

# **OARC Update and IACC Planning Activities for 2011**

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IACC Full Committee Meeting - January 18, 2011

# OARC Staff Update

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- Della Hann, Ph.D., Acting Director
- Susan Daniels, Ph.D., Deputy Director
- Elizabeth Baden, Ph.D., Policy Analyst
- Erin Bryant, M.J., Science Writer
- Sara Dodson, Ph.D., AAAS Science and Technology Policy Fellow
- Nicole Jones, Web Developer
- Lina Perez, Management Analyst

# IACC Portfolio Analysis

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- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides comprehensive 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 monitor progress in fulfilling the objectives of the IACC Strategic Plan
- Highlights gaps and opportunities to guide future activities

# 2009 Portfolio Analysis Update

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- ✓ Data call to collect information from funders
- ✓ Funders code projects according to Strategic Plan objectives
- ✓ Generate draft analysis
- Editing, coding verification, final analysis and opportunity to review
- Publish and distribute final report to IACC and the public – **Early 2011**

# Proposal for 2010 Portfolio Analysis

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## OARC Data Request - Questions for funders:

- Number of research projects
- Total ASD Research Funding
- Project Titles, Principal Investigators/Institutions
- Project descriptions
- How Funded Projects Correspond to the IACC 2011 Strategic Plan (coding)

## Possible new data to gather for the 2010 Portfolio Analysis:

- List of publications stemming from grants?

# Participating ASD Research Funders from 2009 Portfolio Analysis

## Federal Funders of ASD Research

- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare and Medicaid Services (CMS)
- Department of Defense (DoD)
- Department of Education (Ed)
- Health Resource and Services Administration (HRSA)
- National Institutes of Health (NIH)

## Private Funders of ASD Research

- Autism Research Institute (ARI)
- Autism Science Foundation (ASF)
- Autism Speaks (AS)
- Center for Autism and Related Disorders (CARD)
- Organization of Autism Research (OAR)
- The Simons Foundation (Simons)
- Southwest Autism Research and Resource Center (SARRC)

# **Proposed Timeline**

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- Data Call – Spring 2011
- Update IACC at April 11, 2011 Meeting
- Data analysis – Summer 2011
- Draft analysis to IACC – July 19, 2011 Meeting
- Completed analysis – September 2011

# Summary of Advances

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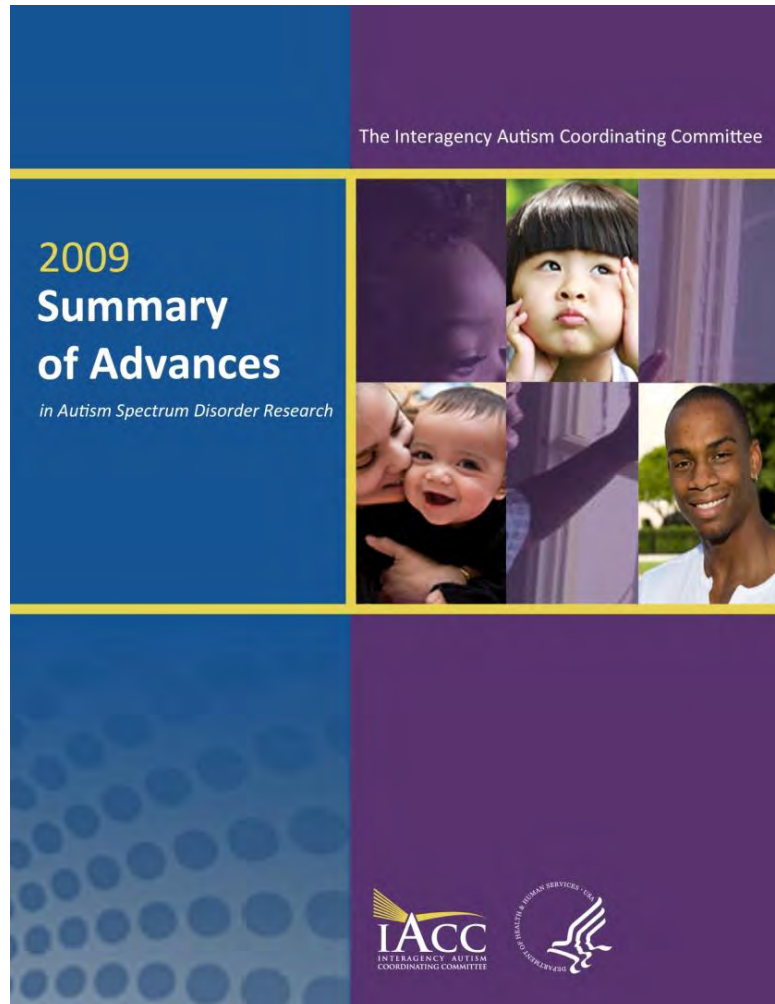
- Required by the Combating Autism Act of 2006

(Public Law 109-416 SEC. 399CC.(b)(1))

“Develop and annually update a summary of advances in autism spectrum disorder research related to causes, prevention, treatment, early screening, diagnosis or rule out, intervention, and access to services and supports for individuals with autism spectrum disorder...”



# 2009 Summary of Advances



- The IACC identified 20 peer-reviewed articles published in 2009 that they felt reflected the most significant advances in ASD biomedical and services research.
- These studies gave important new insight into the prevalence of autism spectrum disorder, the biology of the disorder, potential risk factors, and possible interventions.

# 2010 Summary of Advances

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- The full document will include the 20 advances in the field of autism biomedical and services research deemed most significant by the IACC for calendar year 2010
- *Published research only – does not include advanced e-pubs*

# 2010 Summary of Advances: Part 1

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- Mid-year Installment of 10 articles already completed:
  - Fall 2010 - IACC members nominated 3-5 articles each (34 total)
  - The IACC voted to select the first 10 articles to be included in the Summary

# Mid-year Top 10

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- **Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report.** (Buie et al., *Pediatrics*)
- **Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model.** (Dawson et al., *Pediatrics*)
- **Functional impact of global rare copy number variation in autism spectrum disorders.** (Pinto et al., *Nature*)
- **Longitudinal magnetic resonance imaging study of cortical development through early childhood in autism.** (Schumann et al., *Journal of Neuroscience*)
- **Blood mercury concentrations in CHARGE Study children with and without autism.** (Hertz-Picciotto et al., *Environmental Health Perspectives*)

# Mid-year Top 10 (continued)

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- **Mutations in the SHANK2 synaptic scaffolding gene in autism spectrum disorder and mental retardation.** (Berkel et al., *Nature Genetics*)
- **A prospective study of the emergence of early behavioral signs of autism.** (Ozonoff et al., *Journal of the American Academy of Child and Adolescent Psychiatry*)
- **Changes in autism spectrum disorder prevalence in 4 areas of the United States.** (Rice et al., *Disability and Health Journal*)
- **Consensus statement: Chromosomal microarray is a first-tier clinical diagnostic test for individuals with developmental disabilities or congenital anomalies.** (Miller et al., *American Journal of Human Genetics*)
- **Implementing developmental screening and referrals: lessons learned from a national project.** (King et al., *Pediatrics*)

# 2010 Summary of Advances: Part 2

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- Final Installment to be completed:
  - Ten additional 2010 articles to be identified
  - IACC members will nominate 3-5 articles each:
    - OARC will redistribute articles listed in the Mid-year ballot
    - IACC members may nominate additional articles published anytime in 2010
  - OARC will compile 2<sup>nd</sup> Installment ballot and distribute to IACC members
  - IACC will vote to select the final 10 articles to complete the 2010 Summary

# 2010 Summary of Advances

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- Final Product to be produced by OARC:
  - Collection of independent short summaries of the top 20 ASD research papers, organized according to topics covered in the Strategic Plan
- Timeline:
  - Winter/Spring 2011 – Selection of 2<sup>nd</sup> Installment
  - Draft document with all 20 articles to be presented to IACC in April 2011 for approval
  - Final 2010 IACC Summary of Advances to be released in April 2011

# Future IACC Activities

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- Gathering input from the research community and the public:
  - Workshop or Town Hall Meeting?
  - RFI?