Meeting of the IACC

OARC/IACC Update: New Documents and Web Releases

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National Institute of Mental Health
Executive Secretary, IACC
IACC Full Committee Meeting – July 10, 2012

These slides do not reflect decisions of the IACC and are for discussion purposes only.
2011 Summary of Advances

• Released in April 2011

• The IACC identified 20 research findings and associated peer-reviewed articles published in 2011 that they felt reflected the most significant advances in ASD biomedical and services research.

• Lay-friendly summaries of research findings

• These studies gave important new insight into the prevalence of autism spectrum disorder, the biology of the disorder, potential risk factors, possible interventions, and services needs.

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Publications Selected for 2011
IACC Summary of Advances

Q1 DIAGNOSIS

• Disrupted neural synchronization in toddlers with autism
• Detecting, Studying, and Treating Autism Early: The One-Year Well-Baby Check-Up Approach

Q2 BIOLOGY

• Mutations causing syndromic autism define an axis of synaptic pathophysiology
• Absence of CNTNAP2 leads to epilepsy, neuronal migration abnormalities, and core autism-related deficits
• Protein interactome reveals converging molecular pathways
• Transcriptomic analysis of autistic brain reveals convergent molecular pathways

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Publications Selected for 2011
IACC Summary of Advances

Q3  RISK FACTORS
• Genetic heritability and shared environmental factors among twin pairs with autism
• Rare de novo and transmitted copy-number variation in autistic spectrum disorders
• Exome sequencing in sporadic autism spectrum disorders identifies severe de novo mutations
• Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study
• Multiple recurrent de novo CNVs, including duplications of the 7q11.23 Williams syndrome region, are strongly associated with autism

Q4  TREATMENTS & INTERVENTIONS
• A systematic review of medical treatments for children with autism spectrum disorders
• Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial
• Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders
Publications Selected for 2011
IACC Summary of Advances

Q5 SERVICES
• Post-high school service use among young adults with an autism spectrum disorder

Q6 LIFESPAN
• Epidemiology of autism spectrum disorders in adults in the community in England
• Autism spectrum disorders in older adults: Toward defining a research agenda
• Emerging new practices in technology to support independent community access for people with intellectual and cognitive disabilities

Q7 INFRASTRUCTURE & SURVEILLANCE
• Trends in the prevalence of developmental disabilities in US children 1997-2008
• Prevalence of autism spectrum disorders in a total population sample

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2010 IACC Portfolio Analysis

- 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

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2010 Federal and Private Autism Funding

- Total funding = $408,577,276
- 18 funders
- Overall Increase since 2009 = $93M

The 2010 Portfolio Analysis data reflect a larger proportion of overall funding from Federal sources, largely attributed to increased reporting from HRSA and the Department of Education, as well as several Federal funders of ASD research that were not captured in 2009 – NSF, EPA, ACF, AHRQ. Private funding remained similar to the 2009 level.

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## 2010 Federal and Private Autism Funding

<table>
<thead>
<tr>
<th>Funding Agency/Organization</th>
<th>Number of Projects</th>
<th>Total Funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Institutes of Health (NIH)</td>
<td>545**</td>
<td>$217,143,701</td>
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<tr>
<td>Simons Foundation (SF)</td>
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<td>Health Resources and Services Administration (HRSA)</td>
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<td>Department of Education (ED)</td>
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<td>Centers for Disease Control and Prevention (CDC)</td>
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<tr>
<td><em>Autism Speaks (AS)</em></td>
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<td>National Science Foundation (NSF)</td>
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<td>Department of Defense (DoD)</td>
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<td>Environmental Protection Agency (EPA)</td>
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<td>Centers for Medicare &amp; Medicaid Services (CMS)</td>
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<td><em>Autism Science Foundation (ASF)</em></td>
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<td>Organization for Autism Research (OAR)</td>
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<td>Coalition for SafeMinds (SafeMinds)</td>
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<td>Southwest Autism Research &amp; Resources Center (SARRC)</td>
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<td><strong>GRAND TOTAL</strong></td>
<td><strong>1367</strong></td>
<td><strong>$408,577,276</strong></td>
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</table>

*Annual funding amounts for AHRQ, ED, and NSF are estimated.
**The NIH project number shown reflects unique NIH projects. Projects funded by more than one NIH institute (“co-funds”) were combined and only counted as a single project. Private organizations are indicated in red text.

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How Was 2010 Autism Funding (All Funders) Distributed Across the IACC Strategic Plan Questions?

Total funding = $408,577,276

Q1. Diagnosis 11% ($45,622,080)
Q2. Biology 22% ($91,260,349)
Q3. Risk Factors 20% ($81,231,647)
Q4. Treatments and Interventions 17% ($68,123,890)
Q5. Services 16% ($64,849,122)
Q6. Lifespan Issues 2% ($6,643,124)
Q7. Infrastructure and Surveillance 12% ($50,847,065)

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2010 ASD Funding: Alignment with IACC Strategic Plan Objectives

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New in 2010: Subcategory Analysis

- Subcategories were developed for each of the seven questions of the IACC Strategic Plan
  - Provide a more detailed breakdown of research funding
  - Capture established and emerging research areas and areas of high public interest
  - Identify the types of research addressed by projects that do not correspond to specific objectives of the Strategic Plan
- Each project assigned to a single subcategory

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Strategic Plan Structure and Portfolio Analysis

Subcategories

ASD Research & the IACC Strategic Plan

- Diagnosis
  - 1. When should I be concerned?
  - Topics Covered: Diagnostic and screening tests, early signs, biomarkers, symptomology, subgroups

- Biology
  - 2. How can I understand what is happening?
  - Topics Covered: Neural systems, molecular pathways, developmental trajectory, cognitive studies, immune and metabolic pathways, neuropathology, biosignatures, computational studies, co-occurring conditions, sensory and motor functions

- Risk Factors
  - 3. What caused this to happen and can it be prevented?
  - Topics Covered: Genetic risk factors, environmental risk factors, and the intersection of genetic and environmental risk factors, including epigenetics

- Treatments & Interventions
  - 4. Which treatments and interventions will help?
  - Topics Covered: Pharmacological, behavioral, educational, complementary, dietary, occupational, sensory-based therapies, technology-based interventions and supports, model systems to identify molecular targets

- Services
  - 5. Where can I turn for services?
  - Topics Covered: Utilization and access, evidence-based practices, cost-effective service delivery, practitioner training, family well-being, safety, community inclusion

- Lifespan Issues
  - 6. What does the future hold, particularly for adults?
  - Topics Covered: Adult interventions, service needs, transition services, vocational rehabilitation, adult diagnosis

- Infrastructure & Surveillance
  - 7. What other infrastructure and surveillance needs must be met?
  - Topics Covered: Surveillance and prevalence, research infrastructure, data tools, biobanks, research subject recruitment, research workforce development

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In 2010, How Much Funding Was Devoted to Each Subcategory?

Question 1: Diagnosis (4)
- Diagnostic and Screening Tools: 20% ($9,245,716)
- Intermediate Phenomenology: 9%
- Symptomology: 24% ($11,048)
- Early Signs and Biomarkers: 47% ($21,233,738)

Question 2: Biology (10)
- Cognitive Studies: 5% ($4,170,426)
- CompuVis: 4% ($3,499,502)
- Co-occurring Conditions: 5% ($4,828,514)
- Developmental Trajectory: 11% ($9,920,670)
- Immune/Metabolic Pathways: 0% ($5,385,744)
- Molecular Pathways: 32% ($28,759,657)
- Neural Systems: 15% ($13,952,106)
- Neurobiology: 7% ($6,429,149)
- Sensory and Motor Function: 7% ($6,429,149)
- Subgroups/Biosignatures: 14% ($12,401,283)

Question 3: Risk Factors (4)
- Genetic Risk Factors: 63% ($50,791,381)
- Epigenetics: 7% ($5,540,146)
- Gene-Environment: 25% ($20,466,742)
- Environment: 5% ($4,432,899)
Subcategories by Funding

Question 4: Treatments and Interventions (7)

Question 5: Services (5)

Question 7: Infrastructure and Surveillance (6)
Impact of ARRA on ASD Research Funding in 2009 & 2010

Impact of ARRA on Total ASD Research Funding for 2009 & 2010
Total funding = $722,962,650

Impact of ARRA on Federal ASD Research Funding For 2009 & 2010
Total funding = $571,868,237

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How was 2009 & 2010 ARRA ASD Research Funding Distributed Across the IACC Strategic Plan Questions?

Total ARRA funding = $123,916,638

- Q2. Biology: 23% ($28,223,443)
- Q1. Diagnosis: 13% ($16,554,925)
- Q7. Infrastructure and Surveillance: 6% ($6,836,628)
- Q6. Lifespan Issues: 2% ($2,213,410)
- Q5. Services: 5% ($6,098,982)
- Q4. Treatments and Interventions: 12% ($14,748,849)
Impact of 2009 & 2010 ARRA Funding on ASD Research: Alignment with the IACC Strategic Plan

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What Progress is Being Made on Achieving IACC Strategic Plan Objectives?

- In 2010 progress was underway on 83% of the 78 objectives in the 2011 IACC Strategic Plan.
- Since then two more objectives have been completed.
- Which objectives are not currently underway (i.e., no funding or projects to date)? 11 objectives spanning 6/7 Questions

1.S.C 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.S.D 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.*
Remaining Objectives – Cont’d

3.S.B  Within the highest priority categories of exposures for ASD, identify and standardize at least three measures for identifying markers of environmental exposure in biospecimens by 2011. *IACC Recommended Budget: $3,500,000 over 3 years.*

4.S.E  Convene a workshop to advance the understanding of clinical subtypes and treatment personalization (i.e., what are the core symptoms to target for treatment studies) by 2011. *IACC Recommended Budget: $50,000.*

5.L.B  Test the efficacy and cost-effectiveness of at least four evidence-based services and supports for people with ASD across the spectrum and of all ages living in community settings by 2015. *IACC Recommended Budget: $16,700,000 over 5 years.*

6.L.D  Conduct implementation research to test the results from comparative effectiveness research in real-world settings including a cost-effectiveness component to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2023. *IACC Recommended Budget: $4,000,000 over 5 years.*
Remaining Objectives – Cont’d

7.A  Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in healthcare, education and social services by 2009. *IACC Recommended Budget: $520,000 over 1 year.*

7.F  Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011. *(No recommended budget assigned by the IACC.)*

7.G  Develop a web-based tool which provides population estimates of ASD prevalence for states based on the most recent prevalence range and average identified by the ADDM Network by 2012. *IACC Budget Recommendations: $200,000 over 2 years.*

7.M  Support 10 "Promising Practices" papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities by 2015. *IACC Recommended Budget: $75,000 over 5 years.*
All IACC publications and more information about the IACC are available at:

www.iacc.hhs.gov

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