

IACC Committee Business

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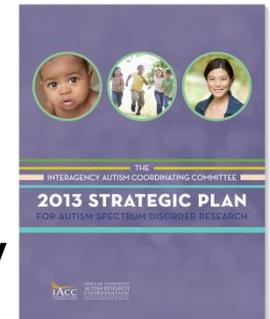
National Institute of Mental Health

IACC Full Committee Meeting

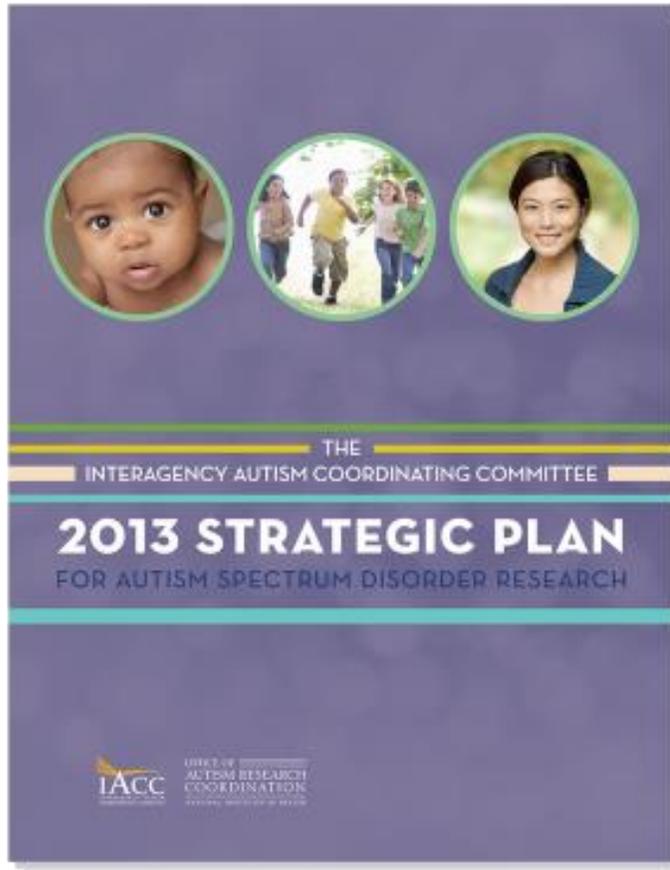
October 26, 2016

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



IACC Strategic Plan Update



Seven working groups composed of IACC Members and invited external experts have been convened to cover the 7 Strategic Plan Questions

IACC Strategic Plan Working Groups

- Question 1: When Should I Be Concerned? **(Screening/Diagnosis)**
- Question 2: How Can I Understand What Is Happening? **(Underlying Biology)**
- Question 3: What Caused This to Happen and Can It Be Prevented? **(Risk Factors)**
- Question 4: Which Treatments and Interventions Will Help? **(Interventions)**
- Question 5: Where Can I Turn for Services? **(Services)**
- Question 6: What Does the Future Hold, Particularly for Adults? **(Lifespan Issues)**
- Question 7: What Other Infrastructure and Surveillance Needs Must Be Met? **(Infrastructure, Surveillance, Outreach, Collaboration)**

Working Group Activities

Each of the 7 working groups held 2 conference calls in September and October to discuss:

- **Progress toward the current Strategic Plan Objectives**
 - Based on information from the 2013 analysis of research funded by federal and private funders
- **Progress in the field:**
 - Research advances
 - Practice to research
 - Gaps, needs, barriers and opportunities
 - New programs and policies
 - New research evidence that can inform policy
 - Services needs/gaps, needed policy changes
- **Aspirational Goal; Chapter Title**

Working Group Activities

Each of the 7 working groups is in the process of or has already scheduled a third conference call where we will discuss:

- **Draft chapter outline for each Question that describes progress in the field, gaps/needs, barriers and opportunities**
- **Development of 3 broad objectives for each Question, including examples of responsive research projects, and services or policy activities**
- ***Today: IACC suggestions re: areas to target in objectives?***

Strategic Plan Update Requirements

- **The Autism CARES Act requires the IACC in its Strategic plan 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.**”
- **This requirement was based on a 2013 report by the GAO that stated concerns about potential for duplication in the research portfolio, but not services**
- **IACC public members responded to the report**

Strategic Plan Update Requirements

- **IACC Public Member Response Letter**
Key Points:
 - **Efforts by multiple agencies with different mission areas to address different aspects of broad, complex issues related to autism spectrum disorders research is important and necessary**
 - **Emphasized the need for corroboration and replication of research**

Strategic Plan Update Requirements

- **Feedback collected from working groups regarding duplication:**
 - **Emphasized the importance of replication of research and reproducibility**
 - **Saw role for closer coordination of large genomic sequencing efforts to avoid resequencing same individuals, more transparency and data sharing to prevent duplication of effort**
 - **Ensuring that the new Strategic Plan objectives have minimal overlap will make it easier to review the portfolio for potential duplication**
 - ***Other suggestions from the committee?***

Strategic Plan Update Requirements

- **Next steps:**
 - **IACC needs to prepare a 1-2 paragraph statement on recommendations to ensure that unnecessary duplication of effort is minimized**
 - **Volunteer(s) to draft a statement for feedback from the working groups and then review by the full committee in January?**
 - **Text of IACC letter is available as a resource**

Strategic Plan Update Requirements

- **The Autism CARES Act requires the IACC Strategic Plan to include “proposed budgetary requirements.”**
- **The previous Strategic Plan provided estimated budgetary requirements for each objective**
- ***Does the committee want to develop budgetary requirements based on the objectives, the questions, or the overall plan, keeping in mind that the new objectives will be broad and inclusive of both research and services activities?***
- ***Does the committee want to try to estimate actual budgets or project percentage increases, decreases, etc.? Growth over time?***

Strategic Plan Next Steps

- **Working Group Calls to be held in November**
- **Working groups to begin writing chapters in November**
- **Chapter drafts will be shared with committee in January, with goal of publication of new Strategic Plan in April 2017**



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