

# Meeting of the Interagency Autism Coordinating Committee

October 26, 2022; 10:00 a.m. - 5:00 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

# Welcome and Announcements



# Virtual Meeting Etiquette



- 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 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.

# Recognition of National Disability Employment Awareness Month (NDEAM)



**Anupa Geevarghese, Esq.**  
**Chief of Staff**  
**Office of the Assistant Secretary**  
**U.S. Department of Labor**

# Update on Autism-Related Research at Mathematica



**Scott Michael Robertson, Ph.D.**  
**Senior Policy Advisor**  
**Office of Disability Employment Policy**  
**U.S. Department of Labor**

# Autism Research at Mathematica, Including Research on Employment of Young Adults on the Autism Spectrum

**Ankita Patnaik, Ph.D.**  
Senior Researcher  
Mathematica

**Paul Shattuck, Ph.D.**  
Senior Fellow  
Mathematica



# Discussion



# Autism-related Research at Mathematica

**Presentation for the  
Interagency Autism Coordinating Committee (IACC)**

October 26, 2022

Ankita Patnaik, Paul Shattuck



# Our team



**Ankita Patnaik**  
Senior Researcher



**Paul Shattuck**  
Senior Fellow



# Agenda

- ／ **About Mathematica**
- ／ **Connecting IACC's strategic goals and Mathematica's expertise**
- ／ **Recent autism-related research at Mathematica**
- ／ **Project spotlight: REYAAS (Research Support Services for the Employment of Young Adults on the Autism Spectrum)**
- ／ **Looking ahead: Informing future research priorities**
- ／ **Q&A**



# About Mathematica | A growing focus on autism

Established in 1968, Mathematica is **driven by our mission to improve public wellbeing**. With more than **1,500 employee owners across the globe**, we apply expertise at the intersection of data science, social science, and technology to **translate big questions into deep insights** that can improve outcomes by informing policy and practice.

## Autism spotlight

With over **20 years of experience researching autism**, Mathematica has long-standing relationships across federal, state, and local agencies as well as clients at foundations, international, and private organizations.

The types of support we provide includes:

- / Engaging community partners and people with lived experience
- / Reviewing system interventions
- / Linking and analyzing administrative and survey data
- / Collecting survey data
- / Conducting evaluations
- / Translating analytic insights into actionable findings



## Clients





# Connecting IACC's strategic goals and Mathematica's expertise

## IACC strategic plan 2018–2019 update

-  **QUESTION 1** HOW CAN I RECOGNIZE THE SIGNS OF ASD, AND WHY IS EARLY DETECTION SO IMPORTANT?
-  **QUESTION 2** WHAT IS THE BIOLOGY UNDERLYING ASD?
-  **QUESTION 3** WHAT CAUSES ASD, AND CAN DISABLING ASPECTS OF ASD BE PREVENTED OR PREEMPTED?
-  **QUESTION 4** WHICH TREATMENTS AND INTERVENTIONS WILL HELP?
-  **QUESTION 5** WHAT KINDS OF SERVICES AND SUPPORTS ARE NEEDED TO MAXIMIZE QUALITY OF LIFE FOR PEOPLE ON THE AUTISM SPECTRUM?
-  **QUESTION 6** HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?
-  **QUESTION 7** HOW DO WE CONTINUE TO BUILD, EXPAND, AND ENHANCE THE INFRASTRUCTURE SYSTEM TO MEET THE NEEDS OF THE ASD COMMUNITY?

/ **Mathematica's past and present work aligns closely with the strategic goals of IACC**

/ **Recent autism research:**

- Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS)
- Promoting Readiness of Minors with Autism Spectrum Disorder: Evidence from a Randomized Control Trial (PROMISE)
- Next Generation of Enhanced Employment Strategies (NextGen)
- HRSA Autism Transitions Research Project (ATRP), 2017–2022 and 2022–2027





# Focus area: Recent autism-related research



**QUESTION 6** HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

1

Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.

Source: Interagency Autism Coordinating Committee *Strategic Plan for Autism Spectrum Disorder: 2018–2019 Update*

## Promoting Readiness of Minors receiving Supplemental Security Income (PROMISE) Evaluation

- Evaluation funded by Social Security Administration; Autism sub-study funded by Autism Speaks
- Six demonstration projects provided transition services to 12,000+ adolescents with disabilities who received Supplemental security income (13% were on the autism spectrum) and their families
- Rigorous impact study found that the programs doubled the share of youth on the autism spectrum who held paid jobs during the following 18 months. A five-year impact study is underway.

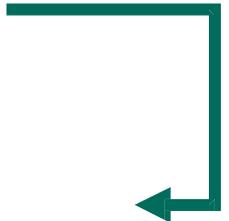


# Focus area: Recent autism-related research

 **QUESTION 6** HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

- 1 Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.
- 2 Support research and implement approaches to reduce disabling co-occurring physical and mental health conditions in adults with ASD, with the goal of improving safety, reducing premature mortality, and enhancing quality of life.
- 3 Support research, services activities, and outreach efforts that facilitate and incorporate acceptance, accommodation, inclusion, independence, and integration of people on the autism spectrum into society.

Source: Interagency Autism Coordinating Committee *Strategic Plan for Autism Spectrum Disorder: 2018–2019 Update*



## Next Generation of Enhanced Employment Strategies (NextGen)

- Research funded by the Administration for Children and Families
- Evaluation of innovative programs designed to promote employment and economic security among individuals with complex challenges to employment
- Sample program: Bridges from School to Work provides intensive employment-related supports to students with intellectual and developmental disabilities as they transition out of high school.
- Evaluation includes an implementation assessment, cost study, and impact analysis.



# Focus area: Recent autism-related research



**QUESTION 6** HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

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Source: Interagency Autism Coordinating Committee *Strategic Plan for Autism Spectrum Disorder: 2018–2019 Update*

## HRSA Autism Transitions Research Project, 2017–2027

- National Autism Data Center
- 35 publications (5 more in pipeline), 75 unique authors
- Key topics: Service systems, health, equity, employment, mental health, financial hardship and social safety net participation, SDOH
- Research funded by Health Resources and Services Administration (HRSA)
- Second round of 5-year funding began September 2022





# Spotlight: Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS)

Project funded by the U.S. Department of Labor's





# REYAAS Project overview



**QUESTION 6** HOW CAN WE MEET THE NEEDS OF PEOPLE WITH ASD AS THEY PROGRESS INTO AND THROUGH ADULTHOOD?

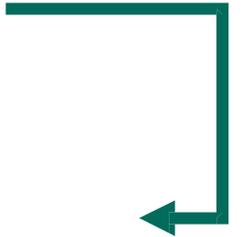
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Support development and coordination of integrated services to help youth make a successful transition to adulthood and provide supports throughout the lifespan.

Source: Interagency Autism Coordinating Committee *Strategic Plan for Autism Spectrum Disorder: 2018–2019 Update*

## / Goals

- Understand barriers and facilitators affecting employment of young adults on autism spectrum
- Identify specific practices, approaches, policies, and programs that can facilitate employment
- Highlight and fill gaps in the research literature
- Suggest new evidence-building activities





# REYAAS project activities

- ✓ **Knowledge development: Literature reviews, listening sessions, and discussions with TWG (currently underway)**
- ✓ **Analyses of existing data**
- ✓ **Evaluation design options and recommendations**
- ✓ **Surveying young adults and stakeholders (optional task)**
- ✓ **Dissemination of findings and insights**



# Literature search

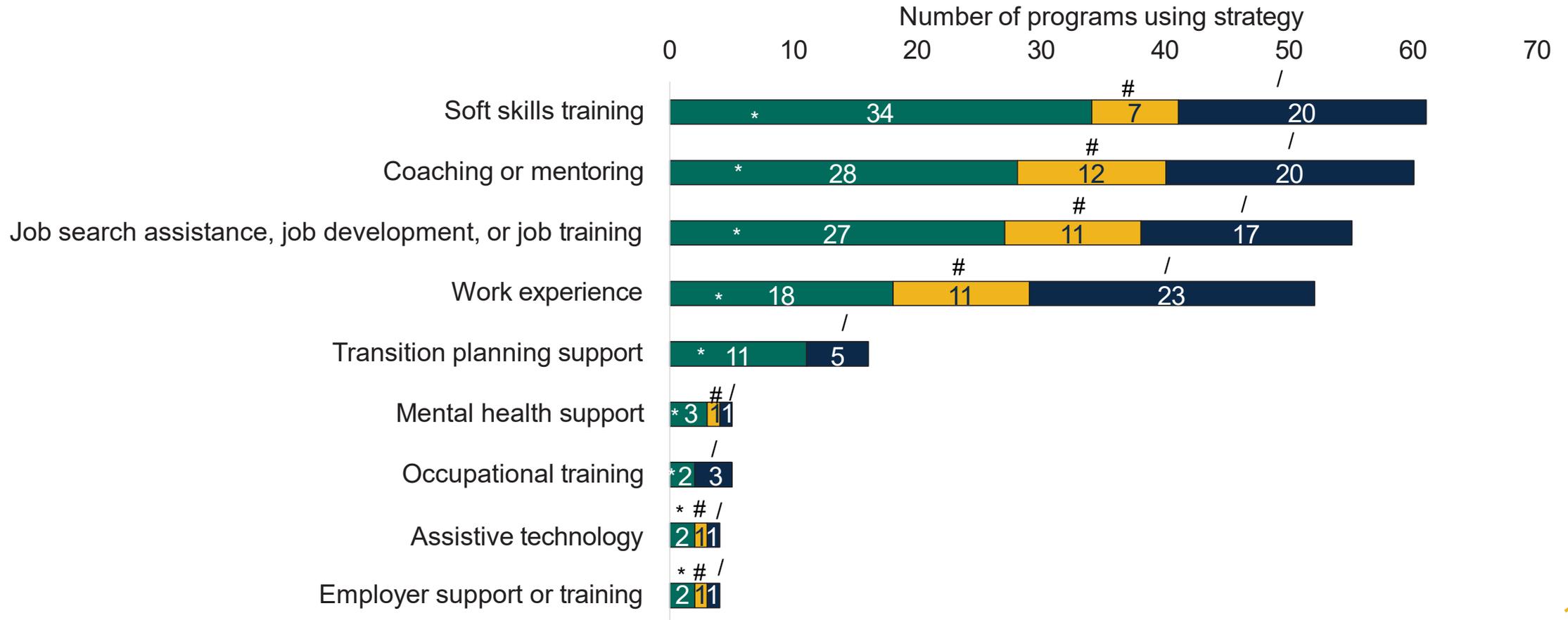
## Two goals:

1. **Identify and summarize the range of programs, models, and strategies used to support employment for young people with developmental disabilities**
2. **Examine the evidence on the effectiveness of those programs in improving employment outcomes**





# Which strategies are being used to support employment of young adults on the autism spectrum?



\* Only those on the autism spectrum  
/ Not specifically including those on the autism spectrum

# Specifically including those on the autism spectrum



# What do we know about the effectiveness of these strategies?

- ✓ **62 effectiveness studies of programs that support employment of young adults with developmental disabilities**
  - 17 examined effects on employment or related outcomes
- ✓ **Only six rigorous evaluations: randomized controlled trials (RCTs) or quasi-experimental designs (QEDs)**
  - 3 RCTs of Project SEARCH plus ASD Supports, a transition-based employment model for high school students on the autism spectrum, showed promising results
  - 2 RCTs of virtual interview training showed that participants secure competitive integrated employment at higher rates than non-participants
  - 1 QED found an association between receiving supported employment services and attaining competitive integrated employment for young adult vocational rehabilitation (VR) clients with intellectual or developmental disabilities



# Listening sessions with young adults on the autism spectrum and professionals who work with them

*"I feel like I face additional challenges related to my position in my society because not everybody knows how to communicate with me, and I cannot get what I need."*

*"I have worked with some programs that have really helped me gain courage while in the job market."*

*"People with autism are also able to make good managers and leaders as long as you accept yourself, surround yourself with a good supportive system and [keep] going towards your dreams."*

*"I enjoy working with others who are neurodivergent because I would never be as confident or successful if it wasn't for older neurodivergent workers who took me under their wing and showed me it was possible."*



# Findings from listening sessions

<b>Barriers to employment</b>	<b>Facilitators to employment</b>
Challenges in job search and finding a good work environment	Encouragement and advice from family members, friends, and staff from job readiness programs Paid internships, career mentoring programs, and customized employment
Biases in typical recruitment and interview process	Cultural shifts and training for employers to encourage inclusive recruitment, hiring, and work environments
Need for greater and enhanced supports and services (addressing transportation or technology, providing ongoing supports, or developing self- advocacy and career advancement skills)	Greater collaboration and funding for needed supports Partnering with neurodivergent consultants or career coaches with disabilities
Challenges with generalizing and scaling services	Coordination with large, established programs



# Inventory of extant data

- / Quality data are needed to build evidence on the needs, barriers and facilitators of employment for young adults on the autism spectrum**
- / Scanned existing survey and administrative data to identify sources that included:**
  - Young adults ages 16 to 28**
  - Information to identify individuals on the autism spectrum**
  - Employment-related measures**



# Inventory of extant data

## / **Identified 11 data sources:**

- Several have small sample sizes of people on the autism spectrum
- Larger administrative datasets are usually not representative of all young adults
- Access to many datasets is restricted
- Most contain limited employment information (e.g., employment status, earnings)
- Often include other information relevant to employment (e.g., health, demographics)

## / **There is a need for more large-sample representative data on young adults on the autism spectrum focused on employment information**



# Analysis of administrative data (underway)

## / **Data: Case service reports from the Rehabilitation Services Administration (RSA-911)**

- **Population data: Covers all 78 agencies and all VR applicants**
- **Large sample size of young people on the autism spectrum**
- **Recent data (2021) and annual files are available**

## / **Sample**

- **Young adults who applied for VR services**
- **Ages 16–28 at the time of VR application**
- **Autism is recorded as the source of primary or secondary impairment**



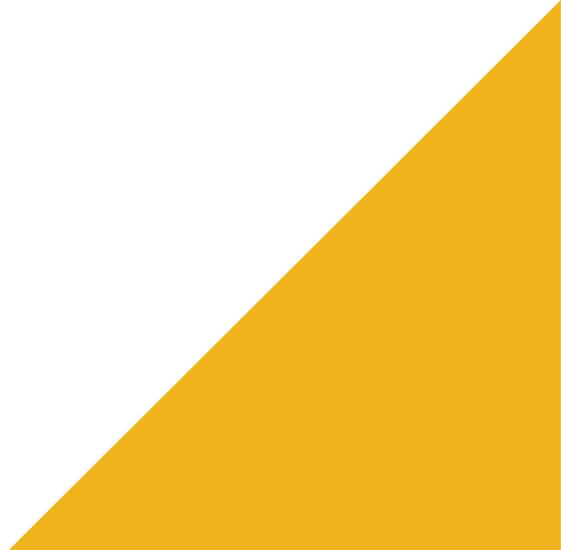
# Research questions



- 1. What are common sources of referral to VR for young adults on the autism spectrum? What are the characteristics and commonly identified barriers to employment for this group?**
- 2. What VR services do young adults on the autism spectrum use? What are the employment outcomes of this group?**
- 3. How do patterns in referrals and outcomes vary across states, disability types, and demographic subgroups?**
- 4. Did patterns in VR applications, service use, and employment outcomes shift during the COVID-19 pandemic?**



# Looking Ahead: Informing Future Research Priorities





# Gaps identified in extant research

- ／ **Inconsistent attention to equity and life course**
- ／ **Little understanding of service ecosystems and policy implementation challenges**
- ／ **Underutilization of big data**
- ／ **Slow response to new challenges like COVID and climate change risks**



# Emerging priorities for Mathematica

- ✓ **Leading on equity and life course SDOH methods, collaborate with academic partners and funders**
- ✓ **Improving already-scaled programs so they better serve autistic people**
  - Safety net programs (e.g., SNAP, SSI)
  - Employment programs (e.g., Job Centers, Job Corps)
- ✓ **Better understand service ecosystems and emerging topics (e.g., COVID, climate change) through advances in working with big data**



# Questions



# National Autism Coordinator Update

IACC Full Committee Meeting  
October 26, 2022

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**Susan Daniels, Ph.D.**

Acting HHS National Autism Coordinator  
Office of the NIMH Director  
National Institute of Mental Health



# Non-Governmental Updates

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- Black Feathers Podcast
- ASF “Participate in Research” Directory
- Autism Speaks: Thought Leadership Summit on Autism and Aging
- Stanford Neurodiversity Summit 2022
- AUCD 2022 Conference: “Health Equity: Serving the Whole Person”

# Launch of Black Feathers Podcast (Disability Conversation for All)

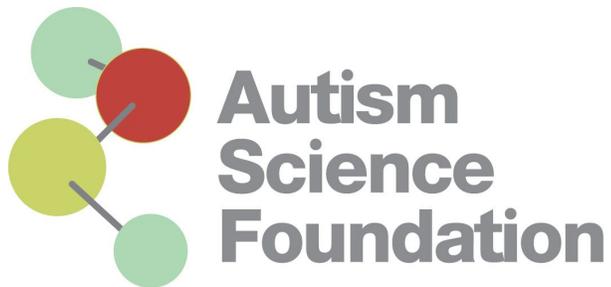
- In this podcast, co-hosts Crystal Hernandez, Psy.D., MBA and mother of a child on the autism spectrum, and Shauna Humphreys, MS, LPC, discuss disability-related topics of interest to Tribal communities through data, storytelling, and innovative content.
- The podcast embraces diversity, equity, and honor within Tribal Nations.
- The podcast is an initiative of the States of the States in Intellectual and Developmental Disabilities Project of National Significance and The Kansas University Center on Excellence in Developmental Disabilities (UCEDD). Funded by ACL.
- Podcast can be listened to [here](#).



**BLACK FEATHERS PODCAST**  
Disability Conversations for All

# ASF Launches Novel 'Participate in Research' Website Directory

- The Autism Science Foundation (ASF) has launched a new directory of research participation opportunities to help individuals on the autism spectrum and their families find and more easily enroll in autism research studies. The directory is free and searchable.
- Press release [available here](#).



# Autism Speaks: Thought Leadership Summit on Autism and Aging

- In June 2022, Autism Speaks hosted a [virtual Summit](#) bringing together families, autistic adults, researchers, and policymakers to discuss the issues facing autistic adults as they age.
- Over two days of sessions, presenters shared the top challenges faced by aging autistic adults, discussed policy considerations, provided an overview of the existing research and identified opportunities for further action to support this community.



**Living with Autism as an Adult:  
Personal Narratives from Self-Advocates**

Moderator: Vanessa Bal, M.Sc., Rutgers University

Panel: Jairo Arana | Anne Grego-Nagel | Elisheva Levin | JoAnne Lovegrove | Karl Wittig



# Stanford Neurodiversity Summit 2022

- The Stanford Neurodiversity Summit was a virtual forum where neurodiverse/neurodivergent people, their family members and friends, educators, clinicians, researchers, and all other stakeholders and professionals will share visions, innovations, and inspirations about how neurodiversity can make our society better.
- The theme of this year's summit was "How do you contribute to the Neurodiverse Community? Education, Service, Research, and/or Advocacy."
- Event details can be [found here](#).



# AUCD 2022 Conference: “Health Equity: Serving the Whole Person”

- This year’s annual AUCD Conference from November 13-16 will celebrate accomplishments and focus on health equity, the social determinants of health, and the steps needed to ensure that every person is provided the best opportunities possible.
- AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary disability programs. Network members consist of:
  - 67 University Centers for Excellence in Developmental Disabilities (UCEDD) – funded by ACL
  - 60 Leadership Education in Neurodevelopmental Disabilities (LEND) programs – funded by HRSA
  - 16 Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers (IDDRC) – funded by NIH
  - 12 Developmental-Behavioral Pediatrics Training Program (DBP) – funded by HRSA



Conference schedule and registration details are [available here](https://www.aucd.org/conference).

# Federal Updates

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- White House
- Updates from Executive Orders 13985 & 14035
- Federal Partners in Transition (FPT)
- Interagency Committee for Disability Research (ICDR)
- National Council on Disability (NCD)
- RAISE Family Caregiving Advisory Council (FCAC)
- Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC)
- Federal Communication Commission Disability Advisory Committee (DAC)
- President's Committee for People with Intellectual Disabilities (PCPID)
- National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

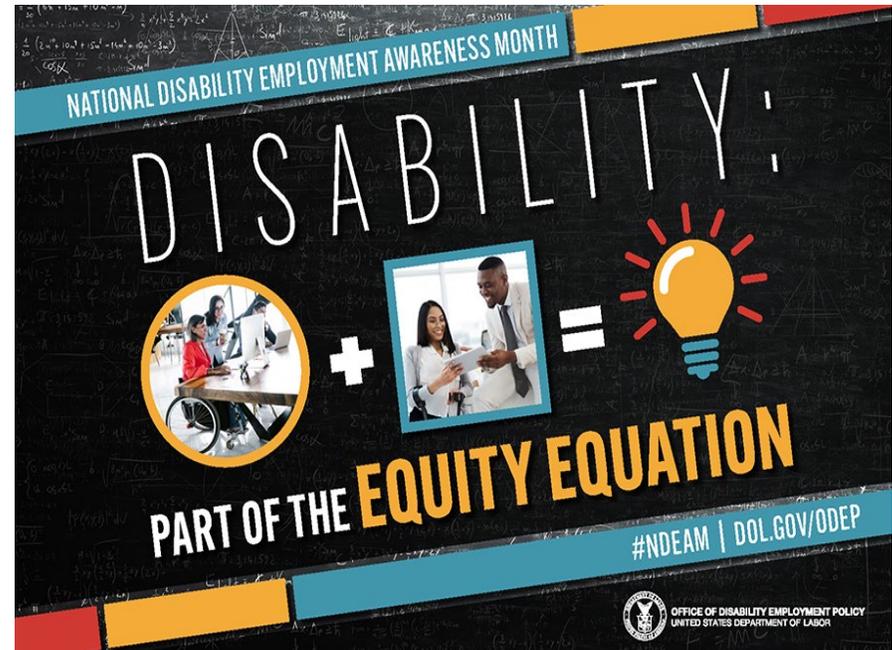
# Federal Updates, continued

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- Agency for Healthcare Research and Quality (AHRQ)
- NIH Awards \$100 Million for Autism Centers of Excellence Program
- Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities

# White House - National Disability Employment Awareness Month (NDEAM)

- President Biden's 2022 [Presidential Proclamation](#) to celebrate National Disability Employment Awareness Month (NDEAM). He honors the contributions of individuals with disabilities to the workplace and recommits to equal opportunity for all.
- The Office of Autism Research Coordination (OARC)/IACC - [NDEAM 2022 Webpage](#) – News, events and resources.
- Department of Labor, ODEP NDEAM page: Disability: Part of the Equity Equation – Home [page](#)



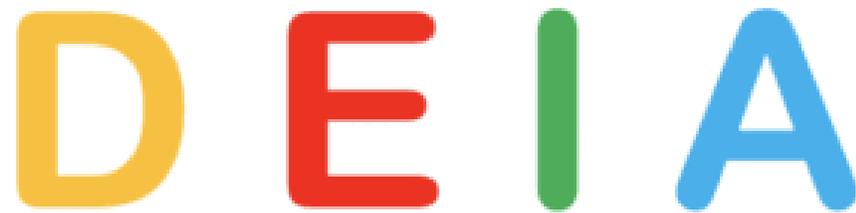
# Federal Efforts toward Diversity, Equity, Inclusion, and Accessibility

## Two Key Executive Orders:

- January 20, 2021, President Biden signed Executive Order 13985 on “[Advancing Racial Equity and Support for Underserved Communities Through the Federal Government](#)” launched a government-wide effort to incorporate the principle of equity throughout the federal government.
  - Our Nation deserves an **ambitious whole-of-government equity agenda** that matches the scale of the opportunities and challenges that we face.
  - It is therefore the policy of my Administration that the Federal Government should pursue a comprehensive approach to **advancing equity for all, including people of color and others who have been historically underserved...**
  - **People with disabilities** are included in the list of underserved communities.
- June 25, 2021, President Biden signed Executive Order 14035 “[Diversity, Equity, Inclusion, and Accessibility in the Federal Workforce](#)”. This EO launched a government-wide initiative to **cultivate a federal workforce that draws from the full diversity of the Nation** and that advances equitable employment opportunities. **People with disabilities** are included.

# Federal Efforts toward Diversity, Equity, Inclusion, and Accessibility

- DEIA efforts across every federal department and agency are creating opportunities to launch initiatives to increase diversity, equity, inclusion and accessibility across many federal programs and activities.
- These efforts are enabling opportunities to address full inclusion and access for people with disabilities, along with people from other underserved groups.
- Multiple working groups, committees, and initiatives.
- New opportunities for disability, disability employment, and neurodiversity initiatives, as well as consideration of intersectionality with race, gender, etc.



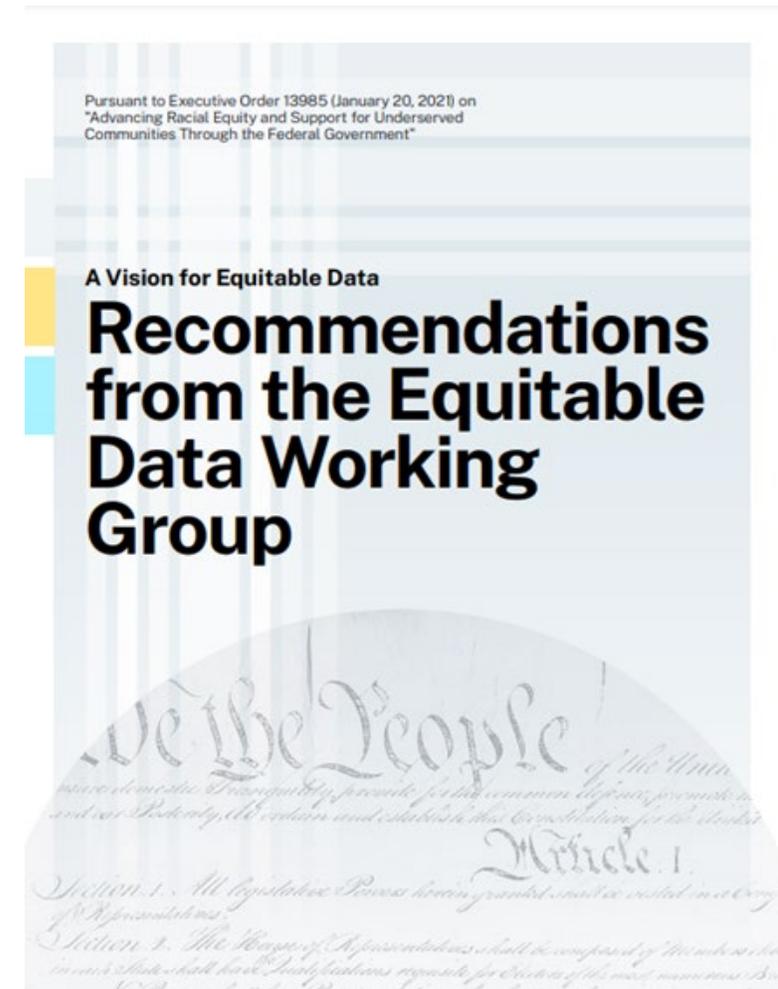
DEIA

Diversity | Equity | Inclusion | Accessibility

# Recent Reports: Equitable Data

- Executive Order 13985 resulted in formation of the Equitable Data Working Group to outline a strategy for increasing data available for measuring equity and diversity.
- The Working Group identified 3 priority uses for equitable data:
  - Generating disaggregated statistical estimates to characterize experiences of historically underserved groups using survey data;
  - Increasing non-federal research and community access to disaggregated data for the evidence-building that supports equity efforts;
  - Conducting robust equity assessments of federal programs to identify areas for improvement.
- [Press release](#), [full report](#), and [fact sheet](#) available online.

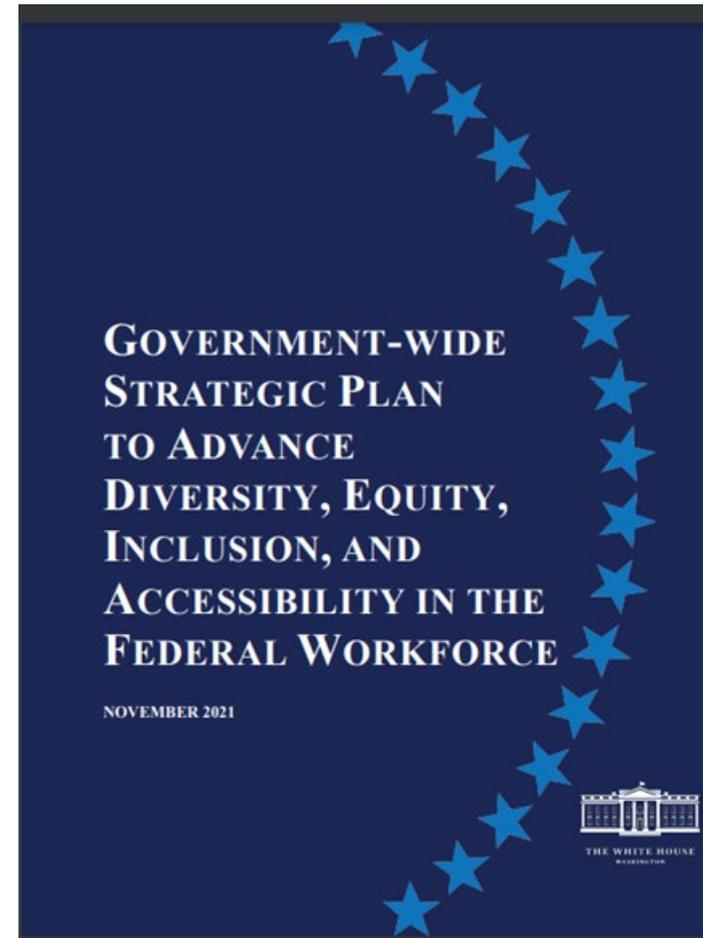
April 2022



# Report: Strategic Plan to Advance DEIA in the Federal Workforce

- EO 14035 established a Diversity, Equity, Inclusion, and Accessibility (DEIA) Initiative. The DEIA Initiative produced a [Government-wide Strategic Plan to Advance DEIA in the Federal Workforce \(Governmentwide DEIA Plan\)](#) which offers a roadmap for implementing the Executive Order and lays out key steps agencies can take to strengthen DEIA in their workforce policies, practices, and culture.
- The EO also charges all agencies with analyzing the current state of DEIA across their workforce by reviewing their agency data to assess whether employees, including members of underserved communities, including people with disabilities, face barriers in accessing federal employment opportunities.

November 2021



# Report: Improving Data Infrastructure for Patient-Centered Outcomes Research for People with ID/DD

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**Developed by the Assistant Secretary for Planning and Evaluation (ASPE),  
U.S. Department of Health and Human Services**

- Published: July 26, 2022
- This report describes insights gained from key informant interviews and an ASPE-hosted listening session on short-term opportunities for improving patient-centered outcomes research (PCOR) data infrastructure that addresses the needs of individuals with intellectual and developmental disabilities (ID/DD).
- Report can be [downloaded here](#).

# NIH Awards \$100 Million for Autism Centers of Excellence Program

- The National Institutes of Health (NIH) [awarded a total of \\$100 million](#) over the next five years to support nine Autism Centers of Excellence (ACEs). Each ACE will include a Plan for Enhancing Diverse Perspectives (PEDP), which outlines strategies to increase the participation of women and people from underrepresented groups.
- Additionally, each ACE will have an advisory board that includes autistic people and/or family members of individuals with autism.
- The *Eunice Kennedy Shriver* National Institute of Child Health and Development also issued a [press release](#).
- The ACE program is supported by NIH's NICHD, NIMH, NIEHS, NIDCD, and NINDS.

# Agency for Healthcare Research and Quality (AHRQ)

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- The Agency for Healthcare Research and Quality (AHRQ) is seeking public input about person-centered care for people at risk for, or living with, multiple chronic conditions (MCC).
- Comments will inform the agency's work and research agenda. Specifically, they are looking for comments on the current state of care and comments about innovative models, strategies, and approaches.
- Comments are due November 15. More information [available online](#).

# Interagency Committee on Disability Research (ICDR)

## Managed by the Administration for Community Living

- All-federal committee established to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
  - Release of a new toolkit called [Getting the Most Out of Stakeholder Engagement: A Toolkit to Better Understand and Measure Engagement](#). It includes practical information about stakeholder engagement – how and when to do it and why it is important – as well as interviews and case studies with examples from across ACL.
  - Held four recent Lunch and Learn webinars, including [Understanding and Responding to the Cultural and Linguistic Differences in the Conduct of Disability Research](#) with Tawara Goode, M.A.

# RAISE Family Caregiving Advisory Council ([FCAC](#))

## Managed by the Administration for Community Living

- Federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support for family caregivers.
- Recent activities include:
  - The RAISE FCAC published the [2022 National Strategy to Support Family Caregivers](#) which is now available for **public comment** through November 30, 2022, via [online form](#).
  - Public comments received will be used to inform the ongoing work of the FCAC and the Advisory Council to Support Grandparents Raising Grandchildren, as well as to inform future updates to the Strategy.
  - Recently held their second joint meeting with the Advisory Council to Support Grandparents Raising Grandchildren on September 21, 2022.

# Federal Partners in Transition (FPT)

## Managed by the U.S. Department of Labor

- All-federal workgroup formed in 2005 to facilitate exchange of information between federal agencies on transition-related issues for youth with disabilities.
- Recent activities include:
  - Members are continuing to work on developing a new Strategic Plan for transition age youth with disabilities. The next meeting is planned for December 15th, 2022.
  - My Future Matters Symposium: Held in-person on October 20 in honor of NDEAM and held jointly by ODEP, The Center for Advancing Policy on Employment for Youth (CAPE-Youth), and the National Working Group on Youth Transition's Youth Members. The focus was future policy considerations for youth and young adults with disabilities transitioning into the workforce.

# President's Committee for People with Intellectual Disabilities ([PCPID](#))

## Managed by the Administration for Community Living

- An advisory committee that aims to provide advice and assistance to the President and the HHS Secretary on a broad range of topics that impact people with intellectual disabilities with the goal of improving the quality of life experienced by people with intellectual disabilities by upholding their full citizenship rights, independence, self-determination, and lifelong participation in their communities.
- Recent activities include:
  - The recently reconvened PCPID held their first meeting on July 28, 2022, and discussed Home and Community Based Services, employment, education, housing, and the direct support professional workforce crisis. The meeting materials (including [recording](#)) are all available online.

# National Council on Disability ([NCD](#))

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- 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:
  - NCD held a Quarterly Business Meeting on July 25th. The Council heard public comment on the April Supreme Court decision *Cummings v. Premier Rehab Keller, P.L.L.C.* The Council also discussed proposed additions to its [Health Equity Framework](#).
  - NCD is currently planning their next [Quarterly Meeting](#) to be in-person October 27-28th in Providence, RI.

# Interdepartmental Serious Mental Illness Coordinating Committee ([ISMICC](#))

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## Managed by the Substance Abuse and Mental Health Services Administration

- Federal advisory committee charged with addressing issues related to serious mental illness (SMI) and serious emotional disturbance (SED).
- Recent activities include:
  - The ISMICC will meet on October 28th at 10:00 a.m. ET. The full agenda for the meeting and the Zoom link are [available at this link](#).

# Disability Advisory Committee ([DAC](#))

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## Managed by the Federal Communications Commission

- Federal advisory committee that provides advice and recommendations to the Federal Communications Commission on a wide array of disability issues, including communications and video programming access.
- Recent activities include:
  - The DAC will hold its [next meeting](#) on Tuesday, November 1st at 1:00 p.m. ET. The meeting will be available online through [FCC Webcast](#).

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

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## Managed by the Administration for Strategic Preparedness and Response

- The NACIDD advises the Secretary of Health and Human Services (HHS) on actions HHS can take before, during, and after disasters and emergencies to meet the unique needs of individuals with disabilities.
- Recent activities include:
  - The National Advisory Committee on Seniors and Disasters and the NACIDD conducted a joint virtual public meeting on August 4, 2022. Meeting agenda [available online](#).

# IACC Committee Business

IACC Full Committee Meeting  
October 26, 2022



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

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

# Committee Business Overview



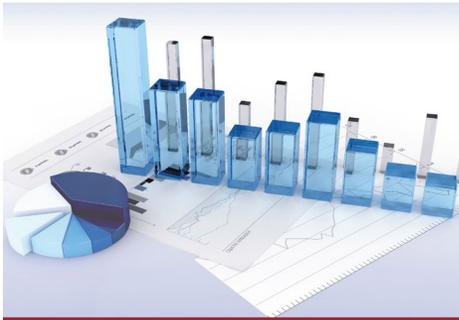
- Update on *IACC Portfolio Analysis Reports*
- Update on *IACC Summary of Advances*
- *IACC Strategic Plan* Discussion

# Update on the IACC Portfolio Analysis Report



INTERAGENCY AUTISM COORDINATING COMMITTEE (IACC)

2019-2020 AUTISM RESEARCH  
PORTFOLIO ANALYSIS REPORT



- The **IACC Portfolio Analysis Report**
  - Provides comprehensive information about autism research funding across federal agencies and private research organizations in the U.S.
  - Tracks progress towards *Strategic Plan Objectives*
  - Provides analysis of funding trends over time
  - Tracks progress towards the *IACC Strategic Plan Budget Recommendation*
  - Tracks funding towards special topics of interest, including research on autism in girls and women and research on racial/ethnic disparities.
- OARC is in the final stages of preparing the *2019-2020 IACC Portfolio Analysis Report*
- OARC is also currently preparing the *2021 IACC Portfolio Analysis Report*

# IACC Summary of Advances Update



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

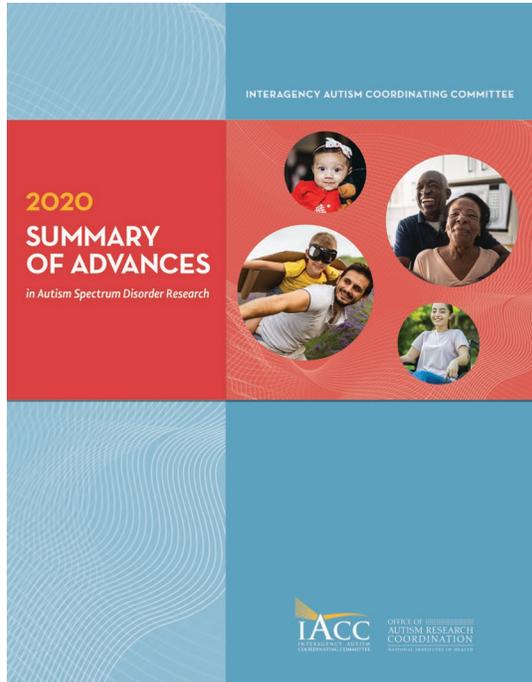
Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

# 2022 IACC Summary of Advances – Available Now!



- Annual report required by the Autism CARES Act of 2019
- Provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Includes articles addressing all 7 topic areas of the *IACC Strategic Plan*
- Final report was published in June 2022
- For the first time, OARC also prepared an easy-read version of the Summary of Advances

Access the full publication and easy-read version on the IACC website:

<https://iacc.hhs.gov/publications/summary-of-advances/2020/>

# 2021 IACC Summary of Advances Process



- ✓ IACC members nominate articles (July-December 2021)
- ✓ IACC members discuss nominations at committee meeting (April 2022)
- ✓ IACC members vote on top 20 articles (Summer 2022)
- OARC prepares article summaries and draft publication** (Fall 2022)
- IACC members preview/comment on draft (Late Fall 2022)
- OARC prepares final publication (Early 2023)

# 2022 IACC Summary of Advances Process



- IACC members nominate articles (October 2022-January 2023)
- IACC members discuss nominations at committee meeting (January 2023)
- IACC members vote on top 20 articles (January 2023)
- OARC prepares article summaries and draft publication (Winter-Spring 2023)
- IACC members preview and comment on draft (Spring 2023)
- OARC prepares final publication (Spring 2023)

# 2021 IACC Summary of Advances

## Next steps



### Upcoming Action Items

- Late Fall 2022: Preview/comment on draft *2021 IACC Summary of Advances* publication
- October 2022 – January 2023: Continue to submit nominations for the *2022 IACC Summary of Advances*

# 2021-2022 IACC Strategic Plan Discussion



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

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health

# 2021-2022 IACC Strategic Plan Process



- ✓ October-November 2021: OARC collected input on the *Strategic Plan* from the general public in a Request for Information (RFI). Results of the RFI were presented at the January 2022 IACC Meeting.
- ✓ November 2021-March 2022: OARC collected input on the *Strategic Plan* from IACC members in a survey. Results of the survey were presented at the April 2022 IACC Meeting.
- ✓ April-June 2022: OARC prepared the first draft of the *Strategic Plan*.
- ✓ July 2022: Strategic Plan Working Group Meeting was held. The first draft of the *Plan* was discussed.
- ✓ July 2022-September 2022 IACC members responded to a second survey to collect input on the *Plan*. Results shared at October 2022 IACC meeting.

# 2021-2022 IACC Strategic Plan Process



- ✓ July-October 2022: OARC prepared a revised draft of the *Strategic Plan*
- ✓ October 2022: OARC sent a second draft of the *Strategic Plan* to IACC members, containing the full content (all sections) of the Plan
- ✓ Throughout entire process, public comments have been reviewed for additional input.
- ❑ **TODAY: October IACC Full Committee Meeting: IACC members will discuss the second draft**
- ❑ November 2022: IACC members may submit feedback on the second draft (a third survey)
- ❑ December 2022: OARC will send a revised draft to IACC members for review
- ❑ January 2023 IACC Full Committee Meeting: IACC members will vote to approve the new *Strategic Plan*

# Updating the IACC Strategic Plan: General Comments



Topics/issues emphasized in the updated Plan include:

- Major research, services, and policy issues
- Increased need for inclusion in research, including community-based participatory research
- Addressing the whole spectrum and the whole lifespan, including those with high support needs
- Commitment to equity and reducing stigma, disparities, and discrimination
- Update on research portfolio and budget recommendation
- Major federal activities and initiatives, interagency coordination

# What's new in the second draft of the 2021-2022 IACC Strategic Plan



- Core chapters of the Plan have been updated/created, incorporating feedback from the Committee
  - Chapter 1: Screening and Diagnosis
  - Chapter 2: Biology
  - Chapter 3: Genetic and Environmental Factors
  - Chapter 4: Interventions
  - Chapter 5: Services and Supports
  - Chapter 6: Lifespan
  - Chapter 7: Infrastructure and Surveillance
  - Cross-Cutting Topic 1: Sex and Gender
  - Cross Cutting Topic 2: Promoting Equity and Reducing Disparities
  - Impact of the COVID-19 Pandemic

# What's new in the second draft of the 2021-2022 IACC Strategic Plan



- Additional sections of the Plan have been developed:
  - Introduction, including the Mission and Vision Statement, Core Values
  - Budget Recommendation (Statutory)
  - Statement on Duplication of Effort (Statutory)
  - Conclusion

# Mission and Vision Statement



The purpose of the *IACC Strategic Plan for Autism Research, Services, and Policy* is to focus, coordinate, and accelerate innovative research and foster development of high-quality services and supports. The *Plan* will emphasize the critical importance of partnerships among government and community partners to address the urgent questions and needs of all autistic people across the spectrum and across the lifespan. Ultimately, the *Plan* will catalyze federal and private activities that will improve health, well-being, acceptance, and inclusion for all people on the autism spectrum and their families.

# Core Values



- **Impact:** We will focus on making a difference in the lives of people in the autism community, including people on the autism spectrum, their families, researchers, medical practitioners, educators, and other service and support providers.
- **Community Focus:** We will emphasize the need for inclusion of community stakeholders with lived experience and partnerships with underserved communities, to enhance research, services, and supports. Increasing the diversity of the research and services workforce will assist in realizing the impact of research, services, and policies on the health and well-being, human rights, and dignity of autistic people across the whole spectrum and across the whole lifespan.

# Core Values



- **Equity and Inclusion:** We will prioritize the need to increase equity and reduce disparities across the lifespan, spectrum of ability and disability, sex and gender, racial and cultural boundaries, socioeconomic status, and geographic location.
- **Excellence:** We will pursue innovative scientific research of the highest quality, foster collaborations, and support the development and equitable dissemination of evidence-based services and practices to maximize the health and well-being of people on the autism spectrum.

# Core Values



- **Responsiveness:** We will focus on responding rapidly and efficiently to the needs and challenges of people on the autism spectrum and their families while identifying opportunities to maximize strengths.
- **Spirit of Collaboration:** We will treat others with respect, listen with open minds to the diverse lived experiences of people on the autism spectrum and their families, consider multiple solutions, and foster discussions where participants can comfortably share different opinions.

# Budget Recommendation



- At the January 2022 IACC Meeting, the Committee voted to recommend increasing the annual investment in autism research to \$685 million by 2025.
- In a survey sent to the IACC in July 2022, Committee members voted to recommend prioritizing research on the following topics:
  - **Lifespan Issues**
  - **Evidence-based interventions and services**
  - **Research on disparities and development of culturally competent tools and services**

# Statement on Duplication of Effort



The Autism CARES Act of 2019 requires that the IACC Strategic Plan include “recommendations to ensure that autism spectrum disorder research, services and support activities, to the extent practicable, of the Department of Health and Human Services and of other Federal departments and agencies, are not unnecessarily duplicative.”

# Statement on Duplication of Effort



- Main ideas
  - Coordinated efforts to fund different projects addressing the same topics represent cooperation and collaboration, not duplication
  - Replication of research to confirm results is valuable
  - Recommendations in the IACC Strategic Plan help to identify areas in most need of investment
  - The activities of the IACC and National Autism Coordinator help to ensure efforts are not unnecessarily duplicative

# Comments on the IACC Strategic Plan Draft?

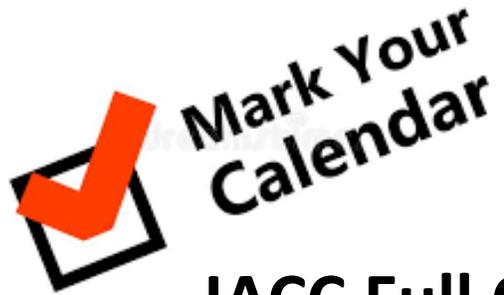


# Final Steps and Upcoming Action Items



- IACC members will receive a survey to provide feedback on the second draft of the *Strategic Plan*
- OARC will prepare a revised draft throughout November 2022.
  - Capture any missing items from the current draft
  - Incorporate plain language
  - Prepare an easy-read version
- In December 2022, OARC will send a third draft to IACC members for review.
- At the January 2023 IACC Full Committee Meeting, IACC members will vote to approve the Plan.

# Next IACC Meeting



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

January 18, 2023

Check the IACC Website for meeting information and updates.

<https://iacc.hhs.gov>

# Public Comment Session



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

Acting National Autism Coordinator

Director, Office of Autism Research Coordination

Executive Secretary, Interagency Autism Coordinating Committee

National Institute of Mental Health



- **Shannon Des Roches Rosa**, Thinking Person's Guide to Autism
- **Judith Ursitti**, Council of Autism Service Providers
- **Amy Lutz**, Ph.D., National Council of Severe Autism
- **Amy Montimurro**, ABILIS
- **Rieko Shepherd**, J.D., Autism Women and Nonbinary Network
- **Elliot Gavin Keenan**, UCLA

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Research and Service Needs, Resources, and Policy Implications - 43 comments***

- Karen Barrett
- Andrea Halliday
- Nancy Cheak-Zamora
- Kathryn Parsons
- Justin Acta
- Eleanor Wildflower
- Kate Davis
- Marc Rosen
- Nina Tobin
- Julia Simko
- Anne Xie
- Tosha Brothers
- Emma Villa
- Silvia Rodriguez
- Eli Estrin
- Katya Siddall-Cipolla
- Linnea Wickstrom
- Jane Horn, M.A.  
(Psychology), M.S.W.
- Allyson Raines
- Michelle Davidson
- Anthony Vizioli
- Nathan R J Destler,  
Ph.D.
- Steven Bruce
- Emily Wilkerson
- Whitney Voltz Voltz
- Naomi Hickey
- Marylyle McCue
- Sarah Gromko
- Melanie Franklin
- Alexander Bishel
- Derek Dunagan
- Betsy Cardenas
- Rebecca McCabe
- Jennifer Degner
- Courtney St. John
- Finn Gardiner
- Tiffany Plato
- June Zhu
- Lori Torres
- Megan McLaughlin
- Dana Carroll
- Nicole Corrado
- E F

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public\\_comments.pdf?ver=3](https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public_comments.pdf?ver=3)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Research, Services, and Supports for Adults with Autism – 15 comments***

- Brittany Daniels
- Kaitlyn Ballenger
- Joy Schneider
- Sigrid Ellis
- Skyler Irons
- Tasha Hansen
- Caroline Pavlecic
- Viola Sanchez
- Cox Amy
- Bill Wong
- Carol Greenburg
- Kellyann Wolfe
- Eileen Nicole Simon, Ph.D., R.N.
- Corinne Fisher
- Autism Housing Pathways, Catherine Boyle

## ***Augmentative and Alternative Communication – 5 comments***

- Amy Montimurro, LMSW, ABILIS
- Ileim Moss
- Marrok Sedgwick
- Iris Warchall
- Kerry Sheehan

## ***Inclusion of Autistic Perspectives in Research – 6 comments***

- Dr. Scott Frasard
- Priya Sall
- Heather Ricks
- Miyako Jones
- Jennifer Broekman
- Reilly MacDonald

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public\\_comments.pdf?ver=3](https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public_comments.pdf?ver=3)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Co-Occurring Mental Health Conditions and Negative Life Experiences – 9 comments***

- Tosha Rollins
- Helen Leung
- Sondra Hardgrave
- Emma Wilkinson
- Anna Tanksley
- Morgan King
- Sheri Waddill
- Meggan Armiger
- Jax Bayne

## ***Addressing the Needs of Autistic Individuals with High Support Needs – 11 comments***

- Allison Leavitt
- Leslie Lussier
- Cove Rathbun
- Jill Escher
- Justin Meade
- Chaula Gupta
- Nancy Boyer
- Robin Suzelis
- Johanna Cascione
- Michelle Trenk
- Lori Kay and Alex Kay, M.D.

**Full text** of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public\\_comments.pdf?ver=3](https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public_comments.pdf?ver=3)

# Summary of Written Public Comments



Written public comments were submitted on topics below by the following individuals:

## ***Concern about Medical Practices – 5 comments***

- Ben Hattingh
- Paityn Bowen
- Carl Muhlbauer
- John McAllister
- Chad Hansen

## ***Increase Autism Acceptance and Reduce Stigma – 3 comments***

- Benjamin Edwards
- Merlin Star, M.S.
- John Espinosa, Esq.

## ***The Role of the IACC and the Federal Government – 5 comments***

- Damon Kirsebom
- JaLynn Prince, B.F.A.
- Su Smith
- Jane Mccready
- Patrice Rohde

## ***Employment – 4 comments***

- Traci Collins
- Justin Robbins
- Jason Brown
- Corben Havener

## ***Potential Causes of Autism – 4 comments***

- Elissa Leonard
- Eileen Nicole Simon,  
Ph.D., R.N.
- Hal Frost, Ph.D.
- Emmet McManus

## ***Wandering and Safety – 1 comment***

- Eileen Nicole Simon,  
Ph.D., R.N.

Full text of public comments available at: [https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public\\_comments.pdf?ver=3](https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/october26/public_comments.pdf?ver=3)

# Discussion



# Autism in Older Adulthood – Panel and Presentation



# Lived Experience Panel



**John Elder Robison**

Neurodiversity Scholar in Residence

**Lisa Morgan**

Founder and Co-Chair, Autism and Suicide Committee of the American College of William and Mary Association of Suicidology

**Yulanda Harris, Ed.D., CNP**

Certified Neurodiversity Professional/CEO, Trainingphase

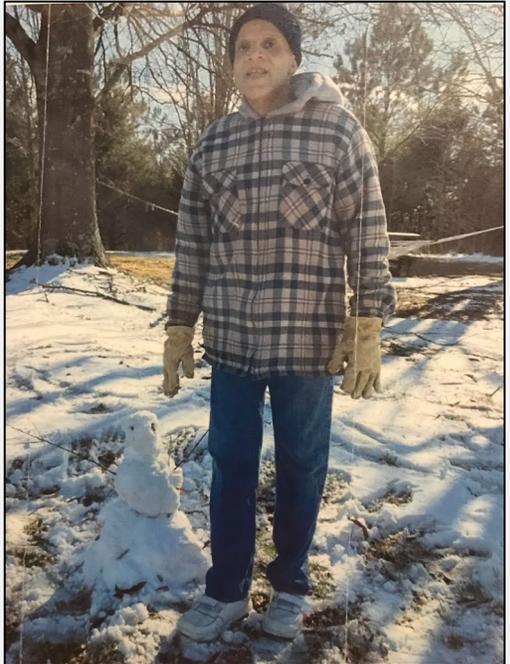
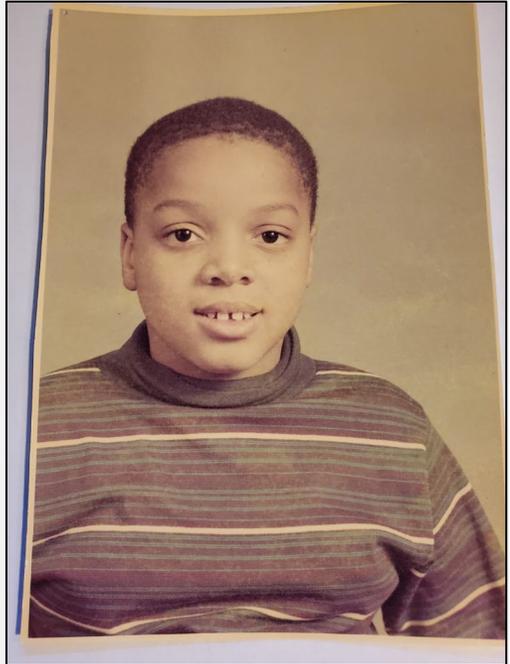
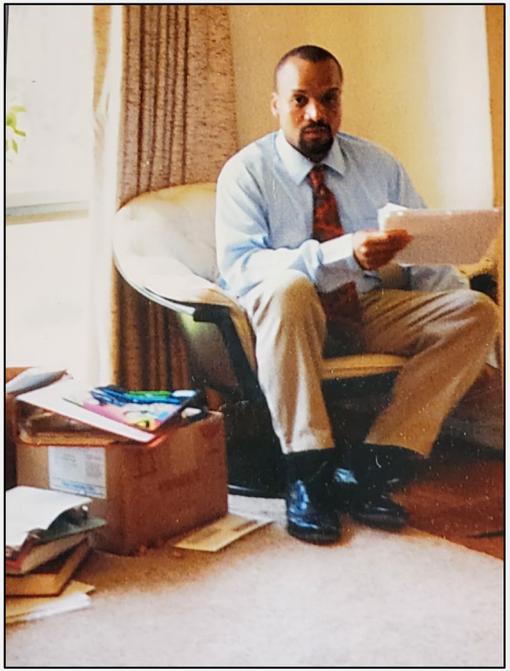
**Ruth Jones**

Family Member

**Sue Swezey**

Family Member

Peter Jones



# Sue Swezey



- Parent of a 59-year-old son with ASD
- Progress has been made, but there are still gaps in autism services for adults
- Parents have difficulty finding residential placements for their adult children
- Quality day programs and activities are hard to find
- Today's autistic adults 60 and older will set a precedent for increasing numbers of adults on the spectrum
- Encourages the IACC to examine the entire spectrum of autism needs and abilities, and to focus attention on the most severely challenged

# A Brief Overview of Research on Autism in Older Age



## **Joseph Piven, M.D.**

Thomas E. Castelloe Distinguished Professor of  
Psychiatry Director, Carolina Institute for  
Developmental Disabilities  
University of North Carolina

## **Marsha Mailick, Ph.D.**

Vaughan Bascom and Elizabeth M. Boggs Professorships, Vice  
Chancellor for Research and Graduate Education, Emeritus,  
Waisman Center, University of Wisconsin-Madison

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Marsha Mailick, Ph.D.

Vaughan Bascom and Elizabeth M. Boggs Professor  
Emeritus Vice Chancellor for Research and Graduate Education  
University of Wisconsin



# A Striking Absence of Knowledge about Autism in Older Age

prevalence: 2-4/10,000

~ 1/50 school age children

1943

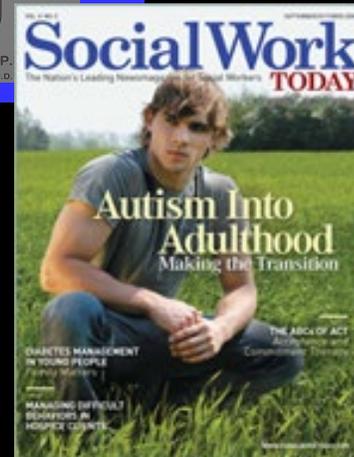
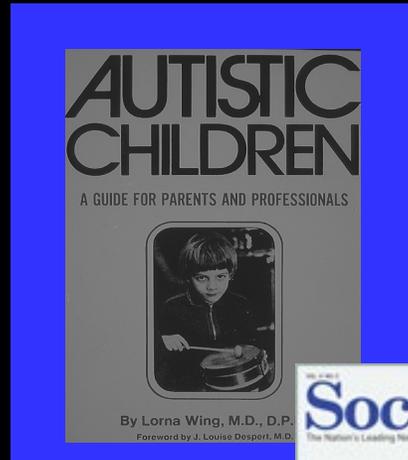
2022

Autistic Disturbances of Affective Contact  
by Leo Kanner (1943)



Infantile  
Autism

Case 1: Donald T., first seen in 1938 at the Harriet Lane Clinic, Johns Hopkins Hospital

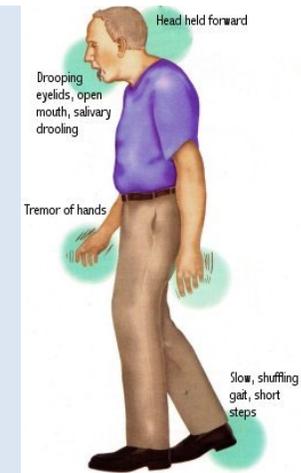


The Atlantic, October 2010  
Donvan and Zucker  
"Autism's First Child" age 77

## High Rates of Parkinsonism in Adults with Autism

Starkstein, Gellar, Parlier, Payne and Piven (2015)

- rate of Parkinson's Disease: 4/20 (20%); 2 independent samples > age 50
- direct assessment
- 200 times the rate (1/1000) in the general population (Wong et al., 2014)



consistent with:

### Croen et al., (2015) reporting elevated rates of Parkinson's Disease

- Kaiser Permanente Medical Record review;  
N=1,507 ASD; N=15,070 controls; > 40 years of age

### Geurts et al., (2022) reporting elevated rates of self-reported Parkinsonism (tremor, stiffness)

- Dutch (N=296;  $\geq$  age 50) and U.S. (N=219;  $\geq$  age 50) samples – **without ID**

# Developmental Disorders Associated with Later-life Degenerative Neurological Changes

**Population-based study of the prevalence and presentation of dementia in adults with Down's syndrome** British J Psychiatry (1998)

A. J. HOLLAND, J. HON, F. A. HUPPERT, F. STEVENS and P. WATSON

elevated rates of dementia occurred 30-40 years earlier in individuals with Down Syndrome than in the general population

**The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder** Autism Research (2021)

Giacomo Vivanti  | Sha Tao | Kristen Lyall  | Diana L. Robins  | Lindsay L. Shea 

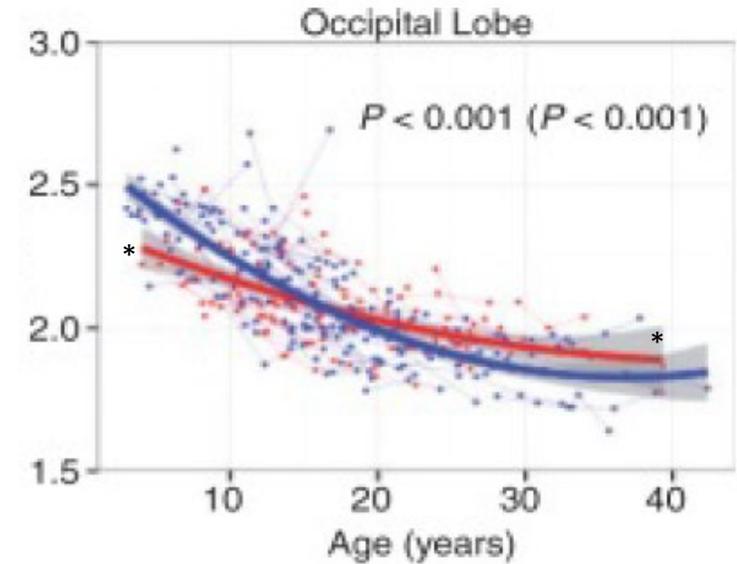
prevalence of dementia was 2.6 times higher in autism spectrum disorder

## Longitudinal changes in cortical thickness in autism and typical development

Brandon A. Zielinski,<sup>1,2,3</sup> Molly B. D. Prigge,<sup>1,4</sup> Jared A. Nielsen,<sup>4</sup> Alyson L. Froehlich,<sup>5</sup> Tracy J. Abildskov,<sup>6</sup> Jeffrey S. Anderson,<sup>4,7</sup> P. Thomas Fletcher,<sup>8,9</sup> Kristen M. Zygmont,<sup>8</sup> Brittany G. Travers,<sup>10</sup> Nicholas Lange,<sup>11,12,13</sup> Andrew L. Alexander,<sup>10,14,15</sup> Erin D. Bigler,<sup>6,16</sup> and Janet E. Lainhart<sup>10,15</sup>

**suggests the possibility of  
specific changes in the brain,  
in autistic adults,  
that differ by age**

consistent with Braden et al., (2019)

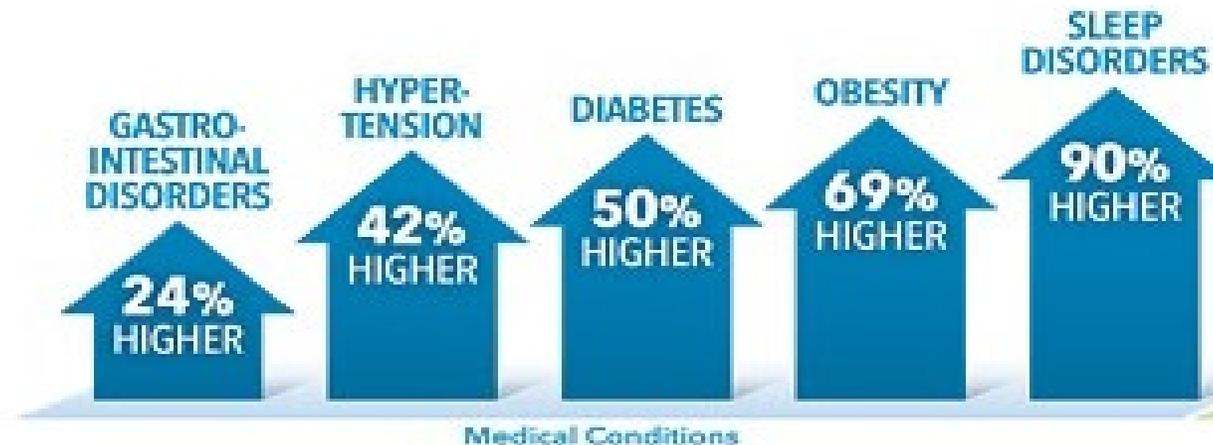


\* TDC  
\* ASD

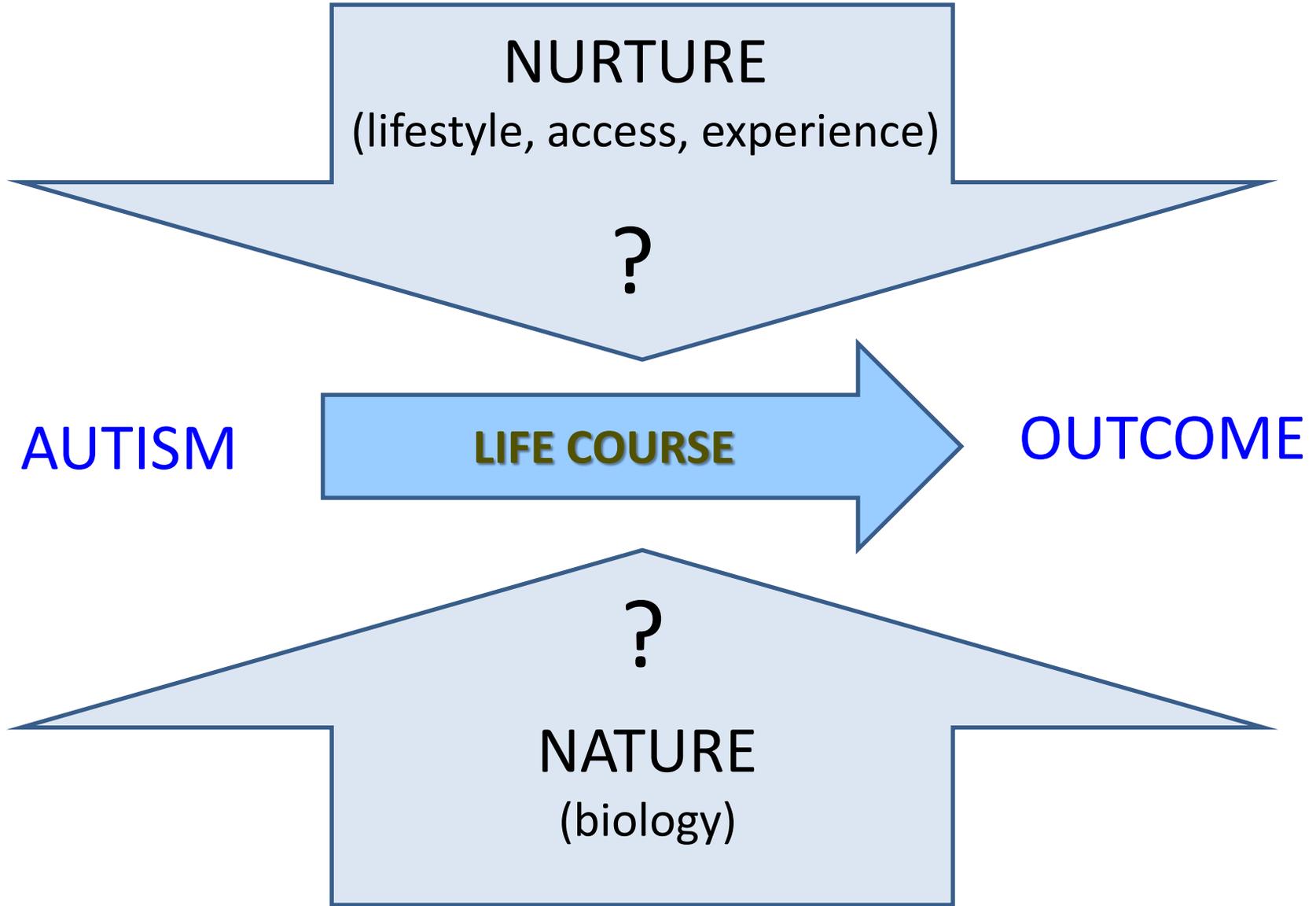
## The health status of adults on the autism spectrum

Autism  
2015, Vol. 19(7) 814–823  
© The Author(s) 2015  
Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/1362361315577517  
aut.sagepub.com  


Lisa A Croen<sup>1</sup>, Ousseny Zerbo<sup>1</sup>, Yingge Qian<sup>1</sup>, Maria L Massolo<sup>1</sup>,  
Steve Rich<sup>2</sup>, Stephen Sidney<sup>1</sup> and Clarissa Kripke<sup>3</sup>



replicated and extended by Hand et al.; Autism (2020); and, DaWalt, Taylor et al., Autism Research (2021)



NURTURE

(lifestyle, access, experience)

?

AUTISM

LIFE COURSE

OUTCOME

?

NATURE

(biology)

# The interaction between ASD and PD

An autistic man had an active and independent life, although he was noted to get upset with any changes in his routine or environment. His routine included morning coffee at a local restaurant. However, with the onset of PD, severe tremor resulted in his being unable to drink his coffee without spilling it, leading to behavior outbursts and ultimately resulting in a substantial disruption of his schedule and notably diminished level of function.

An autistic man with high support needs, living in a group home, had always been able to feed and dress himself. With the onset of a severe tremor he became fully dependent on care by others leading to chronic irritability, frustration and behavioral upsets that required frequent interactions by his physician and group home staff.

An autistic woman developed akinetic-rigid PD with poor balance, frequent falls and a shuffling gait. As a result of an exaggerated fear of falling she became reclusive and developed agoraphobia (fear of open spaces) and panic attacks and her level of function diminished considerably. She was misdiagnosed by a local physician as having a late-onset psychosis. Later, treated with an anxiolytic medication she returned to her baseline level of function.

# Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda (2011)

*Joseph Piven, MD,\* and Peter Rabins, MD,† on behalf of the Autism-in-Older Adults Working Group*

JOURNAL OF THE  
AMERICAN  
GERIATRICS  
SOCIETY



## 2 day meeting in Chapel Hill, North Carolina (2010)

funded by the Ireland Family Foundation

### Autism Experts

Peter Bell  
Elizabeth Berry-Kravis  
Jim Bodfish  
Joe Coyle  
Geri Dawson  
Susan Folstein  
Eric Fombonne  
Lisa Gilotty  
Susan Hyman  
Cathy Lord  
David Mandell  
Declan Murphy  
Mary Van Bourgondien  
Joe Piven

### Geriatrics/Aging Experts

Kitty Buckwalter  
Chris Callahan  
Harvey Cohen  
Peggy Dilworth-Anderson  
Jovier Evans  
Fen-Biao Gao  
Kelly Giovanello  
Daniel Kaufer  
Constantine Lyketsos  
Mary Lynn Piven  
David Riddle  
Alexander Troster  
Peter Rabins

### Developmental Disabilities in Older Adults

Tamar Heller  
Wayne Silverman  
Carl Tyler

### Multi-Disciplinary

- clinicians/researchers
- physicians; med, psych, neuro
- psychologists
- nurses
- basic scientists:
- sociologists
- policy makers
- family members

**RECOMMENDATIONS:** *Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda*

*Joseph Piven, MD,<sup>\*</sup> and Peter Rabins, MD,<sup>†</sup> on behalf of the Autism-in-Older Adults Working Group*

J American Geriatrics Society (2011)

- 1. Screening, Diagnosis and Assessment**
- 2. Cross-sectional and Longitudinal Description**
  - behavioral phenomenology
  - associated medical and psychiatric features
- 3. Biology: clinical and basic science studies**

ASD is heterogeneous - 20% with identifiable etiology.
- 4. Services/Intervention/Long term Care**
- 5. Capacity Building: Training/ Research and Clinical**

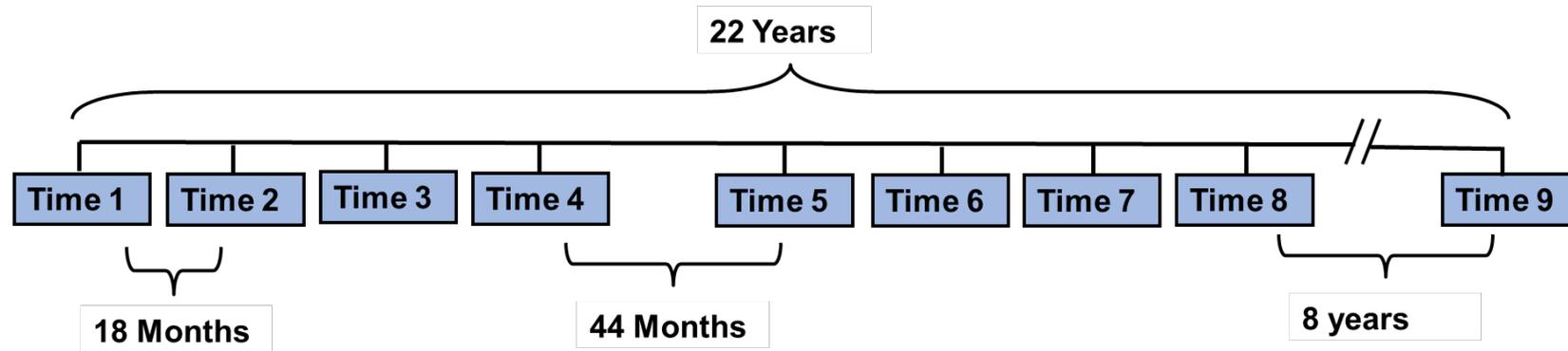


There is an urgent need to  
**fill  
the  
knowledge  
gap**

in research, training and clinical services  
for older adults with autism

# Adolescents and Adults with Autism Study (n=406)

Funding: National Institute on Aging, NIMH, Autism Speaks



- 9 rounds of data collection
  - Age 10-52 at Time 1, average age = 22
  - Birth years: 1946 to 1988
- *Looking forward* to track change prospectively
- *Looking back* to identify predictors of mortality

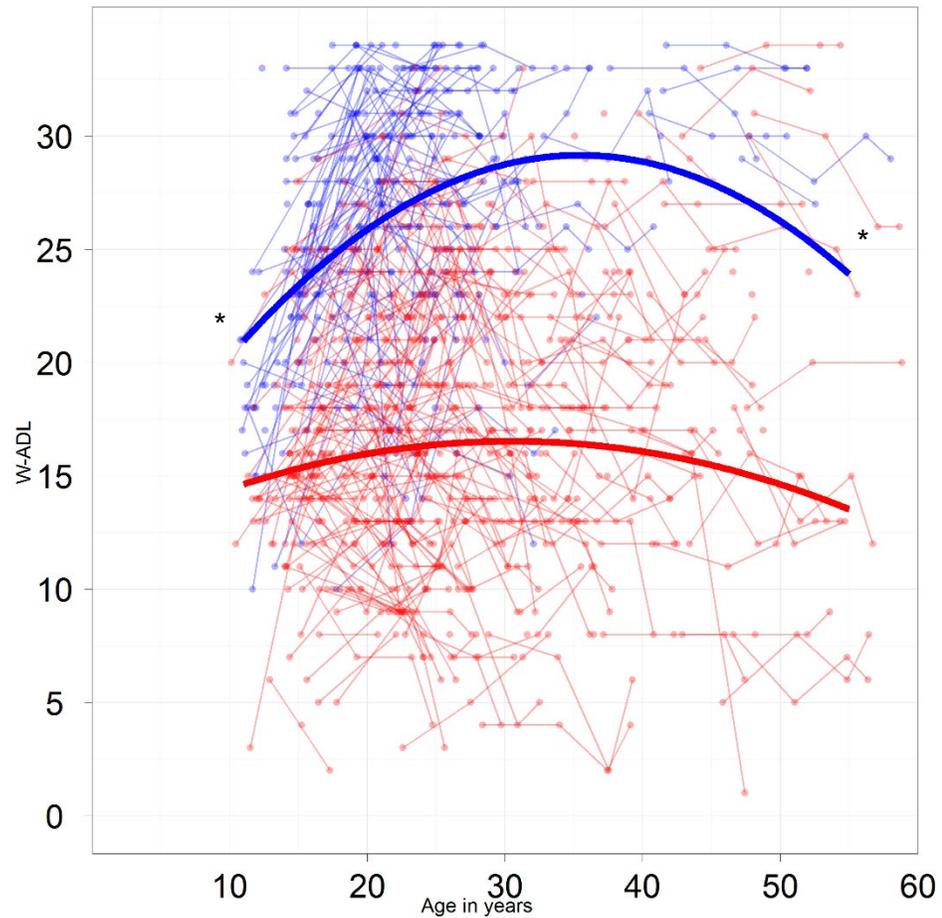
# Time 1 Characteristics

- 73% male
- 65% living with parents
- 74% verbal (use of 3+ word phrases)
- 95% diagnosed with Autistic Disorder
  - All would be considered to have autism using today's diagnostic standards.
- 70% had ID (highest IQ in cohort is 142)
- 51% had co-occurring mental health diagnoses
- Health rating
  - Excellent            35.7%
  - Good                 49.3%
  - Fair                  13.0%
  - Poor                  2.0%

## *Looking Forward Over 2 Decades*

- Changes in indicators of aging over 2 decades to learn how autistic adults change from adolescence through midlife and older age.
- One indicator – activities of daily living (ADLs)
- Differences between those with and without ID
- Is the same trend evident for people with Down syndrome?

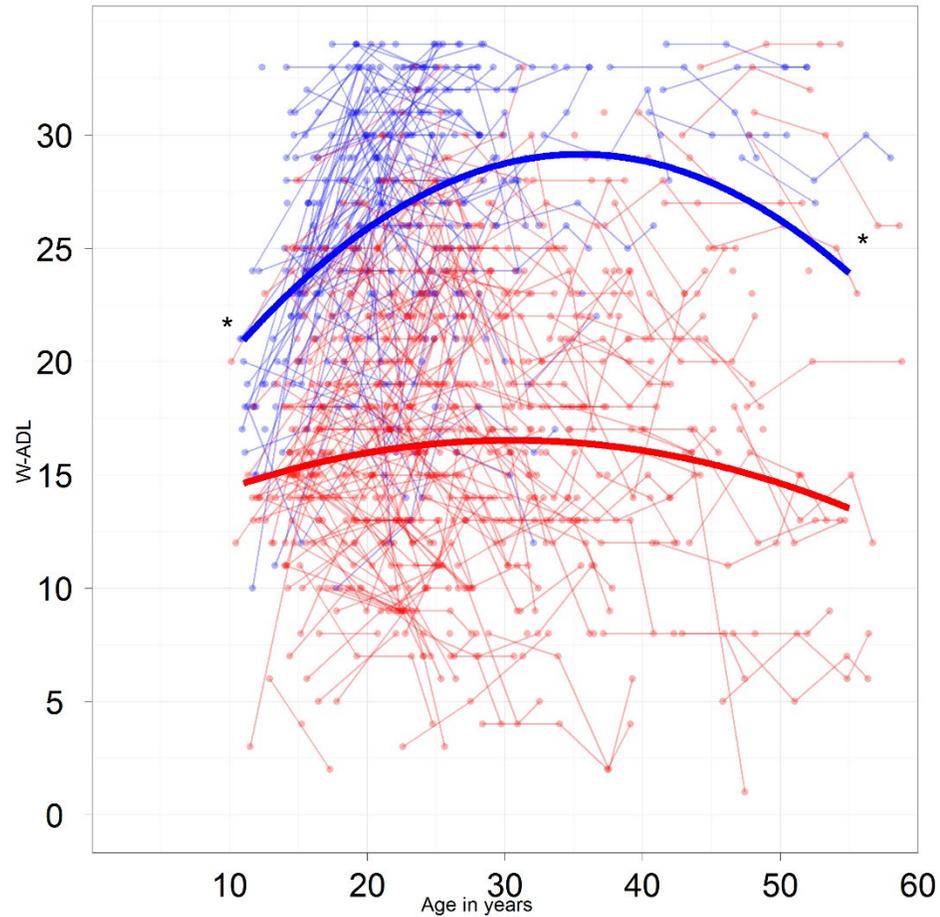
## Activities of Daily Living: Autism



\* **ASD, no ID**  
**ASD and ID**

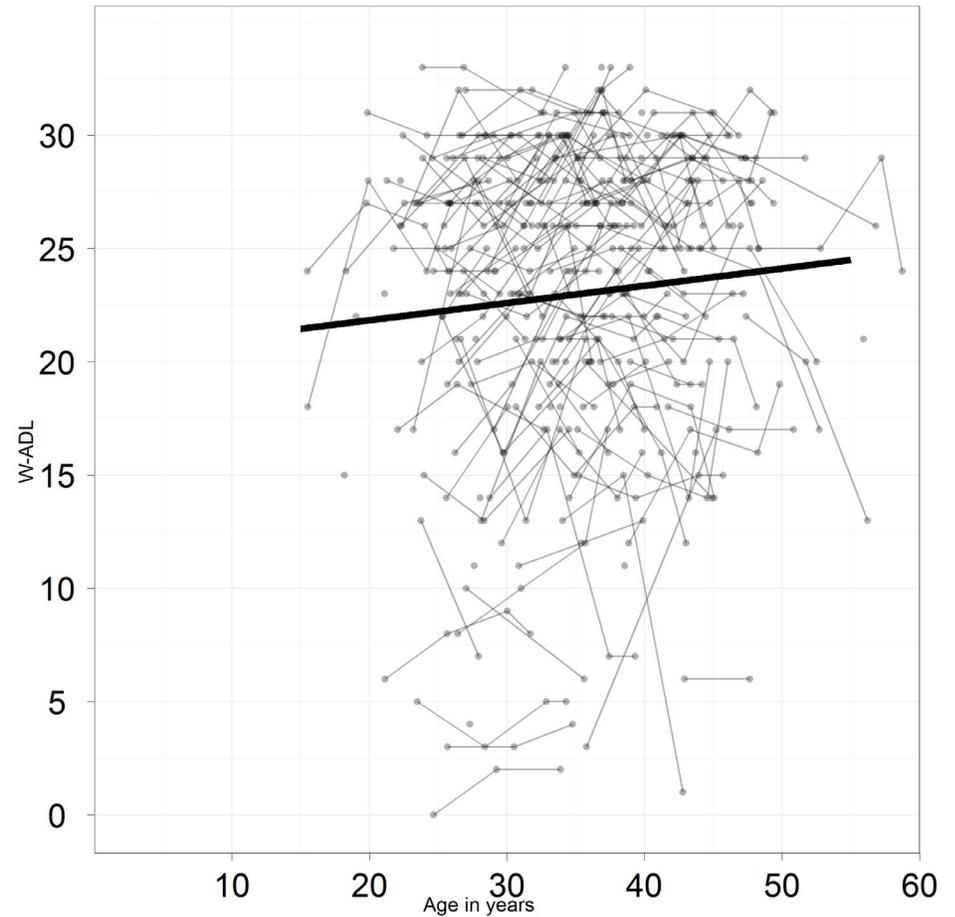
Smith, Maenner, Mailick Seltzer, *Journal of the American Academy of Child and Adolescent Psychiatry*, 2012

## Activities of Daily Living: Autism



\* **ASD, no ID**  
**ASD and ID**

## Activities of Daily Living: Down Syndrome



Smith, Maenner, Mailick Seltzer, *Journal of the American Academy of Child and Adolescent Psychiatry*, 2012

# Is Midlife a Period of Risk for Autistic Adults?

- Population studies have found that adults with ASD have a shorter than average lifespan – by about 20 years.

Hirvikoski et al. (2016) – Sweden

Bishop-Fitzpatrick et al. (2018) – Marshfield WI

## Question 2: *Looking Back*

- 26 adults died during the AAA study period (through 2019; 6.4% of cohort)
- Average age at death = 39 years (18-65 years)
- Causes of death
  - Cardiac (5)
  - Cancer (5)
  - Respiratory (3)
  - Seizures (3)
  - Accidents (3)
  - Medication side effects (2)
  - Unknown (5)

# What Risk Factors Predict Mortality?

Not surprising - **older age and worse health** predicted mortality.

But **sex and ID status** did NOT predict mortality.

Above and beyond age, health, sex, and ID status:

**Activities of daily living skills** - for every 1-point lower on ADL measure at Time 1, **9%** increased risk of death during the study

**Impairments in social reciprocity** - for every 1-point higher on impairments during early childhood, **26%** increased risk of death during the study

*Are these patterns due to barriers to health care and services, or inherent to autism – or both?*

## After the Mother's Death (n=22)

*“In caring for him, family, friends and institutions have frequently let us down. We're on our own with him. **The great fear is: “What happens when we're gone?”**”*

- **Primary source of family support:**

sibling (n=12), father (n=4), none (n=6)

- **Where do these adults live?**

group home or other service setting (n=13)

with father (n=1)

with sibling (n=2)

alone independent (n=2)

alone with support (n=2)

college dorm (n=1)

missing data (n=1)

# Proposed Research Agenda on Aging and Autism

- Need to include **underserved and diverse populations** in longitudinal cohort studies of midlife and older autistic adults
- Study of **how having autism affects aging** (stress, genetics, limited access to health care, long-term polypharmacy)
- How autistic individuals cope with **aging-related loss and grief**
- **Multiple voices** – autistic adults, family, researchers, policy makers
- **We have just begun to understand aging in autism.**
- **This life stage is likely to be as highly complex as earlier life stages – *complexities on top of complexities.***

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# Committee Discussion



# Round Robin Updates



# Closing Remarks

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

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

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





## Upcoming Action Items

- November 2022: Review the current draft of the *Strategic Plan* and provide feedback on missed items via survey
- December 2022 – January 2023: Provide final comments on the forthcoming revised draft of the *IACC Strategic Plan*
- October 2022 – January 2023: Continue submitting nominations for the 2022 *IACC Summary of Advances*
- Next IACC Full Committee Meeting: January 18, 2023 (virtual or hybrid TBA)

# Thank you to the OARC Staff!



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# Adjournment

Thank you for joining us for today's IACC meeting.

<https://iacc.hhs.gov>

