NIH Campus, Bethesda, MD**



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

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

***Or at the IACC booth (Booth #11) at IMFAR!***

# OARC Staff

**Susan Daniels, Ph.D., Director**

**Oni Celestin, Ph.D.,**  
Science Policy Analyst

**Rebecca Martin, M.P.H.,**  
Public Health Analyst

**Karen Mowrer, Ph.D.,**  
Science Policy Analyst

**Ben Feldman, M.A., Ph.D.,**  
Science Policy Analyst

**Angelice Mitrakas, B.A.,**  
Management Analyst

**Julianna Rava, M.P.H.,**  
Science Policy Analyst

**Jeff Wiegand, B.S.,**  
Web Development Manager



*Are you interested in getting involved in IACC via membership, meetings, or activities?*

Email [iaccpublicinquiries@mail.nih.gov](mailto:iaccpublicinquiries@mail.nih.gov).