Meeting of the Interagency Autism Coordinating Committee

Day 1July 21, 2021; 1:00 - 4:00 p.m. ET



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health (NIMH) and Chair, IACC

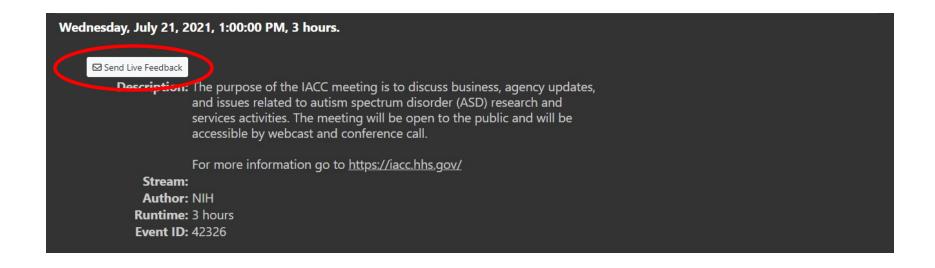
Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC Acting National Autism Coordinator

Submitting Live Feedback



To submit live feedback through NIH VideoCast, please click the "Send Live Feedback" button below the video.





Break

Introductions of IACC Members



Joshua Gordon, M.D., Ph.D.

Director, National Institute of Mental Health (NIMH) and Chair, IACC

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC Acting National Autism Coordinator



Break

National Autism Coordinator Update

Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC Acting National Autism Coordinator

HHS National Autism Coordinator

Susan Daniels, Ph.D., NIMH, was designated as the Acting National Autism Coordinator on July 1, 2021.

The role of NAC:

- Established as part of the Autism CARES Act of 2014
- Oversees ASD research, services, and support activities across the federal government
- Implements ASD activities, taking into account the IACC Strategic Plan
- Ensures that ASD activities across federal departments and agencies are not unnecessarily duplicative

HHS National Autism Coordinator

How will the NAC carry out these requirements and interface with the IACC?

- Strengthening interdepartmental and interagency communication and collaboration on issues related to autism
 - Convening and managing the Federal Interagency Workgroup on Autism
 - An all-federal interagency workgroup to facilitate implementation of autism-related activities and foster interagency collaboration
 - Gathering agency input on tasks mandated under the Autism CARES Act and other interdepartmental/interagency projects
- The NAC will share regular updates with the IACC on relevant interagency autism activities, including reports and other activities of federal committees working on issues related to disabilities

Updates from Relevant Federal Committees

Federal Interagency Workgroup on Autism (FIWA)

Managed/Chaired by the HHS National Autism Coordinator/NIMH/NIH

- All-federal working group includes multiple federal agencies and departments with programs related to autism and disabilities.
- Allows for cross-agency exchange of information on projects and programs related to ASD and consideration of *IACC Strategic Plan* recommendations.
- In the past, has assisted with the development of Reports to Congress required under the Autism CARES Act and other cross-agency reports.
- Current activities:
 - Collaborating with OARC/NIMH on the 2021 Report to Congress on the Health and Well-Being of Individuals with ASD to meet the requirement for this report in the Autism CARES Act.
 - Tracking federal activities related to transition age youth and young adults following the 2017 Report to Congress on that topic.

National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

Managed by the HHS Office of the Assistant Secretary for Preparedness and Response (ASPR)

- New federal advisory committee currently being established.
- Created under the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 to focus on disaster planning for people with disabilities.
- Evaluate issues and programs, and provide findings, advice, and recommendations to support and enhance all-hazards public health and medical preparedness, response activities, and recovery related to meeting the unique needs of individuals with disabilities.
- Includes ASPR, ACL, Biomedical Advanced Research and Development Authority (BARDA), CDC, FDA, NIH, FEMA, NCD, USAB, VA, and public members
- Advise the HHS Secretary on actions HHS can take before, during, and after disasters and emergencies to meet the unique needs of individuals with disabilities.
- Up to 7 new voting non-federal members with expertise in disability accessibility, medical disaster planning, preparedness, response, or recovery will be selected for the Committee.
- Nomination period closed on July 12, 2021.

Federal Partners in Transition (FPT)

Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 with representatives from several federal departments, including ED, HHS, DOL, and SSA, to support all youth, including youth with disabilities, in successfully transitioning from school to adulthood.
- Facilitates the exchange of information between federal agencies on transitionrelated issues for youth with disabilities.
- Developed the <u>2020 Federal Youth Transition Plan: A Federal Interagency Strategy</u>, which outlines how partner agencies will enhance interagency coordination through identification of a shared vision, compatible outcome goals, and policy priorities, ultimately leading to improved outcomes for youth with disabilities by 2020.
- Federal Youth Transition Plan is due for an update in the near future.

Interagency Committee on Disability Research (ICDR)

Managed by the Administration for Community Living

- All-federal committee established under the 1973 Rehabilitation Act to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
 - White paper entitled <u>The Impact of COVID-19 on Disability Research: New Challenges and Widening Disparities</u>
 - Published <u>Health Information Technology Toolkit: A Compendium of Accessible and Usable Health IT Resources</u>
 - Published <u>Aging with Disability: A Toolkit for Interagency Collaboration</u>

National Council on Disability (NCD)

- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- Recent activities include:
 - Conducting comprehensive study to examine effects of the pandemic on people with disabilities across a range of policy topics, including employment, health, education, housing, caregiving, and racial disparities.
 - Made <u>recommendations to National Governors Association</u> on COVID-19 vaccination equity (February 2021)
 - Published Enforceable Accessible Medical Equipment Standards report (May 2021)
 - Published <u>letter to HHS Secretary Becerra</u> concerning health equity (June 2021)
 - Quarterly meetings
- Upcoming meetings: July 22, 2021, and October 7 8, 2021; meetings are open to the public.

RAISE Family Caregiving Advisory Council (FCAC)

Managed by the Administration for Community Living

- The RAISE Family Caregivers Act directs the HHS Secretary to develop a national family caregiving strategy.
- The RAISE Act also directed the establishment of the FCAC, a federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs.
- Includes issues related to family caregiving for older adults and individuals with disabilities.
- The first FCAC meeting was held in August 2019; has met 3-4 times per year since then; meetings are open to the public.

FCAC Recent Activities

- Adopted <u>26 recommendations</u> aimed at establishing a national approach to addressing the needs of family caregivers of all ages and circumstances.
 - Recommendations will be included in FCAC's initial Report to Congress in 2021 and serve as the foundation for the National Family Caregiving Strategy.
- <u>FCAC meeting</u> in April 2021 included discussion with the Older Adults
 Equity Collaborative on access and equity in aging services programs,
 particularly when working with caregivers
 - Development of a Family Caregiving National Strategy was further discussed during FCAC's 3 subcommittee meetings in May 2021.
 - FCAC voted to move the Report to Congress through the official government clearance process.

Other Autism-Related Activities

International Society for Autism Research (INSAR)

- Scientific and professional organization devoted to advancing knowledge about autism by promoting the highest quality of research.
- 2021 Virtual Annual Meeting was held May 3 7, 2021.
- 2021 INSAR Summer Institute webinar series, this year on the topic of Autism and Intersectionality, focuses on understanding autism research and autistic people's experiences across multiple identities and groups (i.e., race, gender, sexual orientation, neurodiversity, culture, poverty).

INSAR Policy Briefs

- INSAR policy briefs are published on the INSAR website and provide an overview of the scientific research, an implications statement, and recommendations for next steps or actions.
 - INSAR policy brief <u>Autism Community Priorities for Suicide Prevention</u> was published April 2021.
 - Developed by an international delegation of researchers, research funders, community stakeholders, and policy professionals.
 - Longer version of the brief aimed at researchers and research funders available:
 <u>Where Do We Go from Here? Autism Community Priorities for Future Suicide</u>
 Research

IACC Committee Business



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH, and Executive Secretary, IACC Acting National Autism Coordinator

Interagency Autism Coordinating Committee



- A federal advisory committee
- Established under the Children's Health Act (CHA) of 2000
- Reauthorized by the:
 - Combating Autism Act (CAA) of 2006
 - Combating Autism Reauthorization Act (CARA) of 2011
 - Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2014
 - Autism CARES Act of 2019 (current)

IACC's Charge



- Provide advice to the Secretary of Health and Human Services (HHS) regarding federal activities related to autism spectrum disorder (ASD)
- Coordinate federal activities related to autism
- Provide a forum for public input on issues related to autism
- Develop and annually update a Strategic Plan for ASD
- Develop an annual Summary of Advances in ASD Research
- Monitor federal activities related to autism
- Meet at least twice annually

Autism CARES Act of 2019



The Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (P.L. 116-60):

- Reauthorized the IACC to continue through September 30, 2024
- Increased membership requirements for certain categories of members; each of the following categories increased from two members required to three members required:
 - Individuals on the autism spectrum
 - Parents/legal guardians of individuals on the spectrum
 - Representatives of leading research, advocacy, and service organizations for individuals on the autism spectrum

Autism CARES Act of 2019 (cont'd)



The Autism Collaboration, Accountability, Research, Education, and Support Act of 2019 (P.L. 116-60):

- Added four new federal departments to the committee:
 The Depts. Of Labor, Justice, HUD, and Veterans Affairs
- Continues to require the IACC to prepare an annual update of the IACC Strategic Plan and a new edition of the IACC Summary of Advances
- Requires that the IACC Strategic Plan continue to address research and also include 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
- Added an emphasis on IACC activities being inclusive of issues "across the lifespan of individuals" on the autism spectrum
- Limits public members to 2 four-year terms on the committee

IACC Composition



The new IACC is composed of:

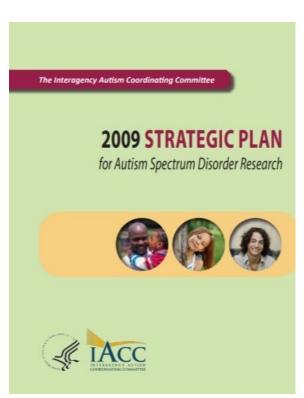
- 23 voting ex-officio federal members representing federal departments and agencies involved in autism and disability research services, and policy.
- 22 public members, including adults on the autism spectrum, family members of individuals on the autism spectrum, representatives of research, services, and advocacy organizations, and other community stakeholders.
- The composition of the IACC allows the collaboration of federal agencies and community stakeholders in addressing autism issues.

IACC Core Values



The following core values were developed by the IACC and shared in its first Strategic Plan in 2009:

- Sense of Urgency
- Excellence
- Spirit of Collaboration
- Community Focus
- Partnerships in Action
- Equity



Ways IACC Can Uphold Core Values



- Respectful dialogue and thoughtfully listening to each other's perspectives
- Seeking and listening to input from community stakeholders
- Bringing forward evidence and best practices to inform decisions
- Being inclusive
- Bringing together diverse points of view and multiple disciplines to address issues

What the IACC Does



- Provides advice to the HHS Secretary in forms such as IACC Strategic Plan recommendations, letters, and statements
- Provides as a forum for public input and discussion of issues related to autism
- Provides coordination for federal and member organization activities through the IACC Strategic Plan, monitoring activities, and fostering collaborations
- Identifies issues and priorities for autism research, services, and policy that can be communicated in the form of recommendations and reports
- Illuminates issues in its meetings, workshops, reports, and other activities

What the IACC Does NOT Do



The IACC is an <u>advisory</u> body; therefore, it does <u>not</u>:

- Fund research (the IACC has no research budget) or allocate research dollars
- Control funding or content of federal programs
- Implement federal programs or policies

It can make recommendations about federal activities

IACC Activities



- Full committee, subcommittee, and working group meetings and discussions
- Publishing reports and documents
- Issuing recommendations
- Writing letters to the Secretary
- Holding workshops, townhalls, and other events
- Listening to and considering public comments
- Publishing Requests for Information
- Coordinating with activities of other federal advisory committees

How Members Can Participate



- Attend meetings
- Plan to share important updates and reports from your agency/organization at each meeting or request time on the agenda for longer presentations
- Actively contribute input to committee discussions
- Suggest topics and speakers for future meetings and workshops
- Identify opportunities for coordination and collaboration
- Volunteer to participate in and/or lead work group activities

IACC Meetings



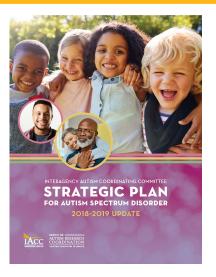
- Committee business (fulfilling responsibilities required in the Autism CARES Act of 2019)
- Panels, presentations, and discussions of timely topics in autism research, services, and policy
- Public comments (written, oral, and live feedback)
- Sharing of agency/organization and committee member and updates

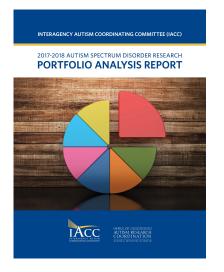
 Schedule: 3 full committee meetings per year – October 2021 (virtual), January 2022 (hybrid?), April 2022, and a slot in July 2022 for an activity like a workshop

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

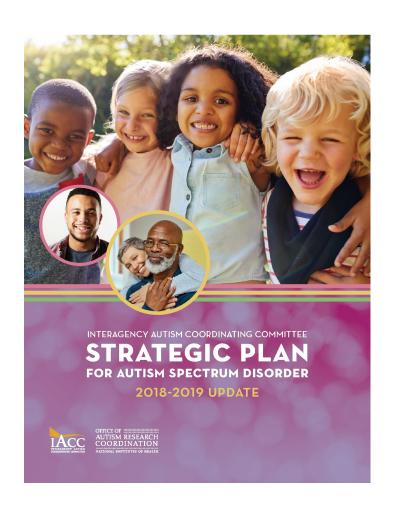






IACC Strategic Plan

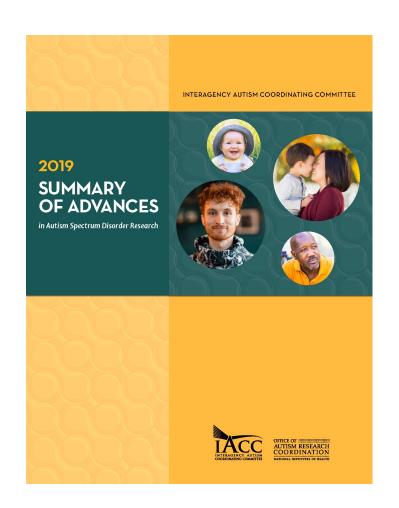




- The IACC Strategic Plan (SP) provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations.
- The IACC SP is organized around 7 communitybased questions.
- The current Plan includes 23 objectives that address both research and services activities and a budget recommendation.

IACC Summary of Advances

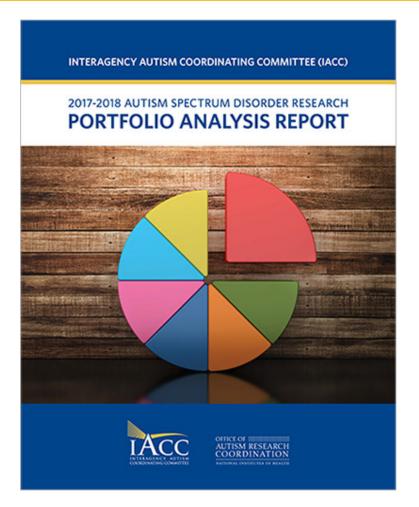




- Annual report required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Includes peer-reviewed articles addressing all 7 topic areas of the IACC Strategic Plan

IACC Autism Spectrum Disorder Research Portfolio Analysis Report





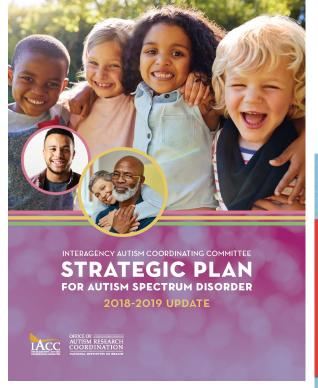
- The CARES Act requires that the IACC "monitor federal activities" and the *Portfolio Analysis Report* is seen as one of the main components of the IACC's monitoring activity.
- The Report prepared by OARC on behalf of IACC tracks progress made each year towards achievement of the Objectives in the IACC Strategic Plan as well as provides analysis of funding trends and funder information.
- To accompany the report, detailed federal and private organization project data are publicly available in the Autism Research Database, accessible via the IACC website; https://iacc.hhs.gov/funding/data

https://iacc.hhs.gov/publications/portfolio-analysis/2018/

Immediate Tasks for the IACC



- Develop and update of the *IACC*Strategic Plan
- Develop two volumes of the IACC Summary of Advances in ASD Research (2020 and 2021)







IACC Strategic Plan Vision Statement



"The IACC Strategic Plan for ASD will accelerate and inspire research, and enhance service provision and access, that will profoundly improve the health and quality of life of every person on the autism spectrum across the lifespan. The Plan will provide a blueprint for ASD research and services efforts, engaging the participation and input of government agencies, private organizations, and the broader autism community."

IACC Strategic Plan for ASD 2018-2019 Update

IACC Strategic Plan Mission Statement



"The purpose of the *Strategic Plan* is to focus, coordinate, and accelerate innovative research and foster development of high-quality services in partnership with stakeholders to address the urgent questions and needs of people on the autism spectrum and their families."

IACC Strategic Plan for ASD 2018-2019 Update

Proposed Plan for IACC Strategic Plan 2020-2021 Update



This proposal was developed with the goal of streamlining the IACC Strategic Plan development process while still gathering needed expert and public input:

- Establish a Working Group for IACC Strategic Plan Update (volunteers can be large or small)
- Request for Information (RFI) to gather public and expert input on areas of the Strategic Plan that need updating
- Discussion session with the committee during the October 2021 IACC
 meeting to identify areas of the SP that need updating, evaluate the current
 list of objectives, and consider public input.
- Review of latest literature, federal reports, including the IACC Portfolio Analysis, HHS Reports to Congress, and other sources of data

Proposed Plan for IACC Strategic Plan 2020-2021 Update





- We could hold a longer public comment session at that meeting if desired, focusing on the Strategic Plan
- If desired, could also include invited experts to share at the next two IACC meetings
- Use OARC to capture comments and develop a draft for review and discussion by committee
- Final Report must be reviewed and approved by the full committee per FACA
- Publish IACC Strategic Plan 2020-2021 Update in spring or summer of 2022

Discussion



- Does the committee generally accept this plan?
 - Approving the convening of a Working Group for the Strategic Plan Update
 - Issuing an RFI to gather public comment and expert opinions on the Strategic Plan
 - Using portions of the next two meetings to discuss the Strategic Plan update, as described
 - Having OARC gather the input from the RFI and comments from the committee and other mentioned sources to prepare a draft for committee discussion, review, and approval.
 - All controversial issues would be discussed and resolved by the committee.

Comments?

IACC Summary of Advances





- Annual report required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Includes peer-reviewed articles addressing all 7 topic areas of the IACC Strategic Plan

https://iacc.hhs.gov/publications/summary-of-advances/2019/

Proposal for IACC Summary of Advances 2020



To facilitate the process of completing a Summary of Advances for 2020, which is past:

- OARC has created a list of peer-reviewed research articles submitted by federal agencies and our team for consideration by the IACC.
- IACC will be given the opportunity to submit additional nominations or suggest deletion of articles on the current list if not deemed to meet the standard of representing a groundbreaking finding that has advanced the field of ASD research.
- Up to 20 publications under each of the seven Questions of the IACC Strategic Plan will be selected by committee vote/ballot
- OARC will draft short, lay-friendly summaries of the selected articles
- The summaries of the 20 articles will be combined into a booklet format that is made available to the public

Comments?

Process for 2020 IACC Summary of Advances



- With the help of federal agencies, OARC has gathered a list of notable and significant ASD-related papers published in 2020. These will be shared with the Committee
- IACC will review and let OARC know of any article that should <u>not</u> be nominated by the end of August 2021
- OARC will send an electronic ballot via email on September 1, 2021
- Each member of the IACC will vote for the top 20 articles by September 15, 2021
- IACC will be notified of the voting results
- OARC will prepare the 2020 IACC Summary of Advances for publication in January 2022

Proposal for 2021 IACC Summary of Advances



- IACC members and OARC staff will nominate ASD-related peer-reviewed articles published in 2021 for inclusion in the 2021 IACC Summary of Advances
- IACC will receive an e-mail soliciting nominations of articles in August and each month thereafter for the rest of 2021.
- Does IACC wish to discuss nominations at every IACC meeting or just at the January meeting?
- OARC will send the IACC an electronic ballot in January 2022
- IACC will vote for the top 20 articles by January 31, 2022
- OARC will prepare the 2021 IACC Summary of Advances for publication by April 2022

Comments?

IACC Working Groups and Workshops



- Working Groups of the previous IACC:
 - Working Group on Housing
 - IACC Workshop: Addressing the Housing Needs of People on the Autism Spectrum (July 2019)
 - Working Group on Improving Health Outcomes for Individuals on the Autism Spectrum
 - IACC Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 2018)
 - IACC Workshop: Addressing the Mental Health Needs of People o the Autism Spectrum (May 2019)
 - "Improving the Physical and Mental Health Outcomes of Individuals with Autism Spectrum Disorder: A Policy Brief of the Interagency Autism Coordinating Committee"
 - Reconvene Working Group and publish policy brief in spring or summer of 2022?

Completion of Co-Occurring Conditions Report



- During its last iteration IACC convened Working Group on Improving Health Outcomes for Individuals on the Autism Spectrum
 - IACC Workshop: Addressing the Health Needs of People on the Autism Spectrum (September 2018)
 - IACC Workshop: Addressing the Mental Health Needs of People o the Autism Spectrum (May 2019)
 - The working group was developing the report: "Improving the Physical and Mental Health Outcomes of Individuals with Autism Spectrum Disorder"
 - Reconvene Working Group to assist the IACC in finalizing this report for publication?
 - Report would come to the new IACC for review and final approval and the report would be issued as a report of the IACC.

Future IACC Meeting and/or activity topics



Sampling of the topics shared by IACC members:

- COVID-19 Pandemic
- Disparities and Health Equity
- Housing
- Food Insecurity
- Law Enforcement Interactions
- Suicide

- Caregiver Supports
- Aging and autism
- Communication supports
- Transition
- Employment
- Healthcare for adults

OARC will send out an e-mail soliciting more topics from IACC members for discussion at the next meeting. Feel free to send topic suggestions at any time.

Introducing OARC





The Office of Autism Research Coordination (OARC) coordinates and manages the IACC and related cross-agency ASD activities, programs, and policies.

OARC's Role



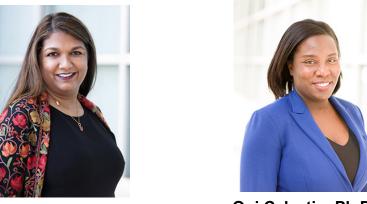
- OARC assists the IACC by:
 - Communicating information about the IACC and federal ASD activities to Congress, other government agencies, and the public
 - Coordinating cross-agency efforts
 - Planning meetings, conferences, and other IACC activities
 - Facilitating the IACC strategic planning process and monitoring ASD-related activities
 - Conducting analyses and preparing reports for the IACC, Congress, and others
 - Gathering public input on issues related to ASD to inform the committee's work
 - Developing and disseminating information about ASD to the public
 - Managing the IACC's public inquiries and public comments.
 - Managing the IACC website and Autism Research Database.

OARC Staff





Susan Daniels, Ph.D. Director



Oni Celestin, Ph.D. Science Policy Analyst



Science Policy Analyst



Steven Isaacson, B.A. Policy Analyst



Tianlu Ma, Ph.D. Science Policy Analyst



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



Angelice Mitrakas, B.A. Management Analyst



Luis Valdez-Lopez, M.P.H. Science Policy Analyst



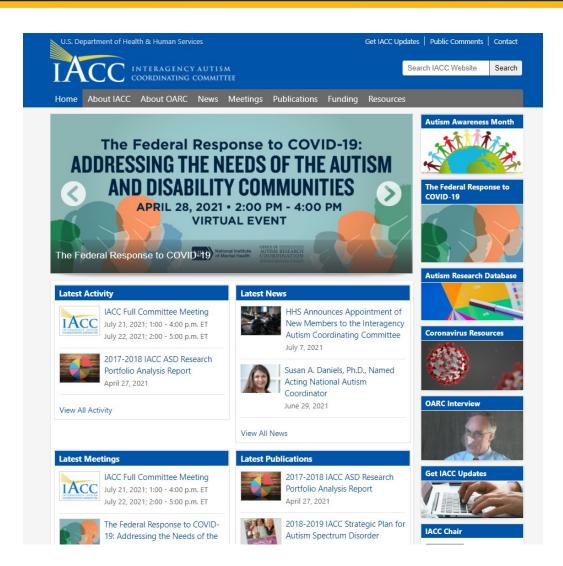
Matthew Vilnit, M.B.A. **Operations Coordinator**



Jeffrey Wiegand, B.S. Web Development and Digital Outreach Manager

IACC Website





The IACC website provides access to the latest information about IACC meetings and activities, autism reports, federal news updates, and more!

OARC Newsletter



AUTISM RESEARCH COORDINATION

Please enjoy OARC's quarterly newsletter, which includes an update on IACC activities, recent events, news, and publications.

Autism Meetings & Events



IACC Full Committee Meeting

The first meeting of the new Interagency Autism Coordinating Committee will take place July 21-22, 2021 This meeting will be virtual.



INSAR Summer Webinar Series

The theme of this year's INSAR Summer Institute is Autism INSAR and Intersectionality. The series focuses on understanding autism research and autistic people's experiences across

multiple identities and groups.

News & Blogs



HHS Announces Appointment of New Members to the Interagency Autism Coordinating Committee

The U.S. Department of Health and Human Services (HHS) announced the appointments of new and returning members

to the Interagency Autism Coordinating Committee (IACC). This is the largest and most diverse IACC to date.



Acting National Autism Coordinator Named

Susan A. Daniels, Ph.D., was designated to serve as Acting National Autism Coordinator on July 1, 2021 following the retirement of Ann E. Wagner, Ph.D., from federal service. Dr.

Daniels will concurrently continue to serve as the Director of the Office of Autism Research Coordination and Executive Secretary of the IACC.



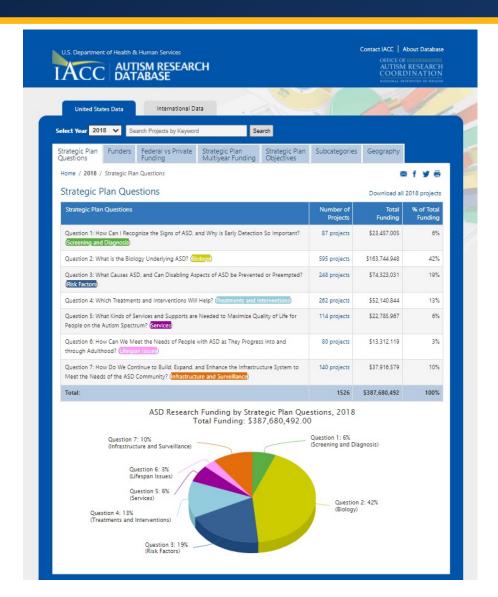
Media Advisory: Prototype App for Mobile Devices Could Screen Children at Risk for Autism Spectrum

A mobile app developed by researchers at the NIH Autism Center of Excellence at Duke University can distinguish between toddlers diagnosed with ASD and typically developing toddlers. Researchers recorded

- The OARC Newsletter provides another way to disseminate the latest news updates.
- IACC members please let us know if you have any highlights that may be suitable for the OARC Newsletter or the IACC website.
- This can include meetings, reports, initiatives, grant awards, etc.

Autism Research Database





data.

The Autism Research Database provides access to autism research project data collected from across the United States and internationally for portfolio analysis projects. The next update will include 2019 and 2020

Thank you!



We are excited to welcome the new IACC and look forward to working with you!

IACC Public Inquiries Inbox:

iaccpublicinquiries@mail.nih.gov

Check the IACC Website for the latest updates:

https://iacc.hhs.gov



Thank you for joining us for today's IACC meeting. Please join us for the continuation of this meeting tomorrow from 2:00-5:00 p.m. ET.

https://videocast.nih.gov/watch=42327 https://iacc.hhs.gov

Thank you!