

IACC Committee Business

IACC Full Committee Meeting
October 24, 2017



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Thanks to OARC Staff



Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

Jamie Kleiner
Science Policy Intern

Rebecca Martin, M.P.H
Public Health Analyst

Angelice Mitrakas, B.A.
Management Analyst

Karen Mowrer, Ph.D.
Science Policy Analyst

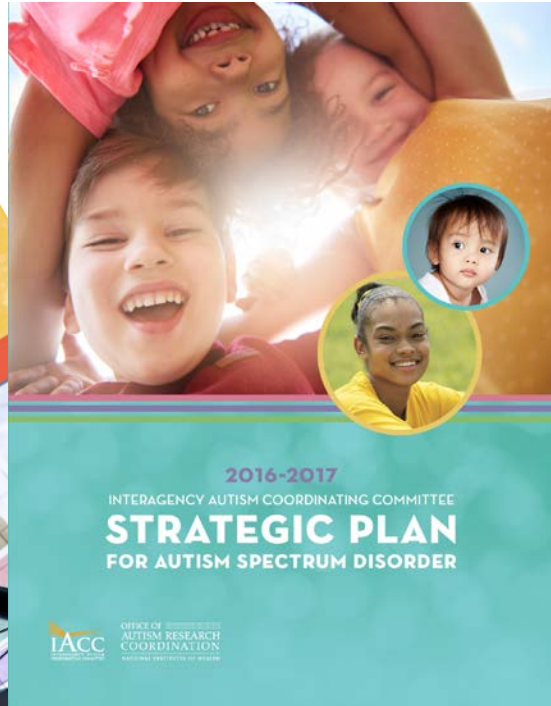
Julianna Rava, M.P.H.
Science Policy Analyst

NEW! Matthew Vilnit, B.S.
Operations Coordinator

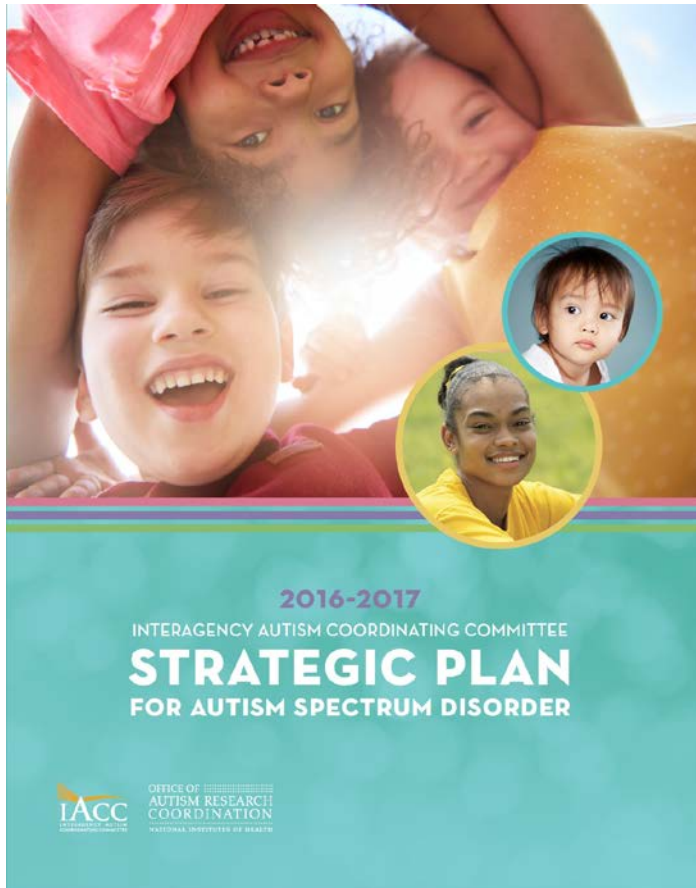
Jeff Wiegand, B.S.
Web Development Manager



New publications available on IACC website



2016-2017 IACC Strategic Plan



- 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 community-based questions.
- The Plan includes 23 new objectives that address both research and services activities.

2016-2017 IACC Strategic Plan – New Objectives



QUESTION 1: HOW CAN I RECOGNIZE THE SIGNS OF ASD, AND WHY IS EARLY DETECTION SO IMPORTANT?

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.

CROSS-CUTTING

1. Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnoses, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.

QUESTION 2: WHAT IS THE BIOLOGY UNDERLYING ASD?

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.

2016-2017 IACC Strategic Plan – New Objectives



QUESTION 3: WHAT CAUSES ASD, AND CAN DISABLING ASPECTS OF ASD BE PREVENTED OR PREEMPTED?

1. Strengthen understanding of genetic risk and resilience factors for ASD across the full diversity and heterogeneity of those with ASD, enabling development of strategies for reducing disability and co-occurring conditions of ASD.
2. Understand the effects on ASD and resilience of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions 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: WHICH TREATMENTS AND INTERVENTIONS WILL HELP?

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

2016-2017 IACC Strategic Plan – New Objectives



QUESTION 5: WHAT KINDS OF SERVICES AND SUPPORTS ARE NEEDED TO MAXIMIZE QUALITY OF LIFE FOR PEOPLE ON THE AUTISM SPECTRUM?

1. Scale up and implement 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.

QUESTIONS 6: HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and 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.

2016-2017 IACC Strategic Plan – New Objectives



QUESTIONS 6: HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and 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.

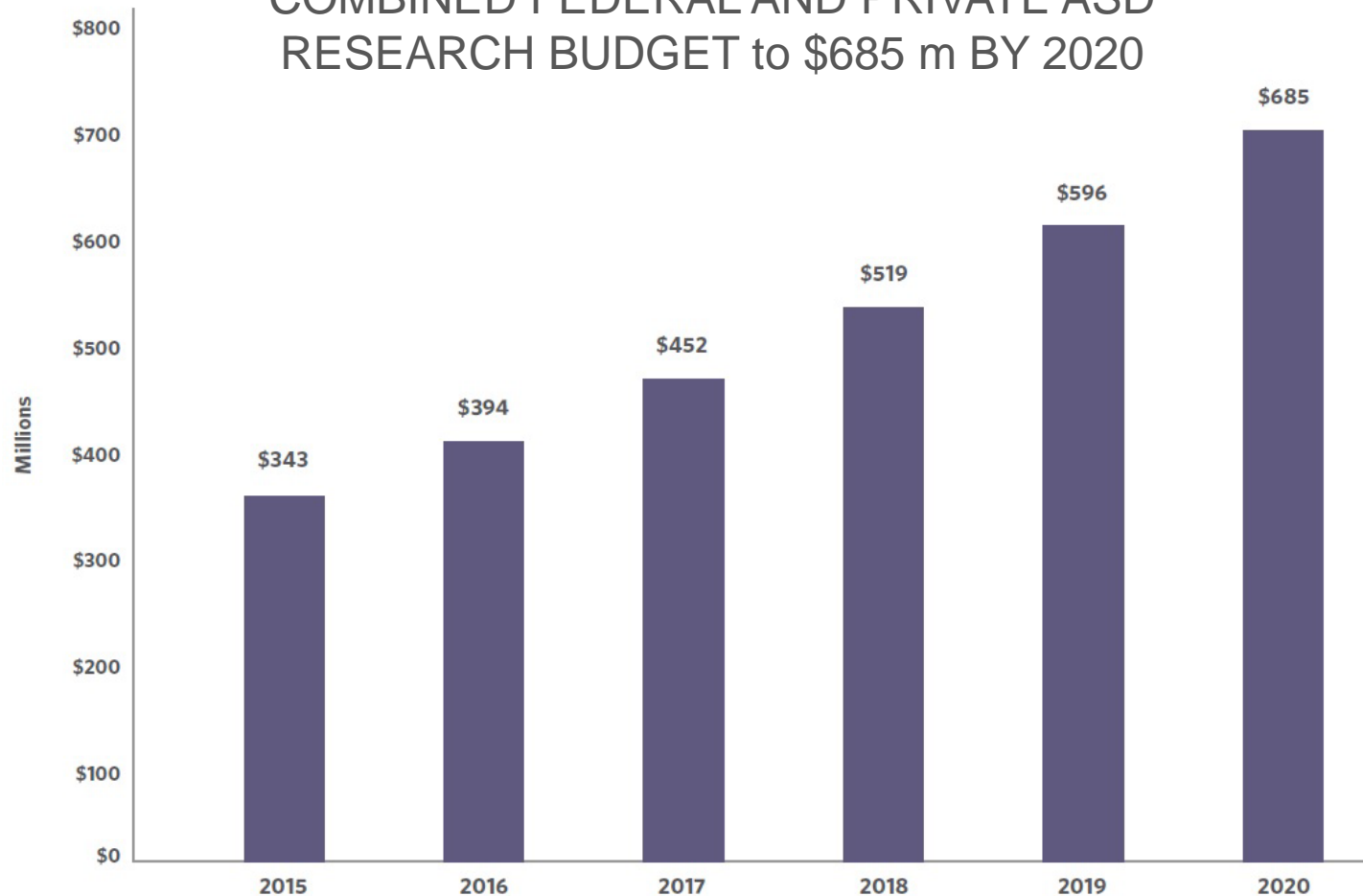
QUESTION 7: HOW DO WE CONTINUE TO BUILD, EXPAND, AND ENHANCE THE INFRASTRUCTURE SYSTEM TO MEET THE NEEDS OF THE ASD COMMUNITY?

1. Promote growth, integration, and coordination of biorepository infrastructure.
2. Develop, enhance, and link data repositories.
3. Strengthen ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible.

2016-2017 IACC Strategic Plan – Budget Recommendation



THE IACC RECOMMENDS DOUBLING THE COMBINED FEDERAL AND PRIVATE ASD RESEARCH BUDGET to \$685 m BY 2020



2014-2015 IACC Portfolio Analysis Report



INTERAGENCY AUTISM COORDINATING COMMITTEE

2014-2015 IACC AUTISM SPECTRUM DISORDER RESEARCH

PORTFOLIO ANALYSIS REPORT

Prepared by the Office of Autism Research Coordination (OARC),
on behalf of the Interagency Autism Coordinating Committee (IACC)

- The *2014-2015 IACC ASD Research Portfolio Analysis Report* represents the eighth year of data collected and the sixth comprehensive report of U.S. ASD research funding across both the Federal and private sectors.
- It is the last analysis that measure research progress by the objectives from the *2011 IACC Strategic Plan*.
- 2014 and 2015 ASD portfolio data are now available through the [IACC/OARC Autism Research Database](https://iacc.oarc.hhs.gov/autism-research-database/)

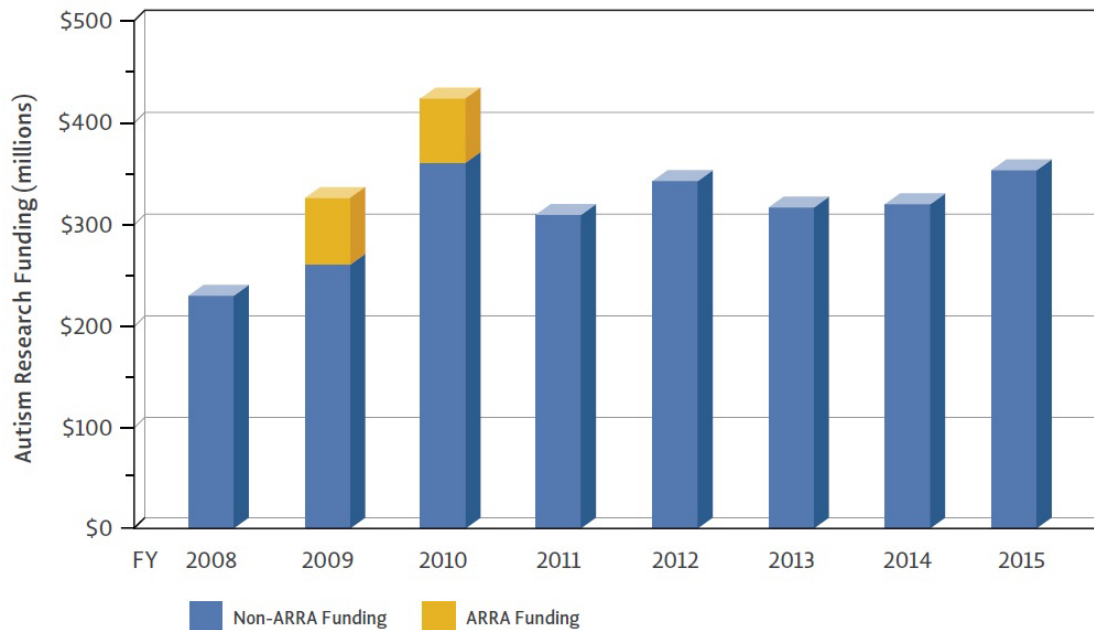


<https://iacc.hhs.gov/portfolio-analysis/2015/index.shtml>

2014-2015 IACC Portfolio Analysis Report



Combined Federal and Private Autism Research Funding
2008 - 2015



- Overall funding for ASD research totaled \$309.9 million and spanned 1,441 projects in 2014 and reached \$342.6 million covering 1,410 projects in 2015.
- Over the eight years, autism research showed a general upward trend in funding, increasing by 35% since 2008.

2014-2015 IACC Portfolio Analysis Report



Summary of Overall Progress on Strategic Plan Objectives through 2015



■ Inactive (Red) Objectives
■ Complete (Green) or Partially Complete (Yellow) Objectives

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Total	Percentage
Number of Complete Objectives	6	7	11	6	4	1	10	45	57.7%
Number of Partially Complete Objectives	3	2	4	6	5	7	4	31	39.7%
Number of Inactive Objectives	0	0	0	0	0	0	2	2	2.6%
Total	9	9	15	12	9	8	16	78	100%



In 2015, significant progress was made toward completing the objectives in the *2011 Strategic Plan*, with 97% (76 objectives) of the 78 objectives either partially or fully completed.

New IACC Working Groups



- In 2016 the IACC agreed to convene 3 working groups on issues of critical importance to the autism community, with work to begin following completion of the 2016-2017 IACC Strategic Plan

Topics:

- Health and Wellness
- Safety
- Housing

Health and Wellness Working Group



- Title: Improving Health Outcomes for Individuals on the Autism Spectrum
- Scope:
 - Health and general wellness
 - Co-occurring conditions and preventative approaches to address them, e.g. obesity
 - Co-occurring mental health conditions
 - Premature mortality
 - Medical practitioner training (i.e. increasing understanding of autism among physicians, supporting community doctors who provide medical care for adults with autism)
 - Parental Mental Health

Safety Working Group



Scope:

- Wandering
- Self-injurious behavior (or this could be part of co-occurring conditions)
- Seclusion and restraint
- Interactions with law enforcement

Housing Working Group



Scope:

- Research and best practices on housing
- Implementation of current federal regulations
- Housing issues faced by those with ASD with more severe disabilities

Working Groups: Next Steps



Questions:

- What products does the IACC want the working groups to develop as an outcome?
- What structure, activities, and timing will be most efficient to develop these products and allow the Committee to complete their work on these topics by September 2019?
- Can the products of the working groups be helpful toward meeting IACC requirements (i.e., producing an annual update of the Strategic Plan)?

Recent Event – Autism in Girls and Women seminar



- A panel discussion of issues concerning autism in girls and women
- Co-sponsored by OARC and NIMH Office of Research on Disparities and Global Mental Health (ORDGMH)
- Link to archived webcast available on IACC website:
<https://iacc.hhs.gov/meetings/autism-events/2017/september19/autism-in-girls.shtml>

