

IACC Committee Business

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Director, Office of Autism Research Coordination

Executive Secretary, IACC

National Institute of Mental Health

IACC Full Committee Meeting

April 19, 2016

April is National Autism Awareness Month



NIMH Special Lecture for Autism Awareness Month

NIMH Special Lecture for Autism Awareness Month

IN A DIFFERENT KEY:

THE STORY OF AUTISM

THEN AND TO COME



**JOHN DONVAN
CAREN ZUCKER**

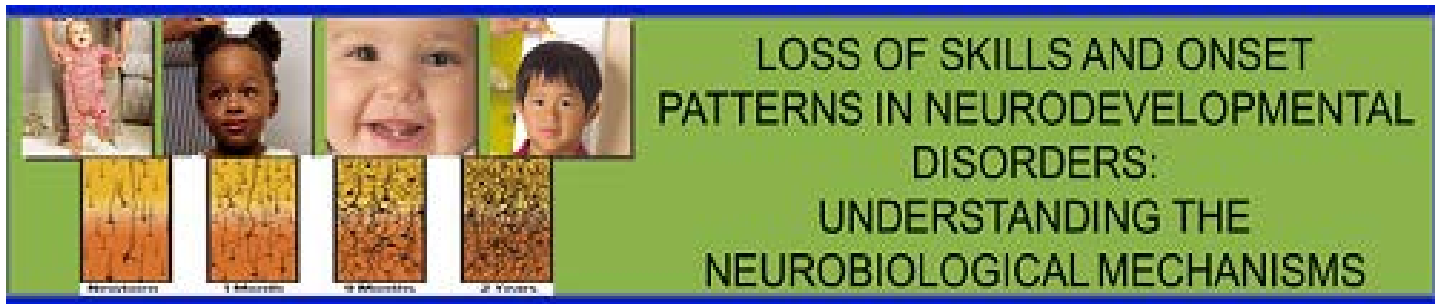
April 11, 2016

Other Recent OARC Sponsored Activities



NIMH Seminar Series: New Discoveries in Mental Health Research - Pathways to New Treatments in Autism Spectrum Disorder

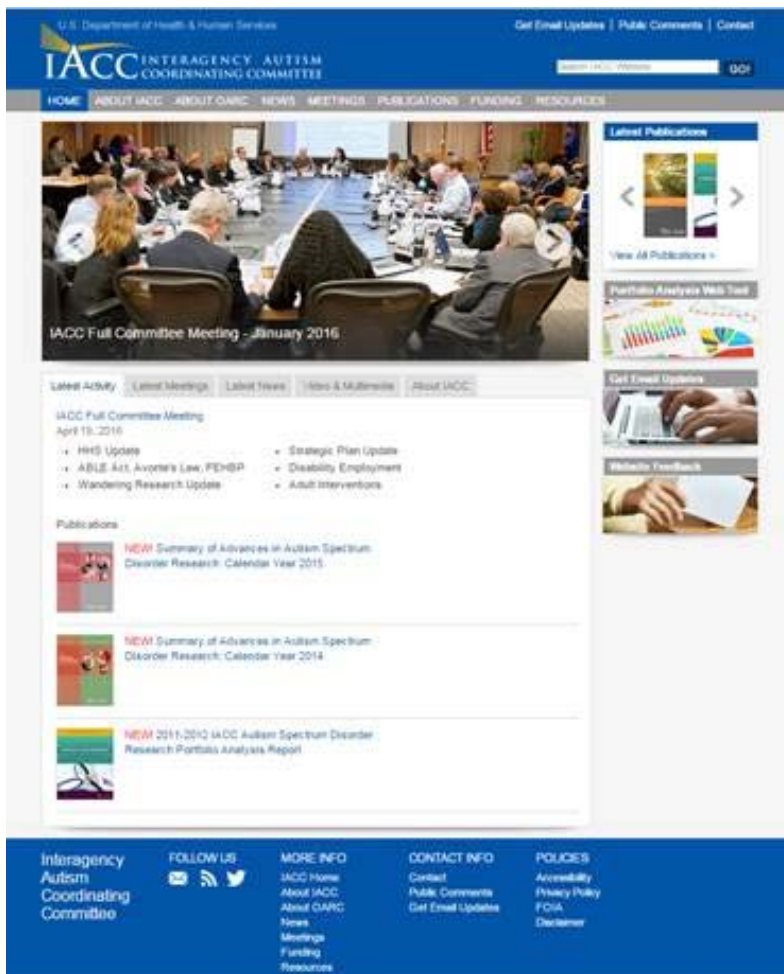
Dr. Jeremy Veenstra VanderWeele – April 13, 2016



NIMH Workshop – February 19, 2016

Agendas and videos available at www.iacc.hhs.gov

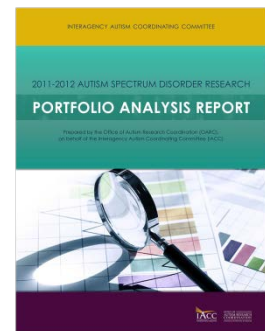
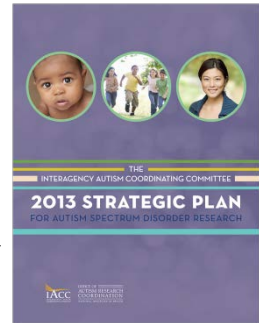
Introducing the IACC's **New Website!**



- Fresh, new look
- Streamlined layout
- Simple navigation
- New features:
 - More autism and disability news & reports
 - Funding opportunities
 - Resources
- Mobile-friendly

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



2015 IACC Summary of Advances



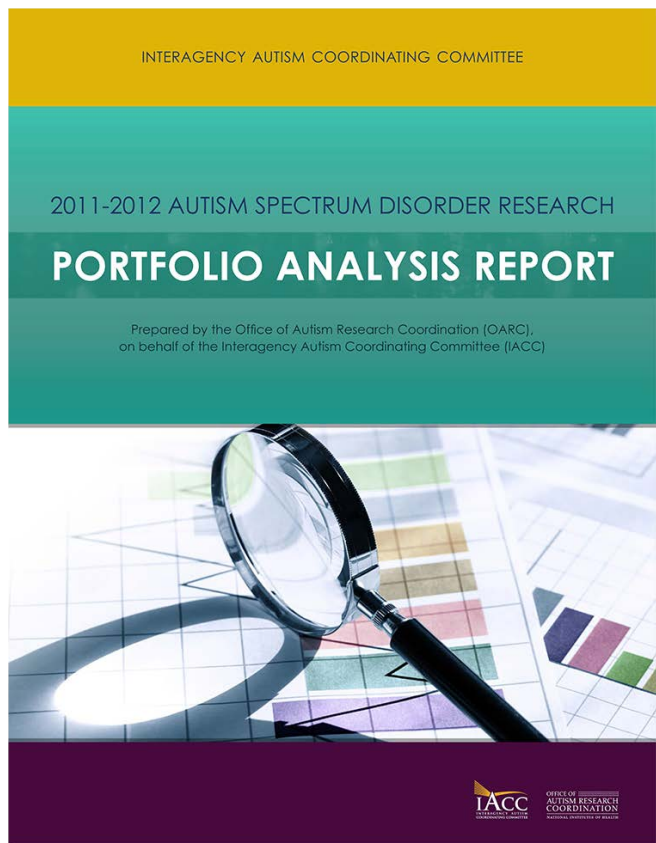
- Annual publication – required by CAA
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
 - Prevalence
 - Diagnosis
 - Biology
 - Risk factors
 - Interventions
 - Lifespan issues

2014 IACC Summary of Advances



- Annual publication – required by CAA
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research selected by the IACC
- Covers:
 - Prevalence
 - Diagnosis
 - Biology
 - Risk factors
 - Interventions
 - Lifespan issues

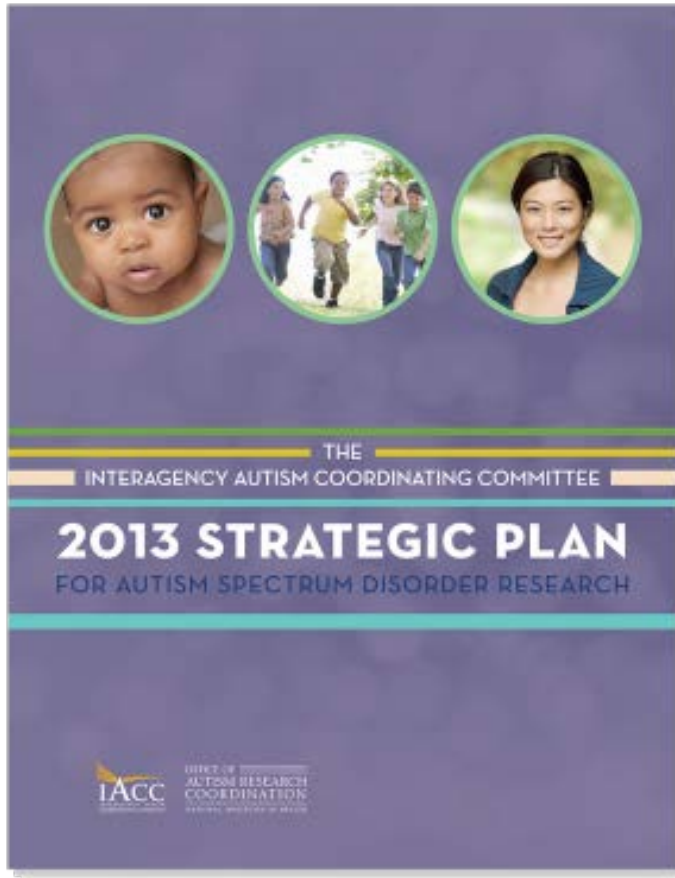
2011-2012 IACC Portfolio Analysis Report



Data sets in PA Web Tool

- Follow-up comprehensive report; overview data published in the 2013 IACC Strategic Plan Update
- Assists the IACC in fulfilling the CAA requirement to monitor Federal activities related to Autism Spectrum Disorder (ASD)
- Provides detailed analysis of the ASD research portfolio across both Federal agencies and private organizations
- Informs the IACC and stakeholders about the funding landscape and current directions in ASD research
- Helps the IACC monitor progress in fulfilling the objectives of the IACC Strategic Plan

IACC Strategic Plan Update



IACC Members volunteered to serve on 7 working groups to cover the 7 Strategic Plan Questions

Members nominated external experts to serve on the working groups

We are in the process of confirming membership of the working groups

Will begin scheduling series of calls To develop updates for each of the 7 Question areas

Structure of IACC Strategic Plan

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 2016 Strategic Plan

- **Introduction**
- **Question description and Aspirational Goal**
- **Progress toward the current SP Objectives**
- **Overview of Progress in the field:**
- **Research Update**
 - Science advances
 - Practice to research
 - Gaps, opportunities, needs
- **Services/Policy Update**
 - New programs and policies
 - New research evidence that can inform policy
 - Services needs/gaps, needed policy changes
- **Progress Toward Aspirational Goal**

2016 Strategic Plan Update

- **Recommendations to ensure non-duplication**
- **~3 Broad Objectives per Question (total ~21 for SP) accompanied by examples of responsive research and services projects/programs:**
- **Examples (Q1):**
 - **Increase early detection of ASD.**
 - Develop and improve screening tools.
 - Support awareness campaigns
 - Provide training for providers to enhance workforce
 - **Reduce health disparities in diagnosis.**
 - Increase outreach to special populations
 - Develop culturally adapted screening tools
 - Improve access to screening services in underserved areas
 - **Add budgetary requirements, Repeat x7**
- **Summary/Conclusion**

2016 Strategic Plan Update Resources

- **Data from the 2013 Portfolio Analysis to review research funding – summary data and grant lists**
- **Literature – from IACC Science Updates and Summary of Advances, literature identified by WGs**
- **External experts**
- **RFI? (archive of regular public comments also available)**
- **2012 services and research information from Report to Congress on ASD Activities**
- **Policy information from IACC members and policy experts**

2016 Strategic Plan Next Steps

- **Confirm SP WG membership**
- **Via e-mail – brainstorm some topics to include under the Questions – for public discussion in WGs**
- **Set working group meeting (conference call) schedule – May, June**
- **Review progress at next full committee meeting – July**
- **The update must be completed in this calendar year**

Topical Working Groups

- In January, IACC voted to form a housing working group
 - Will be sending out list of IACC member volunteers and soliciting nominations for external experts
 - Volunteers to date: Alison Singer, Melissa Harris, Jim Ball, Amy Goodman, David Mandell, Brian Parnell, Kevin Pelphrey, Julie Taylor – others welcome
- For discussion:
 - Safety working group?
 - Co-occurring conditions working group?

2015 Summary of Advances Process

The committee used the same process as previous years:

- OARC provided and full committee nominated peer reviewed research publications
- Committee selected up to 20 advances under each of the 7 areas of the Strategic Plan
- OARC provided short, lay-friendly summaries of the selected articles
- The 20 advances from each year were each combined into a booklet format – 2 booklets
- Final documents were completed in April 2016 – a 3 month timeframe

For discussion: Would you like the final product to be different next time; if so, how?



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