

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

**Day 2**

July 14, 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

# Working Group Meeting Day 1 Summary



- Discussed the purpose of the *IACC Strategic Plan*
- Reviewed the process and timeline for developing the *2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy*
- Feedback provided on the following chapters of the *Strategic Plan*:
  - Question 1: Screening and Diagnosis
  - Question 2: Biology
  - Question 3: Genetic and Environmental Factors
  - Question 4: Interventions

# Day 2 Agenda Overview



- **Question 5:** Services and Supports
- **Question 6:** Lifespan
- **Question 7:** Research Infrastructure and Prevalence
- **Cross-Cutting Objectives:** Sex/Gender and Disparities
- **COVID-19**
- **Closing Remarks**

# Question 5: Services and Supports



## **Proposed Question 5 Text:**

What Services and Supports Are Needed to Maximize Health and Well-Being?

# Question 5: Services and Supports



## Topics Include:

- Education System
- Healthcare System
- Child safety – Wandering, Water safety
- Systems Navigation
- Ensuring Individualization, Choice, Person-Centered Planning, and Self-Direction
- Caregiver and Family Supports
- Outcomes, Quality of Services, and Services Needs
- Services Workforce Training and Development
- Coordination of Services



- 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 6: Lifespan



### **Proposed Question 6 Text:**

How Can We Meet the Needs of People on the Autism Spectrum throughout the Lifespan?

# Question 6: Lifespan



## Topics Include:

- Transition to Adulthood
- Adult Services and Supports – Post-secondary ed, employment, housing, transportation
- Adult Diagnosis
- Adult Health and Well-Being
- Service Delivery for Adults
- Community Integration
- Services and Supports for Adults with High Support Needs
- Older Adulthood in Autism
- Justice, Safety, Emergency Preparedness, and Premature Mortality
- Inclusion of Lived Experiences in Research, Services, and Policy



- 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 7: Research Infrastructure and Prevalence



## **Proposed Question 7 Text:**

How Do We Expand and Enhance Research Infrastructure Systems to Meet the Needs of the Autism Community?

## Question 7: Research Infrastructure and Prevalence



### Topics Include:

- Biorepositories
- Data Infrastructure
- Research Workforce – Diversity, Autistic Researchers
- Epidemiological Data Gathering Systems and Surveys
- Outreach and Dissemination of Research Findings



- 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?



## Cross-Cutting Theme 1: Sex and Gender

### Topics Include:

- Sex/gender disparities in diagnosis/diagnostic criteria
- Biological differences between sex/genders
- Differences in socialization of different sex/genders
- Differences across the lifespan, including for older women
- Differences in sexuality



- 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?



## Cross-Cutting Theme 2: Equity and Disparities

### Topics Include:

- Racial/ethnic, geographic, and socioeconomic disparities (also overlap with sex/gender)
- Disability as a disparity group and intersectionality with race, etc.
- Culturally competent/sensitive interventions and services
- Disparities in age of diagnosis and access to services and supports
- Balanced and representative research samples
- Representation in the workforce
- Inclusion, accessibility, accommodations, universal design




- 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**

## Topics Include:

- COVID-19 and Physical Health
    - Heightened risk of COVID-19 in the autism community
    - Impact of COVID-19 on maternal health and pre- and post-natal development
  - Impact of COVID-19 Mitigation Efforts
    - Vaccination distribution and uptake
    - Sensory and communication issues associated with prevention, intervention
    - Services disruptions and mental health impacts of physical distancing
  - Impact of COVID-19 Pandemic on Autism Research
  - What have we learned? How can we better prepare for the future?
- 
- 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?

# Summary of Discussions



- The *IACC Strategic Plan* is an advisory document required by Congress to provide advice to the HHS Secretary on autism-related efforts and activities.
- The *2021-2022 IACC Strategic Plan for Autism Research, Services, and Policy* consists of 7 community-based Questions and two Cross-Cutting Themes.
- The IACC was given an overview of the first draft of the *Strategic Plan* drafted by OARC and provided input on the topics covered in the plan.

# *IACC Strategic Plan* Next Steps



- OARC will incorporate IACC feedback collected today into the draft *IACC Strategic Plan*.
- IACC members will receive a survey and can continue sending additional feedback to OARC over the summer.
- OARC will present a second draft of the *IACC Strategic Plan* to the IACC in October.
- The IACC will discuss and potentially vote to approve the *IACC Strategic Plan* at the October 26<sup>th</sup> full IACC Committee Meeting.
- OARC will incorporate any additional feedback and prepare the approved *IACC Strategic Plan* for publication.



# Upcoming IACC Meeting



## **IACC Full Committee Meeting (virtual or hybrid)**

October 26, 2022

(If hybrid, only IACC members and staff will be in-person; the audience will be virtual)

Check the IACC website for meeting information and updates.

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

# Thank you to the OARC staff!



**Susan Daniels, Ph.D.**  
Director



**Oni Celestin, Ph.D.**  
Science Policy Analyst



**Katrina Ferrara, Ph.D.**  
Science Policy Analyst



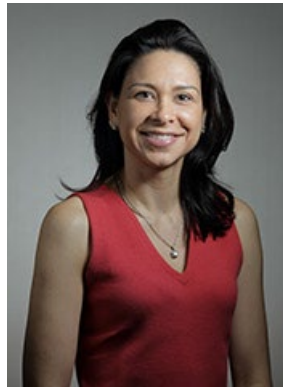
**Steven Isaacson, B.A.**  
Policy Analyst



**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



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

Have a great summer!



# Day 2 Adjournment



Thank you for joining us today for the  
*IACC Strategic Plan Working Group* meeting.

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