

# IACC Committee Business

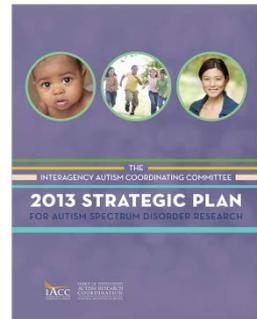
**Susan A. Daniels, Ph.D.**

Director, Office of Autism Research Coordination  
Executive Secretary, IACC  
National Institute of Mental Health

IACC Full Committee Meeting  
January 12, 2015

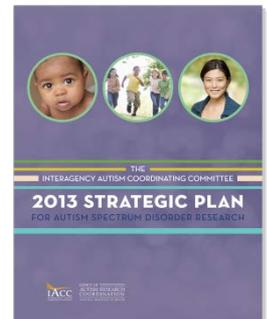
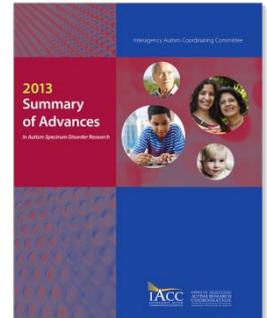
# IACC Responsibilities

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



# Immediate To-Do List

- Develop two volumes of the IACC Summary of Advances in ASD Research (2014 and 2015)
- Develop an update of the IACC Strategic Plan (2016 Update) that will cover progress made in 2014 and 2015



# Summary of Advances Update

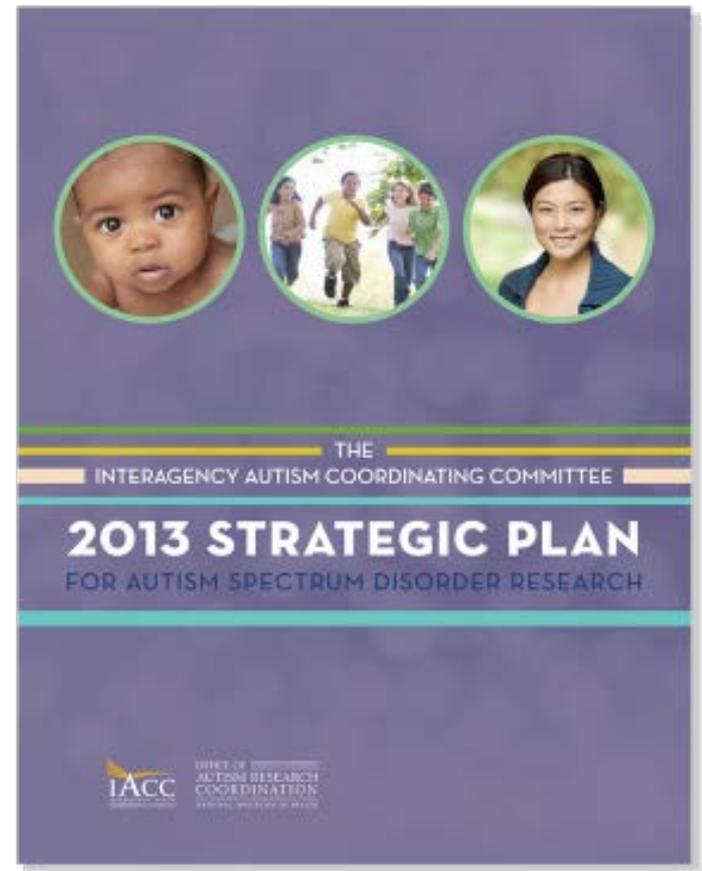
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The committee decided to use the same process as previous years to develop the Summary of Advances:

- OARC provides and committee nominates peer reviewed research publications – **Process started**
- Committee will select up to 20 advances under each of the 7 areas of the Strategic Plan
- OARC will write short, lay-friendly summaries of the selected articles
- The 20 advances from each year are each combined into a booklet format – 2 booklets
- Final documents will be completed in 2016
- Will provide an update in April 2016

# IACC Strategic Plan Update

Finalize plans  
for the next  
IACC Strategic  
Plan Update



# Autism CARES Act and the IACC SP

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## The Autism Collaboration, Accountability, Research, Education and Support Act (P.L. 113-157):

- Continues to require the IACC to prepare an annual update of the IACC Strategic Plan
- Requires that the IACC Strategic Plan continue to address research, but also include as practicable, services and supports for individuals with ASD and their families as well as recommendations to ensure that federal ASD research and services activities are not unnecessarily duplicative:
- The IACC shall “**develop a strategic plan for the conduct of, and support for, autism spectrum disorder research, including as practicable for services and supports...**”

## Autism CARES Act (continued)

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### The Autism Collaboration, Accountability, Research, Education and Support Act (P.L. 113-157):

- The strategic plan, “**shall include proposed budgetary requirements and recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative.**”
- Requires that the IACC Strategic Plan be submitted to Congress and the President

# Structure of IACC Strategic Plan

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## Framed around 7 consumer-based Questions:

- Question 1: When Should I Be Concerned?
- Question 2: How Can I Understand What Is Happening?
- Question 3: What Caused This to Happen and Can It Be Prevented?
- Question 4: Which Treatments and Interventions Will Help?
- Question 5: Where Can I Turn for Services?
- Question 6: What Does the Future Hold, Particularly for Adults?
- Question 7: What Other Infrastructure and Surveillance Needs Must Be Met?

# Structure of IACC Strategic Plan

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Each Question has:

- An **Aspirational Goal**, describing long term goals for the field and outcomes for individuals on the autism spectrum
- **Introduction (What do we know? What do we need?)** that provides background on the field and needs pertaining to that question.
- **Progress toward the SP Objectives** – a summary
- **Progress in the field** – describing recent research advances
- **Progress toward the Aspirational Goal**
- **Research Objectives** (if any new)

# 2016 Strategic Plan Update – Option 1

## Encompassing Both Research and Services

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- **Each of 7 Questions addresses both research and services issues related to the question**
- **Aspirational Goal**, describing long term goals for the field and outcomes for individuals on the autism spectrum
- **Introduction (What do we know? What do we need?)** that provides background on the field and needs pertaining to that question – addressing both research and services
- **Progress toward the SP Objectives** – summarize progress made on previous SP objectives to understand state of funding for all areas of SP

# 2016 Strategic Plan Update – Option 1

## Encompassing Both Research and Services

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- **Progress in the field** – Split into 3 sections:
  - Advances in Research
  - Innovation in Services
  - Changes in Policy
- **Progress toward the Aspirational Goal**
- **Future Directions** - Address remaining gaps and issues related to ensuring the translation of research to services and benefits, and feedback from services experience to enhance research
- **Develop new 2016 Research and Services Objectives**
- Rename the SP the “**IACC Strategic Plan for ASD**”

# 2016 Strategic Plan Update – Option 2

## Separate Research and Services Plans

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- Keep current research Strategic Plan and structure, but develop a new set of research objectives
- Develop a separate Services Plan, with a structure TBD

# Objectives for the 2016 IACC SP

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- Most of the current 78 SP objectives date to 2011 and have been accomplished or are in progress
- Is it time for a new/revised set of objectives? (research and services?)
- If so, how many, or how many per Question?
- Should the format of objectives be similar to current or less specific?

# Objectives for the 2016 SP Update (Cont'd)

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- **Example of current SP Objective:**
  - 1SA. Develop, with existing tools, at least one efficient diagnostic instrument (i.e., briefer, less time intensive) that is valid in diverse populations for use in large-scale studies by 2011.  
IACC Recommended Budget: \$5,300,000 over 2 years.
- Do we need to designate objectives as long term and short term? Was it helpful?
- Do we want specific deadlines tailored to each objective, or have most/all objectives share a common deadline (e.g. 2019 [3yr] or 2021 [5yr])?
- Current objectives are very specific – do we want new objectives to be more inclusive/higher level?

# Planning the SP Update

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Whether Option 1 or Option 2 chosen:

- Start with 7 working groups for the 7 Questions of the SP/research SP. Membership flexible.
- Does the committee want to invite external experts to participate? If so, perhaps 3-6 per WG?
- Structure a series of phone meetings for each WG – 3 meetings to cover the sections of the SP Update.
- Do we need an in-person workshop to discuss draft document among whole group after initial drafts completed?

## Planning the SP Update (cont'd)

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- Each group will be provided with data from the 2013 Portfolio Analysis to review research funding – summary data and grant lists
- IACC required to provide “recommendations to ensure that autism spectrum disorder research, and services and support activities to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies are not unnecessarily duplicative.” - **How to do this?**
- Resources available:
  - 2013 research grant list
  - 2012 services and research information from Report to Congress on ASD Activities
  - Budgetary requirements – discuss in April?

# Next Steps

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- Determine working group composition and chairs?
- Select external experts?
- Via e-mail – brainstorm some topics to include under the Questions – discuss them in WGs
- Set working group meeting (conference call) schedule – February and March
- Review progress in April full committee meeting
- Complete update by July 2016 IACC meeting

## OARC will:

- Contact IACC members to determine WG membership and chairs and select external experts
- Set a meeting schedule
- Prepare materials



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AUTISM RESEARCH  
COORDINATION  
  
NATIONAL INSTITUTES OF HEALTH

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