Interagency Autism Coordinating Committee (IACC)

Full Committee Meeting

January 24, 2024

February 23, 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: Veronica Kim, Dana Carluccio, Christy Huffman, Amy Kiefer, and Nancy Tuvesson.

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a hybrid meeting on Wednesday, January 24, 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; **Thyria Alvarez**, M.S.W., U.S. Department of Housing and Urban Development (representing Leah Lozier, Ph.D.); **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 Anita Everett, M.D., DFAPA); **Monica Bertagnolli**, M.D., National Institutes of Health (NIH); **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); **Sam Crane**, J.D., Quality Trust for Individuals with Disabilities; **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, John Carroll University, SUNY-Upstate; **Dena Gassner**, M.S.W., Adelphi University, Towson University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Kristina Hardy**, Ph.D., M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.); **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Craig Johnson**, M.Ed., Champions Foundation; **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); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Brooke Mount**, Ph.D., U.S. Department of Justice (DOJ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A; **Morénike Giwa Onaiwu**, Ph.D., Autistic Women & Nonbinary Network; **Bobbie Jo Peltier**, M.S., Indian Health Service (IHS)(representing Barbara Roland, M.B.S., LPC); **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); **Amanda Reichard**, Ph.D., ACL (representing Jennifer Johnson, Ed.D.); **Susan Rivera**, Ph.D., University of Maryland; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL) (representing Taryn Mackenzie Williams, M.A.); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC) (representing Karyl Rattay, M.D., M.S., FAAP); **Jane Simoni,** Psy.D., NIH (representing Monica Bertagnolli, M.D.); **Ivanova Smith**, B.A., University of Washington; **Hari Srinivasan**, B.A., Vanderbilt University; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Jodie Sumeracki**, B.A., Centers for Medicare & Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna Tschiffely**, Ph.D., Department of Defense (DoD) (representing Nicole Williams, Ph.D.); **Debara Tucci**, M.D., M.S., M.B.A., FACS, NIDCD;*

***Paul Wang**, M.D., Clinical Research Associates, LLC, Simons Foundation, Yale University School of Medicine; **Nicole Williams**, Ph.D., DoD; **Richard Woychik**, Ph.D., NIEHS*

Welcome and Announcements

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

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

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

- Monica Bertagnolli, M.D., National Institutes of Health (NIH)
- Christy Kavulic, Ed.D., U.S. Department of Education (ED)
- Brooke Mount, Ph.D., U.S. Department of Justice (DOJ)
- Camille Proctor, The Color of Autism Foundation

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

- Dr. Larry Wexler, the longest serving member of IACC, has retired from federal service.
- Dr. Matt Siegel has been appointed to a dual leadership position as the Chief of Clinical Enterprise in the Department of Psychiatry and Behavioral Sciences at Boston Children's and the Chief Behavioral Health Officer at Franciscan Children's.

IACC members voted to approve the October 2023 minutes, which have been posted to the IACC website.

Update from the National Institutes of Health

Monica Bertagnolli, M.D., Director, NIH

Dr. Bertagnolli is a surgical oncologist and scientist who previously served as the director of the National Cancer Institute (NCI). She is currently the 17th director of the NIH and a proud mother of an autistic son. She stated that every autistic person has a unique set of strengths and challenges, and that each autistic person should be able to choose their own life's path and have the support that is needed to achieve it.

NIH plays an important role in identifying priorities for autism research and services. NIH is the largest funder of autism research in the United States. NIH-funded studies have helped translate findings about early emerging signs of autism into advanced, practical screening tools for pediatric screening through telehealth or tablet-based applications. Early intervention programs have increased diagnosis by as much as 60% compared to standard care, including a significant improvement in detection in Spanish-speaking families.

Research efforts include further examination of the biological mechanisms underlying autism and identification of biomarkers and measures of social function and communication. NIH also supports training and services for autistic adults and youths transitioning into adulthood. NIH aims to support interdisciplinary research from multiple perspectives, which includes partnering with autistic individuals and their communities as well as continuing collaboration across federal agencies.

National Autism Coordinator Update

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

ONAC coordinated the development of the *2022 Report to Congress on Supportive Services for Individuals with Autism* on behalf of the U.S. Secretary of Health and Human Services (HHS) and in collaboration with 18 federal departments, agencies, and offices. The report highlights the needs and opportunities to strengthen supportive services for individuals with autism, describes beneficial services to improve outcomes, and reviews existing coverage policies under federal programs. Recommendations include increased focus on navigation services for families, continuity of coverage, workforce shortages, diagnostic services, service waitlist reductions, and telehealth opportunities. The National Autism Coordinator (NAC) Update document is also available online and outlines recent White House activities, federal committees, news, and events.

Federal Interagency Workgroup on Autism (FIWA) Presentation on Agency Initiatives

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

The Federal Interagency Workgroup on Autism (FIWA), chaired by the NAC, is a collaborative effort across 20 federal departments and agencies engaged in autism-related work. NAC works with the FIWA to coordinate research, services, and support activities related to autism, incorporating the Strategic Plan. They also work to prevent duplication of effort. Membership in FIWA is voluntary and open to any federal agency engaged in work related to autism. Several members of this workgroup presented on recent autism related activities at their agencies.

U.S. Department of Education (ED)

Christy Kavulic, Ed.D., Associate Division Director, Office of Special Education Programs, ED

The Office of Special Education Programs (OSEP) within ED administers the Individuals with Disabilities Education Act (IDEA). The IDEA provides services to an estimated 900,000 school-age children with autism in addition to infants, toddlers, and their families. ED funds research, personnel preparation, educational technology and media, and technical assistance that focuses on autism. OSEP will provide various grants for the upcoming fiscal year (FY24), including (1) personnel preparation grants to reduce the workforce shortage; and (2) educational technology grants to support early intervention and to increase accessibility of educational materials for children. Within the Institute of Education Sciences (IES), the National Center for Special Education Research (NCSER) also provides various grants, including (1) special education research across four types of research projects (exploration, development and innovation, impact, and measurement); (2) annual research training programs that prepare early-career researchers to conduct special education and early intervention research; and (3) a research and development center to support the K-12 special education teacher workforce (a new grant for FY24). ED and HHS jointly released an updated policy statement on the Inclusion of Children with Disabilities in Early Childhood Programs. This policy statement sets the expectation that all young children with disabilities should have access to high-quality, inclusive, early childhood programs that provide individualized and appropriate support so that they can fully participate alongside peers without disabilities, meet high expectations, and achieve their full potential.

Centers for Disease Control and Prevention (CDC)

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

The CDC supports various programs that focus on autism across the lifespan and on addressing disparities. The Autism and Developmental Disabilities Monitoring (ADDM) Network offers prevalence tracking of children aged 4 and 8 and seeks to better understand the needs of autistic adolescents in their transition into adulthood. CDC recently established five new ADDM sites to increase data collection. In 2023, CDC published the first two ADDM articles focused on (1) the health and co-occurring conditions in 16-year-olds with autism and (2) services and support indicated in incident action planning and transition planning goals. The Study to Explore Early Development (SEED) program conducts longitudinal research studying autism and other developmental disabilities (DD) in children enrolled between ages 2 to 5 years. The "Learn the Signs. Act Early." program encourages ongoing, family-engaged developmental monitoring for early identification of developmental delays, including autism. This program provides free tools and resources, such as the Milestones Tracker app, and supports state or territorial leaders (i.e., Act Early Ambassadors) to increase collaboration and coordination among early childhood programs. CDC also established partnerships with the U.S. Department of Agriculture Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program to integrate developmental monitoring into systems serving young children and their families, particularly low-resource families. CDC collaborates with the American Academy of Pediatrics to communicate the importance of developmental monitoring, screening, referral, and follow-up. CDC also collaborates with the Health Resources and Services Administration (HRSA) to embed these resources with select health centers to focus on early childhood development.

National Institutes of Health (NIH)

Lisa Gilotty, Ph.D., Program Chief, Research Program on Autism Spectrum Disorders, Division of Translational Research, NIMH, NIH

NIH offers a variety of autism research initiatives. The Autism Centers of Excellence (ACE) program supports research on autism across the lifespan, including innovative and cost-effective services and interventions. Each ACE has adopted a specific Plan for Enhancing Diverse

Perspectives, which outlines strategies to increase the number of individuals from traditionally underrepresented backgrounds in the autism workforce and participatory research. NICHD supports 15 Intellectual and Developmental Disabilities Research Centers that support state-of-the-art research to advance development of services and interventions for intellectual or developmental disabilities (IDD), as well as co-occurring mental health conditions. The National Center for Advancing Translational Sciences (NCATS) leads the Rare Diseases Clinical Research Network to facilitate collaboration between 20 active consortia to advance treatment for rare diseases, including autism-associated Phelan-McDermid Syndrome.

U.S. Department of Labor (DOL)

Scott Michael Robertson, Ph.D., Senior Policy Advisor, Office of Disability Employment Policy, DOL

The Office of Disability Employment Policy (ODEP) at DOL focuses on increasing access to employment and career pathways for diverse individuals with disabilities. ODEP's portfolio focuses on (1) competitive integrated employment (CIE) access, (2) career pathways and the Good Jobs Initiative, (3) diversity, equity, inclusion, and accessibility (DEIA) priorities. Their main autism work includes the Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS) project, which investigates barriers, promising practices, and strategies for employment success. Their other neurodiversity-focused activities include technical assistance centers that provide resources and supports for employers and autistic workers and job-seekers, the Employer Assistance and Resource Network on Disability Inclusion (EARN) and the Job Accommodation Network (JAN), respectively.

Administration for Community Living (ACL)

Jennifer Johnson, Ed.D., Deputy Commissioner, Administration on Disabilities, ACL

The Administration on Disabilities (AoD) is a center within the ACL that seeks to improve the independence, integration, and inclusion of individuals with disabilities in the community throughout the lifespan. ACL prioritizes expanding home- and community-based services (HCBS), supporting caregivers and building the caregiving economy, and advancing equity of marginalized populations. ACL funds various programs and supports to support caregivers, including respite care. Other ACL activities include supporting the Recognize, Assist, Include, Support, & Engage (RAISE) Family Caregivers Act Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren, who worked together to create the *2022 National Strategy to Support Family Caregivers.* Health equity efforts include a partnership with Persons with I/DD to Improve Health Care Outcomes, data collection, and support of various centers (e.g., Center for Transition to Adult Health Care for Youth with Disabilities, National Center for Disability, Equity, and Intersectionality) that provide resources for the IDD population. AoD also promotes the achievement of economic security and mobility. These programs focus on career trajectories for people with disabilities and support CIE. Next, efforts to protect rights and prevent abuse include multiple grants for research projects that examine community health and safety. They also fund the Center for Youth Voice Youth Choice to foster supported decision-making skills. Finally, AoD funds many initiatives to facilitate self-advocacy and selfdetermination skills for individuals with IDD. They also work to raise awareness to help others learn how to support these individuals.

Department of Housing and Urban Development (HUD)

Leah Lozier, Ph.D., Social Science Analyst, Office of Policy Development and Research, HUD

HUD works to create sustainable, inclusive communities and to build quality, affordable homes. In 2023, HUD served 4.6 million households through its rental assistance programs. They offer four programs to assist people with disabilities. The Section 811 Supportive Housing Program offers interest-free capital advances and operating subsidies to develop housing for very low-income persons with disabilities. A related program, Section 811 Project Rental Assistance Program, subsidizes units for extremely-low income people with disabilities in affordable housing developments. This program, which is part of a partnership with state Medicaid and HHS, promotes community integration and subsidizes rent for disabled individuals in up to 25% of units inside a property. In addition, HUD offers rental assistance vouchers to enable rentals in the private housing market. Mainstream Vouchers provide rental assistance for non-elderly people with disabilities. Non-Elderly Disabled (NED) Vouchers provide rental assistance for families whose head of household has a disability and for non-elderly individuals in the transition from nursing homes and other health care institutions back into the community.

Social Security Administration (SSA)

Alison R. Marvin, Ph.D., Statistician/Health Sciences Researcher, Division of the Analytics Center of Excellence, SSA

SSA offers various programs and initiatives that promote equity and accessibility. SSA manages two support programs that provide benefits to individuals with disabilities: the Social Security Disability Insurance (SSDI) program and the Supplementary Security Income (SSI) program. SSA offers employment support through Work Incentive Policies and Resources and Employment Services, such as the Ticket to Work Program, to help beneficiaries return to and succeed in the labor force. In addition, SSA offers various research and demonstration initiatives. Demonstrations are temporary initiatives to help identify services and policies to support individuals with disabilities. They also offer research and analysis resources, such as the Social Security Bulletin and Public Use Files for statistical analyses. Research funding opportunities include the Interventional Cooperative Agreement Program and the Retirement and Disability Research Consortium to enable partnerships with non-federal organizations for interventional research and interdisciplinary extramural research related to SSA programs. SSA is also reviving the Analyzing Relationships between Disability, Rehabilitation and Work stipend program for graduate students, which allows for autism-specific research projects.

National Science Foundation (NSF)

Robert Ochsendorf, Ph.D., Program Director, Division of Research on Learning in Formal and Informal Settings, Directorate for STEM Education, NSF

NSF supports curiosity-driven, use-inspired, basic, and fundamental research across all science, technology, engineering, and mathematics (STEM) disciplines. They are committed to expanding STEM opportunities to individuals from diverse backgrounds (e.g., racial, ethnic, geographic, socioeconomic backgrounds, sexual orientation, gender identities, disabilities). NSF and IES recently funded a National Artificial Intelligence (AI) Institute at the University of Buffalo to transform education for children with speech and language processing challenges. To combat the severe shortage of speech and language therapists, this institute leverages AI to enable more rapid screening of young children and to deploy evidence-based, customized speech and language interventions. NSF recently funded six Convergence Accelerator projects focused on individuals with disabilities, which invests in research solutions to address challenges faced by persons with disabilities (e.g. development of assistive and rehabilitative technology). NSF continues to invest in education, research, accessibility, technology, and workshops focused on individuals with disabilities, including autism.

Committee Discussion

Susan Daniels, Ph.D., Executive Secretary, IACC; HHS National Autism Coordinator; Director, ONAC, NIMH
Joshua Gordon, M.D., Ph.D., Director, NIMH; Chair, IACC

IACC members asked about agencies' dissemination, accessibility, and sustainability plans for the larger autistic community. An example of successful dissemination is CDC's Milestones tracker app, which has nearly 2 million downloads. Another example is ODEP's emphasis on sustainability in its development of long-term work, policy, and practices. The NAC also amplifies each agency's activities through the IACC, including its public meetings, website, newsletters, and more. Ms. Yetta Myrick noted that despite these efforts, many stakeholders (e.g., autistic people, family members, caregivers) are unaware of what federal resources and programs are available. Stakeholders may also be unaware of innovations in the United States not promoted through IACC. IACC welcomes suggestions related to sustainability, scalability, and dissemination of information to the community.

IACC Committee Business

Susan Daniels, Ph.D., Executive Secretary, IACC; HHS National Autism Coordinator; Director, ONAC, NIMH
Joshua Gordon, M.D., Ph.D., Director, NIMH; Chair, IACC

Dr. Daniels summarized updates to ONAC staff and several items of Committee Business.

There are two updates to ONAC staff:

- Ms. Ana Cappuccio, LL.B., is the new Operations Coordinator and will assist with administrative issues.
- ONAC staff member Mr. Steven Isaacson, L.M.S.W., recently completed his master's degree in clinical social work and has taken on a new role as ONAC's first Neurodiversity Liaison. He will assist with community outreach and projects related to issues involving neurodiversity.

The *2022 IACC Summary of Advances* report is available online in both full and Easy Read versions. IACC selected 20 articles that exemplified the most significant advances in autism-related biomedical and services research in 2022. The Autism Collaboration, Accountability, Research, Education and Support (CARES) Act of 2019 requires that the report provide lay-friendly summaries of these articles, which address all seven topic areas of the IACC Strategic Plan.

In October 2023, the IACC voted to focus on co-occurring physical and mental health conditions and their impacts on health outcomes for the *2024 IACC Strategic Plan Update*. The previous Committee initiated a draft report on co-occurring conditions that will be used as the foundation for the 2024 report, which ONAC and original working group chair (Dr. Julie Taylor) will update. On behalf of the IACC, ONAC published a formal Request for Public Comments on co-occurring conditions. The results, which will include demographic data but no identifying information, will be reviewed at the next IACC meeting for feedback. IACC anticipates finalizing the report in 2024.

IACC members discussed the 76 articles that were nominated for the *2023 IACC Summary of Advances* report between April and December 2023. They will soon receive a ballot to vote for the top 20 articles, and ONAC staff will prepare summaries. For each of the seven categories, Committee members were asked to determine which articles were particularly noteworthy or flag ones for removal. Members also discussed criteria to consider when recognizing articles as an important advance.

Public Comment Session

Joshua Gordon, M.D., Ph.D., Director, NIMH; Chair, IACC
Susan Daniels, Ph.D., Executive Secretary, IACC; HHS National Autism Coordinator; Director, ONAC, NIMH
Oni Celestin, Ph.D., Health Science Policy Analyst, ONAC

Three individuals provided oral comments and Dr. Oni Celestin summarized 13 written comments.

Oral Comments

Ms. Nicole Corrado is an autistic adult and shared her lived experience as a civilian advisor to the Toronto Police Services Missing and Missed Implementation Team. She expressed her frustration with mismanagement of her own missing persons file, advocating against the use of

Mental Age Theory and suggested use of more respectful terms (e.g., support needs). She shared suggestions for improving support for missing persons, such as adopting sensory- and animal-friendly women's shelters and respecting gender identity. She also stated that voluntary Vulnerable Persons Registries must be confidential and kept separate from incident reporting software. In addition, she requested that police and public safety policy professionals work directly with autistic individuals when developing safety policies.

Mr. Anthony Tucci is the parent of a non-speaking son with autism and the executive director of the Autism Awareness and Support Foundation, an organization that advocates for the human and civil rights of non-speaking and minimally-speaking autistic people. Mr. Tucci focused on the interplay between communication science advocacy and the protection of communication rights. He is concerned that some members of the scientific community attack useful communication methods, such as spelling to communicate, for lacking scientific validation. He is concerned that such advocacy can impair the human and civil rights of individuals on the autism spectrum. Mr. Tucci emphasized the importance of cross disciplinary approaches to address research gaps. Mr. Tucci offered suggestions to promote scientific advancement while safeguarding human and civil rights of disabled individuals, including the following: (1) formation of committees comprised of legal, scientific, and lived experience stakeholders; (2) additional regulatory guidance through DOJ that requires full disclosure of communication rights available to disabled individuals under the Americans with Disabilities Act (ADA); and (3) implementation of scientific due process methods to challenge studies that may be misused to prevent autistic people from exercising communication rights.

Ms. Jordyn Jensen is the executive director of the Center for Racial and Disability Justice at Northwestern University Pritzker School of Law. Ms. Jensen explained that statistical evidence shows that disabled individuals, especially those with autism, experience high rates of victimization. Autistic people may have additional disabilities (e.g., psychiatric illnesses) and may demonstrate disability-related, non-normative behaviors. Police officers may perceive these behaviors as threatening or dangerous, which leads to intensified police responses and use of excessive force. Ms. Jensen explained that police trainings may not reflect variability of autistic traits between people, which may inadvertently reinforce stereotypes about autistic people and heighten biases related to race and disability. Ms. Jensen suggested that IACC and the community-at-large need to shift away from increased advocacy for police training and instead prioritize amplifying the voices of disabled people, especially disabled people of color, because they are the experts on the issues that directly impact them.

Summary of Written Comments

IACC received 13 written public comments for the January 2024 meeting. Comments focused on the following topics: justice and law enforcement (3 comments); research, services, and supports for adults with autism (2); research and service needs, resources, and policy implications (2); addressing the needs of autistic individuals with high support needs (2); mental health research, services, and treatments (1); concerns about medical practices (1); increasing autism acceptance and reducing stigma (1); and the needs of the direct support professional workforce (1).

Committee Discussion

Ms. Myrick highlighted Ms. Rose Baumann's written comment, who wrote about the challenge of calling 911 for assistance with escalation of aggressive episodes when law enforcement is often ill equipped to handle autistic individuals. This concern has been discussed within the autism community at large and is important to address.

Ms. Dena Gassner highlighted Ms. Nicole LeBlanc's comment on the need for support for autistic adults who require HCBS and lack nursing level of care. Ms. Gassner shared her colleague's story that demonstrates how needs may ebb and flow. Policy ideas about nursing level of care must switch from an assumed constant need to an episodic and intermittent need.

Ms. Sam Crane shared her thoughts regarding Mr. Anthony Tucci's comment on communications support. She noted that there are researchers who engage in public denunciations and harassment of individuals who utilize typing-to-communicate. She suggested that a coalition of communication researchers and stakeholders could develop best practices for determining if an individual is communicating authentically. Individuals may find idiosyncratic communication methods that work specifically for them, but peer-review studies may not reflect these. Dr. Gordon agreed, noting the relevance to IACC's work. Although IACC strives to advocate for investment in services, resources are limited. Precision medicine shows that there is a need for ways to understand whether solutions can be individualized.

Members discussed how scientific evidence directly impacts advocacy and reasonable accommodations. Some researchers advocate against including certain modes of communication as a reasonable accommodation due to not meeting the criteria for best-evidence. However, this ultimately denies communications rights of disabled individuals.

Dr. Scott Michael Robertson reflected on Ms. Corrado's written comment on the direct support professional workforce's needs and her highlight of a Canadian program that employs neurodivergent people as patients in medical simulations to help educate medical students. Dr. Robertson suggested that NIH and its sister agencies help support similar practices to incorporate topics on neurodiversity in medical education.

Justice and Law Enforcement Presentations and Panel

The IACC heard from six presenters on various topics related to law enforcement, who discussed topics such as the ADA, interactions between law enforcement and people on the autism spectrum, and police training.

The Americans with Disabilities Act and Law Enforcement Interactions with People with Autism

Steven Gordon, Esq., Assistant United States Attorney and Civil Rights Enforcement Coordinator, U.S. Department of Justice

ADA is a civil rights statute that prohibits discrimination based on disability and affords protections similar to those in the Civil Rights Act of 1964. ADA covers all state and local entities, including those in the criminal justice system. It requires reasonable modifications to policies, practices, and procedures to avoid discrimination against disabled people and to promote equity and accessibility. An important aim under the ADA is equity, which means that accommodations must be individualized. Mr. Gordon provided examples of ADA violations, including discrimination (e.g., denying employment based on disability status) or failing to modify policies, practices, or procedures (e.g., failing to use alternative responses for behavioral health calls). Relevant accommodations for autistic people include (1) de-escalation training for law enforcement officers and correctional staff; (2) requirement of court staff to explore reasonable modifications through diversion and probation programs; (3) improved collaboration between correctional staff, crisis intervention teams, and mental health professionals; and (4) improved resource allocation to criminal justice agencies and disability service systems to reduce disparities that disabled individuals experience.

The ADA website, hosted by the DOJ, offers a plethora of online resources, including statutory language, regulations, technical assistance, and briefs. Two important technical assistance publications include commonly asked questions and examples and resources to support criminal justice entities in compliance with Title II of ADA. DOJ also offers statistics on crime and related topics through the Bureau of Justice Statistics (BJS). BJS data show that individuals with disabilities are three times more likely than individuals without disabilities to be victims of serious crimes. People with cognitive disabilities had the highest rate of total violent victimization among disability types measured. In addition, 21% of unreported violence against disabled individuals was due to victims fearing lack of helpful responses from police. To raise awareness on these important issues and facilitate discussions across stakeholders, DOJ works with various organizations to offer trainings, including simulations to practice nonthreatening interactions between police officers and individuals with IDD. Mr. Gordon emphasized the importance of community engagement in addressing these issues.

The Autism Justice Center

Carlean Ponder, Esq., Director, Autism Justice Center, Autism Society of America

The Autism Justice Center (formerly the Autism Center for Empowerment, Advocacy and Justice) is a new initiative of the Autism Society that serves as a resource for autistic individuals, family members, and advocates who are impacted by all forms of discrimination, including criminal justice. The Autism Justice Center provides expertise to individuals and their families currently encountering some aspect of the criminal legal system by facilitating access to lawyers, professional advocates, and autistic individuals who have had direct experience with the criminal legal system.

Statistics show that autistic individuals are seven times more likely than non-autistic people to interact with the criminal system because of increased victimization, encounters with police officers, and comorbid mental health issues. Autistic children experience disproportionate levels of school discipline. Group homes and day programs tend to over-rely on police officers to intervene in situations during which an autistic individual displays disruptive behaviors or aggression because of behavioral health needs. An increase in misconduct related to sexual behavior—both in-person and online—also leads to increased contact with the criminal legal system.

The Autism Justice Center strives to combat issues and enforce ADA protections in situations involving autism and race. Black autistic individuals are more likely to be hurt or killed during police encounters and are disproportionally held in jails and sentenced to long prison terms. Biases and competency issues within the judicial system rise when the court does not distinguish mental illness from autism. The court may argue that the disability, such as intellectual or social limitations, are not present or is not relevant to the criminal charge. Strict liability laws often lead a prosecutor to dismiss a victim’s DD, which often results in the victim’s significant and legal criminal entanglement. The Autism Justice Center seeks to train and educate the judicial system about these issues to facilitate the court’s ability to recognize and understand traits of autism so that the court can enforce alternatives to incarceration, such as diversion.

NCCJD: Advocating at the Intersection of Disability Rights and Criminal Justice Reform

Leigh Anne McKingsley, M.S.S.W., M.P.A., Senior Director, Criminal Justice Initiatives, The Arc of the United States

Police encounters with individuals with DD can turn fatal when police lack proper training. Many data highlight the judicial disparities among individuals with IDD. According to data from BJS, the most commonly reported type of disability among incarcerated people was cognitive disability (2 in 10 prisoners; 3 in 10 jail inmates). Additionally, 25% of those later exonerated after giving a false confession had characteristics of ID. Young people with disabilities are 13% (17% for Black youth) more likely to be arrested than non-disabled peers. Disabled individuals have an overall 43% chance of arrest, with disproportionally high arrest rates among young Black men. When it comes to being victims of crime, individuals with cognitive disabilities were seven times more likely than individuals without disabilities to be victims of sexual violence. Individuals with cognitive disabilities face the highest rates of violent victimization.

These disparities are being addressed by the National Center on Criminal Justice and Disability (NCCJD), which is a community-based program that works on numerous projects and initiatives regarding people with disabilities and their interactions with law enforcement. They provide training and technical assistance, information and referral, resource collection and creation, and education. Relevant NCCJD initiatives include the following:

- The Just Policing initiative, which is an online and in-person training for law enforcement focusing on intersectionality issues related to youth with IDD and autism.

- Language Access Barriers to Justice Among Victims with IDD, which is a collaboration with the University of Cincinnati and the University of South Florida to explore methods to increase victims access to resources.
- Pathways to Justice, which is a key training that involves teams of law enforcement officers, attorneys, victim services providers, people with disabilities, and disability advocates that help communities work towards long-term solutions. The *Pathways to Justice* model works to ensure that disability is identified at each step of the justice system, and that accommodations are provided.

In addition, NCCJD has been conducting international work to share and learn what other countries are doing to address interactions between law enforcement and people with autism or IDD.

Enhancing Law Enforcement Response to Individuals with Intellectual and Developmental Disabilities

Brooke Mount, Ph.D., Senior Policy Advisor, Bureau of Justice Assistance, U.S. Department of Justice
Kelly Burke, M.P.H., Senior Program Manager, International Association of Chiefs of Police

The Office of Justice Programs (OJP) is one of three grant-making components in DOJ that provides grant funding, training, research, and statistics to the criminal justice and behavioral health community. Within the Office, the Bureau of Justice Assistance (BJA) focuses on funding training and technical assistance programs, developing guidance and resources, and engaging with stakeholders nationwide. BJA collaborates with the International Association of Chiefs of Police (IACP)—an international nonprofit membership organization of police professionals focused on education, training, advocacy, and engagement—to support the development of training and resources to raise awareness in the law enforcement community. Many of its programs, such as the Academic Training to Inform Police Responses, aim to improve law enforcement responses for people with IDD.

The Academic Training to Inform Police Responses initiative provides training and technical assistance to develop evidence-informed best practices in police crisis response and engagement with individuals with IDD, mental health conditions, and substance use disorders. This initiative led to the development of a 40-hour training known as the Crisis Response and Intervention Training (CRIT). This curriculum seeks to expand the knowledge of IDD, mental health conditions, and substance use disorders; create connections with people with lived experience; enhance awareness of community services; and emphasize de-escalation of crisis situations while supporting officer safety and wellness. CRIT does not focus on diagnoses, but instead on behavior that the officer may encounter in the field. The training also encourages collaboration with stakeholders and includes content on laws and policies related to disability rights.

ICAP also developed a resource page on Mental Health Conditions and Developmental Disabilities, which includes content such as Why Know the Difference, What Law Enforcement

Officers Need to Know, and Steps for Deflection or Pre-Arrest Diversion. These resources emphasize the importance of understanding disabilities, gives examples of IDD-related behaviors, and provides recommended police responses. To further develop resources on training, IACP now leads a new BJA-funded effort that expands CRIT training and technical assistance to 39 sites. BJA is also funding IACP's Kevin and Avonte Program, known as Home Safe, which develops resources to reduce injuries and deaths of individuals who wander or go missing because of IDD or dementia. ICAP works with the Arc, the Autism Society of America, and the National Center for Missing and Exploited Children on this grant.

Montgomery County Police Autism/IDD Unit: Providing a Layered Approach of Service Through Awareness and Action for Those in the Autism/IDD Community

Officer Laurie Reyes, Creator/Coordinator, Autism/IDD, Alzheimer's/Dementia Unit, Montgomery County (MD) Police Department

Over the past two decades, the Montgomery County Police–- Autism/Intellectual and Developmental Disabilities (IDD), Alzheimer's and Dementia Outreach Unit has worked to create a "culture of awareness" around wandering and safety. The MCPD Autism/IDD Unit offers a training and education for officers and through outreach to the community they promote empowerment and provide follow-up and responses to callers. The number of police calls related to autism and IDD has increased since 2004, alongside an increase in the age of individuals involved in these calls. On average, the Montgomery County Police Department (MCPD) receives 30 to 40 calls regarding people with autism each month, and MCPD locates 3 to 8 wandering autistic individuals weekly. They also handle about 2 calls a day related to autism and in one week, MCPD received 27 service calls. They have seen an increase in calls related to autistic people in serious crisis as well as an increase in co-occurring mental health conditions in people with autism. In response to these increasing numbers, MCPD started to provide follow-ups to caregivers and families and had more than 600 follow-ups in 2023.

One of their initiatives includes school and community presentations to educate communities on their program, during which they invite feedback to foster positive interactions with law enforcement. The unit also helps autistic people achieve and maintain independence and works with them to find solutions. They also partner with Pathfinders for Autism to provide mock traffic stops through webinars and interactive simulations of police interactions for autistic people. In addition, the unit educates officers on the importance of an individual's personal choice on whether to disclose disabilities during interactions with law enforcement. The MCPD Autism/IDD Unit offers many resources, available online and in-person.

Community Perspectives on Justice and Law Enforcement in the Autism Community

Susan Daniels, Ph.D., Executive Secretary, IACC; HHS National Autism Coordinator; Director, ONAC, NIMH
Maria Mercedes Avila, Ph.D., M.S.W., M.Ed., Professor, Department of Pediatrics; Director, Vermont LEND Program, Larner College of Medicine, University of Vermont
Lindsay Naeder, M.S.W., Vice President, Services and Supports, Community Impact, Autism Speaks
Camille Proctor, Founder, The Color of Autism Foundation
Amanda Wroten, M.A., Director, Safety on the Spectrum, Autism Society of America
Greg Robinson, M.P.H., Deputy Director of Public Policy, Autistic Self-Advocacy Network

Dr. Daniels introduced the panelists and facilitated the session on community perspectives. Discussion centered around three questions: (1) What are the most important law enforcement and criminal justice issues that you feel affect the autism community?, (2) What is your organization doing to help address some of these issues?, and (3) What are some ways that you feel the federal government or state and local agencies and organizations can help address these issues?

Panelists highlighted important issues impacting the autistic community. Key points made during the discussion include:

- The lack of meaningful law enforcement training related to childhood development and autism, and lack of knowledge on disparities involving race, health, and mental health.
- The need to scale-up law enforcement and first responder training to every zip code in the U.S. Resources should be developed with input from autistic people and there must be frequent updates to the language used in manuals and training procedures to improve inclusivity.
- A widespread need for education on the history of systemic racism, which is still rampant in this country and in law enforcement. Disabled people of color are more likely to experience fatal law enforcement encounters due to a misunderstanding and less likely to have their stories covered in the media.
- A need for improved training of both dispatch and response teams to increase competency. Dispatch-level decisions inform the response team, and alternatives to police for a behavioral health crisis is critical. Police presence is a concern because of the fundamental nature of an officer’s role; officers are armed while on duty and therefore retain the possibility of using force in interactions.
- Concerns related to privacy on the disclosure of a disability through identification markers and databases of autistic people. Although these disclosures are intended to improve the safety of autistic and other disabled people, these disclosures may lead to loss of civil rights and denial of medical care.

Panelists discussed resources and approaches for safety responses and crisis intervention within their organizations. Current efforts include the following:

- The Vermont LEND program has led multiple initiatives to increase safety through fostering cultural understanding between law enforcement and the community it serves:
    - Developed the state's Fair and Impartial Policing training, which was adapted from a training for health and mental health providers. The training includes education on the history of systemic racism, childhood development, intersectional issues, accessibility, and language access.
    - Led the Vermont Cultural Brokering Program enables community leaders to work with law enforcement to bridge the cultural divide between law enforcement and the community, which helped reduce and prevent arrests.
    - Interviewed over a hundred community members on their experiences with law enforcement and the justice system. They found the community lacked knowledge around the role of law enforcement and its limitations, and law enforcement lacked cultural knowledge about their surrounding community.
- Autism Speaks has two main approaches to promoting safety:
    - They have two main approaches for promoting safety, 1) Increasing access to safety resources, services, and funding streams (at state and federal levels) to meet unique individual needs; 2) Increasing first responder training and broadening the definition of first responders beyond law enforcement agencies and officers.
- The Color of Autism Foundation encourages law enforcement to volunteer and work with the Foundation's autistic youth to humanize autistic people and reshape officer response during police interactions. The Foundation ran a six-week long program that aimed to increase understanding and improve police responses.
- The Autism Society of America highlighted the importance of elevating the voices of autistic individuals, caregivers, and parents as part of their community of practice. They work with the Arc and ICAP on the Kevin and Avonte Program grant, Home Safe to bridge the gap between caregivers and law enforcement.
- The Autistic Self-Advocacy Network (ASAN) works with and creates resources for various communities:
    - Connects the disability rights and disability justice communities to the broader civil rights communities to 1) cohesion on important issues such as police violence and 2) provide disability representation and ensure the accessibility of response systems (e.g., 988 Suicide and Crisis Lifeline).
    - Produces educational resources on a wide range of topics (e.g., the criminal legal system, police violence, safety, and sexual violence). These resources also provide strategies for self-advocacy.

Panelists offered the following suggestions to improve safety response and crisis intervention efforts:

- The language used in training, programs, and other resources must be inclusive. Training models must be meaningful and updated annually with new information.
- Those in leadership positions must take action and advocate for change.

- Broaden definitions of first responders to include school resource officers, emergency room personnel, emergency medical technicians, 911 telecom operators, and many more to increase access to safety and crisis response training.
- Provide autism-specific support through the 988 Suicide and Crisis Lifeline.
- Allocate more funding for:
    - Community-centered partnerships and programs, both new and existing. These programs can further develop trainings and help families learn effective strategies for stressful situations.
    - Intersectional work to identify universal practices that can be applied to crisis intervention training.
    - Underserved groups that are disproportionally affected by police violence.
    - Create a federal system for collecting data on how autistic individuals interact with law enforcement and the justice system. The Uniform Crime Reporting (UCR) database is not currently tracking any relevant data regarding diagnosis or disability status at a federal level.
    - Robust HCBS systems, which would ensure access to needed accommodations and decrease the use of emergency response systems.
    - Legislation such as the Safe Interactions Act, which provides nonprofit disability organizations with grants to develop training programs that promote safe interactions between law enforcement and people with disabilities.
- Continue law enforcement collaboration with community organizations, especially in underserved communities, because the disability movement originated from the civil rights movement.
- Minimize police interactions, which remain a major safety risk for autistic individuals, in many cases (e.g., behavioral health crises) to minimize the impact of police violence. There is uncertainty on whether Crisis Intervention Team and co-response models reduce the use of force in police interactions.
- Ensure justice-involved individuals have access to disability assessments, supports, and accommodations.

Panelists also discussed how current law enforcement training regarding autism still leads to problematic interactions with law enforcement, reiterating crime statistics. Currently, autistic people are 7 times more likely than the general population to be a crime victim and 12 times more likely to be unintentionally involved with the criminal justice system. Panelists provided several examples of problematic police interactions, such as individuals who were misidentified as suspects and tazed or killed in their own homes and a case where a caregiver was shot due to mistaken reports. Mr. Robinson expressed his concern that use of some definitions, such as those that refer to autistics with high support needs, may lead to inappropriate institutional responses (e.g., indefinite secure hospital confinement).

Committee Discussion

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

Members discussed key takeaways for individuals and their families navigating the criminal justice system. Caregivers should teach autistic individuals how to respond to law enforcement. They should also immediately contact a justice advocate if their loved one is involved with the justice system, and there should be a training program for advocates.

There is no statute that requires federal court systems to improve accessibility and there is a lack of supportive programs. To address this, command level leadership must be included in autism response training. In addition, members remain concerned with the weaponization of high support needs autism as a reason for problematic practices, such as institutionalization, under the guise of choice. Many problematic practices are falsely labeled as a safe and disability-equipped alternative. Black autistic individuals with high support needs are at increased risk for being victims of these systems. Additionally, Black, transgender women with disabilities are at the highest risk for being victims of violence. Members cautioned against enabling government use of disability databases as they could be used to restrict rights or access to health care. Although state court judges are required to comply with ADA, judges and lawyers may benefit from comprehensive education on autism and other disabilities to help inform court decisions for disabled individuals.

Members also discussed strategies to facilitate positive interactions between law enforcement officers and autistic individuals, including those who are non-speaking. One consideration is to mandate state-level accreditations for law enforcement officers. Laws about training are at the state and local levels, which can be a barrier to expanding training across the country. Teaching children how to interact with law enforcement in schools is important. MCPD has interfaced with schools and educators to share resources and trainings with the broader community. Organizations, including IACC and the Autism Society of America, offer free resources online that cover first responder communication with non-speaking individuals. Members expressed the need for individuals to be quickly and properly diagnosed so that they can receive medical ID bracelets, which are an effective alternative for both speaking and non-speaking individuals to communicate information without making gestures that officers may potentially perceive as threatening.

Round Robin Updates

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

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

IACC Round Robin updates from various agencies and organizations are available online.

Closing Remarks and Adjournment

Joshua Gordon, M.D., Ph.D., Chair, IACC, NIMH
Susan Daniels, Ph.D., Executive Secretary, IACC; HHS National Autism Coordinator; Director, ONAC, NIMH

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

The next IACC Full Committee Meeting will be held on April 17, 2024, in a hybrid meeting format, and meeting updates will be available through the IACC website.