

2013 IACC Strategic Plan Update Workshop

Friday, November 15, 2013

National Institutes of Health
1 Center Drive, Wilson Hall
Bethesda, MD 20892

Conference Call Access:
Phone Number: 888-603-9744
Access Code: 4649252



2013 IACC Strategic Plan Update Workshop

Morning Agenda

8:30 AM **Welcome, Introductions, and Charge**

Susan Daniels, Ph.D.

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

Thomas Insel, M.D.

Director, National Institute of Mental Health
(NIMH) and
Chair, IACC



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Thomas Insel, M.D.

Director, National Institute of Mental Health (NIMH) and Chair, IACC

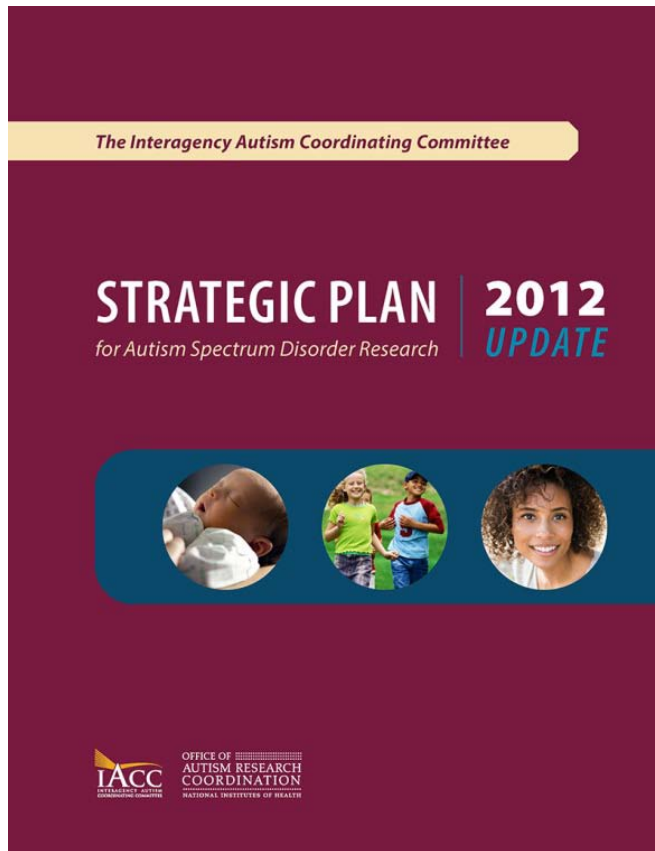
Susan A. Daniels, Ph.D.

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

2013 IACC Strategic Plan Update Workshop

For the 2013 Strategic Plan Update, the committee decided to:

- Conduct a review of progress since the launch of the Strategic Plan in 2009, considering 5 years of data.
- Review both funding and research/activity progress
- Identify advances and changes in the field, gaps, opportunities, and barriers
- Determine priorities
- Use this information to adjust focus and for future updates of the Strategic Plan itself



Update Process

IACC Strategic Plan Update Planning Groups – Composed of IACC Members and Invited Experts

First Call : IACC members from Planning Groups for each Question discussed progress in funding for projects aligned with Strategic Plan objectives

Second Call : Planning Groups for each Question, including invited experts, discussed progress in the field in each Question/Objective area

Update Workshop: The full Committee, along with invited experts, will review the findings of the Planning Groups, sharing information across Question areas

Outcome:
Write-up of
Strategic Plan
Progress
Update

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Morning Agenda – Continued

**9:00 Discussion of IACC Strategic Plan Question 1 –
“When Should I Be Concerned?”
(Screening and Diagnosis)**

**9:50 Discussion of IACC Strategic Plan Question 2 –
“How Can I Understand What Is Happening?”
(Underlying Biology of ASD)**

10:40 Break

Q1. When should I be concerned?

ASPIRATIONAL GOAL: Children at risk for ASD will be identified through reliable methods before ASD behavioral characteristics fully manifest.

- Cost effective, performance based screening and diagnostic tools
- Tools that are effective in diverse cultural settings
- Need to link genetic testing with availability of appropriate interventions or other benefits
- Need for biomarkers of ASD risk

Q2. How can I understand what is happening?

ASPIRATIONAL GOAL: Discover how ASD affects development, which will lead to targeted and personalized interventions.

- Need to further define key research questions in the study of ASD and immune/metabolic mechanisms
- Need for more genotype/phenotype studies
- Need for more longitudinal studies
- Need for increased supply of brain tissue for post-mortem studies and technology
- Need for larger clinical studies
- Need to standardize data collection

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Break

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Morning Agenda – Continued

- 10:55** **Discussion of IACC Strategic Plan Question 3 – “What Caused This to Happen and Can It Be Prevented?” (Risk Factors)**
- 11:45** **Public Comments**
- 12:15 PM** **IACC Member and Invited Participant Box Lunch Pick-Up/Payment (Working lunch will start at 12:45)**

Q3. What caused this to happen and can it be prevented?

ASPIRATIONAL GOAL: Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD.

- Exposome
- Longitudinal studies
- Building onto existing environmental research infrastructure
- Applying approaches from other fields

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Public Comments

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Lunch Break

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Afternoon Agenda

- 12:45 Discussion of IACC Strategic Plan Question 4 –
“Which Treatments and Interventions Will Help?”
(Treatments and Interventions)**
- 1:35 Discussion of IACC Strategic Plan Question 5 –
“Where Can I Turn for Services?”
(Services)**
- 2:25 Discussion of IACC Strategic Plan Question 6 –
“What Does the Future Hold, Particularly for
Adults?”
(Lifespan Issues)**

Q4. Which treatments and interventions will help?

ASPIRATIONAL GOAL: Interventions will be developed that are effective for reducing both core and associated symptoms, for building adaptive skills, and for maximizing quality of life and health for people with ASD

- Need a pipeline of interventions
- Need for biomarkers and outcome measures
- Interventions for underserved populations – cost effectiveness, ease of delivery/use
- Research on subtypes to enable personalized approaches

Q5. Where can I turn for services?

ASPIRATIONAL GOAL: Communities will access and implement necessary high-quality, evidence-based services and supports that maximize quality of life and health across the lifespan for all people with ASD.

- Health disparities: need to move from observation to action –
- begin to use experimental approaches to address issues
- Scaleability of training for service providers
- “Practice to research” models
- Building research partnerships between academia and states
- Building research onto state demonstration projects
- Need to develop and disseminate best practices

Q6. What does the future hold, particularly for adults?

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, meaningful relationships, and access to necessary and individualized services and supports.

- Need improved models of state level coordination of services
- Need to understand the needs of adults in order to plan appropriate services
- Need a plan to provide services to adults who are diagnosed with ASD
- Need measures of quality of life

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Afternoon Agenda – Continued

3:15 **Break**

3:30 **Discussion of IACC Strategic Plan Question
7 – “What Other Infrastructure and
Surveillance Needs Must Be Met?”
(Infrastructure and Surveillance)**

4:20 **Synthesis, Wrap-Up, and Next Steps**

5:00 **Adjournment**

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Break

Q7. What other infrastructure and surveillance needs must be met?

ASPIRATIONAL GOAL: Develop and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of Autism research.

- Need to increase the number of samples in repositories
- Need for standards
- Need for solutions to address privacy, security issues
- Need to build onto established surveillance infrastructure

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Synthesis, Wrap-Up, and Next Steps



Next IACC Full Committee Meeting

January 14, 2014

National Institutes of Health
31 Center Drive, C Wing 6th Floor, Room 6
Bethesda, MD 20892

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Adjournment