Minutes of the Interagency Autism Coordinating Committee (IACC)

Full Committee Meeting

October 26, 2022

January 18, 2023

This meeting summary was prepared by Rose Li and Associates, Inc., under contract to the National Institute of Mental Health (NIMH). The views expressed in this document reflect both individual and collective opinions of the meeting participants and not necessarily those of NIMH. Contributions to this summary by the following individuals is gratefully acknowledged: Carrie Perkins, Rebecca Lazeration, Nancy Tuvesson

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a virtual meeting on Wednesday, October 26, 2022 from 10:00 a.m. to 5:00 p.m. In accordance with Public Law 92-463, the meeting was open to the public. Joshua Gordon, M.D., Ph.D., Director, National Institute of Mental Health (NIMH), chaired the meeting.

Participants

Joshua Gordon, M.D., Ph.D., *Chair*, IACC, NIMH; **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), NIMH; **Courtney Ferrell Aklin**, Ph.D., National Institutes of Health (NIH) (representing Lawrence Tabak, D.D.S., Ph.D.); **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA) (representing Anita Everett, M.D., D.F.A.P.A); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara L. Tucci, M.D., M.S., M.B.A., F.A.C.S.); **Sam Crane**, J.D., Quality Trust for Individuals with Disabilities; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Tiffany Farchione**, M.D., Food and Drug Administration; **Dena Gassner**, M.S.W., Adelphi University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Morénike Giwa Onaiwu**, M.A., Rice University; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Craig Johnson**, B.A., Champions Foundation; **Alice Kau**, Ph.D., NICHD (representing Diana Bianchi, M.D.); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Richard Woychik, Ph.D.); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/ Trainer; **Scott Patterson**, Ph.D., U.S. Department of Veterans Affairs (VA) (representing Matthew Miller, Ph.D., M.P.H.); **Jenny Mai Phan**, Ph.D., Children’s National Hospital; **Joseph Piven**, M.D., University of North Carolina—Chapel Hill; **JaLynn Prince**, B.F.A., Madison House Autism Foundation; **Amanda Reichard**, Ph.D., Administration for Community Living (ACL) (representing Jennifer Johnson, Ed.D.); **Susan Rivera**, Ph.D., University of Maryland; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL) (representing Taryn Mackenzie Williams, M.A.); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC) (representing Georgina Peacock, M.D., M.P.H., F.A.A.P.); **Matthew Siegel**, M.D., Tufts University; **Ivanova Smith**, B.A., University of Washington; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Hari Srinivasan**, Vanderbilt University; **Jodie Sumeracki**, B.A., Centers for Medicare & Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D, Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Stephen Whitlow**, J.D., Gateway Transition Center; **Nicole Williams**, Ph.D., Department of Defense (DoD); **Taryn Mackenzie Williams**, M.A., DOL

Welcome and Announcements

***Susan A. Daniels, Ph.D., Director**, OARC, NIMH; Executive Secretary, IACC; and Acting National Autism Coordinator*
***Joshua Gordon, M.D., Ph.D.**, Director, NIMH and Chair, IACC*

Dr. Susan Daniels and Dr. Joshua Gordon introduced the meeting, which took place during National Disability Employment Awareness Month (NDEAM). Dr. Daniels thanked everyone who participated in the *IACC Strategic Plan* Working Group Meeting, adding that the recordings from that meeting are available on the IACC website.

The Committee voted to approve the April 2022 minutes.

Recognition of National Disability Employment Awareness Month (NDEAM)

***Anupa Geevarghese, Esq.**, Chief of Staff, Office of Disability Employment Policy, U.S. Department of Labor*

The Office of Disability Employment Policy (ODEP) in the U.S. Department of Labor (DOL) is the only non-regulatory federal agency that promotes policies and coordinates with employers and all levels of government to increase workplace success for people with disabilities. The goals of ODEP are to improve access and opportunity and advance workforce inclusion for diverse people with disabilities through policy change and outreach.

The origins of NDEAM trace back to 1945, when Congress declared the first week of October to be "National Employ the Physically Handicapped Week." In 1962 the celebration was expanded to promote the employment of all people with disabilities, and in 1988 to span the entire month of October. This year's theme, "Disability: Part of the Equity Equation," fits perfectly with IACC's emphasis on supporting diversity, equity, and inclusion and accessibility to improve quality of life. Neurodivergent people face major barriers to attaining and maintaining jobs that align with their interests, strengths, and skills. Many people with autism spectrum disorder (ASD) remain unemployed or underemployed and lack access to resources that would help them find gainful employment.

The Biden Administration has demonstrated its commitment to increasing accessibility for diverse job seekers through the president's executive order on diversity, equity, and inclusion and accessibility (DEIA) in the federal workforce. For example, the Good Jobs Initiative, led by DOL, provides critical information to workers, employers, and government entities as they work to improve job quality and create access to good jobs, and the ODEP-funded Partnership on Inclusive Apprenticeship collaborates with employers to design inclusive apprenticeship programs. Furthermore, in early October, ODEP hosted an employer chat on workplace mental health and wellbeing, which included remarks from Secretary of Labor Marty Walsh, Assistant Secretary of Labor for Disability Employment Policy Taryn Williams, and industry, advocacy, and labor movement leaders. Finally, ODEP's Employer Assistance and Resource Network on Disability Inclusion (EARN) provides technical assistance for employers, and the Job Accommodation Network (JAN) features information and resources on how to support workers with disabilities.

Update on Autism-Related Research at Mathematica

Scott Michael Robertson*, Ph.D., Senior Policy Advisor, ODEP, DOL*
Ankita Patnaik, Ph.D.*, Senior Researcher, Mathematica*
Paul Shattuck, Ph.D.*, Senior Fellow, Mathematica*

Introduction

Dr. Scott Michael Robertson introduced Dr. Ankita Patnaik and Dr. Shattuck. He described ODEP's investment in researching support services for young adults on the autism spectrum. The Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS) project is ODEP's biggest investment to date.

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

About Mathematica

Established in 1968, Mathematica is an employee-owned policy research company that aims to improve the lives of citizens through rigorous research that informs public policy, from education to public health. The disability unit at Mathematica, which has more than 20 years of experience researching autism, is staffed by dozens of researchers who are experts in disability research and policy. The unit's past and present projects align closely with the *IACC Strategic Plan*. For example, regarding Question 6, "How can we meet the needs of people with ASD as they progress into and through adulthood," the unit has recently conducted the following research: HRSA Autism Transitions Research Project, 2017-2027; Next Generation of Enhanced Employment Strategies (NextGen); Promoting Readiness of Minors in Supplemental Security Income Evaluation (PROMISE); and the REYAAS Project.

REYAAS Project

The ODEP-funded REYASS Project aims to understand the barriers and facilitators that young adults face as they transition from school to work, identify specific policies or programs that have been shown to facilitate employment, identify and fill gaps in the research literature, and suggest new evidence-building activities. To achieve these goals, the project develops knowledge through literature reviews, listening sessions, and discussions; analyzes existing data; evaluates design options and recommendations; surveys young adults and stakeholders; and disseminates findings and insights.

REYAAS researchers recently conducted two large literature reviews to understand the nature and effectiveness of existing programs that support employment of young adults with ASD. The most common strategies used by the 140 programs identified include soft skills training, coaching or mentoring, and job search assistance, job development, or job training. Very few programs focus on mental health support, occupational training, assistive technology, and employer support or training. REYASS researchers found five randomized controlled trials (RCTs) and one quasi-experimental study that evaluated the effectiveness of these programs. Three of the five RCTs centered on young people with autism who participated in the Project SEARCH plus ASD Supports program, a transition-based employment model for high school students on the autism spectrum. The program showed promising results; young people who participated in the program were more likely to be employed than people in the control group, who did not participate. Similarly, the other two randomized controlled trials, which centered on virtual interview training, showed that participants secured competitive integrated employment (CIE) at higher rates than non-participants. The quasi-experimental study found an association between receiving supported employment services and attaining CIE for young adult vocational rehabilitation (VR) clients with intellectual or developmental disabilities (IDD).

In spring 2022, REYAAS hosted listening sessions with 100 young adults with ASD, who could participate through full video, chat-only, audio-only, and email-only—and anonymously. Additional listening sessions featured advocates, policy makers, educators, and researchers from across the United States.

The listening sessions uncovered numerous barriers to employment for young people with ASD:

- Challenges in finding jobs and a good work environment
- Biases in the typical recruitment and interview processes
- Insufficient supports and services
- Limited capacity to generate and scale services.

The listening sessions also highlighted numerous facilitators to employment:

- Encouragement and advice from family members, friends, and staff at job readiness programs; paid internships, career mentoring, and customized employment
- Cultural shifts and training for employers to encourage inclusive recruitment, hiring, and work environments
- Greater collaboration and funding for needed supports
- Partnering with neurodivergent consultants or career coaches with disabilities
- Coordination with large, established programs

REYAAS recognizes that quality data are needed to build evidence on the needs, barriers, and facilitators of employment for young adults with ASD. Its researchers scanned existing survey and administration data to identify sources that included young adults (ages 16-28), information to identify individuals on the autism spectrum, and employment-related measures. Of the 11 data sources identified, many restricted access, several had small sample sizes of people with ASD, and most contained limited employment information. Large datasets did not focus on autism. These findings demonstrate the need for more large-sample representative data on young adults with ASD, including employment data. Although the researchers found no ideal data source for conducting rigorous study of employment in young adults with ASD, they selected a dataset of case service reports from the Rehabilitation Services Administration (RSA-911) for analysis, which is currently in progress.

New questions that REYAAS researchers are currently addressing include the following:

- 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?
- What VR services do young adults on the autism spectrum use? What are employment outcomes of this group?
- How do patterns in referrals and outcomes vary across states, disability types, and demographic subgroups?
- Did patterns in VR applications, service use, and employment outcomes shift during the COVID-19 pandemic?

Analyses are currently underway to address these questions and a report detailing results will be available in early 2023.

Future Directions of Mathematica

In the field of ASD services and policy research, equity and the life course perspective have received too little attention. The life course perspective is prominent in developmental research, and yet is still poorly integrated into applied work. To close this gap, Mathematica will strive to integrate equity and social determinants of health into intervention, policy, and program evaluation. There is also a lack of understanding of the complexity of the service ecosystem experience; those with ASD must simultaneously navigate education, healthcare, employment, housing, and more. Therefore, Mathematica plans to develop a conceptual framework to make already existing programs better serve autistic people. Another gap in knowledge is the extent to which the COVID public health emergency and climate change affect the lives of people with ASD. Mathematica is using big data to better understand this relationship and is currently using Medicaid data to determine the effect of the pandemic on children and adults with ASD who are enrolled in their programs.

Committee Discussion

Ms. Yetta Myrick asked about the level of diversity among REYASS listening session participants. Dr. Patnaik answered that REYAAS researchers cast a wide net through an open call for participants on social media. They captured high diversity, particularly for the stakeholder listening session, with participants hailing from universities throughout the United States. However, they did not systematically collect data on race and ethnicity to avoid discouraging people from participating. Dr. Patnaik will determine whether she can share demographic information that was voluntarily collected.

Ms. Dena Gassner expressed concern that middle-functioning, middle-aged (ages 30-60) people with ASD remain under supported and thus lack gainful employment. Dr. Shattuck offered to discuss this pressing issue with Ms. Gassner during a follow-up conversation.

Ms. Lindsey Nebeker asked about the percentage of autistic youth who have high support needs and have participated in existing Mathematica studies. Dr. Patnaik answered that such studies lack information on the support needs of autistic young adults. However, Mathematica may conduct surveys in the future that will capture the spectrum of support needs.

National Autism Coordinator Update

Susan A. Daniels, Ph.D.*, Director, OARC, NIMH; Executive Secretary, IACC; and Acting National Autism Coordinator*

Dr. Daniels highlighted the following recent autism-related activities in the nonprofit sector, academia, and federal government:

Nonprofit Organizations and Universities

- The State of the States in Intellectual and Developmental Disabilities Project of National Significance and The University of Kansas Center on Excellence in Developmental Disabilities launched the Black Feathers podcast, which will feature discussions of disability-related topics of interest to Tribal communities through data, storytelling, and innovative content.
- The Autism Science Foundation launched the Participate in Research Directory to help people with ASD and their families to find and more easily enroll in autism research studies.
- In October 2022, the Stanford Neurodiversity Summit brought together neurodiverse/neurodivergent people, their family members and friends, educators, clinicians, researchers, and other stakeholders to share visions and innovations related to how neurodiversity can make our society better.
- In June 2022, Autism Speaks hosted a virtual summit of autistic adults, families, researchers, and policymakers to discuss the issues facing autistic adults as they age.
- The Association of University Centers on Disabilities will hold the 2022 Conference Health Equity: Serving the Whole Person on November 13 – 16, 2022.

Federal Government

- The White House celebrated NDEAM through a Presidential Proclamation. OARC/IACC created a page to share NDEAM news, events, and resources.
- Two key Executive Orders (EO) were issued in 2021 to advance Federal efforts DEIA. EO 13985 "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government" resulted in the formation of the Equitable Data Working Group, which released its vision and recommendations for advancing use of equitable data in April 2022. EO 14035 "Diversity, Equity, Inclusion, and Accessibility in the Federal

Workforce" established a DEIA Initiative, which produced a *Government-wide Strategic Plan to Advance DEIA in the Federal Workforce (Governmentwide DEIA Plan)*.

- In July 2022, the Assistant Secretary for Planning and Evaluation (ASPE) published *Improving Data Infrastructure for Patient-Centered Outcomes Research for People with ID/DD*.
- In September 2022, NIH announced that it has awarded $100 million over the next 5 years to support nine Autism Centers of Excellence.
- The Interagency Committee on Disability Research released a new toolkit titled "Getting the Most Out of Stakeholder Engagement: A Toolkit to Better Understand and Measure Engagement" and held four webinars, including one on "Understanding and Responding to the Cultural and Linguistic Differences in the Conduct of Disability Research."
- In September 2022, the RAISE Family Caregiving Advisory Council published the *2022 National Strategy to Support Family Caregivers*, which will be updated in response to public comments and held its second joint meeting with the Advisory Council to Support Grandparents Raising Grandchildren.
- In October 2022, the Federal Partners in Transition Working Group held the "My Future Matters Symposium" to consider future policy considerations for youth and young adults with disabilities transitioning into the workforce.
- During its first meeting in July 2022, the President's Committee for People with Intellectual Disabilities discussed home- and community-based services (HCBS), employment, education, housing, and the direct support professional workforce crisis.
- During its quarterly business meeting in July 2022, the National Council on Disability heard public comment on the April Supreme Court decision *Cummings v. Premier Rehab Keller, P.L.L.C.*, and discussed proposed additions to its Health Equity Framework.
- AHRQ announced that they were seeking public input about person-centered care for people at risk for, or living with, multiple chronic conditions (MCC). Public comments were due November 15. The Interdepartmental Serious Mental Illness Coordinating Committee will meet on October 28 at 10:00 a.m. ET
- The Disability Advisory Committee will meet on November 1 at 1:00 p.m. ET.

IACC Committee Business

***Susan A. Daniels, Ph.D.**, Director, OARC, NIMH; Executive Secretary, IACC; and Acting National Autism Coordinator*

Update on the *IACC Portfolio Analysis Report*

The *IACC Portfolio Analysis Report*, which provides comprehensive information about autism research funding across federal agencies and private research organizations in the United States, monitors progress toward *IACC Strategic Plan* objectives and budget recommendation, provides analysis of funding trends over time, and tracks funding toward special topics of interest. OARC is in the final stages of preparing the *2019-2020 IACC Portfolio Analysis Report* and is currently preparing the 2021 Report.

Update on the *Summary of Advances*

The *2020 Summary of Advances*, an annual report required by the Autism CARES Act of 2019, was published in June 2022. The report provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, selected by the IACC. For the first time, OARC also prepared an easy-read version. The timeline for development of the *2021 Summary of Advances* is provided in Table 1.

Table 2. Timeline for Development of *2021 Summary of Advances*.

Timeframe	Action
July-Dec 2021	IACC members nominated articles
April 2022	IACC discussed nominations at a committee meeting
Summer 2022	IACC voted on the top 20 articles
Fall 2022	**OARC is drafting the report**
Late Fall 2022	IACC will preview/comment
Early 2023	OARC will finalize the publication

For the 2022 report, IACC members are currently nominating articles (October 2022-January 2023) and final publication is expected for spring 2023.

Committee Discussion

Ms. Gassner expressed concern that qualitative research that can inform larger, quantitative studies can be overlooked in the search for the 20 top articles for the *Summary of Advances*. In particular, she referenced a dissertation by Dr. Katie Savin on the experiences of people who live below the poverty line and must resort to sex work and bartering to survive. Dr. Daniels commented that the dissertation could be considered if published in a peer-reviewed journal; and that qualitative research is welcome if it is published in a peer-reviewed journal.

Update on *2021-2022 IACC Strategic Plan*

The *IACC Strategic Plan for Autism Research, Services, and Policy* moves innovative research forward and fosters development of high-quality services for autistic people. The timeline for development of the *2021-2022 Strategic Plan* is provided in Table 2. Throughout the process, public comments have been reviewed for incorporation into the Plan.

Table 2. Timeline for Development of *2021-2022 IACC Strategic Plan*

Timeframe	Action
Oct.-Nov. 2021	OARC solicited public input on the Plan via a Request for Information (RFI).
Jan. 2022	OARC presented RFI results during the January 2022 IACC Meeting.
Nov. 2021-March 2022	OARC collected input on the Plan from IACC members via a survey.
April 2022	OARC presented survey results during the April 2022 IACC meeting.
April-June 2022	OARC prepared the first draft of the Strategic Plan.

June 2022	The Strategic Plan Working Group convened to discuss the first draft.
July-Sept. 2022	OARC collected input on the Plan from IACC members via a second survey.
Oct. 2022	**OARC sent a second draft of the Plan to IACC members, for discussion during the October 2022 IACC meeting.**
Nov. 2022	IACC members may submit feedback on the second draft.
Dec. 2022	OARC will send a revised draft to IACC members for review.
Jan. 2023	IACC members will vote to approve the Strategic Plan during the January 2023 IACC meeting.

This 2021-2022 version of the Plan will include major research, services, and policy issues; reflect the increased need for inclusion in research, including community-based participatory research; address the whole spectrum and whole lifespan, including for those with high support needs; emphasize a commitment to equity and reducing stigma, disparities, and discrimination; provide an update on research portfolio and budget recommendations; and describe major federal activities and initiatives and interagency coordination.

Committee Discussion

Members of the Committee expressed that mental health concerns should be incorporated into the Plan, as there is an increased frequency of such concerns in autistic people. Additionally, autistic people are often left out of conversations about mental health and disability. Members also expressed that the Plan must consider the impact of misdiagnosis and maltreatment on mental health and that care must be trauma informed. Additionally, members discussed the need for further research on pharmacology, including differences in how autistic people process medication and the development of medications to address underlying causes of self-injurious behavior (SIB) and other challenging behaviors. A Committee member asked if considering the variation in intellectual functioning could also be considered as a cross-cutting theme.

Dr. Jennifer Johnson shared that Administration for Community Living (ACL) has launched a national center on co-occurring mental health disabilities and ID/DD and supports five state teams working to breakdown silos in service systems.

Dr. Daniels concluded the discussion by sharing the revised mission and vision and core values, which were first created in 2009. Dr. Daniels also shared the top 3 priority topics selected by the Committee via an e-mail selection process for highlighting in the research budget section of the Plan: 1) lifespan issues, 2) evidence-based interventions and services, and 3) research on disparities and development of culturally competent tools.

Public Comment Session

Joshua Gordon, M.D., Ph.D., Director, NIMH and Chair, IACC
Susan A. Daniels, Ph.D., Director, OARC, NIMH; Executive Secretary, IACC; and Acting National Autism Coordinator

Oral Comments

Ms. Shannon Des Roches Rosa is the parent of an autistic adult who requires full-time support and supervision and a Senior Editor of the Thinking Person's Guide to Autism. Ms. Rosa commented that the medical community seems unaware that autistic people can have atypical reactions to commonly prescribed medications, such as not reacting to or being overstimulated by sedating drugs. Autistic people often require sedation to tolerate medical procedures, such as dental exams and MRIs, yet sedation is rarely covered by insurance, raising issues of health care access and outcomes that warrant study. Also needed is research on competing sensory and access needs and evaluation methods for individual sensory profiles. Students with competing needs are often inapproproiately placed in the same classroom. Another need is the development of approaches to improve access to autism diagnoses across age, gender, class, and racial gaps, because misdiagnoses often lead to anxiety, depression, isolation, poverty, and suicidality; and the transition from the school system into adulthood, especially for autistic people with the highest support needs. Ms. Rosa also commented on a complete lack of appropriate local adult programs, which is exacerbated by a direct support worker shortage and deprives adults with autism of the support they need, deserve, and have been allocated. Finally, she expressed appreciation for the inclusivity of IACC's membership, because an advisory committee can not be effective if it does not reflect and fully understand the population for whom it is responsible.

Ms. Judith Ursitti is Vice President of Government Affairs for the Council of Autism Service Providers (CASP), a nonprofit trade association composed of autism service providers. She requested that the *Strategic Plan* prioritize generally accepted standards of care, such Applied Behavior Analysis (ABA), to ensure that quality, evidence-based approaches are delivered across the lifespan. CASP launched an accreditation program to support this effort.

Dr. Amy Lutz from the National Council on Severe Autism (NCSA) expressed concern at recent efforts of the IACC to use neutral language in its *Strategic Plan* and discussions about autism. She stated that the brain differences in autism-and their effects on individuals and family members in all aspects of and throughout lives—are not neutral. She added that the shortage of care options and providers to treat the surging population disabled by autism is also not neutral. Dr. Lutz urged the IACC to fully include all realities of autism, especially its most "severe manifestations," and to focus on community priorities using language that accurately and meaningfully captures the community's needs.

Ms. Amy Montimurro described STeP, a supported typing program launched by Abilis, a Connecticut nonprofit. STeP strives to build a community of typers and well-trained facilitators using best practices to ensure that typed words reflect a person with autism's own authentic voice. In response to COVID, STeP began to offer online coaching, training, social groups, and workshops, expanding its reach to 18 states and five countries. Abilis clients and their families often describe the significant life changes that occur when someone learns to type to communicate. However, many school districts rely on dated, limited, and flawed research to deny access to typing support methods—even though parents and therapists have demonstrated successful communication when an autistic child is paired with a trained communication partner. Abilis requests that the IACC acknowledge the current use and value of some forms of Augmentative and Alternative Comunication (AAC)—such as facilitated communication (FC), rapid prompting method (RPM), and spelling to communicate (S2C)—and consider the following research opportunities: How can we better identify individuals who benefit from FC, RPM, and S2C? How do individuals with a communication partner learn independence? And how can we measure the cognitive and social-emotional growth of typers and the impact on independent life skills?

Ms. Rieko Shepard from the Autistic Women and Nonbinary Network (AWN), shared a comment cowritten by the Autistic People of Color Fund. She commented that when research studies do not include or focus on diverse autistic populations, their findings can be misinterpreted as indicating a lower prevalence of autism, which can lead to underfunding services that could best support and respond to the specific needs of marginalized communities. AWN urges the IACC to prioritize the following research, informed and led by autistic principal and co-principal investigators: (1) the impact of racism and anti-immigrant discrimination on the mental health of autistic people; (2) the prevalence of school exclusions and court involvement for autistic students of color; (3) health disparities focused on autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees, with a goal of developing guidelines and standards in cultural competency and communication access; (4) prevalence of housing instability for autistic people; (5) employment rates for autistic people, with a goal of developing strategies for increasing CIE; (6) the effects of linguistic and cultural barriers on autistic immigrants and refugees adjusting to life in the United States; (7) the negative repercussions or permanent punishments for formerly incarcerated autistic people, including but not limited to housing and educational options or health outcomes; and (8) access to AAC. Research into topics 4-8 should include additional demographic analysis across race, LGBTQ+ status, and immigrant and or refugee status.

Mr. Elliot Gavin Keenan, a doctoral candidate at UCLA and a visiting scholar at Stony Brook University, studies autism and is also autistic. He was diagnosed at age 6 as "high functioning"—a metric, along with low functioning and severely autistic, that he described as arbitrary. Mr. Keenan stated that his diagnosis was, in important and meaningful ways, a lie. He has bipolar I disorder, which shares many of the genes that have been identified as causing autism. He described several of his life experiences with these conditions, including 20 hospitalizations in a locked inpatient psychiatric unit, inability to live independently, and chronic suicidality. He commented that many conditions are comorbid with autism and should be considered in assessments of functioning. Mr. Keenan requested that the IACC consider the role that comorbid conditions play in the severity or support needs of autism and how functioning categories may be misleading, and the need to study comorbid conditions in autism across all levels of functioning.

Summary of Written Public Comments

Dr. Daniels shared that 111 written public comments were submitted. Of these comments, 43 comments focused on research and service needs, resources, and policy implications; 15 on research, services, and supports for adults with autism; 5 on AAC; 6 on inclusion of autistic perspectives in research; 9 on co-occurring mental health conditions and negative life experiences; 11 on addressing the needs of autistic individuals with high support needs; 5 on concern about medical practices; 5 on the role of IACC and the federal government; 4 on potential causes of autism; 4 on employment; 3 on increasing autism acceptance and reducing stigma; and 1 on wandering and safety. She acknowledged that the committee had received the comments and had an opportunity to read the, and then opened the committee discussion.

Committee Discussion

Dr. Gordon stated that comments will inform updates to the *Strategic Plan.* Ms. Gassner championed the comments surrounding a meaningful life experience across the autism spectrum after school age, including those who are unable to work fulltime. She highlighted the comments on immigrant needs, homelessness, and health care access. Dr. Robertson further championed the topic of homelessness as an issue that warrants additional attention at later IACC meetings.

Dr. Alison Marvin acknowledged the comment about difficulties with receiving Social Security Administration (SSA) support but emphasized that SSA is only administering the law and is unable to directly address policy. Individuals unhappy with the way SSA supports work need to contact policy makers to enact meaningful change.

Use of Language

Regarding the comments about the language used in the *Strategic Plan*, Dr. Robertson emphasized that the language used by the IACC reflects evidence-based practice and agency DEIA. He stated that research data show the benefits to autistic people and those around them of using inclusive, unbiased, strengths-based language. Language and content are being aligned with this current research to better provide the valued perspective of researchers and autistic individuals with lived experience.

In addition, several IACC members championed the use of compassionate and dignified language that is respectful of the human condition. Mx. Morénike Giwa Onaiwu emphasized that all people on the spectrum should be discussed and described in a respectful, non-stigmatizing manner and receive the personalized level of support and resources needed, regardless of their level of functioning. They emphasized that language that is considered by some as basic, accurate, and meaningful often comes across with highly negative connotations to autistic people, which may undermine the IACC's message. One example is "risk for autism," which suggests that autism is negative or associated with danger. . Dr. Alycia Halladay emphasized that accurate and acceptable terminology is a complex issue that must address a variety of factors, including person versus identity first.

Services for People with High Support Needs

Several members of the Committee appreciated comments on functional support needs, such as medication supports and HCBS. Ms. Prince championed the comments regarding the lack of services available for families to help individuals with high support needs. Ms. Prince shared how autistic individuals often must leave their home or community when their family members can no longer monitor and administer medication. Many of these individuals move to care facilities that can provide appropriate medication support but fail to meet social and mental needs, lowering the individuals' chances of regaining independence. As an alternative option to institutions, families may consider paid home-based support that can provide the necessary level of medication and activity of daily living (ADL) support to help autistic individuals remain at home, regain independence, and maintain their connection to their community.

Autism in Older Adulthood: Panel and Presentation

Lived Experience Panel

Yulanda Harris, Ed.D., CNP*, Certified Neurodiversity Professional/CEO, Trainingphase*
Ruth Jones*, Family Member*
Lisa Morgan*, Founder and Co-Chair, Autism and Suicide Committee of the American College of William and Mary, Association of Suicidology*
John Elder Robison*, Neurodiversity Scholar in Residence*
Sue Swezey*, Family Member*

Panelist Experiences on the Challenges of Neurodiverse Aging
Mr. Robison, an autistic adult, shared that autistic individuals often cannot accurately interpret internal communication from their bodies. This "blindness" to cues (e.g., hunger, cold) can lead to missing medication or overstressing the body, and, in turn, injuries that are more difficult to recover from in older age. He also discussed the impacts of diminishing social skills and increasing social isolation, less cognitive flexibility, and concerns around financial support after retirement, especillay as many autistic adults do not hold jobs that provide pensions. He described how the concept of neurodiversity has been helpful to him, as he said it is empowering because it allows you to consider strengths and not just be defined by your deficits.

Ms. Harris, an autistic adult, described how she feels that with increasing age, she is less able to tolerate stress and has challenges masking or code switching. She also described how difficulty in reading social cues can make relationships challenging, and how sometimes when an autistic person appears competent in some areas of life, people assume that same competence in other areas, but that is not always the case. She also described loneliness as a challenge.

Ruth Jones, a sibling of an aging brother with high support needs who lives in a full time care facility. Described the challenges of parents no longer being able to care for their children due t old age or death, the difficulty and lack of guidance for how to help an autistic person with an intellectual disability cope with grief, and the complexity of caregiver succession and guardianship.

Sue Swezey, a parent of an autistic adult with high support needs, talked about the challenges of being and aging parent responsible for the care of an adult child who needs full time care and worrying about what the future holds after she is no longer able to care for him. She mentioned the great need for caregiver supports.

A Brief Overview of Research on Autism in Older Age

***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*
***Joseph Piven, M.D.**, Thomas E. Castelloe Distinguished Professor of Psychiatry Director, Carolina Institute for Developmental Disabilities*

Co-Occurring Conditions and Biology

There has been a near absence of research on autism in older age, despite similar rates of autism among adults and children. In addition, few geriatric researchers have specialized in autism and few autism researchers have studied older adults. Based on the limited research available, older adults with autism have higher rates of Parkinson's disease (200 times the general population) and dementia. Autistic adults also have higher rates of medical and psychiatric conditions, including hypertension, diabetes, obesity, and sleep problems. At this time, researchers are unable to ascertain whether these differences are related to poor care quality, biological factors of autism, life experiences, or a combination of factors.

Adolescence and Adults with Autism Study

Previously, researchers believed that the biological root of autism was brain changes in early childhood. However, emerging evidence suggests that brain changes are not limited to childhood and that specific brain changes occur across adulthood in autistic individuals. To better understand these changes and the differences in aging between the neurotypical and the autistic populations, researchers launched the Adolescence and Adults with Autism study. This study began 22 years ago with nine rounds of data collection on individuals ages 10-52 at the time of enrollment. Researchers sought to track changes prospectively using indicators of aging (e.g., ADLs) and to collect data to identify predictors of mortality.

When researchers explored ADLs for autistic individuals with intellectual disability (ID) versus autistic individuals without ID, they found that both groups gain ADL skills in the earlier years of adulthood but experience a gradual loss of independence around age 35. This non-linear trend is more pronounced among people without ID. These findings contrast with ADL research in individuals with Down Syndrome, who show a linear upward progression of ADLs throughout life, with no equivalent drop in older adulthood.

The study also found that autistic adults have a shorter than average life span (by about 20 years). Although older age and worse health predicted mortality, sex and ID status did not. In addition, impairments in ADLs and social reciprocity were both associated with increased risk of death during the study. For every 1 point scored lower on ADL skills, an individual's risk of death during the study increased by 9 percent. For every 1 point scored higher on impairments of social reciprocity during early childhood, the risk of death increased by 26 percent. It remains unclear whether these results are due to barriers to health care and services, or are inherent to autism.

The study also showed that six of the 22 individuals who experienced a loss of their primary source of family support has no other source of support.

Future Directions

Drs. Piven and Mailick suggested future research should include underserved and diverse populations in longitudinal cohorts of midlife and older adults; investigate the effects of autism on aging and the ability of autistic individuals to cope with aging-related loss and grief; and involve multiple voices including autistic adults, family, researchers, and policy makers. Further, the field has identified a need for (1) screening, diagnosis, and assessment tools for older adults; (2) cross-sectional and longitudinal studies of development of adults with autism; (3) clinical and basic science biology studies of factors related to aging and health; (4) development of services, interventions, and strategies for long-term care; and (5) capacity-building and training for the workforce.

Committee Discussion

IACC members agreed that autistic high school students are often divided into two groups, one on the college track and one that is not. Students in the latter group receive training in maintaining and developing ADL skills, but those in the former group do not, which leaves them unprepared for the experience of living alone and attending college. Committee members also appreciated comments on the need to better understand neurodegenerative disorders and suicide prevention.

IACC members noted the difficulty of enrolling older adults with autism in studies because they are "hidden"—that is, they were diagnosed in older age or were institutionalized with a different diagnosis at a young age. For example, a study by David Mandell found that approximately 10 percent of individuals at one psychiatric hospital had undiagnosed autism. Mr. Robison cautioned the presenters that the data suggesting a difference in mortality between the autistic population and the general population may be inaccurate for this reason.

Dr. Jennifer Johnson stated that ACL funded a project to bridge aging and disability services. The project seeks to prepare a nationwide network of aging programs to better build their capacity to serve individuals with disabilities, including autistic individuals, with a focus on support for families.

Round Robin Updates

Dr. Alice kau shared that the NICHD Centers of Excellence (ACE) program was established in 2007 and is in its fourth iteration. They recently awarded nine ACEs. In the current round of competition, applicants must enhance diverse perspective and community engagement. Each ACE will have an external advisory committee that includes individuals with autism and parents of individuals with autism. Half of the cohort of grantees are new to the ACE program. Research aims of these newly founded ACEs will address gaps in autism research as identified in the IACC Strategic Plan. The ACEs will enroll a large sample of male and female adults with and without autism to determine how aging-related differences contribute to different health outcomes, including emotional and mental health in autistic adults (e.g., predictors of suicidality).

Dr. Larry Wexler shared that ED's Office of Special Education's Discretionary Grants Program awarded several personal preparation grants focused on doctoral training and masters training related to autism. Another grant is focused on making the Discretionary Grants Program's data accessible to blind and visually impaired individuals. This $15 million software development project will create software that enables someone who is visually impaired to manipulate data.

Dr Jennifer Johnson shared that ACL funded a project to research co-occurring mental health disabilities and IDD to advance health equity. The Administration also funded the National Diversity, Equity, and Inclusion Center focused on health equity and other areas in which people with disabilities experience discrimination. Finally, the Administration announced funding for the national Direct Care Workforce Capacity Building Center focused on building capacity in states and communities to strengthen the direct care workforce.

Ms. Yetta Myrick shared that the DC Autism Parents (DCAP) co-created a new book about developmental milestones titled *Mr. Marshall's Block Party* to support Black families in monitoring child development. DCAP also worked with Family Voices on a PCORI-funded project to train 36 African American parents and stakeholders on managing life after diagnosis and integration into the community across the lifespan. DCAP is supporting the Access for Everyone Initiative. During a public forum in September 2022, people provided testimony and diverse perspectives about an autism-friendly hospital initiative, to ensure that providers clearly understand of how to support individuals and their families across the lifespan.

Dr. Alycia Halladay shared that the Autism Science Foundation introduced new undergraduate and pre- and postdoctoral fellowship mechanisms. The application deadlines are early December 2022. The Foundation is also supporting creation of a research portal where users can seek opportunities to participate in research. This service is free for families and researchers, and interested users can search by age, preferred study type, and study availability in their community and online. The Foundation also convened a meeting to better understand gastrointestinal symptoms in individuals with neurodevelopmental disorders and research gaps and opportunities.

Dr. Jenny Mai Phan described research at California State University, Fresno, to study Asian families with children ages 3-21 with intellectual and developmental disabilities and their experiences with Individualized Education Program meetings.

Ms. Dena Gassner highlighted that Drexel University is sponsoring a power policy luncheon on November 2, 2022, to discuss reproductive health care and disability rights. Finally, a member announced a symposium at Tufts University on November 10, 2022, to address food and nutrition and autism.

Dr. Daniels concluded the session, noting that the complete Round Robin document is available online.

Closing Remarks and Adjournment

Dr. Daniels thanked the panelists and presenters for their insights. Dr. Gordon thanked the presenters and IACC members for their comments on language and inclusion of the full spectrum of autism. The next meeting will be held on January 18, 2023.