

# **Interagency Autism Coordinating Committee Conference Call and Webinar**

## **December 18, 2012**

### **Conference Call Access:**

Phone: (800)369-1881

Access Code: 9976437

# IACC Conference Call and Webinar

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## Agenda

- 10:00 AM**      **Call to Order and Opening Remarks**  
Thomas Insel, M.D.  
Director, NIMH and Chair, IACC
- 10:15**            **Oral Public Comments Session**
- 10:45**            **Public Comments Discussion Period**
- 11:00**            **Discussion and Vote – Question 1**  
**Diagnosis**
- 11:30**            **Discussion and Vote – Question 2**  
**Biology**
- 12:00 PM**      **Lunch**

# IACC Introduction

**Thomas R. Insel, M.D.**

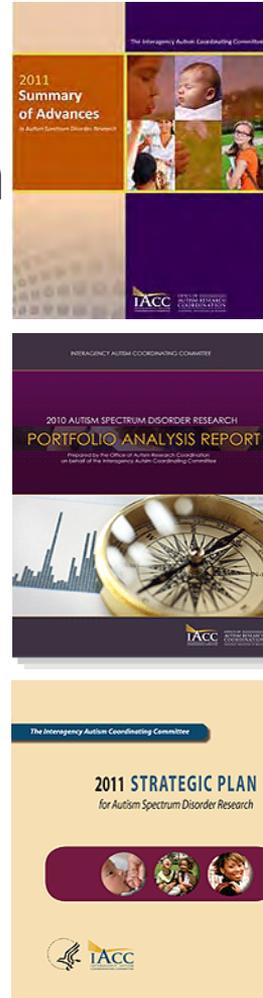
Director, National Institute of Mental Health

Chair, IACC

IACC Full Committee Conference Call and Webinar – December 18, 2012

# Responsibilities of the IACC

- Develop and update annually a summary of advances in ASD research
- Monitor Federal activities with respect to ASD
- Make recommendations to the Secretary DHHS regarding research or public participation
- Develop and annually update and submit to Congress a strategic plan for ASD research



# What the IACC does:

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- Advises HHS Secretary
- Coordinates federal and non-federal activities (research and services)
- Focuses and accelerates research progress via priorities in the IACC Strategic Plan for ASD Research
- Serves as a public forum

# IACC Core Values

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- Sense of urgency
- Scientific excellence
- Spirit of cooperation
- Consumer focus
- Partnerships in action
- Accountability (SMART objectives – specific, measurable, achievable, realistic, time-bound)

**“finding common ground”**

# Research Strategic Plan Update

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- IACC must update Plan in CY 2012
- Decisions from July 2012 meeting
  - Update will focus on “What do we know?” and “What do we need?” sections of the *Plan*
  - Two subcommittees will draft updates (Chapters 1-4 and 7; Chapters 5 & 6)
  - Will utilize external scientific expertise and receive public comment
  - Final draft will be approved by IACC vote
- Principles to consider
  - Include major new discoveries or insights
  - Gaps may be evident from outside of ASD research
  - No need to repeat what is in the current *Strategic Plan*

# Vision Statement

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*The Strategic Plan will accelerate and inspire research that will profoundly improve the health and well-being of every person on the autism spectrum across the lifespan. The Plan will set the standard for public-private coordination and community engagement.*

*Introduction, 2011 IACC Strategic Plan for ASD Research*

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# Public Comments Session

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## Public Comments Discussion Period

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## Discussion and Vote – Question 1 Diagnosis

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## Discussion and Vote – Question 2 Biology

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## Lunch Break

(Call will reconvene at 1:00p.m. ET)

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## Agenda – Continued

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|-------------|--|
| <b>1:00</b> | <b>Discussion and Vote – Question 3<br/>Risk Factors</b>                 |
| <b>1:30</b> | <b>Discussion and Vote – Question 4<br/>Treatments and Interventions</b> |
| <b>2:00</b> | <b>Break</b>   |
| <b>2:15</b> | <b>Discussion and Vote – Question 5<br/>Services</b>                     |

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## Discussion and Vote – Question 3 Risk Factors

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## Discussion and Vote – Question 4 Treatments and Interventions

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## Discussion and Vote – Question 5 Services

# Proposed addition to Question 5 Update

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- Two other major healthcare payers made benefits available for individuals with ASD. The Office of Personnel Management (OPM), which administers health benefits for more than eight million Federal employees and beneficiaries, recently categorized applied behavior analysis (ABA) as medical therapy. Accordingly, insurance plans in the FEHB program were able to propose benefit packages that cover ABA for the 2013 plan year. The OPM decision did not require insurance plans to cover ABA; only 67 of the 230 participating health plans elected to offer this coverage in 2013.

# Proposed addition to Question 5 Update

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- Recent legislation regarding the TRICARE program, the health care program for uniformed service members, retirees, and their families, recently changed its ABA benefit as well. Currently, ABA benefits are restricted to active duty members. An amendment was added to a recent budget bill that would offer behavioral health treatment to all members, as well as lift an annual spending cap on ABA benefits. While the final outcome for ABA coverage under TRICARE remains unknown at this time, recent Congressional actions suggest it will pass.

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## Agenda – Continued

- 2:45**            **Discussion and Vote – Question 6**  
                         **Lifespan Issues**
- 3:15**            **Discussion and Vote – Question 7**  
                         **Infrastructure and Surveillance**
- 3:45**            **Discussion and Vote – Introductions**  
                         **and Conclusion**
- 4:00**            **Wrap-Up and Next Steps**
- 4:15**            **Adjournment**

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## Discussion and Vote – Question 6 Lifespan Issues

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## Discussion and Vote – Question 7 Infrastructure and Surveillance

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## Discussion and Vote

### Introduction and Conclusion

# Question 4: Treatments and Interventions

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Evidence for the benefits of early behavioral intervention continues to mount, with researchers now focusing on testing interventions for infants and toddlers, identifying the most effective aspects of treatments and disseminating these interventions in community settings. While gains have been made in this area of research, the effects of these interventions as measured to date are modest. Positive results of implementation of targeted interventions in community settings have recently been reported (Kaale, Smith & Sponheim, 2012; Lawton & Kasari, 2012).

# Question 4: Treatments and Interventions

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**A randomized clinical trial (RCT) in toddlers with ASD, ~~tested~~ing the efficacy of Hanen’s “More Than Words,” a parent-implemented intervention, found that toddlers with poorer play skills benefited most (Carter et al., 2011). Furthermore, a longitudinal follow up of a targeted, joint attention intervention (Kasari et al., 2012b) found that joint attention and play are important targets for interventions aimed at enhancing language acquisition (and that these functional gains may persist over the long-term).**

# Question 4: Treatments and Interventions

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**Early intensive intervention using the Early Start Denver Model (ESDM) with toddlers (described in the 2011 Strategic Plan) was found to result in improvements in both social behavior and neural responses to social stimuli (Dawson et al., 2012). This was found to the first study to demonstrate that behavioral interventions can result in changes in electrophysiological brain activity (specifically, event related potentials (ERPs) and electroencephalography (EEG) spectral power in response to social stimuli), and that this biological marker correlated with positive changes in behavior. (Dawson et al., 2012).**

# Question 4: Treatments and Interventions

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**In a different RCT, children who received a 12-week, parent-delivered ESDM intervention were compared to a control group of children receiving typical community interventions ~~over the same period of time (although note that the latter group received more intervention hours per week)~~ (Rogers et al., 2012). Both groups of children showed developmental gains and reduced core autism symptoms, although there was no clear advantage of one intervention over the other. However, the degree of improvement across both community and ESDM groups was higher in children that received more hours of intervention, and younger children (14 months) made more developmental gains than older children (24 months).**

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## Wrap-Up and Next Steps

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# Adjournment