

**Meeting of the Interagency Autism  
Coordinating Committee:**  
*2024 IACC Strategic Plan Update Discussion*

September 23, 2024



# Welcome, Roll Call, and Announcements



**Shelli Avenevoli, Ph.D.**

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

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH



- Closed captioning is available in Zoom for IACC members and members of the viewing public.
- IACC members
  - You may turn on your camera during the discussion and unmute yourself to speak.
  - You may submit comments in writing to the panelist labelled “SEND COMMENTS HERE” in Zoom. Steven Isaacson from the ONAC staff will read the comment aloud.

# Legislative Update



**Susan A. Daniels, Ph.D.**  
Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH

# Legislative Update



- The Autism CARES Act of 2019, which authorizes the IACC, will expire September 30, 2024.
- The House of Representatives and the Senate have each introduced draft reauthorizing legislation (the Autism CARES Act of 2024):
  - House version: [H.R. 7213](#) – passed the House on September 18, 2024
  - Senate version: [S. 4762](#)
- A single version will need to be passed by the House and Senate, then signed by the President in order to become law.



# Legislative Update



- If reauthorizing legislation is enacted before expiration of the current legislation:
  - Current IACC member terms will be extended for 180 days to finish reports in progress.
  - A call for nominations of new IACC members will be posted
- In the event of a delay in reauthorization:
  - The work of the IACC **will pause** until the reauthorization is enacted.
  - If the delay is short, after the reauthorization the current IACC will be extended to finish reports.
  - Funding for many federal autism research, services, and support activities **will continue**; some may be impacted by a delay in reauthorization.
  - The work of the National Autism Coordinator and the Federal Interagency Workgroup on Autism (FIWA) **will continue**.
  - Following the enactment of reauthorizing legislation, a call for nominations of new IACC members will be posted.

# *2024 IACC Strategic Plan Update Discussion*



**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC

HHS National Autism Coordinator

Director, Office of National Autism Coordination, NIMH



# 2024 IACC Strategic Plan Update

## Report Overview



- Presents information on a broad array of conditions that commonly co-occur with autism and their impacts on health outcomes.
- Identifies gaps in research, services, and supports to improve health outcomes.
- Highlights IACC workshops, presentations, and other activities that provided the Committee with information on research, services, and supports to address these conditions.
- Summarizes responses to the IACC Request for Public Comments on Co-Occurring Conditions in Autism (issued in January 2024)



# 2024 IACC Strategic Plan Update

## Report Overview



- Introduction
- Chapter 1: IACC Interest in the Impact of Co-Occurring Conditions
- Chapter 2: Community Perceptions of Research and Services Needs
- Chapter 3: Co-Occurring Physical Health Conditions
- Chapter 4: Co-Occurring Mental and Behavioral Health Conditions
- Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities
- Chapter 6: Health Care Service Provision
- Conclusion

# 2024 IACC Strategic Plan Update Timeline



- The previous committee under the Autism CARES Act of 2014 convened a working group and workshops to explore issues related to co-occurring health conditions and began drafting a report that was paused in 2019 after the members' terms expired.
- October 2023: The current IACC voted to focus the *2024 IACC Strategic Plan Update* on **co-occurring physical and mental health conditions** and their impacts on health outcomes, building upon the work of the previous committee and working group.
- January 2024: IACC issued a RFI to collect public feedback on co-occurring conditions.

# 2024 IACC Strategic Plan Update Timeline



- August 2024: ONAC completed a draft of this report and sent it to IACC members for review.
- Former members of the IACC Working Group on Improving Health Outcomes were also invited to provide feedback on the draft.
- Early-mid September 2024: ONAC staff incorporated feedback from IACC members and Working Group members into a revised draft. The revised draft was sent to IACC members for further input. The revised draft report is also posted on the IACC website.
- TODAY: IACC members will discuss the draft report and any additional revisions that are needed. IACC members may vote to approve the draft report.

# 2024 IACC Strategic Plan Update Timeline



- If the IACC **approves** the draft report today, ONAC will prepare the final report, with anticipated publication in December 2024.
- If the IACC **does not approve** the draft report today, ONAC will continue making revisions and finalize the report with IACC members at a later date, which will be determined based on the status of the Autism CARES Act reauthorization.

# 2024 IACC Strategic Plan Update

## Today's Discussion



- We will discuss each section of the report (10-15 minutes per chapter).
- Use the Raise Hand feature in Zoom to be recognized.
- Keep your comments brief to allow colleagues time to also comment.
- Please keep your comments focused on:
  - Overarching themes
  - Additional topics to cover
  - Notable research to reference
  - Corrections
- Note: The draft report balances different points of view in an effort to present a consensus document.

# 2024 IACC Strategic Plan Update

## Today's Discussion



- Chapter 1: IACC Interest in the Impact of Co-Occurring Conditions
- Chapter 2: Community Perceptions of Research and Services Needs
- Chapter 3: Co-Occurring Physical Health Conditions
- Chapter 4: Co-Occurring Mental and Behavioral Health Conditions
- Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities
- Chapter 6: Health Care Service Provision
- Introduction and Conclusion

# 2024 IACC Strategic Plan Update Discussion



## Chapter 1: IACC Interest in the Impact of Co-Occurring Conditions

- Formation and Activities of the IACC Working Group: Improving Health Outcomes for Individuals on the Autism Spectrum
- Recent IACC Activities and Interest Related to Co-Occurring Conditions



# 2024 IACC Strategic Plan Update Discussion



## Chapter 2: Community Perceptions of Research and Services Needs

- Respondent Demographics
- Type of Co-Occurring Conditions
- Impact of Co-Occurring Conditions
- Research Needs
- Services and Supports Needs
- Impact of COVID-19
- Summary



## Chapter 3: Co-Occurring Physical Health Conditions

- Introduction
- Epilepsy
- GI Issues and Disorders
- Sleep Issues and Disorders
- Sensory and Motor Challenges
- Ehlers-Danlos Syndrome
- Dysautonomia
- Immune System Dysfunction
- Physical Health Conditions in Midlife and Older Adulthood
- Summary



## Chapter 4: Co-Occurring Mental and Behavioral Health Conditions

- Introduction
- Anxiety Disorders
- Attention-Deficit/Hyperactivity Disorder (ADHD)
- Catatonia
- Depression
- Obsessive-Compulsive Disorder (OCD)
- Self-Injurious Behavior (SIB), Aggressive Behavior, and Emotion Dysregulation
- Suicidality
- Bipolar Disorders
- Feeding and Eating Disorders
- Gender Dysphoria
- Pathological Demand Avoidance (PDA)
- Schizophrenia
- Substance Use Disorder (SUD)
- Tourette Syndrome (TS) and Other Tic Disorders
- Trauma and Post-Traumatic Stress Disorder (PTSD)
- Wandering and Elopement Behaviors (WAEB)
- Summary



## Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities

- Introduction
- Intellectual Disability
- High Support Needs
- Communication Disabilities
- Related Developmental Disabilities
- Learning Disabilities
- Summary

# 2024 IACC Strategic Plan Update Discussion



## Chapter 6: Health Care Service Provision

- Introduction
- Accessibility of Health Care
- Patient-Provider Interactions
- Considerations for Individuals with Complex and High Support Needs
- Promoting Equity and Reducing Disparities
- Impact of COVID-19
- Federal Agency Activities & Initiatives
- Summary

# *2024 IACC Strategic Plan Update*

## Discussion



- Introduction
- Conclusion
- Any remaining comments

# 2024 IACC Strategic Plan Update Vote



- We will vote using the Zoom polling feature
- Poll Question #1: Given today's discussion, are you comfortable with voting to approve the *2024 IACC Strategic Plan Update* today?
- Poll Question #2: Do you approve the *2024 IACC Strategic Plan Update* (with any revisions discussed today)?

Reminder to federal IACC members: Only one vote per agency



# 2024 IACC Strategic Plan Update Vote



Given today's discussion, are you comfortable with voting to approve the *2024 IACC Strategic Plan Update* today?

**Vote!**

- Yes, I am comfortable voting on approval today.
- No, I would prefer to vote after additional revisions have been incorporated into the draft.
- Abstain from voting.

Reminder to federal IACC members: Only one vote per agency

# 2024 IACC Strategic Plan Update Vote



Do you approve the *2024 IACC Strategic Plan Update* (with any revisions discussed today)?

**Vote!**

- Yes, I approve the report.
- No, I do not approve the report.
- Abstain from voting.

Reminder to federal IACC members: Only one vote per agency

# Closing Remarks

**Shelli Avenevoli, Ph.D.**

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

**Susan A. Daniels, Ph.D.**

Executive Secretary, IACC  
HHS National Autism Coordinator  
Director, Office of National Autism Coordination, NIMH



# Thank you to the members of the Improving Health Outcomes Working Group, 2018-2019



## Co-Chairs

- David Amaral, Ph.D.
- Julie Lounds Taylor, Ph.D.

## Members

- Gregory Barnes, M.D., Ph.D.
- Timothy Buie, M.D.
- Sarah Cassidy, Ph.D.
- Dan Cury, M.D.
- Samantha Crane, J.D.
- Lisa Croen, Ph.D.
- Patricia Dietz, Dr.P.H., M.P.H.
- Craig Erickson, M.D.
- Sarah Gardner
- Dena Gassner, Ph.D.
- Kaite Gotham, Ph.D.
- Antonio Hardan, M.D.
- Darren Hedley, Ph.D.
- Jennifer Johnson, Ed.D.
- Joseph Joyce, M.B.A.
- Alice Kau, Ph.D.
- Connor Kerns, Ph.D.
- Bryan King, M.D., M.B.A.
- Anne Kirby, Ph.D., OTR/L.
- Clarissa Kripke, M.D.
- Brenna Maddox, Ph.D., LCP
- Beth Ann Malow, M.D., M.S.
- Carla Mazefsky, Ph.D.
- Micah Mazurek, Ph.D.
- Donna Murray, Ph.D.
- Christina Nicolaidis, M.D., M.P.H.
- Kevin Pelphrey, Ph.D.
- Dora Raymaker, Ph.D.
- Judith Reaven, Ph.D.
- Scott Michael Robertson, Ph.D.
- Marcella Ronyak, Ph.D., LCSW, CDP
- Nina Schor, M.D., Ph.D.
- Elliott Sherr, M.D., Ph.D.
- Matthew Siegel, M.D.
- Alison Tepper Singer, M.B.A.
- Sarah Spence, M.D., Ph.D.
- Jeremy Veenstra-VanderWeele, M.D.



# IACC members and alternates, 2021-2024

## Thank you all for your service on the IACC!





# Thank you to the ONAC Staff and Meeting Support Team!



**Susan Daniels, Ph.D.**  
HHS National Autism  
Coordinator and  
Director, ONAC



**Oni Celestin, Ph.D.**  
Deputy Director



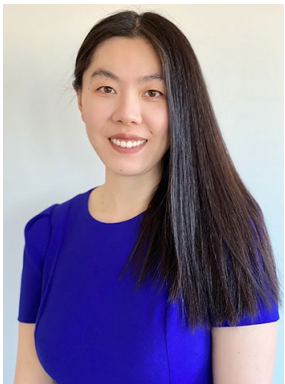
**Ana Cappuccio, LL.B.**  
Operations Coordinator



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



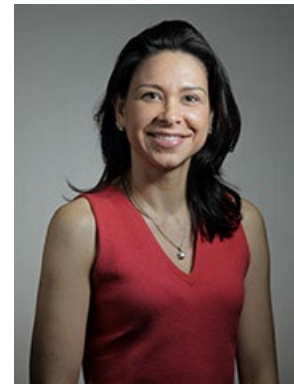
**Steven Isaacson, L.M.S.W.**  
Neurodiversity Liaison



**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



# Keep in touch with the Office of National Autism Coordination



Check the IACC website for updates:

<https://iacc.hhs.gov>

Join the ONAC mailing list for email updates:

<https://iacc.hhs.gov/about-iacc/subscribe/>