

# Meeting of the IACC

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## Committee Business

- **IACC Strategic Plan Update**
  - Discussion of chapters and objectives
  - Discussion of duplication of effort statement

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH and  
Executive Secretary, IACC

# IACC Committee Business

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

Director, Office of Autism Research Coordination

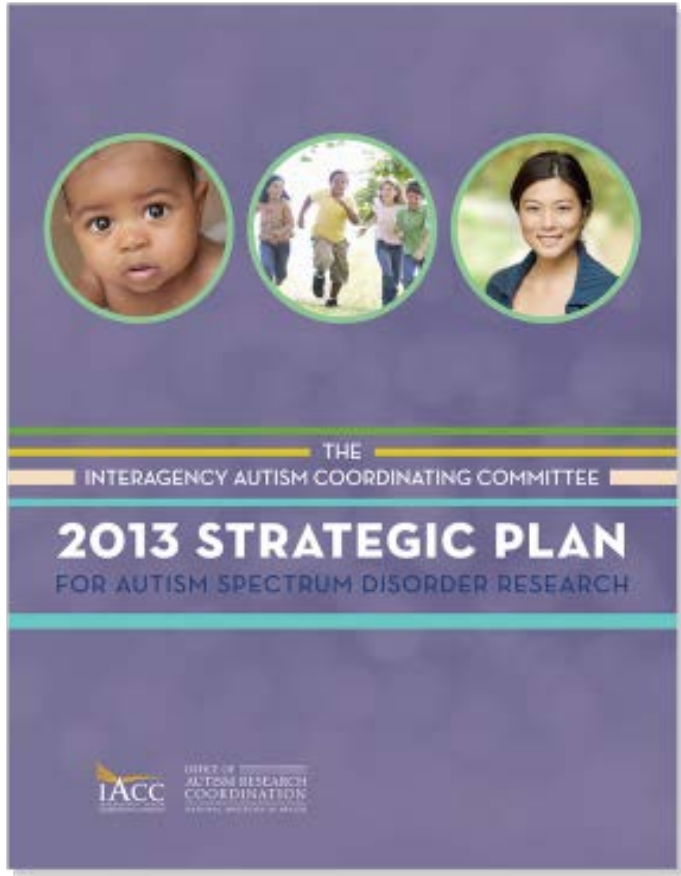
Executive Secretary, IACC

National Institute of Mental Health

IACC Full Committee Meeting

January 13, 2017

# IACC Strategic Plan Update



- **The IACC Strategic Plan provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.**
- **The first IACC Strategic Plan was launched in 2009 and its focus was research efforts.**
- **Under the Autism CARES Act, the IACC Strategic Plan is being expanded to address both research and services activities.**
- **The IACC Strategic Plan is organized around 7 consumer-based questions.**

# Working Group Activities

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- **The Committee formed 7 working groups to address the 7 questions of the Strategic Plan.**
- **Each of the 7 working groups completed a series of 3 conference calls and have developed the following for each of the 7 Question areas:**
  - **Draft chapter outline that describes progress in the field, gaps/needs, barriers, and opportunities**
  - **Proposed revisions to Chapter Titles and Aspirational Goals**
  - **Three broad draft objectives for each Question; examples of responsive research projects and services or policy activities may be included under each objective**
  - ***Today: Review and discuss draft Strategic Plan materials***

# Structure of Strategic Plan Chapters

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For each Question:

- **Title**
- **Aspirational Goal**
- **Introduction that describes content of question area**
- **Overview of progress toward meeting previous plan's objectives (OARC will provide)**
- **For each of the key topics identified:**
  - **Overview of recent progress in the field**
  - **Gaps, opportunities, and needs in research, services, and policy**
- **3 New Broad-based Objectives that can address research, services, and policy**

# Question 1

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## Question 1 Key Topics

- **Improve implementation of diagnostic and screening tools, especially in community settings**
- **Address disparities through improved early access to diagnostic and screening tools and culturally appropriate instruments**
- **Develop a culturally competent workforce through increased workforce training and funding**
- **Improve collaboration among different sectors of the service system**

# Question 1

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## Question 1 Title

**Previous:**

**When Should I Be Concerned?**

**Proposed:**

**What Are the Signs of ASD and Why Is Early  
Detection So Important?**

# Question 1

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## Question 1 Aspirational Goal

### **Previous:**

Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest.

### **Proposed:**

**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.**



# Question 1

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## Question 1 Objectives

- 1. Strengthen the evidence base for the benefits of early detection of ASD.**
- 2. Reduce disparities in early detection by removing barriers to access and enhance culturally appropriate outreach efforts.**
- 3. Improve/validate existing, or develop new tools, methods, and service delivery models for detecting ASD that will facilitate timely linkage of individuals with ASD to early, targeted interventions and supports.**

# Question 2

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## Question 2 Key Topics

- **Understand the molecular mechanisms by which genetic mutations or common variants lead to ASD, brain structure and function in individuals with ASD, and brain circuit abnormalities implicated in validated animal models**
- **Understand the underlying biology of co-occurring conditions, as well as phenotypes and subtypes of ASD**
- **Need for more longitudinal data to understand brain development and developmental trajectories**
- **Establish standardized data elements and data acquisition parameters, and improve replicability**
- **Assemble larger research teams, including the participation of individuals on the autism spectrum, and grow a more diverse workforce**

# Question 2

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## Question 2 Title

### **Previous:**

How Can I Understand What Is Happening?

### **Proposed:**

**What Is the Biology Underlying ASD?**

# Question 2

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## Question 2 Aspirational Goal

### Previous:

Discover how ASD affects development, which will lead to targeted and personalized interventions.

### Proposed:

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

# Question 2

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## Question 2 Objectives

- 1. Foster research to better understand the genetic and non-genetic components 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.**

# Question 3

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## Question 3 Key Topics

- **Identify genetic risk factors in the context of diverse populations and sex differences**
- **Understand how multiple risk factors combine to result in phenotype**
- **Understand the effects of environmental exposures during early development in diverse populations**
- **Understand interactions between genes and environment and the biological mechanisms underlying risk factors**
- **Improve data access and data sharing**
- **Foster a multidisciplinary workforce**

# Question 3

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## Question 3 Title

### **Previous:**

**What Caused This To Happen and Can It Be Prevented?**

### **Proposed:**

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

# Question 3

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## Question 3 Aspirational Goal

### Previous:

Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD.

### Proposed:

Causes of ASD will be discovered that inform **diagnosis**, prognosis, and interventions and lead to prevention/preemption of the challenges and disabilities of ASD.



# Question 3

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## Question 3 Objectives

- 1. Strengthen understanding of genetic risk 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 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 factors interact through specific biological mechanisms to manifest in ASD phenotypes.**

# Question 4

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## Question 4 Key Topics

- **Develop a range of different intervention types, including technology-based and parent- and caregiver-mediated interventions, among others**
- **Improve evidence-based approaches, community-based approaches, and treatments for co-occurring conditions, minimally verbal individuals, and different age groups**
- **Improve outcome measures and metrics for measuring treatment response, including in the context of sex differences, subgroups, and personalized medicine**
- **Recommend strategies for accelerating research translation, providing incentives for industry involvement, and increasing access to treatments and interventions**
- **Prepare a workforce skilled in implementation and dissemination of evidence based practices**

# Question 4

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## Question 4 Title

**Keep current:  
Which Treatments and Interventions Will  
Help?**

# Question 4

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## Question 4 Aspirational Goal

### Previous:

Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for maximizing quality of life and health for people with ASD.

### Proposed:

**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.**

# Question 4

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## Question 4 Objectives

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

# Question 4

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## **Cross-cutting themes (applicable to all three Question 4 objectives)**

- 1. Enhance understanding of the brain basis and mechanisms underlying these therapeutic approaches.**
- 2. Maximize effectiveness for individuals by taking advantage of combination therapies.**
- 3. Develop more robust standardized outcome measures, including adaptive measures, predictive measures, measures that address heterogeneity, and measures of practical outcomes that will help better target therapies to individual needs.**
- 4. Ensure support for the entire intervention research and development pipeline.**
- 5. Support translation of research to community-based practice and use of effective dissemination strategies to maximize uptake of evidence-based practice.**

# Question 5

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## Question 5 Key Topics

- **Improve the quality of the education and healthcare systems through increased portability, better access, and valid outcome measures**
- **Ensure lifelong supports, including services for co-occurring conditions, person-centered planning and choice, and housing and communication supports**
- **Foster a larger, appropriately trained, diverse workforce, including providers and practitioners, who can meet service needs across a variety of community contexts**
- **Address existing policy barriers to coordination of services/providers and personalized services**

# Question 5

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## Question 5 Title

**Previous:**

**Where Can I Turn for Services?**

**Proposed:**

**What Kinds of Services and Supports Are Needed to Maximize Quality of Life for People on the Autism Spectrum?**



# Question 5

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## Question 5 Aspirational Goal

### Previous:

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

### Proposed:

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**.

# Question 5

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## Question 5 Objectives

- 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

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## Question 6 Key Topics

- **Support individuals with ASD as they transition to adulthood, including aspects of health, employment, education, and social and community participation**
- **Improve the full range of health and healthcare for adults on the spectrum, including preventative care, mental health, physical health, co-occurring conditions, and aging**
- **Address issues of safety, including wandering, self-harm, criminal justice issues, and victimization**
- **Provide adults with employment and financial planning supports, social and recreational opportunities, housing, and long-term supports**
- **Increase research on effective caregiver supports across the lifespan**

# Question 6

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## Question 6 Title

### **Previous:**

**What Does the Future Hold, Particularly for Adults?**

### **Proposed:**

**How Can We Meet the Needs of People With ASD [As They Progress Into and Through Adulthood] [Or Across the Lifespan]?**

# Question 6

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## Question 6 Aspirational Goal

### Previous:

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

### Proposed:

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.

# Question 6

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## Question 6 Objectives

- 1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and continue to provide additional supports throughout the lifespan.**
- 2. Improve health, safety, and well-being of individuals on the autism spectrum across the lifespan.**
- 3. Increase acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum.**

# Question 7

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## Question 7 Key Topics

- **Support brain banking, tissue collection, and efforts to encourage donation and participation in research**
- **Continue ongoing surveillance efforts, and consider methods for understanding prevalence in adults**
- **Provide resources to support and expand data networks for the purpose of improved data sharing and data accessibility**
- **Build virtual cohorts, and use technology and surveys to collect data**
- **Support workforce training that fosters skills in collaboration, dissemination of science, and communication with the public**
- **Engage in global efforts, sharing strategies and best practices to support people on the autism spectrum and their families**

# Question 7

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## Question 7 Title

### **Previous:**

**What Other Infrastructure and Surveillance Needs Must Be Met?**

### **Proposed:**

**How Do We Continue to Build, Expand, and Enhance the Infrastructure System to Meet the Needs of the ASD Community?**



# Question 7

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## Question 7 Aspirational Goal

### Previous:

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

### Proposed:

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

# Question 7

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## Question 7 Objectives

- 1. Promote growth and integration of the biorepository infrastructure.**
- 2. Develop, enhance, and link the data infrastructure.**
- 3. Develop the human infrastructure to disseminate research, support community-based service delivery, and communicate science.**

# Strategic Plan Update Requirements: Duplication

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- **The Autism CARES Act requires the IACC in its Strategic Plan to provide:**
  - **“Recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative.”**
- **This requirement was based on a 2013 report by the GAO that stated concerns about potential for duplication in the research portfolio**
- **At the October 2016, the committee shared input on this topic; Alison Singer volunteered to draft a statement to meet the Autism CARES Act requirement**
- **The draft statement has been circulated**

**Comments?**

# Meeting of the IACC

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## Committee Business

- **IACC Strategic Plan Update (continued)**
  - Discussion of budgetary requirements
- **IACC Summary of Advances**

**Susan Daniels, Ph.D.**

Director, Office of Autism Research Coordination, NIMH and  
Executive Secretary, IACC

# Strategic Plan Update: Budgetary Requirements

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- **The Autism CARES Act requires the IACC Strategic Plan to include “proposed budgetary requirements.”**
- **The previous Strategic Plan provided estimated budgetary requirements for each objective**
- **Does the committee want to develop budgetary requirements based on the objectives, the questions, or the overall plan, keeping in mind that the new objectives will be broad and inclusive of both research and services activities?**
- **Does the committee want to try to estimate actual budgets or project percentage increases, decreases, etc.? Growth over time?**

# Preliminary Data: 2015 IACC Portfolio Analysis Report



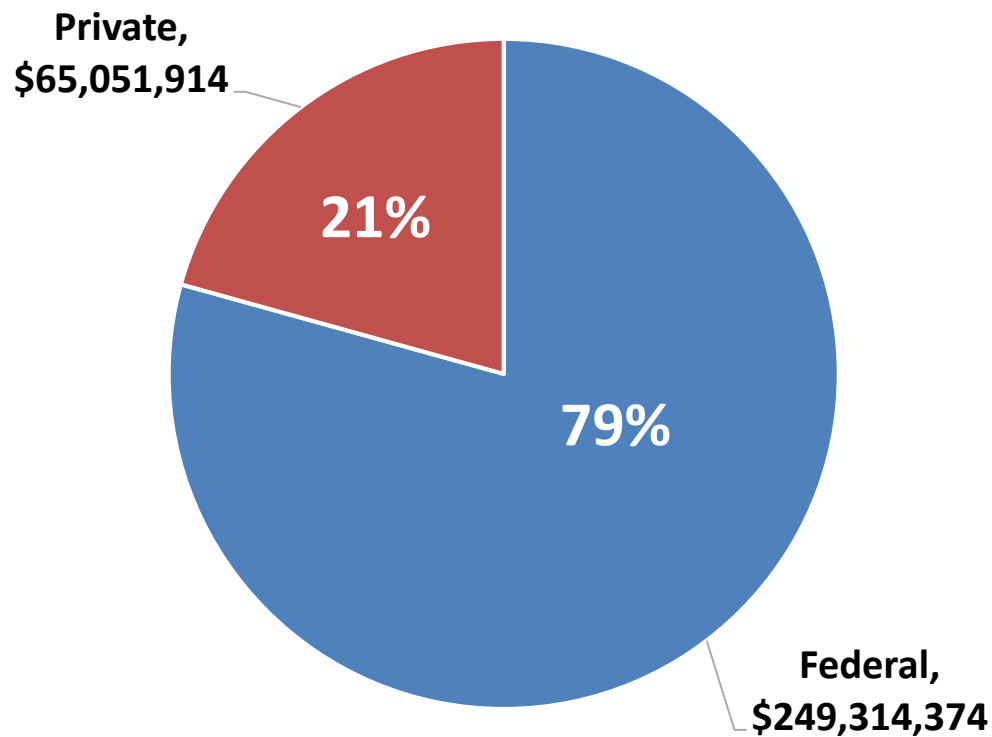
- 2015 ASD research portfolio data have been collected from 18 funders, and preliminary analysis is available for use by the IACC for the IACC Strategic Plan Update
- The analysis provides detailed information about the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the research funding landscape and trends
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan

# Proportion of Federal and Private Funds Supporting ASD Research - 2015

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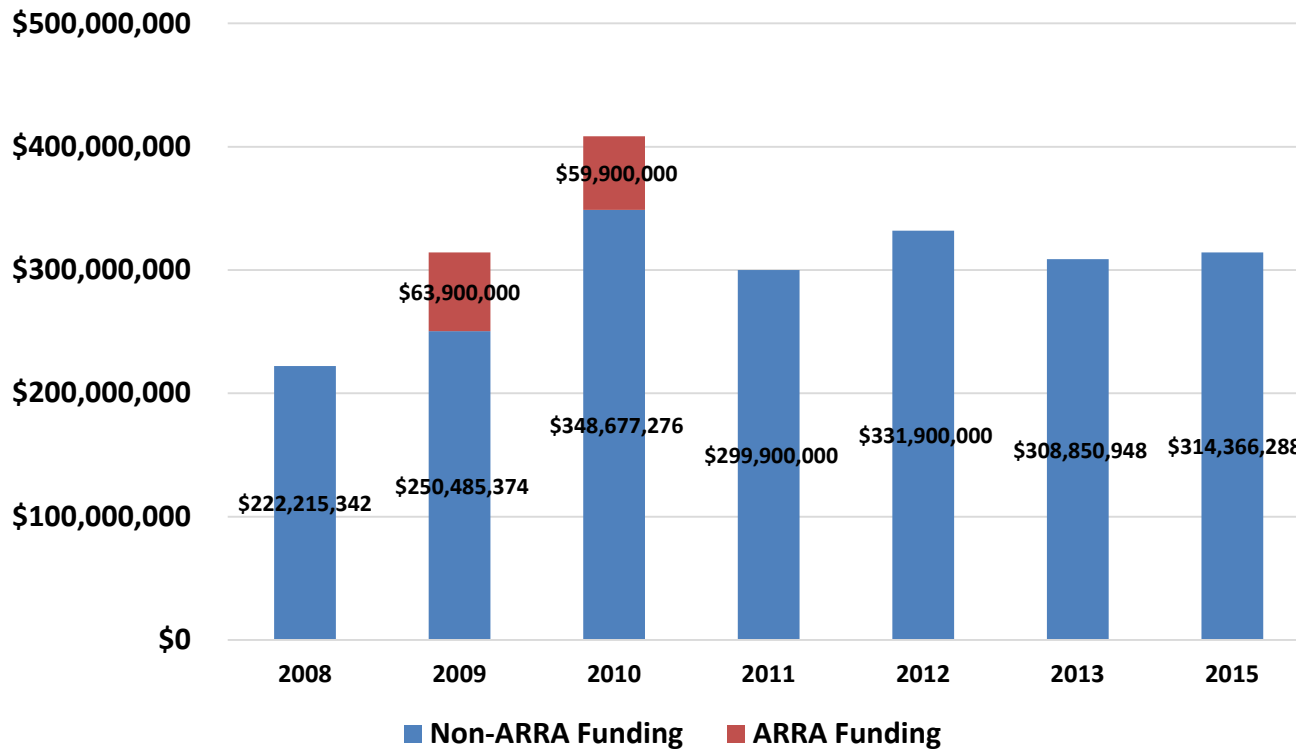
**2015 Total Funding: \$314,366,288**

**Number of Projects: 1,311**



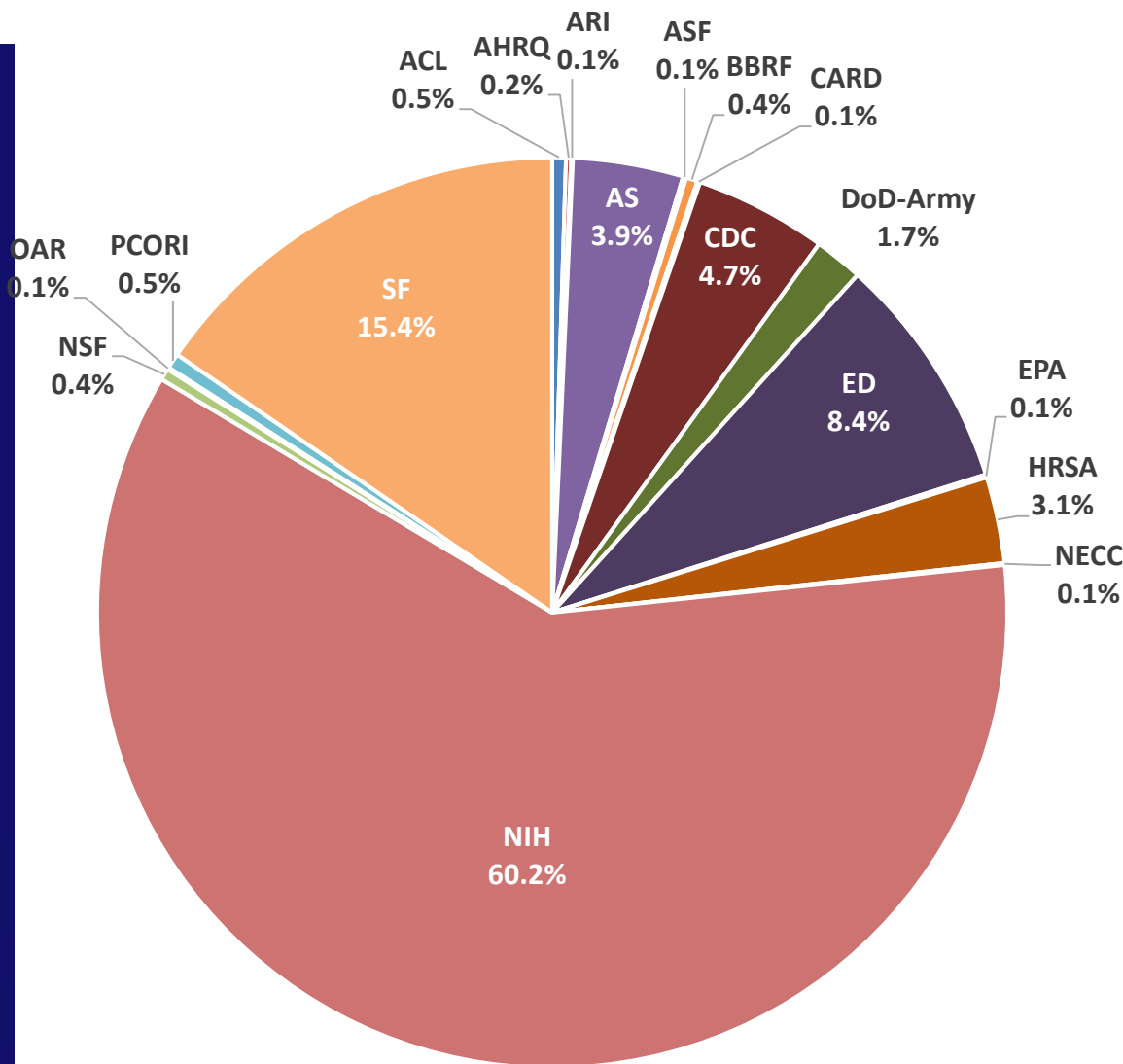
Overall funding has decreased since 2012 from \$331.9 m; federal was 78% \$260 m; private was 22% \$71m

## Combined Federal and Private Autism Research Funding 2008-2015 *(not including 2014 data)*



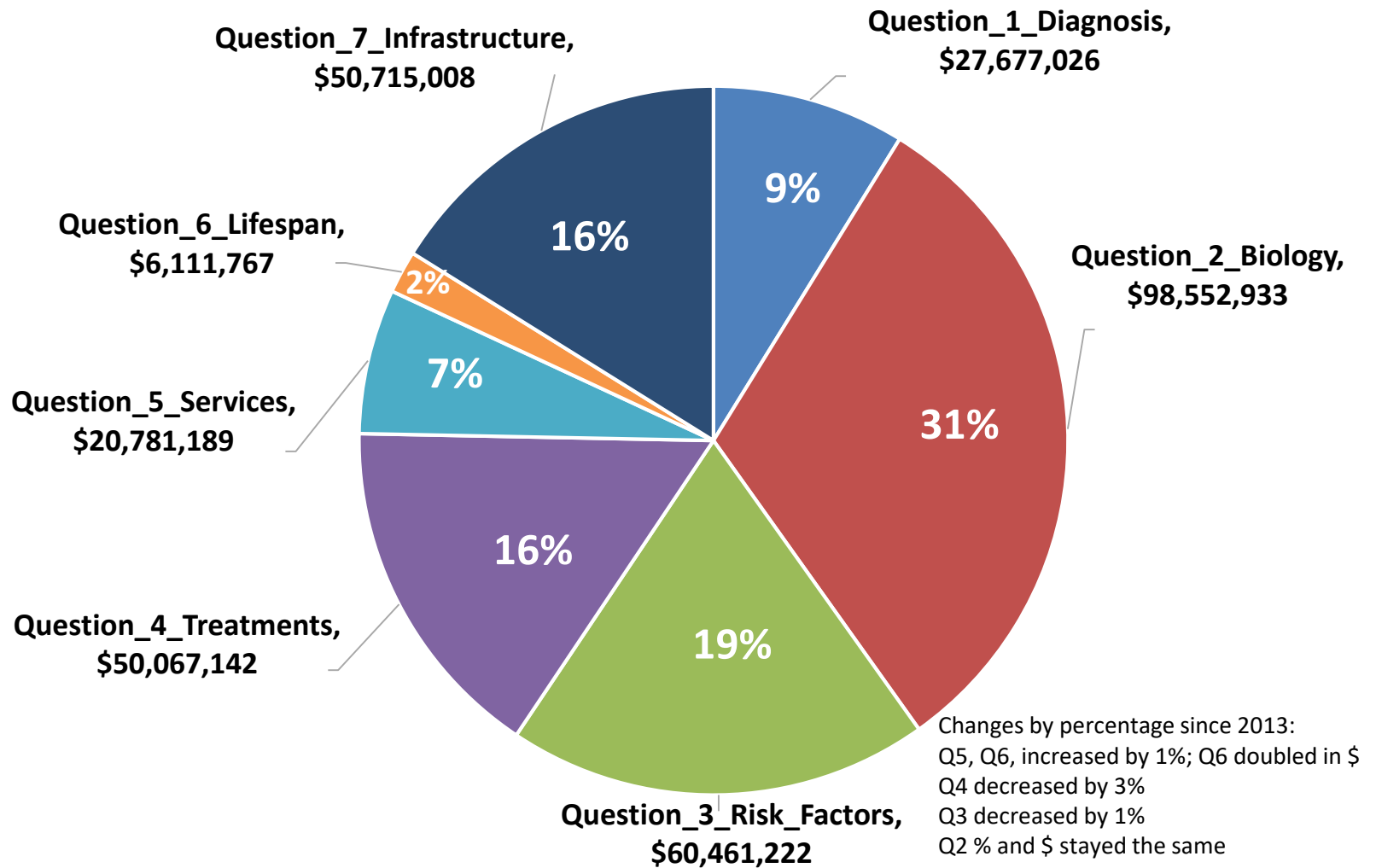


# 2015 ASD Research Portfolio Analysis: Preliminary Data



Federal or Private Funder	2015 Funding	Percentage of 2015 Funding
ACL	\$ 1,528,535	0.5%
AHRQ	\$ 576,949	0.2%
ARI	\$ 179,456	0.1%
AS	\$ 12,324,957	3.9%
ASF	\$ 355,000	0.1%
BBRF	\$ 1,290,484	0.4%
CARD	\$ 314,060	0.1%
CDC	\$ 14,789,418	4.7%
DoD-Army	\$ 5,440,886	1.7%
ED	\$ 26,362,194	8.4%
EPA	\$ 343,850	0.1%
HRSA	\$ 9,618,017	3.1%
NECC	\$ 219,416	0.1%
NIH	\$ 189,362,799	60.2%
NSF	\$ 1,291,726	0.4%
OAR	\$ 229,755	0.1%
PCORI	\$ 1,695,006	0.5%
SF	\$ 48,443,781	15.4%
<b>TOTAL</b>	<b>\$ 314,366,288</b>	<b>100%</b>

## Percentage of 2015 Funding by IACC Strategic Plan Question



# Proposed Budgetary Requirements for Research

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## Possible Options:

- **Base proposed budgetary requirements on Questions?**
- **Base proposed budgetary requirements on objectives?**
- **Base proposed budgetary requirements on the entire research budget or on the federal research budget?**
- **Could set a target amount of funding to reach by a certain year; percentage increase to reach by a certain year.**

# Services Budget Estimate

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**How can the IACC get a baseline on services expenditures that it can use as a basis for recommendations?**

**Proposal:**

**Number of people served and budget for key categories:**

- **Medicaid** (CMS)
- **Private insurance** (NIH, others?)
- **Public education** (Dept. of Ed.)
- **Vocational rehabilitation** (ACL/NIDILRR)

# Services Budget Estimate

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## **Alternative or Additional Services Data Collection:**

**Identify gaps on a qualitative basis by requesting data from federal agencies about autism-specific service programs?**

# 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 selected by the IACC
- Covers:
  - Prevalence
  - Diagnosis
  - Biology
  - Risk factors
  - Interventions
  - Lifespan issues

# Summary of Advances Process

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- **Monthly solicitation from OARC to collect nominated advances from IACC members**
- **Advances compiled quarterly and discussed at IACC meetings**
- **At January IACC meeting, discussion of top articles among those nominated**
- **Decide on remainder of process – additional nominations or vote based on revised list from today’s discussion?**
- **Does the Committee want to accept other organizations’ lists as “en bloc” nomination submissions?**

# Summary of Advances Nominations Stats

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- **15 IACC members submitted a total of 59 nominations:**
  - **Question 1 (Diagnosis & Screening): 5**
  - **Question 2 (Biology): 14**
  - **Question 3 (Risk Factors): 7**
  - **Question 4 (Treatments & Interventions): 19**
  - **Question 5 (Services): 4**
  - **Question 6 (Lifespan Issues): 8**
  - **Question 7 (Infrastructure & Surveillance): 2**



# Summary of Advances Process

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- **After today – solicit more nominations or vote from current list?**
- **Do we still want to select a top 20/21?**

## **Process following final selections:**

- **Selected articles are summarized**
- **Nominated articles not selected are listed in the appendix**
- **Draft publication is prepared and sent out to committee for very brief review**
- **Final publication is prepared for release**
- **Target date – April 26**



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