Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

July 21 and 22, 2021

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a virtual meeting on Wednesday, July 21, 2021, from 1:00 p.m. to 4:00 p.m. ET and July 22, 2021, from 2:00 p.m. to 5:00 p.m. ET.

In accordance with Public Law 92-463, the meeting was open to the public. Joshua Gordon, M.D., Ph.D., Director, National Institute of Mental Health (NIMH) chaired the meeting.

Participants

Joshua Gordon, M.D., Ph.D., *Chair*, IACC, NIMH; **Susan Daniels**, Ph.D., *Executive Secretary*, IACC, Office of Autism Research Coordination (OARC), NIMH; **Courtney Ferrell Aklin**, Ph.D., National Institutes of Health (NIH) (representing Francis Collins, M.D., Ph.D.); **Thyria Alvarez**, M.S.W., U.S. Department of Housing and Urban Development (HUD) (representing Teresa Souza, Ph.D.); **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont; **Skye Bass**, L.C.S.W., Indian Health Service (IHS); **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA) (representing Anita Everett, M.D., D.F.A.P.A.); **Diana Bianchi**, M.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Judith Cooper**, Ph.D., National Institute of Deafness and Other Communication Disorders (NIDCD) (representing Debara Tucci, M.D., M.S., M.B.A., F.A.C.S.); **Sam Crane**, J.D., Autistic Self Advocacy Network; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Tiffany Farchione**, M.D., U.S. Food and Drug Administration (FDA); **Maria Fryer**, M.S., U.S. Department of Justice (DOJ); **Dayana Garcia**, M.Ed., Administration for Children and Families (ACF); **Dena Gassner**, M.S.W., Adelphi University; **Morénike Giwa Onaiwu**, M.A., Rice University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Craig Johnson**, B.A., Champions Foundation; **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., NICHD (representing Diana Bianchi, M.D.); **Walter Koroshetz**, M.D., NINDS (representing Nina Schor, M.D., Ph.D.); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Richard Woychik, Ph.D.); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Lindsey Nebeker**, B.A., Freelance Presenter/Trainer; **Valerie Paradiz**, Ph.D., Autism Speaks; **Scott Patterson**, Ph.D. HSPP, U.S. Department of Veterans Affairs (VA) (representing Matthew Miller, Ph.D., M.P.H.); **Georgina Peacock**, M.D., M.P.H., F.A.A.P., Centers for Disease Control and Prevention (CDC); **Jenny Mai Phan**, Ph.D., University of Wisconsin-Madison; **Joseph Piven**, M.D., University of North Carolina - Chapel Hill; **JaLynn Prince**, B.F.A., Madison House Autism

Foundation; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration (HRSA); **Susan Rivera**, Ph.D., University of California, Davis; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL) (representing Jennifer Sheehy, M.B.A.); **Robyn Sagatov**, Ph.D., M.H.S., R.D.N., AHRQ (representing Kamila Mistry, Ph.D., M.P.H.); **Nina Schor**, M.D., Ph.D., National Institute of Neurological Disorders and Stroke (NINDS); **Stuart Shapira**, M.D., Ph.D., CDC (representing Georgina Peacock, M.D., M.P.H., F.A.A.P.); **Jennifer Sheehy**, M.B.A., DOL; **Matthew Siegel**, M.D., Tufts University; **Ivanova Smith**, B.A., University of Washington; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Teresa Souza**, Ph.D., HUD; **Hari Srinivasan**, University of California, Berkeley; **Jodie Sumeracki**, B.A., Centers for Medicare and Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Debra Tidwell-Peters**, M.A., SSA (representing Alison Marvin, Ph.D.); **Debara Tucci**, M.D., M.S., M.B.A., F.A.C.S., NIDCD; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Nicole Williams**, Ph.D., U.S. Department of Defense (DoD).

DAY ONE

Welcome

Joshua Gordon, M.D., Ph.D., Director, NIMH and *Chair*, IACC
Susan Daniels, Ph.D., Director, OARC, NIMH; *Executive Secretary*, IACC; and Acting National Autism Coordinator
Courtney Aklin, Ph.D., Acting Associate Deputy Director, NIH
The Honorable Andrea Palm, Deputy Secretary, Department of Health and Human Services (HHS)
The Honorable Chris Smith, U.S. House of Representatives, 4th District of New Jersey
The Honorable Robert Menendez, U.S. Senate, New Jersey

Dr. Susan Daniels welcomed everyone to this inaugural meeting of the new Committee and thanked them for their attendance.

Dr. Joshua Gordon talked about the purpose of the IACC, which is to advise the Secretary of HHS with recommendations concerning autism spectrum disorder (ASD), to coordinate ASD efforts across HHS, and to act as a liaison between the public and the government. The Committee gives a voice to the full spectrum of people with autism, who are best equipped to communicate the needs, ideas, issues, and controversies within the community. The Committee is charged with bringing forward the issues, ideas, and controversies that need attention; disseminating the latest and most impactful research findings; and identifying the way forward to improve the lives of those affected by autism. To this end, Dr. Gordon intends to foster a robust exchange of ideas among Committee members, invited guests, and the public.

Dr. Daniels welcomed the special guests and asked them to provide an introduction and their intended contribution to the discussion.

Dr. Courtney Aklin is Acting Associate Deputy Director of NIH and attended on behalf of Dr. Francis Collins, Director of NIH. She expressed excitement and appreciation that the Committee is tackling important issues related to autism such as research, housing, health care, and services. She was particularly impressed by the size and diversity of the Committee and was hopeful that these unique perspectives will foster innovation and advancement in biomedical research, diagnostic techniques, and interventions and services. She highlighted important topics such as the COVID-19 pandemic and racial inequity, which have substantially impacted the autism community, and described recent NIH efforts to address these issues. Dr. Aklin thanked Senator Robert Menendez and Representative Chris Smith and their colleagues for their instrumental role as sponsors of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019 and Deputy Secretary Andrea Palm and HHS for their leadership in enhancing the wellbeing of those on the autism spectrum.

Deputy Secretary Andrea Palm echoed Dr. Aklin's comments and expressed gratitude for the Committee's continued commitment to support the autism community. She highlighted some of the Committee's most impactful work, such as calling for the investigation of autism rates in Somali children living in Minneapolis which led to the development of treatment programs and support networks. IACC also brought attention to unintentional injury and death due to wandering, particularly among children with autism. These efforts sparked national awareness, resulting in improved training for first responders and school personnel and sparked research on locating technologies to reduce this risk. Kevin and Avonte’s Law was passed in 2018, which protects those with autism and other developmental disabilities who may wander away from safety. Deputy Secretary Palm emphasized that the COVID-19 pandemic has exacerbated the systemic barriers to health care, education, and other vital services faced by individuals on the autism spectrum. The Biden administration has committed itself to funding cutting-edge research to better understand autism and to improve the quality of life for people with autism and their families. The administration's Build Back Better agenda will expand access to home- and community-based services so that individuals with autism can access needed services in their communities.

Senator Robert Menendez expressed his pride in championing the Autism CARES Act of 2019 and reiterated his commitment to meeting the needs of the autism community. For the first time, the legislation directed the federal government to consider the changing needs of autistic individuals across the lifespan. He explained that New Jersey has one of the highest rates of autism in the nation and was also one of the hardest-hit states at the onset of the pandemic. People with autism and their loved ones endured the destabilizing impact of disruptions to education, therapeutic services, and safety in group settings. Senator Menendez was pleased to see the addition of four new federal departments to the Committee, HUD, DOL, DOJ, and VA, and noted that their participation will facilitate the Committee's influence on a wider range of policy, including disability housing, interaction with law enforcement, and greater economic opportunities. He congratulated the 20 new public members of the Committee on their appointments.

Representative Chris Smith said that addressing ASD is a bipartisan team effort and talked about his involvement with autism since his first term in 1981. Years after his first efforts, there was an investigation of the apparent prevalence spike of autism in Brick Township and surrounding areas. This investigation eventually led to the establishment of IACC. He commended the Committee for its exemplary work in bringing together effective autism advocates from both inside and outside of government. The Committee's recommendations are influential and heard by those in Capitol Hill. Representative Smith discussed co-establishing the bipartisan Congressional Autism Caucus with Representative Mike Doyle (PA) in 2007. When he first introduced autism legislation in 1997, the federal government was only spending $287,000 to address the condition. Today, the government is spending $23 million. They are now calling for an increased appropriation of $150 million more in aggregate.

Representative Smith reminded the Committee that they influence both the executive and legislative branches of government. Currently, his concern is that not enough individuals on the autism spectrum have received the COVID-19 vaccine. However, there have been programs to increase vaccination rates that have been successful and can be replicated. Given the number of co-occurring conditions seen in individuals with autism, they should be prioritized for vaccination. He reiterated how the Committee has influenced conversations about housing, education, and employment and thanked the Committee for their extraordinary work.

Dr. Daniels and Dr. Gordon thanked the guest speakers. Dr. Gordon echoed comments from Senator Menendez and Representative Smith that the Committee has directly impacted the efforts of Congress and federal agencies. In its previous incarnation, the Committee focused intently on the needs of individuals with autism as they transition from childhood to adulthood. At the behest of the Committee, the NIMH launched a ten-year effort to enhance the research in this area. Dr. Gordon also expressed how he was personally affected by public comments from parents who are dealing with self-injurious and aggressive behavior from profoundly disabled children with autism, particularly as they age into their teenage years. NIMH has started a program to understand the underlying reasons for dysregulation and aggressive behavior and to develop therapies and treatments.

Introductions of IACC Members

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

Dr. Daniels invited Committee members to introduce themselves and describe their backgrounds in the context of autism research and advocacy. This is the largest and most diverse Committee to date.

Joshua Gordon, M.D., Ph.D. is the Director of NIMH and serves as Chair of the Committee. He is trained in medicine, psychiatry, and neuroscience, and his work focuses on the neural underpinnings of cognition as they pertain to disorders such as schizophrenia.

Susan Daniels, Ph.D. is the Director of OARC, Executive Secretary of the IACC, and Acting National Autism Coordinator. She is also a neuroscientist.

Public Members

Maria Mercedes Avila, PhD., M.S.W., M.Ed**.** is a parent, advocate, and researcher. She is an Associate Professor of Pediatrics at the University of Vermont and is the Director of the Vermont Leadership Education in Neurodevelopmental Disabilities (LEND) Program. She strongly believes that high-quality, rigorous research should inform accommodations, services, and equitable distribution of resources for all children across the nation. She is proud to represent the state of Vermont and expressed her commitment to educating providers about the intersection of systemic racism and health inequities.

Alice Carter, Ph.D. is a Professor of Psychology at the University of Massachusetts, Boston. She conducts clinical research on the early detection of social, emotional, and behavioral problems associated with autism. She also focuses on reducing health disparities, improving access to high-quality care, and promoting family wellbeing.

Samantha Crane, J.D. is the Legal Director for the Autistic Self Advocacy Network (ASAN). In her role at ASAN, she focuses on access to high-quality health care, community supports, inclusion, and self-determination. She is a returning member of the Committee, and in its last iteration she particularly enjoyed discussions about adult's needs, research on co-occurring medical conditions, and community inclusion.

Aisha Dickerson, Ph.D. is an Assistant Professor of Epidemiology at Johns Hopkins University. She studies environmental risk factors for autism and other neurodevelopmental disorders, as well as environmental justice and health disparities among historically marginalized populations.

Dena Gassner, M.S.W. is a doctoral candidate at Adelphi University and an adjunct professor at Towson University. Her focus is on social security access for autistic individuals. She is the co-Chair of the Autistic Researchers Committee for the International Society for Autism Research (INSAR) and is a reviewing member of the Autism Intervention Research Network (AIR-P). She also is a mother to an autistic adult.

Morénike Giwa Onaiwu, M.A. is an educator, writer, public speaker, parent, and global advocate. Her work focuses on meaningful community involvement and leadership, disability, and racial and gender equity, as well as dismantling stigma and promoting inclusion and empowerment. She draws on her personal background as a late-diagnosed person of color with autism. She is the parent of six disabled children, including one with intellectual disability and two with autism. Mx. Giwa Onaiwu is a humanities scholar at Rice University and a doctoral candidate in education.

Alycia Halladay, Ph.D. is the Chief Science Officer of the Autism Science Foundation (ASF) and was recently appointed Board President of the Phelan-McDermid Syndrome Foundation. ASF focuses on research across the lifespan and supports the Baby Siblings Research Consortium and a collaboration of a patient advocacy groups called Alliance for Genetic Etiologies of Neurodevelopmental Disorders and Autism (AGENDA). ASF also funds COVID-19 research grants and produces a weekly lay-accessible podcast.

Craig Johnson, B.A. has three children, one of whom is on the autism spectrum. He is the President and founder of the Champions Foundation and Champions Club Developmental Centers for special-needs children, which serve several thousand families across 95 centers around the world. He is also the associate pastor at Lakewood Church in Houston, which serves 300 families with special needs, primarily autism.

Yetta Myrick, B.A. was unable to attend the meeting.

Lindsey Nebeker, B.A. has served on the national staff of the Autism Society of America for nearly a decade. She also provides freelance presentations, trainings, and educational workshops for professionals, families, and individuals on the autism spectrum. She is a self-advocate advisor for Felicity House and was a founding board member of the Autistic Women and Nonbinary Network. She and her sibling are on the autism spectrum.

Valerie Paradiz, Ph.D. is the Vice President of Services and Supports at Autism Speaks. She was diagnosed with autism in her early 40s and is a mother to an adult diagnosed with Asperger syndrome.

Jenny Mai Phan, Ph.D. is a post-doctoral fellow at the University of Wisconsin. Her research focuses on mental and physical health outcomes of adolescents on the autism spectrum. She was diagnosed with autism later in life and is a mother to four children, two of whom are on the autism spectrum and one of whom has an intellectual disability.

Joseph Piven, M.D. is a child and adolescent psychiatrist at the University of North Carolina – Chapel Hill. He directs the Carolina Institute for Developmental Disabilities, which provides services to people with neurodevelopmental disorders. He oversees a large research network on brain and behavior development in autism from infancy through school age.

JaLynn Prince, B.F.A. is the founder and President of the Madison House Autism Foundation, which works nationally on policy and provides a 400-acre farm for adults with autism. She considers the inclusion of adults with autism to be a humanitarian issue in the Madison House farm offers living space and work opportunities to adults with autism.

Susan Rivera, Ph.D. is a professor and current Chair of the Department of Psychology at the University of California (UC), Davis, and a faculty member of the UC Davis Mind Institute. She is a developmental neuroscientist by training and has conducted research on autism and other developmental disorders for more than two decades. Her work uses brain imaging and infrared eye tracking to capture information on visual attention, base processing, sensory processing, and emotion regulation.

Matthew Siegel, M.D. is an Associate Professor of Psychiatry and Pediatrics at Tufts University and is also the Vice President of Medical Affairs for the Development Disorders Service Line at Maine Behavioral Healthcare. He is trained as a child psychiatrist and has been working with patients with autism for more than 15 years. His work has informed the development of a system of care from outpatient to specialized school settings to partial hospital to in-patient hospitalization for people with autism.

Ivanova Smith, B.A. is a self-advocate leader and faculty member at the University of Washington Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program. Ivanova is Chair of the Self-Advocates in Leadership (SAIL). As a person with Intellectual and Developmental Disabilities, Ivanova was institutionalized for the first five years of her life, but Ivanova overcame many challenges and is now married with children.

Hari Srinivasan is a minimally verbal autistic person who uses alternative communication technologies, such as text-to-speech. He attends the UC Berkeley, where he studies psychology and disability studies. He is a student journalist for the UC Berkeley newspaper, The Daily Californian, and is the first non-speaking President of the school's Autism Student Body. Additionally, Mr. Srinivasan will conduct his own mentored research program involving emotions in autism and hopes to attend graduate school in the near future.

Helen Tager-Flusberg, Ph.D. is a developmental scientist at Boston University, where she also acts as Director of the Center for Autism Research Excellence (CARE). She has been researching autism since the 1970s and focuses primarily on neurodevelopmental disorders from childhood through young adulthood. Her research focusses on language and communication. For the last decade, she has focused on children who were excluded from her early research: minimally and nonverbal individuals with other complex problems. She is a past President of the International Society for Autism Research (INSAR).

Julie Lounds Taylor, Ph.D. is a returning member of the Committee. Her training is in developmental psychology. She currently is an Associate Professor of Pediatrics at the Vanderbilt University Medical Center. She is primarily a clinical researcher. Her work focuses on improving transitions from childhood to adulthood, adult outcomes, and attempts to understand the implications of day-to-day experiences on mental health. She also conducts intervention studies to improve service access for youth on the autism spectrum as they transition to adulthood.

Paul Wang, M.D. is Deputy Director of Clinical Research at the Simons Foundation, which includes the Simons Foundation Autism Research Foundation (SFARI). His experience is in academic medicine, and he has worked with hundreds of children and adolescents in the autism community. He has also worked in industry, clinical trials, pharmaceuticals, and biotechnology for neuropsychiatric conditions.

Steven Whitlow, J.D. was unable to attend the meeting.

Federal Members

Courtney Aklin, Ph.D. is Acting Associate Deputy Director at NIH and began her federal career as a fellow working to help stand up the IACC. She is a clinical psychologist by training, and she specializes in pediatrics and anxiety disorders. She is the alternate for Francis Collins, M.D., Ph.D.

Skye Bass, L.C.S.W. is a Program Coordinator at IHS, which is responsible for providing health care to American Native and Alaska Native communities. She works to provide training and education on excellent care for autism in the Tribal and Urban Indian Health Clinics.

Diana Bianchi, M.D. is Director of NICHD, which co-funds the Autism Centers of Excellence program and the Intellectual and Developmental Disabilities Research Network. She also is co-Chair of the INCLUDE initiative, which investigates co-occurring conditions across the lifespan to better understand Down syndrome. Her medical training is in medical genetics and newborn intensive care. She focuses on prenatal genomics and fetal therapy in her research lab at NIH. She is a returning IACC member.

Anita Everett, M.D., D.F.A.P.A. from SAMHSA was unable to attend the meeting.

Tiffany Farchione, M.D. is Director of the Division of Psychiatry in the Center for Drug Evaluation and Research at the FDA. She is a child and adolescent psychiatrist by training. This Division evaluates and reviews drugs and study designs. This could include drugs that that target autism-associated features such as behavioral symptoms or aggression. If the drug were to move forward, the Division of Psychiatry would be the first to approve it.

Maria Fryer, M.S. is a Policy Analyst at the DOJ, where she oversees justice and mental health work at the Bureau of Justice Assistance. She has worked with criminal justice professionals and law enforcement to improve responses to people with autism. She is the mother of a daughter with autism.

Dayana Garcia, M.Ed. is a Disabilities and Inclusion Specialist with the Office of Head Start at ACF. She has experience as an early childhood special education teacher, disabilities coordinator, and family advocate. She works with Early Head Start programs to promote collaborations between Head Start grantees and Part C and Part B agencies to promote services for children with disabilities.

Elaine Cohen Hubal, Ph.D. from EPA was unable to attend the meeting.

Jennifer Johnson, Ed.D. is the Deputy Commissioner of the Administration on Disabilities (AOD) at ACL. AOD seeks to equip people with the opportunities, supports, and tools to lead the lives of their choice in their community. Their four priority areas are promoting health equity; achieving economic security and mobility; empowering individuals, families, and communities; and protecting rights and preventing abuse. She is a returning member.

Cindy Lawler, Ph.D. is the Chief of the Genes, Environment, and Health Branch in the Division of Extramural Research and Training. She was trained as a behavioral neuroscientist and works with institutions across the nation that are conducting research to understand the impact of environmental exposures on autism. She is the alternate for Richard Woychik, Ph.D. at NIEHS.

Alison Marvin, Ph.D. is a statistician and health sciences researcher for the Division of Analytics Center of Excellence at SSA. Her projects involve supplemental income redeterminations, case selection, and statistical support. Prior to joining the SSA, she was a research manager at the Interactive Autism Network (IAN). She continues her association with the Kennedy Krieger Institute as the Research Manager of the Autism Research and Engagement Core at the Maryland Center for Developmental Disabilities. She has published extensively on autism research.

Scott Patterson, Ph.D., HSPP is a licensed clinical psychologist and Local Recovery Coordinator with the VA and VHA. He specializes in assessment of adults with autism, peer support models, and general recovery efforts in the community. He is the alternate for Matthew Miller, Ph.D., M.P.H.

Kamila Mistry, Ph.D., M.P.H. is Associate Director for the Office of Extramural Research, Education, and Priority Populations and a Senior Advisor for Child Health and Quality Improvement at AHRQ, where she focuses on health equity, maternal health, and child health. She is a health services researcher by training.

Georgina Peacock, M.D., M.P.H, F.A.A.P. is the Director of the Division of Human Development and Disability at the CDC's National Center for Birth Defects and Developmental Disabilities (NCBDDD). She oversees CDC's Autism and Disability portfolio, including the Act Early program.

Lauren Raskin Ramos, M.P.H. is Director of the Division of Maternal and Child Health Workforce Development at Maternal and Child Health Bureau at HRSA, where she oversees autism investments, including training, research, and state systems development programs. This includes the LEND Program. Her background is in public health and maternal child health.

Nina Schor, M.D., Ph.D. is the Deputy Director and Acting Scientific Director of NINDS. She is a pediatric neurologist with experience in researching preclinical pharmacology for tumors in the nervous system in children. She was previously Chair of the Department of Pediatrics and the Pediatrician in Chief at the University of Rochester where she launched the first Project SEARCH chapter in the region. She is a returning Committee member.

Jennifer Sheehy, M.B.A. is the Deputy Secretary for the Office of Disability Employment Policy (ODEP) at DOL. Their mission is to develop policies and practices that increase the number of quality employment opportunities for all people with disabilities. In September, ODEP will launch its newest research project on supporting employment for young adults on the autism spectrum. ODEP is also commemorating its 20-year anniversary, and its commemoration theme is America's Recovery Powered by Inclusion.

Teresa Souza, Ph.D. is a Social Science Analyst at HUD, where she oversees the evaluation of contracts and grants focused on supportive housing programs for persons with disabilities. HUD is a new member of the Committee.

Jodie Sumeracki, B.A. is a Senior Policy Advisor at the Disabled and Elderly Health Programs Group at CMS. She has previous experience as a health insurance specialist for CMS, where she focused specifically on benefits and coverage for autism spectrum service-related benefit policy. Prior to joining CMS, she worked at the National Association of State Medicaid Directors supporting individuals with multiple disabilities and was a service coordinator for individuals enrolled in the Autism Waiver program in Maryland.

Debara Tucci, M.D., M.S., M.B.A., F.A.C.S is the Director of NIDCD. She previously practiced at Duke University as a otolaryngologist and head and neck surgeon. Her work focuses primarily on hearing. NIDCD supports research for speech language disorders, hearing balance, taste, and smell. Most of their work with autism is related to communication challenges.

Larry Wexler, Ed.D. administers the discretionary program under the Individuals With Disabilities Education Act (IDEA) at the Office of Special Education Programs (OSEP) at ED. The program manages a portfolio of state professional development grants, 35 technical assistance and dissemination centers, and more than a hundred parent centers. Their personal preparation portfolio supports about 5,000 graduate students. Dr. Wexler oversees data for more the 7 million children with disabilities in the U.S. He is a returning member of the IACC.

Nicole Williams, Ph.D. is the Program Manager of the Autism Research Program (ARP), one of 36 Congressionally Directed Research Programs (CDRP) at DoD. Her organization manages funding for biomedical research programs directed by Congress. The ARP has been appropriated $119 million in total and has funded 181 awards on preclinically and clinically focused autism research. She is a returning member of the IACC.

Dr. Gordon thanked the members for their introductions and expressed his pride for their experience and the diversity of their perspectives and abilities. He noted that representation from government and broader representation across the autism spectrum will yield higher impact.

National Autism Coordinator Update

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

Dr. Daniels reviewed the role of the National Autism Coordinator, which was first established as part of the Autism CARES Act of 2014. The National Autism Coordinator oversees ASD research, services, and support activities across the federal government, ensuring that these activities are not duplicative and are aligned with the *IACC Strategic Plan*. As Acting National Autism Coordinator, Dr. Daniels will strengthen interdepartmental and interagency communication and collaboration on issues related to autism. She will also gather agency input on tasks mandated under the Autism CARES Act and share updates with the IACC on relevant interagency autism activities and reports.

Dr. Daniels provided an update on the Federal Interagency Workgroup on Autism (FIWA), for which she is the Chair. FIWA includes multiple federal departments and agencies with programs related to autism and disabilities, which allows for cross-agency exchange of information on ASD activities. FIWA assists with the development of the reports to Congress that are required by the Autism CARES Act, and they are currently working on a *2021 Report to Congress on the Health and Wellbeing of Individuals on the Autism Spectrum.* They are also tracking federal activities related to their 2017 *Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder*.

Dr. Daniels also provided updates on several other federal advisory committees that are working n issues related to autism and disabilities, including:

The National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD) is a new committee under the Federal Advisory Committee Act (FACA). NACIDD was established under the Pandemic and All-Hazards Preparedness and Advancing Innovation Act of 2019 and will make recommendations for enhancing public health and medical preparedness related to people with disabilities. NACIDD includes a number of relevant federal partners and openings for seven public members for which the nomination period just closed.

The Federal Partners in Transition (FPT) is an all-federal workgroup managed by DOL and formed in 2005 to support all youth, including youth with disabilities, in the successful transition from high school to adulthood. FPT coordinates activities through their *2020 Federal Youth Transition Plan: A Federal Interagency Strategy*, which will be updated in the near future.

The Interagency Committee on Disability Research (ICDR) is an all-federal committee managed by ACL that was established under the 1973 Rehabilitation Act and promotes coordination and collaboration between federal agencies and departments that have disability, independent living, and rehabilitation research programs. Recent activities include a white paper entitled *The Impact of COVID-19 on Disability Research: New Challenges and Widening Disparities* and the publication of two toolkits; *Health Information Technology (IT) Toolkit: A Compendium of Accessible & Usable Health IT Resources* and *Aging with Disability: A Toolkit for Interagency Collaboration*.

The National Council on Disability (NCD) is an independent federal agency charged with advising the President, Congress, and other federal agencies on the policies, programs, practices, and procedures related to people with disabilities. Their meetings are open to the public, and members of NCD are sometimes invited to present to the Committee. Recent activities include conducting a study to examine the effects of the pandemic on people with disabilities, making recommendations to the National Governor's Association of COVID-19 equity, publishing a report entitled *Enforceable Accessible Medical Equipment Standards*, and publishing a letter to HHS Secretary Xavier Becerra on health equity.

The RAISE Family Caregiving Advisory Council (FCAC) was established in 2019. They are managed by the ACL and are charged with providing recommendations to the HHS Secretary on models for both family caregiving and support to family caregivers, as well as improved coordination across federal programs. As caregiving is an issue that has previously been brought up by the Committee, it will be important to follow their work. FCAC recently adopted 26 recommendations and is currently working on a report to Congress.

Dr. Daniels also mentioned the International Society for Autism Research (INSAR), which is a professional, scientific organization dedicated to advancing knowledge about autism and promoting high quality research. INSAR has a summer institute, which this focused on autism and intersectionality this year. INSAR also produced the Autism Community Priorities for Suicide Prevention policy brief, which has been another topic of interest to the Committee. A longer version of the brief aimed at researchers and research funders, *Where Do We Go from Here? Autism Community Priorities for Future Suicide* Research, is also available.

Committee Discussion

Dr. Wang expressed gratitude for Dr. Daniels holding this interim role and asked when a permanent appointment will be made. Dr. Gordon answered that a search will be conducted to make a permanent appointment for the role of National Autism Coordinator and they hope to have an appointment made by the end of the calendar year.

Ms. Gassner shared that the INSAR Autistic Researchers Committee has an open call for members. She asked Dr. Daniels if any of the workgroups or committees she reviewed address adults with autism who are not of transition age but seeking employment, as many adults do not have access to accommodations or supports. Dr. Daniels says that employment is discussed in these committees, such as in FPT as a part of discussions on transition, but employment is not the sole focus. Dr. Daniels asked Dr. Scott Michael Robertson, the alternate for DOL, to provide input. Dr. Robertson shared that DOL has its own research project on employment opportunities for young adults on the autism spectrum that was requested by Congress. Given that employment is an important social determinant of health, he looks forward to contributing to other employment-related facets. Dr. Robertson asked if there is an update from the Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC). Dr. Gordon said that ISMICC had been on hold while the new Assistant Secretary for Mental Health was confirmed. Now that he has been confirmed, there should be an update soon.

Dr. Johnson reiterated that a priority area at AOD is achieving economic security and mobility, and there are a number of employment-related activities aligned under that priority. For instance, last year, they announced a competition on building inclusivity within talent pipeline programs within businesses, for which they plan to announce a grand prize winner this fall. Dr. Marvin mentioned that the SSA's Ticket to Work program supports free career development for Social Security disability beneficiaries aged 18-64 who wish to work. Mr. Johnson added that he has worked with the Texas Workforce Commission to hold a job fair with 60 businesses that were willing to hire adults with special needs, and approximately 150 adults submitted applications.

IACC Committee Business

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

Dr. Daniels reviewed the history and charge of IACC. IACC is a committee under the Federal Advisory Committee Act (FACA). It was first established under the Children's Health Act of 2000 and reauthorized most recently under the Autism CARES Act of 2019. The charge of the Committee is to provide advice to the HHS Secretary on issues related to ASD, coordinate federal activities related to autism, provide a forum for public input on issues related to autism, develop and annually update a *Strategic Plan for ASD*, develop an annual *Summary of Advances in ASD Research*, and monitor federal activities related to autism. The Committee is also required to meet at least twice a year.

The Autism CARES Act of 2019 reauthorized IACC to run through September 30, 2024. It also requires Committee membership to include at least three members from each of the following categories: individuals on the autism spectrum; parents and legal guardians of individuals on the spectrum; and representatives of leading research, advocacy, and services organizations for individuals on the autism spectrum. There are more than three members in each of these categories, with some members representing multiple categories, in this iteration of the Committee. The reauthorization also added DOL, DOJ, HUD, and VA to the ex-officio federal membership. The new law requires *the Strategic Plan* to continue to address services and supports for individuals with ASD and their families in addition to research. The new law also emphasizes being inclusive of issues across the lifespan. There are now 23 voting ex-officio federal members and 22 public members representing a diverse composition for collaboration. Public Committee members are now limited to two four-year terms.

The Committee's core values from the initial conception of IACC were outlined in the first *Strategic Plan* in 2009. Those values expressed a sense of urgency, excellence, spirit of collaboration, community focus, partnerships in action, and equity. These core values are still timely today. The Committee upholds these values through respectful dialogue and thoughtful listening, seeking and listening to community perspectives, bringing forward evidence and best practices to inform divisions, being inclusive, and bringing together diverse points of view and multiple disciplines. IACC also provides advice to the HHS Secretary through reports, letters, and statements; provides a forum for public input; provides coordination for federal and member organization activities; identifies issues and priorities for autism research, services, and policy; and illuminates important and emerging issues.

IACC is an advisory body and does not fund research or allocate federal funds. It does not control or implement federal programs or policies. It can only make recommendations. Dr. Daniels encouraged all Committee members to attend meetings, share updates, and offer information and resources during discussion. Committee members can also suggest topics and speakers for future meetings and opportunities for collaboration. The Committee often creates subcommittees or working groups, and members are encouraged to join those activities. Committee meetings will always include a review of Committee business panels, presentations, and discissions of timely topics; public comments; and Committee member updates.

For this Committee meeting, Dr. Daniels asked members to provide written updates. Going forward, there will be three full Committee meetings each year. The next full Committee meeting will be in October 2021 and will be virtual. The January 2022 Committee meeting may be a hybrid of virtual and in-person. There will also be a Committee meeting in April 2022 and a potential workshop meeting in July 2022.

IACC Strategic Plan Update

The Committee is responsible for developing a *Strategic Plan*, which is updated annually. The *Strategic Plan* provides a blueprint to guide autism-related efforts across federal agencies and partner private organizations. It is organized around seven community-based questions. The current *Strategic Plan* has 23 objectives that address research, services, and policy and provides a budget recommendation. The Committee is also required to develop an annual *Summary of Advances* each year, which is a report of lay-friendly summaries of the 20 most significant advances in ASD research that year. These are nominated and selected by Committee members and are aligned with the seven guiding questions in the *Strategic Plan*. To fulfill the requirement to monitor federal activities, the OARC prepares an annual *Portfolio Analysis Report* of public and private funding to identify gaps and trends and to determine if the *Strategic Plan* objectives are being met. This portfolio analysis typically includes two years of funding data. A detailed federal and private organization database is publicly available, called the Autism Research Database.

Immediate tasks for the IACC are to develop and update the *IACC Strategic Plan* and to develop two volumes of the *IACC Summary of Advances* (2020 and 2021).

Dr. Daniels reviewed a proposed plan for updating the *Strategic Plan* for 2020-2021. The IACC would establish a working group of members to work closely with OARC to develop initial plans. The IACC can authorize OARC to issue a Request for Information (RFI) to gather public and expert input on areas of the strategy that need updating. At the October Committee meeting, members would review and evaluate the current *Strategic Plan* and provide thoughts and suggestions and consider public input. OARC would also gather recent scientific literature, federal reports, and other data to help with the process. Additionally, the public comment session at the next meeting could be extended and IACC could invite experts to share input. Once all the information and feedback are collected and evaluated, the OARC would draft an updated *Strategic Plan* for Committee review and comment. Finally, the full Committee must approve the final *Strategic Plan* before it is published. The goal is to publish the update in2022.

Committee Discussion

Dr. Gordon asked the Committee to discuss the proposed method of updating the *Strategic Plan*. Ms. Prince asked if there was a way to invite people from around the country to discuss certain strategic priorities, such as a town hall meeting. Dr. Daniels said that the virtual Zoom platform would make this possible, and there would have to be a schedule for people to comment or share experiences. This could be a town hall meeting or a full Committee meeting with a long public comment section. Keeping it within a full Committee meeting would ensure that most Committee members would hear these comments.

Dr. Paradiz said that she supports the proposed process and expressed interest in serving on a working group. She suggested that the *Strategic Plan* be made accessible to a wide audience, and Dr. Daniels agreed that accessibility is important and that OARC works to capture the content in plain language. Dr. Johnson added that ODEP ensures that their key documents are accessible across a wide range of abilities, and that they can provide expertise in publishing what they call "clear language" documents. They typically release two versions of each report, one of which is in plain, accessible language. Dr. Robertson concurred that enhanced accessibility is important and encouraged the Committee to consider including a lay summary in the *Strategic Plan*. He also referred back to the earlier discussion on employment and mentioned his work as the federal project manager for the Partnership on Inclusive Apprenticeship.

Dr. Taylor expressed strong support for the proposed plan, which she said is more streamlined than past efforts. Ms. Gassner asked how to request other information from collaborative agencies, and Dr. Daniels answered that there are already quite a few data calls to these agencies, but they would also consider specific information requests. Ms. Gassner also expressed an interest in a discussion on language use.

Ivanova Smith asked about visual and audio supports for people who cannot read and people with intellectual disabilities. Dr. Daniels said that the federal government requires all website content to be 508-compliant, which typically includes screen reader accessibility.

Summary of Advances

Dr. Daniels reviewed the process for developing the *Summary of Advances* report. The 2020 Summary of Advances was not issued while the committee was out of session, so OARC created a list of peer-reviewed articles submitted by federal agencies and their team as a starting point. The Committee can also nominate other articles from 2020. Once all of the nominations are in, the Committee votes by electronic ballot. Up to 20 articles are selected and aligned under the seven guiding questions in the *Strategic Plan*. Then, OARC drafts short, lay-friendly summaries of the selected articles and publishes the complete *Summary of Advances*.

The proposed list of 2020 articles has been provided to the Committee. Dr. Daniels asked Committee members to review the list and email any other nominations with a justification for why the article is worthy of consideration. OARC will provide the Committee with full text versions of all articles and then ask for their vote. Dr. Daniels said they will send an email with instructions and plan to send the ballot out in September 2021 and the 2020 *Summary of Advances* published by early 2022.

Dr. Daniels then reviewed the process for the 2021 *Summary of Advances*. In the past, OARC solicited Committee nominations year-round via a monthly email. She asked the Committee to consider whether they would rather receive solicitations on a monthly or quarterly basis.

Committee Discussion

Dr. Gordon clarified that this nominating process typically starts in January, but this proposal is to complete the 2020 report. Dr. Robertson said it was particularly important to capture 2020 articles because of the COVID-19 pandemic and encouraged members to include articles relevant to COVID-19 and autism.

Dr. Rivera suggested that a monthly solicitation for 2021 nominations is a good strategy because it helps keep the nominations current. Ms. Gassner agreed with Dr. Rivera. Dr. Wexler said that in his experience as a previous member, a monthly email did not work well and suggested a twice a year solicitation with the ability to nominate any time. Mr. Srinivasan voted for quarterly solicitations. Dr. Robertson suggested that a monthly email worked, but a quarterly email may be a good compromise over twice a year.

Ms. Gassner and Ms. Smith asked if OARC could offer hard copies of the past *Strategic Plan* and *Summary of Advances* for people who have difficulty reading on a screen.

Dr. Daniels asked the Committee for permission to reconvene the Working Group for Improving Health Outcomes for Individuals on the Autism Spectrum because a draft report needs to be finalized for publication in 2022. Committee members agreed. Dr. Robertson asked about the Working Group for Addressing Housing Needs, and Dr. Daniels said that because that working group had started late in the last IACC term, the workshop only had a summary. The working group did not create a report. She said that if the Committee would like to reconsider housing as an issue of focus, that can be discussed at a future Committee meeting. Dr. Robertson suggested this may be a good idea because there is now a HUD representative on the Committee. Dr. Souza said that she would be glad to participate in future discussions on housing. Mr. Srinivasan asked if topics were considered finalized once a report was published, and Dr. Daniels answered that the discussion can be ongoing.

Adjournment

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

Dr. Daniels introduced the OARC team, as they will be working closely with the Committee, and thanked them for their work in preparing the meeting. She also shared the OARC quarterly newsletter and IACC website as resources for more information on the IACC and federal and community activities.

Dr. Daniels adjourned Day One of the meeting at 4:05 p.m.

DAY TWO

Committee Discussion of COVID-19 Impact, Response, and Recovery

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

Dr. Gordon reviewed the agenda, which included a discussion COVID-19 and the autism community. There will be a public comment session followed by a Committee discussion of the issues brought up. Finally, there will be a discussion on racial equity and health disparities in autism. He asked Committee members to be open and frank with their thoughts. While it is important to hear and understand differing perspectives, it is also important to respectfully express these differences and disagreements. He expressed that he is looking forward to future discussions and moving forward.

Dr. Gordon kicked off the discussion on COVID-19 response and recovery. He spoke about anticipating the significant mental health consequences of a major public health crisis. In the early days of the COVID-19 pandemic, NIMH expected to see a large number of Americans with mental health symptoms of depression, stress, anxiety, substance use, and suicidal thoughts. NIMH also predicted that many people would recover over time, but a minority would experience chronic or severe mental health symptoms that required professional help.

Now, well into the pandemic, they are indeed seeing that up to 50 percent of Americans are experiencing one or more symptoms of mental distress. There is an increased demand for mental health services and an increasing number of emergency room visits for self-harm behaviors in adolescent girls and calls to suicide and disaster hotlines. But there was also a remarkable response from the mental health community. Services pivoted to telehealth, and there is data suggesting that this approach was effective. For example, there have not been the increases in overall suicide rates that were expected, and in fact, the national suicide rate was lower overall during the pandemic.

However, like many other health outcomes in the nation, the mental health consequences of the pandemic were not felt equally. For instance, there is evidence of increased suicide rates among Black

Americans compared to White Americans, in which the suicide rate decreased. The BIPOC communities have felt the direct and indirect impacts of the pandemic the most acutely. There is still a dearth of data on the impact of the pandemic. There are researchers on the Committee who are currently studying these impacts, and Dr. Gordon looks forward to those results in the near future. In the meantime, both quantitative and anecdotal evidence heard within a federal platform such as IACC may help develop a response for a particularly disadvantaged community, such as people on the autism spectrum.
Dr. Gordon asked Committee members to consider some of the ways COVID-19 impacted people on the autism spectrum and the areas that IACC can help mitigate the impact through recommendations for research, improvements in services and supports, and/or improved coordination and policies.

Ivanova Smith talked about the discrimination Ivanova and many others in Ivanova's self-advocacy group are still experiencing due to the pandemic. For instance, many people on the autism spectrum cannot tolerate face masks and wear face shields instead. But this need is often not honored by others, which leaves people with sensory issues excluded from their community or unable to participate in activities that require a face mask, such as travel. This is an exclusion from society, and people on the autism spectrum are seen as a burden because they cannot do what others do. There need to be exemptions for people who are unable to follow all protocols so that they are not restricted from their communities. Furthermore, while many people on the autism spectrum have received a COVID-19 vaccination, many care providers have not. This results in many not being allowed to leave a residential facility for fear of community spread.

Mr. Srinivasan said that one negative aspect that he has observed is a disruption of services, especially for special education. Although many students moved to a virtual learning platform, virtual learning did not substitute for hands-on learning for people with autism. On the positive side, virtual platforms like Zoom have provided more employment opportunities for adults with autism. There is a potential for higher employment rates among people with autism if employers could see virtual employment as a value. Similarly, he has had success with virtual cognitive behavior therapy without having to travel. It is still important to understand that not all services are effective virtually.

Dr. Taylor spoke about her ongoing research and her interest in learning if their findings are consistent with the lived experience of those on the Committee. One study collected mental health and mental health services data at the end of February and beginning of March 2020, just before there was a shutdown in response to the pandemic. This provided baseline data on a large population of over 300 autistic adults. They collected data again two months later and found very high rates of depression and anxiety, but those rates were also high before the pandemic. On average, there was not a worsening of mental health. There was, however, significant variability in people's experiences. Those who lost their job early in the pandemic tended to experience worsening depression. Those who experienced depression prior to the pandemic seemed to be more negatively impacted by the pandemic as well. There was also variability in mental health improvements. Those who were able to work remotely, but would not have had that opportunity otherwise, reported improvements in their mental health. Dr. Taylor said they are wrapping up another wave of data collection a year into the pandemic and will examine the long-term mental health effects of the pandemic.

They have another study on service access and are currently collecting data on how adults and young adults were impacted. They are also looking at special education. Initial data shows that it was easier to apply for adult services, although this varied by type of service and across states and agencies. Some service applications moved online, while others remained in person. It was much harder to make use of services and find providers due to social distancing restrictions. Dr. Taylor said that they published two papers on mental health and they have one paper under review on the impact of employment changes on mental health.

Ms. Gassner said vocational rehabilitation programs asked her, as well as other colleagues who have transition-aged children, to close their rehabilitation system cases and to end services such as training. This occurred across different states. In her personal experience, they found that online services were either not effective or created other barriers to employment. She also spoke about an article in Time magazine about the supports needed by people with long-haul COVID. SSA is being inundated with new applicants who do not have a history of disability. These new applicants are struggling with more internalized needs that are difficult to measure, much like the needs of autistic people. The system is struggling to meet demand. The proposed 10 percent increase to these programs in the federal budget will not cover the 22 percent that was previously cut. The continued loss of services, decreased employment opportunities, and delays in Social Security Income (SSI) will result in the system being flooded.

Dr. Paradiz responded to Ms. Gassner's comments about disability resources. Her son on the autism spectrum lost his job early in the pandemic and recently returned to work. He experienced significant challenges communicating with the SSI office near him when he returned. The delays in communication caused him to experience anxiety and panic attacks and he had to be hospitalized. She also shared that Autism Speaks issued a special report on COVID-19 and autism in March 2021. Some high-level takeaways were that households with people with autism are experiencing significant food insecurity, especially among minority households. A greater percentage of people with autism and people with both autism and intellectual or developmental disability (IDD) are both being hospitalized with COVID-19 and dying from COVID-19 than people with no chronic conditions.

Dr. Marvin addressed the concerns about SSA, which has been very active since the beginning of the pandemic. SSA launched both a COVID waiver program and a suspension of adverse actions program. The Division of Analytics Center of Excellence has been analyzing applications to determine who is and is not applying for benefits to support SSA outreach efforts to reach those who may qualify but are not applying. SSA's outreach efforts include publicity, radio, and television. While it is true that many SSA offices are closed, it is possible to make an appointment to meet in person. People can contact SSA by telephone and access some services online. She encouraged everyone who thinks they may qualify to apply and provided a link to SSA COVID-19 resources at https://www.ssa.gov/coronavirus.

Dr. Halladay thanked those who have made their research reports available online and highlighted two other reports. A study from Simons Searchlight looks at service availability for people with autism and rare genetic diseases. Another study led by University of California, Los Angeles dovetailed that effort by reporting on the people with rare diseases not covered by Simons Searchlight. Both studies showed that before the pandemic, people were hesitant about telehealth, but now that everyone has used it during the pandemic, it is likely here to stay. This is good news for some, such as those who no longer need to take time off work or for adolescents in mental health treatment. However, it is sobering news for others, such as young children who need behavioral interventions across the lifespan. There needs to be an acknowledgment of what is good about telehealth, and an understanding of parts of telehealth that do not work. She acknowledged that telehealth does not address SSI directly, but it does address access to services.

Dr. Avila talked about the limitations of telehealth among families that do not have access to WiFi or devices. There are there are surprisingly many areas in the United States that do not have access to this technology. There are many others with language barriers and other health literacy challenges. For instance, virtual platforms that use long consent forms can create barriers to equitable access. There was online registration required for COVID-19 testing in Vermont that was not written in plain language. Many people needed the assistance of an advocate just to receive a COVID-19 test. Some communities were not able to access timely information about the pandemic because of English language proficiency. These limitations and delays led to COVID-19 outbreaks in several Vermont communities. Many important press conferences did not have translators, such as for ASL. These language barriers highlight the need to improve the infrastructure around public health.

Dr. Avila was also involved in advocacy groups for vaccination among racially diverse and vulnerable communities. They found a need for community education to address vaccine hesitancy and distrust of the health care system. Addressing vaccine hesitancy needs to be done proactively. Also, every state had different priority groups for vaccinations. Vermont made those with underlying conditions a priority population, but the original policy required medical proof and a doctor's name. This type of policy creates a barrier to reaching as many people as possible and heightens distrust. The pandemic has provided several lessons in what infrastructure improvements are needed for public health going forward.

Dr. Gordon added that individuals with mental health conditions are at higher risk of contracting COVID-19, and those with COVID-19 are at greater risk of being hospitalized or dying. It is important to consider people with mental illness and autism as a high-risk population for COVID-19.

Ms. Crane commented on the different experiences between people living independently and people living in an institutional setting. ASAN is concerned about those living in institutional settings and their increasing isolation. This population is also more likely to contract COVID-19 and die as a result of COVID-19 despite restrictions to prevent outbreaks. ASAN is tracking COVID-19 cases and deaths among residents of institutional settings and staff. They found that residents are more likely to die of COVID-19, despite restrictions. These restrictions also prevent this population from seeing their friends and family, even at this point when many people are vaccinated. There are other ways that COVID-19 restrictions have significant impacts on people with disabilities. For instance, people in need of health care are not able to bring a supporter with them to the hospital or clinic. This is especially troubling for those with IDD, anxiety, or communication disorders. ASAN has drafted model policies to balance the need for safety with the need for equitable access to health care, including care that requires the presence of support.

Dr. Marvin added that SSA also maintains a site in Spanish as well as brochures in several different languages.

Mr. Srinivasan provided a comment expressing his unhappiness about the trend from large organizations that view work-from-home as a top executive's privilege and not for other employees. This results in many autistic people are left out of hybrid and work-from-home solutions. Dr. Gordon added that many organizations seem to be reevaluating their policies, and some are moving to increased flexibility, although there are some that are not. Hybrid work does present an opportunity for increased participation for some people on the autism spectrum.

Dr. Bianchi said she is deeply troubled by the short- and long-term effects of distance learning on children, particularly those with special needs. For this reason, they convinced the Office of the Director to prioritize a safe return-to-school in the Rapid Acceleration of Diagnostics (RADx) for Underserved

Populations program. This is a $50 million program that started in the spring to understand the disparities associated with COVID-19. They hope to provide data by early August that will show evidence for a safe return-to-school. Additionally, several investigators are looking at populations of students who have challenges with the typical mitigation strategies. They understand that some populations are unable to wear face masks and others have difficulty following directions for hygiene or social distancing. Investigators are looking at these and other populations across different races, ethnicities, disabilities, and geographic locations to understand these needs. Dr. Gordon added that there are other NIH-sponsored studies on the impact of school closures and the effect on children such as those with autism.

Ms. Gassner said that it is also important to consider the high frequency of neurodiversity among the parents of neurodiverse children. Parents could be experiencing a learning disability, autism, or attention deficit disorders, and these may be compounded by issues such as language or communication barriers. Social Security offices may also have challenges in implementing requested supports such as a separate waiting area. Another challenge is people may not have access to a navigator that can help individuals understand questions that are being asked.

Ivanova Smith added that face shields as an alternative to face masks are not being recognized, and that a policy to clarify reasonable accommodations so that businesses, health care facilities, and other locations will recognize a face shield as acceptable and not deny services. Ivanova reiterated that access to technology is required for virtual services and that some residential facilities cannot afford or limit access to these technologies. Many of these facilities do not allow or limit WiFi access.

Dr. Piven asked about the extent to which the *Strategic Plan* can be modified to address COVID-19, and suggested IACC could review specific research or implement working groups to address these challenges. Dr. Gordon said that a special activity to specifically address challenges and disparities from the pandemic would be helpful.

Ms. Prince’s organization has seen single parents with multiple children, who usually receive support from teachers and schools, that were isolated from their families during the pandemic. They did not receive additional help from schools. A lot of damage was done to their confidence in parenting as well as to their children's language and speech skills. She is also concerned about clinicians who do not understand these issues or the fears of those in emergency care who are unable to receive support from their families due to the pandemic. This can result in challenges, such as nightmares, upon returning home.

Dr. Wang said that access to broadband is critical in terms of a solutions perspective, but it remains a challenge in some communities, such as rural areas or Native American reservations. There additionally needs to be an effort to understand how to optimize telehealth services and parent-mediated interventions.

Dr. Gordon read a statement from Mx. Giwa Onaiwu expressing that access to WiFi is a much greater issue than people realize. Autistic people in congregate care settings or similar types of housing settings may technically have access to WiFi, but it is so slow and unreliable that it is not possible to actively participate in virtual therapy, distance learning, or social engagement.

Mr. Srinivasan added that it can take many years to build the skills to manage face-to-face social interaction. The pandemic was a huge setback in terms of loss of these social skills. There will be a difficult transition back that may seem like a relearning of these skills. While many students may feel excited about returning to school, he feels stressed about how to assimilate and recover those skills with less than a month away. Additionally, his college will be requiring weekly COVID-19 tests once a person is six months past vaccination. His experience with the vaccine was stressful with multiple attempts and special accommodations. He expressed that having a COVID-19 test that requires a nasal swab will be a sensory nightmare. Dr. Gordon suggested that there are saliva-based tests that may be worth looking into as an accommodation.

Public Comment Session

Summary of Oral Comments

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

Dr. Daniels introduced the oral commenters.

Ms. Jill Escher is the President of the National Council on Severe Autism (NCSA), a research philanthropist, an autism housing provider, and mother of two children with autism who are nonverbal. Ms. Escher asked if the community is better off than 20 years ago when the IACC was first established. Her opinion is that it is not, with modest exceptions. Scientists are not close to identifying the causes of autism or any meaningful roots for prevention. The prevalence of autism continues to climb, with some claiming that the increase is not real and others pushing the dangerous and debunked idea that vaccines cause autism. She said the science of autism seems stuck on irrelevant research that does not help people with autism with treatment and tools. There is also the growing crisis of adults with autism, many of whom live with aging parents due to lack of housing options. There are fewer opportunities for employment, and Medicaid funding only supports a fraction of disabled adults. There are few to no supports for families living with a self-injurious loved one. Ms. Escher asked the Committee to ignore the efforts to trivialize autism. Instead, she asks the Committee to focus on federal efforts to identify the cause, prevention, and treatment of autism across the lifespan as directed by Congress.

Mr. Bin Feng is an Autism Speaks advocacy ambassador and father of a 21-year-old son on the autism spectrum who works independently as a janitor in New York City. During the pandemic, his son had to learn to wear a mask and work in a locked down city as a frontline worker. This job helped his son learn to manage a schedule, travel independently, communicate, and learn from mistakes. They are very proud of his accomplishments and see that employment will provide a path towards independence. The next challenge towards his independence is finding supportive housing options, but there are significant challenges. One challenge is his access to Social Security support, which is at risk and prevents him from taking on more hours. There is also a lack of prevocational training, especially after the pandemic closed many of these opportunities. New York state is also closing sheltered workshops, which may be the only place some adults with autism can work.

Mr. Chris Banks is President of the Autism Society of America, which is a network of 74 affiliates in 33 states that serves over 668,000 individuals and families affected by autism. Their mission is to support the autism community with advocacy, education, information, referrals, supports, and community building. The Autism Society of America is the nation's oldest and largest grassroots autism organization. At the onset of the pandemic, they were the first national organization to produce and share a COVID-19 toolkit, which 135,000 users have accessed. They also provide a live series on their Facebook page, viewed by nearly 200,000 people. They promoted Autism Acceptance Month in April and campaigned for the media and government officials to change the words from "awareness" to "acceptance." Acceptance is a barrier to being valued and to finding a strong system of support. Acceptance leads to inclusion, and inclusion leads to belonging and community. Mr. Banks hopes for future representation on the IACC and asked the Committee to consider first responder training to reduce injury, fatalities, and arrests in the autism community; water and wandering programs to address the high risk of drowning in the autism community; and to support systemic change to increase employment opportunities for people with autism. They are also concerned about vaccine hesitancy, food scarcity, housing, transitional services, diversity, and inclusion. They welcome the assistance of IACC in coordinating strategic initiatives towards addressing these priorities.

Ms. Kelly Israel is a Policy Analyst at ASAN. ASAN is pleased to see IACC resume its efforts to properly allocate funding for autism research. They hope the IACC will work to accelerate and inspire research and enhance service provision and access, which will improve the health and quality of life of every autistic person across the lifespan. ASAN supports the research projects and workshops included in the *IACC Strategic Plan* and their proactive steps to include the perspectives of autistic adults. Nonetheless, she stated, autism research funding remains excessively directed towards topics that are of little benefit to autistic people who are alive today. According to the latest *Portfolio Analysis Report*, over 61 percent of total autism research funding went towards the biology and causation of autism. Only 3 percent of funding was dedicated to services and supports. ASAN urges the Committee to shift direction towards research that primarily benefits autistic children and adults who are alive right now. They also recommend the Committee collaborate with researchers on other IDD because both populations experience similar challenges and needs. ASAN requests the Committee prioritize research on effective communication tools for nonspeaking autistic people, rather than focusing on verbal speech.

Dr. Noemi Spinazzi is an assistant professor at the UC San Francisco, and Medical Director of the Down Syndrome Clinic. It has previously been thought that autism rarely occurs with Down syndrome, but it is now known that the prevalence of autism spectrum disorders in people with Down syndrome is between 16 and 18 percent. This means that approximately 1,000 of the 6,000 children born with Down syndrome each year in the United States will eventually be diagnosed with autism. Co-occurring Down syndrome with autism leads to a complex neurodevelopmental profile in which the characteristics of autism are superimposed on common challenges in Down syndrome, such as IDD, speech impairment, short attention span, and memory impairment. These children are also more likely to be diagnosed with mental health conditions such as anxiety, attention deficit hyperactive disorder (ADHD), aggression, self-injury, and elopement. There is a lack of evidence-based diagnostics and guidelines, which delays diagnosis and the start of targeted therapies that could improve functioning and quality of life. There is also inadequate research on which interventions are most successful in those with a dual diagnosis. Given the high prevalence of autism and Down syndrome and the significant impact of the dual diagnosis on families, there is a need to direct attention to this underserved population. Dr. Spinazzi talked about the Down Syndrome Medical Interest Group, which is partnered with Autism Speaks and AGENDA to promote collaboration, raise awareness, and accelerate research.

Summary of Written Public Comments

Luis Valdez-Lopez, M.P.H., Policy Analyst, OARC, NIMH

Mr. Luis Valdez-Lopez summarized the written comments. Since July 2019 Full Committee meeting, IACC has received written comments from 47 commenters. OARC organized these comments into seven broad topics: 1) programs, supports, and housing options for individuals on the autism spectrum with high support needs, 2) concerns about medical practices and potential causes of autism, 3) the role of IACC and the federal government, 4) service needs, resources, and policy implications, 5) the COVID-19 pandemic, 6) employment, and 7) graduated electronic decelerators (GEDs). Over 120 public comments were received after the public comment deadline on the overturn of an FDA ban on GEDs. About half of these comments were from three email campaign form letters. The letter writers are asking IACC to support the ban of the device.

Summary of Live Feedback Comments

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

Dr. Daniels reviewed live feedback comments from eight commenters on transition supports, high support needs, a need for IACC to increase its public presence, concern for the direction of research funding, the need to expand social security disability insurance for those with autism without IDD, and gratitude for the IACC.

Oral and written public comments and live feedback comments can be found on the IACC website.

Committee Discussion

Ms. Crane agreed with the importance of participatory community-driven research. This type of research is more responsive to questions that are important to the community. It tends to have a better research design and analysis because it was built with participation from people with lived experience.

Ms. Gassner said the comment about limitations of both unionized and nonunionized self-funded plans and their provision of insurance for individuals with autism was an important issue. Regarding the comment about school resource and law enforcement officers, identification cards may create a risk when the individual tries to reach for the card from their pocket. She added to ASAN's recommendation, stating that communication tools should include all kinds of intervention tools. Ms. Gassner also said that the American Dental Association started mandating IDD training for all dental students, which may be a model to use in the future. She stated that she is committed to hearing and supporting the voices of people with a variety of needs.

Dr. Marvin responded to the comment about expanding SSI to people with ASD but without IDD. She said there is a recent article on the increased number of people with ASD as a primary diagnosis qualifying for SSI, and she encourages people to apply if they think they may qualify. She added that people without access to broadband can also call SSA at 800-772-1213, and there are interpreters in nearly every language.

Dr. Robertson said that the employment-related comments resonated with him, and he recognized the additional stress of unemployment and shifts in telework policies during the pandemic. He emphasized that ODEP has resources for accommodations in the workplace and for seeking employment that can be found at the Job Accommodation Network (AskJAN). AskJAN also has resources related to COVID-19 and provides free expert, confidential assistance. ODEP also has technical assistance centers for employers, such as Employer Assistance and Resource Network on Disability Inclusion (EARN). As an autistic person, the comments on quality of life and communication access resonated with him, and he hopes that the Committee will look deeper into the marginalization that occurs for people on the autism spectrum who need alternative communication supports.

Dr. Souza shared some information concerning the comments on housing assistance. HUD's housing assistance program that serves about a quarter of people who are eligible. An analysis of those who receive housing assistance found that people with disabilities have higher assistance rates than people without disabilities. She mentioned the mainstream voucher program, which received new awards this year and will serve people with disabilities and people at risk of homelessness. HUD also has a new Emergency Housing Voucher program, which will award 70,000 vouchers to 626 public housing agencies. They launched Eviction Protection Grant Program in July and is currently receiving applications.

Dr. Halladay asked the extent to which the public comments and discussion are considered for inclusion in the *Strategic Plan* because many ideas need further research. Dr. Daniels answered that OARC is collecting this information and will provide it to the committee for consideration in the *Strategic Plan* process. They will also solicit public comment specifically for the *Strategic Plan*. Dr. Gordon added that Committee members are expected to identify topics from the public comments that need to be further examined, included in the *Strategic Plan*, or other recommendations. Sometimes, a suggestion will result in a future expert presentation to expand on the idea.

Dr. Farchione addressed the comments about the ban on GEDs. She said she has forwarded these concerns to the FDA team that worked on the overturned original rule, and they are now aware of their concerns.

Mr. Srinivasan added his thoughts on people with moderate to severe autism, such as himself. He has seen many gradually disappear into group homes, which means that their issues become out of sight and out of mind. This affects their access to spaces, funding, and resources. Providers tend to want easy cases and tell those with moderate to severe autism that they are not a good fit. This is another way of saying that the person is too much work. Even day programs will not take severe cases, and he has adult friends who are stuck at home because no one will take them. There is also an impending crisis of aging autistic adults who are unhealthy because of the side effects of their psychiatric medications, which often do not work well with their physiology. People with moderate to severe autism already have many challenges accessing services and health care. Insurance often does not cover the added services needed, such as anesthesia for dental services. Dr. Gordon said that this is precisely the reason that IACC gives individuals with more moderate to severe autism a seat at the table, and these comments will become future meeting topics.

Dr. Dickerson highlighted the comments about interactions with school and law enforcement officers as an important issue for future discussion and advocacy.

Ms. Prince agreed about the comments on the direction of autism research and the need for more information on lived experience across the lifespan. If this is not addressed now, it will become an even greater crisis, especially with many people aging and the unanticipated issues that may bring.

Ms. Gassner commented that they need to acknowledge GEDs and perhaps invite people to provide testimony.

Dr. Daniels read a comment from Mx. Giwa Onaiwu stating she prefers the use of the term "people with higher support needs" rather than "severe" autism, which can be stigmatizing. Dr. Daniels thanked all those who submitted public comments.

Committee Discussion of Racial Equity and Health Disparities in ASD

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

Dr. Gordon said that there are known facts of inequality in autism, particularly in regard to diagnoses and treatment access. One known fact is that individuals from minority groups tend to have diagnoses delivered much later in life than those who belong to majority groups. There are also disparities in diagnoses related to socioeconomic status, race, and ethnicity. This gap is narrowing somewhat as there is increased knowledge of tools such as universal screening. There are also documented disparities in access to quality care that is impacted by where one lives and who one is, rather than what one needs. The goal of this discussion is to identify the issues that should be further explored in the coming months.

Ivanova Smith said that a lot of immigrants are having a hard time applying for services because the requirements for medical documentation are strict. There are a disproportionate number of people of marginalized identities who are being institutionalized and not receiving community supports. Additionally, the vast majority of people at the Judge Rotenberg Center who are subject to GEDs are BIPOC. There are also language barriers for receiving community services and supports. People may be afraid to access services, including vaccinations, because of being institutionalized or from fear related to their immigration status.

Dr. Phan reiterated that community-based participatory research is a pathway for including racial minority groups and ensuring representation for caregiving, housing, and mental health services. A recent paper showed that Asian American children are more likely to receive an autism diagnosis through school rather than a clinical diagnosis. This may be due to existing stigma around ASD within Asian communities. Bridging the community to the research will provide insight about issues such as stigma. Dr. Gordon suggested that this comment was an example of a mechanistic-focused approach, which is used at NIH and is not incompatible with community-based research or social determinants of health research. Dr. Phan identified a problem, hypothesized a mechanism, and provided evidence behind that mechanism. If one understands the mechanism, one can identify a solution based on that mechanism.

Ms. Gassner disclosed that she is also a social worker by training, and she sees many BIPOC people who do not attempt to apply for disability. These clients are mired in the ideas of a school-to-prison pipeline, as their children’s behaviors are seen as disciplinary issues rather than a form of communication. Parents also lack information about autism and some view it as a White person's condition. Anything that can be done to better inform these communities and help them navigate systems will help, and social workers may have the skill set needed to meet that need.

Dr. Dickerson talked about seeing disparities in the age of diagnosis, not only in her research but also within the Black community. It is primarily due to a lack of screening with general practitioners, who rarely screen for autism during well-child visits. Children from marginalized populations will not typically be diagnosed until they are in school, which is known to be a little too late. Dr. Gordon pointed out that the U.S. Preventive Services Task Force (USPSTF) declined to endorse autism screening in early childhood. However, many professional organizations, such as the American Academy of Pediatrics endorse it. NIMH is working to get that endorsement from USPSTF and answer their questions. One remaining question is whether screening can help change the age for diagnosis and outcomes in minority communities.

Dr. Dickerson agreed with Ms. Gassner that the Black community sees autism as a White person's disorder. She stated that screening and diagnosis questionnaires must be culturally competent and that health care providers of Black children need to understand cultural and social differences between families. She added that, even as a neurotypical and highly educated Black woman, she often receives unfair treatment from the health care community. It is important to understand that marginalized communities are already not getting fair treatment within the health care system.

Dr. Carter talked about a study she just completed that addresses health disparities in the age of autism diagnosis that was funded by NIMH. The project was unusual in that they implemented screening in the IDEA Part C early intervention system. They have observed that pediatricians may refer children who flag positive for autism to early intervention but not a diagnostic evaluation. They also found issues of cultural competence. They were able to address the gap in age of diagnosis between Latinx and White children when screenings were done in both Spanish and English. Practitioners were provided training on cultural responsiveness. Dr. Carter’s group has qualitative data suggesting that families do not see early intervention providers as culturally competent as providers see themselves. Increasing cultural responsivity and understanding systemic racism will help improve gaps in diagnosis and care.

Dr. Avila shared her experience in providing racial equity workshops. Her research has found that most providers do not know the history of systemic racism in the United States or how it impacts health disparities and racial inequities. She reiterated that participatory research is one of the most effective ways to work with communities. It is the Committee’s responsibility make recommendations about working directly with underserved communities to ensure that research benefits them. She is also talked about the need to train school resources officers on anti-racism, anti-ableism, structural competency, and cultural humility. Everybody could benefit from this type of training. Although law enforcement is in the news right now, mental health providers, special educators, and all other health providers should receive extensive training towards health and racial equity.

Mr. Srinivasan said he is a BIPOC autistic person, and he wrote a short paper on race and autism diagnosis for his stigma and discrimination class. In his literature review, he found that there is a societal judgment that the Black community is somehow less deserving and that Black children are less innocent than White children. This racial bias translates to substantial delays in an autism diagnosis for Black children, even when their parents expressed concerns and have health insurance. Delays in the referral process and lack of timely diagnosis leads to missing crucial, early interventions that can lead to more positive outcomes. Non-White parents are often told that their child does not have autism or had a different diagnosis, such as conduct disorder. The literature also demonstrates implicit racial bias in autism identification and delays from Black parents reporting autism symptoms. Although his research was specific to the Black community, he imagines that other BIPOC communities have similar experiences. These are fundamental, systemic inequities in receiving a diagnosis and services. There is also an added stigma against disability among many cultural communities. This causes people with disabilities and their families to be excluded from supports from their community. This increases isolation and families are double excluded from both their culture and services.

Dr. Carter added that the Committee could also recommend a requirement to have a diverse representation on Data Safety and Monitoring Boards (DSMB) for autism studies as well as an advocacy consultation group. Dr. Gordon thought that the Autism Centers of Excellence might require the involvement of people with lived experience on oversight or advisory boards. Dr. Alice Kau said that it might not be a requirement, but community engagement is a requirement. She can look into it and report at the next meeting.

Ms. Gassner shared that the Autistic Researchers Committee is currently working on a database to help researchers find collaborators who represent a variety of experiences related to autism, socioeconomic status, and race. This will help with community-based participatory research.

Dr. Robertson highlighted the Executive Orders related to the issues being discussed. Executive Order 13985 advances racial equity and support for underserved communities throughout the federal government and Executive Order 14035 supports diversity, equity, inclusion, and accessibility in the federal workforce. These are shaping much of DOL's activities, and the same is likely true across many other agencies. DOL is connecting to Historically Black Colleges and Universities (HCBU) and other minority serving institutions to promote access to gainful employment and career pathways. Additionally, there are local autism work groups throughout the country that are focusing on racial equity and outreach to BIPOC communities. These groups are working to ensure that BIPOC communities have full access to employment and career pathways that are linguistically and culturally competent. Dr. Robertson suggested that racial equity, gender identity, sexual orientation, socioeconomic status, and intersectionality be woven into the updated *Strategic Plan*.

Dr. Gordon added that NIMH is also enhancing research in disparities and equity and invited other agency representatives to comment on their efforts. Preceding the Executive Orders, NIH and all individual Institutes have a renewed focus on diversity to understand the mechanistic basis of disparities and the social determinants of health and develop interventions to reduce disparities. NIH has an explicit call for the need for increased community-based participatory research.

Ms. Prince said that the term "social determinants of health" was unknown to her until recently when she read a CDC statement on social determinants of health in the Black community. She thought that a similar list of determinants for people with autism would help highlight issues in a population that is in large part invisible in their communities. She also expressed that adults with autism are invisible and that a larger government agency needs to recognize some of these issues. Dr. Gordon said that the former Executive Director of the National Alliance on Mental Illness (NAMI) identified mental illness as one of the greatest but most unrecognized health disparities. This recognition could be equally applied to autism and other marginalized identities.

Ms. Bass appreciated the discussion on cultural competency and talked about the cultural competency training that IHS released for serving American Indians and Alaska Natives (AI/AN). This training is free, on-demand and provides continued education credit. They also released 13 trainings on trauma-informed care to help health care providers be mindful of the historical trauma faced by AI/AN and improve their ability to diagnose and treat them. They have also released training on autism screening and diagnosis.

Mr. Johnson talked about the importance of training and stated that service providers often lack resources and tools. He asked if IACC could become a resource for training or a collaborator with other experts to develop training. Dr. Gordon answered that IACC is not a service-providing organization and therefore is not able to provide or develop training. However, it is within the Committee's purview to recommend to the HHS Secretary that there be an organization that develops training. There are varied approaches to training. Some are for health care providers, medical schools, and professional organizations. Training for law enforcement was mentioned, which is under the purview of the DOJ. There are many federal agencies, but the IACC has the most direct influence with HHS, which will listen to and act on some of these recommendations. Committee members can also make known the different training resources available. These resources can be publicized through IACC, which has a large web and social media presence.

Ms. Gassner said that Arc is having their convention in November. Their self-advocate orientation and training session will focus on teaching people IDD how to engage with first responders.

Dr. Gordon read a comment from Mx. Giwa Onaiwu, who, as a multiethnic Black autistic person with Black disabled children, shared her concern for the people in her community who have been largely ignored. She expressed that it is an enormous disservice when White people make insensitive comparisons that trivialize the experience of those living at the intersection of race, disability, and other marginalizations.

Dr. Peacock said that Dr. Rochelle Walensky, the new CDC Director, has challenged CDC staff to look at all of their programs through a health equity lens. This includes focusing on health inequities for people with disabilities. In NCBDDD, they are working with other HHS agencies to look at disability as a demographic indicator on national health surveys. This will help describe the gaps and needs of disability communities.

Dr. Dickerson concurred that everyone needs some cultural competence training. She heard from parents of Black adults with autism that their primary concern is interactions with police. A child who is considered disruptive can be easily handled in most cases. When the police encounter a Black adult with language comprehension issues who is also showing disruptive behaviors, then the situation becomes exponentially dangerous. She hopes that the Committee will discuss training for law enforcement officers for handling not only adults with autism but also adults with autism from marginalized communities.

Ms. Fryer said that her work at the Bureau of Justice Assistance at DOJ is to enhance responses to people with mental illness and disabilities. They are engaging national experts, organizations, and the Arc to undertake an expansion of the national curriculum for law enforcement. They have an event this fall in which they will explore alternatives to law enforcement responses specifically for people with disabilities. They are collecting feedback from communities to determine if this is an appropriate direction and to identify best practices.

Ms. Prince said that defense attorneys and judges also need training. This effort needs to be expanded across the system. Ms. Fryer responded that DOJ is exploring this suggestion and other tools. They began this effort years ago with the Arc and Pathways to Justice when people with IDD were flooding jails due to lack of treatment and services options in the community. The advocacy and mental health communities then helped build on that portfolio of work. Then DOJ began to work more with law enforcement and the courts. DOJ recently convened a focus group called the Prosecutors Call to Action through the National District Attorneys Association. She will share some of the videos and products with the IACC.

Dr. Paradiz said there is an INSAR policy brief on the criminal justice system in autism that is forthcoming.

Ms. Gassner encouraged the Committee to be vigilant about their phrasing when speaking about people in this marginalized population and to ensure their voices have priority.

Closing Remarks and Adjournment

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

Dr. Gordon thanked the Committee for their discussion and those who submitted public comments. They have been provided a lot to think about in terms of what to address in the coming years. He thanked them for the free exchange of ideas, which he found to be respectful. He agreed that sometimes language is not always as clear as it is intended, and continued discussion would help address that issue.

Dr. Daniels thanked the Committee for their participation and the viewing audience for their attendance. She informed the committee that there is a Round Robin document on the website with all of the Committee Members' updates.

The next full Committee meeting is on October 13 and 14, 2021, and will be virtual.

Dr. Daniels adjourned the meeting at 5:00 pm ET.