

Interagency Autism Coordinating Committee (IACC) Strategic Plan Working Group Meeting

Day 1

July 13, 2022; 1:00 – 4:30 pm ET



Susan A. Daniels, Ph.D.

Director, Office of Autism Research Coordination, NIMH

Executive Secretary, IACC

Acting National Autism Coordinator

Meeting Logistics and Housekeeping



- Please keep microphones off unless you are speaking
- You are welcome to turn your cameras on when you are speaking, but may leave them off if you prefer.
- During discussion, please keep your comments brief (~1-2 minutes) to enable other members to have a turn speaking
- For Committee members that would like a comment read aloud:
 - Please send the text of your comment via the Zoom chat function to the OARC Staff Member who is using the Zoom screen name “SEND COMMENTS HERE.”
 - When it is your turn to be recognized, the OARC staff member will read your comment to the group.
 - Mr. Steven Isaacson from the OARC team will be reading member comments sent through the Zoom chat.
- Closed captioning is available in Zoom for Committee members and on Videocast for members of the viewing public.

Purpose of the Working Group Meeting



- The purpose of this Strategic Plan Working Group meeting is to focus on development of the *2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy*.
- Other regular Committee business will not be discussed at this meeting.
- While public comments will not be presented at this meeting, they will be presented at the next IACC Full Committee meeting on October 26, 2022.
- Attendance at this meeting is voluntary for IACC members/alternates.

IACC Members and Alternates in Attendance



Federal Members/Alternates

- Mitchell Berger, M.P.H. (SAMHSA, alternate for Anita Everett, M.D., D.F.A.P.A.)
- Elaine Cohen Hubal, Ph.D. (EPA)
- Judith Cooper, Ph.D. (NIDCD, alternate for Debara Tucci, M.D., M.S., M.B.A., F.A.C.S.)
- Courtney Ferrell Aklin, Ph.D. (NIH, alternate for Lawrence Tabak, D.D.S., Ph.D.)
- Dayana Garcia, M.Ed. (ACF)
- Jennifer Johnson, Ed.D. (ACL)
- Alice Kau, Ph.D. (NICHD, alternate for Diana Bianchi, M.D.)
- Walter Koroshetz, M.D. (NINDS, alternate for Nina Schor, M.D., Ph.D.)
- Kamila Mistry, Ph.D., M.P.H. (AHRQ)
- Lauren Raskin Ramos, M.P.H. (HRSA)
- Scott Michael Robertson, Ph.D. (DOL, alternate for Taryn Williams, M.A.)
- Stuart Shapira, M.D., Ph.D. (CDC, alternate for Georgina Peacock, M.D., M.P.H., F.A.A.P.)
- Martine Solages, M.D. (FDA, alternate for Tiffany Farchione, M.D.)
- Teresa Souza, Ph.D. (HUD)
- Jodie Sumeracki, B.A. (CMS)
- Debara Tucci, M.D., M.S., M.B.A., F.A.C.S. (NIDCD)
- Nicole Williams, Ph.D. (DoD)

Public Members

- Alice Carter, Ph.D.
- Sam Crane, J.D.
- Dena Gassner, M.S.W.
- Morénike Giwa Onaiwu, M.A.
- Alycia Halladay, Ph.D.
- Craig Johnson, B.A.
- Julie Lounds Taylor, Ph.D.
- Jenny Mai Phan, Ph.D.
- Yetta Myrick, B.A.
- Lindsey Nebeker, B.A.
- Joseph Piven, M.D.
- JaLynn R. Prince, B.F.A.
- Susan Rivera, Ph.D.
- Matthew Siegel, M.D.
- Hari Srinivasan
- Ivanova Smith, B.A.
- Paul Wang, M.D.
- Stephen Whitlow, J.D.

Day 1 Agenda Overview



- **Introduction**
- **Question 1:** Screening and Diagnosis
- **Question 2:** Biology
- **Question 3:** Genetic and Environmental Factors
- **Question 4:** Interventions

Purpose of the *IACC Strategic Plan*



- Required by Congress in the Autism CARES Act of 2019.
- Serves as a guide, outlining priorities and directions for autism-related efforts across federal agencies and partner private organizations.
- One of the main ways the IACC provides advice and recommendations to the HHS Secretary on autism-related activities.
- Includes Objectives (Recommendations) that address research, services, and policy activities and a budget recommendation.

The *IACC Strategic Plan* Process



- Public input is solicited.
 - Public comments at full committee meetings
 - Special Request for Information
- Input is gathered from IACC membership.
- IACC develops draft through a consensus process.
- Questions, concerns, and conflicts are resolved.
- Final draft is reviewed by IACC and accepted by the IACC by majority vote.
- Strategic Plan is published and used by federal agencies and other community members.

2021-2022 IACC Strategic Plan Timeline



- ✓ July 2021 Full Committee Meeting: *Strategic Plan* development process introduced
- ✓ October 2021: Public Request for Information (RFI) posted (closed November 2021)
- ✓ November 2021: IACC Member Feedback survey sent (closed March 2022)
- ✓ January 2022 Full Committee Meeting: Public RFI submissions presented to the IACC
- ✓ April 2022 Full Committee Meeting: IACC Member Feedback presented to the IACC

2021-2022 IACC Strategic Plan Timeline



- ✓ July 2022: First draft of *Strategic Plan* chapters posted on IACC website
- ❑ July 2022 Working Group Meeting: IACC members provide additional input on *Strategic Plan* topics
- ❑ July-August 2022: IACC members will receive online survey to provide additional feedback, OARC incorporates and makes edits
- ❑ Early October 2022: Revised draft of *Strategic Plan* will be distributed
- ❑ October 2022 Full Committee Meeting: IACC members will discuss the draft *Strategic Plan*, with a goal of approving the plan

Notes about the *IACC Strategic Plan*



- Each *IACC Strategic Plan* chapter gives an overview of relevant topics, recent advances/changes/trends in the field, and remaining gaps and opportunities for research, services, and policy.
 - It is not intended to provide a full literature review of any topic.
 - The *Plan* presents diverse perspectives presented in a respectful and inclusive manner.
- The *Strategic Plan* is advisory to the HHS Secretary and federal agencies and can be used to guide federal agency efforts.



The *IACC Strategic Plan*

is organized around 7 topic areas (each of which is associated with a community-based Question):

- **Question 1:** Screening and Diagnosis
- **Question 2:** Biology
- **Question 3:** Genetic and Environmental Factors
- **Question 4:** Interventions
- **Question 5:** Services and Supports
- **Question 6:** Lifespan
- **Question 7:** Research Infrastructure and Prevalence

Each topic area has its own Chapter.

Additional Sections



The new *IACC Strategic Plan* will also include:

- 2 crosscutting themes that are connected to all 7 topics:
 - The Sex and Gender
 - Promoting Equity and Reducing Disparities
- A section on the impacts of COVID-19 on the community, research, services, and policy.
- A section describing progress made on previous Strategic Plan objectives.
- A budget recommendation, required by the Autism CARES Act.
- Themes of acceptance and inclusion of individuals on the autism spectrum are interwoven throughout.
- Next draft will include revisions for plain language

Question 1: Screening and Diagnosis



Each Chapter has an associated community-based Question, which is meant to capture the theme in a brief, accessible, and overarching goal.

Proposed Question 1 Text:

How Can We Improve Identification of Autism?

Question 1: Screening and Diagnosis



Topics Covered Include:

- Screening and Diagnosis research, tools, and technology
- Early Signs and Biomarkers
- Disparities in Autism Screening and Diagnosis
- Access to Screening and Diagnosis Services, Systems Navigation, and Workforce Needs
- Adult diagnosis is covered in more detailed in Question 6



- Are there any other important topics or points that we need to include?
- Have there been recent significant changes that could impact the direction of this field?



Break

Question 2: Biology



Proposed Question 2 Text:

What Is the Biology Underlying Autism?

Question 2: Biology



Topics Include:

- Molecular Mechanisms and Genes Implicated in Autism
- Structure and Function of Brain Circuits in Autism
- Sensory and Motor Differences
- Cognitive and Communication Differences
- Immune System and Autism Development
- Sex and Gender Differences
- Longitudinal Studies
- Co-occurring Conditions
- Research Policy Issues – data sharing, ethics, inclusion of diverse research participants and autistic individuals across the spectrum and across the lifespan



- Are there any other important topics or points that we need to include?
- Have there been recent significant changes that could impact the direction of this field?

Question 3: Genetic and Environmental Factors



Proposed Question 3 Text:

What Are the Genetic and Environmental Factors that Contribute to Autism?

Question 3: Genetic and Environmental Factors



Topics Include:

- Genetic Factors
- Environmental Factors
- Gene-Environment Interactions and Epigenetics
- Studies in Diverse Populations
- Resources to Accelerate Research on Genetic and Environmental Factors
- Policy and Ethical Implications of Advances in Genetic and Environmental Science



- Are there any other important topics or points that we need to include?
- Have there been recent significant changes that could impact the direction of this field?



Break

Question 4: Interventions



Proposed Question 4 Text:
Which Interventions Will Improve
Quality of Life?

Question 4: Interventions



Topics Include:

- Medical and Pharmacological Interventions
- Behavioral and Developmental Interventions
- Complementary and Alternative Approaches
- Technology-Based Interventions and Communication Interventions & AAC
- Interventions for Co-occurring Conditions
- Outcome Measures and Biomarkers
- Research & Policy Issues – inclusion in research, disparities in access to interventions, needs of individuals with high support needs, workforce needs



- Are there any other important topics or points that we need to include?
- Have there been recent significant changes that could impact the direction of this field?

Day 1 Adjournment



Thank you for joining us for today's IACC Strategic Plan Working Group meeting.

Please join us for the continuation of this meeting tomorrow from 1:00 – 4:30 p.m. ET.

<https://videocast.nih.gov/watch=45677>

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

Thank you!