

IACC Committee Business

Susan Daniels, Ph.D.

Executive Secretary, IACC

Director, Office of Autism Research Coordination

National Institute of Mental Health

IACC Strategic Plan Update

- **IACC Strategic Plan Working Groups have been formed – see IACC website for roster**
- **Will be convening working groups by phone between now and October to work on Strategic Plan Update**
- **All calls will be announced in advance and open to the public for listening**

In the meantime, OARC has:

- **Prepared preliminary 2013 Portfolio Analysis data for use in the updating process**
- **Launched an open Request for Public Comments to collect public input on issues to consider for the 2016 SP update**

2013 ASD Research Portfolio Analysis Preliminary Data

Susan Daniels, Ph.D., Director

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

Office of Autism Research Coordination

National Institute of Mental Health

Preliminary Data: 2013 IACC Portfolio Analysis Report

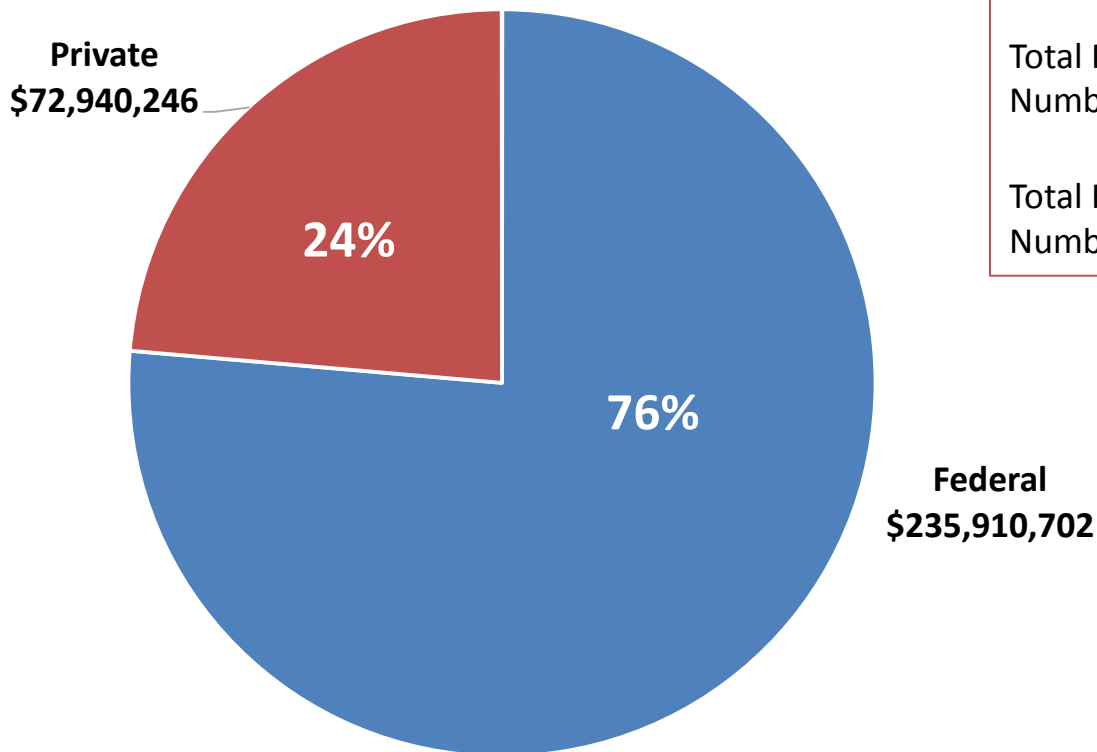


- 2013 ASD research portfolio data have been collected from 19 funders and preliminary analysis is available for use by the IACC for the IACC Strategic Plan Update
- The analysis provides detailed information about the ASD research portfolio across both Federal agencies and private organizations
- Informs 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 - 2013

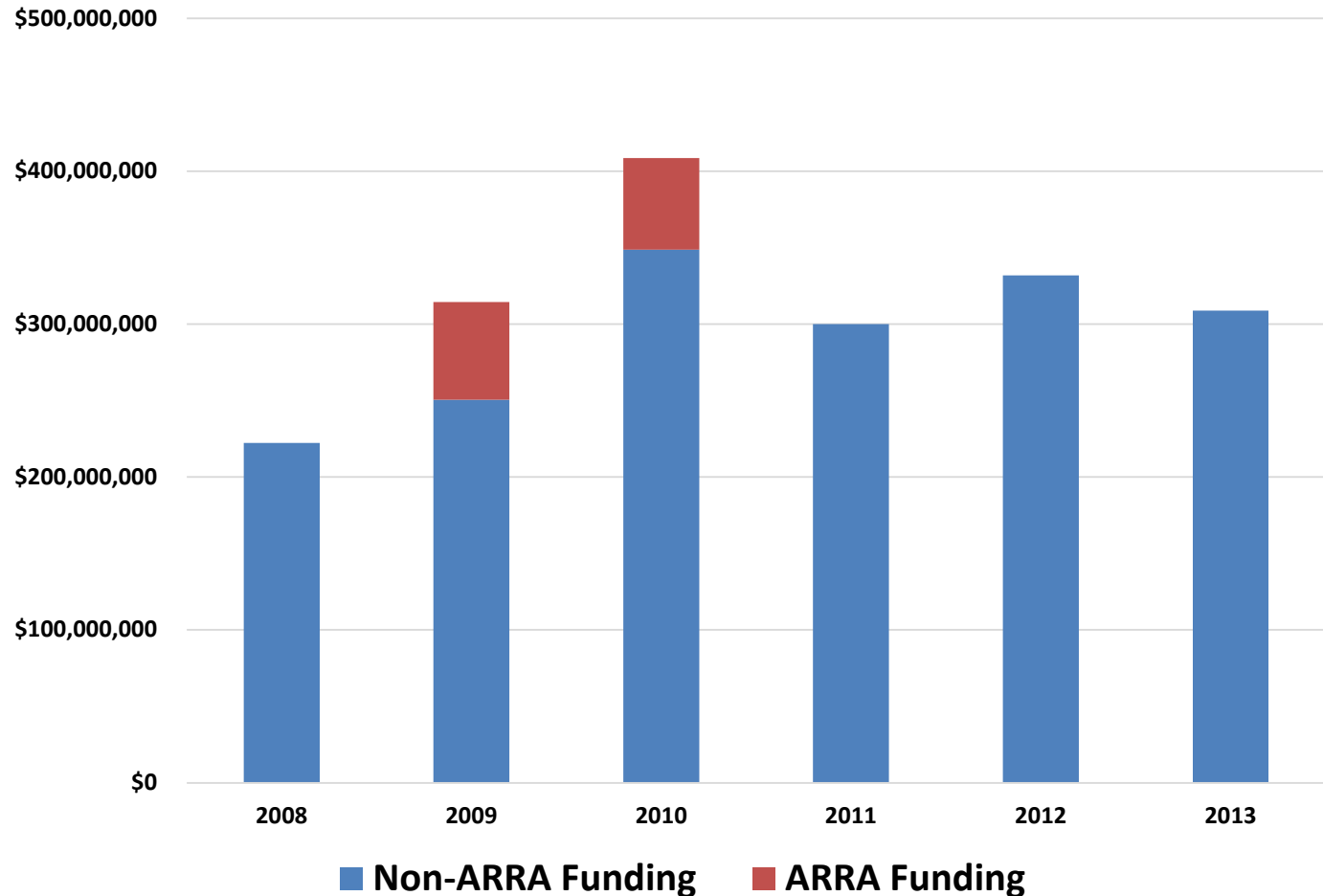
2013 Total Funding: \$308,850,948

Number of Projects: 1,291

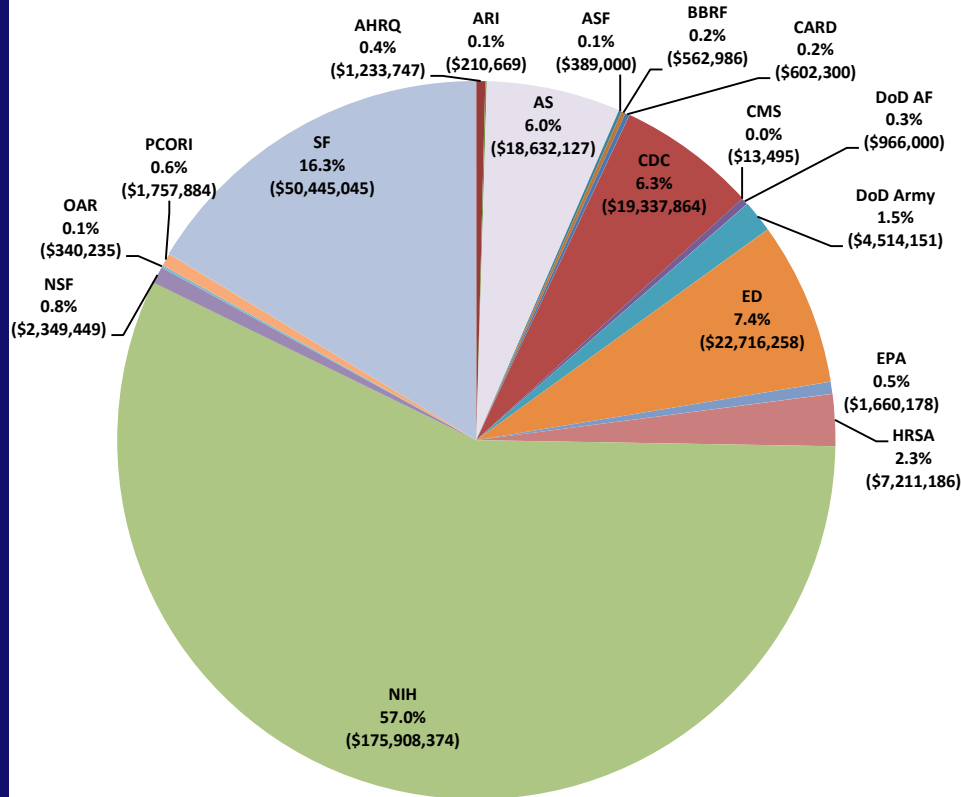


2008
Total Funding: \$222,215,342
Number of Projects: 744
2012
Total Funding: \$331,949,933
Number of Projects: 1,321

Combined Federal and Private Autism Research Funding 2008-2013



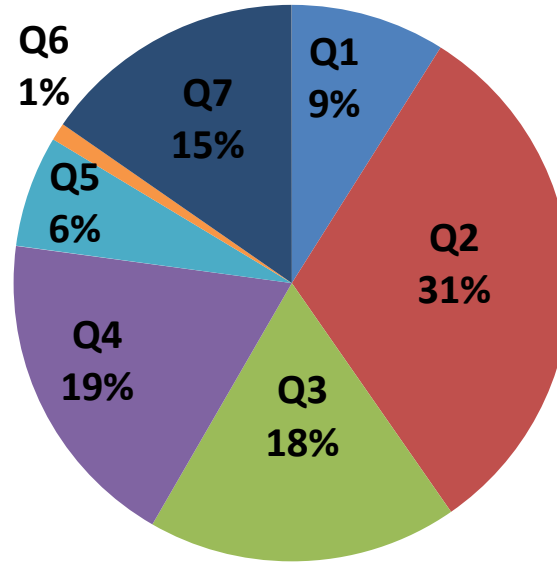
2013 ASD Research Funding by Agency/Organization



Federal or Private Funder	2013 Funding	Percentage of 2013 Funding
National Institutes of Health (NIH)	\$ 175,908,374	57.0%
Simons Foundation (SF)	\$ 50,445,045	16.3%
Department of Education (ED)	\$ 22,716,258	7.4%
Centers for Disease Control and Prevention (CDC)	\$ 19,337,864	6.3%
Autism Speaks (AS)	\$ 18,632,127	6.0%
Health Resources and Services Administration (HRSA)	\$ 7,211,186	2.3%
Department of Defense – Army (DoD Army)	\$ 4,514,151	1.5%
National Science Foundation (NSF)	\$ 2,349,449	0.8%
Patient-Centered Outcomes Research Institute (PCORI)	\$ 1,757,884	0.6%
Environmental Protection Agency (EPA)	\$ 1,660,178	0.5%
Agency for Healthcare Research and Quality (AHRQ)	\$ 1,233,747	0.4%
Department of Defense – Air Force (DoD AF)	\$ 966,000	0.3%
Center for Autism and Related Disorders (CARD)	\$ 602,300	0.2%
Brain and Behavior Research Foundation (BBRF)	\$ 562,986	0.2%
Autism Science Foundation (ASF)	\$ 389,000	0.1%
Organization for Autism Research (OAR)	\$ 340,235	0.1%
Autism Research Institute (ARI)	\$ 210,669	0.1%
Centers for Medicare and Medicaid Services (CMS)	\$ 13,495	0.01%
Administration for Children and Families (ACF)	\$ -	0%
TOTAL	\$ 308,850,948	100%

These slides do not reflect decisions of the IACC and are for discussion purposes only.

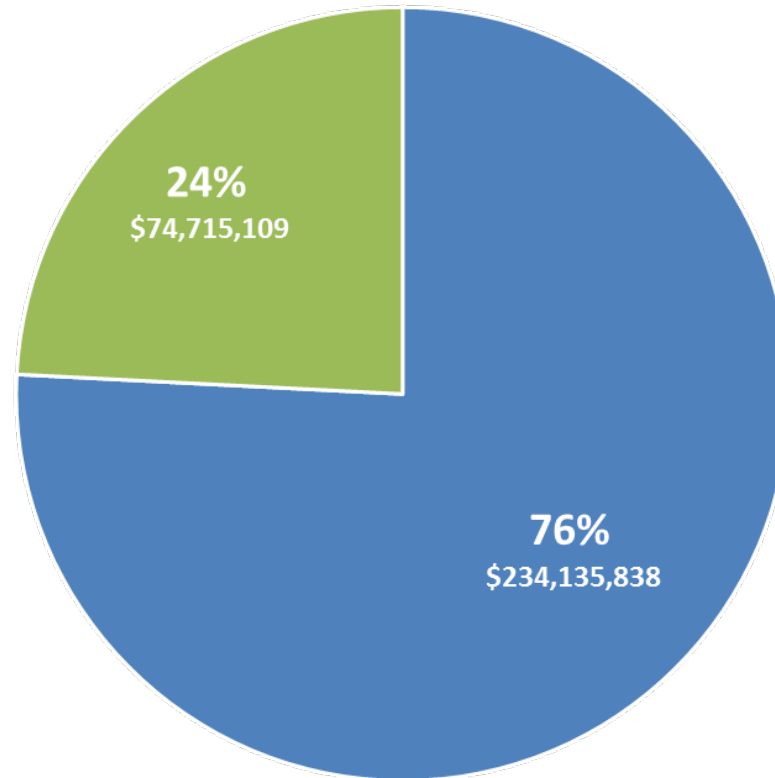
Percentage of 2013 Funding by *IACC Strategic Plan Question*



Strategic Plan Question	2013 Funding	Percentage of 2013 Funding
Question 1: Diagnosis	\$ 27,652,658	9%
Question 2: Biology	\$ 96,872,439	31%
Question 3: Risk Factors	\$ 55,666,351	18%
Question 4: Treatments	\$ 58,065,840	19%
Question 5: Services	\$ 20,026,744	6%
Question 6: Lifespan	\$ 3,152,885	1%
Question 7: Infrastructure	\$ 47,414,030	15%
TOTAL	\$ 308,850,948	100%

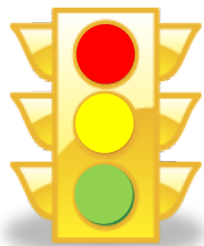
2013 ASD Funding: Alignment with IACC Strategic Plan Objectives

About $\frac{3}{4}$ of the funding was for projects related to the SP objectives.
About $\frac{1}{4}$ was directed toward core/other projects.



■ Specific to Question Objectives ■ Core/Other

Summary of Overall Progress in Strategic Plan Objectives through 2013

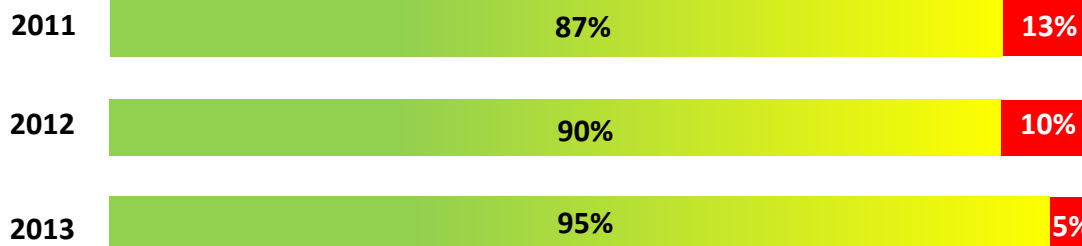


Inactive (Red) Objectives



Fulfilled (Green) or Partially Fulfilled (Yellow) Objectives

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Total	Percentage
Number of Fulfilled Objectives	4	5	9	4	3	0	9	34	44%
Number of Partially Fulfilled Objectives	4	4	6	8	6	8	4	40	51%
Number of Inactive Objectives	1	0	0	0	0	0	3	4	5%
Total	9	9	15	12	9	8	16	78	100%



Data on Progress Toward SP Objectives

Additionally, OARC will be providing the following items to the Strategic Plan working groups to assist them in their assessment of progress:

- **Table of objectives, funding, and status of each objective**
- **Full listing of projects for each objective that can be used to identify trends and gaps**
- **Breakdown of funding and projects according to research subcategories**

Question 1 Table of Objectives, Funding, & Status

	2013 Funding*	2013 Project Count	Percentage of 2013 Question Funding
Question_1_Diagnosis	\$ 27,652,658.19	128	100.00%
1SA. Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. IACC Recommended Budget: \$5,300,000 over 2 years.	\$ 3,200,651.80	10	11.57%
1SB. Validate and improve the sensitivity and specificity of new or existing screening and diagnostic tools, including comparative studies of general developmental screening versus autism-specific screening tools, in both high-risk and population-based samples, including those from resource-poor international settings and those that are diverse in terms of age, socio-economic status, race, ethnicity, gender, characteristics of ASD, and general level of functioning by 2012. IACC Recommended Budget: \$5,400,000 over 3 years.	\$ 3,634,193.24	20	13.14%
1SC. Conduct at least three studies to identify reasons for the health disparities in accessing early screening and diagnosis services, including identification of barriers to implementation of and access to screening, diagnosis, referral, and early intervention services among diverse populations, as defined by socioeconomic status, race, ethnicity, and gender of the child, by 2012. IACC Recommended Budget: \$2,000,000 over 2 years.	\$ 1,038,848.00	5	3.76%
1SD. Conduct at least two studies to understand the impact of early diagnosis on choice of intervention and outcomes by 2015. IACC Recommended Budget: \$6,000,000 over 5 years.	\$ -	0	0.00%
1SE. Conduct at least one study to determine the positive predictive value and clinical utility (e.g., prediction of co-occurring conditions, family planning) of chromosomal microarray genetic testing for detecting genetic diagnoses for ASD in a clinical setting by 2012. IACC Recommended Budget: \$9,600,000 over 5 years.	\$ 983,936.00	3	3.56%
1SF. Convene a workshop to examine the ethical, legal, and social implications of ASD research by 2011. The workshop should define possible approaches for conducting future studies of ethical, legal, and social implications of ASD research, taking into consideration how these types of issues have been approached in related medical conditions. IACC Recommended Budget: \$35,000 over 1 year. (This objective was fulfilled in 2011.)	\$ -	0	0.00%
1LA. Identify behavioral and biological markers that separately, or in combination, accurately identify, before age 2, one or more subtypes of children at risk for developing ASD, and evaluate whether these risk markers or profiles can improve early identification through heightened developmental monitoring and screening by 2014. IACC Recommended Budget: \$33,300,000 over 5 years.	\$ 9,357,850.65	37	33.84%
1LB. Develop at least five measures of behavioral and/or biological heterogeneity in children or adults with ASD, beyond variation in intellectual disability, that clearly relate to etiology and risk, treatment response and/or outcome by 2015. IACC Recommended Budget: \$71,100,000 over 5 years.	\$ 7,822,254.50	38	28.29%
1LC. Identify and develop measures to assess at least three "continuous dimensions" (e.g., social reciprocity, communication disorders, and repetitive/restrictive behaviors) of ASD symptoms and severity that can be used by practitioners and/or families to assess response to intervention for people with ASD across the lifespan by 2016. IACC Recommended Budget: \$18,500,000 over 5 years.	\$ 1,224,987.00	7	4.43%
10. Not specific to Question 1 objectives	\$ 389,937.00	8	1.41%

*Any objective colored **green** has funding which is greater than or equal to the recommended funding for the year (determined by annualizing the recommended budget associated with that objective); any objective colored **yellow** has active projects, but with funding that totals less than the annualized recommended amount, while any objective colored **red** has no active projects and received no funding in 2013. Objectives whose overarching aim (e.g., the ultimate goal of the research) was achieved in a previous year are colored **pale green**.

Question 1: Full Listing of Projects for Each Objective

QUESTION 1: WHEN SHOULD I BE CONCERNED?

2013 Projects: 128

2013 Funding: \$27,652,658

1.S.A

Develop, with existing tools, at least one efficient diagnostic instrument (e.g., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011. *IACC Recommended Budget: \$5,300,000 over 2 years.*

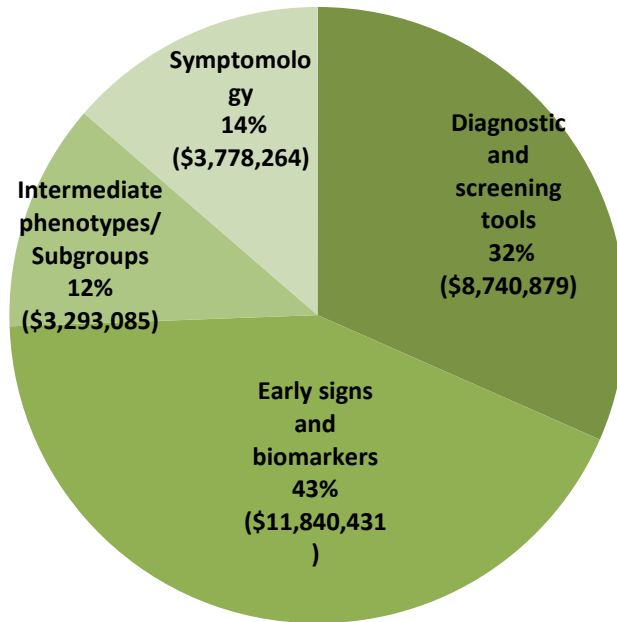
2013 Projects: 10

2013 Funding: \$3,200,652

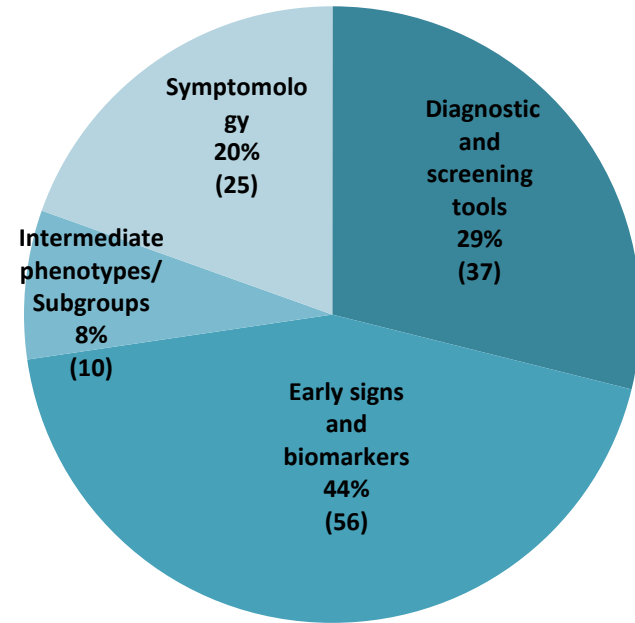
Project Title	Principal Investigator	Institution	Funding	Funder
Cross-Model Automated Assessment of Behavior during Social Interactions in Children with ASD	Naples, Adam	Yale University	\$5,000	Autism Science Foundation
Biomarkers and diagnostics for ASD	Bahn, Sabine	Institute of Biotechnology	\$0	Autism Speaks
Assessing the accuracy of rapid phenotyping of nonverbal autistic children	Law, Paul	Kennedy Krieger Institute	\$124,998	Autism Speaks
Early detection of pervasive developmental disorders	Fein, Deborah	University of Connecticut	\$924,542	National Institutes of Health
Solid-state patch clamp platform to diagnose autism and screen for effective drug	Garner, Craig	Stanford University	\$196,247	National Institutes of Health
Enabling use of blood spot cards for accurate high throughput Fragile X screening	Latham, Gary	Asuragen, Inc.	\$1,142,346	National Institutes of Health
The use of interactive television in identifying autism in young children	Reese, R. Matthew	University of Kansas Medical Center	\$217,440	National Institutes of Health

Subcategory Analysis: Question 1 – Screening & Diagnosis

Percentage of 2013 Funding by Subcategory



Percentage of 2013 Project Count by Subcategory



Question 1: Screening and Diagnosis	2013 Funding	Percentage of 2013 Funding	2013 Project Count	Percentage of 2013 Project Count
Diagnostic and screening tools	\$ 8,740,879	32%	37	29%
Early signs and biomarkers	\$ 11,840,431	43%	56	44%
Intermediate phenotypes/Subgroups	\$ 3,293,085	12%	10	8%
Symptomology	\$ 3,778,264	14%	25	20%
TOTAL	\$ 27,652,658	100%	128	100%

Questions or comments?

**Are there any other breakdowns
of data that would be helpful to
the working groups?**

Update on IACC 2016 Strategic Plan Request for Public Comment



2016 IACC Strategic Plan Request for Public Comment

- On behalf of the IACC, OARC issued a Federal Register Notice soliciting public comment on the research, service, and policy priorities for the topics addressed by the current strategic plan:
 - Diagnosis and Screening (Question 1)
 - Underlying Biology (Question 2)
 - Risk Factors (Question 3)
 - Treatments & Interventions (Question 4)
 - Services (Question 5)
 - Lifespan (Question 6)
 - Research Infrastructure and Surveillance (Question 7)
- Comments will be provided to Strategic Plan Working Groups by SP question, and will be made publicly available on the IACC website within 90 days of the closing date
- Within each question comments are grouped by themes addressed; some comments are coded for more than one theme
- **As of 7/18/2016, 827 comments have been received**

Current Responses and Preliminary Data

Response Demographics (based on Affiliations provided) (N=583 as of 6/29/16)	
Parent/Family Member	86
Service Provider	30
Researcher	19
Advocate/Professional Society	15
Educator/Educational Service Provider	12
Medical/Therapy Practitioner	10
Family Assistance/Navigator	7
Self Advocate	7
Community Educator	2
Research Trainee	2
Government Employee	1
International	1
No Affiliation Provided	391

Question 1: Diagnosis & Screening

(363 responses to Q1 rec'd as of 6/29)

- Need better recognition and diagnosis of subgroups
- Need better understanding of early signs and symptoms
- Families need emotional support following diagnosis and assistance in navigating access to services
- Improve accuracy and awareness of diagnosis in females/address sex and gender disparities in diagnosis
- Improvements in the accuracy and usability of screening and diagnosis tools
- Need more and increased access to genetic screening
- Need greater research and identification of biomarkers, and use of these biomarkers in screening and diagnosis
- Need improvements in access and accuracy of adult and adolescent diagnosis
- Need to address the multifaceted disparities in diagnosis across racial, cultural, socioeconomic, and regional lines
- Need to increase/decrease early screening and diagnosis of ASD in children
- Need to reduce the time to diagnosis by improving service access and diagnostic tools/process
- Need to strengthen link between initial diagnosis and access to services and interventions
- Parents and caregivers need greater education so that they can recognize signs and symptoms
- Practitioners need to listen to and consider parent concerns about early signs and symptoms
- Universal screening for ASD is needed
- Workforce development, including access to qualified practitioners and improvements in the training of the existing workforce
- Current priorities are appropriate (diagnosis and screening tools, early signs, symptoms and biomarkers, identification of subgroups, disparities in diagnosis)

Question 2: Underlying Biology

(351 responses to Q2 rec'd as of 6/29)

- Need further research on the genetics of autism, and genetic tests should be more accessible
- Need more developmental biology research
- Need more research and a better understanding of genetic syndromes related to ASD
- Need more research and better understanding of the biomarkers and symptoms of ASD, and the heterogeneity of symptoms
- Need more research into the contribution of immune and metabolic pathways to autism
- Need more research on cognitive and behavioral biology
- Need more research on the basic neuroscience of ASD
- Need more research on the biology and relationship of co-occurring conditions in ASD
- Need more research on the molecular biology of ASD
- Need more research on sex and gender differences, inclusive of both biological sex and self-identified gender
- Need research to better understand, differentiate, and treat subgroups of people with autism
- Need more research to better understand sensory processing and motor function in ASD
- Need more translational and interdisciplinary research to improve the lives of people with ASD
- Need to prioritize gut-brain interaction research
- Current priorities are appropriate (molecular biology and neuroscience, developmental biology, cognitive and behavioral biology, genetic syndromes related to ASD, sex differences, immune and metabolic aspects, and co-occurring conditions in ASD)
- Understanding the biology of ASD is not a priority, relative to other areas (i.e. treatment and services)

Question 3: Risk Factors

(363 responses to Q3 rec'd as of 6/29)

- Need better methods for testing contributions of risk factors from multiple domains to better understand risk of autism
- Need more research into better understanding of environmental risk factors, defined broadly to including both chemical and social environments
- Need more research on epigenetic risk factors
- Need more research on genetic risk factors
- Need more research on immune and metabolic risk factors
- Need more research on maternal and prenatal factors
- Need more research on the interaction of genetic and environmental factors
- Need more research on the risk factors for co-occurring conditions in autism
- Need more research on the role of the microbiome and gastrointestinal risk factors
- Need more research to better understand heritability and risk of autism in families
- Need more research to understand the role of vaccines in causing autism
- Need less/no additional research on the role of vaccines in autism
- Current priorities are appropriate (genetic and environmental risk factors, gene-environment interactions, and the potential role of epigenetics and the microbiome)
- The cause and prevention of autism are not a priority, either because resources can be better used in other areas or because preventing autism should not be a goal

Question 4: Treatments & Interventions

(385 responses to Q4 rec'd as of 6/29)

- Need a qualified workforce trained in providing treatments and interventions ; need both a greater number and improved training of current clinicians, therapists, and school employees
- Need to prioritize early intervention
- Need to educate parents about available treatments and interventions, and to help provide these interventions
- Endorsement of specialized or ASD specific treatments and interventions
- Improve availability and efficacy of treatments and interventions specifically for adult and adolescents with ASD
- Improve efficacy and availability of behavioral treatments and interventions
- Improve efficacy and availability of interventions in educational settings
- Improve the evidence base for treatments and interventions, and make that information more readily available and widely used
- Personalized combinations and types of treatments and interventions will be the most efficacious
- Positive and negative comments about searching for a “cure” rather than treatments or interventions
- Research and availability of technology based or assistive technology treatments and interventions
- Research and availability of treatments and interventions for co-occurring conditions
- Need research on biomedical and pharmacological treatments and interventions to improve efficacy and reduce side effects
- Need research on the efficacy and availability of complementary, alternative or integrative treatments and interventions
- Need research on long term outcomes of treatments and intervention, as well as the translation and implementation of research based treatments and interventions
- Improve coordination of treatments and interventions between services and practitioners
- Current priorities are appropriate (behavioral, medical/pharmacologic, educational, technology-based, and complementary/integrative interventions)

Question 5: Services

(467 responses to Q5 rec'd as of 6/29)

- Access to early intervention services is a priority
- Disparities in access to services should be addressed
- Families need access to services to reduce the mental and emotional burden of caring for those with ASD
- Improve the efficacy and cost effectiveness of services and service delivery
- Improve the quality and availability of services within the educational systems
- Improve the service systems and service models
- Increase the accessibility and utilization of services.
- Need better coordination between service providers, taking into account what is relevant for the individual and the choices of those with ASD and their families/caregivers
- Need for an adequately trained and compensated workforce to improve available services and service delivery
- Need for better services to foster community inclusion of those with ASD
- Need to be more and better access to specialized services for ASD
- Parents/caregivers need assistance navigating complicated service systems.
- Prioritize services to improve the health and safety, including addressing interactions with law enforcement and wandering
- The broader community needs to be better educated about ASD, to lead to better understanding and inclusion
- The cost of services is prohibitive, and research and policies are needed to reduce these barriers to access
- Current priorities are appropriate (service access and utilization, service systems, education, family well-being, efficacious and cost-effective service delivery, health and safety issues affecting children, and community inclusion)
- Focus on the treatment or cause of autism rather than the delivery of services

Question 6: Lifespan

(481 responses to Q6 rec'd as of 6/29)

- Improve access to and quality of adult services, including additional research to improve evidence based services for adults
- Improve access to diagnosis for adolescents and adults
- Improve community integration/inclusion, including social isolation and community education about ASD
- Improve the quality, accessibility of housing options
- Improve transition services, and provide better assistance for young adults and their families during transitions
- Long term and financial planning are a priority for research, services, and policy
- Need assistance for adults with autism and their families in navigating available adult services
- Need for a larger, better trained and compensated workforce for adults with ASD
- Research and services to improve health, medical care, safety and quality of life across the lifespan
- Research, services and policies are needed to improve vocational/employment and post-secondary education opportunities
- Services and research should take into account the perspective and choices of adults and their families/caregivers
- Current priorities are all important/relevant (health and quality of life across the lifespan, aging, transition, and adult services, including education, vocational training, employment, housing, financial planning and community integration.)
- Focus should be on early intervention or developing effective treatments; adults/lifespan are not a research priority

Question 7: Research Infrastructure and Surveillance (246 responses to Q7 rec'd as of 6/29)

- Improve services infrastructure
- Increase collaboration and coordination among services providers
- Increase collaboration and coordination of research including interdisciplinary research
- Increase the dissemination of research, and the translation of research into practice
- Need greater development of the research workforce
- Need more and improved surveillance of ASD prevalence, including by race/ethnicity, gender and age
- Need research infrastructure, i.e. databases, research and clinical trial policies
- Research should include the voices and participation of individuals with autism and their families
- Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
- Prioritize services and interventions rather than research

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- Current priorities are appropriate/important (research infrastructure needs, ASD surveillance research, research workforce development, dissemination of research information, and strengthening collaboration)
- Prioritize services and interventions rather than research



Are there any specific topics that the IACC would like to hear about from the public about in addition to what has already been shared?

It's Not Too Late to Share your Thoughts with the IACC!

Comment Period is open until **JULY 29, 2016**
<https://iacc.hhs.gov/>



The screenshot shows the IACC website homepage. At the top, it features the U.S. Department of Health & Human Services logo and the IACC logo. Navigation links include 'HOME', 'ABOUT IACC', 'ABOUT OARC', 'NEWS', 'MEETINGS', 'PUBLICATIONS', 'FUNDING', and 'RESOURCES'. A search bar is present with a 'GO!' button. The main banner area displays a large red arrow pointing right with the text 'Share your Thoughts' and '2016 Strategic Plan - Open Request for Public Comment (June 15 - July 29)'. Below the banner, there are tabs for 'Latest Activity', 'Latest Meetings', 'Latest News', 'Video & Multimedia', and 'About IACC'. The 'Latest Activity' tab is selected, showing a list of items including 'IACC Full Committee Meeting' on July 19, 2016, with sub-items like 'Strategic Plan Update', 'Interventions for Challenging Behaviors', 'Vocational Rehabilitation', and 'Updates from Private Organizations'. There is also a 'Publications' section with a link to 'NFWI Summary of Advances in Autism Spectrum'. On the right side, there are several widgets: 'Latest Publications' with a 'View All Publications >' link, 'Portfolio Analysis Web Tool' with a colorful chart, 'Get Email Updates' with a laptop image, and 'Request for Comment' with a 'Share your Thoughts' graphic.

Questions? iaccpublicinquiries@mail.nih.gov

2016 Summary of Advances Process



Summary of Advances Process

- **Monthly solicitation from OARC to collect nominated advances from IACC members**
- **Advances compiled quarterly and discussed at IACC meetings**
- **At end of year, after January meeting discussion, IACC will vote on top ~20**
- **Does the IACC want to select a certain number per Question area, or just select the top 20 overall?**
- **Selected advances will be prepared in summary format similar to current document?**

Comments?



OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Director

Benjamin Feldman, Ph.D., Science Policy Analyst

Amanda Garton, M.S., M.P.P., Presidential Management Fellow

Angelice Mitrakas, B.A., Operations Coordinator

Karen Mowrer, Ph.D., Science Policy Analyst

Miguelina Perez, B.A., Management Analyst

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

Jeff Wiegand, B.S., Web Development Manager

Nam-Andrew Kim, B.S., UI/UX Designer