

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
April 26, 2017

Susan Daniels, Ph.D., Director

Oni Celestin, Ph.D., Science Policy Analyst

Ben Feldman, M.A., Ph.D., Science Policy Analyst

Rebecca Martin, M.P.H., Public Health Analyst

Angelice Mitrakas, B.A., Management Analyst

Karen Mowrer, Ph.D., Science Policy Analyst

Julianna Rava, M.P.H., Science Policy Analyst

Jeff Wiegand, B.S., Web Development Manager



April is Autism Awareness Month



NIMH Special Event for Autism Awareness Month

NIMH/Office of Autism Research Coordination (OARC)
SPECIAL EVENT FOR AUTISM AWARENESS MONTH
FILM SCREENING of "AS ONE: THE AUTISM PROJECT"
TUESDAY, APRIL 25, 6:00 PM | LIPSETT AMPHITHEATER | BUILDING 10, NIH

Film screening
is free and open
to the public and
will be video cast.

IACC, HHS.gov
iacc@hhs.gov

CONTACT
If you have any
questions about the
event please contact
Teresa M. Miller at
teresa.miller@nih.gov or 301-443-0996.

ACCOMMODATIONS
Individuals with
disabilities who
need sign language
interpreters or
other reasonable
accommodations to
participate in this
event should contact
the organizers at least
30 days in
advance of the event.

AS ONE
THE AUTISM PROJECT

NIH
National Institute of Mental Health

Film Screening of “As One: The Autism Project”

Tuesday, April 25

Image Nation has
kindly made free
access to the film
available through
August 22, 2017

<https://iacc.hhs.gov/>

National Autism Awareness Month Events

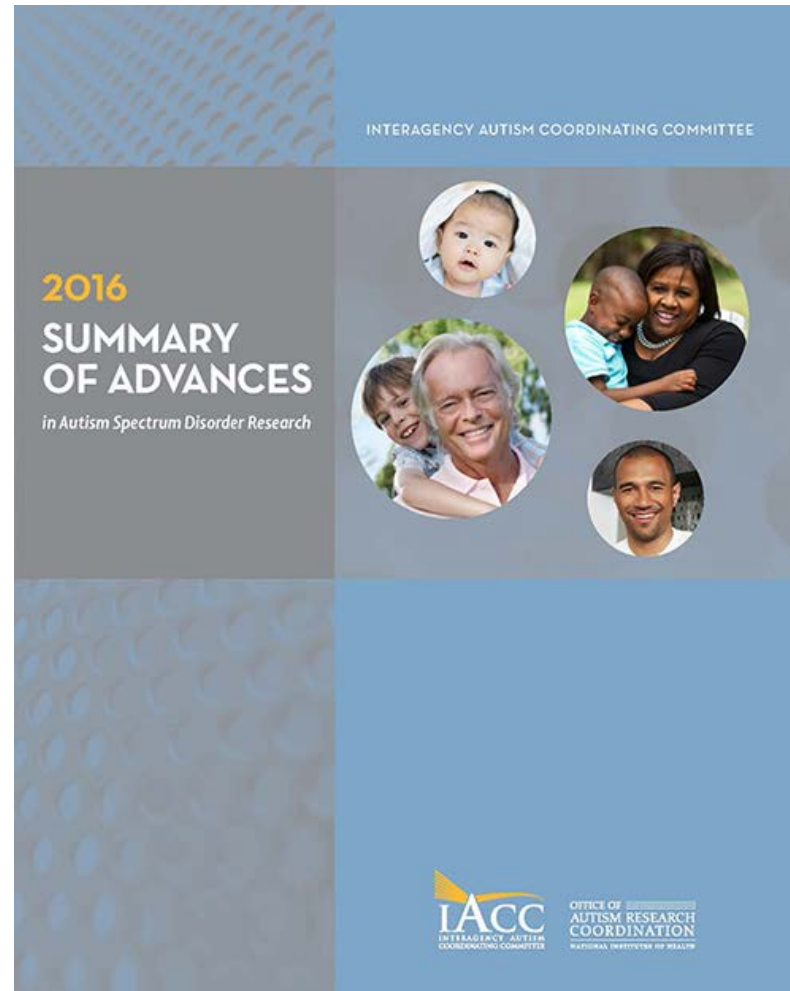
Other recent events:

- March 31, NY - UN World Autism Awareness Day Event: [Toward Autonomy and Self-Determination](#)
- April 20, Atlanta - [CDC Autism Awareness Month Event](#) that featured a lecture by Daniel Share Strom, A panel on transition to adulthood, and an improvisation performance
- As well as events sponsored by other agencies and organizations worldwide.

National Autism Awareness Month News

- [Statement of U.N. Secretary-General for World Autism Awareness Day 2017](#), Secretary-General António Guterres
- [Presidential Proclamation: World Autism Awareness Day, 2017](#), President Donald J. Trump
- [Autism Awareness Month: Genes and Development in Autism Spectrum Disorder](#), Dr. Joshua Gordon, Director, NIMH and Chair, IACC
- [Youth With Autism Spectrum Disorder Transitioning To Adulthood](#), Robin Harwood, Health Scientist and Tom Novotny, Deputy Assistant Secretary for Health

2016 IACC Summary of Advances



- Annual publication – required by CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Covers articles aligning with all seven Strategic Plan Question areas

<https://iacc.hhs.gov/publications/summary-of-advances/2016/>

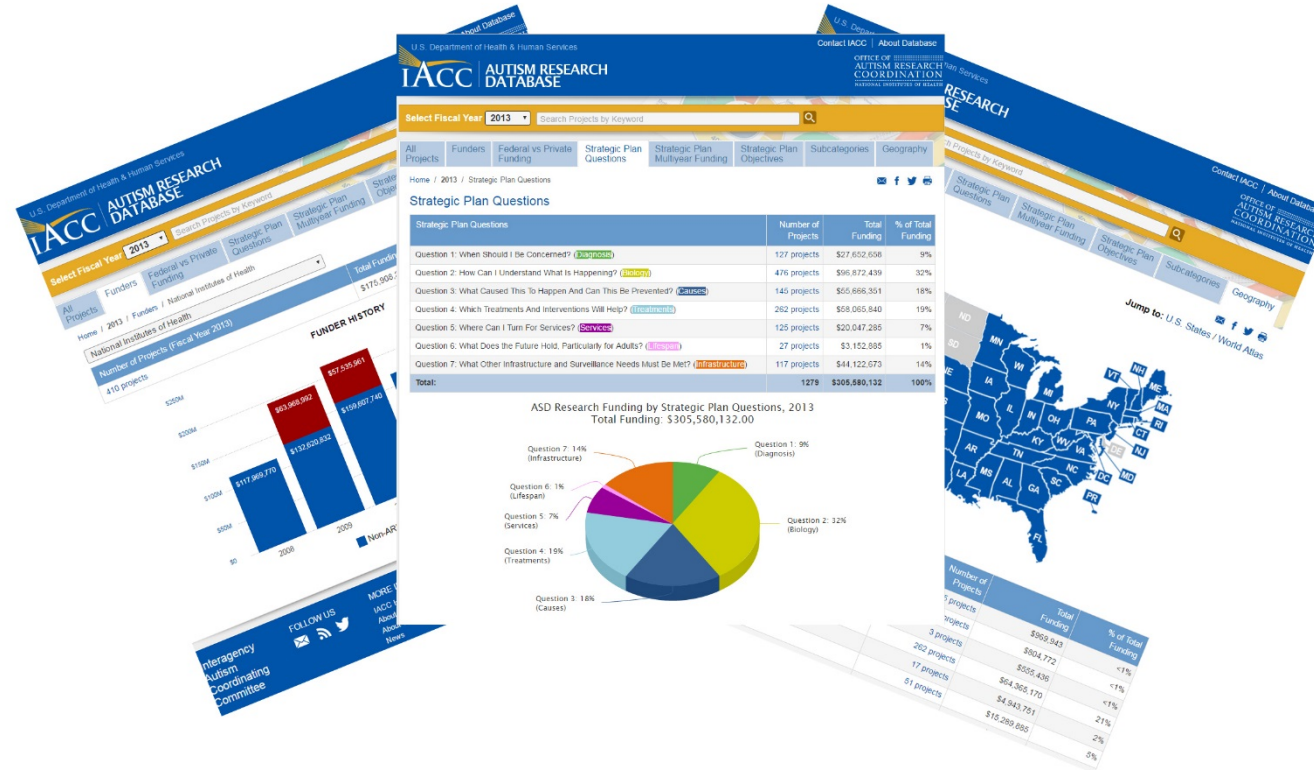
2013 IACC Portfolio Analysis Report



- **Assists the IACC in fulfilling the CARES Act 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**

<https://iacc.hhs.gov/portfolio-analysis/2013/index.shtml>

Autism Research Database

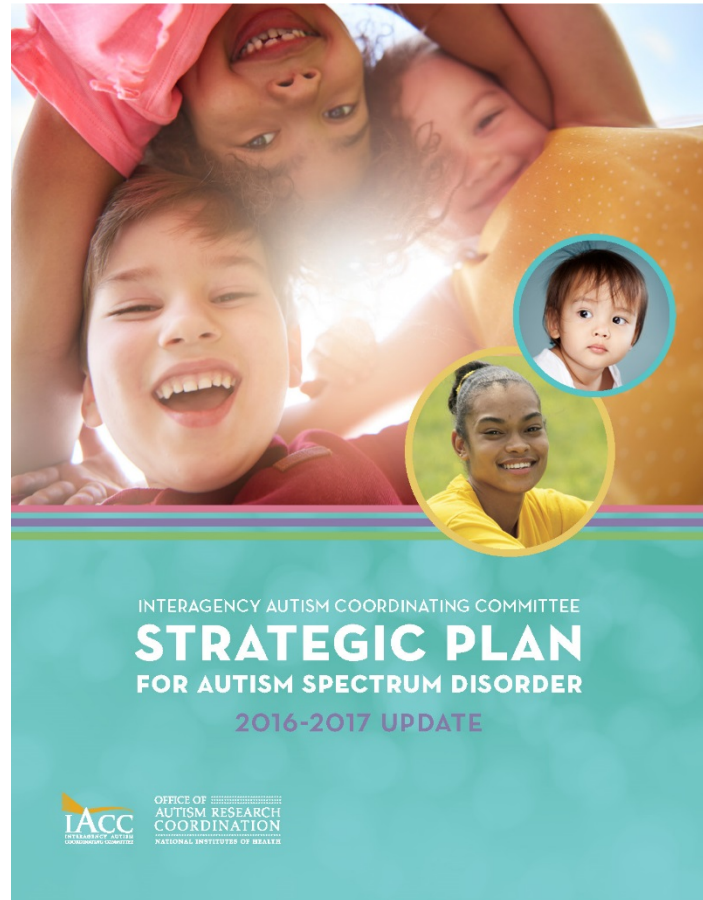


- A newly designed online database of ASD research
- Replaces the *IACC/OARC Autism Spectrum Disorder Research Portfolio Analysis Web Tool*
- New features: federal vs. private funding; geography
- Includes release of the *2013 ASD Research Portfolio Analysis data*

<https://iacc.hhs.gov/funding/data/>

IACC Strategic Plan Update

IACC Strategic Plan Update



- The IACC Strategic Plan (SP) provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.
- The IACC SP is organized around 7 consumer-based questions.
- The first IACC SP was developed in 2009 and focused on research efforts.
- Under the Autism CARES Act, the new IACC Strategic Plan will address both research and services activities.

Working Group Activities

- **The IACC formed 7 Working Groups to address the 7 chapters of the Strategic Plan.**
- **Drafts of the 7 chapters have been completed by the Working Groups, including:**
 - **Revised titles and aspirational goals**
 - **Three broad objectives for each Question**
 - **Overview of progress, gaps, opportunities, and needs**
- **Drafts of the 7 chapters have been shared with The Committee for review**

Strategic Plan Issues for Discussion

- **Q1:**
- **Q2: Overlap between Q2 and Q3?**
- **Q3: Prevention of ASD vs. prevention of disabling aspects of ASD**
- **Q4:**
- **Q5: Housing, person centered planning**
- **Q6:**
- **Q7:**

- **Other items?**

Q1. When should I be concerned?

nature

Feb 2017

Early brain development in infants at high risk for autism spectrum disorder

Hazlett HC, Gu H, Munsell BC, Kim SH, Styner M, Wolff JJ, Elison JT, Swanson MR, Zhu H, Botteron KN, Collins DL, Constantino JN, Dager SR, Estes AM, Evans AC, Fonov VS, Gerig G, Kostopoulos P, McKinstry RC, Pandey J, Paterson S, Pruett JR, Schultz RT, Shaw DW, Zwaigenbaum L, Piven J; IBIS Network; Clinical Sites; Data Coordinating Center; Image Processing Core; Statistical Analysis.



Mar 2017

Neural circuitry at age 6 months associated with later repetitive behavior and sensory responsiveness in autism

Wolff JJ, Swanson MR, Elison JT, Gerig G, Pruett JR Jr, Styner MA, Vachet C, Botteron KN, Dager SR, Estes AM, Hazlett HC, Schultz RT, Shen MD, Zwaigenbaum L, Piven J; IBIS Network.

Q2. How can I understand what is happening?

JAMA Psychiatry

Formerly *Archives of General Psychiatry*

Apr 2017

Association between the probability of autism spectrum disorder and normative sex-related phenotypic diversity in brain structure

Ecker C, Andrews DS, Gudbrandsen CM, Marquand AF, Ginestet CE, Daly EM, Murphy CM, Lai MC, Lombardo MV, Ruigrok AN, Bullmore ET, Suckling J, Williams SC, Baron-Cohen S, Craig MC, Murphy DG; Medical Research Council Autism Imaging Multicentre Study (MRC AIMS) Consortium.



Feb 2017

Enhanced expression of ADCY1 underlies aberrant neuronal signalling and behaviour in a syndromic autism model

Sethna F, Feng W, Ding Q, Robison AJ, Feng Y, Wang H.

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



Apr 2017

Refining the role of de novo protein-truncating variants in neurodevelopmental disorders by using population reference samples

Kosmicki JA, Samocha KE, Howrigan DP, Sanders SJ, Slowikowski K, Lek M, Karczewski KJ, Cutler DJ, Devlin B, Roeder K, Buxbaum JD, Neale BM, MacArthur DG, Wall DP, Robinson EB, Daly MJ.



Feb 2017

Maternal immunoreactivity to herpes simplex virus 2 and risk of autism spectrum disorder in male offspring

Mahic M, Mjaaland S, Bøvelstad HM, Gunnes N, Susser E, Bresnahan M, Øyen AS, Levin B, Che X, Hirtz D, Reichborn-Kjennerud T, Schjølberg S, Roth C, Magnus P, Stoltenberg C, Surén P, Hornig M, Lipkin WI.

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



Feb 2017

Sex-specific gene-environment interactions underlying ASD-like behaviors

Schaafsma SM, Gagnidze K, Reyes A, Norstedt N, Månsson K, Francis K, Pfaff DW.



Apr 2017

Targeted sequencing identifies 91 neurodevelopmental-disorder risk genes with autism and developmental-disability biases

Stessman HA, Xiong B, Coe BP, Wang T, Hoekzema K, Fenckova M, Kvarnung M, Gerds J, Trinh S, Cosemans N, Vives L, Lin J, Turner TN, Santen G, Ruivenkamp C, Kriek M, van Haeringen A, Aten E, Friend K, Liebelt J, Barnett C, Haan E, Shaw M, Gecz J, Anderlid BM, Nordgren A, Lindstrand A, Schwartz C, Kooy RF, Vandeweyer G, Helsmoortel C, Romano C, Alberti A, Vinci M, Avola E, Giusto S, Courchesne E, Pramparo T, Pierce K, Nalabolu S, Amaral DG, Scheffer IE, Delatycki MB, Lockhart PJ, Hormozdiari F, Harich B, Castells-Nobau A, Xia K, Peeters H, Nordenskjöld M, Schenck A, Bernier RA, Eichler EE.

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

**Molecular
Psychiatry**

Nov 2016 [Epub ahead of print]

Gestational vitamin D deficiency and autism-related traits: the Generation R Study

Vinkhuyzen AA, Eyles DW, Burne TH, Blanken LM, Kruithof CJ, Verhulst F, Jaddoe VW, Tiemeier H, McGrath JJ.

**nature
neuroscience**

Apr 2017

Whole genome sequencing resource identifies 18 new candidate genes for autism spectrum disorder

Yuen RKC, Merico D, Bookman M, L Howe J, Thiruvahindrapuram B, Patel RV, Whitney J, Deflaux N, Bingham J, Wang Z, Pellecchia G, Buchanan JA, Walker S, Marshall CR, Uddin M, Zarrei M, Deneault E, D'Abate L, Chan AJ, Koyanagi S, Paton T, Pereira SL, Hoang N, Engchuan W, Higginbotham EJ, Ho K, Lamoureux S, Li W, MacDonald JR, Nalpathamkalam T, Sung WW, Tsoi FJ, Wei J, Xu L, Tasse AM, Kirby E, Van Etten W, Twigger S, Roberts W, Drmic I, Jilderda S, Modi BM, Kellam B, Szego M, Cytrynbaum C, Weksberg R, Zwaigenbaum L, Woodbury-Smith M, Brian J, Senman L, Iaboni A, Doyle-Thomas K, Thompson A, Chrysler C, Leef J, Savion-Lemieux T, Smith IM, Liu X, Nicolson R, Seifer V, Fedele A, Cook EH, Dager S, Estes A, Gallagher L, Malow BA, Parr JR, Spence SJ, Vorstman J, Frey BJ, Robinson JT, Strug LJ, Fernandez BA, Elsabbagh M, Carter MT, Hallmayer J, Knoppers BM, Anagnostou E, Szatmari P, Ring RH, Glazer D, Pletcher MT, Scherer SW.

Q4. Which treatments and interventions will help?

Journal of
JCAP
Child and Adolescent
Psychopharmacology

Mar 2017 [Epub ahead of print]

Repetitive transcranial magnetic stimulation for the treatment of executive function deficits in autism spectrum disorder: clinical trial approach

Ameis SH, Daskalakis ZJ, Blumberger DM, Desarkar P, Drmic I, Mabbott DJ, Lai MC, Croarkin PE, Szatmari P.

AUTISM
RESEARCH
January, 2017 | Volume 10 | Number 1

Feb 2017 [Epub ahead of print]

Parent-delivered early intervention in infants at risk for ASD: effects on electrophysiological and habituation measures of social attention

Jones EJ, Dawson G, Kelly J, Estes A, Jane Webb S.

Q4. Which treatments and interventions will help?

*Journal of Autism
and Developmental Disorders*

May 2017

Medical conditions and demographic, service and clinical factors associated with atypical antipsychotic medication use among children with an autism spectrum disorder

Lake JK, Denton D, Lunsky Y, Shui AM, Veenstra-VanderWeele J, Anagnostou E.

PLOS ONE

Feb 2017

Ketogenic diet improves behaviors in a maternal immune activation model of autism spectrum disorder

Ruskin DN, Murphy MI, Slade SL, Masino SA.

Q5. Where can I turn for services?

*Journal of Autism
and Developmental Disorders*

Apr 2017 [Epub ahead of print]

Brief report: examining the association of autism and adverse childhood experiences in the National Survey of Children's Health: the important role of income and co-occurring mental health conditions

Kerns CM, Newschaffer CJ, Berkowitz S, Lee BK.

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

**AUTISM
RESEARCH**
January 2017 | Volume 10 | Number 1

Feb 2017 [Epub ahead of print]

Participation in recreational activities buffers the impact of perceived stress on quality of life in adults with autism spectrum disorder

Bishop-Fitzpatrick L, Smith DaWalt L, Greenberg JS, Mailick MR.

*Journal of Autism
and Developmental Disorders*

Feb 2017

A profile on emergency department utilization in adolescents and young adults with autism spectrum disorders

Liu G, Pearl AM, Kong L, Leslie DL, Murray MJ.

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

Psychiatric
Services

Mar 2017 [Epub ahead of print]

**The transition to the adult health care system among youths with
autism spectrum disorder**

Nathenson RA, Zablotsky B.

AJPH
A PUBLICATION OF THE
AMERICAN PUBLIC HEALTH ASSOCIATION

May 2017

Injury mortality in individuals with autism

Guan J, Li G.

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

AUTISM
RESEARCH
January, 2017 | Volume 10 | Number 1

Feb 2017

Prevalence and associated features of autism spectrum disorder in extremely low gestational age newborns at age 10 years

Joseph RM, O'Shea TM, Allred EN, Heeren T, Hirtz D, Paneth N, Leviton A, Kuban KC.

Core Values Statement

Working Group 1 Recommendation:

- Add a value regarding **Equity** in access to screening, diagnosis, and treatment, across race, ethnicity, socioeconomic status, geographic location (rural vs. urban) etc. and that this value affirms a commitment to reduce disparities.

For your reference, the values included in 2011 are:

Sense of Urgency
Excellence
Spirit of Collaboration
Consumer Focus
Partnerships in Action
Accountability

Budget Recommendations

- **Services Budget Recommendations plan**
 - **Developed around 5 areas**
 - **Medicaid**
 - **Tricare**
 - **Private insurance**
 - **Public education**
 - **Vocational rehabilitation**
 - **Timeline developed for inclusion in next SP update**
 - **We will provide updates at future IACC meetings**

Budget Recommendations

- **Research Budget Recommendations plan**
 - **OARC is currently gathering data and performing analyses**
 - **OARC will plan a meeting with the Budget Working Group to discuss**
 - **Narrative with figures will be developed and shared with the IACC before July 2017 meeting**

Strategic Plan: Next Steps

- **Edits and comments from committee due to OARC by May 5**
- **OARC will edit revised drafts and submit to the Full Committee for review; complex edits or concerns may be brought back to WG chairs or IACC chair for resolution**
- **Draft introduction will be revised by OARC and IACC chair to incorporate elements discussed in draft plan and shared**
- **Final document with all sections will be approved at the July IACC meeting.**