

# Interagency Autism Coordinating Committee (IACC)

## Full Committee Meeting

*April 17, 2024*

June 19, 2024



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 are gratefully acknowledged: Jeremy Bradshaw, Cherie Dewar, Carrie Perkins, Dana Carluccio, Christy Huffman.

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a hybrid meeting on Wednesday, April 17, 2024, 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, NIMH; **Deirdra Assey**, M.A., U.S. Department of Justice (DOJ); **Shelli Avenevoli**, Ph.D., NIMH; **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont Larner College of Medicine; **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA)(representing Sunny Patel, M.P.H.); **Diana Bianchi**, M.D., NICHD; **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara Tucci, M.D., M.S., M.B.A., FACS); **Allyson Dean**, Ed.D., Administration for Children and Families (ACF); **Aisha Dickerson**, Ph.D., Johns Hopkins University Bloomberg School of Public Health; **Tiffany Farchione**, M.D., U.S. Food and Drug Administration (FDA); **Thomas Frazier**, Psy.D., Autism Speaks; **Dena Gassner**, M.S.W., Adelphi University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)(representing Diana Bianchi, M.D.); **Christy Kavulic**, Ed.D., U.S. Department of Education (ED); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS)(representing Richard Woychik, Ph.D.); **Leah Lozier**, Ph.D., U.S. Department of Housing and Urban Development (HUD); **Laura Mamounas**, Ph.D., National Institute on Neurological Disorders and Stroke (NINDS)(representing Kristina Hardy, Ph.D., M.D.); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A.; **Morénike Giwa Onaiwu**, Ph.D., Autistic Women & Nonbinary Network, Advocacy Without Borders; **Sunny Patel**, M.P.H., SAMHSA; **Scott Patterson**, Ph.D., HSSP, Department of Veterans Affairs (VA); **Jenny Mai Phan**, Ph.D., Children’s National Hospital; **JaLynn Prince**, B.F.A., Madison House Autism Foundation; **Camille Proctor**, The Color of 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); **Susan Rivera**, Ph.D., University of Maryland; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL)(representing Taryn Mackenzie Williams, M.A.); **Robyn Schulhof**, M.A., HRSA; **Matthew Siegel**, M.D., Boston Children’s Hospital; **Jane Simoni**, Ph.D., National Institutes of Health (NIH) (representing Monica Bertagnolli, M.D.); **Laura Ivanova Smith**, B.A., University of Washington; **Hari Srinivasan**, B.A., Vanderbilt University; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna Tschiffely**, Ph.D., U.S. Department of Defense (DOD)(representing Nicole Williams, Ph.D.); **Debara Tucci**, M.D., M.S., M.B.A., FACS, NIDCD; **Paul Wang**, M.D., Simons Foundation; **Nicole Williams**, Ph.D., U.S. DOD; **Emily Weaver**, ED (representing Christy Kavulic, Ed.D.).

## Welcome and Announcements

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

*Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator*

Drs. Joshua Gordon and Susan Daniels welcomed participants to the meeting and introduced the new IACC members:

- Sunny Patel, M.D., M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA)
- Deirdra Assey, M.A., U.S. Department of Justice (DOJ)

Dr. Gordon gave a brief overview of the agenda and acknowledged IACC member updates, as listed below:

- Dr. Gordon will be stepping down from the National Institute on Mental Health (NIMH) and the IACC chairship in June of 2024.
- Shelli Avenevoli, Ph.D., will be the new IACC Chair.
- Hari Srinivasan has received an NSF Graduate Research Fellowship.

Dr. Gordon also acknowledged that April is Autism Acceptance Month and highlighted the IACC's appreciation for the White House's recent change from Autism Awareness Month to Acceptance.

The IACC voted to approve the [January 2024 minutes](#).

## IACC Update

*Joshua Gordon, M.D., Ph.D., Director, NIMH*

*Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator*

Dr. Joshua Gordon will be stepping down from his roles as director of NIMH and chair of IACC effective June 2024. He noted that his experience in these roles has helped increase his understanding of autism and the needs of the autistic community. He also reflected on the accomplishments of the IACC under his tenure as Chair.

IACC is due to sunset this fall with the expiration of the current Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019. A draft reauthorization bill that would reestablish the IACC has been introduced in Congress.

Dr. Gordon thanked past and present IACC members and the Office of National Autism Coordination (ONAC), which will keep IACC stable after his departure. The acting director of NIMH and next IACC chair will be Dr. Shelli Avenevoli, a trained clinical psychologist and researcher with a specialty in child development.

Dr. Avenevoli introduced herself and noted that she has learned so much from IACC over the past decade. She appreciates IACC's steadfast commitment to promote high quality research and autism services. She appreciates Dr. Gordon's leadership, and she will work closely with Dr. Daniels.

## **Global Autism Activities at the World Health Organization**

*Chiara Servili, M.D., M.P.H., Ph.D., Technical Officer, Department of Mental Health and Substance Use, WHO*

Dr. Gordon introduced Dr. Leonardo Cubillos, director for NIMH Center for Global Mental Health Research and NIMH's liaison with the World Health Organization (WHO).

Dr. Cubillos introduced Dr. Chiara Servili, who is a technical officer at the Department of Mental Health and Substance Use at WHO in Geneva, Switzerland. Dr. Servili acts as the clinical focal point for WHO and the United Nations Children's Fund's (UNICEF) joint program on mental health, psychosocial development, and well-being for children and adolescents. This program will continue to 2030. Dr. Servili focuses on the promotion and protection of mental health in children throughout the world.

Dr. Servili identified three pathways to transform environments and health systems for persons with neurodevelopmental conditions: (1) deepening value and commitment, (2) reshaping environments, and (3) strengthening systems and services. WHO and UNICEF's [Global Report on Children with Developmental Disabilities](#) provides a vision to address the needs of children with developmental disabilities and neurodevelopmental conditions.

UNICEF estimates that 317 million children and adolescents worldwide have developmental disabilities (DD). Although this community needs strong support and care, resources are scarce — with countries spending just 2% of their health budgets on mental health.

The global report highlights health inequalities and discusses social determinants of health (SDOH). Certain SDOHs — such as experiencing poverty, violence, and lower access to education — can lead to obesity, type 2 diabetes, health and respiratory diseases, and mental health conditions. These conditions can result in an increased risk of avoidable, treatable, and/or premature mortality.

The global report also presents an ecological approach in order to optimize trajectories of those with DD in the following areas: health, development, well-being, and participation. This approach encompasses efforts by society, policies, community and services, proximal context, and individuals. Opportunities to employ an ecological approach entail: (1) international commitments, (2) countries' demands and readiness to take action, (3) strong voices from disability and neurodiversity advocates, and (4) an increased attention to mental health.

To help people with DD, the global report listed the following 10 priority actions for its member states: 1) Strengthen coordination and accountability; 2) Deepen commitment at all levels; 3) Promote participation in advocacy, leadership, policy, programming, and monitoring; 4)

Address SDOH, well-being, and social participation; 5) Strengthen multi-sectional policymaking to address inequities in health care; 6) Strengthen services inclusive of all people, centered on evidence-based care; 7) Address stigmatization and foster inclusive enabling environments; 8) Inform, empower, and support caregivers; 9) Strengthen data and research; and 10) Develop inclusive plans and protocols for health surrounding preparedness and response to individuals with DD. Each action is addressed in a specific chapter of the global report. Dr. Servili highlighted several of these priority actions, including policymaking, services, caregivers, participation, monitoring, and research.

The section of the global report on policy making and implementation highlights rights-based approaches to promote health and inclusion for persons with disabilities. Across countries with different economies, researchers have noted consistent gaps in public policies and similar barriers to improving health and inclusion of persons with DD. These gaps lead to persistent human right violations, long waiting lists for services, and more.

Policymaking can improve through three different approaches: (1) adopting a twin-track approach, which encompasses mainstream inclusion services and provides targeted provisions for the empowerment, care, and support of children with DD; (2) considering the health of children with DD in all policies; and (3) reflecting real-life concerns and actively involve young people and their families in policymaking.

The next aspect highlighted of the global report is the transformation of care system and care services. Interventions can be divided into two broad areas: (1) those that focus on promoting health capital, teaching function and skills, and (2) those that remove barriers and promote access to resources. Services should embrace person-centered and family-centered care.

WHO and UNICEF also incorporate the twin-track approach into designing services to health care services includes both (1) access to mainstream interventions and (2) access to targeted resources and interventions.

Over the past few years, WHO has focused on the need to integrate early detection and continuous support for young children into existing health care systems. The principles for organizing and delivering services requires a stepped approach to building tiered care systems. This would allow people access different health care options at various levels of intensity. Care systems must be flexible in order to accommodate the evolving needs of individuals and their families. Individualized service plans are one example of how care pathways can cross sectors and agencies.

Harmful care practices, such as involuntary care and restraint measures and inappropriate prescription of medications, have also been examined by WHO. The keys to ending these harmful practices include strong leadership in care facilities, national policy, strict monitoring of systems, and adequately trained staff.

WHO updated its [Mental Health Gap Action Programme \(mhGAP\) Guidelines for Mental, Neurological, and Substance Use Disorders](#) in December 2023. These official guidelines include a section on autism and intellectual disabilities.

To inform, empower, and support caregivers, WHO has developed a [Caregiver Skills Training \(CST\)](#) program to teach evidence-based parenting approaches to families of children with developmental delays or disabilities. The training, which enhances nonspecialist providers' abilities to teach skills to families, should be integrated into primary healthcare, as has occurred in Italy and Perú.

Strong social participation in different aspects of life is linked to health, well-being, and development. Participation occurs at the community, family, and individual levels. Involving community members in developing services can help surmount barriers to care.

Public health monitoring is needed to hold member states accountable for necessary changes that will improve outcomes for people with DD. Monitoring and evaluation efforts could be strengthened by a dedicated WHO assembly resolution that requires states requirement to report on their efforts.

Research priorities and key recommendations include (1) developing interventions that optimize well-being beyond childhood; (2) understanding of the core social determinants of health inequalities; (3) monitoring system performance; (4) improving transition services and addressing barriers to services; (5) utilizing inclusive approaches when testing early childhood development and mental health interventions; (6) incorporating person-centered and individualized approaches in implementing interventions; (7) researching how to scale-up high quality services; (8) understanding the role of digital technology; and (9) developing strategies to improve participation in research.

Dr. Servili noted that WHO and UNICEF will continue to work together to promote actions that can improve the mental health and well-being of children and young people with DD.

### **Committee Discussion**

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

IACC members asked if WHO has developed services for adults. They also asked how their work on SDOH can be incorporated into vocational training for autistic adults and adolescents. Dr. Servili said that WHO's work on mental health in the workplace includes neurodiversity. They plan to have dedicated discussions with neurodiverse adults on this topic to guide future work. She also said that WHO's lessons on social-emotional learning, which are written for schools, can be adapted for autistic adolescents. Ms. Dena Gassner emphasized the importance of providing autistic adults with leadership opportunities in future work on autism services.

Dr. Gordon said that WHO's plans presented by Dr. Servili highlight many of NIMH's evidence-based approaches and correspond with concerns expressed by the autistic community at IACC meetings. He asked how WHO will disseminate its plan for supporting the autistic community to

other countries and evaluate their progress. Dr. Servili said that WHO can require countries to report on a core set of indicators. WHO is also collecting data on brain health, and autism is one of the priority conditions included under that resolution. WHO also works directly “on the ground” with some member states and countries to help them develop policies and put plans into action.

Dr. Gordon has visited many countries and member states that are engaged in WHO’s mental health programs. He has seen how their programs can be transformative in low resource settings. Dr. Servili noted that some countries did not prioritize DD when implementing WHO programs in the past. WHO has seen a shift in this mindset. In the past year they trained over 2,000 providers on WHO’s *mhGAP* developmental disability module.

Dr. Paul Wang asked Dr. Servili for her thoughts on what the U.S. does well and where they are lagging in support for the autistic community. Dr. Servili said that WHO looks to the U.S. as an example for how it changed the stigma surrounding autism. WHO would like the U.S. to lead the way in forming a common, international narrative around autism. WHO is also concerned about how countries deal with lack of access to diagnostic assessments and early interventions.

Dr. Susan Rivera asked for more detail about WHO’s actions around digital literacy. Dr. Servili said that a focus on digital literacy is new to WHO, and that it is an area for opportunities for participation and inclusion. WHO does not have specific training for digital literacy for autistic individuals.

Ms. Yetta Myrick expressed the need for WHO CST to include autistic adolescents and adults. She asked whether WHO has considered using navigation services to help strengthen family participation. Dr. Servili said that WHO advises countries to use its care navigation model when planning and designing autism services. She highlighted the importance of working with and empowering families.

## **National Autism Coordinator Update**

*Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator*

Dr. Daniels next presented several updates on federal activities related to autism.

President Joseph R. Biden, Jr. issued a [proclamation](#) on April 1 recognizing World Autism Acceptance Day. The U.S. Department of Health and Human Services (HHS) has officially changed its designation of April to National Autism Acceptance Month. There have been several events in honor of Autism Acceptance Month across the nation and the globe:

- On April 2, the Indian Health Service (IHS) posted a message celebrating Autism Acceptance Month and held a webinar on April 5 on Applied Behavior Analysis
- The National Institute for Environmental Health Sciences (NIEHS) held an event with Eric Garcia, the author of *We’re Not Broken: Changing the Autism Conversation*.



- The United Nations (UN) also held an observance event recognizing World Autism Awareness Day, highlighting the experiences of autistic individuals from different regions of the world.
- On April 16, NIMH and ONAC hosted a special event, [Sound Tracks: An Artistic Journey to Belonging](#), which featured multiple autistic artists: photographer Blair Bunting, violinist Laura Nadine, and neurodivergent filmmaker John Schaffer. The event was sponsored by First Place Arizona's Mulzet Center for Expression.

Dr. Daniels and Dr. Gordon co-authored the [NIMH Director's blog post](#) for Autism Acceptance month. The post highlighted the importance of centering the lived experience of autistic people in the development of federal autism research, services, and policies.

Dr. Daniels notified the committee that the *2019-2023 Report to Congress on Federal Autism Activities* would be available on the IACC website soon. The report covers the autism-related activities and efforts of 25 different federal government entities, particularly federal programs on biomedical services research, education, health, employment, housing, disability benefits and services, and justice. The report also includes an update on the implementation of provisions from the Autism CARES Act of 2019.

In his [2024 State of the Union](#) address, President Biden expressed to Congress the importance of increased funding for Medicaid Home- and Community-Based Services (HCBS). The President's budget request for FY 2025 also requests funding for special education services and autism training for providers. In addition, a recent [executive order](#) created more Registered Apprenticeship (RA) programs in the federal workforce.

Dr. Daniels further outlined the activities of other federal advisory committees related to disabilities and autism:

- The Interagency Committee on Disability Research (ICDR) recently launched an Interagency Rehabilitation and Disability (IRAD) [Research Portfolio](#). In addition, ICDR released new toolkits for [participatory action research](#) and [interagency data and statistical collaboration](#).
- The U.S. Food and Drug Administration (FDA) [proposal](#) to ban electrical shock devices (ESDs) for self-injurious or aggressive behavior.
- The Government Accountability Office (GAO) has released a [report](#) on strengthening interagency autism coordination, which was informed by the work of the ONAC and IACC.
- The [U.S. Census Bureau](#) announced its next steps related to the assessing disability using the American Community Survey.

Multiple federal legislative bodies have held hearings on autism and IDD:

- The House Energy and Commerce Committee's Subcommittee on Health held a [hearing](#) on support for patients and caregivers on February 14.



- The Senate Special Committee on Aging conducted a [hearing](#) on disability employment on February 29.
- The House Committee on Small Business had a [hearing](#) on supporting entrepreneurs and employees with disabilities on January 30.

Dr. Daniels also highlighted recent or upcoming activities and updates from non-governmental groups, such as conferences and webinars on autism research and advocacy. This included the International Society for Autism Research conference, which took place in May 2024 in Melbourne, Australia.

A more detailed National Autism Coordinator Update [document](#) is available on the IACC website.

## **IACC Committee Business**

*Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator*

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

There has been one update to the ONAC staff: Oni Celestin, PhD, has been promoted to Deputy Director of ONAC.

The [2019-2020 Autism Research Portfolio Analysis Report](#) is now available. It includes comprehensive information and trends in autism research funding among federal agencies and private research organizations from 2008 to 2020. The report aligns research projects with the objectives from the 2016-2017 IACC Strategic plan. It also includes an analysis on research focused on autism in women and girls and projects focused on racial, ethnic, geographic, and socioeconomic disparities. For the first time, the report includes an accompanying At-a-Glance summary.

The Portfolio Analysis Report includes funding data from 14 federal agencies and 16 private organizations. In 2020, total autism research funding in the U.S. was approximately \$418.9 million across more than 1,500 projects. The largest portion of funding went to research on the underlying biology of autism. The ONAC is currently working on the 2021 and 2022 IACC Portfolio Analysis Reports and will continue to identify U.S. autism research funders for inclusion in the report. The upcoming reports will evaluate research progress using the recommendations for the [2021-2023 IACC Strategic Plan](#).

In 2016, the IACC conducted an [International Portfolio Analysis Report](#) that included autism research funding data from the U.S., U.K., Canada, and Australia. The comparison of portfolios revealed areas of emphasis, similarities, and differences in autism research funding, and gaps. ONAC intends to begin work on a new edition of the international report that will focus on 2023 autism research funding. They are seeking more international collaborators. Several Committee members expressed their support for developing a new report. Dr. Rivera emphasized the importance of bringing in collaborators from countries outside of North America and Europe.

Dr. Daniels encouraged IACC members to connect the Committee with international points of contact.

Ms. Gassner suggested the IACC promote the implementation of systems navigation support for autistic individuals, systems navigations currently just focuses on families. She further suggested that federal agencies examine barriers autistic individuals may encounter to accessing services.

Dr. Helen Tager-Flusberg recommended including autism researching funding from international or multinational organizations such as the European Union in the next international report, rather than just individual countries.

Ms. Lindsey Nebeker asked whether publishing a new international report will impact the U.S. research portfolio. Dr. Daniels responded that they would publish both reports without any effect on their usual portfolio analysis, as both will be produced in house. IACC voted in favor of ONAC taking on this project during the Committee's hiatus.

Committee members noted that the amount of research devoted towards lifespan issues is still small. More research is needed on the later stages of life for autistic people, especially considering the advanced age of some caretakers. Members suggested that the Committee could support calls for proposals specific to aging research, noting the success of past IACC efforts to encourage research on adolescence and the transition to adulthood. Members also noted the need to support directly applicable research. Dr. Gordon noted that the field currently lacks the capacity to give this issue the attention it needs, and that IACC should work to increase interest in these projects.

Dr. Daniels informed the committee that ONAC is currently preparing article summaries for the *2023 IACC Summary of Advances*. The summaries should be ready for review by the July IACC meeting. Dr. Daniels noted that committee members' terms could be extended by 180 days if the publication is not complete by the end of the current IACC term in September. Dr. Gordon also encouraged committee members to nominate articles for the 2024 publication before the July meeting.

The IACC had previously decided to combine the strategic plan update with the co-occurring conditions report. Dr. Daniels updated that committee that the ONAC team has begun working to align the draft with the latest research and equity priorities identified by the IACC. In addition, ONAC put out a Request for Information (RFI) to gather public feedback on the types of co-occurring physical and mental health conditions they want to see included in the report. The RFI received more than 1,200 responses which are available on the [IACC website](#).

Dr. Oni Celestin provided an overview of the results of the RFI. The RFI asked respondents to identify: the most significant challenges caused by physical, mental, and other co-occurring health conditions; what kinds of additional research on co-occurring conditions is needed; what improvements can be made to autism services and supports; and the lasting impact of COVID-19 infection and societal change. The ONAC team reviewed the responses and organized them

into six categories: 1) demographic of respondent, 2) types of co-occurring conditions described, 3) impact of co-occurring conditions, 4) research needs, 5) service needs, and 6) the impacts of the COVID-19 pandemic. More than half of the respondents identified as autistic individuals or a family member. Thirty-nine percent of respondents identified as belonging to multiple groups.

The top ten co-occurring conditions were 1) sensory and motor, 2) anxiety, 3) sleep, 4) attention deficit hyperactivity disorder (ADHD), 5) gastrointestinal issues, 6) mood disorders, 7) communication challenges, 8) self-injurious or aggressive behavior, 9) learning and memory difficulties, and 10) suicidal ideation. The top ways in which these conditions impacted autistic individuals were difficulty finding providers, communication issues, social challenges, bias and stigma, executive function challenges, inaccessibility and lack of accommodations, academic challenges, difficulty with daily living skills, and reduced health and well-being.

Responses to the RFI regarding research needs were aligned with the question areas from the strategic plan, with respondents ranking autism biology, interventions, and services and supports as the greatest research needs. In terms of service improvements needed, respondents highlighted provider training, more insurance coverage, accessibility of services, personalized services, and services systems improvements. Finally, responses identified a variety of impacts of the COVID-19 pandemic on autistic people, including benefits from new remote technologies, new or exacerbated health challenges, hardships due to increased isolation, decreased availability of services, disruption of routines or regression, benefits from reduced social obligations, and hardships caused by a lack of in-person services. A full analysis of the RFI responses will be available with the draft of the report. IACC members will have an opportunity to discuss a draft of the full report in the future, and input from that discussion will be incorporated into a second draft. Full publication is anticipated during December 2024.

Ms. Myrick suggested that ONAC include recommendations for capacity building. Dr. Julie Lounds Taylor noted that reimbursement issues prevent many providers being able to devote additional time to provide care, which particularly impacts patients on public health insurance. Dr. Gordon suggested that the report could include references to billing codes that account for the increased time that it takes to care for patients with complex needs. Ms. Myrick also noted that [Got Transition](#) (the National Resource Center for Transition) has previously provided a coding and payment tip sheet for the transition from pediatric to adult healthcare. Ms. Myrick disclosed that she had previously served on Got Transition's Health Care Transition Family Advisory Group but did not contribute to the tip sheet. Dr. Thomas Frazier added that adult services and day programs also experience similar insufficient reimbursement rates that impact their ability to enroll autistic individuals.

Dr. Aisha Dickerson suggested that future reports could separate autism biology into different questions or include smaller sub-categories indicating different fields of biology. Dr. Daniels stated that the portfolio analysis report does employ sub-category coding and that the committee can consider adding similar sub-categories to other reports.

Dr. Scott Robertson noted his appreciation for the inclusion of both qualitative and quantitative data regarding the needs of autistic people and for the practical implications for policy that could be informed by the report.

Dr. Wang highlighted the need for more translational research on services and community-based support. However, he also emphasized the continuation of federal funding for basic research, as many fundamental aspects of autism biology are not fully understood, such as the main drivers of sleep difficulties and sensory issues in autistic people.

The [IACC Round Robin Updates](#) are available on the IACC website.

## Public Comment Session

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

*Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator*

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

## Oral Comments

Dr. Sharief Taraman is a pediatric neurologist and former division chief of pediatric neurology at The Children's Hospital of Orange County (CHOC). He is also an associate professor at the University of California – Irvine and affiliate professor at Chapman University. Dr. Taraman highlighted the high number of requests for autism evaluation and diagnosis at CHOC due to families and caregivers not receiving evaluation at local autism or neurodevelopmental centers. Within the last five years, Dr. Taraman has seen an increase in the number of older children and adults who are often persons of color, children of lower socioeconomic status, and children of immigrants seeking an evaluation for a concern that commonly results in an autism diagnosis. Dr. Taraman believes these people could have received an earlier diagnosis and early interventions but were unable to receive care due to a shortage of specialists. Dr. Taraman is also the CEO of Cognoa, a health technology company that is developing a diagnostic using artificial intelligence to support primary care physicians and support evaluations of neurodevelopmental conditions. Furthermore, Dr. Taraman emphasized the importance of alleviating the burden of evaluation and diagnosis from specialists, allowing them to focus more on treatment, and leveraging primary care physicians to take on a portion of the diagnostic and evaluation process for neurodevelopmental conditions and autism.

## Summary of Written Public Comments

IACC received nine written [public comments](#) for the April 2024 meeting. Comments focused on the following topics: research and service needs, resources, and policy implications (3); mental health research, services, and treatment (2); the role of IACC and the Federal Government (2); addressing the needs of autistic individuals with high support needs (1); inclusion of autistic perspectives in research (1).

**Committee Discussion**

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

Dr. Wang noted that Dr. Taraman's statement could be biased by his financial interest in his company, Cognoa. Dr. Wang suggested that the IACC implement a requirement for disclosure of financial conflicts of interest in public comments. Dr. Tager-Flusberg shared Dr. Wang's concern and suggested a system of flagging comments that do not have significant scientific basis. Dr. Gordon clarified that IACC is unable to edit or reject public comments.

Ms. Gassner highlighted Ms. Jinny Davis's comment concerning representation of Social Security Disability recipients on the IACC and noted that she and several other IACC members are Social Security Disability recipients. She encouraged Ms. Davis to apply to become a Committee member to increase representation of people receiving Social Security benefits for disabilities.

Dr. Robertson highlighted several comments raising concerns about employment opportunities and job retention for autistic people. He noted his appreciation for the diverse voices providing input on their employment experiences as autistic people.

Ms. Nebeker pointed to a comment from Ms. Lisa Morgan, who highlighted that autistic people who are in crisis are concerned that they might have a harmful experience accessing support due to their communication differences and sensory issues. Ms. Nebeker noted the need for more training on autism for first responders, emergency room professionals, and crisis center workers.

Several members called attention to a comment from Ms. Tiffanie Smith, who has experienced difficulties locating providers who can address the needs of her non-speaking autistic son. Committee members noted that this is reflective of a larger issue for non-speaking autistic people seeking medical care. Autistic individuals who move frequently or live in remote areas also face this issue. Telehealth has relieved some of this burden for people in isolated areas, but barriers to telehealth still exist. Members also discussed the need for capacity building for providers. Ms. Myrick also encouraged the Committee to review the consensus statement from the [Supporting Access for Everyone \(SAFE\) initiative](#) that discussed developing healthcare standards for youth with neurodevelopmental disabilities.

Dr. Wang asked Dr. Tiffany Farchione from the FDA to provide insight on potential court challenges to the FDA's ban on ESDs for aggressive and self-injurious behaviors. She did not have additional insight beyond what is publicly available. Dr. Robertson noted that previously the FDA ban had been overturned by the courts due to limitations on the FDA's ability to regulate the practice of medicine, as the FDA did not issue an outright ban of ESDs. The latest activity may be related to that court decision.

Two members of the audience provided clarification on this issues: Mr. Greg Robinson from the Autistic Self Advocacy Network stated that the previous court decision was on the basis that the FDA did not have the legal authority to introduce a ban on specific practices. However, the 2022

Omnibus Appropriations Bill included language that clarified the FDA's authority to ban a devices for a specific use. The new FDA rule is largely the same as before. Mr. Stuart Spielman of Autism Speaks clarified that the FDA's authority was changed by the appropriations bill.

Ms. Nebeker expressed appreciation for Dr. Gordon's work and dedication over the past seven years.

## **Presentation Session: Global Perspectives on Autism**

*Planned Collaboratively by the U.S. Office of National Autism Coordination/NIMH/NIH and the Autism Alliance of Canada*

Dr. Gordon introduced the Global Perspectives on Autism session and highlighted that this session was held jointly with the Canadian Autism Leadership Summit in Ottawa, Canada. The leadership summit was organized by the Autism Alliance of Canada, which seeks to inform policy and practice at a national level. Membership includes autistic individuals and their family members, clinicians, advocates, service providers, researchers, and policy influencers from across Canada.

### **Autism Speaks Global Autism Public Health Initiative**

*Andy Shih, Ph.D., Chief Science Officer, Autism Speaks*

Dr. Andy Shih is the Chief Science Officer for Autism Speaks. He outlined the international efforts of Autism Speaks under their Global Autism Public Health Initiative (GAPH). GAPH is a community participatory research and advocacy effort intended to inform autism policy development, provide technical advice to national governments, and ensure the inclusion of autistic individuals and their families in the policy process. The initiative's main programmatic pillars are research, policy, capacity building, and advocacy.

Dr. Shih described the WHO CST program, which was developed in partnership with Autism Speaks. The WHO CST empowers caregivers with skills they can use in daily routines to promote development. It has been implemented in more than 35 countries. The program is for caregivers for autistic children aged two to nine years with developmental delays or disabilities, with a specific emphasis on caregivers of children with social and communication delays. The program consists of nine group sessions and three at-home visits. It focuses on engaging children in everyday activities, understanding and improving children's communication and behavior, teaching everyday life skills, and promoting the well-being and problem-solving skills of caregivers. During home visits, facilitators coach and provide feedback to caregivers in a natural play and living environment. The CST utilizes naturalistic and developmental approaches for promoting shared engagement and communication, encourages positive parenting approaches through the promotion of positive behavior and management of challenging behavior, and promotes caregiver problem solving and well-being.

Dr. Shih also highlighted eLearning CST (eCST), which was recently developed to facilitate self-paced learning for caregivers, allowing more caregivers to receive crucial training. It is currently being translated into Arabic, Chinese, Spanish, Hindi, Marathi, Yoruba, and Portuguese. WHO

has trained over 250 Master Trainers worldwide, who will take over training caregivers in their own countries. Eight states in the U.S. have opened CST sites, with more planned.

Dr. Shih noted several findings for field testing of CST/eCST in both high-income countries (HIC) and low- and middle-income countries (LMIC). They found that CST has a high level of feasibility of implementation, was well-received by caregivers, and can be adapted for a variety of remote-delivery options. Caregivers have reported increased confidence in their parenting skills as well as a reduction in stress. In the near-term, Autism Speaks aims to explore incorporation of CST into U.S. programs and systems such as Head Start and Part C Early Intervention. Long term, they seek to make CST as broadly accessible as possible. Internationally, Autism Speaks hopes to continue to increase the number of countries implementing CST and create an online community of practice to enhance its accessibility.

Dr. Shih then outlined the Autism Speaks Advocacy Leadership Network (ALN), which is responsible for the implementation of approximately half of the existing CST sites. The ALN includes international leaders in autism advocacy, including self-advocates, families, professionals, and policy makers. The network also utilizes social media to regularly engage with the community and hosts biennial workshops and working groups to collaborate and exchange knowledge. The ALN focuses on advocacy, dissemination, implementation, and research and has produced multiple UN and World Health Assembly resolutions and the *Global Report for Children with Developmental Disabilities*. Since its inception in 2010, the ALN has grown to incorporate a diverse range of experts and advocates from a variety of countries and now hosts regional workshops across the globe. The ALN is currently developing an Advocacy Training Package, which was designed with input from autistic adults for use by other autistic individuals. They intend to launch an African Research Consortium for Neurodevelopmental Disabilities. The next Biennial Meeting will be in 2025.

### **Australia's National Autism Strategy**

*Pru McPherson, LL.B., Director, Autism Policy, Foundational Support and Early Childhood Reform Branch, Department of Social Services of the Australian Government*

Ms. Pru McPherson is the Director of Autism Policy at the Australian government's Department of Social Services (DSS). DSS aims to improve the economic and social well-being of Australians through social security assistance, support for families and communities, improved choice and autonomy for individuals with disabilities, and housing support. They launched the [National Disability Strategy](#), a ten-year national policy framework for disability, in 2021. In 2022 the Australian Government committed to the development of the National Autism Strategy (NAS). The Australian Government also committed to the development of the [National Roadmap To Improve the Health and Mental Health of Autistic People](#) (the Roadmap).

The NAS is expected to: 1) be a whole-of-life plan; 2) build on the understanding and recognition of autism; 3) improve service integration and coordination at all levels of government; 4) make education, employment, and health care more inclusive and accessible; 5) provide better support for parents and carers; 6) establish a national autism research agenda.



The development of the NAS has been divided into three phases, two of which are complete. The first phase of development aimed to create an evidence base by assessing current research and data. The DSS developed a discussion paper that outlined previous input from autistic and disabled people, researchers, professionals, and the broader community. Various disability representative organizations commissioned additional papers on key areas that impact different communities, including First Nations autistic people, autistic women and girls, and autistic people with intellectual disabilities. The Minister for Social Services also held a number of meetings with international representatives. Phase one also saw the creation of the National Autism Strategy Oversight Council to ensure that the voices of the community are included in the NAS. The Council is supported by four working groups that focus on key outcome areas: 1) social inclusion; 2) economic inclusion; 3) diagnosis, support and services; 4) and health and mental health. Working groups consisted of people from the autism community, researchers, and government representatives.

In the second phase of NAS development, the Australian government engaged a third-party group to conduct a national consultation process around the country from September to December 2023. Consultations included a variety of engagement activities, which were co-led by autistic people, including a discussion paper, a public submission process and questionnaire, community consultations, autistic voices forums, a webinar, and one-on-one interviews. Phase two also included methods for engaging marginalized or hard to reach groups, such as First Nations communities, culturally and linguistically diverse communities, autistic women and people who communicate with methods other than spoken language, autistic LGBTQIA+ people, autistic children and young adults, older people, and people with complex support needs and co-occurring conditions. More than 2,000 people contributed to the consultation and identified five major themes: (1) inclusion; (2) acceptance; (3) recognition of autistic strengths; (4) recognition of individual diversity and capacity; (5) better quality of life.

These first two phases resulted in the release of the Draft National Autism Strategy in April 2024, which is undergoing a public consultation process and will be submitted to the Australian government by the end of 2024. The draft includes a vision for a safe, inclusive, society where all autistic people can fully participate in all aspects of life and lays out a specific goal of improving life outcomes for all autistic people. The guiding principles of the draft strategy emphasize coordination and partnership with autistic individuals at all phases, accessibility, self-determination and autonomy for autistic people, aligned outcomes across government policies, acceptance and inclusivity, respect for the rights of all people, and recognition of individual and holistic factors. The NAS draft also outlines 24 policy commitments from the Australian government in social inclusion, economic inclusion, diagnosis, services and supports, governance, research and evidence, and evaluation and reporting.

### **Canada's Autism Strategy**

*Mark Nafekh, Director General, Centre for Health Promotion, Public Health Agency of Canada*

Mr. Mark Nafekh leads the Public Health Agency of Canada's (PHAC) autism policy team, who are developing a person-centered autism policy that addresses the complex and diverse needs

of autistic people in Canada. The PHAC is developing two documents to guide autism policy: a [Framework for Autism in Canada](#) and [Canada's Autism Strategy](#). These policy guides were developed with provincial and territorial governments as well as autistic individuals, caregivers, family members, indigenous partners, and other stakeholders. The autism framework will outline broad principles and best practices for national autism policy, programs, and activities at all levels of government. The Autism Strategy will focus on short and medium-term federal initiatives and builds on existing programs and measures over the course of multiple years. It supports the implementation the autism framework.

The PHAC coordinated with the Canadian Academy of Health Sciences to conduct an assessment on autism, including a scientific review and consultation process. They also hosted a national conference in 2022 that brought together a diverse array of autism advocates and stakeholders. The activities helped to inform the development of the framework and the strategy. The development of the framework and strategy were also informed by international commitments and will respect the principles established by the UN Convention on the Rights of Persons with Disabilities. Mr. Nafekh noted the PHAC took cues from autism initiatives in the U.S. and the U.K., which emphasize the lived experiences of people with autism in the development of autism strategies.

The framework and strategy outline five priority areas for autism policy: (1) screening, diagnosis, and services; (2) financial support; (3) data collection, public health surveillance, and research; (4) public awareness, understanding, and acceptance; (5) tools and resources.

A challenge to Canadian autism policy is the shared responsibility of the federal, provincial, and territorial governments in social services, education, and medical care. The PHAC works aims to foster collaboration through a variety of efforts such as the Federal, Provincial, Territorial Working Group on Autism, which was established in 2022. Also, the PHAC aims to ensure the voices of autistic Canadians are considered in the Disability Inclusion Action Plan led by the Ministry of Employment and Social Development. The plan includes federal initiatives seeking to help persons with disabilities find jobs, advance in their careers, or become entrepreneurs; support employers as they develop inclusive workplaces; and aid organizations and individuals who support persons with disabilities and employment. The PHAC and other federal government agencies will also include input from national Indigenous organizations.

Finally, the PHAC is developing an implementation plan to put in action the recommendations and policies included in the autism framework and Canada's Autism Strategy. This implementation plan will be developed in collaboration with a national autism network. This will include the creation of advisory committees that includes partners, stakeholders, and people with lived experiences. Mr. Nafekh emphasized the importance of including diverse voices in the development of the framework and strategy and re-asserted the crucial role of autistic individuals and advocates in the development of autism policy.

**Enhancing Support for Autistic Children in Egypt**

*Menan Abdelmaksoud, M.D., Secretary General for Mental Health and Addiction Treatment, Ministry of Health and Population of the Government of Egypt*

Dr. Menan Abdelmaksoud leads the General Secretariat of Mental Health and Addiction Treatment, which is responsible for providing mental health and addiction treatment prevention programs and awareness campaigns in Egypt. The General Secretariat aims to provide quality services for children and adolescents without stigma across Egypt. The initiative to support autism care and awareness in Egypt began in 2012, when the Egyptian government partnered with the Embassy of Slovenia to create an implementation plan. The plan included a model of autism services as well as national recommendations. There are autism clinics in three of Egypt's governorates, each of which have different demographics.

The next step for the General Secretariat was to develop a national autism framework alongside the Egyptian legislature, including adding autism to the nation's disability protection law. The CST program began in Egypt in 2016 with the support of WHO and Autism Speaks. CST implementation began with the training of Master Trainers who trained caregivers in Cairo, Alexandria, and Assiut. The COVID-19 pandemic led to the implementation of the online training program. Trainees have responded enthusiastically to the online CST option.

A breakthrough in their efforts occurred when the Egyptian Minister of Health, Dr. Khaled Abdel Ghaffar, presented Egypt's autism plan and framework to the international community. Dr. Ghaffar later announced a presidential initiative to promote the early detection and treatment of autism and develop supports for caregivers. With the support of the Minister of Health, the General Secretariat trained staff at primary care facilities on how to recognize signs of autism and how to provide initial support for families. In addition, the General Secretariat introduced the National Mental Health Platform of Egypt, a public online resource that provides tools for caregivers to assess the social, mental, and psychological development of their child. Dr. Abdelmaksoud highlighted a prototype of an autism center developed by the General Secretariat and Ministry of Health, which includes playrooms for children and facilities to conduct parent and caregiver assessments. She stated that the government aims to open similar facilities in each of Egypt's regions over the next half decade.

Dr. Abdelmaksoud also highlighted some of Egypt's public awareness efforts related to autism, including the recognition of International Autism Day in which Egypt's famous monuments were lit with blue lights. She further noted the role of journalism in spreading awareness. Other forms of entertainment media have also played a role in autism awareness in Egypt, such as the film Arabic "Hala Khasa" (Special Case) which Dr. Abdelmaksoud credited with spreading awareness of the characteristics of autism. Finally, Dr. Abdelmaksoud highlighted the upcoming International Mental Health Conference, which will focus on autism, in Alexandria, Egypt from April 18-20.

Lastly, Dr. Abdelmaksoud outlined some key challenges to autism policy and awareness in Egypt. A main challenge is capacity building, as there is high turnover among medical professionals due to low pay. The next challenge is to develop an efficient supervision system to

monitor and regulate service provision, which is difficult due to the size, diversity, and isolation of parts of Egypt's geography and population. The next challenge is continuous learning that will keep Egyptian providers up-to-date in advancements in the field. Finally, the General Secretariat must establish effective partnerships to ensure resources are available across the country.

### **Committee Discussion**

Ms. Myrick asked what lessons were learned from engaging with autistic individuals and carers. Ms. McPherson stated that they learned the importance of time: autistic people need time to prepare, and the Government needs to take the time to provide accommodations. Ms. Gassner expressed her concern about the utilization of M-CHAT, as some people might be left behind. She also asked Dr. Shih how autistic leadership has influenced their work and the use of applied behavior analysis (ABA) in the WHO CST training. Dr. Shih stated it is important to recognize the priorities in the U.S. may not be the same priorities in other countries, and this may depend on what resources are available. In implementing CST, WHO and Autism Speaks work with smaller communities in order to facilitate change and influence national programs. Dr. Robertson expressed interest in learning from other countries between the iterations of the Committee. Mr. Nakfeh stated that Canada is interested in having people with lived experiences drive new initiatives. Dr. Shih expressed that learning about challenges from those with first-hand experiences is the most important value of the ALN.

### **Panel Discussion: International Autism Research and Advocacy**

*James Cusack, Ph.D., Chief Executive, Autistica (United Kingdom)*

*Gauri Divan, Ph.D., Director, Child Development Group, Sangath (India)*

*Liliana Mayo, Ph.D., Executive Director and Founder, Centro Ann Sullivan del Perú*

*Amina Abubakar, Ph.D., Professor and Director, Institute for Human Development, Aga Khan University (Kenya)*

*Clare Gibellini, Autistic Co-Chair, National Autism Strategy Oversight Council (Australia)*

*Moderated by: Susan Daniels, Ph.D., Director, ONAC, NIMH; Executive Secretary, IACC; HHS National Autism Coordinator, and*

*Karen Bopp, Ph.D., Co-Chair, Autism Alliance of Canada Board of Directors*

Dr. Daniels introduced her panel co-host, Dr. Karen Bopp, as well as the panelists. Discussion centered around four questions: (1) What is your role in advocacy or research in your country? (2) Can you share some background on the perception of autism in your country, major challenges faced in your country, and how your work is helping to address those challenges? (3) What role are parent advocates, autistic self-advocates, advocacy organizations, and the government playing in addressing autism in your country? (4) What progress do you hope to see regarding inclusion and support for all autistic people across the life course in your country in the next 5 years?

Panelists introduced themselves and described their roles in autism advocacy and research:

- Dr. Amina Abubakar is a professor and developmental psychologist who specializes in autism research in East Africa. She also works closely with parent advocacy groups.
- Ms. Clare Gibellini is an autistic woman who works in disaster preparedness with a specific focus on autistic individuals. She also conducts policy work to increase employment opportunities for people with autism.
- Dr. Gauri Divan is a developmental pediatrician and director of a non-profit organization. She seeks to improve resources for young children with autism and their families.
- Dr. James Cusack is autistic, he works to improve the lives of autistic people in the U.K. through research and campaigning. He is also a board member of INSAR.
- Dr. Liliana Mayo is an advocate and clinician dedicated to enhancing the lives of people with IDD. She seeks to empower families to foster independence and productivity in their loved ones.

Panelists highlighted challenges faced by their countries:

- Lack of autism awareness: Teachers, healthcare workers, and others lack adequate understanding of autism. As a result, parents of autistic children do not know who to ask for help and many do not receive a diagnosis.
- Negative perceptions of autism: Stigma against autistic individuals results in reluctance to receive a diagnosis, marginalization, low expectations, and parents hiding their autistic children. Autistic people may be reluctant to disclose their diagnosis, which leads to being unable to access accommodations, services, and care. Stigma also creates barriers to inclusion in the workplace and other areas of life.
- Lack of resources: Certain places, such as low-resource or rural areas, lack culturally appropriate and accessible resources. Some countries also have a lack of services and evidence-based interventions, particularly for adolescents and adults. Countries also lack specialist care clinicians.
- Lack of detection and prevalence tracking: It is difficult to push for policy changes in countries that do not have accurate autism prevalence data.
- Long waitlists: As an example, the waiting list for an autism diagnosis in the U.K. has grown by 5 times since before the pandemic, and there are currently 172,000 people waiting for a diagnosis. Such issues make it difficult to implement an autism strategy.

Several panelists are working to develop tools to aid in autism diagnosis and intervention. Tools should be culturally appropriate, open source, accessible, language-free, and not require the use of WiFi. Panelists discussed training non-specialists to use these tools.

Panelists highlighted the role that parent advocates, autistic self-advocates, advocacy organizations, and the government play in addressing autism in their countries:

- Panelists discussed the importance of including parent and autistic-self advocates in their work. They agreed that it is necessary to include a variety of perspectives and lived

experiences when creating policies, discussing language, developing services and supports, and creating a shift towards acceptance.

- Panelists stated that parents are strong advocates for their children, and help get their children the services they need while promoting acceptance. For example, Dr. Abubakar and her team established a stakeholder group composed of academic institutions, parents, and government officials who collaborate to support children and families.
- However, panelists noted tension that sometimes occurs between parent advocates and autistic self-advocates. They expressed the importance of developing services that meet the needs of both parents of autistic children and autistic self-advocates.

Panelists discussed progress they hope to see regarding inclusion and support for all autistic people across the life course in their countries in the next 5 years:

- Support for transition-aged youth to ensure economic inclusion of autistic people. Autistic people should be included and supported in all workspaces, such as emergency management, defense forces, and more.
- Development of pathways to care so that autistic individuals and their parents can easily access support.
- Better awareness of intersectionality and how different identities impact how autistic individuals interact with different systems (e.g. how identifying as both autistic and First Nations impacts interactions with the healthcare, education, and housing systems).
- Improvement of fit-for-purpose diagnostics to aid in obtaining accurate autism diagnoses.
- Increased equitable access to autism resources, therapies, treatments, and healthcare.
- Increased accessible public spaces for autistic and disabled people, such as the consideration of sensory needs in architectural designs.
- Representation of autistic people on corporate boards and government agencies.
- Reduction of the stigma around autism.
- Incorporation of evidence-based best practices into policies and supports.
- Training for educators and parents on how to support children with autism.

## **Closing Remarks and Adjournment**

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

Dr. Gordon thanked the panelists and presenters for their insights.

The next IACC Full Committee Meeting will be held on July 10, 2024, in a hybrid meeting format, and meeting updates will be available through the IACC website.