

IACC Committee Business

IACC Full Committee Meeting
January 16, 2019



Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Thank you to OARC Staff



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New option for submitting public comments



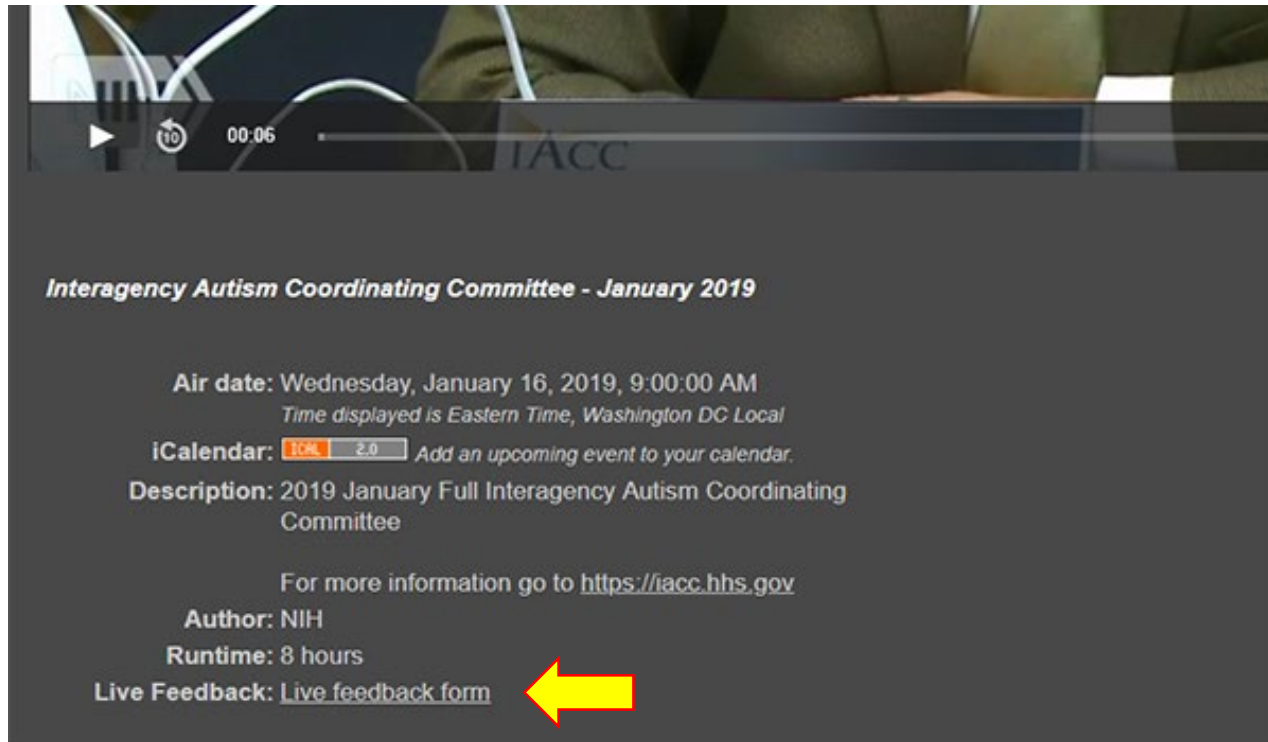
- Since 2008, the IACC has had two methods for public comment:
 - Written comments (submitted in advance)
 - Oral comments (presented in person)
- These are the methods used by the vast majority of federal advisory committees across the government

New option for submitting public comments



- The IACC is now offering a third option for public comments:
Live Feedback
 - This option will provide additional flexibility to those who are not able to attend the meetings in person or submit a written comment in advance
 - Comments can be submitted online from **9:00am – 11:00am** on the day of the meeting
 - Comments that adhere to the guidelines will be collected and presented to the IACC before the public comment session in the afternoon

Live feedback instructions



- Live feedback form is accessible from the IACC meeting videocast page: <https://videocast.nih.gov/summary.asp?live=29099&bhcp=1>
- For commenting guidelines, visit: <https://iacc.hhs.gov/meetings/iacc-meetings/2019/full-committee-meeting/january16/live-feedback.shtml>

Live feedback instructions

A screenshot of the NIH VideoCasting and Podcasting website. The header includes the U.S. Department of Health & Human Services logo and a search bar. The main banner features a woman's profile and a video player showing a man speaking. Below the banner is a navigation menu with links: VideoCast Home, FAQs, Player Software, Podcasts, RSS, Contact Us, Test Computer, Home, and New Features. The page content is titled "Live Feedback for Interagency Autism Coordinating Committee - January 2019". On the left, there is contact information for the NIH IT Service Desk. On the right, there is a feedback form with fields for "Your name", "Email address", "Organization" (with a dropdown menu showing "Non-NIH"), "Phone number", "Subject", and a "Comment" text area. A "Submit" button is at the bottom of the form. The NIH logo and "Center for Information Technology" text are at the bottom center.

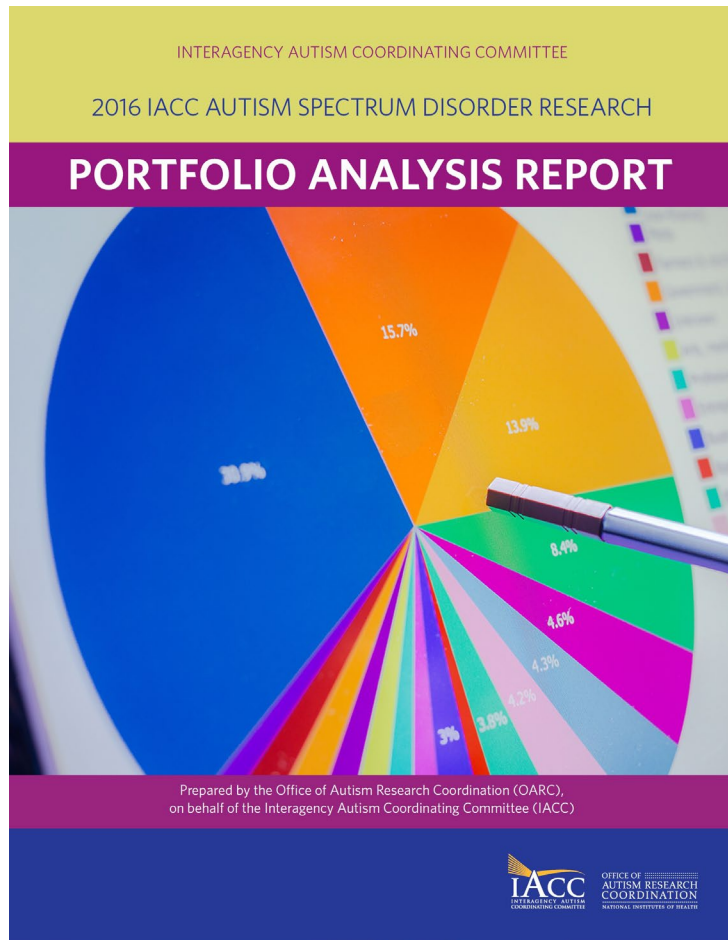
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Disability Accommodations



- Closed Captioning – available through the NIH VideoCast
- Quiet Room – started in April 2018
- CART Services – started in October 2018
- Other disability accommodations may be made available upon request

2016 IACC ASD Portfolio Analysis Report – Available now!



- This is the first *Portfolio Analysis Report* coding projects to the 23 new objectives of the 2016-2017 *IACC Strategic Plan*.
- To accompany the Report, detailed 2016 project data are now available in the [Autism Research Database \(ARD\)](https://iacc.hhs.gov/publications/autism-research-database/), accessible via the IACC website.

2016 IACC ASD Portfolio Analysis Report: Highlights



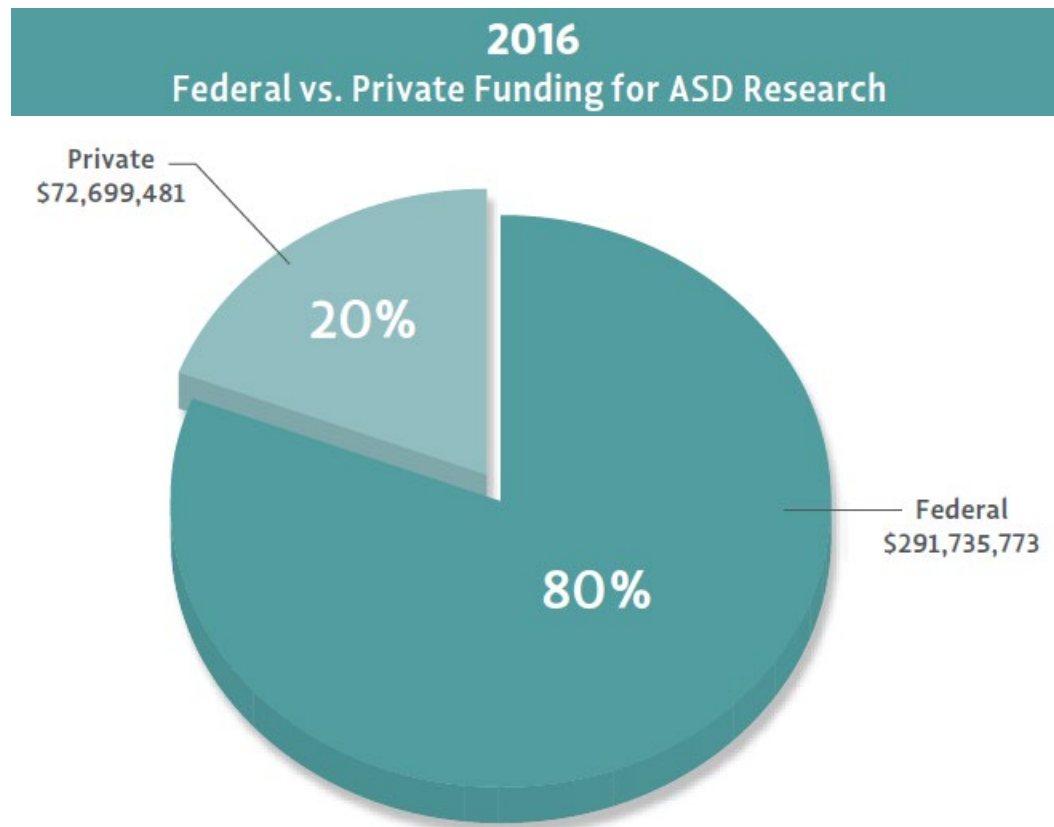
The analysis includes data from 18 federal agencies and private organizations.

FEDERAL AGENCIES	PRIVATE ORGANIZATIONS
<ul style="list-style-type: none">• Administration for Community Living (ACL)• Agency for Healthcare Research and Quality (AHRQ)• Centers for Disease Control and Prevention (CDC)• Department of Defense – Army (DoD – Army)• Department of Education (ED)• Environmental Protection Agency (EPA)• Health Resources and Services Administration (HRSA)• National Institutes of Health (NIH)• National Science Foundation (NSF)	<ul style="list-style-type: none">• Autism Research Institute (ARI)• Autism Science Foundation (ASF)• Autism Speaks (AS)• Brain & Behavior Research Foundation (BBRF)• Center for Autism and Related Disorders (CARD)• New England Center for Children (NECC)• Organization for Autism Research (OAR)• Patient-Centered Outcomes Research Institute (PCORI)• Simons Foundation (SF)

2016 IACC ASD Portfolio Analysis Report: Highlights



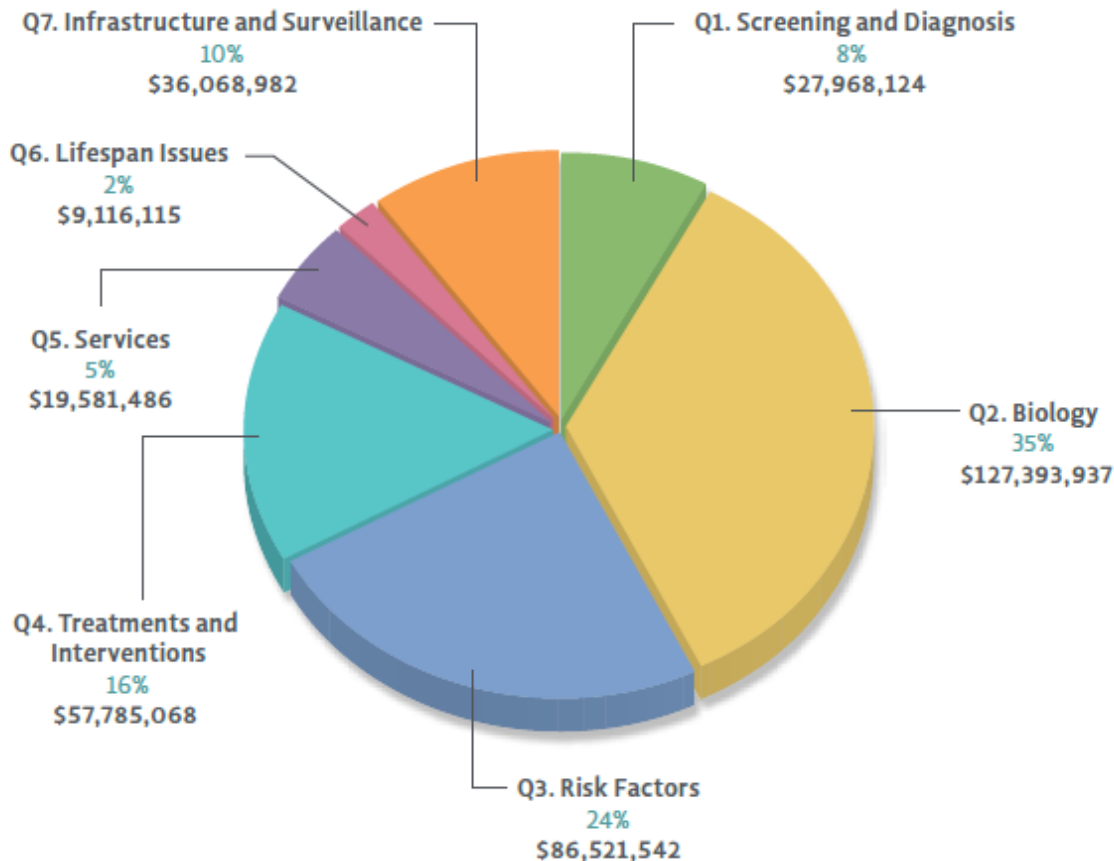
- ASD research funding totaled \$364,435,254 and included 1,360 projects.
- Federal agencies supported 80% of overall funding.



2016 IACC ASD Portfolio Analysis Report: Highlights



2016
ASD Research Funding by IACC Strategic Plan Question
Total Funding: \$364,435,254

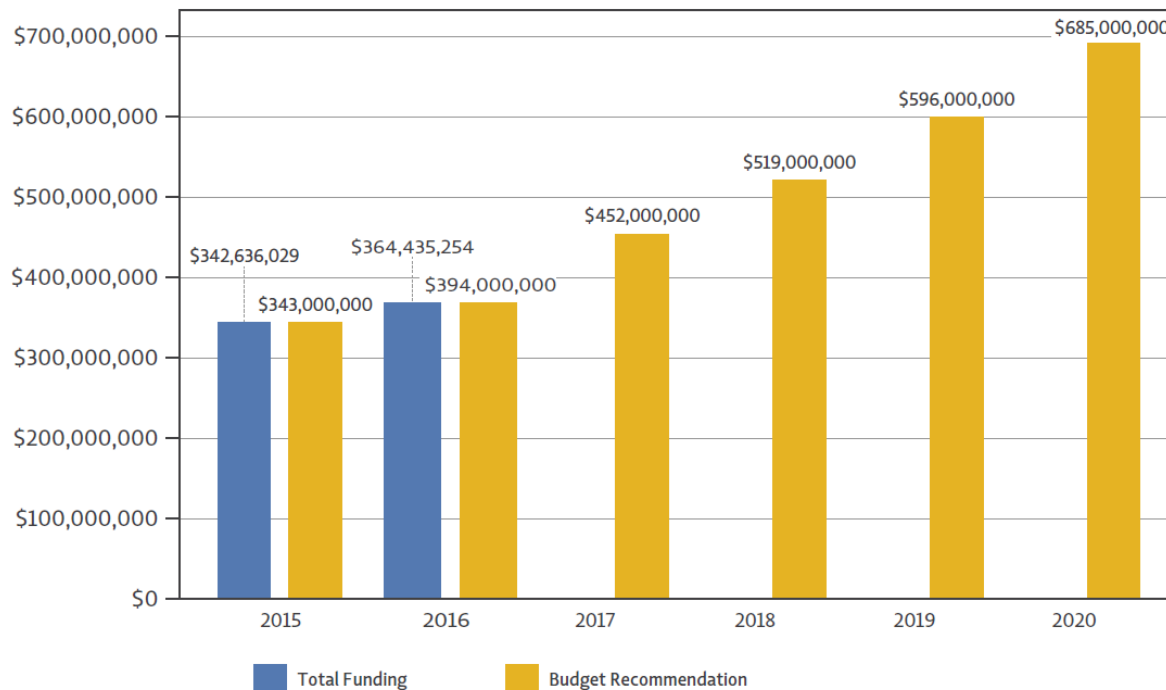


- Federal agencies and private organizations supported research in all seven of the *IACC Strategic Plan* questions.
- In 2016, Question 2 (Biology) continued to be the most highly-funded research area.

2016 IACC ASD Portfolio Analysis Report: Highlights



Total Reported ASD Funding compared to IACC Budget Recommendations



- The 2016-2017 IACC *Strategic Plan* calls for a doubling of the 2015 ASD research budget to \$685 million by 2020. To accomplish this goal, the Committee recommended a nearly 15% annual increase in ASD research funding.
- Since 2015, funding for autism research increased 6.3% in funding.

2016 IACC ASD Portfolio Analysis Report: Highlights



<i>IACC 2016-2017 Strategic Plan Objectives</i>	2016 Funding	Project Count
Question 1 - Screening and Diagnosis	\$27,968,124	107
1.1. Strengthen the evidence base for the benefits of early detection of ASD.	\$1,105,355	5
1.2. Reduce disparities in early detection and access to services.	\$6,728,655	16
1.3. 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.	\$19,941,251	82
1.O. Not specific to Question 1 objectives	\$192,864	4
Question 2 - Biology	\$127,393,937	491
2.1. 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.	\$ 96,027,190	402
2.2. Support research to understand the underlying biology of co-occurring conditions in ASD and to understand the relationship of these conditions to ASD.	\$8,449,763	37
2.3. 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.	\$12,885,786	17
2.O Not specific to Question 2 objectives	\$5,101,895	20

2016 IACC ASD Portfolio Analysis Report: Highlights



<i>IACC 2016-2017 Strategic Plan Objectives</i>	2016 Funding	Project Count
Question 3 - Risk Factors	\$86,521,542	240
3.1. 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 in ASD.	\$52,584,621	143
3.2. Understand the effects on ASD risk and resilience of individual and multiple exposures in early development, enabling development of strategies for reducing disability and co-occurring conditions in ASD.	\$14,434,906	46
3.3. Expand knowledge about how multiple environmental and genetic risk and resilience factors interact through specific biological mechanisms to manifest in ASD phenotypes.	\$18,728,984	46
3.O. Not specific to Question 3 objectives	\$547,789	1
Question 4 - Treatments and Interventions	\$57,785,068	254
4.1. Develop and improve pharmacological and medical interventions to address both core symptoms and co-occurring conditions in ASD.	\$23,567,797	70
4.2. Create and improve psychosocial, development, and naturalistic interventions for the core symptoms and co-occurring conditions in ASD.	\$24,175,752	118
4.3. Maximize the potential for technologies and development of technology-based interventions to improve the lives of people on the autism spectrum.	\$7,861,639	54
4.O. Not specific to Question 4 objectives	\$2,144,880	11

2016 IACC ASD Portfolio Analysis Report: Highlights



<i>IACC 2016-2017 Strategic Plan Objectives</i>	2016 Funding	Project Count
Question 5 – Services	\$19,581,486	84
5.1. Scale up and implement evidence-based interventions in community settings.	\$7,791,530	19
5.2. Reduce disparities in access and in outcomes for underserved populations.	\$209,020	3
5.3. 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.	\$7,500,189	39
5.O. Not specific to Question 5 objectives	\$4,080,747	23
Question 6 - Lifespan Issues	\$9,116,115	48
6.1. Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.	\$6,733,188	24
6.2. 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.	\$574,730	3
6.3. 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.	\$1,234,501	16
6.O. Not specific to Question 6 objectives	\$573,696	5

2016 IACC ASD Portfolio Analysis Report: Highlights



<i>IACC 2016-2017 Strategic Plan Objectives</i>	2016 Funding	Project Count
Question 7 - Infrastructure and Surveillance	\$36,068,982	136
7.1. Promote growth, integration, and coordination of the biorepository infrastructure.	\$4,202,497	17
7.2. Develop, enhance, and link the data repositories.	\$11,553,624	25
7.3. Expand and enhance the research and services workforce and accelerate the pipeline from research to practice.	\$9,891,875	58
7.4. 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.	\$7,422,083	18
7.O. Not specific to Question 7 objectives	\$2,998,903	18
Cross-Cutting Objective		
CC1. Support research to understand the underlying biology of sex differences in ASD, possible factors that may be contributing to underdiagnosis, unique challenges that may be faced by girls/women on the autism spectrum, and develop strategies for meeting the needs of this population.	\$5,189,546	20
Grand Total	\$364,435,254	1360

2016 IACC ASD Portfolio Analysis Report: Highlights



In addition, the *2016 IACC ASD Research Portfolio Analysis Report* includes:

- A map displaying institutions involved in ASD research across the U.S.
- A list of countries receiving ASD research funding from U.S. funders
- Funder contributions aligned with the seven *Strategic Plan* questions
- Subcategory analyses for each *Strategic Plan* question
- ASD research funding trends from 2008-2016 by *Strategic Plan* question

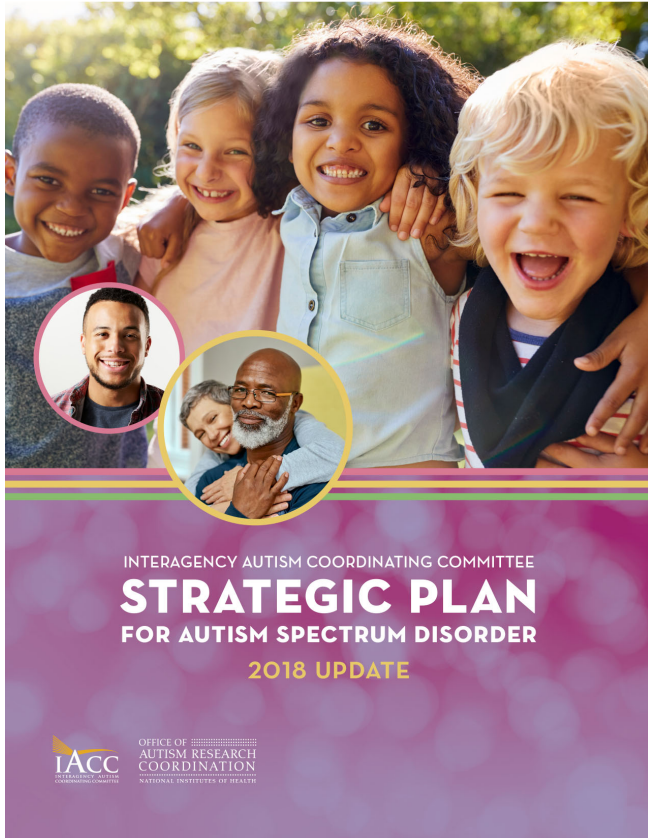
The full report is available at
<https://iacc.hhs.gov/publications/portfolio-analysis/2016/>

Autism CARES Act Report to Congress



- Report required by the Autism CARES Act
- Report details progress on activities related to ASD and other developmental disorders across the federal government
- On behalf of HHS, OARC coordinated responses from federal Departments/agencies and prepared the report
- Report expected in 2019

2018 IACC Strategic Plan Update



- The *2018 IACC Strategic Plan Update* will provide a summary of the IACC's 2018 activities and progress related to the *Strategic Plan*, including:
 - Summary of Health Outcomes working group and workshop
 - Summary of *2016 IACC Portfolio Analysis Report*
 - Summary of Autism CARES Act *Report to Congress*
- Committee members will receive a draft for review and comments
- Final publication expected in Spring 2019

Other reports in preparation



- *2017 IACC Portfolio Analysis Report*
 - OARC has collected 2017 data from funders, is in the process of performing analysis
 - Final report expected in 2019
- *2016 International Portfolio Analysis Report*
 - Canada, the United Kingdom, and the United States have contributed data for this report
 - Final report expected in Spring 2019

Improving Health Outcomes for Individuals on the Autism Spectrum WG



- The IACC voted to convene a working group on health and wellness issues for individuals with ASD
- Co-chairs: Dr. David Amaral and Dr. Julie Taylor
- The Working Group is exploring ways to:
 - Support research to better understand the health conditions that affect individuals on the autism spectrum
 - Increase community/provider awareness of these conditions and their treatment
 - Foster development of practice guidelines, policies, service approaches and other efforts to improve the health and quality of life of people on the autism spectrum



Health Outcomes Working Group: Scope



- Health and general wellness for people with ASD
- Co-occurring physical and mental health conditions
- Premature mortality
- Patient-provider interactions (including medical practitioner training)
- Parental/family mental health



Health Outcomes Working Group: Previous Activities



- Working Group conference call (September 5, 2018)
- Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 27, 2018)
 - Health Epidemiology
 - Three co-occurring conditions: epilepsy, gastrointestinal disorders, and sleep disturbances
 - Improving patient-provider interactions
- Working Group conference call (December 17, 2018)
 - Discussion of plans for written product
 - Discussion of plans for a workshop on mental health issues in ASD

Health Outcomes Working Group: Expected Activities and Products



- A written document providing an update on issues
- A workshop addressing mental health conditions and ASD – in 2019
- Continued discussions in Working Group conference calls and/or IACC full committee meetings
- Working Group activities will run from September 2018 – September 2019

Housing Working Group



- The IACC voted to convene a working group on housing issues for individuals with ASD.
- Scope
 - Research and best practices on housing
 - Implementation of current federal regulations
 - Housing issues faced by autistic individuals with more severe disabilities
- Alison Singer has volunteered to serve as chair of this working group



Housing Working Group



Draft mission statement

In the autism community we face a mounting housing crisis, with a growing population of autistic adults with diverse needs lacking appropriate living situations. The goal of this subcommittee is to examine a wide variety of housing options and service models for people with autism, and to develop strategies to achieve a broad array of supported housing options throughout all of our communities that enable autistic individuals to achieve person-centered outcomes.

Housing Working Group: Expected Activities and Products



- Activities will include:
 - Working group phone calls
 - Possible in-person meeting or workshop
- Working group activities will run through September 2019