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Minutes of the Interagency Autism Coordinating Committee

Full Committee Meeting

April 13-14, 2022

The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a virtual meeting on Wednesday, April 13, 2022 from 1:00 p.m. to 5:00 p.m. ET and Tuesday, April 14, 2022 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 Lawrence Tabak, D.D.S., 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);**Kristie Brackens**, M.P.A., M.S., Department of Justice (DOJ) (representing Maria Fryer, M.S.); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara L. Tucci, M.D., M.S., M.B.A., F.A.C.S.); **Sam Crane**, J.D., Quality Trust for Individuals with Disabilities; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Tiffany Farchione**, M.D., 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; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Morénike Giwa Onaiwu**, M.A., Rice University; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Craig Johnson**, B.A., Champions Foundation; **Alice Kau**, Ph.D., NICHD (representing Diana Bianchi, M.D.); **Walter Koroshetz**, M.D., National Institute of Neurological Disorder and Stroke (NINDS) (representing Nina Schor, M.D., Ph.D.) **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Richard Woychik, Ph.D.); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/Trainer; **Scott Patterson**, Ph.D., U.S. Department of Veterans Affairs (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; **Amanda Reichard**, Ph.D., Administration for Community Living (ACL) (representing Jennifer Johnson, Ed.D.); **Susan Rivera**, Ph.D., University of California, Davis; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL) (representing Taryn Mackenzie Williams, M.A.); **Robyn Schulhof**, M.A., Health Resources and Services Administration (HRSA); **Stuart Shapira**, M.D., Ph.D., Centers for Disease Control and Prevention (CDC) (representing Georgina Peacock, M.D., M.P.H., F.A.A.P.); **Matthew Siegel**, M.D., Tufts University; **Ivanova Smith**, B.A., University of Washington; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Teresa Souza**, Ph.D., U.S., Department of Housing and Urban Development (HUD); **Hari Srinivasan**, University of California, Berkeley; **Jodie Sumeracki**, B.A., Centers for Medicare & Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education (ED); **Stephen Whitlow**, J.D., Gateway Transition Center; **Nicole Williams**, Ph.D., Department of Defense (DoD); **Taryn Mackenzie Williams**, M.A., DOL.

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 Committee meeting, which took place during Autism Awareness Month. He stated that April is a time to celebrate the strengths, accomplishments, and contributions of people on the autism spectrum. He asked Committee members to reflect on and commit to their understanding of inclusion and acceptance of autistic people, their families, and their communities and to take the actions needed to meet the challenges that the autism community faces.

In this spirit, Dr. Gordon recognized two Committee members for their recent accomplishments. Ms. Sam Crane has taken a new position as the legal director for the Quality Trust for Individuals with Disabilities in Washington, D.C. Mr. Hari Srinivasan was recently accepted to a neuroscience doctoral program at Vanderbilt University. Mr. Srinivasan was also selected as a recipient of the Paul and Daisy Soros Fellowships for New Americans, a merit-based graduate school program for immigrants and children of immigrants.

Dr. Susan Daniels reiterated the importance of Autism Awareness Month and invited attendees to review news and activities on the IACC's Autism Awareness Month webpage.

Dr. Daniels received some minor corrections to the January 2022 meeting minutes and the Committee voted to approve the minutes.

Autism Awareness Month Greeting from the National Institutes of Health (NIH)

Tara Schwetz, Ph.D., Acting Principal Deputy Director, NIH

Dr. Tara Schwetz acknowledged the United Nation's 15th Annual World Autism Day, which was on April 2, 2022, and National Autism Awareness Month. In the United States, one in 44 children and one in 45 adults is on the autism spectrum. NIH promotes the acceptance, understanding, and inclusion necessary to create a world in which all people with autism have the support needed to pursue the lives they want to lead and to reach their full potential. As a research organization, NIH is committed to funding research that supports the health and wellbeing of autistic people and their families across the lifespan.

Dr. Schwetz provided a few examples of NIH's activities that support autistic people. The Early Autism Screening Initiative (EASI) focuses on developing and validating screening tools to detect autism in the first year of life. NIH also supports the flagship Autism Centers of Excellence (ACE) that funds different areas of autism research including understanding the biology and genetics of the autism spectrum, improving developmental outcomes, increasing access to services, and developing novel interventions and innovative delivery methods. NIH also funds research aimed to benefit transition-aged youth and adults with autism through a focus on improving employment outcomes and strategies to manage co-occurring conditions. NIH is dedicated to diversifying the autism research workforce through career development and enhancement awards.

Dr. Schwetz said that NIH looks forward to the updated *IACC Strategic Plan* and will work with the Committee to ensure that people on the autism spectrum benefit from advances in biomedical research, receive evidence-based services and supports, and have access to enhanced opportunities for community participation.

Committee Discussion

Dr. Mercedes Avila asked about the NIH requirement for common data elements, which include identifiable information about participants and may deter some vulnerable populations from participating in research. She emphasized the importance of building trust with vulnerable populations. Dr. Schwetz agreed that it is important to fully engage communities in the research process. Trust is a necessary component, and it can only be built through time. The issue is program-dependent but there have been ongoing discussions on how to better support underserved populations, particularly within the Rapid Acceleration of Diagnostics (RADx) initiative.

Dr. Amanda Reichard asked how ACL can help NIH-funded autism researchers access disability statistics. Dr. Schwetz answered that the issue of data access is broad across all of biomedical research. It is anticipated that NIH will launch various data sharing efforts by January 2023, including policy revisions to help address access to data.

Dr. Scott Robertson asked if NIH was exploring creative approaches to promote lifespan research, particularly for autistic adults. He provided employment and social determinants of health as examples. Dr. Schwetz said that NIH always seeks opportunities to engage the research workforce in cross-cutting areas across the lifespan. Dr. Gordon added that there have been efforts to build a workforce for research in lifespan issues and will continue expand those opportunities.

Ms. Dena Gassner added that both the *IACC Strategic Plan* and *IACC Portfolio Analysis Report* emphasize the importance of young children receiving intensive early intervention supports at the time of diagnosis, but do not equally address adults who are diagnosed later in life. Providing intensive supports and services for adults could be a strong addition to the research portfolio. Dr. Schwetz agreed that, despite an increasing focus on transition, research has missed addressing support needs for adults with autism.

Ms. Ivanova Smith asked if NIH was investigating how COVID-19 pandemic policies and recommendations caused discrimination against autistic people, resulting in increased segregation and isolation. Dr. Schwetz said that NIH does support research related to this issue and agreed that it is an important topic needing further exploration to ensure that future policies are enhanced by knowledge. The pandemic is still in a dynamic phase and there is an opportunity to explore what has and has not worked in order to improve future outcomes. Dr. Gordon added that NIH provides the scientific evidence for the development of policies but does not create policy. The Committee can make recommendations to alter policies such that they better support the needs of autistic people and their families.

Updates on Disability Housing Programs

U.S. Department of Housing and Urban Development (HUD) Supportive Housing Programs and Research

Teresa Souza, Ph.D., Social Science Analyst, Office of Policy Development and Research, HUD

Dr. Teresa Souza began by reviewing HUD's mission, which is to create strong, sustainable, inclusive communities and quality, affordable homes for all. HUD serves a fraction of people who are eligible for housing assistance. In 2019, HUD assisted 4.6 million households, but there were 13.3 million very-low income households that did not receive HUD assistance. Of these, 7.8 million were categorized as "worst case housing needs," where households paid more than 50 percent of their income towards rent, lived in severely inadequate housing, or both. HUD is only able to provide assistance to 26 percent of households in need.

HUD's three largest housing programs include the Housing Choice Vouchers, which provides rental assistance for affordable housing in the private market; the Project-Based Rental Assistance program, which provides rental assistance for housing owned by nonprofit organizations; and the Public Housing program, which provides rental assistance for housing owned by local public housing agencies. HUD's smaller programs include the Section 202 Supportive Housing for Older Adults program, which supports older adults and the Section 811 Supportive Housing for Non-Elderly People with Disabilities program, which supports people with disabilities. Dr. Souza emphasized that people with disabilities can be supported across all HUD programs. Between 2012 and 2021, the number of HUD-supported older households has increased (as a result of the aging population) while the number of HUD-supported non-elderly households with disabilities had remained relatively stable.

The Section 811 program has traditionally operated by providing capital grants and operating subsidies to nonprofit developers of affordable housing for people with disabilities. In 2012, the Section 811 program also began providing project rental assistance to state housing agencies. The Section 811 Project Rental Assistance (PRA) program was first implemented as a demonstration project in 2012, awarding rental assistance grants to state housing agencies that had formed partnerships with state Medicaid and health and human service agencies to subsidize rent for people with disabilities. Individuals eligible for the Section 811 PRA program must have extremely low income (i.e., at or below 30 percent of the local median income), be aged 18 to 61 years at time of admission and meet eligibility for Medicaid or other health and human services. The program subsidizes up to 25 percent of the units in an affordable housing development to ensure that individuals with disabilities can integrate into the community. Since the 2012 PRA demonstration project, HUD has awarded $342 million to more than

3,000 households. Of these households, 46 percent were homeless or at risk of homelessness and 43 percent were transitioning from institutional care or were at risk of institutional placement.

Dr. Souza reviewed the results of an evaluation of the Section 811 program across six states, which found it to be effective and well-targeted to individuals with lower incomes and greater healthcare needs. Recipients reported high levels of autonomy and independence. They lived in neighborhoods with higher poverty rates but greater access to public transit and higher walkability ratings compared to similar people in other HUD programs. Dr. Souza also reviewed the results from the second phase of the evaluation, which found that the majority of Section 811 PRA residents reported receiving tenancy support such as help with the rental application, setting up an apartment, resolving disputes, and paying bills. A majority of residents reported a positive experience with receiving community-based services. However, a small percentage reported gaps in care

Dr. Souza reviewed the Mainstream Voucher Program, which assists non-elderly people with disabilities who are transitioning out or are at risk of institutional care, experiencing or at risk of homelessness, or had previously been homeless. Local Public Housing Agencies (PHAs) administer the vouchers and are encouraged to partner with homeless assistance and health and human services agencies. HUD has awarded approximately 67,000 vouchers to PHAs, for which 45,000 households have been assisted and approximately 20,000 vouchers are available for eligible new households.

The Emergency Housing Voucher (EHV) is a new program that provides temporary housing assistance under the American Rescue Plan. HUD has awarded approximately 70,000 vouchers to subsidize rent for households facing housing instability during the COVID-19 pandemic. Housing instability is defined as homelessness; recent homelessness; or fleeing or attempting to flee domestic violence, sexual assault, stalking, or human trafficking. EHV provides $3,500 for housing assistance services such as security and utility deposits, moving expenses, landlord incentives, or housing search assistance. The vouchers are administered by local PHAs and participants are required to have a referral from a homeless assistance agency. Approximately 16,000 households have used an Emergency Housing Voucher and another 27,500 have received a voucher but are currently seeking a rental unit.

Dr. Souza reviewed two research areas that are critical to understanding the housing needs and barriers experienced by people with disabilities. There are several federal laws that prohibit housing discrimination on the basis of disability. The HUD Office of Policy Development and Research has been conducting research on the presence and extent of housing discrimination in the rental market for over 40 years. Some of the at-risk populations that experience housing discrimination include people who are deaf or hard of hearing, use wheelchairs, have mental illness, or have intellectual or developmental disabilities (IDD). The studies have found evidence of unfavorable treatment of these populations during their housing search process. Another research area focuses on linking health and housing data, which aims to understand the prevalence and needs of people with disabilities in HUD-assisted housing. For example, there is an ongoing collaboration between HUD and the National Center for Health Statistics (NCHS) that continuously updates housing-health data linkages. Several published reports have used this NCHS-HUD linked data, which has provided valuable insight into the connections between housing and health. Dr. Souza encouraged researchers to use these data to further improve the understanding of the needs and barriers of vulnerable populations.

Overview of the Housing and Service Resource Center

Lori Gerhard, B.S., Director, Office of Interagency Innovation, Administration for Community Living (ACL)

Ms. Lori Gerhard provided an overview of the ACL's new Housing and Services Resource Center, which was created through partnership with HUD. She talked about the challenges met by people with disabilities in finding accessible and affordable housing, as well as solutions and opportunities. Although more than 15 percent of households in the nation include a person with a disability, only six percent of homes nationwide are accessible. Less than one percent of homes are wheelchair accessible and less than five percent can accommodate an individual with moderate mobility disabilities. The 2021 The Gap Report from the National Low Income Housing Coalition indicated that only about 40 affordable homes are available for every 100 extremely low-income renter households. Most of these renters are either cost-burdened (spending more than 30 percent of income on housing) or severely cost-burdened (spending more than 50 percent of income on housing). Severely cost-burdened renters in the lowest income bracket spend 38 percent less on food and 70 percent less on health care than renters living in affordable housing.

Homelessness is increasing among people with disabilities and older adults. HUD's *2018 Annual Homeless Assessment Report to Congress* indicated that nearly half of sheltered homeless single adults and heads of households reported having a disability. The number of sheltered homeless older adults has significantly increased from 16.5 percent to 23 percent between 2007 and 2017.

Each year, nearly 900,000 people become homeless. Between 2017 and 2020, the average point-in-time count (the number of sheltered and unsheltered people experiencing homelessness on a given night) was 562,4310 people. Root causes for homelessness include poverty, domestic violence, acute physical or behavioral health crisis, and periods of transition (e.g., from institutions or systems). Housing services and programs are often complex to navigate, negatively impacted by workforce shortages, or unknown to the people who need them. Some programs have successfully addressed aging, disability, and housing and health sectors, but it is difficult to expand these programs available across the nation.

Ms. Gerhard said that, despite these challenges, there are several efforts to address this growing public health crisis. The American Rescue Plan has provided 70,000 EHVs that include wraparound supports. The Medicaid Money Follows the Person (MFP) Program has also been infused with an additional $110 million to expand access to home and community-based services (HCBS).

In addition, the Older Americans Act received an additional $400 million to increase access to HCBS and assistive technology. In July 2021, HHS and HUD partnered to coordinate the implementation of the American Rescue Plan investments and to further strengthen their partnership in support of states, communities, and organizations to help people obtain and maintain stable and safe housing and housing services. One collaborative effort is the Housing and Services Resource Center, which provides resources, guidance, and technical assistance to Medicaid, disability, and aging agencies; state and local public housing agencies; disabilities and aging networks and providers; behavioral health providers; and housing and homeless providers. Ms. Gerhard invited the Committee to join an Open Door Forum to review these initiatives on April 19, 2022, the details of which can be found on the Housing and Services Resource Center What's New webpage. She also invited the Committee to email the center to share information about partnerships, to receive updates, or to ask questions.

Autism and Homelessness: Experiences from the Bergen County, New Jersey (NJ) Housing, Health, and Human Services Center

Julia Orlando (Presented by Susan Daniels, Ph.D.), Director, Bergen County, NJ Housing, Health, and Human Services Center

Dr. Daniels shared a video recorded by Ms. Julia Orlando, who presented on the Bergen County Housing, Health, and Human Services Center's program to end homelessness. The program provides social and shelter services for people in Bergen County who are experiencing homelessness and are aged 18 years or older. She shared her experience in working with people on the autism spectrum or who have an IDD. Individuals with IDD face several challenges in receiving appropriate services, especially if they had not previously been connected to resources before they turn 18 years of age. In addition, shelters are not set up to appropriately manage an individual with impulse control challenges or physical accommodation needs beyond assistive devices. The shelters are also unable to accommodate adults who have a parent caregiver. People who are nonverbal can experience extensive challenges in communicating their needs and tend to struggle in the independent environment of the shelter. The shelter staff do not have the specialized care training for supporting individuals who are not able to live independently.

The greatest challenge for an adult with autism and IDD is when they had not been connected to appropriate resources before they became an adult. Often, parents themselves have a disability or health condition that may have hindered their ability to link their child to resources and benefits. Other times, a parent becomes homeless or is no longer able to care for their adult child. Another barrier is the lack of appropriate facilities needed to service this population when they are homeless. There is therefore a need for toolkits and training for homeless shelter employees to help them recognize signs of IDD and to provide best practices and resources.

Ms. Orlando said that the population of displaced people with autism and IDD has grown during the COVID-19 pandemic. Increased attention and access to resources would help programs place these individuals in safe housing so that they can maintain a meaningful and productive life.

Committee Discussion

Dr. Daniels reiterated that Ms. Orlando identified two primary groups of concern. One group is the youth and young adults with autism and IDD whose families are unable to care for them or whose parents experience economic hardship, autism or IDD, mental illness, substance use disorders, or other complex needs. The other group is the population of middle-aged to older adults with autism or IDD who may have lived with their parents and did not have a care plan in place when their parents passed away. The major barriers that both groups face include not being connected to services earlier in their lives; shelter environments that are not conducive to the social, emotional, communication, or independent living skills; and vulnerability to unsafe situations from others in the shelter. There is a need for support in providing homeless shelter staff with guidance, training, and toolkits to help them identify and address the needs of individuals with autism or IDD.

Ms. JaLynn Prince asked if HUD is considering housing navigation services paired with housing assistance to help transition people from their elderly parents' homes before they become homeless. Dr. Souza clarified that HUD programs help both people who are homeless or in an institution as well as those who are at risk of becoming homeless or of moving to an institution. HUD does recognize that there is a need for more research to understand the different needs of people with disabilities who experience homelessness.

Ms. Prince added that older parents of adults with autism often find it difficult to secure their adult child's appropriate housing. Some parents may leave their home to their adult child without ensuring funds to pay for housing maintenance or taxes. She said there were many paths to homelessness and asked how HHS was working to overcome the different economic boundaries to appropriate housing. Dr. Souza answered that HUD receives resources that can only assist a fraction of the people who need and are eligible for housing assistance. However, there can be improved connections between housing and health, such as the HHS-HUD partnership. Ms. Prince added that many builders would like to construct affordable housing, but red tape makes these efforts cost-prohibitive.

Ms. Gassner talked about her experience helping an older adult with autism apply for housing. The program's requirement for a co-signer may prevent some people from applying at all. She was also concerned that an individual who does not receive an autism or IDD diagnosis before the age of 18 will not have access to programs and services when they become an adult. There is limited research and policy specifically about autistic people. Additionally, vulnerable people tend to be treated disrespectfully and there is a need for a better understanding of autism in the community to facilitate respectful treatment. Dr. Souza agreed there is limited research, but HUD is working with other agencies to link data and better understand different types of disabilities, including their specific housing needs and barriers. Ms. Gerhard added that raising awareness of the needs of people with autism is similar to the need to train emergency staff when emergencies or disasters occur. Assistive technology has been instrumental in such situations because it provided a means for nonverbal individuals with autism to communicate their needs. Ms. Gerhard agreed that more work is necessary to improve knowledge and responsiveness to the needs of autistic people.

Mx. Morénike Giwa Onaiwu submitted a comment explaining that they have experienced homelessness, as many in their community have. There are bureaucratic barriers, such as requirements to provide multiple legal and medical documents, that can be especially challenging for an individual with executive functioning issues. Being transgender and non-gender conforming can also become a challenge in providing required documentation. In addition, the environments tend to be sensory nightmares. Often, an individual will be given only a packet of resources and will have to wait an extended time before a case manager is available to help. There are generally no alternative means of communication available to help individuals navigate through a cognitively inaccessible process. Stimming, vocalizations, and movements may be misunderstood by staff as violence or being inebriated. It is also an environment in which predators can easily assault people. There is little to no understanding of the unique needs of the autistic population. It is traumatic to be in an unstable housing situation, and this trauma is compounded by these experiences and among those who are part of a racial, sexual, or gender minority. Dr. Souza responded that HUD is conducting a study on successful approaches in the housing search process for people with disabilities, which includes the major barriers experienced by people with different disabilities across different settings. The partnership between health and housing services is important for identifying these specific needs to guide the implementation of new programs and resource allocations.

Ms. Smith asked if there were efforts to look at discrimination policies to address the barriers to accommodating autistic people. Dr. Souza answered that HUD has a Fair Housing and Equal Opportunities Office that is devoted to enforcing policies and practices to reduce discrimination against people with disabilities. They are currently working to address discrimination against people with autism to ensure that it does not occur in the housing market. Ms. Gerhard added that ACL funds Protection and Advocacy Systems in each state to support people with disabilities who feel that they are not being treated appropriately or are being discriminated against. In addition, the Older Americans Act provides a network of elder rights services in all states and territories.

Dr. Robertson commented on Ms. Orlando's request for a toolkit. He said that there was NIMH-funded research that led to the development of the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit for autistic adults. The toolkit is a portal for health care providers, autistic adults, and allies to connect with resources for accessing health care. Dr. Robertson suggested that ACL and HUD could explore a partnership with sister agencies such as DOL for a similar effort. He commented that much of DOL's data on homelessness and autistic people comes from the United Kingdom. He asked if ACL and HUD maintain any data that is specific to autism and housing that could be interconnected to DOL data on workplace and employment. Dr. Souza answered that the American Community Survey and the American Housing Survey include six questions that provide data about people with cognitive disabilities. Additionally, the NCHS-HUD linked data includes a question that could provide relevant data. They hope more researchers access these data and help expand the understanding of the people on the autism spectrum in HUD-assisted housing. Ms. Gerhard added that ACL would be interested in partnering with DOL to build toolkits. ACL funds the University Centers for Excellence on Developmental Disabilities (UCEDD), where they focus on gaining a better understanding of people with developmental disabilities and how to supports them. Dr. Daniels added that the Federal Interagency Workgroup on Autism (FIWA) would be glad to facilitate a partnership.

Ms. Crane expressed concern that use of the Federal Housing Authority (FHA) may not be adequate for addressing structural barriers to shelter programs. Structural barriers can make shelters programmatically inaccessible and unsafe for autistic people. Shelters cannot accommodate home- and community-based service providers and shelter staff cannot provide personal care assistance. A person with assistive technology may not be able to access a shelter because of the high likelihood of technology being stolen. She suggested that Title II of the American with Disabilities Act, which prohibits discrimination of an otherwise qualified person with a disability from equal access to programs, should also provide options for equivalent programs for people with disabilities who cannot access a homeless shelter. This could include Housing First approaches to place people in individual housing as soon as possible.

Ms. Lindsey Nebeker asked why the age cutoff for participation in the subsidized rent program and vouchers is 18 to 61. Dr. Souza answered that HUD considers individuals over the age of 61 to be older adults and are supported by programs specific to that population, such as the Section 202 Supportive Housing for Older Adults program.

Dr. Jenny Mai Phan asked if there were toolkits for displacement resulting from natural disasters and if there were any follow-up efforts to ensure that autistic people and their families transition into temporary housing and, ultimately, permanent housing. Ms. Gerhard answered that assistive technology helps emergency management agencies with the training and technical assistance their staff needs to better interact with people with autism and provide appropriate supports. ACL funds regional aging and disabilities agencies to respond to emergencies, including assistance for temporary housing and services. Dr. Souza added that HUD provides Community Development Block Grants (CDBG) to quickly address housing needs after a disaster. There may be training and guidance to help local agencies administer

HUD programs to address the needs of people with autism and disabilities during emergency disaster situations, and she will follow-up with those resources.

Ms. Yetta Myrick talked about families who support an autistic adult who has not been diagnosed. The lack of access to diagnostic services can contribute to barriers to services when these individuals become adults. More work is needed to train and educate providers who serve these often marginalized individuals. There is often no consideration for the homeless population or families that experience abuse when research or programs are funded. Additionally, the COVID-19 pandemic reduced the number of mandatory reporters who could identify these situations. She spoke about her organization's interest in the D.C. Child and Family Service Agency and the Family Success Centers to serve lower resourced families. There is also a need for autism knowledge and training, as well as strategic inclusion of these populations in research efforts.

Discussion of the IACC Charge

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

Dr. Gordon talked about the Committee's charge and highlighted the importance of respectful communication. Congress has mandated specific duties for the Committee and the Autism CARES Act of 2019. The Committee is charged with monitoring federal autism research, developing a *Strategic Plan* and a *Summary of Advances*, and making recommendations to the HHS Secretary regarding federal autism activities writ large. In addition to the Autism CARES ACT of 2019, another federal law that governs the Committee's conduct is the Federal Advisory Committee Act (FACA), which ensures that IACC activities are objective, transparent, and accessible to all. The *Chair* and the Executive Secretary of the Committee are responsible for guiding IACC in meeting these responsibilities.

Dr. Gordon said that it is clear that Committee members take their responsibilities seriously and each member is greatly appreciated for the substantial time commitment they have volunteered in this capacity. He acknowledged the risk members take when discussing issues important to the autism community and the importance of ensuring an experience in which all voices are equally heard. IACC has adjusted meeting operations and processes to optimize this experience. The most recent iteration of the Committee represents the largest and most diverse group in IACC's history, which has broadened its membership to represent a greater scope of federal agencies and communities, as well as self-advocates across the autism spectrum. Many members serve more than one role. For instance, some are individuals on the autism spectrum and also an autism researcher. Others are parents of a child on the autism spectrum and also head of a federal agency.

It is important for the Committee to find common ground across the diverse points of view, experiences, and breadth of expertise in order to identify the needs of the autism community and to provide recommendations to the Secretary on the actions necessary to meet those needs. To make progress, it is important to maintain a balance between sharing and listening, avoid polarization, and be willing to understand different perspectives. Given the complex challenges that people with autism face every day, it is inevitable that some Committee discussions will become emotional and stressful. There may be disagreements, given the wide range of opinions and experiences that are represented on the Committee.

Dr. Gordon reiterated that it is important to not make assumptions about another person's experience and to treat each person who is willing to share with respect. Each Committee member shares a commitment to improve the lives of people with autism and it is important to remember that, even when there is disagreement, each Committee member is on the same side. With greater representation in the Committee, there is also a greater need to ensure that each person can be understood and can understand others. Therefore, Dr. Gordon urged the Committee to speak slowly, with plain language, and without terms that might demean others. It is also important that Committee members communicate when different language is preferred, when words need to be repeated, or when people need to speak more slowly. The goal of the Committee is to create a collective voice, which can only come from respectfully listening to others as they share experiences and differing points-of-view.

National Autism Coordinator Update

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

White House and Global Policy Updates

Dr. Daniels provided an update on White House activities. In March 2022, President Biden appointed 21 new citizen members to the President's Committee for People with Intellectual Disabilities, which is a committee managed by ACL. On March 15, 2022, President Biden signed into law the $1.5 trillion Consolidated Appropriations Act of 2022 that provides $14.5 million to federal agencies for special education and $6 million for home- and community-based services. On April 2, 2022, President Biden issued a 2022 Presidential Proclamation for World Autism Awareness Day, which reaffirmed his administration's commitment to people on the autism spectrum and their families.

In April 2022, the United Nations (UN) observed World Autism Awareness Day. UN Secretary-General António Guterres affirmed his support for the rights of people on the autism spectrum to fully participate in society in accordance with the UN Convention on the Rights of Persons with Disabilities and the 2030 Agenda for Sustainable Development. The UN Secretary-General also acknowledged the inequalities exacerbated by COVID-19 and emphasized the importance of community-based support systems. On April 8, 2022, the UN held a special event, Inclusive Quality Education for All, which was organized with the support of partners such as the Autistic Self Advocacy Network (ASAN), the Global Autism Project, and the Specialisterne Foundation.

The World Health Organization (WHO) launched an online version of their training program for caregivers of children with developmental delays or disabilities, which addresses the wellbeing of both the children and caregivers. In April 2022, the WHO will launch companion manuals for facilitators of the in-person trainings, which were developed in collaboration with Autism Speaks.

The Canadian Autism Spectrum Disorder Alliance (CASDA) is an alliance formed in 2007 to address the needs of autistic Canadians and their families. CASDA issued a Blueprint for a National Autism Strategy in 2019, which outlined the development of their 2020-2023 Strategic Plan and a Roadmap for a National Autism Strategy in 2020, which described the process and timeline for implementing their Strategic Plan. CASDA also oversees the Ready, Willing, & Able inclusive employment program. On April 4 and 5, 2022, CASDA held their annual Canadian Autism Leadership Summit, which covered a broad range of themes related to the experiences of people with autism. Dr. Daniels attended the Summit and presented on the IACC and the *IACC Strategic Plan* during a panel discussion on the different autism strategic plans from around the world.

U.S. Federal Advisory Committee Updates

Dr. Daniels provide updates from U.S. Federal Advisory Committees that work on disability-related issues. Federal Partners in Transition recently met on March 17, 2022 to share presentations from the DOL Office on Disability Employment Policy (ODEP) and included representatives the Center for Advancing Policy on Employment for Youth (CAPE-Youth).

The Interagency Committee on Disability Research (ICDR) published their 2021 ICDR Accomplishments Report, which highlighted their research efforts. The ICDR Executive Committee also held a meeting on February 24, 2022 to discuss their three new focus areas: equity, disability data and statistics, and COVID-19 and disability rehabilitation research.

The National Council on Disability (NCD) is charged with advising the President, Congress, and other federal agencies on policies, programs, practices, and procedures that affect people with disabilities. In February 2022, NCD published a new Health Equity Framework for People with Disabilities, which outlines their four core goals for helping policymakers address health disparities. These four core goals include designating people with disabilities as a Special Medically Underserved Population, implementing a standardized Comprehensive Disability Clinical-Care Curricula to train providers, requiring Accessibility of Medical Diagnostic Equipment, and improving data capture of indicates of disability status in surveillance systems. NCD also published a report on Medicaid Oral health Coverage in Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis.

The RAISE Family Caregiving Advisory Council is managed by ACL and is charged with providing recommendations to the HHS Secretary on effective models of family caregiving. ACL recently held an open call for nominations for up to 15 non-voting members for this council.

The Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) is managed by SAMHSA and is charged with addressing issues related to serious mental illness in adults and serious emotional disturbance in children. ISMICC held a meeting on April 13, 2022 and included a presentation on how state courts address mental illness.

The Disability Advisory Committee (DAC) provides recommendations to the Federal Communication Commission (FCC) on disability issues and is seeking public feedback on the implementation of the 21st Century Communications and Video Accessibility Act for their biannual report that is anticipated to be released in October 2022.

Committee Discussion

Dr. Robertson recommended another federal committee to monitor in these updates. The Office of the Assistant Secretary for Preparedness and Response recently launched the National Advisory Committee on Individuals with Disabilities and Disasters. They conducted a joint meeting with the National Advisory Committee on Seniors and Disasters in March 2022 and will likely continue meet separately to focus on meeting the needs of individuals with disabilities in the context of disasters and emergencies such as the COVID-19 pandemic.

IACC Committee Business

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

Autism Awareness Month

Dr. Daniels invited the Committee to join the IACC special event for Autism Awareness Month called Animating the Future for Exceptional Minds on April 27, 2022. IACC published its April 2022 edition of the OARC newsletter and has created a webpage for Autism Awareness Month that includes information about other special events.

IACC Strategic Plan

Dr. Daniels said that IACC plans to hold a virtual Strategic Plan Workgroup Meeting on July 13 and 14, 2022. In the January 2022 Committee meeting, OARC presented results from the request for information (RFI) to obtain feedback on the IACC *Strategic Plan*. Committee members discussed several aspects of the *Strategic Plan* and voted to add a section on the impact of the COVID-19 pandemic, add a cross-cutting objective to address disparities, and extend the timelines on the current budget recommendation by five years. Additionally, OARC collected Committee feedback for the IACC *Strategic Plan* from a survey that was open from November 2021 to March 2022.

Going forward, OARC staff will synthesize this input to prepare a draft IACC *Strategic Plan*, which is anticipated to be shared in early July, prior to the July 2022 Strategic Plan Workgroup Meeting. OARC will send the Committee another survey in May 2022 to collect feedback on the IACC Mission, Vision, and Values statements. From July to September 2022, OARC staff will revise the draft IACC *Strategic Plan* from the feedback received and hope to have a final draft for approval at the October full Committee meeting. If approved by the Committee, the updated *Strategic Plan* will be prepared for publication in November and December 2022.

Dr. Daniels reviewed the Committee feedback that was received from the March 2022 survey. The Committee provided feedback on different aspects and sections of the IACC *Strategic* Plan. The majority of Committee members voted to change the title to IACC *Strategic Plan for Autism Research, Services, and Policy*. In addition, Committee members provided general input on areas that the IACC *Strategic Plan* should highlight, such as emphasis on equity, inclusion, lifespan, and community and the use of inclusive and accurate language. Committee members also provided feedback specific to each of the seven research questions covered by the IACC *Strategic Plan* and for important special topics to include such as the COVID-19 pandemic; reducing disparities in diagnosis and access to services and supports; and increased inclusion, diversity, and cultural competency.

Committee Discussion

Ms. Gassner said that trauma-informed care was an important topic that was missing from the list of suggestions. Additionally, it should be acknowledged that there are very few autistic adults who do not require some level of individualized community-based services and supports. She suggested that the Committee discuss the issue of gender and different presentations of autism, not only across the binary of male and female phenotypes, but also in subsets of individuals who may present with different externalized and internalized autism traits and/or who identify as gender nonconforming or nonbinary.

Ms. Crane agreed with Ms. Gassner and added that it can be presumptive to assume that disparities in diagnoses are caused by phenotypic differences. Gender stereotypes can affect the public's perception of autism traits and behaviors and the scope of research on gender differences should be widened to include the differences in how people are socialized or other non-biological differences. Dr. Gordon responded that it is important that the IACC *Strategic Plan* recognizes the specific questions that need to be addressed, such as the conceptualization of nonbinary gender. He pointed out that the next iteration of the *Summary of Advances* has a number of articles that address issues related to gender disparities.

Dr. Gordon invited Ms. Gassner to clarify if her suggestion to include trauma-informed care in the IACC *Strategic Plan* indicated a need for more research in appropriate delivery models or the need to recommend trauma-informed care approaches that have demonstrated evidence of effectiveness. Ms. Gassner responded that the trauma literature is continuing to disregard lower grade trauma experiences such as chronic microaggression, denial of services, or social isolation. Cumulatively, these lower grade trauma experiences could meet the same criteria for "big T" trauma, such as threats to health and welfare. There is therefore a need for foundational research to understand how autistic people experience trauma before there is a recommendation for trauma-informed interventions. Dr. Gordon pointed out that there are some current studies looking at cumulative effects of microaggressions or similar types of lower grade trauma experiences. Ms. Gassner reiterated that the need is for an understanding of how autistic individuals experience exposures or triggers.

Ms. Crane suggested that, in addition to trauma-informed intervention, there is also a need for the inclusion of mental health measures in the evaluation of efficacy in interventions. Some people with autism have said that an intervention itself can cause trauma. Dr. Julie Lounds-Taylor said that there have been some published studies that have addressed the unintended consequences of interventions. The scientific community is thinking more holistically about the impact of interventions and measuring not only primary outcomes, but also the potential for harm.

Dr. Alice Carter said that the urgency to move interventions into the community can lead to a tendency to overlook both unintended consequences and unintended benefits. Even if a full, structured diagnostic interview to capture the wide range of co-occurring challenges cannot be included in these trials, there can at least be the use of broad symptom checklists. Ms. Gassner said that some of this information is being captured in suicide prevention studies, but the chronic effects on quality of life has not adequately been addressed. Dr. Carter added that researchers have become interested in adverse childhood events (ACEs) but its literature seems to be separate from trauma literature. The more classic literature on trauma has indicated that the cumulative effect has the most significant mental health impact. She reiterated that the important topics are traumatic events, assessing mental health effects from interventions, and the harms and benefits of interventions.

Dr. Robertson said that burnout or similar concepts such as "spoon theory" (in which a child with autism has half the number of spoons, or energy to cope with daily demands, in their drawer than a typically developing child) have not made their way into trauma research. There could be an opportunity to focus on positive psychology approaches in terms of coping with adversity and barriers. For instance, relative to the exceptional circumstances of the COVID-19 pandemic, there is a lack of supports and services needed for people with autism to manage mental and physical complexities and challenges. He added that there may be a committee charged with women and trauma that may have an opportunity for cross-collaboration with disability.

Ms. Prince suggested there are three areas related to supports that need attention. First, families need resources to help navigate issues that their children might be experiencing such as sleep problems, aggressions, dietary requirements, or other special needs. There are very few community resources or supports for these families. Second, individuals also need these supports and there could be training programs in community colleges or universities, not necessarily specific to social workers or clinical providers, but for anyone who may encounter individuals with autism. Finally, there is a need for more training for medical professionals. People with autism can experience trauma when they meet with a physician who does not understand or know how to manage their sensory needs. She frequently hears instances in which a doctor refused to take on a patient with autism because they did not have the expertise or skills. Specialists also need training on how to manage sensory issues in those on the spectrum.

Ms. Gassner mentioned that the CDC study of autism in eight-year-old children may not be measuring gender and there is a need to also evaluate adolescent and adult rates of autism, which would more accurately depict gender issues. Dr. Daniels responded that CDC is working to address this challenge.

Ms. Myrick implored the Committee to truly work towards inclusion in research to ensure that diverse communities are considered in the development of interventions. A Spectrum News article indicated that 60 percent of participants in autism research are White. There is also a need to address intersectionality. For instance, she is both African American and an autistic adult and these different intersections should be reflected in research. Intersectionality is a topic that is receiving attention internationally and should be woven into the IACC *Strategic Plan*. One way to help diversify research participation is to provide stipends because this conveys that a person's participation is valuable. Dr. Gordon said that research participants are often recompensed for their time and asked if Ms. Myrick was suggesting a greater level of compensation. Ms. Myrick confirmed that more substantial stipends were needed.

Mr. Craig Johnson talked about how families have multiple needs and asked how long it takes to move from research to tangible solutions. Dr. Daniels answered that the IACC *Strategic Plan* is broad and encompasses both research and immediate action. Dr. Gordon added that the answer to "how long" is dependent on the type of research being conducted. Most services and supports available today were pioneered in research settings before being applied in the community. While genetics research may be decades away from affecting new interventions, research on screening practices could have an impact within the next year. Research translation has different timeframes. One purpose of the Committee is to recognize when a scientific advance is ready to become a recommendation. For instance, the discussion during this meeting on individuals with autism who are exposed to trauma was based on past research. While more research may be needed to understand specific effects, a recommendation can still be made for ensuring that exposure to trauma is taken into consideration. Dr. Daniels said that the representation of additional federal agencies and departments on the Committee can also help move services and supports more immediately into the community.

Dr. Reichard noted that ACL had been focusing on intersectionality in both services and research. All funding mechanisms have included a requirement to include race and ethnicity proportional to the population being served. ACL is not only focused on diverse representation in research participants but also in the workforce, from leadership to grantees. She said that the President had released an Executive

Order on Advancing Racial Equity and Support for Underserved Communities that included an Equitable Data Working Group. Dr. Reichard believes that this workgroup has recognized that people with multiple vulnerabilities can experience exponential effects. Additionally, ACL's National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) shares its research findings on their website. They require all grantees to include the input of people with disabilities throughout the research process, from design to the development of practical products. Grantees are also expected to write fact sheets or blog posts to help reach people with disabilities and their families. NIDILRR also considers what funding mechanisms are needed to bring research from one stage to the next, for instance from creating an evidence-based product to distributing it to a larger population.

Mr. Stephen Whitlow said that those who provide services often find that the practical application of a program that already exists is more urgent than research. On a practical level, there is a need to address coordinating services, developing a plan for the individual and family, identifying available resources, and anticipating future hurdles. This was demonstrated in the discussion about housing in which not adequately planning earlier in life can cause hurdles as the individual transitions into adulthood. There needs to be a practical aspect to help connect families to services embedded in the IACC *Strategic Plan*.

Dr. Robertson concurred with the importance of emphasizing intersectionality in the IACC *Strategic Plan*, which can reference the six executive orders related to diversity, equity, inclusion, and accessibility. These topics have become priority areas across the federal government and should be woven into the tapestry of the *Strategic Plan*. He suggested that there may be specific studies that could be cited within the IACC *Strategic Plan* that he will send to OARC. Dr. Daniels thanked Dr. Robertson and encouraged the Committee to send OARC any feedback or articles that might be helpful in the development of the IACC *Strategic Plan.*

IACC Summary of Advances

Dr. Daniels reminded the Committee that the *Summary of Advances* is a report required by the Autism CARES Act of 2019 to provide lay-friendly summaries of the 20 most significant advances in autism biomedical and services research each year. The Committee voted on the *2020 Summary of Advances* articles and is in process of being published for release in May 2022. Nominations have been submitted for the *2021 Summary of Advances* and Committee members will receive a ballot to vote on their top 20 choices. Once the voting process is complete, OARC will prepare the summaries and anticipates publishing the final report in fall 2022.

Dr. Gordon led the nomination discussion. He asked Committee members to flag any articles that they find either noteworthy for inclusion or that should potentially be removed from the list.

Question 1: Screening and Diagnosis

There were seven articles nominated under Question 1.

Dr. Paul Wang highlighted the *Effect of Family Navigation on Diagnostic Ascertainment among Risk for Autism* article as important work in promoting recognition, diagnosis, and connection to services.

Dr. Matthew Siegel referenced the *Rethinking Autism Spectrum Disorder Assessment for Children during COVID-19 and Beyond* article and asked about recent studies on remote or telehealth diagnoses during the pandemic. Dr. Gordon said that NIMH has funded a supplemental grant for remote diagnosis but none of the nominated articles specifically reflected that topic. He pointed out that the study *Computational Methods to Measure Patterns of Gaze in Toddlers with Autism Spectrum Disorder* was relevant to remote diagnosis because it addressed automated methods for screening. In this study, the researchers developed a mobile device for tracking gaze in toddlers to determine differences between those who are later diagnosed with autism and those who are not. Dr. Carter added that there were other articles published in 2021 that focused on remote diagnosis but may not have met the criteria for inclusion in the *Summary of Advances.* She said that comparison studies of remote versus in-person diagnosis during the pandemic was a challenge. Dr. Alice Kau agreed that the mobile device for eye tracking study was exciting and looks forward to its further development.

Question 2: Biology

There were 14 articles nominated under Question 2.

Ms. Gassner reported on a recent study showing that highly structured, academic preschools obtained better short-term outcomes, but worse long-term outcomes in all children (not just those with disabilities). She suggested that this finding was significant in the context of early screening and diagnosis tools because it may indicate a need for more socialization and play time rather than intensive normalization and compliance training. Dr. Gordon said that this point was also made in the U.S. Preventive Services Task Force in their decision that there was insufficient evidence for universal primary care screening for autism spectrum disorder. Their recommendation highlighted the need for research to demonstrate early identification tools that result in better outcomes.

Ms. Crane added that although the goal of identifying children from age three compared to age eight is reasonable, there is no evidence that identifying children at 12 months of age results in better long-term outcomes. She suggested that the IACC *Strategic Plan* should have language to clarify this. Dr. Gordon said that there were two reasons to conduct early identification studies. One was that these studies are needed to determine whether there is evidence for long-term benefits. The other is that it is currently unknown how the biology of autism unfolds at earlier ages. Understanding the biology of autism will ultimately help improve the lives of children with autism.

Dr. Gordon commented on the *Long-term Maturation of Human Cortical Organoids Matches Key Early Postnatal Transitions* article. It is difficult to study the development of brains very early in life and this study showed an effective alternative through studying cells in a dish. Dr. Elaine Hubal responded that conducting biology studies in addition to intervention studies is important for identifying information such as modifiable risk factors such as the environment or chemical exposures.

Ms. Gassner commented on the *Age of Walking and Intellectual Ability in Autism Spectrum Disorder and Other Neurodevelopmental Disorders* article, suggesting that it could be an exciting insight about an externalized expression of delay onset. She asked the nominator, Dr. Alycia Halladay, to provide further insight. Dr. Halladay said that this study looked at developmental milestones in general and also the genetic factors that support early diagnosis. Dr. Gordon added that this study showed that the relationship between walking and intellectual ability was not present in children with autism without lower IQ. It would be important that the summary of this article accurately reflects the findings. Dr. Robertson pointed out that diagnostic criteria tend to focus on social communication and underemphasize motor-sensory functioning. It is helpful to have studies that examine the connection between motor skills and other functions. He suggested that this need be highlighted in the IACC *Strategic Plan*.

Dr. Susan Rivera said that it was important to carefully consider language to avoid stigmatizing terms. For instance, "risk factor" should be replaced with "predictive factor." Dr. Gordon thanked her identifying a term that might be perceived as demeaning. He agreed that the term "predictive factor" could be used to reduce value judgement and suggested that the IACC *Strategic Plan* use this language. He added that the terms "risk" and "resilience" are often used in the context of illness and may not be preferred language by the autism community.

Dr. Gordon commented on the *Parallel In Vivo Analysis of Large-effect Autism Genes Implicates Cortical Neurogenesis and Estrogen in Risk and Resilience* article, which looks into the influences of genetics and sex hormones that are associated with the generation of neurons and may present significant predictive value for diagnosis.

Dr. Halladay spoke about the *Influence of Siblings on Adaptive Behavior Trajectories in Autism Spectrum Disorder* article, suggesting that it may be more appropriately placed in Question 6: Lifespan Issues.

Question 3: Risk Factors

Dr. Gordon reiterated that this question will be changed to "Predictive Factors." There were 10 articles nominated under this question.

Ms. Gassner talked about the *Impact of Autism Genetic Risk on Brain Connectivity: A Mechanism for Female Protective Effect* article that found a 4:1 difference in autism prevalence for males to females in very young children. This difference has not been found in adults. Dr. Gordon clarified that, like gender, sex is not binary. This study found genetic risk affected by connectivity in males but not females. This could arise through biological factors, even prenatally, that are more related to sex but that could also arise from a gender effect. Dr. Gordon said that the effect is complicated and thanked Ms. Gassner for highlighting it.

Dr. Gordon referred to the *How Rare and Common Risk Variation Jointly Affect Liability for Autism Spectrum Disorder* and asked Dr. Joseph Piven if this article fell within the policy to exclude commentaries unless they broke new ground. Dr. Piven agreed that a commentary could be accepted if it were transformative or provided a very new perspective, but that this article presented more than a commentary. The field has advanced through the recognition that single-gene disorders are impacted by more than a mutation in a single gene. This article helps move the conversation forward into why some children with a single-gene disorder, such as Fragile X, will also develop autism while others do not.

Dr. Hubal suggested that the *Prenatal Exposure to Per- and Polyfluoroalkyl Substances in Association with Autism Spectrum Disorder in the MARBLES Study,* the *Association between Self-reported Caffeine Intake During Pregnancy and Social Responsiveness Scores in Childhood*, and the *Gestational Exposure to Phthalates and Social Responsiveness Scores in Children using Quantile Regression* should be removed because they were more hypothesis-development efforts. While they provided valuable information, they should not be shared with the public as evidence.

Dr. Wang agreed with Dr. Piven that the article on risk variation provided more than commentary. He added that the *Rethinking Autism Spectrum Disorder Assessment for Children during COVID-19 and Beyond* under Question 1 was a commentary and should be removed. He highlighted the *Patterns of De Novo Tandem Repeat Mutations and Their Role in Autism* for its identification of a new class of genetic differences as an important advance in the understanding of genetics in autism. Dr. Gordon suggested removing the commentary from Question 1 unless there was objective from the Committee.

Mx. Giwa Onaiwu agreed on removing the three commentaries nominated under Question 3. However, there are times in which such "gray literature" is the only information available that is relevant to underrepresented and/or marginalized communities. Dr. Gordon noted that the commentary in Question 1 may address underrepresented minorities even if it was not specifically cited. He will look further into the article to determine whether it should be considered.

Dr, Gordon said that the *Summary of Advances* discussion will continue at the next Committee meeting.

Public Comment Session

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

Dr. Eileen Nicole Simon is a parent to an autistic son. She spoke about the failure of language development in children and its impact on social development. Her son required resuscitation at birth and, although he met began to speak around the age of one year, his nursery school teacher suggested that he be evaluated by a psychiatrist. Despite clear, articulate language, her son used the pronoun "you" instead of "I" or "me." He was diagnosed with autism shortly before his third birthday. She encouraged the Committee to discuss language disorders.

Mx. Stevie Mays works at Reach Every Voice, an education and activist group. They previously worked as a Registered Behavior Technician in the field of Applied Behavioral Analysis (ABA). They had found that the Behavior Certification Board (BACB) had demonstrated poor critical analysis of the moral and ethical responsibility for its practices for student access to appropriate modalities of communication. Augmented Alternative Communication (AAC) refers to any method of communication outside of spoken language or verbalization, including sign language, gestures, picture boards, or other assistive devices. According to ASAN, one-third of autistic people fall under the category of non-speaking and require AAC to support their communication. Differences in muscle control can be an inherent trait in autism and may affect the use of voice. ABA forces autistic children who have some verbal capacity to prioritize their limited verbal communication, but AAC could help extend their full range of communication. Children with autism who are given access to AAC show both verbal improvements and AAC gains. However, the BACB does not provide curriculum and training on AAC. There should be a shift towards more intensive AAC in ABA practices for communication and language. This can be achieved through training for therapists, as well as conducting research into the functional communication benefits that AAC provides to children who otherwise show little to no progress. Mx. Mays suggested that all children with autism should have access to AAC.

Ms. Lisa Morgan is an autistic self-advocate who was diagnosed at 48 years old. She has often found that people who are considered authorities on autism do not understand what it is like to live with autism in both professional and personal situations. While autistic people have recently been brought into the conversation, they are often not listened to in a meaningful way. Autistic people should be the ones to drive research priorities; participate in the development of resources; and effect social change through collaboration with professionals, researchers, and other stakeholders. Professionals in the field of autism must listen to autistic people towards a true collaboration. Lived experience should be regarded as the most important part of understanding challenges and developing solutions that make a positive impact on the quality of life. No amount of book learning, training, or years of professional experience working with autistic people can match the knowledge and experience of actually living with autism. Now that autistic people have been invited into the conversation, it is time to acknowledge them as competent, knowledgeable collaborators.

Mr. Bob Williams is the Policy Director of CommunicationFIRST, the only organization led by and for the estimated five million people in the U.S. who have significant speech-related disabilities, including the 13 to 14 percent who are autistic. Like many of his nonspeaking friends and colleagues, he was considered "severely and profoundly disabled" and subsequently institutionalized. Although he was able to type words and eventually transition into college, many youth and adults are denied the same opportunities despite federal law meant to guarantee these rights. Many continue to be considered "severely and profoundly disabled," a vague and dehumanizing term that can become a justification for giving up on the person. In its recommendations for the use of certain terminology, the IACC should work in equal partnership with nonspeaking autistic people and their organization. He urged the Committee to consider the written comments that he also submitted.

Dr. Edlyn Peña served as a Committee member from 2016 to 2020. She is currently editor and author of the books *Communication Alternatives in Autism* and *Leaders Around Me*. Dr. Peña spoke about AAC and the debate on whether parents and practitioners should support text-based AAC methods that require a one-on-one communication partner for prompting and support. The primary debate is focused on whether the author of the message being typed is the facilitator/communication partner or the student. Published studies have indicated that typed responses in facilitated communication are either influenced by the facilitator or a result of the communicator not being able to independently pass a message. However, although these forms of communication can indeed be subject to influence, there is evidence that students do become independent in their communication. Despite this finding, critics of this form of AAC refuse to admit that the typed messages are authentic forms of communication. Dr. Peña implored the Committee, and any other researcher or stakeholder focused on AAC, to explore research questions beyond the debate of authorship. For instance, research questions could explore the circumstance under which a communicator becomes independent or the supports and processes needed for the communicator to become independent. Dr. Peña provided additional guidance for AAC research. Because It may take years for a student to become independent, AAC research should be longitudinal. Additionally, because nonspeaking and minimally-speaking autistic people face a number of challenges that impact the dynamics of AAC, the research should also focus on sensory differences, motor planning differences, and anxiety. AAC research will require multiple sources of data, including both quantitative and qualitative data sources. Dr. Peña suggested that research professionals should be committed to understanding ways in which to reduce influence in AAC and support progressive independence and communicator reliability.

Summary of Written Public Comments

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

Dr. Daniels said that 271 written public comments were submitted—the most robust set of comments that OARC has ever received that was not related to a specific solicitation. Of these, 153 comments focused on research and service needs, resources, and policy implications; 43 comments focused on medical practices; 21 comments focused on the role of IACC and the federal government; 22 comments focused on research, services, and supports for adults on the autism spectrum; three comments were related to the needs of direct support professionals in the workforce; four comments pertained to employment; eight comments pertained to potential causes of autism; five comments were made on the needs of autistic people with high-support needs; and 12 comments focused on increasing autism acceptance and reducing stigma.

Committee Discussion

Dr. Alison Marvin addressed the comments suggesting that SSA take steps to better accommodate those on the autism spectrum. She replied to those commenters that their recommendations were passed to appropriate individuals within SSA. Additionally, SSA has released its first Equity Action Plan in support of President Biden's whole-of-government agenda to advance equity, civil rights, racial justice, and equal opportunity for all. SSA Acting Commissioner Kilolo Kijakazi has stated that systematic values may prevent people who need SSA programs from accessing them. The Equity Action Plan will help reduce these barriers to access. Dr. Daniels added that additional questions that were submitted after Dr. Hemmeter's presentation at the January 2022 Committee meeting SSA presentation can be found online.

Ms. Gassner referenced the number of comments calling for more autistic people to serve on the Committee. She asked Dr. Daniels to provide clarification on the construction of Committee membership across agency representatives and community members. Dr. Daniels said that the Autism CARES Act of 2019 provides guidance that Committee membership includes autistic individuals; parents and family members; and leaders of national services and supports, research, and advocacy organizations. Many Committee members belong to more than one of these roles. For example, Ms. Gassner is both a parent with an adult child on the autism spectrum and an autistic self-advocate. The HHS Secretary is taking action to appoint people who represent broad perspectives across the autism community.

Dr. Rivera expressed appreciation for Dr. Peña's comment on the research needed for AAC. She added that technology such as eye tracking can be useful in understanding self-initiated augmentative communication. She encouraged the Committee to consider a recommendation in the *Strategic Plan* for this this type of research, as well as the involvement of all points-of-view to provide input on what is helpful or not.

Dr. Robertson suggested that recommendations for AAC should be woven through the *Strategic Plan* as a long-term priority. There are multiple, creative ways to enhance a focus on AAC research and communication across the lifespan as a means to improve quality of life. A good time for this conversation would be October, which is National AAC Month. He encouraged OARC to consider a panel of autistic AAC users or relevant federal agencies at the next Committee meeting. Dr. Robertson also expressed appreciation for the written comments related to employment and access to career paths for autistic people. He mentioned that DOL has a research project on support services for young adults on the autism spectrum and they are currently conducting listening sessions of different perspectives on reducing barriers and identifying solutions. DOL is also addressing data gaps on the current state of unemployment, underemployment, and the barriers to jobs that fit autistic people's interests and skills.

Dr. Wang thanked Mx. Mays, Dr. Peña, and those who submitted written comments on AAC. There is no disagreement that communication is central to quality of life. He concurred with the call for more AAC research and mentioned that the Simons Foundation Autism Research Initiative (SFARI) has sponsored research showing that nonverbal autistic people can demonstrate, through eye tracking, the ability to read and comprehend words. It is therefore clear that these individuals could benefit from AAC. He suggested that it was important to consider the debate about who is communicating. If the facilitator, and not the student, is communicating then the autistic student is not being appropriately supported, represented, or helped. He does not believe that an ABA therapist is the best role for implementing AAC. Rather, it should be an individual with speech language pathology training.

Ms. Smith also expressed support for AAC research. Young children may use body language as a form of communications and therefore should be seen as such rather than as a challenging behavior. Sign language is another good form of alternative communication. She said that there is a need to ensure that the rights of nonspeaking people are the same as speaking people.

Dr. Taylor said that she is conducting a study focused on understanding what is helpful for autistic adults to find a positive employment trajectory. They are closely following 200 adults over three years to understand what workplace characteristics enhance employment stability and upward trajectories. She suggested that Dr. Robertson could collaborate with her team to share lessons learned.

Mr. Srinivasan thanked Dr. Peña for her comment on the inclusion of the entire community to access opportunities that contribute to their success, education, wellbeing, and employment.

Dr. Halladay suggested that AAC and facilitative communication (FC) were being combined and asked for clarification on the distinction between the two to ensure that the Committee can be very specific with its recommendation. Dr. Daniels said that this distinction may be addressed in the next presentation.

Ms. Gassner talked about people who are primarily verbal but who may have episodic mutism in circumstances that cause anxiety or extreme pressure. They are also often AAC users and should be included in discussion.

Ms. Prince said that her son with nonverbal autism uses art as a form of communication. She mentioned a program called Autism After 21 and a video that will feature three young men and their experience with AAC. These efforts will help demystify those who are nonverbal, especially in terms of employment.

Ms. Nebeker said that it should be acknowledged that some people have not yet found ways to successfully use available communication devices. This highlights a need to ensure that the diversity of voices are heard, including those with high support needs. She encouraged the Committee to continue to improve the diversity of its members and to not lose sight of the need to amplify the voices of those who have higher needs.

Mr. Johnson expressed excitement about the research efforts that were mentioned by Dr. Robertson and Dr. Taylor and would also like to explore national and statewide efforts to help employers provide jobs. Texas has supported three job fairs in the last three years. The Texas Workforce Solutions program has partnered with more than 40 employers willing to work with special needs adults and many have provided jobs. He would like to hear what other Committee members know about similar efforts in their state.

Dr. Robertson responded that DOL ODEP is engaged with state and local policymakers. The State Exchange on Employment and Disability (SEED) is a state-local policy interchange that engages in collaboration and technical assistance for employment-related needs such as assistive technology or transportation. He recommended that the Committee review their Work Matters report.

Dr. Phan said that Committee discussion on AAC should also consider families for which English is not their primary language.

Mr. Srinivasan commented on the anxiety related to the expectation to type at the speed of instant spoken language. There is a need for research into the sensory and physical schema related to communication support challenges.

Dr. Aisha Dickerson said that the written comments indicated that there is still significant interest in the etiology, or cause, of autism. She suggested that commenters interested in genetic markers for autism could review the ongoing genetic research at SFARI. She also addressed one comment that focused on vaccines and pointed out that it is a very dangerous direction to place blame on vaccines, particularly during an ongoing pandemic. Studies have clearly shown that vaccines are not within the causal pathway of autism.

Perspectives on Addressing Diverse Communication Needs in Autism

Introduction

Judith Cooper, Ph.D., National Institute of Deafness and Other Communication Disorders (NIDCD)

Dr. Judith Cooper provided an overview of NIH's activities to address communication in autism. Beginning with the NIH Collaborative Programs of Excellence in Autism that started in 1997, NIH has supported research to better understand communication in autism spectrum disorders, including the assessment of and interventions for nonverbal school-aged children with autism. Since 1998, NIH has offered reissues of a grant solicitation for research on autism with noted support for research specific to communication. NICDC supports research and training on both normal and disordered processes of hearing balance, taste, smell, and speech and language. Within this scope, NICDC has a long history of commitment to autism research focused primarily on speech and language. NICDC research topics have spanned communication profiles, minimally verbal individuals, behavioral interventions, AAC, and communication differences among autistic siblings.

In 2009, a mother of a nonverbal child with autism approached Dr. Cooper with a request to include nonverbal, low-communicating, and minimally verbal children with autism in NIDCD research. She stressed that the then common misconception that these children were "low functioning" was a result of the children's inability to demonstrate their cognitive capacity and communication ability. In response to this request, NIDCD and other Institutes initiated a planning committee and a workshop dedicated to children with autism who had not developed functional verbal language by the age of five. The workshop was held in 2010 and addressed the gaps in knowledge about who these children were, how their skills and knowledge could be assessed across different domains, and what interventions could be effective in improving their communication.

After the 2010 workshop, NIDCD and NIMH released supplemental funding opportunities to focus on the characterization of the population and pilot studies of assessment tools and treatment. A small work group was organized to focus on assessment. Between 2010 and 2012, this workgroup identified the areas of assessment important for this population, publishing one article on the state of the science on minimally verbal school-aged children with autism and another article on assessment.

In 2011, NIH issued a request for applications on psychosocial and behavioral interventions, including research on studies of adaptive or novel treatments for nonverbal children with autism. In 2012, NIDCD released a Strategic Plan that outlined its commitment to support research to improve the diagnosis of autism spectrum disorder and to develop new or improved treatments for language deficits. Subsequent versions of the NIDCD Strategic Plan maintained these priority areas and added a focus on AAC. In 2012, Dr. Helen Tager-Flusberg received Autism Center of Excellence funding for her "Minimally Verbal ASD: From Basic Mechanisms to Innovative Interventions" study. In 2019, NIDCD awarded Dr. Connie Kasari and Dr. Tager-Flusberg funding for their study, "Predicting and Optimizing Language Outcomes in Minimally Verbal Children with Autism Spectrum Disorder."

Dr. Cooper said that NIDCD recognizes the need to address the continued gaps in research on nonverbal and minimally verbal children with autism and will continue their long-standing commitment and support. She emphasized that opportunities and needs should be sought from all sources—from advisory panels, such as IACC, to individuals with lived experience.

Advancing Research on Minimally Verbal ASD

Helen Tager-Flusberg, Ph.D., Professor, Department of Psychological and Brain Sciences; Director, Center for Autism Research Excellence, Boston University

Dr. Tager-Flusberg said that there is significant heterogeneity across the minimally verbal population and stressed the importance of treating each individual as an individual. She referred to the minimally verbal side of the autism spectrum as the "forgotten end of the spectrum."

She first reviewed data on the receptive and expressive language skills in minimally verbal children and adolescents. One of her team's studies found that most parents report that their children use very few to no expressive words (i.e., words the child used to express oneself). In contrast, parent report of receptive language (i.e., words from others that the child understands) varied widely. Therefore, Dr. Tager-Flusberg and her team sought novel approaches for assessing receptive vocabulary.

They first administered two validated tests of language, the Peabody Picture Vocabulary Test and parent report of word lists, for a small cohort of minimally verbal adolescents. They then explored novel approaches of assessment. First, they added eye-tracking to determine the number of times a participant looked at a target picture after hearing its matched verbalized word. They then conducted a similar experiment using an adapted touchscreen. They found that participants looked longer at target pictures than non-target pictures. Both novel approaches were found to be highly significant and correlated to the validated tests. Interestingly, they found individual differences in which some adolescents performed better with touchscreen than eye tracking.

Dr. Tager-Flusberg talked about a long tradition for those in the field of language acquisition to collect natural language samples from one individual interacting with another. However, these efforts did not include standard protocols to enable comparisons across different studies. To address this limitation, her team developed the Eliciting Language Samples for Analysis (ELSA) for toddlers (ELSA-T) and adolescents (ELSA-A) to provide a sequence of fun activities to keep the participant engaged as language samples were collected. They first tested ELSA in the lab with an examiner and then sent ELSA home with parents to compare the amount and type of language produced in each environment They found that parents were much more engaged with their children, with approximately twice the frequency of utterances, frequency of words per minute, and number of conversational turns than the examiners. Similarly, the children expressed twice as many utterances, words and conversational turns with their parents than with the examiners. Although there were individual differences, they found that parents were consistently useful in eliciting expressive language from their children.

Nest, Dr. Tager-Flusberg reviewed her team's study of *why* minimally verbal children do not learn to verbalize spoken language. They first considered behavioral correlates of expressive language. In a group of nearly 60 children and adolescents, using objective measures of joint attention (e.g., behavioral regulation, initiation, response to joint attention) to evaluate developmental play skills, imitation, nonverbal cognition, and the extent to which these measures were correlated to expressive vocabulary. They found that joint attention and age were not predictors of expressive vocabulary in older children, but cognitive level, imitation, and play were significantly associated. The most significant predictor of these was imitation, such that older children who had better imitation skills also had higher expressive vocabulary. This finding indicated that the behavioral profile of a child is important for determining the type of training needed. Older children had joint attention skills, but younger children did not. Therefore, a younger child might need a focused intervention for joint attention as a precursor to language.

Next, they considered speech motor impairment. They sought to determine whether minimally verbal children had co-occurring childhood apraxia of speech (CAS), a rare neurological disorder that occurs in people with and without autism. CAS is associated with impairments in speech movement precision and consistency (i.e., speech planning). Using a structure protocol to capture speech production, Dr. Tager-Flusberg and her team coded speech patterns for CAS and found CAS in approximately 25 percent of their sample of minimally verbal children and speech/motor problems (that did not meet CAS criteria) in the rest.

Her research team then considered auditory processing to determine the extent of auditory sensory sensitivity related to receptive language. They videotaped minimally verbal and verbal autistic children and coded observations of behaviors that indicated auditory sensory issues, such as avoidance or filtering. They found that the minimally verbal children with autism were far more likely to exhibit auditory sensory behaviors than verbal children with autism, despite being relatively equal in visual sensory sensitivity.

Finally, the team considered whether they could identify a brain marker for auditory processing sensitivity in minimally verbal and low verbal children with autism. Using electroencephalography (EEG) to measure brain response, they administered repeated tones that would occasionally deviate (i.e., either louder or softer). Brains typically respond differently to a deviant tone than to a repeated tone, however, in minimally and low verbal children, brain response to deviant tones was smaller in individuals who exhibited more auditory sensory behaviors.

Dr. Tager-Flusberg summarized that there are new methods for assessing receptive and expressive language but these need to be tailored to each individual. There are many explanations for a lack of acquisition of verbal language, from speech motor impairment to how the brain processes sound. The significant individual variance that was found in the research is important for informing interventions.

Connie Kasari, Ph.D., Profession of Human Development and Psychology, University of California, Los Angeles (UCLA) Graduate School of Education and Information Studies; Professor of Psychiatry, UCLA Department of Psychiatry and Biobehavioral Sciences

Dr. Kasari said that minimally verbal children are often excluded from intervention studies and traditional assessments are often not useful for determining their needs. It is known that the window of learning spoken language is between five and seven years of age. Research suggests that interventions should focus on requesting language for determining a child's needs rather than conversational language or joint attention language. It is also known that some children who are considered nonverbal are actually minimally verbal, which is defined as having fewer than 20 functional words by the age of five or six. It is also important to understand that people cannot continue to learn to speak after childhood. There are many reports of people who do not speak their first words until they are adults. It is also known that some children can speak but will only do so in a certain context or using certain phrases.

Dr. Kasari talked about important considerations for interventions such as the approach, dose, and metrics to measure response and outcomes. She said that it is important to personalize interventions towards an outcome that is meaningful to the individual and recognize that a single intervention may not be effective for all people. Her team has focused on adaptive intervention design approaches that have been informed by cancer and substance abuse research and applied to autism research in order to systemize clinical practices. A systemized clinical practice includes a sequence of decision rules that specify whether, how, or when to use an intervention; what dosage duration, frequency, or amount to use; type of treatment delivery over the course of care; and outcome measures.

Dr. Kasari and her team applied this model to the use of augmentative devices, which some suggest may delay or prevent spoken language. Her team conducted an intervention with 61 minimally verbal children aged five to eight. The children had already received two years of intensive early intervention, had showed slow progress towards spoken language, and had not previously used an augmentative device. All children received a Joint Attention, Symbolic Play and Engagement Regulation (JASPER) intervention in combination with a spoken language intervention called Enhanced Milieu Teaching. Half of the children who were identified as slow responders to spoken language were then randomized to receive an augmentative device to facilitate spoken language. Children who continued to respond slowly were provided with either an additional session per week or an augmentative device, as an embedded adaptive intervention approach.

They found significant increases in spoken utterances, novel words, and novel comments among the children who received the augmentative device. The children who did not receive an augmentative device showed slow and steady progress, but not nearly as rapid progress as those who received the augmentative device. When Dr. Kasari and her team looked specifically at the embedded adaptive treatments, they found that children who received the augmentative device and stayed with it showed increased spoken language and also increased initiation of joint attention. Children who received the augmentative device later in the study period showed some benefit, but not nearly as great as those who had the device from the beginning. Of the utterances that were recorded in those who received the augmentative device from the beginning, approximately 10 percent were generated on the device and 90 percent were spoken language.

Dr. Kasari emphasized that the behavioral intervention was important for the success of the augmentative device because it provided context and support. The interactions between adult and child were also important, especially for the adult to model initiated interactions that the child could then imitate. She summarized that minimally verbal children can benefit from interventions supported by technology such as speech-generating devices. Counter to the controversy that AAC may delay spoken language, the devices in this study supported the development of spoken language. Further, even when a child does not develop spoken language, the devices provides them with a means of communication. More research is needed to determine the specific components of the intervention that are most important to children, how early technology should be added, and the mechanism of how the technology provides a benefit. More studies are also needed to determine how to personalize the intervention to individuals.

Augmentative and Alternative Communication Supports for Individuals with Autism

Janice Light, Ph.D., The Hintz Family Endowed Chair in Children's Communicative Competence; Professor of Communication Sciences and Disorders, Pennsylvania State University

Dr. Janice Light said that there are more than five million Americans and 97 million people worldwide who have minimal or no speech. This population is diverse with a wide range of needs and skills—from those who acquired the disability through a brain injury or neurological disorder to those who have faced communication challenges since birth, such as people with autism. Without access to speech, these individuals face substantial challenges in expressing their needs and wants, interacting socially with others, and sharing experiences and information with others. These challenges can restrict their participation in all aspects of daily life such as education, employment, health care, family life, and community living.

Tremendous advances have been made in AAC, which provides the ability to augment speech and enhance communication and expression. Despite the common idea that AAC for autism is limited to tools such as the Picture Exchange Communication Systems (PECS) or Proloque2Go, there is a wide array of tools and strategies that can be used to enhance communication in autism. For instance, AAC can include unaided strategies such as signs and gestures, low-tech systems such as visual schedules, and high-tech tools such as text-to-speech devices.

Dr. Light spoke about her team's NIDILRR-funded Rehabilitation Engineering Research Center (RERC), which is mandated to conduct research to advance knowledge and improve services and outcomes for people with complex communication needs. Their research supports the development of improved AAC technology, training to build capacity in the field, and dissemination of knowledge to all stakeholder groups to ensure that "what is possible" becomes "what is probable." The RERC envisions a world in which all individuals with complex communication needs have access to AAC to realize their basic human right to communication.

Although the RERC conducts research on a wide range of AAC applications, Dr. Light focused her presentation on their projects with immediate application for individuals with autism. Research has shown that AAC can enhance language development, increase the acquisition and use of vocabulary, and increase the complexity of communication—all of which can increase participation in society and decrease challenging behaviors that can occur without a means to communicate effectively. She reiterated that AAC does not pose a risk to speech development but rather enhances speech production.

An AAC intervention must be maintained with sufficient intensity in order to achieve meaningful gains. Dr. Light's team recently completed a study showing that Black children with complex communication needs receive less AAC intervention than their White peers. Approximately 65 percent of Black children received less than 60 minutes of AAC intervention per week, which was not sufficient for attaining meaningful gains. These results indicate an urgent need for systematic changes to ensure equal access to AAC services, regardless of race, ethnicity, or primary language.

AAC interventions should also be provided as early as possible. The use of AAC should not be considered a "last resort" intervention because it can prevent children with autism from falling further behind their peers. Dr. Light's team has found that access to AAC at 12 months of age can result in the expression of first words as early as nine months of age—well before some typically-developing peers express words. Dr. Light stressed that, despite the benefit of early intervention, it is never too late to provide AAC intervention. Their research has shown that adolescents and adults can still attain meaningful gains from appropriate AAC.

AAC interventions are often targeted towards requesting communications, but AAC can be leveraged to address independent communication across a wide range of communication including social interactions and the sharing of experiences and information—both of which are challenges for many on the autism spectrum. AAC technology is often developed by neurotypical adults who do not have insight in how people with autism think, learn, or communicate. There is a need for better AAC design to reflect the needs and skills of those who use it and that is based on what is known from research about motor, cognitive, sensory, and language development. AAC technologies should also be appealing, easy to learn, and powerful enough to provide access to communication and participation.

Too often, AAC technology is prescribed on the basis of clinician familiarity rather than the needs, skills, and preferences of the individual using it. One size does not fit all, and there is a need to develop a greater range of personalized AAC approaches. Dr. Light's team has conducted research on the visual, cognitive, and motor demands of using AAC, finding that even very small changes in layout, display, color, and organization can impact the user's accuracy and efficiency. Traditionally, AAC is displayed on a grid, with language represented by symbols without context. Their research has shown that children have difficulty learning these systems and that the lack of context is especially challenging for beginning communicators.

Dr. Light's team has been working on alternative AAC displays, such as visual and video screen displays with photographs or videos of meaningful events from the individual's life embedded with language concepts. These displays seem to offer significant linguistic and cognitive advantages. Additionally, their eye tracking research has shown that these displays result in longer attention and more rapid processing speed in people with autism, as well as increased visual attention to the embedded language concepts. Visual and video screen displays provide an easy, just-in-time tool that can be personalized with vocabulary and events and provided to children as young as 12 months of age. Their research has shown that these AAC approaches have resulted in increase communication turns, increased vocabulary expression, and greater diversity in vocabulary expressed.

Visual and video screen displays have also been shown to increase social interactions and play between children with autism and their peers. These benefits also extend to adolescents and adults with limited speech—less than five minutes using this AAC technology was shown to increase social interactions between adolescents with autism and their peers. The technology has also been shown to increase independent participation in community and vocational activities.

Unfortunately, more than 90 percent of individuals with complex communication needs enter adulthood without functional literacy skills. Traditional AAC technologies do not support the transition from picture symbols to literacy and Dr. Light's team is working on a series of literacy transition features to embed in visual screen displays. These features use visual attention concepts to drive the user's attention towards a written word, which is then said out loud to support phonological processing. Their research on this technology has shown significantly increase literacy skills in 89 percent of participants.

Dr. Light spoke about technology supports for communication partners. Many communication partners are not trained in AAC and therefore preempt the opportunity to use it with a person with autism. There is therefore a need for the development of assistive technologies that support family members and other communication partners, such as first responders. Dr. Light's team is currently developing a user-friendly mobile application to not only provide communication supports for individuals, but also mobile training for their communication partners. Dr. Light summarized that much more research is needed to advance knowledge and improve AAC technologies. Training and dissemination to build capacity is also needed to close the gap between research and practice and to ensure equal access to AAC.

Lived Experience Perspectives
Jordyn Zimmerman, M.Ed., Autistic Self-Advocate; Director of Professional Development, The Nora Project; Board Member, Communication First

Ms. Jordyn Zimmerman shared her lived experience as a nonverbal person with autism and provided recommendations based on those experiences to the Committee. She first pointed out that she was the only nonverbal person to present at a meeting on autistic communication. She recommended that the Committee include more nonspeaking autistic members to ensure that IACC includes the view of people with lived experience in their priorities and recommendations.

Her challenges with speech production were related to motor movement and the process of producing each word was difficult. Although the Individuals with Disabilities Education Act (IDEA) expects students to start their education in the general classroom, her school assumed that she could not communicate with speech and labelled her as having challenging behaviors. She was given access to picture cards to communicate requests, but the system did not work for her. By the time she entered high school, she had been sent to multiple alternative schools, none of which were able to provide adequate communication supports. She could only communicate with her body, which was misinterpreted as challenging behaviors. She experienced bruising, injury, and seclusion at school, which was the direct result of not having access to AAC. She therefore recommended that the Committee prioritize the use of early communication supports for students and legislation to ban the use of restraints and seclusion.

By her fourth year in high school, she was placed in a room with a teacher who had no training in meeting the needs of an individual with communication needs. She recommended that the Committee also prioritize the provision of extensive training on early communication support to all educators.

Her curriculum in high school was focused on basic skills such as washing windows or putting clothes on hangers. It was assumed that she could not understand anything beyond basic language. She was given candy as a reward for touching her nose or head when asked. The school took her to visit a rehabilitation program without informing her parents, told her parents that she loved it (despite her preference against it), and moved her into the program. She said that when a nonverbal person does not have access to effective and reliable communication support, people in power will make often destructive decisions for them. Additionally, she received an IQ score of 61 that impacted people's assumptions about what she could understand and conveyed that she was a failure in society.

Therefore, she recommended the Committee prioritize policies that ensure that IQ tests are not administered to people who do not have access to effective and reliable communication support.

Following another restraint incident at school, Ms. Zimmerman's mother involved Disability Rights Ohio, which helped her access an iPad for communication support. However, the iPad did not provide immediate benefit and school staff would often use the iPad to mock and bully her. Her mother then found a school an hour away that supported autistic students. It took Ms. Zimmerman over a year to become acclimated to the school, but with intensive support in the use of AAC, she was able to communicate, collaborate, and build relationships. For the first time, she was able to fully immerse in the school setting and was able to participate in regular academics and extracurriculars such as cheerleading and the speech and debate team. At the age of 19, she felt a sense of belonging and inclusiveness for the first time.

At the age of 21, she graduated high school and attended Ohio University. Despite facing challenges in harmful assumptions about her abilities yet again, she persevered and graduated with a bachelor's degree in education policy. She then enrolled in a Master of Education program at Boston College and taught high school students who did not have access to effective AAC and struggled as a result. After graduation, she began working as the Director of Professional Development at The Nora Project, which helps educators and community leaders think critically about disability and diversity. She was featured in a documentary about nonspeaking autistic people called *This Is Not About Me*. She serves on the Board of Directors at CommunicationFIRST and has been a keynote presenter at several conferences. She was recently appointed by President Biden to the President's Committee for People with Intellectual Disabilities. None of these accomplishments would have been possible without access to robust AAC. However, access to AAC alone is not enough. She still experiences disregard when she communicates. She recommended that the Committee prioritize the right for nonverbal autistic people to communicate about themselves and their needs, using methods that work best for them.

She reiterated that IACC should include more nonspeaking autistic people on the Committee. AAC users specifically should be invited to help shape research funding and strategies. As President Biden said on World Autism Day, more is needed to incorporate the lived experiences of individuals with autism in research. IACC must do better to ensure that each person who needs AAC receives access, training and support as early as possible. Without it, too many people will be disregarded. Too many people will be subjected to lives of oppression and segregation. Too many educators and caregivers will make harmful assumptions. People should not have to rely on luck or prove worthiness to gain access to reliable communication or inclusive education.

Benita Shaw, B.S., Parent Advocate; Community Education Specialist, Resource Center; Facilitator, Sankofa Parent Support Group, University of California, Davis (UC Davis) MIND Institute

Ms. Benita Shaw is a parent to two sons, one of whom is a minimally verbal young man with autism. She is also a community education specialist at the UC Davis MIND Institute. She shared the challenges she experienced in advocating for communication supports for her minimally verbal son with autism. He started his education at a non-public school, but Ms. Shaw felt that it was important for him to be integrated and sought to transition him into a public school. She was warned that he had too many challenging behaviors—which were a result of his sensory integration issues—to be successful in the transition. Ms. Shaw fought for the supports and services needed for her son to be included in the public education system. He was provided with speech, occupational, and music therapy but spent 15 years struggling to use an AAC device.

Ms. Shaw described how teachers would talk negatively about her son in front of him, despite the fact that he could understand what was being said. He experienced bullying, which led him to engage in self-injurious and other challenging behaviors. After struggling with the school system for 15 years, her son is only now—at the age of 20—beginning to have literacy addressed. Her son was additionally discriminated against because of his tall size and the color of his skin and people made false assumptions about his abilities and capacity for learning.

The educational system is not set up for the integration of AAC or assistive devices for those who need them. There are multitudes of older people who need these interventions and there should be a focus on ensuring adults also have access to AAC. Ms. Shaw commended Ms. Zimmerman for her advocacy efforts and asked the Committee to consider her important recommendations.

Committee Discussion

Ms. Crane echoed Ms. Shaw's recommendation for research on access to high-quality AAC for adults. Research has largely focused on young language learners and there is little information on what works for adults. There are critical developmental periods for language and therefore people will learn language and communication skills very differently in their adulthood.

Ms. Myrick agreed that more AAC research is needed, specifically as it relates to parent interventions because this will help bridge gaps between disciplines and service systems and increase access to AAC supports. She is unfortunately not surprised about the disparities in access to AAC. She also experienced difficulty adopting the use of AAC at home for her son when providers at both school and community would not use the technology. She can see now that training is needed across disciplines to support the use of AAC at different levels. She added that the inability to communicate can become a critical issue of safety when there is no way to report being sick or experiencing abuse. She asked Ms. Zimmerman what technology she used to communicate and what advice she would give to family members who are trying to determine the best AAC support for their loved ones. Ms. Zimmerman answered that she currently uses Proloquo4Text. She said that the communication needs of every individual fluctuates over the life span, which is why her recommendation to include more nonverbal individuals on the Committee is important.

Ms. Gassner talked about her experience in advocating for AAC for her son. Her son speaks with direction and is highly fluent in his special interests. However, he did not use interrogatory language until the age of 32. She knows that he was bullied in high school but does not know the details because he could not communicate about emotional experiences. If he had access to technology while in high school, he might have talked about it to process the trauma he experienced, but he did not have access to technology until he was in college. The denial of access to technology is directly linked to the inability to help people therapeutically process trauma. If one cannot write, draw, or speak about it, there is no ability to "unpack" a traumatic event. Ms. Gassner asked Dr. Light if, in their research with preverbal children, they saw a reduced need for behavioral interventions as a result of lower frustration and better self-regulation after receiving technology. Dr. Light emphasized that the children in this study were suspected of having autism and not formally diagnosed until later. The interventions occurred at six to seven months of age in many of the children. They did see increases in turn taking, communication, social participation, and language—with their first words beginning sooner than normally expected. They saw very low levels of behavior challenges because the root of most behavioral challenges is the inability to communicate effectively with others. Interestingly, they have tracked many of the children over time and discovered that they often begin school with literacy skills. This can change their entire educational experience because they have a proven ability and the educational system can provide better supports.

Ms. Maria Fryer commented on her personal experience of parenting a daughter who did not speak first words until after the age of four. She found the research on imitation compelling because she experienced it firsthand. Within her role at the Bureau of Justice Assistance (BJA) at DOJ, she was also interested in the safety aspects of not being able to communicate victimization and trauma. BJA supports the Stop School Violence Program, which trains school resource officers and educators about students on the autism spectrum and she wondered what could be done to improve such programs. Specifically, she would like to know how best to respond to nonverbal students who experience trauma and need to communicate their experience and connect to appropriate treatment and services.

Mr. Srinivasan commented on his hope for more research on apraxia auditory processing sensory systems and body schema. Current technology is often confusing, not intuitive, has short battery life, and has too many complicated menus to navigate. In addition, the screens can be overstimulating. The PECS technology that he used as a child never included Indian foods and often made errors with foreign words, including his name. The technology does not function well at the pool or other outside events, even though communication is still needed in those environments. He asked if visual scene displays and text-to-language (T2L) devices are available to the general public. Dr. Light answered that those technologies are available from different manufacturers and mobile application developers and suggested that she could share links to those resources. She appreciated his comments about the limitations of technology and agreed that there should be a focus on those challenges to design more effective supports rather than forcing people to learn ineffective tools.

Dr. Siegel said that the randomized controlled trial is the standard for moving research into recommendations, dissemination to clinicians, and practice. Interventions such as medications and cognitive behavioral therapies are studied through randomized controlled trials. However, there are few large randomized controlled trials in communication interventions. The research that was presented provides compelling evidence of benefit, but to make these interventions accessible to the community there needs to be evidence generated from randomized controlled trials. He asked Dr. Cooper how to provide funding support for greater dissemination of these critical interventions. Dr. Cooper answered that NIDCD would welcome such applications and may seek to create more encouragement through specific funding announcements. NIDCDC also has a clinical trial program that researchers can contact.

Dr. Kasari talked about the traumatic experience that the nonverbal and minimally verbal autistic students experience at school. There should be a cross-agency effort to tackle the challenge of inclusion, perhaps through joint funding initiatives. Dr. Gordon responded that NIMH has funded large randomized controlled trials for adoption in school systems but agrees that the trial is often not enough to translate into adoption within schools.

Dr. Robertson added that federal policies, practices, and initiatives should focus more on employment, education, and health care. For instance, research may focus on general access to AAC but not access specific to school or employment settings, where the barriers actually exist. For AAC users on the autism spectrum to have equal access to inclusive education, gainful employment, and health care and community-based services, there needs to be a literature base that is broad and can direct federal policies and practices. There needs to be a cross-connection from the emphasis on communication and empowerment to diversity, equity, inclusion, and accessibility policies and executive orders. He suggested that the Committee and partners such as FIWA could collaborate to recommend policies and practices towards reducing barriers.

Ms. Shaw said that much of the challenge she experienced was from a lack of training for educators, the inability to include technology in the system, and a lack of collaborative planning with speech pathologists and teachers. Materials in classroom, such as books, were not tangible to her son because of how he communicated. The barriers exist within the educational system.

Mr. Srinivasan commented that his communication shuts down during times of intense emotion. AAC is not much use during these times and yet he is expected to continue communicating fluently. Neurotypical people also have a hard time forming sentences during an emotional state.

Ms. Crane commented that insurance, including Medicare and Medicaid, is often limited in its coverage of AAC devices. This is a policy issue that the Committee can address. Dr. Gordon reiterated Dr. Siegel's point about randomized controlled trials and said that these trials are what insurance providers need to see before agreeing to pay for services.

Ms. Prince spoke about a time in her son's life in which he experienced a crisis that he was unable to communicate about. This led to his not attending school for 18 months and self-harm behaviors, such as pulling out large chunks of his hair, because of his inability to communicate what he needed. For the first time in his life, he needed medication to help him modulate these behaviors but the medications created weight gain and other challenges. Her son is now 33 years old. She wanted to continue his speech classes but could only find two providers who would even consider working with an adult and, ultimately, chose not to. There is a dearth of opportunities for adults to continue improving their language.

Ms. Crane pointed out that randomized controlled trials might not always be a prerequisite for insurance coverage. For instance, she rarely sees insurance companies requiring such trials for wheelchairs before providing coverage. The issue is one of both policy and science. Dr. Halladay added that AAC is considered an intervention and not durable medical equipment. AAC can mix an intervention with equipment such as an iPad. Insurance companies would still want to understand the role of the intervention and its effect on independent communication.

Dr. Gordon expressed his appreciation for the presentations and recognized the challenge in ensuring that interventions have sufficient evidence to ensure that the right intervention occurs at the right time within educational and health care systems. He acknowledged the Committee members who use assistive communication devices and their valuable contributions to IACC. He pointed out that many program staff from NIH Institutes listen to Committee meetings and may develop programs from these conversations. Additionally, many federal partners in attendance are deeply interested in these conversations to learn how to overcome barriers and to collaborate across agencies to encourage the development and use of the tools that were discussed.

Round Robin Updates

Committee members offered Round Robin updates.

Dr. Gordon shared that Dr. Robertson was awarded the prestigious Henry Viscardi Achievement Award by the Henry Viscardi Center in New York. The award is given to exemplary leaders in the global disability community who advance work to empower children, youth, and adults with disabilities to protect their rights and expand access to supports and services. Dr. Robertson is one of the first two autistic individuals to receive this international award since its inception in 2013.

Dr. Daniels shared an announcement from Dr. Larry Wexler that on March 21, 2022, ED's Rehabilitation Services Administration (RSA) released a notice of applications for the Subminimum Wage to Competitive Integrative Employment demonstration project, which aims to increase access for people with disabilities to jobs that pay good wages. The deadline for submissions is June 21, 2022.

Dr. Marvin asked Committee members to see the Round Robin document for information about the SSA's first Equity Action Plan and their plan for in-person appointments and walk-in services. Additionally, SSA will soon release an opportunity to apply for the Interventional Cooperative Agreement Program. She indicated that the Round Robin documents also include SSA responses to Dr. Hemmeter's presentation at the January 2022 Committee meeting.

Dr. Halladay announced that ASF was collaborating with the Phelan McDermid Syndrome Foundation, the International CDKL5 Foundation, and Indiana University on an National Center for Advancing Translational Science (NCATS)-funded consortium. The Consortium for Autism, Neurodevelopmental Disorders, and Digestive Diseases (CANDID) meeting will take place on June 8 and 9, 2022 and will focus on gastrointestinal issues and neurodevelopment disorders. They are also collecting information from families and individuals through a survey. ACF is also hosting a Day of Learning conference that will include presentations on the prevalence of autism, mobile technologies for early detection and intervention, and the importance of leisure activities.

Dr. Phan shared that she will be presenting on the importance of research on puberty and autism with Dr. Kristy Anderson and Dr. Lindsey Shea at the AIR-P Autism Awareness Moth Double Webinar on April 19. 2022.

Mr. Stephen Isaacson shared that OARC has included housing resources in their Resources webpage and that the full report of Round Robin updates will be available online.

Dr. Reichard asked the Committee to review the notices of funding opportunities from ACL in the Round Robin document. Additionally, ACL has announced Ms. Jill Jacobs as Commissioner for the Administration on Disabilities.

Ms. Gassner shared that she will be presenting on autism and masking at the 2022 American Speech-Language-Hearing Association (ASHA) Conference

Closing Remarks and Day Two Adjournment

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

Dr. Gordon thanked the Committee for their participation and their respectful discussion of issues, which provided valuable insights for the IACC *Strategic Plan*. He also recognized Dr. Daniels and the OARC staff for their excellent work.

Dr. Daniels thanked the Committee for their work towards developing a collective voice. She reminded Committee members that they will continue to refine the *2021 IACC Summary of Advances* list through either email or an additional meeting, if necessary. The *2020 IACC Summary of Advances* is anticipated to be published in May 2022. OARC will also send Committee members a survey on the IACC Mission, Values, and Vision, as well as an opportunity to provide additional input on the IACC *Strategic Plan*. They plan to solicit global feedback before the Strategic Plan Workgroup Meeting on July 13 and 14, 2022.

Dr. Daniels invited Committee members to attend the virtual International Society for Autism Research (INSAR) meeting from May 11 to 14, 2022 and the Autism at Work Research Workshop from May 16 to 18, 2022.

The next full Committee meeting is on October 26, 2022 and will be virtual.