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

• 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

• 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

- 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., Vencerx 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
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 IACC Strategic Plan

### IAAC Strategic Plan Questions and Corresponding Research Areas

1. **Question 1: When should I be concerned?**  
   **Screening & Diagnosis**

2. **Question 2: How can I understand what is happening?**  
   **Biology**

3. **Question 3: What caused this to happen and can it be prevented?**  
   **Risk Factors**

4. **Question 4: Which treatments and interventions will help?**  
   **Treatments & Interventions**

5. **Question 5: Where can I turn for services?**  
   **Services**

6. **Question 6: What does the future hold, particularly for adults?**  
   **Lifespan Issues**

7. **Question 7: What other infrastructure and surveillance needs must be met?**  
   **Infrastructure & Surveillance**
Question 1: Screening and Diagnosis

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

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
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

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
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

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

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!

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

Private $65,026,914
Federal $277,609,115

19%
81%
2015 IACC ASD Portfolio Analysis

Combined Federal and Private Autism Research Funding 2008-2015

- Non-ARRA Funding
- ARRA Funding

2008: $222m
2009: $222m
2010: $408m
2011: $343m
2012: $343m
2013: $343m
2014: $343m
2015: $343m
2015 IACC ASD Portfolio Analysis
ASD Research Funding by IACC Strategic Plan Question

All Funders
Total Funding: $342,636,029

- Question 1: Screening & Diagnosis
  - Total: $32,085,844
  - Percentage: 9%

- Question 2: Biology
  - Total: $107,671,690
  - Percentage: 32%

- Question 3: Risk Factors
  - Total: $62,565,031
  - Percentage: 18%

- Question 4: Treatments & Interventions
  - Total: $59,619,317
  - Percentage: 17%

- Question 5: Services
  - Total: $21,280,931
  - Percentage: 6%

- Question 6: Lifespan Issues
  - Total: $6,111,767
  - Percentage: 2%

- Question 7: Infrastructure & Surveillance
  - Total: $53,301,448
  - Percentage: 16%

- Infrastructure & Surveillance
  - Total: $53,301,448
  - Percentage: 16%

- Total Funding: $342,636,029
2015 IACC ASD Portfolio Analysis

2008-2015 ASD Research Funding

Q1
Q2
Q3
Q4
Q5
Q6
Q7

Question 1
Question 2
Question 3
Question 4
Question 5
Question 5 Estimated
Question 6
Question 7
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?

**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

Next IACC Meeting:
Wednesday, July 26th, 2017
NIH Campus, Bethesda, MD

All IACC publications and more information about the IACC are available at:
www.iacc.hhs.gov
OARC Staff

Susan Daniels, Ph.D., Director

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.