

Interagency Autism Coordinating Committee (IACC)

Full Committee Meeting

October 11, 2023

November 28, 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 are gratefully acknowledged: Sparsha Muralidhara, Christy Huffman, and Cherie Dewar.

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a hybrid meeting on Wednesday, October 11, 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, National Autism Coordinator, Director, Office of National Autism Coordination (ONAC), NIMH; **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA)(representing Anita Everett, M.D., D.F.A.P.A.); **Amanda Bryans**, M.S., Administration for Children and Families; **Anita Everett**, M.D., D.F.A.P.A., SAMHSA; **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (representing Debara Tucci, M.D., M.S., M.B.A., F.A.C.S.); **Sam Crane**, J.D. Quality Trust for Individuals with Disabilities; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Tiffany Farchione**, M.D., U.S. Food and Drug Administration; **Dena Gassner**, Ph.D., M.S.W., Adelphi University; **Morénike Giwa Onaiwu**, Ph.D., Rice University; **Kristina Hardy**, Ph.D., National Institute of Neurological Disorders and Stroke (representing Walter J. Koroshetz, M.D.); **Alycia Halladay**, Ph.D., Autism Science Foundation; **Craig Johnson**, M.Ed., Founder and President, Champions Foundation; **Jennifer Johnson**, Ed.D., Administration for Community Living; **Alice Kau**, Ph.D., Eunice Kennedy Shriver National Institute of Child Health and Human Development; **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (representing Richard Woychik, Ph.D.); **Leah Lozier**, Ph.D., U.S. Department of Housing and Urban Development; **Alison Marvin**, Ph.D., Social Security Administration; **Matthew Miller**, Ph.D., M.P.H., U.S. Department of Veterans Affairs; **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/ Trainer; **Jenny Mai Phan**, Ph.D., University of Wisconsin—Madison; **JaLynn Prince**, B.F.A., Madison House Autism Foundation; **Laura Raskin Ramos**, M.P.H., Health Resources and Services Administration; **Susan Rivera**, Ph.D., University of California, Davis; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL)(representing Taryn Mackenzie Williams, M.A.); **Barbara Roland**, Indian Health Service; **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (representing Karyl Rattay, M.D., M.S.); **Matthew Siegel**, M.D., Tufts University; **Ivanova Smith**, B.A., University of Washington; **Hari Srinivasan**, B.A., University of California, Berkeley; **Jane Simoni**, Psy.D., Director, Office of Behavioral Sciences and Research, NIH (on behalf of Lawrence Tabak, D.D.S., Ph.D.); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., Department of Defense; **Taryn Mackenzie Williams**, M.A., Assistant Secretary, Office of Disability Employment Policy, DOL

Welcome and Announcements

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

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

Drs. Joshua Gordon and Susan Daniels welcomed participants to the meeting and gave a brief overview of the meeting agenda, noting that all meeting materials could be found [on the IACC website](#). Dr. Gordon acknowledged the NIMH's 75th anniversary and encouraged participants to learn more about the NIMH's work on its [website](#). Dr. Gordon also acknowledged several IACC member updates, as listed below:

- Dr. Daniels was appointed as the National Autism Coordinator in May 2023;
- Dr. Julie Taylor was appointed Co-Director of the Vanderbilt Kennedy Center University Center for Excellence in Developmental Disabilities Education, Research, and Service;
- Mr. Craig Johnson recently completed his Master of Education in Special Populations; and
- Ms. Dena Gassner recently had her dissertation defense accepted.
- Dr. Jane Simoni will now serve as the alternate for Acting NIH Director Dr. Lawrence Tabak
- Ms. Barbara Roland is replacing Ms. Skye Bass as the representative for Indian Health Service

The IACC voted to approve the [April 2023 minutes](#), which have been posted to the IACC website.

National Disability Employment Awareness Month (NDEAM) Recognition

Anupa Geevarghese, Esq., Chief of Staff, Office of Disability Employment Policy (ODEP), DOL

The 2023 NDEAM theme of advancing access and equity commemorates 50 years since the Rehabilitation Act of 1973 (Rehab Act), the first piece of legislation to formalize equal employment opportunities for people with disabilities. Ms. Anupa Geevarghese commended President Joseph R. Biden's recent executive order to expand diversity, equity, inclusion, and accessibility (DEIA) within the federal workforce and highlighted ODEP's own efforts in its commitment to DEIA. ODEP's Employer Assistance and Resource Network (EARN) provides guidelines and training resources for employers to accommodate neurodiverse employees, including a Workplace Mental Health Toolkit. ODEP also funds several other initiatives to support neurodiverse members of the workforce, including funding the Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS), the Job Accommodation Network (JAN), and a recent project for employing individuals with varying mental health conditions called Advancing State Policy Integration for Recovery and Employment. Ms. Geevarghese encouraged IACC members to [host NDEAM events](#) throughout

October and thanked the Committee for their ongoing efforts to support economic opportunities and the overall quality of life for people with disabilities.

National Autism Coordinator Update

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

White House Updates

President Biden recently issued proclamations that focused on NDEAM, the 50th anniversary of the Rehab Act, and the 33rd anniversary of the Americans with Disabilities Act (ADA). President Biden announced plans to nominate Dr. Monica Bertagnolli as Director of the NIH. Dr. Bertagnolli will be invited to speak at a future IACC meeting.

Federal Committee Updates

Dr. Daniels presented the following updates from various federal committees:

- The Interagency Committee on Disability Research (ICDR) completed several webinars and held its annual stakeholder meeting regarding social equity considerations for people with disabilities, which included a [State of the Science Conference on Disability Statistics](#).
- The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council recently held its first meeting of the new council and launched the Advisory Council to Support Grandparents Raising Grandchildren. The two Councils met to address RAISE's national strategy to support family caregivers.
- The National Council on Disability (NCD) released a report last May about the impacts of extreme weather on people with disabilities. NCD is preparing for a November council meeting that will focus on housing and transportation issues within the disabled community.
- The Federal Partners in Transition (FPT) workgroup met in August for a general committee meeting about disability resources for Native Americans and for a steering committee meeting to continue developing the FPT Strategic Plan.
- The Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) will meet on October 18 to discuss various issues related to serious mental illness and serious emotional disturbance.
- The Disability Advisory Committee held a committee meeting in September about the intersection of disability rights, artificial intelligence (AI) accessibility, and audio descriptions for media.
- The President's Committee for People with Intellectual Disabilities held a committee meeting in May that focused on the support needs for home- and community-based services (HCBS).
- The National Advisory Committee on Individuals with Disabilities and Disasters held a joint public meeting with the National Advisory Committee on Seniors and Disaster to discuss each committee's respective reports and recommendations.

- The Coordinating Council on Access and Mobility held a public webinar and approved its Strategic Plan.
- The Interagency Task Force on Trauma-Informed Care published its Strategic Plan in November 2021.

Federal Department and Agency Updates

Dr. Daniels presented the following updates from federal departments and agencies:

- The NIH and National Institute on Minority Health and Health Disparities (NIMHD) recently designated people with disabilities under their recognized populations with health disparities.
- NIH released a Notice of Funding Opportunity for research regarding the intersecting impacts of social determinants of health on health care access and health outcomes.
- NIH also issued a public Request for Information (RFI) on language updates to the NIH mission statement with a deadline of November 24.
- A proposed update to Section 504 of the Rehab Act would prohibit discrimination on the basis of disability in HHS-funded programs; this proposal is currently accepting public comments through November 13.
- Nearly 500,000 families and children wrongly dis-enrolled from Medicaid or the Children's Health Insurance Program regained coverage following Centers for Medicare & Medicaid Services' (CMS) effort to correctly identify people eligible for those programs.
- Initiatives by the Department of Justice (DOJ) and DOL have advanced additional programs focused on ensuring accessibility for public services.

Dr. Daniels presented the following updates on her activities as the National Autism Coordinator:

- The Federal Interagency Workgroup on Autism met in September and plans to meet in November to discuss agency initiatives and activities related to autism.
- Dr. Daniels spoke in June 2023 as a panelist about the IACC's Strategic Plan at the Conference of States Parties to the Convention on the Rights for Persons with Disabilities at the United Nations in New York City.
- Dr. Daniels gave a keynote lecture on the IACC's work, "Federal Efforts to Strengthen the Neurodiverse Community" and hosted a panel featuring neurodivergent members of the IACC at the 2023 Stanford Neurodiversity Summit in October.
- Dr. Daniels will speak about the IACC the Ohio Center for Autism and Low Incidence online conference in November 2023.
- ONAC also attended the International Society for Autism Research (INSAR) conference in Stockholm, Sweden in May and shared updates about the IACC at the IACC booth and poster session.

Round Robin Updates

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

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

Dr. Gordon noted several events being hosted by the NIMH for its 75th anniversary, which include symposia, lectures, scientific meetings, and various media campaigns that highlight the Institute's achievements. IACC members shared the following autism advocacy updates:

- Quality Trust for Individuals with Disabilities received additional grant funding to develop best practices to support individuals with intellectual and developmental disabilities (I/DD) affected by sexual abuse, and it will soon release initial findings in a grant report.
- At the April IACC meeting, the Committee discussed a proposal by the Accreditation Council on Graduate Medical Education (ACGME) that sought to change requirements for pediatrician training. The Committee issued a statement cautioning that this proposal could negatively impact care for autistic children. Dr. Paul Wang shared that ACGME has decided against continuing with their proposed changes.
- DC Family Voices published a white paper and executive summary about patient-centered research for autistic individuals in the African American community.
- ODEP published several materials for public access, including (1) blog posts about disability research related to both NDEAM and National Hispanic Heritage Month, (2) a report about vocational rehabilitation services, and (3) upcoming materials for National Apprenticeship Week.
- The Social Security Administration's (SSA) Supported Employment demonstration project found that individuals receiving intervention had significantly higher employment rates than individuals who did not receive intervention; all reports from the demonstration project have been released for public access. The SSA also created Spanish translations for their public materials to increase accessibility. Upcoming SSA meetings will address (1) amendments to disability determination criteria, and (2) the National Disability Forum for redetermination of disability when people transition from adolescence into adulthood.
- SAMHSA Interdepartmental Health Committee and Interdepartmental Substance Use Disorders Coordinating Committee will hold respective meetings, which will be open to public comment.
- ED's Office of Special Education Programs distributed \$35 million in personnel preparation grants to support roughly 6,000 students in disability-related fields of study. Other available sources of grant funding exist for doctoral candidates in disability education and for students from historically Black colleges and universities.
- The Autism Science Foundation's special interest group that focuses on aggressive behaviors in autism is seeking interested members. The foundation also launched an online forum to facilitate support networks for siblings of autistic people.

- The Madison House Autism Foundation’s pilot program in Utah has collected data from autistic adults to inform policy regarding specific housing needs of autistic individuals living in municipalities.
- The Administration for Community Living (ACL) recently launched an enhanced website for the Disability Information and Access Line to centralize resources for state and local ACL services. The ACL and the Administration on Disabilities disbursed awards for multiple projects, including (1) the National Center for Disability Grassroots Advocacy, (2) peer-to-peer support models for augmentative and alternative communication (AAC), and (3) the I/DD Counts Initiative.
- The Champions Clubs Foundation worked in war-torn areas of Ukraine to establish help centers to support families of children with autism and I/DDs, and it recently launched its first site in Bucha.

IACC Committee Business

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

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

IACC Strategic Plan and Committee Activity Update

The 2021-2023 [IACC Strategic Plan for Autism Research, Services, and Policy](#) has been published in both full text (200 pages) and easy-read (16 pages) versions. The Strategic Plan will be submitted to Congress and to the President in line with the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 requirements. The Strategic Plan comprises 24 recommendations for activities to improve the overall health and well-being of autistic individuals across the community. In addition to themes addressed in the previous Strategic Plan, the updated version focuses on health equity considerations and on how various factors, such as sex, gender, and COVID-19, impact autism support needs.

Dr. Daniels shared that neurodivergent members of the Committee joined her as panelists for a breakout session at the 2023 Stanford Neurodiversity Summit that she hosted. In the panel, Dr. Dena Gassner, Dr. Morénike Giwa Onaiwu, Ms. Lindsey Nebeker, Dr. Jenny Mai Phan, and Ms. Ivanova Smith shared their perspectives on what it is like to be on the Committee and the impact the Committee has on the community.

Since October 2022, IACC members have nominated, discussed, and selected 20 articles to be included in the *2022 IACC Summary of Advances*. IACC members will receive a preview of the summary to provide feedback before its publication. Discussion of the new Summary of Advances nominations was deferred to the next meeting.

IACC’s authorization under the Autism CARES Act of 2019 will end on September 30, 2024. Dr. Daniels noted the following status updates for the Committee’s remaining deliverables:

- Members are invited to continue to nominate articles for the **2023 IACC Summary of Advances**, and they will vote on the articles in January 2024.

- ONAC will begin collecting nominations for the **2024 IACC Summary of Advances** in January 2024.
- Article nominations for the 2023 Summary of Advances will be discussed during the January 2024 IACC meeting.
- A required update of the IACC Strategic Plan

Upcoming Activities

Dr. Daniels noted two options to complete the required update of the IACC Strategic Plan in 2024: (1) summarize IACC activities related to themes in the 2021-2023 Strategic Plan with a separate report on co-occurring physical and mental health conditions, or (2) focus the 2024 Strategic Plan Update on co-occurring conditions, which would be merged with content from the draft report that was started by the previous committee. The IACC members voted with a majority in favor of doing the following: (1) incorporate the draft report on co-occurring mental and physical health conditions that was started by the previous committee into a special-topic focused 2024 IACC strategic Plan Update to meet the requirements of the committee to produce an update and also focus in greater depth on an issue of great interest to the community, (2) issue an RFI for public input about needs related to co-occurring health conditions, and (3) take a survey of the Committee about what to include in the report.

Discussion

Some IACC members expressed concern that its current Committee members had less-than-typical length of time to serve on the IACC. Dr. Daniels clarified that the law authorizing the committee expires in September 2024, and committee member terms will expire with the Autism CARES Act of 2019. She said, however, that public members who have only served one term to date are eligible to be nominated for a second term.

Members suggested the following topics of interest for the 2024 Strategic Plan Update that will focus on co-occurring conditions: (1) explore the lifelong impact of early traumatic experiences in autistic people, (2) emphasize needs from persons with more pronounced autistic characteristics, and (3) include the impact of housing insecurity on mental health and diagnosis; however, (3) was considered outside the scope of co-occurring health conditions and was subsequently excluded.

NDEAM Spotlight: Sunflower Bakery

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

John Katz, Director of Programs, Sunflower Bakery

Dr. Daniels introduced Mr. John Katz of Sunflower Bakery in Rockville, MD, which is a workforce development site for people with disabilities. Mr. John Katz briefly presented achievements by Sunflower Bakery, one of the largest workforce development programs in Maryland for people with learning disabilities. He shared that 70% of individuals in the program found employment after concluding their training in a variety of both technical and soft work skills (e.g., time

management, problem solving). Mr. Katz presented a brief [video](#) outlining Sunflower Bakery's work and experiences from individuals currently enrolled in the program.

IACC members expressed support for Sunflower Bakery's initiative to connect youths with learning differences to meaningful employment opportunities, and asked how the program supports upward mobility and leadership roles for its students. Mr. Katz clarified that, through employee partnerships, the program's clients are often matched with jobs organically designed for growth promotion, including pay and role advancements over time. Mr. Katz noted that many potential partnerships with large-scale vendors have been turned down to prioritize student training and program quality.

Public Comment Session

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

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

Oral Comments

Ms. Cheryl Chafos shared her family's struggle seeking mental health care for her autistic son, Zachary, who passed away in August 2021 while receiving treatment at the Sheppard Pratt psychiatric hospital. After her son was diagnosed as autistic in 2004, Ms. Chafos's said that her family faced several challenges in securing adequate schooling, therapy, and health care to accommodate Zachary's physically aggressive behaviors. Limited resources and general isolation during the COVID-19 pandemic only exacerbated Zachary's emotion dysregulation. In order to get her son admitted to Sheppard Pratt, a specialized psychiatric unit, Zachary was admitted to the emergency room (ER), which contributed to significant traumatic stress. Zachary waited indefinitely in a windowless room for an available bed in the psychiatric unit, often with medical providers unfamiliar with autistic support needs. The first time he was admitted to the ER he waited four-weeks for a spot at Sheppard Pratt, and the second time he waited seven weeks. Ms. Chafos noted failures across the board in providing adequate care and oversight for patients like Zachary, who passed away from an epileptic attack at Sheppard Pratt 10 days after admission. She emphasized that the military lifestyle also poses a unique struggle for autistic people, and that the resources to address these unique needs are limited.

Staff member Mr. Steven Isaacson read Ms. Nicole Corrado on her behalf. Ms. Corrado described the barriers she has faced in living independently as an autistic adult. Ms. Corrado said that key considerations that assisted her housing search were limiting the number of people involved in the rental process and living near a network of supportive individuals. Ms. Corrado has found various daily tasks dependent on executive functioning to be challenging, and she has been actively seeking opportunities for financial and personal independence.

Summary of Written Comments

Dr. Daniels noted 100 [written public comments](#) centered around the following issues: (1) addressing the needs of autistic individuals with high support needs; (2) research and service needs, resources, and policy implications; (3) research, services, and supports for autistic

adults; (4) inclusion of autistic perspectives in research; (5) employment concerns; (6) mental health research, services, and treatments; (7) the role of the IACC and the federal government; (8) potential causes of autism; (9) autism acceptance and stigma reduction; (10) inclusion of underrepresented groups; (11) educational needs and workforce training; (12) communication and use of AAC; (13) parent or caregiver support needs; (14) medical practice concerns; (15) language regarding autism; and (16) needs of the direct support professional workforce.

Committee Discussion

Committee members identified several overarching themes across the written public comments, and that over a third of comments focused on the need to improve services and programs for persons with people with high support needs and their families. One member highlighted the importance of representing different minority groups within the autistic community and stated that the IACC works to benefit individuals across the spectrum — including those who may feel unrepresented by the specific language used during discussions. Members also expressed interest in a further discussion of the difficulties many encounter in accessing supports, noting that difficulty navigating systems causes delays in receiving care. Dr. Gordon briefly noted that, while Centers for Disease Control and Prevention (CDC) data demonstrate significant strides in increasing accurate diagnoses for autistic individuals from minority backgrounds, several disparities remain.

One member appreciated the written comments around workplace-related barriers for autistic individuals and suggested expanding research to include the burnout.

Other members addressed specific comments as points of interest for future IACC meetings, such as therapeutic support systems for autistic adults and addressing systemic delays in access to care. Several members expressed support for Ms. Chafos’s personal struggle with getting care for her son, highlighting the severe consequences of systemic delays and lack of capacity within health care networks. One member shared a similar experience as part of a military family with autistic children in which indefinite Medicaid waiting lists caused the family’s eligible candidates to age out before they could receive services. A member noted that the National Academies of Science, Engineering, and Medicine recently released two recommendations to improve health care capacity: (1) Medicaid reimbursements should match Medicare reimbursements to incentivize care providers, and (2) the “relative value system” currently used to determine providers’ payments needs a massive overhaul to be equitable. Members agreed that future health policy should recognize that blanket generalizations about autism health care can be more harmful than positive, citing the need for individualized protocols to meet the diverse needs of the autistic community.

Autism Mental Health Research: Progress and Needs

Overview

Carla Mazefsky, Ph.D., Nancy J. Minshew, MD Endowed Chair in Autism Research; Professor of Psychiatry, Psychology, and Clinical and Translational Science; University of Pittsburgh

Reports on the rate of co-occurring mental health conditions (e.g., mood disorders) in autistic individuals are variable, given the wide range of observed behaviors and the challenges in differential diagnosis of these conditions. However, it is known that anxiety, depression, obsessive-compulsive disorder (OCD), and attention-deficit hyperactivity disorder (ADHD) commonly co-occur with autism. Additionally, autistic individuals have higher rates of psychosis and bipolar disorder than non-autistic populations. Autistic adults frequently experience challenges related to physical disability, isolation, and independence which are exacerbated by these mental health conditions. While research on various co-occurring mental health conditions in autistic people has rapidly grown in the past five years, much work is still yet to be done to better characterize how these conditions present in autistic individuals across spectrums of cognitive ability, gender, race, ethnicity, and age.

Emotion Dysregulation, Behavior, and Mental Health Across the Autism Spectrum

Carla Mazefsky, Ph.D., Nancy J. Minshew, MD Endowed Chair in Autism Research; Professor of Psychiatry, Psychology, and Clinical and Translational Science; University of Pittsburgh

Research findings from the University of Pittsburgh's Regulation of Emotion in Autistic Adults, Children, and Teens (REACT) program demonstrate the impacts of emotion dysregulation on increased rates of mood disorders, hospitalization, police contact, and psychiatric medication use in autistic individuals. To better characterize emotion dysregulation in autistic populations, REACT developed the Emotion Dysregulation Inventory (EDI) to measure reactivity and dysphoria in autistic individuals at all levels of verbal and intellectual ability. EDI data revealed clinically elevated rates of emotion dysregulation in 58% of autistic children by five years of age, making autistic children four times more likely to experience disruptive emotion dysregulation than their non-autistic peers. Dysphoria was two to three times more common in autistic children than non-autistic children. Aspects of reactivity were also strongly associated with behaviors such as aggression and self-injurious behavior (SIB), further driving the need for comprehensive research to inform behavior-focused mental health treatment options for autistic children.

Similar to REACT, the Autism Center for Excellence (ACE) has expanded similar work on mental health outcomes in autistic adults, with a strong focus on suicide. ACE utilizes a multidisciplinary research approach to consider a wide range of biopsychosocial factors that contribute to mental health challenges in autistic adults. The ACE team developed the Autism Suicidality Inventory, which is currently being validated. They are also working to improve emotional regulation skills through the Emotion Awareness and Skills Enhancement Program (EASE), which has demonstrated success at various levels of intellectual and verbal ability. Future work from the University of Pittsburgh will focus on further characterizing emotion

dysregulation and its interactions with lifestyle factors, as well as identifying technological and therapeutic supports for support across the spectrum of behavioral needs.

Mental Health, Self-Injury, and Aggression in Autistic People

Matthew Siegel, M.D., Professor of Psychiatry and Pediatrics, Tufts University School of Medicine; Vice President of Medical Affairs, Developmental Disorders Service Line, Maine Behavioral Healthcare

During clinical assessments, 53% of parents of autistic children report their child demonstrates physically aggressive behavior, frequently stating that this aggression impacts day-to-day activities more than other social and communication traits of autism listed in the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. A 2023 CDC Autism and Developmental Disabilities Monitoring (ADDM) report found that 26.7% of autistic individuals meet the criteria for profound autism, and that these individuals are more likely to demonstrate aggression and SIB than autistic individuals that did not meet the criteria. This percentage of individuals with more pronounced autistic characteristics may be even higher given that adaptive functioning was not considered in CDC assessments. Dr. Matthew Siegel emphasized that aggression and SIB should be considered a final symptom or outcomes of various underlying mechanisms. These mechanisms must be targeted first to alleviate the impacts of aggressive physical behavior.

One potential contributing factor for aggressive behavior is the treatment continuum for children with autism. One study showed autistic children are six times more likely than non-autistic children to be psychiatrically hospitalized. However, many psychiatric hospital units are not specifically designed to address externalizing behaviors.

Dr. Siegel's team recently examined the efficacy of specialized inpatient units for treating autistic and I/DD patients. The team developed a care pathway for youth with autism or I/DD, which included increased communication and involvement with patients and their families. Dr. Siegel's team found that the average length of a hospital stay for patients in the care pathway group decreased 40% when compared to controls. Additionally, the use of physical restraints during hospitalization decreased by 77% in this group. In addition to addressing the lack of specialized psychiatric units for this population, it is important to address other gaps in treatment and research. There are many residential treatment centers in the U.S. but there is very little data about their efficacy. There are also gaps in knowledge on how to address these kinds of behaviors. Dr. Siegel emphasized the need for clinical evidence to support widespread health policy changes, noting that research representation for autistic individuals with high support needs continues to dwindle.

Supporting Autistic Individuals with Traumatic Stress Across the Lifespan

Christina McDonnell, Ph.D., Assistant Professor of Clinical Psychology, University of Wyoming

The effects of traumatic events and traumatic stress on mental health in autistic individuals is not well-characterized, making it difficult for health care systems to develop adequate support for this population. A 2019 analysis of adverse childhood experiences (ACEs) reveals that one in five children with autism experience maltreatment, which is significantly higher compared than

their non-autistic peers. Rates of maltreatment were even higher in autistic children with accompanying I/DD, with one in three experiencing abuse and neglect. A breakdown of types of maltreatment showed that children with autism and I/DD were up to three times as likely to experience certain types of maltreatment as children with autism alone. There were also significantly higher rates of ACEs in general among autistic youth compared to non-autistic youth. Adverse events and post-traumatic stress disorder (PTSD) symptoms are also reported at much higher rates in autistic adults than adults without autism. A lack of trauma-informed care combined with high rates of untreated PTSD in autistic adults may contribute to health disparities across the lifespan.

To address this the lack of interventions for traumatic stress, by Dr. Christina McDowell and her colleagues conducted a pilot study to assess the efficacy of trauma-focused cognitive behavioral therapy (TF-CBT) with autistic youth. The study demonstrated significant improvements in self and caregiver reports of PTSD and co-occurring PTSD and mental health symptoms. The same improvements were seen at one month post. The team also began a pilot study to evaluate the feasibility a narrative-based trauma program for autistic adults. Future directions include work to better understand positive experiences of autistic people, explorations of caregiver and intergenerational trauma, and how autistic individuals navigate pregnancy services.

Perspectives from Autistic People, Parents, and Clinicians: Mental Health Interventions and Areas of Need

Kelly Beck, Ph.D., L.P.C., C.R.C., Assistant Professor of Psychiatry, University of Pittsburgh

Dr. Kelly Beck and her colleagues conducted a study to better understand the factors that contribute to mental health conditions in autistic people and the barriers that limit treatment access and efficacy. Qualitative analysis of mental health treatment experiences among autistic individuals and their families/caregivers found that the top reasons for seeking mental health treatment were: (1) emotion dysregulation, (2) sensory overload that contributes to emotion dysregulation, and (3) traumatic experiences and chronic invalidation. Nearly every autistic adult shared a story about a meltdown or emotional dysregulation that related to accessing healthcare. Autistic teenagers frequently reported emotion dysregulation in school settings. Both groups attributed emotion dysregulation to inaccessible environments, discrimination, masking, feeling unsafe, lack of awareness of emotion dysregulation, and chronic social rejection. Disclosing emotion dysregulation resulted in impactful consequences, including involuntary sedation, loss of healthcare services, severed social bonds, job dismissal, and disciplinary action at school. Many existing mental health intervention treatments do not honor lived experiences of autistic people, translate poorly to real-world applications, and fail to account for diversity within the autistic community. Dr. Beck shared various anecdotes from study participants that highlighted the pain they had experienced in trying to seek respectful mental health services—several participants expressed frustration with the reliance on behavioral regulation and deficit-based approaches. Dr. Beck emphasized the need for long-term mental health care for autistic individuals across their lifespans, particularly for individuals expressing aggressive behaviors during emotion dysregulation. Overall barriers and themes

included long waiting lists, interventions not fitting needs, and a lack of provider training and support. The project team identified several avenues for improving mental health care for autistic communities, such as designing and developing interventions with the autism community and community mental health providers.

Committee Discussion

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

Committee members discussed how increasing daily autonomy for autistic individuals with high support needs might decrease aggressive behavior. Members also noted opportunities for researchers to delineate differences in mental health treatment experiences for autistic individuals by gender or nonbinary status. Panelists noted their efforts to use participant samples who are representative of autistic individuals across various spectrums of race, gender, ethnicity, age, and ability.

In response to a question from Dr. Helen Tager-Flusberg, Dr. Siegel acknowledged that, besides the growing use of EASE and EASE-ID for autistic individuals with high support needs, little advancement has been made in interventions for aggressive behavior over the past 15 years. Treatments tend to rely on antipsychotic medications, which are largely overemployed for autistic individuals with accompanying I/DD and often result in long-term negative health impacts. Dr. Gordon noted that autistic people and their families had previously emphasized during previous IACC meetings the need for preclinical animal models of aggressive behavior. Members emphasized that social rejection resulting from aggressive behavior compounds traumatic stress. They also highlighted that hospitalization needs to be supplemented by other changes to social infrastructure, such as destigmatizing aggressive behavior in health care settings.

Community Perspectives on Mental Health in Autism

Panel Discussion

Xenia Borue, M.D., Ph.D., Psychiatrist, Full Spectrum Psychiatry, Lead Advisor, University of Pittsburgh Autism Center of Excellence

*Lisa Morgan, M.Ed., C.A.S., Founder and Co-Chair, Autism and Suicide Prevention Workgroup
Kayla Rodriguez, Co-Chair, Executive Advisory Board, Autistic Women and Nonbinary Network (AWN)*

Ian Neumaier, Student, Frederick Honors College, University of Pittsburgh

Morénike Giwa Onaiwu, Ph.D., Equity, Justice, and Representation Executive Committee Chair, AWN; Humanities Scholar, Center for the Study of Women, Gender, and Sexuality, Rice University

Angie¹, Mother of a Young Adult Son on the Autism Spectrum

Dr. Xenia Borue is a late diagnosed autistic adult, who transitioned from autism research to serving autistic individuals in her clinical practice. She said that lack of provider training leads to

¹ Last name omitted for privacy, at request of this speaker.

misunderstanding, miscommunication, and misdiagnosis. This results in individuals not getting the care they need. Ms. Lisa Morgan added that, despite increasing availability of mental health resources, the lack of professional training meant that services, such as the National Crisis Hotline, were still inaccessible to autistic individuals. Lack of autism-focused training can lead to unintentional harm of someone already in crisis. Autistic individuals are already seven times more likely to die from suicide than non-autistic individuals. Training programs for mental health professionals also continue to marginalize autistic people. Ms. Kayla Rodriguez cautioned against intervention treatments that consider autism a condition to be cured or prevented, as therapies based on this paradigm (e.g., applied behavioral analysis [ABA]) frequently exacerbate co-occurring mental health conditions among autistic people. Ableism in our society also contributes to mental health challenges. Mr. Ian Neumaier echoed Dr. Borue's statements on the need for provider training and collaboration. He also noted that autism and mental health act as a constant feedback loop — particularly when it comes to trauma. Dr. Morénike Giwa Onaiwu stated that it is important to recognize that everyone has layers and different life experiences, and that these experiences interact with mental and physical health conditions. Dr. Onaiwu shared their own experience as an autistic person managing advocacy work, their career, and parenthood, who has also experienced abuse and poverty. Angie, a mother of an autistic child, illustrated several real-world consequences her family had experienced from inadequate mental health care support for her son's more disruptive behaviors, including various forms of SIB. Her son has been discharged from services because providers were unable to manage his behavior and she has no crisis supports. Panelists recommended a range of potential improvements for autism-focused mental health care, such as better recognition of disabilities related to autism, required autism-focused training for health providers and first responders, inclusion of autistic individuals in development of mental health resources and training, increased funding for mental health care, and inclusive systems that reflect the diversity within the autistic community.

Committee Discussion

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

Committee members discussed the need for tools that can accurately diagnose autism in adults, who may have mental health challenges exacerbated by a lifetime of misdiagnosis. Several members brought up opportunities to bridge support gaps using recent advancements in technology. The internet can foster positive social connections for autistic individuals struggling with feelings of isolation. More autism-focused online resources are needed; however, Committee members acknowledged that potential exposure to mental health triggers should be considered when assessing how to implement internet-based support. Ms. Morgan noted recent efforts by the Autism and Suicide Prevention Work Group to expand [online resources](#) for identifying and supporting mental health conditions in autistic individuals. Members also expressed support for current research efforts to make existing mental health tools more accessible and relevant to the autistic community.

In response to an observation from the Committee that existing strategies for aggression and SIB are limited to largely ineffectual antipsychotic medications or behavioral therapy, Dr. Mazefsky highlighted current research efforts to characterize physiological measures that may signal distress that precedes and can lead to aggressive behaviors.

IACC members asked whether SIB may be an externalization of suicidal behaviors. The panelists did not rule out the possibility that SIB may be a self-regulating response to a lack of control.

Addressing the Mental Health Needs of Autistic People Through the Mental Health Service System

The Link Center: Bridging I/DD and Mental Health Systems

Stacy Nonnemacher, Ph.D., Director of Cross System Strategies, National Association of State Directors of Developmental Disabilities Services (NASDDDS)

The implementation of health systems equipped to provide individualized treatments for people with co-occurring cognitive and mental health support needs requires incorporation of five key strategies: (1) modernizing outdated healthcare policies, (2) developing community supports both pre- and post-crisis, (3) building clinical capacity for patients with complex needs, (4) increasing collaboration between state systems, and (5) prioritizing individuals with lived experiences to inform strategy development. The Link Center is working to advance behavioral health systems, build workforce capacity, and increase service accessibility through an ACL-funded partnership with the National Association of State Mental Health Program Directors (NASMHPD), the National Association for Dual Diagnosis (NADD), and NASDDDS. This partnership will begin hosting quarterly shared learning groups as part of its ongoing effort to identify and evaluate existing resources for I/DD support capacity in mental health systems. The Center will house these resources in a centralized national repository on an accessible website. The team is also collaborating with SAMHSA to train workers and expand outreach efforts for the 988 Suicide & Crisis Lifeline as they pertain to individuals with I/DDs.

Dr. Nonnemacher said that the NASMHPD/NADD/NASDDDS partnership has a two-year national initiative to build clinical and system capacity for trauma-informed mental health treatments for underserved patients with I/DD.

Mental Health Services Presentation

Debra Pinals, M.D., Medical and Forensic Advisor, National Association of State Mental Health Program Directors

Autistic individuals have a high rate of co-occurring mental illness, and some autism behaviors may be interpreted as solely related to mental illness. This exacerbates various issues already present in mental health services for individuals with I/DDs, as the departments of mental health and departments of developmental disability have been historically siloed. System issues also include a lack of staff training, lack of training, overgeneralized treatment plans, over reliance or opposition to medication, and insufficient family engagement. Narrowed eligibility

criteria for fee-for-service programs and limited access to Medicaid waiver programs further contribute to systemic barriers for individuals with co-occurring I/DD and mental health conditions. NASMHPD is working to reduce these barriers to care by taking advantage of opportunities to expand collaborative partnerships (such as the Link Center) and reforming service delivery structures. Dr. Debara Pinals presented the following brief overview of NASMHPD's recommendations:

- Enhance psychiatric treatment options along a continuum of care
- Recognize that conditions can occur at the same time in a person
- Develop organizational structures to meet needs
- Enhance workforce knowledge and availability
- Foster trauma-informed and person-centered care
- Consider biology, social circumstances, and environmental issues
- Develop alternatives to the use of law enforcement, arrest, and incarceration for autistic individuals experiencing mental health crises, whenever feasible and safe
- Expand crisis services to address the needs of people with ASD
- Promote examples, such as Health Resources & Services Administration Pediatric Mental Health Care Access Programs

NASMHPD, in collaboration with SAMHSA, has published a series of papers that address best policy practices for behavioral health services tailored to complex populations. Dr. Pinals emphasized the importance of a trained behavioral health workforce that is sensitive to the broad spectrum of needs for people with I/DD.

Partners in Progress: How I/DD and Behavioral Health Face Similar Challenges and Opportunities

Jonah Cunningham, President and C.E.O, National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)

NACBHDD and an affiliate, National Association for Rural Mental Health (NARMH), empower local organizations serving individuals with I/DD or behavioral health concerns through community building. The [State Comparison Project](#) reveals that (1) populations in need of behavioral health resources frequently overlap with populations with I/DDs, (2) I/DD services gain unique benefits and drawbacks from being co-located with either older adult services or behavioral health services, and (3) funding streams for mental health services are often tenuous due to requirements for funding renewal. Transformative services, such as the 988 Suicide & Crisis Lifeline, have brought a new assistance framework that Dr. Cunningham summarized as “someone to contact, someone to respond, and somewhere to go.” Dr. Cunningham described multiple initiatives working to increase the coverage and capacity of such crisis response systems, including the expansion of Certified Community Behavioral Health Clinics to all 50 US states by 2030. The high turnover rate for I/DD and behavioral health direct support professionals continues to be a primary challenge NACBHDD must address to effectively implement their crisis response framework. They recently identified available federal funding and infrastructure resources to remedy additional challenges in funding and healthcare

coverage. Dr. Cunningham noted that the lack of federal funding for I/DDs or autism might be an avenue of interest for future advocacy work. NACBHDD is currently releasing monthly messaging documents for various members of local leadership to supplement the National Association of Counties [Crisis Continuum Funding Chart](#).

Committee Discussion

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

In response to a question about the Link Center website's sustainability, Dr. Nonnemacher clarified that the team hoped to secure additional funding to keep the site running after the current grant period concludes. The goal of the Link Center website is to identify and adapt existing crisis services based on input from people with lived experiences. These resources will largely be designed for accessible use by autistic individuals and their families or caregivers.

Dr. Nonnemacher and other panelists also addressed representation concerns from the Committee by highlighting several efforts to keep autistic voices at the forefront of project development. One IACC member emphasized that efforts to involve individuals with lived experience should include efforts to employ autistic individuals in mental health service systems.

Panelists described how they have accounted for substance abuse disorders (SUDs) in autistic populations, which included incorporating SUD assessment and treatment into behavioral health concerns and addressing the dearth of information on SUD in this population. Panelists suggested the following proposals regarding how federal institutions could best support ongoing mental health care accessibility projects:

- DOJ, SAMHSA, and ACL should develop alternatives to law enforcement for mental health crisis services.
- SAMHSA should continue to partner with CMS to inform strategies that will make Medicaid accessible to populations with co-occurring conditions.
- Identify opportunities to integrate mental health and employment services for individuals with autism.

IACC members highlighted a recurring recommendation across panels to provide both available and *accessible* mental health resources for autistic people, which should be incorporated into the next IACC Strategic Plan. Panelists and IACC members concluded the discussion by listing available resources for autism-oriented mental health screening, specifically identifying Ms. Morgan's extensive work on crisis intervention instruments and measures.

Closing Remarks and Adjournment

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

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

Dr. Daniels and Dr. Gordon thanked the panelists and presenters for their insights on mental health needs for autistic people. Dr. Daniels concluded the meeting after confirming that the IACC will continue revising its Strategic Plan, per the Committee's vote.

The next IACC Full Committee Meeting will be held on January 24, 2024, in a hybrid meeting format, and meeting updates will be available through the IACC website.