

Conference Call and Webinar of the Interagency Autism Coordinating Committee

July 27, 2012

Conference Call Access:

Phone: (800)857-7423

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Conference Call and Webinar of the IACC

Agenda

- 10:00 AM** **Call to Order and Opening Remarks**
Thomas Insel, M.D.
Director, NIMH and Chair, IACC
- 10:10** **Orientation Items**
- 10:30** **IACC Business**
- 10:30** **Subcommittee Establishment**
- 11:00** **Strategic Planning**
- 11:30** **Summary of Advances**
- 11:45** **Portfolio Analysis**

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Agenda – Continued

12:00 PM Public Comments Discussion

1:00 Closing Remarks



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IACC Orientation

Susan A. Daniels, Ph.D.

Acting Director, Office of Autism Research Coordination and
Executive Secretary, IACC

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

IACC Statutory Responsibilities

- Advise HHS Secretary Sebelius
- Establish autism research priorities
 - **IACC Strategic Plan for ASD Research**
- Communicate advances in the field
 - **IACC Summary of Advances in ASD Research**
- Monitor Federal activities and analyze research trends
 - **IACC ASD Research Portfolio Analysis**





OFFICE OF 
AUTISM RESEARCH
COORDINATION

NATIONAL INSTITUTES OF HEALTH

Susan Daniels, Ph.D., Acting Director

Elizabeth Baden, Ph.D., Policy Analyst

Cyrus Davani, Scientific Program Analyst

Sara Dodson, Ph.D., AAAS Science and Technology Policy
Fellow

Nicole Jones, Senior Web Developer

Lina Perez, Management Analyst

Sarah Rhodes, Ph.D., Policy Analyst/Detailee, NIMH
Intramural Program

Office of Autism Research Coordination

*The Office of Autism Research Coordination (**OARC**) coordinates and manages the Interagency Autism Coordinating Committee (IACC) and related cross-agency autism spectrum disorder (ASD) activities, programs, and policies.*

- Planning meetings, conferences, and other venues for interaction between the IACC and the public
- Assisting the IACC in its strategic planning and ASD research monitoring activities
- Conducting analyses and preparing documents and reports for the IACC and Congress
- Gathering public input on issues related to ASD on behalf of the IACC to assist them with their work
- Communicating information about the IACC and federal ASD research activities to Congress, other government agencies, and the public

IACC Meetings

- CAA/CARA requires minimum of 2 meetings of the full IACC per year
- In past, IACC has had ~6 full committee meetings per year, plus ~8-10 other meetings and phone calls of subcommittees, convened workshops, etc.
- All full committee, subcommittee meetings and workshops, etc. are open to the public – accessible by phone, webcast and/or webinar
- Meetings where substantive items are discussed must be announced in the Federal Register, which requires ~30 day lead time
- New federal meeting regulations require additional approvals before in-person meetings can be scheduled, also adding to needed lead time
- In some cases, phone calls/webinars can be substituted
- Meeting requests to help committee achieve goals will be balanced with budget and timing considerations



All IACC publications and more information about the IACC are available at:

www.iacc.hhs.gov

Final documents from IACC meetings are publicly available on web or by request

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IACC Business

Thomas R. Insel, M.D.

Director, National Institute of Mental Health and
Chair, IACC

Susan A. Daniels, Ph.D.

Acting Director, Office of Autism Research Coordination and
Executive Secretary, IACC

IACC Subcommittees

- Subcommittees from the previous iteration of the IACC sunset with the end of the Combating Autism Act
- New subcommittees must be formed under the Combating Autism Reauthorization Act
- Co-chairs (federal and non-federal)
- Members limited to IACC members
- All meetings public
- Reports/recommendations/actions subject to full IACC approval

IACC Subcommittees (Revised)

Services and Safety

- Services Provision and Policy
- (Access, housing, employment, transition, social inclusion, health disparities, costs, implications of ACA, etc.)
- Services research
- Safety
- Update of Strategic Plan Questions 5 & 6 and objectives/topics in other chapters related to services and safety

Science

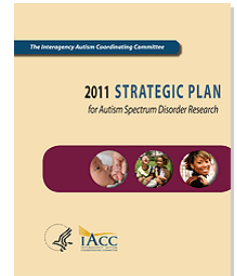
- Scientific research (Biomedical, behavioral), Collaborations, Biobanks, Registries, etc.
- Update of Strategic Plan Questions 1, 2, 3, 4, 7

Decisions for Today

- Are these the right subcommittees?
 - Which subcommittee will you serve on?
-
- Appointment of federal and public co-chairs

Strategic Plan Progress Update

- 2012 Update
- Updates on “What do we know?”
and “What do we need?” sections
 - Limited timeframe – aim to complete by December 2012
 - Product – a brief, stand-alone document describing current progress on the “What do we know?” and “What do we need?” sections of the Strategic Plan
 - Conclusions based on multiple data sources
 - Subcommittees will work on specific sections



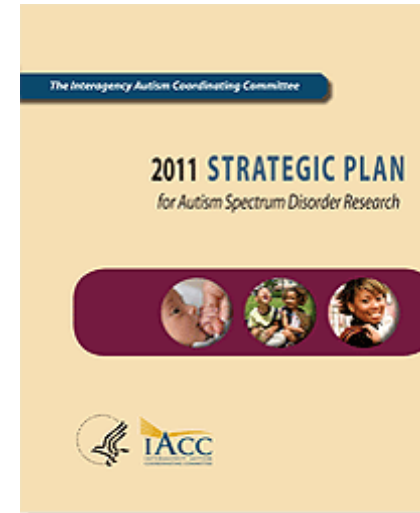
2012 Strategic Plan Progress Update

- **Data Sources**

- *IACC Portfolio Analyses and Web Tool*
- *IACC/OARC Publications Analysis*
- *IACC Summary of Advances*
- Literature searches
- Government reports
- Expert Input – Strategic Plan Workshop on Science and Services?

- **Goals**

- Qualitative assessment
- Identify progress in each field
- Identify remaining needs, laying foundation for 2013 Strategic Plan update



Possible Schedule for Progress Update

- Subcommittee meetings/phone calls in September 2012 to review data sources
- Drafting begins within subcommittees
- 2-day Strategic Planning workshop in November 2012 to provide expert input
- Drafting/Subcommittee phone calls in early December 2012
- Committee discussion and approval of Progress Update in mid-December 2012
- Final publication of document in early 2013, as we start next strategic planning effort

2012 IACC Summary of Advances



- Previous format and procedure
 - 2007 and 2008 – integrated narrative, was very brief on each article, sometimes was difficult to tie advances together
 - 2009-2011 – IACC selected top 20 articles, summarized each separately
 - All articles selected by committee vote
 - Document written in lay-friendly language for accessibility
 - IACC members asked for opportunity to nominate and vote on articles twice per year, selecting 10 articles at mid-year and 10 at the end of the year
 - Pro – Earlier selection of some articles to use in Strategic Plan update
 - Con – Was confusing and time consuming for some
 - Only articles fully published in print during the calendar year were eligible

2012 IACC Summary of Advances



- Alternate procedure
 - Keep format?
 - If so, nominate and vote for all 20 articles in January 2013 (for the 2012 edition) to allow equal consideration of all articles published throughout the year
 - Any article published online (includes e-pub ahead of print) in 2012 would be eligible

2012 IACC Summary of Advances



Decisions:

- Does the committee want to continue with the current format?
- If so, which process would the new committee like to use - voting twice a year or once a year?
- Would the committee like to start including e-publications ahead of print in the Summary of Advances?

IACC Portfolio Analysis



- Provides quantitative analysis of the ASD research portfolio across both Federal agencies and private organizations
- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan
- Informs the IACC and stakeholders about the funding landscape and current directions in ASD research
- Highlights gaps and opportunities to guide future activities
- Can serve as a foundation for other analyses – data publicly accessible

2011 IACC Portfolio Analysis

- Approval to begin data collection for 2011 Portfolio Analysis?
 - Suggestions for addition of **1 new private funder**? (Up to 9 allowed currently, unless OMB clearance obtained.) New funders suggested by IACC or that have approached us – Hussman, FRAXA, Nat'l Fragile X, other family foundations
 - Other suggestions from the committee for private or federal funders to check?
- OARC will request feedback from the IACC at future subcommittee meetings regarding any new types of analyses the committee might want OARC to consider including in the next Portfolio Analysis report

IACC Workshops

- The IACC may convene workshops on areas of interest pertinent to the autism community
- Recent IACC workshops have included scientific and services topics:
 - 2009 IACC Scientific Workshop (Strategic Plan–related)
 - 2010 IACC Services Workshop: Enhancing Supports for People with Autism and Their Families: Community Integration and the Changing Delivery System
 - 2011 IACC Services Workshop: Building a Seamless System of Quality Services & Supports Across the Lifespan
- Subcommittees/working groups are generally responsible for planning workshops
- Recommend 1 additional workshop in 2013 due to budget and planning considerations
- Subcommittees may generate topics for full IACC consideration and approval

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Public Comments Discussion

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Closing Remarks