

# Interagency Autism Coordinating Committee (IACC)

## Full Committee Meeting

*April 4, 2023*

*April 4, 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: Rebecca Lazeration, Octavia Martin, Nancy Tuvevsson

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a virtual meeting on Tuesday, April 4, 2023, 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.); **Thyria Alvarez**, M.S.W., U.S. Department of Housing and Urban Development (HUD) (representing Leah Lozier, Ph.D.); **Shelli Avenevoli**, Ph.D., NIMH (representing Joshua Gordon, M.D., Ph.D.); **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont; **Skye Bass**, L.C.S.W., Indian Health Service (IHS); **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA) (representing Anita Everett, M.D., D.F.A.P.A.); **Diana Bianchi**, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); **Amanda Bryans**, M.S., Administration for Children and Families (ACL); **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; **Anita Everett**, M.D., D.F.A.P.A., SAMHSA; **Tiffany Farchione**, M.D., Food and Drug Administration (FDA); **Maria Fryer**, M.S., U.S. Department of Justice (DOJ); **Dena Gassner**, M.S.W., Adelphi University; **Morénike Giwa Onaiwu**, Ph.D., Rice University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Kristi Hardy**, Ph.D., M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.), **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., NICHD (representing Diana Bianchi, M.D.); **Walter Koroshetz**, M.D., NINDS; **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Richard Woychik, Ph.D.); **Leah Lozier**, Ph.D., HUD; **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Matthew Miller**, Ph.D., M.P.H., U.S. Department of Veterans Affairs (VA); **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., HSPP, 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; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration (HRSA); **Karyl Rattay**, M.D., M.S., FAAP, Centers for Disease Control and Prevention (CDC), **Amanda Reichard**, Ph.D., 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., CDC (representing Karyl Rattay, M.D., M.S., FAAP); **Matthew Siegel**, M.D., Tufts University; **Ivanova Smith**, B.A., University of Washington; **Hari Srinivasan**, B.A., 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; **Debara Tucci**, M.D., M.S., M.B.A.,

F.A.C.S., NIDCD; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Taryn Mackenzie Williams**, M.A., DOL; **Richard Woychik**, Ph.D., NIEHS

## **Welcome and Announcements**

*Joshua Gordon, M.D., Ph.D., Chair, IACC, NIMH*

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

*Shelli Avenevoli, Ph.D., Deputy Director, NIMH*

Dr. Joshua Gordon introduced the meeting, reviewed the meeting agenda, and acknowledged Autism Awareness Month. He also introduced Dr. Shelli Avenevoli, who led this meeting. Dr. Gordon announced that Ms. Dayana Garcia, Mr. Stephen Whitlow had recently stepped down from the committee and that this would be Dr. Joseph Piven's last meeting because he was also planning to step down. Dr. Gordon also congratulated IACC member, Dr. Morénike Giwa Onaiwu, on the recent completion of their doctoral studies.

The Committee voted to approve the January 2023 IACC meeting minutes, which will be posted to the IACC website.

## **Autism and Developmental Disabilities Monitoring Network Update**

*Karyl Rattay, M.D., M.S., F.A.A.P., Director, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, CDC*

*Matthew Maenner, Ph.D., Chief, Child Development and Disability Branch, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, CDC*

*Kelly Shaw, Ph.D., Acting Team Lead, Surveillance Team, Child Development and Disability Branch, Division of Human Development and Disability, National Center on Birth Defects and Developmental Disabilities, CDC*

Dr. Karyl Rattay introduced the Autism and Developmental Disabilities Monitoring (ADDM) Network, which is a program funded by the Centers for Disease Control and Prevention (CDC) to monitor the prevalence of autism spectrum disorder (ASD) and other developmental disabilities across the United States. The CDC currently funds 11 geographically and demographically diverse ADDM Network sites. The ADDM Network has reported autism prevalence among eight-year-old children every two years since the year 2000. Dr. Matthew Maenner shared that they have expanded to include data on four-year-old children and sixteen-year-old adolescents. The most recently published surveillance data were collected in 2020 and published in March 2023.

In 2020, 1 in 36 children aged eight years at ADDM Network sites were identified as autistic. When researchers calculated the prevalence of autism diagnosis by racial and ethnic groups, 2020 ADDM Network surveillance data showed that that White children were less often diagnosed with autism than Black, Hispanic, and Asian. Prior to 2014, White children were disproportionately more likely to be diagnosed with autism than Black, Hispanic, or Asian or

Pacific Islander children. Dr. Kelly Shaw stated that researchers observed that prior progress in early autism detection was disrupted during the COVID-19 pandemic, particularly from March to June 2020. The ADDM Network releases data through multiple user-friendly platforms, including the [ADDM Network website](#), a [Community Report on Autism](#), [easy-to-read summaries](#), an [Autism Data Visualization Tool](#), and invited commentary in *STAT News*.

The ADDM Network recently published the first CDC data on adolescents with autism. One major finding was the increase in diagnoses of attention-deficit/hyperactivity disorder (ADHD), anxiety, depression, epilepsy, and obsessive-compulsive disorder (OCD) between ages eight to sixteen. Dr. Shaw noted that these findings indicate that autistic children may require special services as they transition from childhood into adolescence and then from adolescence into adulthood.

Researchers also used the ADDM Network data to investigate the rate of “profound autism,” defined in a [report by the Lancet Commission](#) as having an IQ less than 50 or being non- or minimally verbal. They found that approximately 27% of 8-year-old children with an ASD diagnosis met the definition of profound autism. Researchers also found that the prevalence of profound autism increased over the years, although the rate of non-profound autism increased even more rapidly.

The ADDM Network also recently published findings from a pilot study of statewide county-level ASD prevalence estimates. The data included individuals aged 3-21 years in seven states. Researchers estimated prevalence by linking statewide health and education data and then comparing their estimates to actual prevalence rates in counties with ADDM Network sites. Although these data do not include information on co-occurring intellectual disability or age of diagnosis, this approach could help researchers determine the prevalence of autism in areas lacking adequate resources for intensive research methods.

### **Committee Discussion**

Both Drs. Maenner and Shaw appreciated Dr. Larry Wexler’s offer to connect the CDC with data collected under the Individuals with Disabilities in Education Act (IDEA). In response a question about state representation in the ADDM Network and next steps, Dr. Shaw explained that as of 2000, ADDM Network sites have spanned a total of 20 states. Dr. Maenner shared that in early 2023, Congress provided CDC with additional resources to increase the total number of ADDM Network sites and to incorporate cerebral palsy tracking at some sites. The ADDM Network aims to move to a national perspective and to begin collaborations with or comparisons to international autism research.

Ms. Lindsey Nebeker asked the presenters about their process for selecting ADDM Network sites. Dr. Maenner explained that their process is competitive, and starts with CDC releasing Funding Opportunity Announcements (FOAs). Proposals, mostly from health departments, describe their geographic coverage, experience with the FOA topics, and relationships with the community. The proposals are reviewed and scored by a set of independent reviewers.

Dr. Giwa Onaiwu addressed the harm of autistic children of color historically being misdiagnosed as having a conduct disorder. Dr. Maenner noted that until recently, non-White children have been unlikely to be identified as having autism unless they also had a co-occurring intellectual disability. He and Dr. Shaw noted that there have been calls to investigate and emphasize this persistent finding.

Dr. Giwa Onaiwu also expressed concern over the proposed criteria for defining profound autism. Dr. Amanda Bryans seconded this concern, noting that these labels often influence the services that individuals receive, and the diverse non- and minimally speaking autistic population should not be generalized into one category. Dr. Maenner clarified that CDC did not create this definition; rather it leveraged the definition created by the *Lancet* Commission on the future of care and clinical research in autism.

Dr. Piven asked the presenters to consider the potential for ascertainment biases—particularly when diagnosis occurs within the education system. In remote regions, some children may receive an autism diagnosis because that is the only way to access services. Dr. Maenner noted that the standards of different methods for collecting prevalence data have long been debated, with more direct surveillance requiring considerations for consent, scale, and access to communities.

Dr. Maenner also clarified that the ADDM Network data visualizations of ASD prevalence rates present 95% confidence intervals—meaning that researchers are 95% confident that the actual prevalence rates fall within the range. Some groups (e.g., Asian and Pacific Islanders) have larger confidence intervals because of their smaller population sizes. The only way to reduce the intervals is to oversample these smaller populations.

## **National Autism Coordinator Update**

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

Dr. Daniels highlighted autism and disability related activities across the federal government:

- During Black History Month (February), the White House released a [Fact Sheet on the Biden-Harris Administration’s Work to Support Black Disabled Americans](#).
- President Biden issued a [Proclamation on World Autism Awareness Day, 2023](#), renewing the Administration’s commitment to equal rights, inclusion, and support for people on the autism spectrum.
- On February 16, 2023, the National Council on Disability (NCD) held its quarterly business meeting.
  - The NCD issued a Notice of Funding Opportunity (NOFO), titled “[The Absence of People with Disabilities in Clinical Trials](#),” to select an awardee to prepare a report on recommendations and promising practices to increase the inclusion of people with disabilities in clinical trials.

- In collaboration with the National Indian Council on Aging, NCD released a toolkit titled [Understanding Disabilities in American Indian & Alaska Native Communities](#) to share resources and recommendations on disability services and protections for Tribal Nations.
- On March 23, 2023, NCD issued an [update](#) on its [Health Equity Framework](#) published last year.
- In March 2023, the Interagency Committee on Disability Research held a Lunch & Learn webinar titled “[COVID-19 Data on Individuals with Intellectual and Developmental Disabilities.](#)”
- The Federal Partners in Transition held a General Committee meeting and is continuing to develop a new Federal Youth Transition Plan.
- The Interdepartmental Serious Mental Illness Coordinating Committee held a meeting that included a presentation on “The One Mind Initiative: Social Innovation for Better Mental Health.”
- The Indian Health Service (IHS) will hold two events relevant to autism.
  - On April 12, 2023, IHS will host a webinar in celebration of Autism Awareness Month titled “[American Indian/Alaska Native Parents of Children with Autism Panel.](#)”
  - On April 27, 2023, IHS will host a webinar titled “[The Importance of Screening for Autism Spectrum Disorder and Use of the M-CHAT.](#)”

Other upcoming events include the following:

- On April 20, 2023, the National Institute of Environmental Health Sciences (NIEHS) will host a special virtual event for World Autism Awareness Month titled “[Identifying Early Brain Markers in Infancy in Autism and Associated Developmental Disabilities.](#)”
- On April 27-28, 2023, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) will host a two-day virtual workshop titled “[Ableism in Medicine and Clinical Research.](#)”

Finally, Dr. Daniels welcomed IACC members to participate in the NIMH/OARC Autism Awareness Month special event “[A Portrait of Autism: Artists and Their Works](#)” on April 14, 2023. More information about Autism Awareness Month and related events can be found on the [IACC website](#). In addition, the [OARC Newsletter](#) provides updates on autism news from around the community.

Dr. Daniels provided the following highlights from nongovernmental organizations:

- On March 9, 2023, the Policy Impact project released the latest edition of the A.J. Drexel Autism Institute’s National Autism Indicators Report series, titled [Introduction to Medicaid and Autism.](#)
- On March 22-24, 2023, the Kennedy Krieger Research Institute hosted the [Neurodiversity in the Workplace Conference](#) in Washington, D.C.

- On March 28, 2023, United Nations (UN) Secretary General, António Guterres, issued a [statement](#) to recognize World Autism Awareness Day that focused on building inclusive environments.
- On April 2, 2023, the UN observed World Autism Awareness Day with a global virtual event on the theme “[Transformation: Toward a Neuro-Inclusive World for All.](#)”
- On March 30, 2023, the Autism Science Foundation held its [10th Annual Day of Learning](#).
- On May 3-6, 2023, the International Society for Autism Research will host its annual scientific meeting in Stockholm, Sweden. More information can be found on the [event webpage](#).

## **IACC Committee Business**

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

### **Committee Activity Updates**

#### *2021-2023 IACC Strategic Plan*

The IACC approved the draft *2021-2023 IACC Strategic Plan* during the January 2023 Full Committee Meeting, and OARC is preparing the Plan for publication in May 2023. The Strategic Plan will be published on the IACC website, distributed via the IACC mailing list, and transmitted to Congress and the President. Simultaneously, OARC will release an accessible, “easy-to-read” version of the Strategic Plan.

#### *Health Outcomes Working Group Report*

The IACC Health Outcomes Working Group report was a project started by the previous IACC following two workshops held in September 2018 and May 2019 that focused on co-occurring health conditions. OARC will revise the Health Outcomes Working Group Report during the coming months. Once the report has been updated, IACC members will have a chance to review the report and suggest additional revisions. OARC will provide a status update during the October 2023 IACC Meeting.

#### *2021 IACC Summary of Advances*

The *2021 IACC Summary of Advances* is now available [online](#), along with an easy-read [version](#). It includes Provides lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC. The articles address all seven topic areas of the IACC Strategic Plan.

#### *2022 IACC Summary of Advances*

The *2022 Summary of Advances* is in preparation. IACC members voted in February and March 2023 on the top 20 articles. OARC is currently preparing article summaries and a draft publication. IACC members will provide draft comments before final publication in Summer 2023.

### *2023 IACC Summary of Advances Update*

For the 2023 Summary of Advances, IACC members will nominate articles throughout 2023 and discuss them at IACC Full Committee Meetings through January 2024. After January 2024, IACC members will vote on the top 20 articles with a goal of publishing the Summary of Advances in spring 2024. Dr. Daniels presented IACC members with a list of [20 articles nominated to date](#) and asked IACC members to share their support of noteworthy articles or their concerns about articles that may warrant removal from consideration. IACC members are encouraged to continue submitting article nominations, and new nominations will be discussed during the October 2023 IACC Full Committee Meeting.

### **2023 IACC Summary of Advances Committee Discussion**

Ms. Ivanova Smith expressed support for the article, “Sex Differences in Social and Emotional Insight in Youth with and without Autism,” noting the importance of studies of sexuality in autistic individuals. Ms. Dena Gassner highlighted that a strength of this article is its comparison of autistic girls to non-autistic girls, because many studies fail to include a non-autistic cohort.

Dr. Alison Marvin mentioned that she nominated the article, “Preparing Law Enforcement Officers to Engage Successfully with Individuals with Autism Spectrum Disorder: An Evaluation of a Performance-Based Approach,” despite its small sample size, because of the importance of the study topic and minimal research on the topic to date. Ms. Maria Fryer seconded the importance of the topic and highlighted the article’s overlap with the U.S. Department of Justice’s (DOJ) work. Ms. Myrick encouraged IACC members to nominate more articles that consider how different groups (e.g., educators, law enforcement) interact with the autistic community. She also encouraged members to nominate articles that address unmet needs and disparities. Dr. Scott Michael Robertson made a general statement of support for articles addressing diversity, including gender identity and race/ethnicity.

Dr. Rattay highlighted the importance of the articles that used ADDM Network data, including those on autism prevalence among children aged 4 years and 8 years. She also noted that the article “Adolescents with Autism Spectrum Disorder: Diagnostic Patterns, Co-occurring Conditions, and Transition Planning” is important for understanding the needs of transition aged youth.

### **Public Comment Session**

*Joshua Gordon, M.D., Ph.D., Director, NIMH and Chair, IACC*

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

### **Oral Comments**

Geraldine Dawson, Ph.D., is a professor at Duke University and the Director of the Duke Center for Autism and Brain Development. She discussed a proposal by the Accreditation Council for Graduate Medical Education (ACGME) to remove two requirements for pediatric resident training: (1) that pediatric residency program faculty must include a developmental-behavioral pediatrician and other subspecialists and (2) that pediatric residents must gain “adequate”



exposure to the normal developmental spectrum and undergo training in the longitudinal care of children with special healthcare needs. Dr. Dawson stated that these changes will negatively impact the already inadequate care of autistic children. Removing the requirement for adequate exposure to patients with neurological conditions and other special health care needs during medical training could lead to significant long-term consequences for health, quality of life, and mortality. Dr. Dawson strongly encouraged the IACC to [submit a comment](#) to ACGME by the April 5, 2023, deadline, expressing disapproval of the proposed changes.

Miya Asato, M.D., is the Vice President of Training at the Kennedy Krieger Institute and Director of the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Dr. Asato also expressed concern about the changes proposed by ACGME. Removing the requirement for programs to include a developmental-behavioral pediatrician faculty member will impact future pediatricians' foundational understanding of the wide range of human development. Without exposure to and understanding of intellectual and developmental disorders (I/DD), pediatricians will feel uncomfortable addressing developmental concerns, an issue already commonplace across pediatric practices and specialists. This change may also reduce the number of future developmental-behavioral pediatricians—negatively impacting comprehensive programs (e.g., Down Syndrome centers) that provide a medical home, care supervision, and management to critical populations. Dr. Asato noted that the ACGME proposal also suggests that, instead of pediatricians, alternate specialists may be leveraged to diagnose and manage the care of autistic patients. However, the specialists listed are not adequately trained to handle the complexity of managing care for pediatric conditions that alter developmental trajectories. Dr. Asato concluded by asking the IACC to share its concern with the ACGME and to consider advocating for federal and state funding to support existing clinics that identify and treat children with increased likelihood of developmental disorders.

Christopher Banks, M.B.A., M.S., President and CEO of the Autism Society of America, announced that the Autism Society of America is continuing its annual Celebrate Differences campaign for the fifth year. Mr. Banks then presented an overview of the Autism Society's health equity work. In 2021, the Autism Society received funding from CDC to develop the Vaccine Education Initiative (VEI)—a public health model that reduces barriers to vaccination faced by the autism community. Through VEI, the Autism Society promotes vaccine education within the autism and disability community; equips health care providers with the training and resources needed to meet the diverse health care needs of the autism community; and creates community connections that lead to improved patient-provider confidence, communication, interaction, and outcomes. Mr. Banks noted that the Autism Society recently received additional funding through the Administration for Community Living to expand the VEI program within the Autism Society network of approximately 70 affiliates across 34 states. Mr. Banks also spotlighted the crisis of understaffed and underpaid direct support professionals, inequitable access to home and community-based services, and systemic environmental barriers that impact the health of autistic Americans. Mr. Banks emphasized that the Autism Society will continue to work through public policy efforts and national programs to address the needs of autistic community members in other areas of health equity, including mental health, suicide prevention, and law enforcement and first responder training. Lastly, Mr. Banks also

expressed his concern about the proposed changes by ACGME to pediatric residency education, requesting that the IACC provide feedback. The Autism Society will also submit feedback on the proposed changes.

Idil Abdull is a Somali mother to an adult son on the autism spectrum, retiring advocate, and former IACC member. Ms. Abdull noted that although much progress has been made since she left the IACC, two areas still require additional attention: adult services and communication. Regarding adult services, Ms. Abdull explained that the current system for autistic adult care is not set up for employment, housing, or safety. Ms. Abdull asked IACC members to concentrate on person-centered and culturally responsive services and support for adults with autism. Ms. Abdull also emphasized the importance of increasing methods for higher quality communication for non- or minimally verbal autistic individuals. Somalis are an oral society, and Somali children with nonverbal autism lack adequate means for communicating in a culturally significant way. Ms. Abdull asked the IACC to increase awareness of the spell-to-communicate method and to encourage insurance companies and Medicaid to cover communication tools and services that will ensure that autistic individuals can communicate fully and openly and thus live healthier and happier lives.

Anthony Tucci, L.L.M., E.S.Q., C.P.A, Director of the Autism Awareness and Support Foundation and father of a 19-year-old nonverbal autistic son, highlighted two main topics. First, he expressed the need for multidisciplinary and interdisciplinary research, as it provides the best opportunities to effectively understand the communication challenges of non- and minimally verbal autistic individuals. Second, human rights and equitable rights must always lead an evidence-based practice model. Nonverbal individuals should not be discriminated against for selecting modes of communication that are effective for them. Advocacy against such methods of communication violates the rights of non- and minimally verbal individuals and represents a violation of the evidence-based practice model. To prevent these challenges, Mr. Tucci asked the IACC to form a committee that could guide the scientific community on ways to develop due process methods before professional and trade associations issue position statements that may deny communication rights to some individuals. This approach will help to ensure that position papers are founded on fairness and best practices.

Mariam Egal is a Somali mother of a 25-year-old with an undiagnosed behavioral condition. Ms. Egal shared challenges and recommendations from parents in the Somali community. Many parents reported encountering racism when trying to access services., most U.S. service providers are not culturally inclined and ignore racially diverse communities. Barriers to service include poverty, large households, lack of knowledge of existing services and supports, and single-parent households with no family or community supports. In addition, grassroots community-based organizations that provide culturally responsive services and supports are often overlooked for funding. Overall, postsecondary educational institutions and adult day services are not available to autistic adults, and undiagnosed autistic youth do not receive service supports that they may need. Additionally, many large families face eviction and parents and siblings show signs of depression, anxiety, chronic diseases, and other relating issues. Ms. Egal recommended increased resources and funding directed at community-based grassroots

organizations led by parents of individuals with autism. She encouraged the IACC to change communication strategies to become culturally and linguistically appropriate. Ms. Egal also encouraged diversity in the workforce, especially inclusive of minority communities with cultural and linguistic differences, to address barriers to accessing care. Lastly, she recommended that researchers investigate the factors underlying the high prevalence of autism with co-occurring intellectual disability among the Somali community in Minnesota.

### **Summary of Written Public Comments**

Dr. Daniels stated that 38 [written public comments](#) were submitted. Of these comments, 28 focused on research and service needs, resources, and policy implications; 4 on research, services, and supports for adults with autism; 2 on mental health research, services, and treatment; 1 on the role of the IACC and the federal government; 1 on employment; 1 on inclusion of autistic perspectives in research; and 1 on concern about medical practices.

### **Committee Discussion**

Similar to several of the oral commenters, many IACC members expressed strong concern with the ACGME's proposed changes to pediatric resident training. They also expressed concern about the limited timeframe for the public to respond to the ACGME proposal (by April 5, 2023). To ensure that their opinion would be heard before the response deadline, IACC members drafted a statement during this meeting for submission to the ACGME, expressing their strong disagreement with the proposed rule changes. Members voted to submit the statement to ACGME. In addition to drafting the statement, IACC members expressed interest in meeting with ACGME to learn about its justification for the proposed changes.

Ms. Gassner expressed concern about the IACC's efforts to improve outcomes for autistic adults. The IACC has not focused as strongly on certain groups, including those diagnosed later in life. Many cannot attain employment, and many experience trauma from a lack of diagnosis. She encouraged the IACC to shift its focus in addressing gaps in adult services and outcomes.

Dr. Giwa Onaiwu added that a subminimum or lower wage for autistic is unacceptable and that there is a need for innovative training models. Another member noted that many autistic adults are either chronically unemployed or in a state of burnout in their employed positions because of a lack of support.

Ms. Smith added that "mental age" theory—by which doctors assign an individual with intellectual or developmental disabilities with a "mental age" equivalent to their functioning—is often inaccurate and consequently harmful to autistic individuals. She emphasized that the use of this theory to describe individuals with intellectual disabilities denies them the ability to be seen as adults. People with intellectual disabilities have the right to function in their adulthood without being subject to the imposition of restrictions because of their disabilities.

## **Increasing Racial Equity and Improving Disparities in Autism Outcomes**

### **Why Understanding the Impact of Racism and Discrimination Matters in Autism Research**

*Brian Boyd, Ph.D., Interim Director, Frank Porter Graham Child Development Institute; William C. Friday Professor, School of Education, University of North Carolina at Chapel Hill*  
*Jill Locke, Ph.D., Co-Director, SMART Center; Associate Professor, Psychiatry & Behavioral Sciences, University of Washington*

Dr. Brian Boyd opened the presentation by describing how racism has public health consequences. First, he shared the differences in equality and equity. Next, he shared Dr. Camara P. Jones' definitions of four different kinds of racism: institutional or structural racism, cultural racism, interpersonal racism refers, and internalized racism. He argued that it is important to understand how different types of racism and discrimination affect the autism community and their outcomes.

Dr. Jill Locke explained how structural inequities created by institutional racism lead to differential access to goods, services, and resources and outcomes for autistic individuals of color. For example, the average timeline for definitive diagnosis of ASD is ages 3 to 4 years. However, children from ethnic minority backgrounds often receive ASD diagnoses at ages 5 to 6 years or older.

Institutional racism also affects autistic children of color in the school system. For example, Black students, regardless of diagnosis, have a significantly higher likelihood of being placed in a special, contained classroom. Black autistic children have an even higher likelihood of being placed in a self-contained setting or special day class. These numbers correspond with findings that non-Asian autistic children in Kindergarten through Grade 2 are significantly less integrated in the classroom setting than neurotypical White children.

Autistic children from minority backgrounds also face disadvantages on a broader policy scale regarding funding for special education. Researchers showed that states with larger shares of children eligible for special education receive on average fewer dollars per child than states with less need. In addition, large states and states in which more children experience poverty receive fewer Individuals with Disabilities Education Act (IDEA) funding dollars per child.

The evidence of discrimination against autistic people of color can also be seen at the level of interpersonal racism. In an examination of autistic and non-autistic Black young adults, researchers found that while autistic Black young adults experienced fewer everyday discriminatory events, they reported feeling the same level of stress as their non-autistic counterparts. In addition, while most non-autistic Black individuals listed race as the primary source of discrimination experiences, autistic Black individuals listed both their autism and race as sources of discriminatory experiences.

Dr. Boyd noted that it is important to consider the historical context of the treatment of the Black community in research and medicine. He stressed the importance of achieving health equity—the state in which everyone has the opportunity to attain full health potential, and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstance. He also emphasized the importance of achieving racial equity—the process of eliminating racial disparities by changing policies, practices, systems, and structures to prioritize measurable changes in the lives of people of color.

Dr. Locke noted that one pathway to achieving health equity, especially for autistic people of color, is development of new, inherently culturally grounded interventions. These interventions, when developed by and for communities of color, may have a better chance of being used and sustained by the community because they are more culturally relevant and actionable as compared to interventions developed in a laboratory setting.

Researchers must think beyond traditional methods and include communities in the development of culturally grounded interventions. Dr. Locke shared several areas for improvement to address health and racial equity for autistic individuals of color. She shared that researchers need to:

- Disentangle and unpack the impact of race/ethnicity on research
- Involve autistic self-advocates of color in research to better understand intersectionality
- Develop and evaluate culturally responsive interventions and antiracist programming for racially minoritized autistic individuals and families
- Increase workforce diversity (e.g., among research teams, healthcare providers)
- Fund existing systems aimed at changing policies that contribute to inequities

Dr. Locke also emphasized that institutions funding research need to provide funding mechanisms beyond single investigator R01s to improve health and racial equity in autism.

### **Racial and Ethnic Disparities in Healthy Weight and Culturally Tailored Interventions to Address Them**

*Sandy Magaña, Ph.D., M.S.W., Professor in Autism and Neurodevelopmental Disabilities; Executive Director, Texas Center for Disability Studies (TCDS), University of Texas at Austin*

Dr. Sandy Magaña opened by noting that, to date, research on equity in autism has examined disparities and differences in diagnosis and access to specialty services and healthcare. More research is needed in these areas, but researchers should also focus on the health outcomes of autistic individuals and identify factors that may contribute to those outcomes.

Dr. Magaña next described some of her work with the Healthy Weight Research Network, which examined racial and ethnic disparities in obesity and overweight status among 9- and 10-year-old boys with autism. Her research team utilized data from the NIH-funded Adolescent Brain Cognitive Development (ABCD) study. The study found that non-Latino White autistic boys were less likely to be overweight or obese than Latino or Black autistic boys.

Based on the overwhelming rates of obesity identified among autistic children in prior studies, Dr. Magaña developed the Promoting Obesity Prevention among Latinx Children with Developmental Disabilities and Families through Engaged Research (PODER) study. The study, in part, investigated methods of managing body mass index (BMI) among autistic children and found that controlling strategies (i.e., parents dictating exactly what to eat) were associated with lower BMI while monitoring strategies (i.e., parents monitoring consumption without input) were associated with higher BMI. These findings are in opposition with research among neurotypical children, in which controlling strategies are often associated with higher BMI.

A review of published autism intervention studies found that only 25% of 1,013 articles reported data on race and ethnicity. In studies that did report race and ethnicity, the majority of participants (64.8%) were White. Dr. Magaña discussed several reasons for the underrepresentation of racially and ethnically diverse populations in autism research that have been identified, including (1) mistrust of health care providers and researchers, (2) unfamiliar study settings or settings out of reach of diverse communities, (3) inability to take time away from other responsibilities (e.g., caretaking, work), (4) inability to participate in online portions due to lack of internet access, (5) lack of multilanguage representation, or (6) lack of diagnosis.

Finally, Dr. Magaña noted that cultural tailoring of approaches could help address some of these barriers to participation. Cultural adaptations (e.g., multilingual materials) have been widely used effective in mental health interventions, leading to moderate to large effects compared to non-culturally adapted approaches. Cultural adaptation of interventions requires researchers to update the intervention based on feedback from stakeholders and patients. Best practices for developing and adapting culturally tailored interventions include involving stakeholders and utilizing community members for recruitment and delivery. She also suggested creating and translating materials for the target group and ensuring accessibility and reducing barriers to access. Finally, she suggested using the Ecological Validity Framework, which guides the culturally sensitive adaptation of interventions for new cultural groups. Dr. Magaña concluded by noting that one critical aspect to culturally tailoring approaches is a diverse research workforce that reflects the populations being enrolled into studies or treated at clinics.

### **Community Perspectives**

*Gyasi Burks-Abbott, M.S., LEND Fellow, Boston Children's Hospital and University Center for Excellence in Developmental Disabilities (UCEDD), Institute for Community Inclusion, University of Massachusetts, Boston*

*Lydia X. Z. Brown, J.D. Founder and Director, Autistic People of Color Fund*

*Camille Proctor, Founder and Executive Director, The Color of Autism Foundation*

*Crystal Hernandez, Psy.D., M.B.A., Executive Director, Tulsa Center for Behavioral Health*

Mr. Gyasi Burks-Abbott shared that many of the challenges faced by individuals on the autism spectrum are related to disinvestment by government services, based in the legacy of systemic racism. For example, the Supplemental Security Income (SSI) asset limit, set in 1989, mandates that individuals whose countable resources exceed \$2,000 may lose their Social Security

Administration (SSA) benefits. This SSI asset limit means that many individuals earn just enough to lose their benefits but not enough to be able to afford necessary services on their own. Such policies disproportionately impact minorities with disabilities. Mr. Burks-Abbott also described how systemic racism, specifically regarding the integration of hospitals in the 1940s, is also the reason that universal health care has not been established in the United States. Those policies were enacted to appease the those who were opposed to providing health care coverage that would benefit minority populations. America has a long history of funding tax cuts for the wealthy and defense agency budgets while neglecting social services. Mr. Burks-Abbott encouraged forward movement of the country away from trickle-down economics and towards policies that lift up those who are currently disadvantaged.

Ms. Camille Proctor, mother of a child with autism, emphasized that, despite increasing diagnosis rates among autistic people of color, disparities in diagnosis still persist in certain areas of the country. For example, she shared her experience with a Georgia community of Black upper-middle-class individuals who do not have access to service providers for their autistic community members. She emphasized the importance of the research shared by Dr. Boyd and Dr. Locke on racial and health equity and culturally adapted autism interventions.

Mx. Lydia Brown, a disability rights advocate and attorney, spoke about the lifelong economic, racial, and disability-based disparities that autistic people of color experience. Statistics on employment outcomes show that autistic people, and others in the broader disability community, face higher rates of unemployment and poverty compared to the general population. People with disabilities are expected to earn lower wages and have lower lifetime earnings compared to those without disabilities, and these disparities are further exacerbated for autistic people of color. Because of these disparities, autistic people of color often struggle to meet basic financial obligations (e.g., rent, utilities), making them more vulnerable to homelessness and chronic housing instability. Often, autistic people of color are discriminated against and denied access to assistance services meant to act as a safety net against financial insecurity. Autistic people of color from all minority communities and backgrounds face higher rates of school pushout, job discrimination, housing discrimination, credit and lending discrimination, and lowered ability to maintain community integration. Mx. Brown noted that leadership of the Autistic People of Color Fund are relatively privileged within the community compared to those who they assist because they can access community support, employment, and housing. They also noted that autistic people of color who are part of the LGBTQIA+ community also face direct attack on their rights of bodily autonomy and culturally responsive care in dozens of states across America. They concluded by emphasizing the need for the financial and health impact on autistic people of color who also serve as family caregivers—particularly given the potentially compounded impact of discrimination against them as autistic individuals and as racial minorities.

Dr. Crystal Hernandez shared how she turned her negative experiences trying to access care for her autistic child into action. Her family members are Native American Cherokee Nation citizens and Latinos. She uses her experiences to improve the lives of other caretakers of autistic individuals of color. She stressed the importance of building systems of equity and safety for

autistic individuals of color, and that supports should be built by and for the communities they serve. Researchers need to focus on creating culturally centered services and practices to benefit autistic people of color. Dr. Hernandez directed the IACC members to the [Black Feathers Podcast](#), a space that focuses on Native American people's experiences with intellectual and developmental disabilities. Dr. Hernandez concluded by highlighting that many of the health care service centers utilized by Latino families and individuals have high turnover rates, reducing the consistency of care and monitoring provided. Furthermore, high turnover rates at these centers may negatively impact the opportunity for early detection of autism and other developmental disabilities in the Latino community.

### **Committee Discussion**

IACC members expressed their appreciation to the panelists, noting the vital nature of their work to ensure health and racial equity for autistic individuals of color.

Dr. Jenny Mai Phan asked the panelists to consider how autism is addressed among community partners of racial and ethnic minorities. First, she noted that some racial and ethnic minority communities have low levels of autism awareness, leading to abuse and neglect of autistic community members. Grassroots programs exist that provide education to these communities to fight stigma against autism and encourage better treatment and integration in the community. Second, she noted that children in English-as-a-Second-Language (ESL) classrooms who meet the criteria for autism are often not referred for diagnostic services. Additionally, their academic and behavioral challenges are attributed to their limited English language proficiency rather than underlying developmental disabilities. Dr. Phan noted that ESL teachers often are not qualified to make recommendations, or supported in their recommendations, about autism diagnoses for these children. Ms. Gassner added that navigating services as a caretaker of an autistic individual is difficult for English-speaking individuals and significantly more difficult for non- or minimally English-speaking individuals.

Mr. Burks-Abbott noted that the LEND program works to educate underserved communities about autism and to increase the availability of community-based services. Ms. Proctor added that the Color of Autism Foundation educates parents on how to support their children and encourage them to embrace their child's identity and integrate their children into their community. Mx. Brown reiterated the importance of continued focus on the disenfranchised communities that have faced systemic racism throughout America's history.

Ms. Gassner emphasized the fact that the identification rates for girls on the autism spectrum are incredibly low. Girls on the autism spectrum one of the most marginalized populations in terms of diagnosis, with autistic girls of color even more marginalized. Dr. Hernandez suggested that one reason for the lack of diagnosis among autistic females may be that women, particularly women of color, are underrepresented in autism research and clinical settings. Because of historic limitations in the field that have led to under- or misdiagnosis of autistic women, many women are not diagnosed with autism until after age 30.

Ms. Proctor suggested that another reason for lack of diagnosis among autistic females may be cultural in nature. She shared that Black women are often the foundation of the family unit,



and any intellectual/developmental disabilities (IDDs) that prevent them from performing as a family leader may go unacknowledged to avoid disrupting the family unit. She suggested that communities and parents of color need to be educated to feel comfortable embracing their autistic children as they are. She also emphasized the need to recruit people of color into the autism services workforce so that autistic children of color can see themselves represented in the community.

Dr. Hernandez agreed that accepting an autism diagnosis can be a challenging process for families, particularly families of color, and may lead to feelings of denial and anger. She shared that she feels compounded concerns about the struggles that her child will face both for their race and for their disability.

Dr. Magaña added that the suppression of diagnosis goes deeper into the culture of the United States, where girls are taught to internalize their problems—including signs of IDD that may lead others to label them as disruptive or disobedient. She noted that both her son and daughter were diagnosed with ADHD, but that her daughter was diagnosed later than her son because her behaviors were not recognized as behavioral challenges..

Panelists and IACC members further discussed discrimination. Dr. Boyd emphasized that understanding the intersectionality of race and disability is critical for understanding the experiences of autistic people of color. He noted Blackness was historically considered a disability in this country, and that Native Americans also have a traumatic history . The long history stigma of racialized and ableist prejudice in the U.S. affect the experiences and outcomes of these populations.

Mx. Brown added that East Asian immigrant families also face historical trauma in feeling required to perform to high standards to prove themselves as compliant members of White settlement–inspired communities. In addition, people of color often disavow disability in their community because of the perspective among White communities that Whiteness and Able-Bodiedness are intertwined. Mr. Burks-Abbott noted that both people of color and people with disabilities are often forced to go above and beyond to demonstrate their humanity.

Mx. Brown added that many adults diagnosed with autism struggle with the diagnosis because of the internalized ableism created by our society. They encouraged disconnecting ableism from policies and practices of health care and support services settings.

Dr. Robertson highlighted that the focus on intersectionality of race and autism aligns with the priorities for Diversity, Equity, Inclusion, and Accessibility (DEIA) of the Department of Labor (DOL)'s Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS) project. He asked IACC members and panelists what more could be done in the workforce to promote diversity.

Mx. Brown commented that autistic individuals are often hired with the assumption that they will have low absentee rates and will be willing to work additional hours as needed. However, they noted that these patterns are often the result of exploitation and traumatic experiences.

Mx. Brown shared that most individuals in the workforce who are categorized as developmentally disabled are relegated to jobs that are paid minimum or sub-minimum wages and lack opportunity for advancement. Even individuals in employment assistance programs are placed in entry-level positions with no expectations of advancement. This disparity is often due employer bias.

Dr. Locke noted that many services exist to assist individuals in establishing employment, but few services exist to assist these individuals with retaining employment. Autistic people are more prone to be “written up” or to struggle with creating connections with their coworkers. Employers and managers should structure the workplace to support autistic people and programs should provide support to autistic people in the workplace—rather than placing the onus on the autistic individual. These structural changes will require research to better understand the current landscape and best practices for improvement.

Mr. Burks-Abbott agreed, noting that many workplaces will resist accommodations. He provided the example that, before the pandemic, many employers resisted allowing autistic individuals to work remotely; however, during the pandemic remote work became the norm—meaning that the accommodations were feasible and that the resistance was unnecessary. Dr. Locke added that autistic individuals may be unaware of the services that may need to succeed. Therefore, support systems that provide guidance on requesting accommodations are necessary. Organizations that support autistic people and those with disabilities should hire people from the communities they support, but autistic people should not be siloed into advocacy work only.

Some recent discussions by policymakers in the autism field have focused on the return of institutionalization for individuals with IDD, which will negatively impact marginalized communities first. Ms. Smith inquired about the IACC members’ or speakers’ plans to prevent this change. Mx. Brown said that because homelessness is one reason why autistic individuals may be institutionalized, the Autistic People of Color Fund uses a micro-grant program to help autistic people of color retain housing. However, Mx. Brown noted that the micro-grant program is not sufficient to prevent the establishment of policies that would increase the rate of institutionalization. Mr. Burks-Abbott stated that there are some bills introduced to Congress to address these issues, but they need support to move them forward.

Panelists provided recommendations on supporting sustained funding for programs, such as leadership training for autistic people from marginalized communities (e.g., non-English speaking, people of color) or with marginalized experiences (e.g., incarceration, addiction, chronically homeless). Panelists also encouraged IACC members to lead the field by demonstrating best research practices and advocating for policy change. Finally, panelists encouraged IACC members to be more conscious of the different cultures represented by the diverse communities that are part of the autism community at large and to interact more openly with these diverse communities.

Mx. Brown encouraged supporting the integration or reintegration of autistic individuals into society following schooling, incarceration, or other institutionalizations during which these

individuals did not receive autism support services. They encouraged support for autistic people within the LGBTQIA+ community who are denied access to culturally sensitive and gender supportive care. Finally, they encouraged support for autistic family caregivers, who often struggle to earn enough income to pay for all their family's necessary services but could earn too much income to receive federally funded or subsidized services.

Dr. Magaña encouraged funding lifespan research to understand the experiences of autistic people as they age. She also encouraged studies of different subpopulations, such as cultural adaptation projects.

Dr. Boyd suggested IACC members consider different funding vehicles to address the mechanisms of systemic racism that affect autistic people of color. He stressed the importance of funding and supporting community partners in research projects. Researchers need to better understand the cultural assets and cultural wealth of the communities with whom they are working. Similarly, Dr. Locke supported the inclusion of self-advocates in research to ensure that their voices are incorporated into the research process. She also strongly encouraged the inclusion of more researchers of color. Finally, she suggested supporting the work of organizations such as the Color of Autism Foundation and others represented in this meeting.

## Round Robin Updates

The SSA is preparing to post a solicitation in April or May 2023 for a new grant administrator for the Analyzing Relationships between Disability, Rehabilitation, and Work small grant program.

The National Institute on Deafness and Other Communication Disorders sponsored a webinar in January 2023 titled "[Minimally Verbal/Non-Speaking Individuals with Autism: Research Directions for Interventions to Promote Language and Communication](#)." A summary of the meeting, including participant-suggested publications, is [available online](#).

The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is mandated by Congress to develop a Long-Range Plan every five years that includes guiding principles, priorities, and focus areas for research related to the rehabilitation of individuals with disabilities. Last year, NIDILRR initiated the development of the 2024-2028 plan, including input from the field about current gaps, needs, experiences, and opportunities. Based on feedback received, NIDILRR finalized the direction of the new plan and will host a [webinar](#) on April 19, 2023, to present the key themes and priorities.

DOL's Office of Disability Employment Policy's (ODEP's) Job Accommodation Network is hosting a webinar titled "[Accommodation Solutions for Neurodivergent Workers](#)" on April 13, 2023. In addition, ODEP's Partnership on Inclusive Apprenticeship's latest [podcast episode](#) focused on strength-based practices to support neurodiversity at work. The episode is part of an Apprenticeship for All series featuring interviews with various ODEP staff members.

The University of Pittsburgh's Pitt Autism Center of Excellence is hosting a free webinar titled "[Suffering in Silence: Suicidality in Neurodiverse Communities of Color](#)" on April 28, 2023.

The Madison House Autism Foundation will host its annual Autism After 21 Breakfast on April 21, 2023 (Autism After 21 Day), which it founded in 2016 to celebrate the abilities and contributions of autistic adults in their communities.

Dr. Daniels concluded the session, noting that the complete [Round Robin document](#) is available online.

### **Closing Remarks and Adjournment**

Dr. Daniels and Dr. Avenevoli: thanked the panelists and presenters for their insights.

The next IACC Full Committee Meeting will be held in October 2023, and the meeting format and registration information will be announced on the IACC website.