

# **An Update on the Interagency Autism Coordinating Committee (IACC) and the IACC Strategic Plan**

**Autism CARES Grantee Meeting  
July 10, 2017**

**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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- Coordinates efforts among federal agencies, as well as member private organizations concerning autism spectrum disorder (ASD).
- Provides advice to the HHS Secretary on matters related to ASD.
- Facilitates exchange of information among the member agencies in order to enhance coordination of research and services activities.
- Increases public understanding of federal autism activities, programs, policies and research.
- Serves 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., Vencorex Therapeutics
- John Elder Robison, College of William and Mary
- Alison Tepper Singer, Autism Science Foundation
- Julie Lounds Taylor, Ph.D., Vanderbilt University

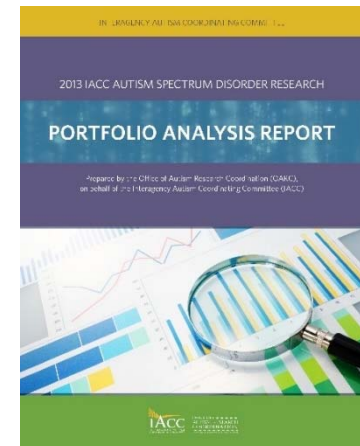
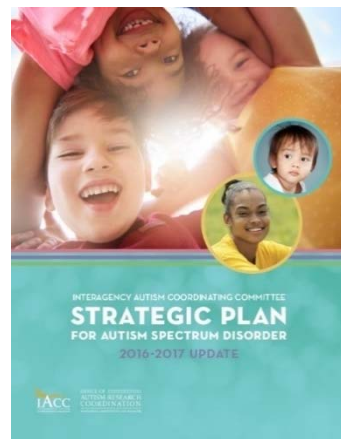
# What Does the IACC Do?

## Responsibilities under the CARES Act:

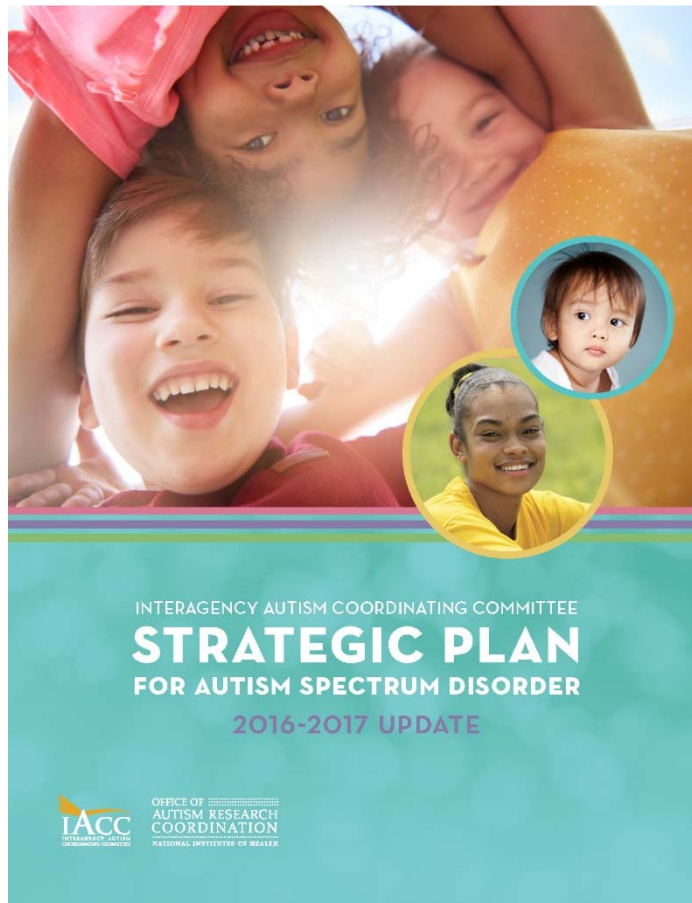
- Develop and regularly update a Strategic Plan for ASD
- Prepare an annual Summary of Advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the HHS Secretary regarding research or public participation in decisions regarding ASD

## How?

- Meetings, speaker presentations, workshops, 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 and contains a list of 22 strategic objectives.
- The first IACC SP was developed in 2009 and focused on research efforts.
- Under the Autism CARES Act, the new IACC Strategic Plan addresses both research and services activities.

# Structure of IAACC Strategic Plan

## IAACC 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





# Question 1: Screening and Diagnosis

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## Chapter Title

***How can I recognize the signs of ASD, and why is early detection so important?***

## Aspirational Goal

***Provide the earliest possible diagnosis for children and adults on the autism spectrum, so they can be linked to appropriate interventions, services, and supports in as timely a manner as possible to maximize positive outcomes.***

## Objectives

***Strengthen the evidence base for benefits of screening; reducing disparities; improved tools, access, and service delivery models***



## Question 2: Biology

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### Chapter Title:

***What is the Biology Underlying Autism Spectrum Disorder?***

### Aspirational Goal:

***Discover how alterations in brain development and the function of physiological systems lead to ASD in order to enable development of effective, targeted interventions and societal accommodations that improve quality of life for people on the autism spectrum.***

### Objectives

***Research on development and neurobiology of autism; biology of co-occurring conditions; longitudinal studies that cover the full lifespan***



## Question 3: Risk Factors

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### Chapter Title:

***What Causes ASD, and Can ASD or Disabling Aspects of ASD Be Prevented or Preempted?***

### Aspirational Goal:

***Causes of ASD will be discovered that inform diagnosis, prognosis, and interventions and lead to prevention or preemption of ASD and/or its disabling aspects.***

### Objectives

***Research on genetic risk and resilience factors; research on environmental risk and resilience factors; research to understand how genetic and environmental factors interact***



# Question 4: Treatments and Interventions

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## Chapter Title:

*Which Treatments & Interventions Will Help?*

## Aspirational Goal:

*Develop a range of interventions that optimize function and abilities across the lifespan to achieve meaningful outcomes and maximize quality of life for people on the autism spectrum*

## Objectives

*Development of medical and pharmacological interventions; psychosocial and naturalistic interventions; technological interventions*



## Question 5: Services

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### Chapter Title:

***What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?***

### Aspirational Goal:

***Communities will develop, access, and implement high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD and their families.***

### Objectives

***Scale up evidence based interventions; reduce disparities in access and outcomes; improve service models***



## Question 6: Lifespan Issues

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### Chapter Title:

***How can we meet the needs of people with ASD as they progress into and through adulthood?***

### Aspirational Goal:

***All people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, satisfying relationships, and meaningful access to services and supports.***

### Objectives

***Development and coordination of transition services; approaches to reduce comorbid conditions and premature mortality; research and services to promote acceptance, accommodation, inclusion, independence, and integration***



# Question 7: Infrastructure

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## Chapter Title:

***How do we continue to build, expand, and enhance the autism research and services infrastructure to meet the needs of the ASD community?***

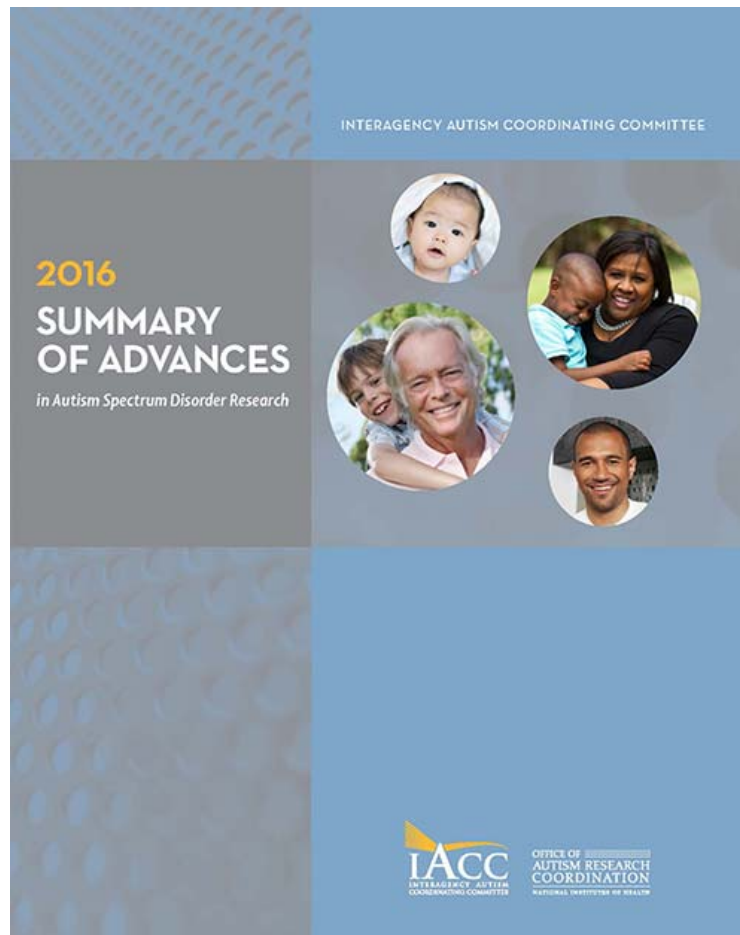
## Aspirational Goal:

***Develop, enhance and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research and services.***

## Objectives

***Encouraging tissue donation, data standardization, and data sharing; training for researchers and service providers; expanding surveillance to cover adults and comorbid conditions***

# 2016 IACC Summary of Advances



- 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

**AVAILABLE NOW!**

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



# IACC Portfolio Analysis Report



- 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

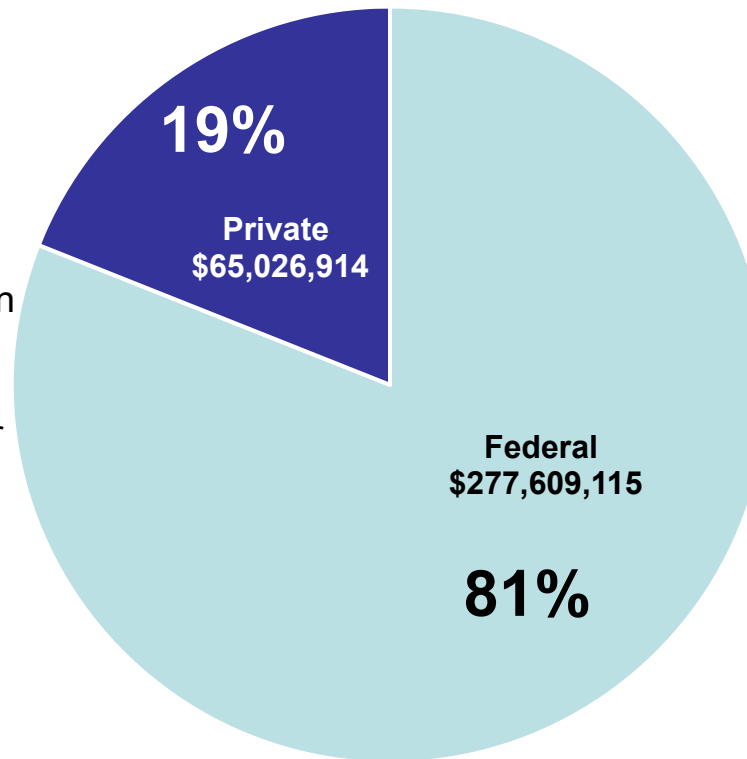
<https://iacc.hhs.gov/portfolio-analysis/2013/index.shtml>

# 2015 IACC ASD Portfolio Analysis

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

### 9 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

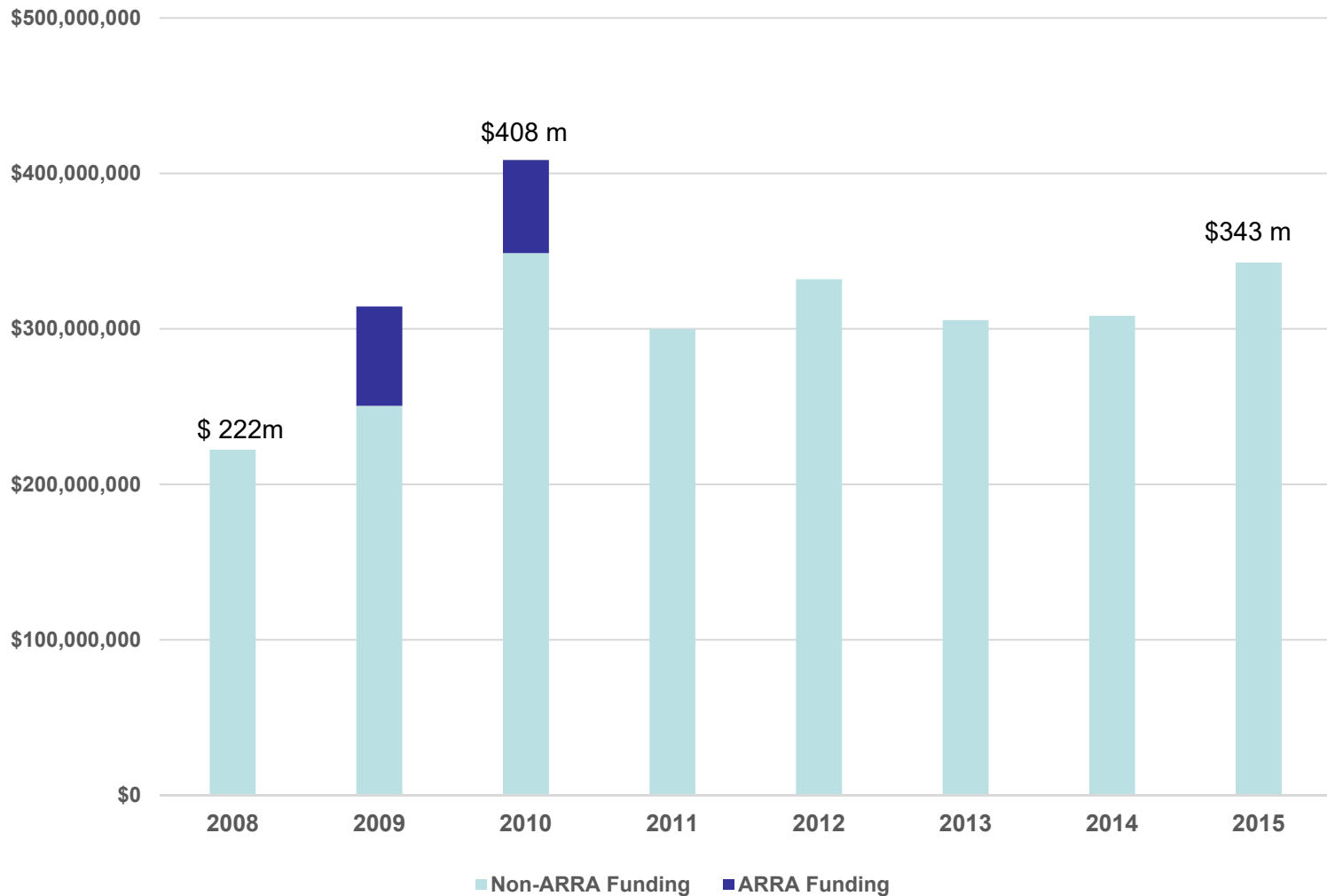


### 8 Federal Agencies:

- 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

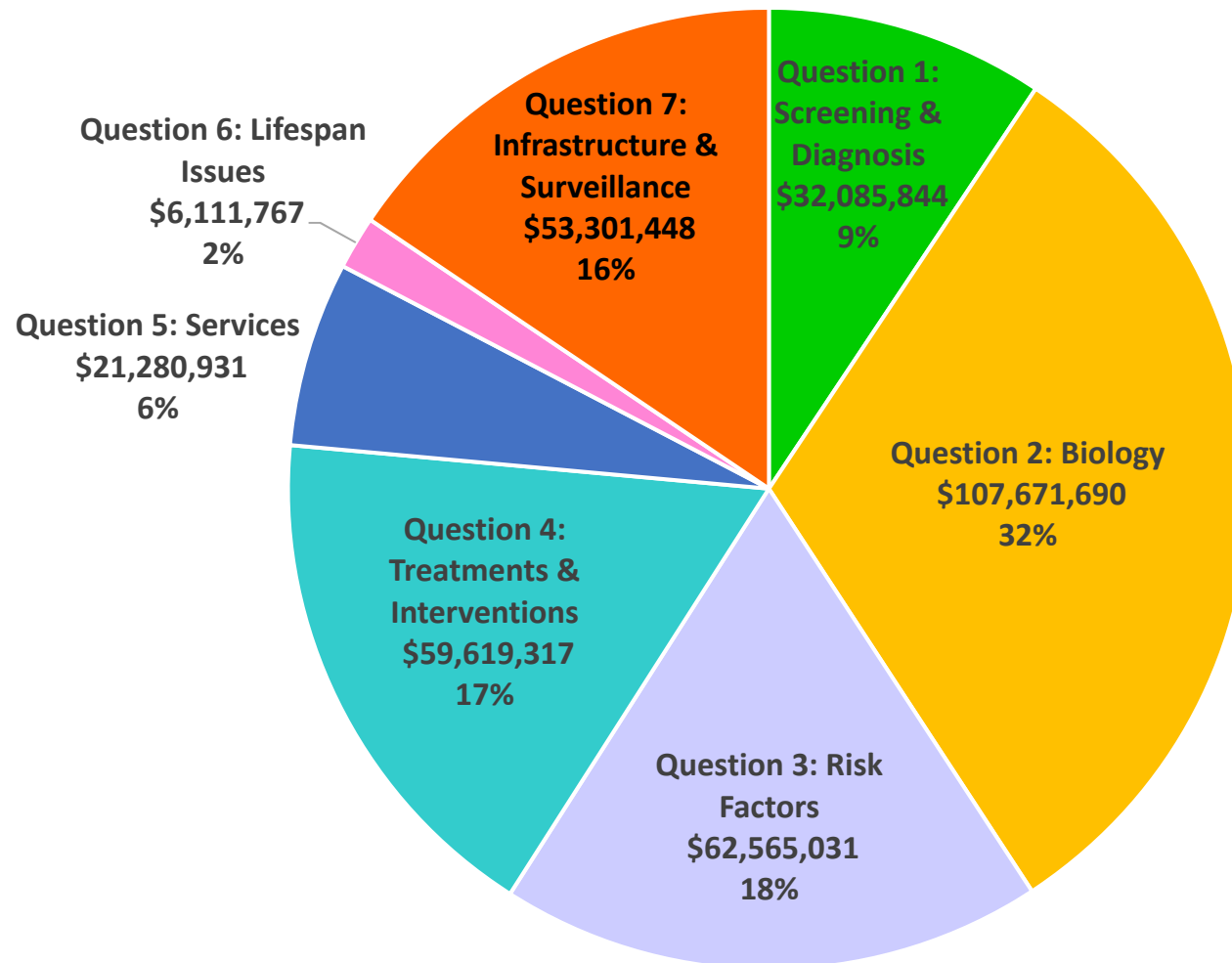
Combined Federal and Private Autism Research Funding  
2008-2015



# 2015 IACC ASD Portfolio Analysis

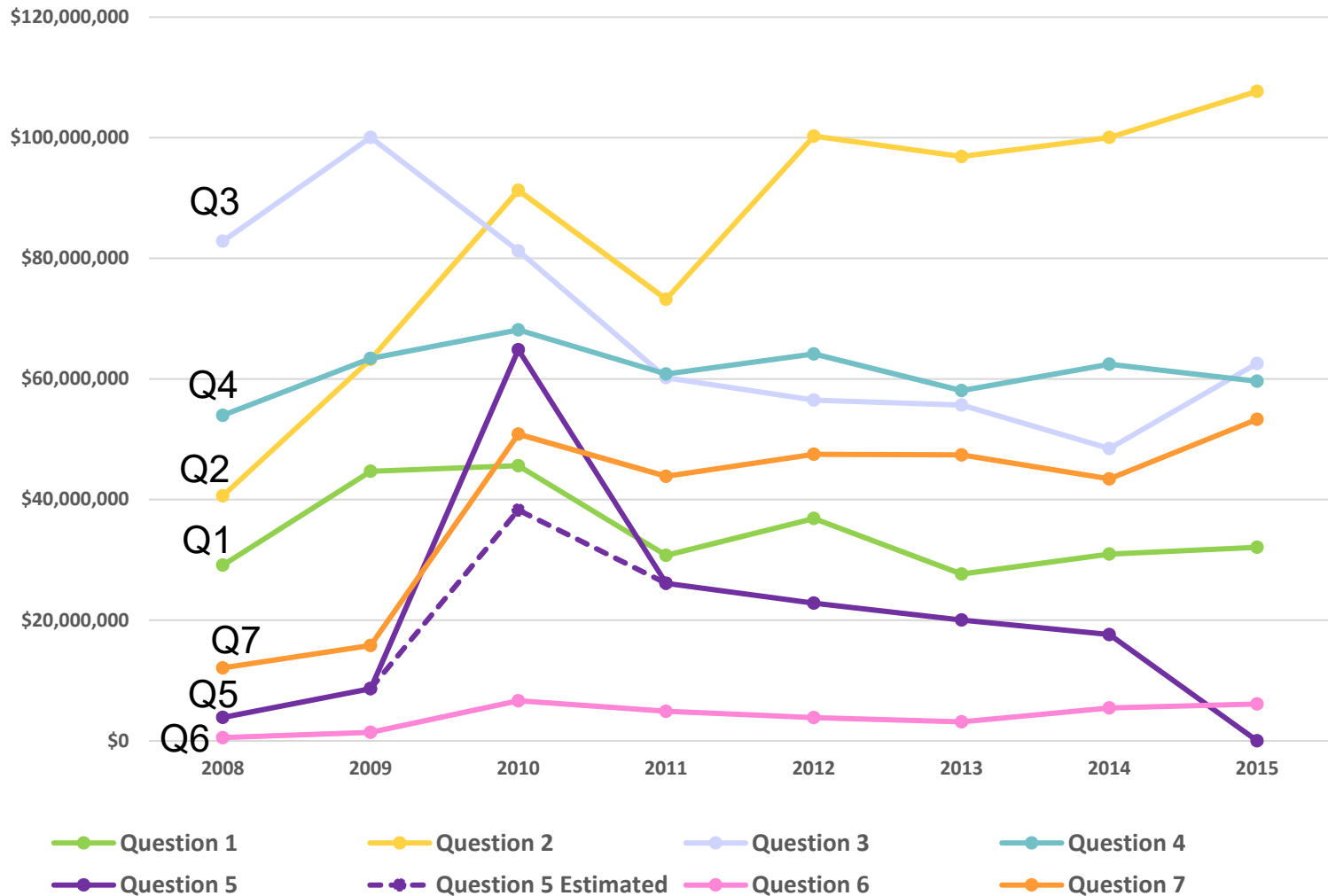
## ASD Research Funding by IACC Strategic Plan Question

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

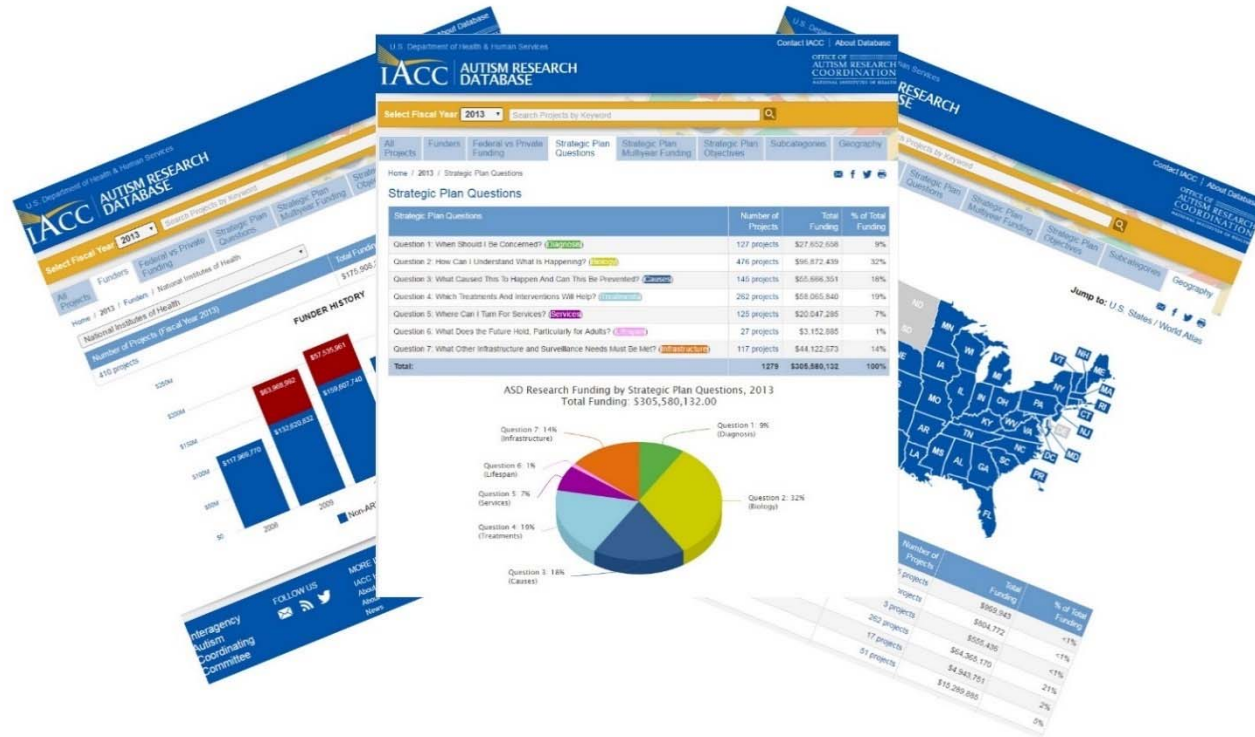


# 2015 IACC ASD Portfolio Analysis

2008-2015 ASD Research Funding



# 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/>

# 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:*

- Providing oral public comments at future IACC meetings or submitting written public comments for the meeting record
- Presenting 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)**



# OARC Staff

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

**Jamie Kleiner  
Summer Intern**

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

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

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

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

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



*Are you interested in getting involved in IACC?*

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