



Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

October 13 and 14, 2021

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a virtual meeting on Wednesday, October 13, 2021 from 1:00 p.m. to 5:00 p.m. ET and Thursday, October 14, 2021 from 1:00 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; **Rebecca Dzubow**, M.P.H., EPA (representing Elaine Cohen Hubal, Ph.D.); **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; **Adam Hartman**, M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Nina Schor, M.D., Ph.D.); **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); **Matthew Miller**, Ph.D., M.P.H., U.S. Department of Veterans Affairs VA; **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/Trainer; **Valerie Paradiz**, Ph.D., Autism Speaks; **Scott Patterson**, Ph.D. HSP, (VA)

(representing Matthew Miller, Ph.D., M.P.H.); **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., 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; **Cornelia Sigworth**, M.S., DOJ (representing Maria Fryer, M.S.); **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; **Anna Tschiffely**, U.S., Department of Defense (DoD) (representing Nicole Williams, Ph.D.); **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Stephen Whitlow**, J.D., Gateway Transition Center; **Nicole Williams**, Ph.D., 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

Dr. Joshua Gordon welcomed attendees to the meeting. He noted that Dr. Francis Collins, NIH Director, will step down from his position by the end of 2021. His support for the Committee's mission will be missed.

Dr. Susan Daniels said that she received some small corrections to the July 2021 meeting minutes and the Committee voted to approve the minutes.

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 two public members who were unable to attend the July Full Committee Meeting to introduce themselves.

Ms. Yetta Myrick is a parent of a youth who was diagnosed with autism, intellectual disability, and attention deficit hyperactivity disorder (ADHD). She is the president and founder of [D.C. Autism Parents \(DCAP\)](#), an organization created to connect with other families experiencing challenges in navigating services and resources for their children. She is the Centers for Disease Control and Prevention (CDC)'s [Act Early Ambassador](#) to DC. She is leading the DC Act Early COVID-19 Response Team. Act Early aims to equip families with the resources necessary to monitor their child's development, engage with

providers, and receive early services and supports. Ms. Myrick also noted that she chairs the Developmental Monitoring, Screening, and Evaluations Subgroup of the [DC Autism Collaborative](#). The Collaborative is a multidisciplinary public-private coalition of stakeholders who aim to address barriers to care and advocate for solutions that facilitate access to high-quality diagnosis, treatment, and coordinated care. In addition, Ms. Myrick is a parent, educator, and advocate on the [ECHO Autism Hub Team](#) at the Center for Autism Spectrum Disorders at Children’s National Hospital. She emphasized that people across the autism spectrum deserve equal representation in research, especially those of color, of low socioeconomic status, non-English speaking populations, and from historically underserved and underrepresented backgrounds.

Mr. Stephen Whitlow is a father to a 21-year-old son with autism. In 2005, he and his wife established a small non-profit organization called Gateway Transition Center to provide transition services to young adults in the Baton Rouge, Louisiana area. Gateway Transition Center has expanded to include services such as pre-employment and residential facilities. Gateway has been taken over by [Merakey](#), a multi-state non-profit services provider. Mr. Whitlow now serves as their Transition Director.

Dr. Gordon noted that the Committee is working to improve their capacity for enabling attendees with verbal communication challenges to participate in the meeting. He encouraged anyone who encounters difficulties to contact him or Dr. Daniels directly.

Update from U.S. Department of Labor and Celebration of National Disability Employment Awareness Month

Taryn Williams, M.A., Assistant Secretary, Office of Disability Employment Policy, DOL

Ms. Taryn Williams provided an update from the U.S. Department of Labor (DOL) in recognition of [National Disability Employment Awareness Month \(NDEAM\)](#). She explained that the [Office of Disability Employment Policy \(ODEP\)](#) at the DOL was established in 2001 to ensure that there was a federal agency to work across agencies, programs, and sectors, to increase employment opportunities for people with disabilities.

NDEAM is held each October. It is an awareness campaign that honors the varied and many contributions of people with disabilities to the nation’s workplace and economy. Ms. Williams briefly reviewed the history of NDEAM, which began in 1945 when Congress declared the first week of October to be “National Employ the Physically Handicapped” week. The word “physically” was dropped in 1962 to acknowledge all people with disabilities. In 1988, Congress expanded the week to the entire month and changed the name to NDEAM.

One of ODEP’s top priorities has been to ensure a disability-inclusive COVID-19 response and recovery effort, reflected in the 2021 NDEAM theme: “America’s Recovery, Powered by Inclusion.” While ODEP spearheads NDEAM, the true spirit of the awareness month is driven by advocates across the country, from individuals to organizations to federal agencies. NDEAM is an optimal time to educate the nation about the importance of ensuring that all Americans—including those with disabilities—can put their skills and talents to work. To this end, ODEP makes publicly available several materials such as posters, newsletters, documents, and other educational tools at <https://www.dol.gov/agencies/odep/initiatives/ndeam>.

The NDEAM webpage also provides 31 ideas for honoring disability employment. One idea is to encourage employers and advocates to hold discussions with colleagues and friends to talk about NDEAM. Another idea is to develop trainings for supervisors on how to create a disability-friendly workplace. This year, ODEP also offered a social media toolkit with a range of ready-to-use materials, including NDEAM advocate spotlights from diverse backgrounds.

Additionally, ODEP recently launched a research project on supporting employment for young adults on the autism spectrum. This project was initiated in response to a request by Congress in fiscal year (FY) 2021. The three-year \$2.1 million contract was awarded to Mathematica and officially launched in August 2021. The project will examine strategies that promote workplace learning, gainful employment, and career pathways for autistic young adults using listening sessions, surveys, and other methods. The aim of the study is to improve employment outcomes for autistic young adults. The findings will also inform the work of ODEP regarding people on the autism spectrum of all ages. The study places special emphasis on autistic people who have diverse communication styles, support needs, and demographic backgrounds.

Committee Discussion

Dr. Gordon thanked Ms. Williams for her presentation. Dr. Kamila Mistry asked about quantitative and qualitative aspects of the study. She asked if they were using focus groups or interviews, and how they were sampling different populations. Ms. Williams answered that ODEP is working with the contractor to finalize the workplan, which will include the full design and further detail on quantitative analyses. Qualitative analyses will focus primarily on listening sessions, although there may be an opportunity to conduct individual interviews. Dr. Mistry expressed her appreciation for the project.

Ms. Dena Gassner asked about the ages of the study participants. Ms. Williams explained that the study will include young adults aged 16-24 years. Ms. Gassner pointed out that diagnostic delays among marginalized populations, diagnostic trauma, and medical maltreatment can lead to inconsistent employment. This may necessitate the examination of underemployment among more senior adults currently struggling to secure employment. She also asked whether autistic researchers would collaborate on the study as researchers rather than as participants. Ms. Williams responded that the team has already convened a group of experts that includes autistic advocates and researchers as part of the launch of the study. The study will continue to focus on the young adult age group as mandated by Congress, but Ms. Williams noted that their findings may have important implications for other age groups.

Ms. Sam Crane expressed her excitement about the study.

Ms. Ivanova Smith pointed out that many autistic people seeking employment cannot access job coaches and consultants. These services often require the individual to have a low IQ score, posing challenges for autistic people with IQ in the borderline range or above. Accessing these services also requires executive functioning skills, something that many autistic people struggle with. Ms. Smith asked if there is room to make job coaches more accessible to autistic people who have average or above IQ scores. Ms. Williams appreciated Ms. Smith's input and said that the team hopes to better understand these types of issues.

Mr. Hari Srinivasan noted that many autistic people enter education late and thus may enter employment later as well. Consequently, the target age range for this study may only include those who followed neurotypical timelines, leaving behind the majority. He felt that the age range should expand up to 35 years old. Ms. Williams said that she would take his feedback to the contractors.

Ms. Myrick asked about community outreach efforts, particularly for historically underrepresented groups. Ms. Williams said the team has not yet finalized the outreach strategy but reiterated that equity for marginalized communities is a priority for the project and across ODEP and DOL more broadly. The inclusion of people who are racial or ethnic minorities or have other intersectional identities is a critical part of how they will design the project.

Dr. Scott Robertson added that ODEP values collaboration and is working to ensure that Mathematica receives input and feedback from the Committee. While Congress has directed ODEP to study a younger population, lessons from this project will apply across age ranges and to people with other disabilities.

Dr. Gordon asked how DOL will implement study findings, specifically what goals or tools they have to address anticipated issues. Ms. Williams said that ODEP is a small, non-regulatory agency that advises the Secretary of Labor and agencies across the federal government about policies and practices that can advance the employment of people with disabilities. In the past, ODEP has used research findings to fund pilot programs to test the impact of interventions on outcomes, such as competitive integrated employment and earnings over time. She anticipates that the findings of the current study will inform future research questions to pursue in collaboration with other DOL agencies or external partners such as the ED and the Department of Health and Human Services (HHS). Ms. Williams added that ODEP provides technical assistance to individuals and policy developers. Dr. Gordon said that NIMH is working to build its research portfolio in this area, and he is looking forward to information that will guide intervention research.

Ms. JaLynn Prince commented that some individuals are disincentivized to gain employment, as they may lose some of their supports and services. She encouraged starting conversations with the Social Security Administration (SSA) about how these disincentives can penalize society and the individuals. Ms. Williams said they will consider this in their work. She wants to respect areas in which Congress has jurisdictions but plans to note input about such barriers to employment. Dr. Alison Marvin, representing the SSA, expressed interest in further discussion in this area. She said that understanding disincentives to employment is important to understand.

Ms. Crane pointed out that this problem particularly affects people who have high support needs related to activities of daily living. Some Medicaid buy-in programs were intended to address this problem, where a person who needs home- and community-based services (HCBS) were allowed to earn up to a certain amount while paying a Medicaid premium to keep their coverage. However, these programs are limited and vary from state-to-state. For instance, in Washington, DC, individuals who earn more than \$3,000 per month cannot buy into Medicaid. Ms. Crane said that programs with no income cap should be encouraged. She encouraged people to engage in local advocacy on this issue.

U.K. National Strategy for Autistic Children, Young People and Adults: 2021 to 2026

James Cusack, Ph.D., Chief Executive, Autistica

Dr. James Cusack introduced [Autistica](#), the U.K.'s leading autism research charity. They strive to enable autistic people to live happier, healthier, and longer lives. Autistica funds and campaigns for autism-related research, engages in advocacy and policy work, and shares national resources and information. They work closely with the autistic community, families, and other stakeholders to set an evidence-based agenda for change. They use their research to influence government and partners, which ultimately allows them to reach their goal of changing lives. About one-quarter to one-third of Autistica employees are autistic themselves, including Dr. Cusack. The organization prioritizes engagement with autistic people and their families at every stage of their work. Autistica values a change-driven approach that reflects the immense diversity of the autistic community.

Dr. Cusack described significant inequalities that autistic people experience in the U.K., some of which are similar to the experiences of autistic people in the U.S. While many do live fulfilling lives, autistic people continue to die decades earlier than the general population, face the lowest employment rate of any disabled group, and dominate admissions to inpatient mental health care. Stories about neglect and abuse in state-funded care facilities hit headlines on a monthly, sometimes weekly, basis. Access to specialized services or adapted supports remain limited. Diagnostic services are overstretched and post-diagnostic supports are limited or non-existent. Diagnosis may take years and autistic adults are especially unable to access post-diagnosis supports. Health care services are not designed for autistic patients. There is a lack of social care services for autistic people that enable them to live independently. There is currently no model for social care in the U.K. and the government has only recently started to address this issue. Public employment and specialist education services exist but are limited and difficult to access. About half of autistic people in the U.K. have been informally excluded from school due to lack of accommodations. Data shows that autistic people's use of services is low, but they are improving and systems are being built to improve utilization. Furthermore, understanding of autism is low, and attitudes towards autistic people are poor. The COVID-19 pandemic has further exacerbated these challenges, and there is a huge backlog in diagnosis. Consequently, autistic people experience crisis situations, such as avoidable death, inpatient admissions, and crisis hospital visits.

Various groups in the U.K. have made policy commitments to address autism. This year, Her Majesty's Government developed a [National Strategy for Autistic Children, Young People, and Adults: 2021 to 2026](#), which has committed to developing an Autism Research Action Plan and to improving systemic issues. Specific goals include improving diagnostic post-diagnostic pathways, education, employment, access to welfare support, public understanding of autism, healthcare accessibility, community care, and support in the criminal justice system. The team behind the strategy is made up similarly to the IACC. In 2019, the [National Health Service \(NHS\) Long Term Plan](#) made autism an NHS clinical priority for the first time. This led to NHS England setting up their first Autism Team, who will develop a long-term plan to address issues related to autism and coordinate services. Autistica's Heads of Research and Policy will help develop a Research Strategy and other workshops.

Dr. Cusack further discussed the Autism Strategy's commitments, including developing a research action plan to identify priorities. He discussed the timeline for reaching the aforementioned commitments over the next five years. He explained that Autistica welcomes these new initiatives given that the two previous Autism Strategies lacked serious investment or implementation planning. Unfortunately, the new Autism Strategy only includes a first-year implementation plan, and NHS England's Autism Program currently lacks funding to deliver goals laid out by the Long-Term Plan. However, the U.K. government currently is completing a Comprehensive Spending Review, which may enable stronger implementation

planning for the Autism Strategy. These initiatives can also help start conversations about funding partnerships.

Dr. Cusack discussed how Autistica has evolved over the past few years. They have a policy group and are sharing more information. He then outlined Autistica's ambitious goals for 2030. These are to influence policy and practice for autism with a focus on early death, to ensure more of their work improves lives, and to increase impact by narrowing scope of focus. They will develop detailed, long-term plans and clear deliverables for each goal and will focus on projects that are most likely to achieve breakthroughs. Autistica developed guiding principles for each goal to ensure that they are a community priority with opportunities to make a difference, conduct good research, and raise necessary funding.

Autistica has six goals for 2030: 1) Autistic people will have support from day one, 2) The employment rate for autistic people will double, 3) Autistic people will have proven treatments for anxiety, 4) Every autistic adult will be offered a yearly, tailored health check, 5) Public spaces will be more accessible for neurodivergent people, and 6) Attitudes towards autistic people will change. Autistica is developing detailed plans for each goal. They have conducted some initial scoping activities and held a workshop with autistic people and professionals and scientific experts. Based on this feedback, they drafted a plan and sent it to staff experts, including those who are autistic and/or have scientific expertise. They plan to hold partner meetings to share the draft plans with funders and other charities before finalizing them.

Autistica aims to be concrete and clear about the people they serve and the outcomes they seek. Because autism is complex, some organizations lack a well-defined vision for improving people's lives. Accordingly, Dr. Cusack reiterated that each goal has a specific action plan. He described the pillars of Autistica's plans. Each plan has two or three pillars and are based on empirical evidence, and each project they support will fit under a pillar. For example, the pillars of the Support Plan are Support Around Diagnosis, Support Preparing for the Future, and Lifelong Support. The Personal Support Profiles is an upcoming project that fits under Support Around Diagnosis. The goal of this project is to create accurate, holistic, and consistently formatted profiles of a person's support needs. This could enable healthcare providers to offer supports they would benefit from rather than providing generic offerings.

Dr. Cusack explained that Autistica is developing concrete goals in order to be more transparent with the people that they serve. Providing clarity can be inspiring. They also want to know what success looks like and believe transparency is the best way to make an impact.

Committee Discussion

Dr. Alycia Halladay was interested in how Autistica coordinates priorities with the autism community and other organizations that work towards similar goals. Dr. Cusack said they hold regular meetings with the National Autistic Society, government ministers, and large charities across the U.K. that focus on a variety of issues.

Dr. Robertson asked to connect offline about resources and information on employment that would be helpful for the DOL and its research and integrative employment pursuits. Dr. Cusack said he would be happy to connect and agreed that work in the U.S. and U.K. can inform and improve each other.

Mr. Srinivasan expressed support for the Spaces Plan and tailored health checks. He asked whether the latter would include examination of medical comorbidities in autistic people. Dr. Cusack said that the health check will correctly identify health problems that autistic people most frequently experience. Often an autism diagnosis will overshadow identifying health problems. Autistica aims to advance clinicians' understanding and compassion for autistic patients and the serious comorbidities they often face.

Dr. Helen Tager-Flusberg asked about the definition of "anxiety" in the context of plans and projects supported by Autistica. She pointed out that severely impaired individuals with behavioral challenges may express anxiety through self-injurious behavior, aggression, wandering, and other behavioral patterns. Treatments that work for people without these challenges may not work for this group. Dr. Cusack said that Autistica prioritizes groups that are commonly under researched, such as people with a learning disability, and are funding several projects related to anxiety. One is an effort to improve clinicians' ability to recognize anxiety in autistic people with a learning disability or who are minimally verbal. Another is a pilot intervention for parents to help their autistic child manage anxiety. Autistica remains conscious of the need to serve the entire spectrum and is conducting a pilot trial to personalize and match treatments for different types anxiety in autistic adults.

Ms. Gassner pointed out that more than half of autistic adults have experienced global losses in job coaching, support services, and social programs during the COVID-19 pandemic. The forward-facing agencies responsible for these services have been overwhelmed by patients with long COVID who require tremendous support. She asked if there were similarities in the U.K. Dr. Cusack answered that, at this point, they are unsure. The National Autistic Society found that the autistic people felt isolated from the services they rely on. Dr. Cusack expressed concern that many autistic people are struggling to re-adapt to a post-pandemic world. The U.K. has an aggressive approach to the pandemic, and people in England no longer need to wear masks.

Ms. Smith talked about autistic people losing access to their community during the pandemic. Ms. Smith asked about efforts to ensure that autistic people can remain in their communities without fear of institutionalization. Dr. Cusack emphasized the importance of building support systems that prevent autistic people from needing inpatient mental health settings. The U.K. takes a community-based social supports approach, but it is not always successful.

National Autism Coordinator Update

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

Dr. Daniels provided an update on coordination activities between the Committee and several partners across the federal government. First, she explained that the *2021 HHS Report to Congress*, which is required under the [Autism CARES Act of 2019](#), has been completed. It includes 23 recommendations for federal agencies to address health and well-being of people on the autism spectrum. It will be available on the IACC website in the coming weeks. OARC worked with the [Federal Interagency Workgroup on Autism](#) to assist in the development of their recommendations.

She discussed the [Federal Partners in Transition \(FPT\) Workgroup](#), which addresses issues related to transition-age youth with disabilities. At this time, the FPT Workgroup is developing a new Federal Youth Transition Plan to enhance coordination of activities, goals, and policy priorities across federal agencies.

The [Interagency Committee on Disability Research \(ICDR\)](#), managed by the [Administration for Community Living \(ACL\)](#), has recently published two toolkits, one focused on [disability and emergency preparedness](#) and the other on [employment](#). They held a [virtual symposium](#) in July 2021 on employment for youth with disabilities in the context of the COVID-19 pandemic.

The [National Council on Disability \(NCD\)](#), an independent federal agency, held its most recent meeting on October 7, 2021, during which they discussed home- and community-based services (HCBS), health equity, voting rights, and employment. Their upcoming 2021 Progress Report will focus on the impact of COVID-19 on people with disabilities, and the 2022 Progress Report will address the impact of climate change and extreme weather events.

The [RAISE Family Caregiving Advisory Council \(FCAC\)](#) is a federal advisory committee managed by ACL that is charged with providing recommendations to the HHS Secretary on effective models of family caregiving and support to family caregivers. In September 2021, the RAISE FCAC delivered an [Initial Report to Congress](#) that focused on infrastructures and systems to appropriately recognize, assist, include, support, and engage family caregivers. They also created an [inventory](#) of relevant federal programs related to caregiving. Their September 22, 2021 [full council](#) meeting included a discussion on developing a National Family Caregiving Strategy.

The [Interdepartmental Serious Mental Illness Coordinating Committee \(ISMICC\)](#) is managed by the [Substance Abuse and Mental Health Services Administration \(SAMHSA\)](#). ISMICC's 2017 Report to Congress titled [The Way Forward: Federal Action for a System That Works for All People Living With SMI and SED and Their Families and Caregivers](#) mentioned autism in the context of co-occurring serious emotional disturbance (SED) in children. ISMICC met on August 27, 2021 and will hold another virtual meeting in October.

The [Disability Advisory Committee \(DAC\)](#) of the [Federal Communications Commission \(FCC\)](#) provides advice and recommendations on an array of disability issues such as communications and video programming access. DAC met on [September 9, 2021](#). They hosted the White House Office of Public Engagement Associate Director Emily Voorde, who emphasized the Biden Administration's commitment to partnering to advance the priorities of the disability community.

Last, [MITRE](#) is collaborating with federal, academic, and private industry partners on a new [Neurodiverse Federal Workforce Pilot Program](#) to increase high-tech career opportunities within the federal government for autistic individuals. The effort aims to change the narrative about workers with disabilities and to open the federal government to improved neurodiversity inclusion. MITRE will hold a federal [Autism Work Summit](#) on October 19-20, 2021 to discuss issues related to this effort.

IACC Committee Business

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

Dr. Daniels presented Committee business, including OARC updates, a discussion of the *IACC Summary of Advances*, and updates to the *IACC Strategic Plan*.

OARC has developed a new [resources section](#) on the IACC website in response to feedback from Committee members and members of the public. At this time, topics include about autism, transition, housing and employment. OARC also revamped their COVID-19 page and have a new section on agencies and organizations. It also offers federal and non-federal resources such as websites, toolkits, videos, reports, and journal publications. The [fall 2021 IACC Newsletter](#) is also available on the website.

Summary of Advances

Dr. Daniels described the process for developing the *IACC Summary of Advances*, which includes a summary of research articles representing groundbreaking and significant progress in the field. At this time, nominations for articles have been solicited from Committee members. The next step is to refine the list of nominations, at which point OARC will create a ballot and ask Committee members to vote on the articles via email. OARC will then develop summaries of the top 20 articles selected by the IACC and prepare a report.

Gordon thanked the Committee for their submissions. He reminded the Committee that in the past the *Summary of Advances* has excluded editorials and opinion pieces, preliminary studies, studies of small sample size, literature and systematic reviews, expert recommendations and reports from panels/taskforces, and literature non-specific to autism spectrum disorder (ASD). Above all, the IACC aims to capture state-of-the-science, high-powered research articles that capture a fuller heterogeneity of the autism spectrum.

Committee Discussion

Ms. Gassner noted that qualitative research, by nature of its methodology, often uses significantly smaller sample sizes. Dr. Gordon said the Committee must weigh the significance of qualitative findings for advancing the field alongside the generally small sample size of such studies. Mixed methods studies may be more promising. Ms. Gassner expressed her concern that autistic people's voices may be excluded. Dr. Gordon reassured her that such papers can still be discussed and appreciated her input.

Dr. Halladay asked the Committee to reconsider exclusion of systematic reviews given that they use existing literature to aggregate data, identify gaps, and answer research questions that no single study can answer alone. Dr. Gordon said that meta-analyses are preferable to systematic reviews in terms of methodological rigor. He agreed that inclusion of highly rigorous, informative systematic reviews may be valuable to include. They may address this in discussion.

Ms. Smith asked for a plain-language or audio format of the nominated research articles to review. Dr. Gordon said that many scientists on the Committee struggle to understand papers outside their own fields and often look to multiple levels of expertise to judge the paper. At this time, only voted-in articles will receive lay-accessible summaries due to lack of manpower. Some journals included lay-friendly summaries of their articles. Dr. Daniels suggested that her team could set up individual meetings with members to answer their questions. Ms. Crane pointed out that the Committee member who nominates

an article also submits a brief summary alongside it. She challenged members to write that summary in plain language. Ms. Gassner agreed that plain-language summaries would be beneficial.

Dr. Paul Wang offered his support for the guidelines and principles for *Summary of Advances* article selection. He said that in an ideal world they would want publications that show how the field is moving forward. However, he pointed out that several biology-oriented papers may convey important science but fail to meet criteria for “significance to the community” as experts do not know how important certain findings will be. He also wondered about inclusion of papers with negative results. Dr. Gordon noted the importance of separating basic science (however important) from major advances with demonstrable impact. As for papers with negative results, he personally believes that the Committee should prioritize studies that clearly demonstrate harm or a lack of efficacy.

Dr. Joseph Piven echoed Dr. Halladay’s point about reviews and opinion pieces. He said that papers presenting conceptual frameworks can have a huge impact on the field. Several members of the Committee indicated their support for this idea. Dr. Gordon cautioned that the Committee is tasked to provide Congress with a list of advances—not plans, perspectives, or opinions. While frameworks can alter the course of research and offer new ways to think about old results, they should not be represented as advances. Dr. Piven clarified that he was referencing to conceptual issues such as early intervention and diagnosis that cross levels of analysis and domains, which may require a broader view to arrive at a given conclusion.

Ms. Crane said that her understanding of Congress’ mandate for the *Summary of Advances* is to create an impactful report for the autism community, including autistic people, family members, and practitioners in the field. She said that this is a resource for people in the community, not necessarily for researchers aiming to stay abreast of advances in the field. Exclusion from the summary does not mean a study had bad science. Dr. Gordon agreed.

Ms. Myrick asked about alternative options to recommend important frameworks and other research findings beyond the *Summary of Advances*. Dr. Daniels replied that the *Strategic Plan* traditionally includes reviews of important work in the field that may not fit inclusion criteria for the *Summary of Advances*.

Dr. Larry Wexler agreed with Ms. Crane’s understanding of the *Summary of Advances* and added that smaller-sample studies should not be diminished in terms of their potential impacts. He suggested adding a section for promising, interesting preliminary studies with small sample sizes. Dr. Gordon said that the absolute number of participants in a study is less of a concern than confidence in results based on that number. Given the heterogeneity of ASD, this is rare in underpowered studies. He expressed hesitance in the Committee calling a study promising when they do not know if the results can be reproduced.

Ms. Gassner supported Dr. Wexler’s position and pointed out that many autistic and other neurodiverse researchers still face gatekeeping problems that prevent them from attending major universities where large-scale studies are possible. She agreed that the *Summary of Advances* may benefit from a section for “promising future studies” that allow smaller sample sizes which could allow a larger university could replicate it and create collaborations.

Mr. Whitlow suggested that the Committee is discussing two different ideas about what should be considered an advance: the factual findings of a study and what the study means to the community.

Dr. Robertson agreed that practical value for the community is a priority. He recommended a separate section or document for explaining the implementation of findings. This document could explain how research translates into advancements in service provision and improvements in quality of life.

Dr. Marvin said that many investigators start with smaller grants such as R03 or R21 and use these findings to secure an R01. Smaller studies may already exist in the pipeline to be used for a major grant. A smaller study could be included in the *Summary of Advances* in the future once there is science to back it up. She also said she would appreciate if experts in certain areas, such as biology, could do advanced vetting for those who do not have the background to determine if a study is meaningful.

Dr. Gordon briefly summarized the content of the *Summary of Advances* discussion. Many Committee members expressed concerns that exclusion of small studies might also exclude potentially impactful papers. In particular, members were concerned about the exclusion of qualitative studies and those that reflect the voices of autistic people. Others noted that systematic reviews may also have value. Some members also supported including research reviews and opinion pieces that represent a novel framework. There was general support for a section to recognize papers that are exciting and provocative but not ready for full inclusion. Dr. Gordon recommended that the Committee hold to its current exclusion criteria, but some studies could be considered. Dr. Daniels and her staff may be equipped to consider how to recognize of smaller studies.

Dr. Daniels recommended discussing the list of nominated articles next meeting. Anyone that is having trouble understanding an article can meet with her staff prior to the meeting. Dr. Gordon suggested that members can also ask the individual who nominated an article for further explanation.

There were no objections to this plan.

Strategic Plan

Dr. Daniels discussed updates to the *IACC Strategic Plan*. First, she noted that OARC has made a request for public comments to solicit public feedback on the new Strategic Plan. The request is available until November 30, 2021. Commenters will provide their input on the seven questions of the current *Strategic Plan* as well as two supplemental questions. OARC will gather, compile, organize, and analyze this feedback and present it to the Committee.

She reviewed the current seven questions of the *Strategic Plan*:

1. Screening and Diagnosis: How can I recognize the signs of ASD, and why is early detection so important?
2. Biology: What is the biology underlying ASD?
3. Risk Factors: What causes ASD, and can disabling aspects of ASD be prevented or preempted?
4. Treatments and Interventions: Which treatments and interventions will help?
5. Services: What kinds of services and supports are needed to maximize quality of life for people on the autism spectrum?
6. Lifespan Issues: How can we meet the needs of people with ASD as they progress into and through adulthood?

7. Infrastructure and Surveillance: How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the ASD community?

The two supplemental questions are on 1) the impact of the COVID-19 pandemic on the autism community and 2) the needs of underserved populations within the autism community, including racial and ethnic minorities, economically disadvantaged communities, and rural populations. OARC will send a similar form to the Committee to provide their input across the *Strategic Plan*. Dr. Daniels asked the Committee to consider if they want to change the structure of the next *Strategic Plan*.

Committee Discussion

Dr. Wang asked whether this document is a plan for research or for supporting the community. Dr. Daniels explained that the *Strategic Plan* began as a research plan but was expanded in 2014 by Congress to address services and supports.

Ms. Gassner said that an enhanced version of Question 5 could include the quality of supports and services, especially related to attempts to navigate government agencies. She also mentioned that the *Strategic Plan* lacks reference to the relationship of law enforcement and first responders to the autism community. Additionally, there is no specific reference to disparities across intersectional, marginalized communities. Dr. Daniels said that quality of services could be incorporated into Question 5, and that law enforcement is included in this area and can be expanded. Dr. Daniels clarified that marginalization is a cross-cutting issue embedded across all seven questions. While it was not formally named as a cross-cutting objective in the last *Strategic Plan*, the last Committee created a cross-cutting objective on women and girls. She said that intersectionality and disparities could be expanded upon in the *Strategic Plan*. Ms. Gassner expressed her support for this idea.

Dr. Robertson agreed that intersectionality should be a key focus of the *Strategic Plan*, and should include race/ethnicity, gender identity, sexual orientation, socioeconomic status, and more. These topics dovetail with federal priorities on equity. He also suggested including communication issues. Dr. Robertson also said the Committee should consider the ways that the Autism CARES Act has changed, as it now highlights the importance of quality-of-life. He suggested that Question 5 should be reworded as quality-of-life must be embedded across all questions. Dr. Robertson suggested modernizing the wording of all questions and emphasized the importance of inclusive, strengths-based language valued by the autism community.

Dr. Susan Rivera was concerned by the absence of references to psychological processes such as language, anxiety, sensory issues, and mental health issues. She worried that Question 2 is too restrictive and may exclude these important processes. Dr. Daniels said that Question 2 already includes these areas, which are further detailed in the body of the *Strategic Plan*. However, the Committee may consider rewording it. Dr. Wang agreed with Dr. Rivera. Dr. Alice Carter added that the wording of Question 2 implies a static biology of ASD despite mounting evidence for cascading developmental processes. The idea that ASD is not static should be cross-cutting.

Dr. Jennifer Johnson concurred with Dr. Robertson, pointing out that Questions 3 and 4 should be revised with more empowering, strengths-based language. She felt that ASD research should not be limited to “preventing” and “preempting” autism. Dr. Maria Mercedes Avila agreed and said that the *Strategic Plan* should address social determinants of health.

Dr. Matthew Siegel felt that Question 1 focuses too narrowly on young children. He suggested broadening the focus to the identification, definition, and expression of ASD. There is now research suggesting that ASD presents differently in females, and the wording of this question feels outdated.

Mr. Srinivasan said that Questions 5 and 6 should consider access issues across different demographics. He pointed out that the aging autistic population will experience health conditions, higher risk of mental health conditions such as dementia and Parkinson's, psychotropic medication overuse, and dwindling supports as family members pass away. He also noted that Question 1 assumes diagnosis only during early intervention age, but not everyone has equal access to diagnostic resources in early life, and diagnosis may occur years later. Dr. Daniels said that the previous Committee put adult diagnosis in Question 6.

Budget Recommendations

Dr. Daniels explained that Congress requires that the *Strategic Plan* include a budget recommendation. The *2016-2017 Strategic Plan* called for a doubling of the 2015 ASD research budget to \$685 million by 2020. To do accomplish this goal, the IACC recommended a nearly 15 percent annual increase in ASD research funding across combined federal and private funders. To date, annual funding has not increased to this level, although it continues to rise slowly. Dr. Daniels asked Committee members to comment on the current budget recommendation.

Committee Discussion

Mr. Whitlow asked how the IACC counts and identifies funding in non-governmental entities. Dr. Daniels said that the OARC collects this information from non-governmental organizations that have partnered with IACC/OARC. This information is available in the [Autism Research Database](#) on the IACC website. The database has been updated through 2018, and the 2019 and 2020 datasets are underway.

Dr. Tager-Flusberg said that the IACC should not remain static in its budget recommendation; rather, the recommendation ought to reflect the expanded scope of the *Strategic Plan*. Ms. Gassner agreed, pointing out that the full extent of the implications of the COVID-19 pandemic remains unknown. She anticipated the community will have significant needs given that many people have gone without services for nearly two years. She felt that a higher rate of budget increase was appropriate, given COVID-19 and intersectionality issues. She also wanted to know the proportion of funds allocated to biology research versus service delivery research. Dr. Daniels explained that the *2017 - 2018 Portfolio Analysis Report* includes pie charts that show funding distribution. She said that there is no central autism fund that gets distributed, but that each federal agency receives its own appropriation. Each agency has programs that are already funded and may only have flexibility if there is an increase in funding.

Ms. Crane echoed Ms. Gassner's point that the Committee should address rebalancing funding to ensure that new funds go towards underserved topics of research. She said that they should recommend that agencies reconsider their portfolio if funding is inadequate. Dr. Daniels agreed that the role of the Committee is to make recommendations to agencies and communities about priorities.

Dr. Robertson said that the issue is not just about the numerical value of the money, but about priorities. He reiterated his point that the IACC should consider the importance that the Autism CARES Act places on quality-of-life issues. Although each agency has their own priorities, the Committee should make bold recommendations about what they would like to see moving forward, such as new focuses on quality-of-life, life course, intersectionality, and inclusion. The Autism CARES Act of 2019 also increased funding toward autism research. He said as funding increases in certain areas then research will increase as well. Dr. Gordon clarified the appropriations process, stating that Congress has consistently authorized increased expenditures for autism care and research, but they have not consistently appropriated dollars at the authorized levels.

Ms. Smith encouraged the Committee to support research on the impact of institutionalization and how it affects trauma response.

Mr. Srinivasan said that the biology funders should increase its focus on comorbidities as they affect quality-of-life and lifespan.

Statement on Duplication of Efforts

Dr. Daniels explained that the law requires a statement on duplication of effort in the *Strategic Plan*, including recommendations to ensure that ASD research services and support activities of the HHS and other Federal departments are not unnecessarily duplicative, to the extent practicable. The last *Strategic Plan* clarified that coordinated efforts to fund different types of projects within the same Objective represent cooperation and collaboration. The plan states that the scientific process requires replication. It also noted that the portfolio did not include duplicated efforts but did have gaps in research. Dr. Daniels asked the Committee members to comment on the duplication issue for this version of the *Strategic Plan*. Recommendations may include examples of interagency coordination and public-private partnership efforts that function to avoid duplication.

Committee Discussion

Ms. Gassner pointed out a lack of unified partnership on autism services. Most systems are siloed and difficult to navigate. She suggested creating a means for collaboration that would examine eligibility for services such as housing, food and nutrition benefits, and social security using a single application.

Dr. Carter agreed and recommended prioritizing evaluations of services that enhance current delivery systems. There are many intervention grants that are done outside existing services, which promotes more lack of coordination. There could be a dramatic impact if evidence-based practices were implemented within existing services or if such grants promoted coordination and communication across services.

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 adjourned Day One of the meeting at 5:05 p.m.

DAY TWO

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

Dr. Gordon welcomed the Committee and attendees to the meeting. Dr. Daniels provided an overview of the day's agenda.

Update on Kevin and Avonte's Law

Kristie Brackens, M.S., M.P.A., Senior Policy Advisor, Bureau of Justice Assistance, Office of Justice Programs, U.S. Department of Justice

Joy Paluska, Program Manager, Missing Children Division, National Center for Missing & Exploited Children (NCMEC), NCMEC Data, Resources, & Outreach Related to Children on the Autism Spectrum

Ms. Kristie Brackens provided updates to Kevin and Avonte's Law, which was enacted by Congress in 2018 in response to the wandering and drowning deaths of two autistic children, 9-year-old Kevin Curtis Willis and 14-year-old Avonte Oquendo. The Bureau of Justice Assistance (BJA), which is housed within the U.S. Department of Justice (DOJ), has awarded grants in support of that law. The program's primary objective is to reduce and prevent injuries and deaths of individuals with dementia and developmental disabilities who wander from safe environments. To do so, they partner with law enforcement, non-profit organizations, and other public safety entities. The program has two components, the distribution of tracking devices to aid in successful recovery of those who do wander and prevention of wandering programs.

To date, the Kevin and Avonte Program has made 26 awards totaling approximately \$3.6 million. Performance monitoring has revealed that location devices in grant program areas reduce average time between a wandering report and safe recovery from 72 hours to just 5 hours. Ms. Brackens highlighted work from several of the most successful Kevin and Avonte sites:

- The Alzheimer's Community Care ID Locator Service is a comprehensive dementia-specific provider that has distributed locator devices to more than 500 patients in the last year, yielding a 100 percent elopement recovery success rate. The program has established an advisory committee with law enforcement and has developed a technology platform.
- The ReUnite Program is a non-profit community-based collaborative program between United Way and the Lee, Hendry, and Glades County Florida Sheriff's Offices. It aims to assist in the safety and security of community members at high risk to wander through Scent Evidence K9 kits, bloodhounds, and location technology. To date, the program has enrolled 228 participants in just 10 months. Between January and April 2021, 218 people reported missing to the Lee County Sheriff's Office and all 47 who were ReUnite members were found.
- Mental Health America of the Midsouth provides education, information, and resources for those struggling with mental health issues, including Alzheimer's disease and dementia. The program has conducted 15 wandering response trainings attended by 389 first responders,

provided File of Life cards to more than 5,000 Tennessee residents, and distributed more than 7,000 pieces of information to the older adult population in 13 counties.

- The Boston Police Department (BPD) aims to provide lifetime SafetyNet service and/or ID bracelets to 225 families of individuals who wander due to dementia or developmental disabilities. As of June 2021, the program enrolled 26 new clients in SafetyNet Radio Frequency tracking. A total of 65 clients have been enrolled in the program since the inception of the BPD-SafetyNet partnership in 2012.
- The Osceola County Sheriff's Office offers a Project Lifesaver band to residents with cognitive disorders that may increase risk for elopement. The bands are available at no cost, and the Sheriff's Office changes out batteries and checks in every 60 days. To date, 30 clients have participated in the program, and two wanderers have been found.
- The Sumter County Sheriff's Office has distributed 59 GPS-enabled devices since December 2020. Nine participants who wandered have been located and brought home safely by family, and four wandering incidents were prevented altogether.

Another component of Kevin and Avonte's Law required BJA to develop standards and best practices for tracking technology. To this end, they convened a Locative Technology Roundtable with the 26 active Kevin and Avonte grantees. The goal of the roundtable was to discuss practices and standards for using tracking technology, collaborations with the community and law enforcement, and opportunities for non-invasive practices. They also discussed proactive programming, reasons for wandering, and considerations for improvement. A key takeaway includes the need for federal and national standards for the use of tracking technology to locate missing individuals who have wandered. These standards must include the perspective of everyone who is affected and be flexible and adaptable to different departments and jurisdictions. Critically, locative tracking technology is a last resort, and all other prevention methods should be employed first. The group also determined that it is difficult to determine a single cause for wandering across a large population and that first responders need to be trained on identifying key characteristics associated with intellectual or developmental disabilities (IDD) and dementia.

Ms. Brackens reviewed ongoing training and technical assistance efforts. The Kevin and Avonte Program is supported by the [International Association of Chiefs of Police \(IACP\)](#), the [National Center for Missing and Exploited Children \(NCMEC\)](#), and the [Arc of the United States](#). They developed [HomeSafe](#) with IACP, which includes information about Kevin and Avonte sites; resources for training and technical assistance; and a library with webinars, workshops, tools, and publications. The grantees also have a secure peer-sharing platform to discuss challenges and successes.

The Kevin and Avonte Program plans to make 17 new awards totaling \$2.3 million in FY 2021. A stakeholder workshop is planned for spring 2022, and FY 2022 program enhancements will involve the development of a prevention toolkit, increased focus on public education and awareness, and expansion to resources specific to exploitation of children who wander.

Ms. Joy Paluska discussed autism-relevant activities at NCMEC, the mission of which is to find missing children, reduce child sexual exploitation, and prevent future victimization. She and her colleagues recently compiled a report on [Missing Children on the Autism Spectrum](#). Between 2011 and 2020, 1,516 autistic children were reported missing to NCMEC. Sixty-four of these children were recovered; the vast majority of these died by drowning.

Data shows that there is a spike in missing children during the summer months. About 98 percent of cases reported to NCMEC end in a safe, successful recovery. Accordingly, the organization strongly encourages families and law enforcement partners to report the case directly to NCMEC so that they can deploy their many resources. The organization's call center is open 24/7 to provide support to caregivers and law enforcement and to connect them with a case manager. The case manager creates and disseminates missing posters, coordinates with law enforcement, gathers information and coordinates analytic support, and refers the family to advocacy services. If necessary, the case manager connects with Team Adam consultants and federal liaisons. Team Adam consultants are retired law enforcement officers, forensic specialists, and other specialists who deploy and provide on-site assistance, critical case assistance, and long term case assistance. Posters enable the public to participate in the location of missing children and analytic support enables law enforcement to use public and private data.

Ms. Paluska discussed family services offered by NCMEC. Family Services are led by the Family Advocacy Division, which offers specialized crisis intervention support and reunification assistance; and by Team HOPE, a peer support program for families with missing or sexually exploited children. NCMEC also leverages the expertise of federal partners, including the U.S. Postal Inspection Service, the Department of Homeland Security (DHS), the U.S. Secret Service, and U.S. and Immigration and Customs Enforcement (ICE).

The organization prioritizes outreach and awareness strategies. Earlier this year, NCMEC trained law enforcement partners to build their own outreach and awareness programs. They also offer [model programs and resources for law enforcement and families](#), [NCMEC CONNECT](#) which provides trainings and webinars, search protocols for missing autistic children, and blogs on safe swimming and water searches. NCMEC partners with the [National Autism Association \(NAA\)](#), IACP, and BJA.

Ms. Paluska reviewed NCMEC efforts to reduce child sexual exploitation, which may include child sex abuse materials (CSAM), child sex trafficking, child sex tourism, child sexual molestation, online enticement of children, and sending of unsolicited obscene materials to children. She described the NCMEC [CyberTipline](#) workflow, which allows any individual to make a report. Additionally, electronic service providers are mandated by law to report CSAM to NCMEC. CyberTipline workers determine the urgency of each case: Priority 1) the child is in immediate danger, Priority 2) the child will or may be in danger, or Priority 3) the danger has passed. Analysts use the reported information to identify and locate the child, the offender, and other useful information for law enforcement. NCMEC finds that half of exploiters had direct access to the child and were considered "trusted adults." During the COVID-19 pandemic, NCMEC has seen a 28 percent increase in CyberTipline reports and a 97.5 percent increase in online enticement reports.

Children with IDD are at particularly high risk for exploitation. Abusers often view them as "easy targets" who can be manipulated, and many children with IDD struggle to discern risky behavior or situations. NCMEC is working to develop protocols to address these specific vulnerabilities and to raise awareness for caregivers of autistic children.

To conclude, Ms. Paluska described several NCMEC resources to prevent future victimization. [NetSmartz](#) is an online safety program for children and their families to open the discussion about victimization and online safety from a young age. Resources include activity guides, online games, tip sheets, and videos. NCMEC also offers technical, emotional, legal, and informational support [services to CSAM survivors](#).

Ms. Paluska encouraged Committee members to visit NCMEC CONNECT for additional resources and materials.

Committee Discussion

Mr. Srinivasan said that school districts, service providers, and other organizations underreport wandering. He shared a personal experience when a classmate wandered away from their elementary school. When the child was returned some hours later, the classroom staff intentionally hid the incident from the family. Ms. Paluska said that law enforcement can only respond if the incident is reported. NCMEC encourages school administrators to contact NCMEC and law enforcement as early as possible during a wandering incident. Ms. Brackens added that there is a need to educate the public to recognize signs of a missing or wandering individual and know what steps to take.

Mr. Craig Johnson asked whether NCMEC provides training for parents to help teach their children safety practices in dangerous situations. Ms. Paluska answered that NCMEC will soon hold a webinar focused on caregivers of children on the autism spectrum.

As a Black autistic parent of children on the autism spectrum and of a child with intellectual disability, who are also Black, Mx. Morénike Giwa Onaiwu expressed deep concern and fear about the implications of surveillance and tracking devices. She reminded the Committee that disabled people of color are at high risk for challenging encounters with law enforcement. She said that police reform must occur before location and tracking tools are considered. At this time, law enforcement lacks competent developmental disability knowledge and sufficient cultural competency to be entrusted with such authority. Ms. Paluska said that NCMEC has similar concerns and is working to address racial biases among law enforcement partners. Ms. Brackens added that the BJA has a large law enforcement training component, including justice and mental health collaboration and crisis intervention training. There has been a focus on Constitutional policing and violence reduction strategies.

Public Comment Session

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

Ms. Adrienne Robertiello is an educator at Children's Specialized Hospital and the parent of an autistic child. Through her work, made possible by the New Jersey Department of Human Services, the hospital has identified several indications of safety risks, many compounded by issues such as communication, hearing vision, physical impairments, IDD, and mental health. Poison control centers do not record potential factors that might influence repeat episodes of poisoning, such as autism or intellectual disability. There is no quantitative or qualitative data available of the occurrence of most safety incidents. Efforts to record this information may help to identify patterns in households and communities to inform more effective prevention and safety education. Ms. Robertiello emphasized the need to study the efficacy and impact of current and emerging safety education to determine safety risks, identify disparities, and inform the development of effective safety education and professional training. This effort will require expanded and improved data collection given that most functional data for autism safety are subjective, discriminatory, or otherwise inadequate. She noted that this work should be equitable and ensure methods that prevent misuse and bias. The ultimate goal is to empower autistic people to better understand practice safety skills.

Dr. Crystal Hernandez is a Cherokee Latina mother of an autistic child. She is a Tribal mentor parent and serves on support groups and panels that work on Tribal inclusion projects and research. Although Tribal Nations are increasingly included in autism work, many still struggle to find services and treatments for their autistic loved ones. Autism in Indian Country is underrepresented in national and state data due to non-inclusive measures of measurement and distrust. There is a need to improve culturally relevant diagnostic tools and screening instruments and train those working in the field on cultural humility and responsiveness. Appropriate, culturally relevant screening practices should be embedded in conventional and unconventional settings such as health care clinics, day cares, community centers, nutrition programs, Head Start programs, and behavioral health care settings. A focus on community and extended-family compositions in systems building design is desperately needed. Representation and improving access to care in community settings are priority areas. She recommended that stakeholders look beyond gap analysis to focus on actionable items for continued system overhaul characterized by culturally rooted care.

Ms. Julia Bascom is the Executive Director of the [Autistic Self Advocacy Network \(ASAN\)](#). The organization is concerned by the lack of comprehensive research aimed at ethically supporting autistic people who lack effective means of communication, struggle with self-injury or aggression, or otherwise require intensive support. She emphasized that effective communication is an urgent human rights issue, but few studies on services and supports have focused on this area. Given that one in three autistic people do not develop usable oral speech, it is imperative that significant research dollars be dedicated to understanding and scaling effective approaches for these individuals. A robust body of evidence indicates that augmentative and alternative communication (AAC) is effective for individuals with speech-impacting disabilities, including those with IDD or ASD. Despite evidence that communication is key to improving quality of life, research on best practices is limited. Most communication research targets motor, cognitive, and language differences. Ms. Bascom urged the IACC to prioritize development of substantial research on best practices for supporting robust, effective AAC for autistic people. She also noted that many autistic people who struggle with self-injury or aggression lack access to mental health services and are only offered behavior modification programs or medication with little attempt to address their underlying needs. Autism research should aim to understand and address the root causes of self-injury and aggression, and ASAN recommends that the IACC lead the charge in prioritizing research that expands options for autistic individuals with challenging behaviors. Critically, this research must be conducted, to the maximum extent possible, in partnership with autistic people.

Dr. Eileen Simon is mother to an autistic son who learned to speak at six years old. She expressed her belief that language disorders are the most serious handicap of autistic children. Although language disorders may underlie social disorders, most research since the 1980s has focused on the latter aspect of ASD. Dr. Simon urged the IACC to maintain its focus on developmental language disorder and its causes. Furthermore, she felt that the IACC should name language development as the most important area of research for autistic children.

Ms. Shannon Des Roches Rosa is the mother of a 20-year-old high-support autistic young man and the senior editor of the autism information and advocacy community [Thinking Person's Guide to Autism](#). She expressed her concern that public and private autism efforts focus disproportionately on theoretical unborn autistic people rather than on best practices to support existing autistic people. Per the Committee's analysis, autism research funding is primarily allocated to risk factors and biology, while less than 10 percent is reserved for lifespan issues and services. Ms. Des Roches Rosa said that the

autistic community needs well-paid and trained educators and support workers, medical professionals versed in best practices for autism, and frameworks to support life transitions. While her own family has been privileged to access ASD services in their area, many less-advantaged autistic people and their families are partially or totally excluded from services, as are those perceived to have low-support needs. Finally, she stated that autism issues must have autistic insights and guidance. She urged the IACC to revise their outlook and directions to consider that every autistic child and adult in the nation deserves the same opportunities and benefits.

Summary of Written Public Comments

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

The Committee received a number of [written public comments](#). These comments focused on several important topics, including programs, supports, and housing options for autistic individuals with high-support needs; concerns about medical practices and potential causes of autism; the role of the IACC and the federal government; service needs, resources, and policy implications; needs of the direct support professional workforce; treatment of autistic individuals in medical settings; services and supports for adults; and comments for the *Strategic Plan* update. There is additional [packet of comments](#) that are about concerns about the use of graduated electronic decelerators (GEDs) on people with disabilities, such as autism.

Committee Discussion

Dr. Gordon thanked the oral commenters for presenting their comments directly and invited Committee members to make comments or ask follow-up questions.

At Dr. Daniels' request, Dr. Tiffany Farchione sent public comments about the use of GEDs, also called electronic stimulation devices (ESDs), to the Food and Drug Administration (FDA). The FDA banned the use of ESDs, but the ban was overturned by two judges on a three-judge panel on the D.C. Circuit of the U.S. Court of Appeals. The FDA and DOJ appealed this decision, and the case is now pending decision by the full D.C. Circuit.

Ms. Gassner appreciated Ms. Robertiello's comments and reminded the Committee to remember that not all high support needs issues are subjectively observable. These issues include housing, mental health services, safety training, and interventions. She also told Ms. Peggy Kilty, who submitted a written comment on the issue of individualized education plans (IEPs), to reach out to the IACC, who will put them in touch. She also supported ASAN's comments on the need to include people with high support needs. Last, she pointed out a need to expand training and education for autistic individuals to learn functional skills and how to be safe in the community.

Dr. Halladay echoed the importance of safety skills and urged the Committee to address this area further. Although Kevin and Avonte's Law has been vital, she felt that more can be done. She referenced some written comments from families who expressed an urgent need for hospitals that can provide crisis care for people with autism. There are pilot programs that have trained hospital personnel to assist during severe mental health crises, but these have not been adapted for autism.

Ms. Smith said that autism advocacy work should support autistic people who want to explore their communities safely, such as nature walks or swimming lessons. Ms. Smith also expressed support for the FDA ban on ESDs. These devices cause pain, which violates the Constitutional ban on cruel and unusual punishment.

Mx. Giwa Onaiwu thanked Ms. Robertiello for emphasizing the importance of accurate safety data. However, she pointed out that she could not ethically advise most families to report the frequency of these events given that caregivers of autistic children—especially those who are disabled themselves—already suffer under intense scrutiny and are disproportionately involved with child protective services.

Ms. Lindsey Nebeker addressed toxicity and divisions within the autism community. She has advocated for increasing support for non-speaking autistic people since she first attended an IACC Full Committee Meeting eleven years ago. She and her colleagues joined the Committee because supporting people at all levels of need is important to them. She said that her ability to perform effectively as a Committee member is difficult when she receives hurtful comments and attacks from people who do not believe she understands complex or high-support needs. She urged the public to learn about a person's history before passing judgment. Ms. Nebeker explained that she has an autistic brother with coexisting intellectual disability; he is non-speaking, does not use AAC, and has lived in a group home since age 16. He is a significant motivator of her advocacy efforts to ensure happiness and safety for all autistic people. Several public comments have disparaged and invalidated Committee members' experiences, suggesting that they have "never seen a truly autistic person" or have "hijacked a diagnosis." She reminded the public to consider that all IACC members participate on the Committee to improve life for every person on the autism spectrum.

Ms. Crane appreciated that the Kevin and Avonte Program has connected with diverse stakeholders, but she was concerned that these efforts have not included autistic people themselves. Those who have had wandering behaviors in the past could provide insight interventions that have hurt or helped them and how to safeguard their rights. She also pointed out that many tracking devices are marketed by private companies, enabling anyone to track the location of a nonconsenting person. Ms. Crane encouraged members of the program to address abuse and misuse of these devices when creating federal standards for their use both privately and by law enforcement.

Ms. Paluska responded that NCMEC focuses on missing children, though at times they provide help in locating people under age 21. They prioritize proactive, non-tracking approaches over device-based methods. NCMEC considers location tracking to be a last resort. Ms. Brackens said that the Locative Technologies Working Group did not include the perspectives of autistic people who have wandered. However, a key takeaway from their discussion is that the voices of individuals with lived experiences must be included in all future efforts.

Dr. Robertson emphasized his appreciation for his federal colleagues at the FDA who have worked to restrict harmful devices. He expressed that the devices violate human rights. He agreed with other Committee members that safety skill development is a key priority. Funding for water safety skills activities should include all marginalized groups that are disproportionately likely to drown, not just autistic people. He also spoke about the need for linguistically and culturally competent strategies to support diverse, underrepresented populations. He noted that the federal government is charged to ensure diversity, equity, inclusion, and accessibility in research and supports and services.

Dr. Jenny Mai Phan agreed that swimming is an important focus. As a parent to two autistic children, she recently sought community support to find swimming instructors trained to work with autistic children. It was difficult to find instructors that can work with her children's needs, and she had to teach them despite being unable to swim herself. She reminded the Committee that caregiver support is a high priority because many of these needs fall on family members. Autistic family members and caregivers of autistic children often lack support themselves. Additionally, racial/ethnic minority families disproportionately lack support. Dr. Phan also emphasized the importance of bilingual services and translators for non-native English-speaking families.

Dr. Judith Cooper commented on relevant efforts at the National Institute on Deafness and Other Communication Disorders (NIDCD). They support a program on AAC and have encouraged research on minimally verbal autistic individuals more the last decade. She encouraged people with further concerns about this issue to send in comments, which she and Dr. Debara Tucci can share with their staff. Dr. Gordon encouraged the Committee to learn more about the NIH research portfolio as they prepare for the *Strategic Plan*.

Ms. Smith talked about being institutionalized for the first five-and-a-half years of life. Ms. Smith was only able to learn, gain skills, and participate in the community after receiving one-on-one support. Teachers and parents must be equipped with the knowledge that autistic children can grow and learn. People with intellectual disabilities deserve the supports necessary to access education, literacy, and the community. In the context of tracking devices, autistic people should have informed consent.

Ms. Paluska said that NCMEC plans to partner with other organizations, such as the Y, to support inclusive swimming lessons. She also talked about doing more work with Native American and Indigenous communities.

Mx. Giwa Onaiwu asked Ms. Paluska to share the mechanisms used to distinguish between a potential trafficking victim from an individual who is engaged in commercial sex work or transactional sex. The sex industry can be a means of survival when employment options are limited. This is especially true for gender diverse or queer autistic individuals, or others with intersectional marginalizations. Ms. Paluska encouraged Mx. Giwa Onaiwu to reach out by email to be connected to colleagues who work in the Exploited Children Division, who are experts in this area.

Dr. Daniels offered to connect Ms. Paluska and Ms. Brackens with the CDC program on water safety.

National Autism Indicators Report: Mental Health

Lindsay Shea, Dr.P.H., Director, Policy and Analytics Center, A.J. Drexel Autism Institute, Drexel University

Jessica Rast, M.P.H, Research Associate, A.J. Drexel Autism Institute, Drexel University

Ms. Jessica Rast talked about priorities and potential for autism and mental health research. Mental health is a vital component of health and mental health care is an integral part health care for all people, especially those with autism. Dr. Lindsay Shea provided an overview of the [Policy and Analytics Center \(PAC\)](#) at the [A.J. Drexel Autism Institute](#). PAC aims to understand how the health care system can improve access and services for autistic individuals.

Dr. Shea briefly introduced the [National Autism Indicators Report: Mental Health](#), which was first-authored by Ms. Rast. This product is part of a Health Resources and Services Administration (HRSA)-funded initiative, called [Autism Transitions Research Project \(ATRP\)](#), which examines the transition from adolescence to adulthood. The A.J. Drexel Autism Institute believes that mental health matters in life transitions, systems, and families. Additionally, mental health diagnoses are common, especially among people on the autism spectrum, and care is complex for those with multiple needs. This work uses large data sources to analyze needed services and ensure that individuals with complex care needs have equitable access.

Ms. Rast explained that the *National Autism Indicators Report* catalogs indicators of mental health and mental health care and highlights areas for improvement in policy and practice. This document is a follow-up to the 2019 *National Autism Indicators Report: Health and Autism*. It focused on health and healthcare and found that autistic children have high rates of many mental health conditions. The new report found that autistic children in particular have high rates of mental health conditions. They are also more likely to see a mental health provider and to use psychotropic medication than their peers with other special healthcare needs. While almost all the autistic children they surveyed had health insurance, fewer than half of parents reported that insurance adequately covered their mental health needs.

She reiterated that ASD is not a mental health condition. Higher rates of mental illness among autistic individuals may be due to family history, adverse childhood experiences (ACEs), discrimination, isolation, and stigma. There is also emerging evidence that camouflaging is associated with increased depression and anxiety in autistic adults. Research also finds that mental health difficulties are linked to stigma and lack of understanding as well as challenges to accessing services and supports.

Primary care providers in the U.S. play a key role in identifying and managing patients' mental health needs. They are well-positioned to identify emerging concerns, but they typically lack expertise in mental health care. However, many mental health specialists are inadequately prepared to care for autistic patients. Other barriers to care include intersecting marginalized identities, fragmentation of service systems, high costs, and stigma.

To compile the *National Autism Indicators Report*, Ms. Rast and her team analyzed several large data sources. For children, they used two national surveys of mental health care, services, and experiences. They also used a national source of hospital inpatient stays and Medicaid records. Adult data were drawn from the same latter two sources as well as a large sample insured by Kaiser Permanente of Northern California. Ms. Rast noted that little data exist on mental health of autistic adults at the national level. Using multiple data sets allowed Ms. Rast and her team to build a picture of mental health across the life course.

They found that the most common co-occurring mental health conditions in autistic children were behavior and conduct problems, ADHD, and anxiety. These varied by race and ethnicity. Anxiety was more commonly reported by parents of White autistic children than for children of any other race/ethnicity. Hispanic parents endorsed relatively low rates of co-occurring mental health conditions in their autistic children. About 1 in 4 autistic adults enrolled in Medicaid had anxiety, bipolar, ADHD, and/or depression. With the exception of depression, rates of these mental illnesses were significantly higher among those with ASD compared to those with IDD. All seven mental health conditions were higher among autistic adults than the general population.

Other important health risks include ACEs, such as difficulty paying for basics such as food and housing. More than half of autistic children experienced at least one ACE, which was similar to children with other special health care needs. This rate is 20 percent higher than children with no special health care needs. About 12 percent of autistic children experienced at least four ACEs. However, there are many unmeasured ACEs such as discrimination, marginalization, isolation, and camouflaging.

Management of these mental health concerns is critical for health, quality of life, safety, and other positive outcomes. While autistic children are more likely than children without special health care needs to receive mental health care, parents of autistic children were significantly more likely to report challenges to services access. Among White and Hispanic children and adults, the most common reason for inpatient hospitalization was mood disorders. However, the primary reason among Black children and adults was schizophrenia.

Ms. Rast explained that medication is an important component of condition management, which should also include psychosocial interventions and trauma informed care. About half of autistic children took a psychotropic medication in the past year, most commonly for co-occurring depression. Psychotropic medication use was significantly more common among autistic adults than those with ADHD alone or with no special health care concerns.

Ms. Rast discussed findings related to mental health and community participation in autistic youth. Mental health providers can support autistic people by encouraging activities such as sports, recreational activities, community engagement, and employment, all of which have a positive impact on mental health and well-being. Ms. Rast and her team found that autistic youth aged 12- 17 with unmet mental health care needs are significantly less likely to participate in community activities than those whose needs are met.

Based on these findings, her team made a series of recommendations. They highlighted the importance of equitable access to care and evidence-based practices, integration of mental health care into primary care, de-siloing systems of care, and training providers to competently treat autistic patients with trauma-informed approaches.

Mental Health Priorities to Guide Research in Autism: Autistic Adults and Other Stakeholders Engage Together

Teal Benevides, Ph.D., Associate Professor, Augusta University

Stephen Shore, Ed.D., Assistant Professor of Special Education, Adelphi University

Dr. Teal Benevides and Dr. Stephen Shore shared mental health priorities in autism research. They co-lead a project called [Autistic Adults and Other Stakeholders Engage Together \(AASET\)](#), an effort that works to meaningfully include and engage autistic stakeholders in research. At this time, little research authentically involves autistic people in setting priorities for research and practice.

Dr. Shore shared several strategies to enhance engagement of autistic partners. First, researchers should provide materials in advance to research partners to provide time to process. Materials should be presented in multiple accessible formats such as email, video, and live Zoom meetings. Interaction in various modalities should be encouraged and must remain flexible by need and context. These include text-based options, support for AAC devices, opportunities for spoken and non-spoken activities. It is

also important to adapt the environment for in-person meetings and provide appropriate compensation. Critically, research teams must avoid tokenism by fostering genuine trust, respect, and support. Like any research collaborator, autistic partners must feel safe, valued, and heard equally.

Dr. Benevides discussed their priority-setting methods for the AASET project. They used a multi-tier process that took place over two years. The project began in July 2017 with a group stakeholder meeting before a large autism conference. The meeting included 51 adults, most of whom were autistic, who were asked about areas with gaps in evidence and what types of research they would like to see. Next, they worked closely with the community council and other members of the stakeholder team to identify methods to engage the autistic community. In August 2018 they used these recommendations to disseminate an online survey (which included visual and non-spoken options) to gather priorities from 236 autistic adults. From August to November 2018, they also conducted face-to-face focus groups with 26 autistic adults. The AASET team wanted to understand the priorities of people from rural, suburban, and urban settings. The second large group stakeholder meeting was held in November 2018 with 64 stakeholders, including advocacy organizations, community and academic partners, autistic adults and caregivers, and researchers. The purpose of the meeting was to understand the gathered information and to draft and prioritize specific elements of priorities for future research and practice.

Dr. Benevides described some of the strategies her team used to engage non-speaking participants in these activities. For instance, they used visual sliding scales on the survey that allowed participants to respond using pictures. In focus group setting, the AASET team ensured individuals using AAC or those with inconsistent speech had the opportunity to participate. These methods included having participants move around the room and use sticky notes to indicate their preferences. The participants reported that these efforts were useful and appreciated.

These activities revealed three priority areas: mental health interventions and outcomes; access to health care and accommodations; and gender inequalities in diagnosis, treatment, and sexual health. Dr. Benevides noted that approximately 23 percent of their sample was male, 59 percent were female, and 18 percent were nonbinary. About 4 percent identified as Hispanic, and 13 percent identified as non-White.

Dr. Benevides and her team learned that the top mental health priority is the impact of trauma on mental health outcomes on autistic individuals. Many participants experienced PTSD, trauma, and ACEs and wanted to know the best indicators or measures of these experiences in autistic people. Further, many participants asked for evidence-based approaches to effectively address trauma. Trauma-informed care was discussed frequently.

The second priority was the impact of social isolation, stigma, discrimination, and marginalization on the mental health and well-being of autistic individuals. They also want to know the impact of radical inclusion, such as being part of a social movement.

The third priority related to self-managed interventions and activities as important drivers of quality of life and reduced mental health symptoms. Autistic people wanted evidence of the effectiveness of self-managed services and programs that do not require a gatekeeper. They also wanted evidence for community-available approaches, such as peer-led activities. They also asked about medical marijuana and other available treatments.

Their fourth priority was on the long- and short-term negative effects or adverse outcomes associated with currently recommended therapies and interventions, including behavioral and pharmacological, across the lifespan.

The fifth and final priority was on the need to develop better measurement tools for autistic quality of life, depression, anxiety, social well-being, and sleep. Above all, these assessments should measure the interests and priorities of autistic people, even if these do not align with general societal norms. Participants were asked to rank order different outcomes that they felt were important for mental health. The top ten important outcomes included quality of life, anxiety, depression, social well-being, and sleep.

Dr. Benevides concluded that mental health is an essential component for overall well-being and quality of life among autistic adults. Accordingly, there is an urgent need for evidence-based practices to equip autistic people with skills to self-manage their mental health needs and lead fulfilling lives. Finally, she stated that society needs to create spaces and places where autistic people have a sense of belonging and are supported.

Ms. Rast highlighted some comparisons between the *National Autism Indicators Report* and AASET. While they took different approaches and asked different questions, their work can be used together to move the field forward. They developed a conceptual framework for advancing mental health research that has three phases: detecting, understanding, and reducing. In the first phase, researchers create indicators and identify vulnerable populations. Next, they identify determinants of health disparities at individual, provider, clinical, and system levels. Finally, they work to reduce disparities through intervention, policy changes, system changes, and implementation. Currently, most autism research about mental health is in the detection phase.

Dr. Shore discussed priority differences. Autistic adults are becoming more involved in research and developing priorities. Reliable and valid measures of mental health are needed. Autistic voices should drive priorities and action in understanding and improving mental health. Dr. Shore reiterated that mental health is an important component of health for all people.

Dr. Benevides listed actionable gaps in the data, which included expanding the ability to harness national data from autistic adults. It is important to include diverse groups and gather longitudinal data. Additionally, survey and administrative claims data can answer many questions, but they need to be supplemented with measures of preferences and context.

Dr. Shea closed the panel with discussing the need to match investment to priorities. Mental health is a flagship issue. Continuous engagement of diverse autistic voices and support for autistic leadership is required. Investment in mental health research and the service delivery system is necessary for detecting, understanding, and improving mental health.

Committee Discussion

Dr. Phan expressed her appreciation for this work and wondered whether the AASET team is working on culturally sensitive mental health materials for autistic people or provider trainings. She also wanted to know which races were categorized as “Other” in their demographic data and hoped to see disaggregated data. Last, she urged grant funders to work with the autistic community, stakeholders, and researchers to develop guidelines for the study of trauma and abuse among autistic people.

Dr. Halladay said that Dr. Shore’s comments on the lifespan encouraged her to reconsider the name “Lifespan Issues” in the *Strategic Plan*. It is necessary to understand the varying causes, diagnoses, and treatment of depression, sleep, and anxiety in autistic people. These issues may be underrepresented in their current categorization. Dr. Gordon said he appreciated the presenters’ conceptualization of autism as its own form of disparity that leads to challenges in accessing care.

Dr. Piven said as a psychiatrist he recommends the use of prediction models. Although prediction of psychiatric disorders is challenging among people who do not use language, it is critical to detect and treat these disorders early. Parental history of an affective disorder is important information, as such disorders run in families. Dr. Gordon added that it is important to predict different outcomes within autism in order to provide treatment. NIMH strongly supports the inclusion of prediction models in its research portfolio.

Ms. Prince complimented Ms. Nebeker on her earlier statement about division within the autism community. She then described her work as founder of the [Madison House Autism Foundation](#), a national organization dedicated to the lifespan issues of adults with autism. Madison House Autism Foundation works nationally with advocacy, policy, education and housing. Madison Fields is an on-the-ground project of Madison House Autism Foundation located in Dickerson, Maryland, and is dedicated to those with autism and IDD. The program provides therapeutic horse riding, job readiness, and community engagement, all of which have improved mental health and wellness among their participants. Others, such as first responders, have enjoyed the farm as well. She has found that outdoor time, community, and nature are powerful tools for promoting health among autistic people, just as they are in the general population. Many mental health experts have stated how important this location is to improving the mental wellbeing of many of our participants and our community. Ms. Nebeker also expressed her appreciation for the work that the presenters have accomplished.

Ms. Gassner appreciated Dr. Shore and Dr. Benevides’ email system for communication, which is very effective for people who struggle with deadlines. She then referenced Ms. Rast’s presentation, noting an overlap in reporting basic need deficits among the IDD community during the COVID-19 pandemic. A recent study found that 54 percent of families in the IDD community have reported employment changes due to loss of services and loss of physical therapy, job coaching, therapeutic support, and transportation. Ms. Gassner said that this group primarily included white and financially privileged people, and that there was likely a higher rate of these losses among people with other marginalizations. She also referenced another study that showed that many people experienced loss of income and difficulty paying household expenses. She also pointed out that researchers using large datasets must keep in mind that misdiagnosis is common and medical maltreatment has not been studied.

Dr. Robertson echoed the importance of trauma-informed care, research partnership and collaboration with autistic people, and positive approaches to mental health. The DOL recognizes that access to gainful employment is a strong determinant of health, particularly in terms of access to health care supports. He noted that mental health research rarely includes positive psychology, such as optimism and resilience, but could be particularly relevant in the autism field. Positive psychology may be a valuable component of the *Strategic Plan*. Last, he asked presenters to comment on efforts to reduce marginalization, trauma, and barriers to care for autistic people in inpatient settings. Dr. Shea agreed with Dr. Robertson. Data and solutions are needed now.

Ms. Rast added that the data on inpatient settings was drawn from many kinds of hospitals, covering about 97 percent of the U.S. However, this likely is not fully representative of autistic inpatients. She noted that the data are limited in that they describe diagnoses and procedures but do not capture their true experiences during hospitalization, such as use of restraint. Her work has been primarily focused on primary care, rather than hospitalization.

Mr. Srinivasan expressed his appreciation for the presenters and agreed that autistic people do not have parity for mental health coverage. He pointed out that research hospitals like Stanford and University of California, San Francisco do not accept state Medicaid for mental health care. He also cited research that finds that psychotropic medications work differently—and perhaps less effectively—for autistic people than in the general population. Yet, these medications remain first-line treatments for any autism behavior. Studies show that long-term use of psychotropics cause health problems, such as liver damage, weight gain, and Parkinson's. These issues plus the increased risk of neuropsychiatric disorders make aging frightening.

Ms. Smith asked about research on outpatient alternatives to institutionalization for crisis care. Ms. Rast said that the U.S. lacks crisis care systems in general, and are much less able to support autistic patients in crisis. Dr. Gordon said that NIMH has a research portfolio in crisis intervention services, but he was unsure whether any studies focus specifically on ASD.

Ms. Myrick expressed that disparities in mental health care should be highlighted as a specific objective in the *Strategic Plan*. The disparities were not surprising personally and the data highlighted that there is more work to be done.

Dr. Gordon and other IACC members thanked the panelists.

Round Robin Updates

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

Committee members offered Round Robin updates.

Dr. Marvin followed up on the previous day's discussion about ODEP efforts. Last month, Assistant Secretary Williams and the SSA Commissioner Kilolo Kijakazi met to discuss strategies to address common goals and will meet again this month with a larger group. ODEP and SSA collaborated on several projects over the past decade. SSA has also worked with agencies to promote employment and

well-being for all people with disabilities. Dr. Jeffrey Hemmeter, the Acting Deputy Associate Commissioner of the Office of Research Demonstration and Employment Support at the SSA, has agreed to speak at the next IACC meeting to present ongoing work. She also highlighted an open [Request for Information](#) (RFI) about potential disability insurance and supplemental security income demonstration. Input would inform deliberations about future demonstrations and tests.

Dr. Diana Bianchi informed the Committee that the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) has launched the [Strategies to Enrich Inclusion and Achieve Equity \(STRIVE\) Initiative](#), which aims to improve equity, diversity, and inclusion in all aspects of their research and workforce. They are also seeking ideas and feedback to inform research on health disparities across their portfolio for the next five years. Input is being collected through an [Ideascale platform](#). She briefly reviewed findings of a new study that found oxytocin does not improve social functioning of autistic children and adolescents. She concluded by noting that the application deadline for the [Autism Centers of Excellence: Centers](#) request is November 9, 2021.

Dr. Halladay gave funding announcements for the [Autism Science Foundation](#). The organization announced an award cycle for pre- and post-doctoral fellowships with a new mechanism for post-undergraduates, which is analogous to the NIH post-baccalaureate mechanism to support young or junior-level scientists. She encouraged the IACC to collaborate with the FDA to stringently regulate marketing practices based on minimal findings. At this time, a company is moving forward with a stem cell therapy for autism despite insufficient scientific evidence. They plan to charge families out of pocket for the treatment.

Dr. Rivera invited all participants to attend University of California, Davis' third annual [Neurodiversity Summit](#) on November 5, which will include presentations, panel discussions, and moderated debates. This year's topic is non-speaking autism and IDD and neurodiversity. Discussants will focus specifically on experiences of discrimination and stigma.

Dr. Robertson said that the DOL is seeking input for the ODEP research project referenced yesterday by Ms. Williams. He hoped to connect with committee members offline. He also suggested inviting Maryland's new state autism coordinator to speak at a future IACC meeting.

Ms. Gassner said that collaborators from the INSAR's [Autistic Researchers Committee](#) are nearing a launch date for their database of autistic individuals who wish to participate in research or otherwise engage the autism community.

Dr. Johnson announced several new awards from the [Administration for Community Living \(ACL\)](#), including a self-advocacy resource and technical assistance center and a project to bridge aging and disability services. They are also funding community collaborations to support competitive integrated employment and issues related to dual diagnosis.

Ms. Crane referenced several new [Autistic Self Advocacy Network](#) resources, including a toolkit to help autistic people navigate home- and community-based services (HCBS) services as well as a resource for women and families on reproductive health issues that intersect with disability. They are also asking their community members to share their COVID-19 vaccine experiences to help others access the vaccine.

Mr. Srinivasan is conducting a study on the experience of awe among autistic people and interested parties should reach out to become participants.

Dr. Walter Koroshetz referenced the previous [IACC workshop](#) that discussed gastrointestinal issues (GI) and autism. The [National Institute of Neurological Disorders and Stroke \(NINDS\)](#), NICHD, and [National Institute of Diabetes and Digestive and Kidney Diseases \(NIDDK\)](#) has opened a call for grants on this topic. NINDS is also conducting medication trials tuberous sclerosis and Fragile X syndrome, which are associated with autism.

Closing Remarks and Adjournment

Dr. Daniels thanked the Committee for their participation and the viewing audience for their attendance.

The next full Committee meeting is on January 19, 2022 and will be virtual.