



## Minutes of the Interagency Autism Coordinating Committee

### Full Committee Meeting

January 19, 2022

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The Interagency Autism Coordinating Committee (IACC, also referred to as "the Committee") convened a virtual meeting on Wednesday, January 19, 2022, from 10:00 a.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); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Sam Crane**, J.D., Autistic Self Advocacy Network; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Anita Everett**, M.D., D.F.A.P.A., Substance Abuse and Mental Health Services Administration (SAMHSA); **Maria Fryer**, M.S., U.S. Department of Justice (DOJ); **Dayana Garcia**, M.Ed., Administration for Children and Families (ACF); **Dena Gassner**, M.S.W., Adelphi University; **Morénike Giwa Onaiwu**, M.A., Rice University; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Elaine Cohen Hubal**, Ph.D., Environmental Protection Agency (EPA); **Craig Johnson**, B.A., Champions Foundation; **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Alice Kau**, Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) (representing Diana Bianchi, M.D.); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS) (representing Richard Woychik, Ph.D.); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/Trainer; **Scott Patterson**, Ph.D., HSPP, 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; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration (HRSA); **Susan Rivera**, Ph.D., University of California, Davis; **Robyn Sagatov**, Ph.D., M.H.S., R.D.N., Agency for Healthcare Research and Quality (AHRQ) (representing Kamila Mistry, Ph.D., M.P.H.); **Nina Schor**, M.D., Ph.D., National Institute of Neurological Disorders and Stroke (NINDS); **Stuart Shapira**, M.D., Ph.D., 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., U.S., Food and Drug Administration (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 and Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University; **Debara Tucci**, M.D., M.S., M.B.A., F.A.C.S., National Institute on Deafness and Other Communication Disorders (NIDCD); **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., U.S. Department of Labor (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 meeting. He noted that Dr. Francis Collins has stepped down from his role as National Institutes of Health (NIH) Director. Dr. Lawrence Tabak is currently the Acting NIH Director and officially serving as a member of the Committee until a new NIH Director is appointed. Dr. Gordon welcomed new Committee member, Ms. Taryn Williams, and invited her to introduce herself. Ms. Williams said she serves as the Assistant Secretary of the U.S. Department of Labor's (DOL) Office of Disability Employment Policy (ODEP). Their Senior Policy Advisor, Dr. Scott Robertson, who has been actively involved with the Committee for several years, will continue to serve as an alternate.

Dr. Gordon said that Dr. Valerie Paradiz has retired from Autism Speaks and stepped down from the Committee. It is expected that the Department of Health and Human Services (HHS) Secretary Xavier Becerra will soon identify a replacement from the existing pool of Committee nominees.

Dr. Daniels welcomed Dr. Anita Everett and invited her to introduce herself. Dr. Everett is the Director for the Center for Mental Health Services at the Substance Abuse and Mental Health Services Administration (SAMHSA). She formerly served as a Division Director for a community psychiatry program at Johns Hopkins University, where they had clinical services for adults who aged out of autism services. Her alternate is Mr. Mitchell Berger.

Dr. Susan Daniels said that she received minor corrections to the October 2021 meeting minutes, and the Committee voted to approve the minutes.

## The Social Security Administration and the Autism Spectrum: Disability Insurance, Supplemental Security Income, and Work

**Jeffrey Hemmeter, Ph.D.**, Acting Deputy Associate Commissioner; Office of Research, Demonstration, and Employment Support; SSA

Dr. Jeffrey Hemmeter described the role of the SSA and their policies and programs to support individuals with autism. SSA is an independent federal agency with approximately 60,000 employees

across more than 1,500 field offices. Additionally, SSA contracts with every state's disability determination service, providing funding for approximately 15,000 physicians who are responsible for making a first disability determination for every claim. SSA has two primary programs: the Old-Age, Survivors, and Disability Insurance (OASDI) program, which is further split between Old-Age and Survivors Insurance (OASI) and Disability Insurance (DI) programs, and the [Supplemental Security Income](#) (SSI) program. The SSI program pays out about \$56 million to children, adults, and the elderly.

SSA manages a significant workload every year. In fiscal year 2021, SSA fielded approximately 2.5 million disability claims. The average claim takes about 171 days to adjudicate through the disability determination service. Denied claimants can file a first appeal for a second review and a further appeal with an administrative law judge, if needed. SSA holds approximately 400,000 to 500,000 such hearings a year, taking an average of 310 days to process. If the claimant continues to disagree with the decision, they can continue to file appeals to the Appeals Council, and then the federal, public, and Supreme Courts. Additionally, SSA fields more than 1.6 million continuing disability reviews, which include approximately 500,000 full medical reviews and more than two million non-medical redeterminations of eligibility.

Dr. Hemmeter reviewed eligibility requirements. Although medical requirements are the same for both DI and SSI, the non-medical requirements differ. For instance, DI is based on past earnings, is funded by Federal Insurance Contributions Act (FICA) contributions, and pays benefits regardless of resources and income. SSI is not tied to past earnings but is needs-based (funded through general funds from the U.S. Treasury) and has significant limitations on resources and income.

In determining eligibility for disability, there is a three-step process for children and a five-step process for adults. For both children and adults, step one is to determine if earnings are above the substantial gainful activity (SGA) level, and step two is to determine if there is severe impairment. Step three for both children and adults determines if the individual's disability is within the list of medical conditions SSA considers severe enough to prevent substantial gainful activity. In addition, step three for children determines if there is marked and severe functional limitation. Step four for adults determines if the individual can perform past relevant work, and step five determines if the individual can perform any work.

The statutory definition of disability for adults is "the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment" that is determined to be long-lasting. This definition is the same for children but is based on "impairment that causes marked and severe functional limitations," instead of the inability to do SGA. The term *marked* indicates that functioning is at least two, but less than three, standard deviations below the mean in standardized test scores. The term *severe* indicates functioning at least three standard deviations below the mean.

The SSA "[Blue Book](#)" describes the criteria under which claimants can qualify for benefits. It is geared towards physicians and other health professionals. To qualify for benefits for ASD, individuals must meet two criteria. First, individuals must have medical documentation of both qualitative deficits in verbal communication, nonverbal communication, and social interaction, as well as significant, restricted, repetitive patterns of behavior, interests, or activities. Individuals must also demonstrate extreme limitation of one, or marked limitation of two, area(s) of mental functioning. These areas include the ability to understand, remember, or apply information; interact with others; concentrate, persist, or maintain pace; or adapt or manage oneself. SSA will review the individual's medical history for evidence of these criteria or will conduct consultative examinations if no evidence is found in medical records.

Of children applying for disability for autism, approximately 75 percent fulfill criteria upon initial evaluation. Fewer claims are approved as individuals move through each phase of the appeals process. The volume for adults applying for disability for autism is lower, but the pattern of approvals is similar. According to legislation (and not determined by SSA), monthly SSI payments are currently capped at \$841 for individuals and \$1,261 for couples. It is reduced by certain amounts for earned and unearned income. Individuals and couples are also restricted in the value of their assets, excluding certain assets such as the individual's primary home or first car. The cap for assets has not changed since 1989 and is \$2,000 for an individual and \$3,000 for a couple. These rules are set by legislation. DI is paid according to a complex calculation based on past earnings and family size. Beneficiaries will receive their full benefit regardless of earned income for nine months within a rolling 60-month window, after which benefits may be suspended if the beneficiary continues to perform SGA. Benefits will be terminated if the beneficiary is working above SGA after 36 months.

There are over 215,000 children and 190,000 adults with autism currently receiving SSI. Approximately four percent of adults receiving SSI have a primary diagnosis of ASD as compared to only one percent of those receiving DI. However, more than six percent of individuals labeled "disabled adult children" (i.e., adults diagnosed before age 22 receiving benefits based on a parent's SSA benefit) with a primary diagnosis of ASD receive DI. These data likely underestimate the number of individuals with autism receiving benefits because of the way SSA collects data on primary and secondary impairments. In general, SSI payments to adults with ASD are above the average payment while DI payments to this group are below average.

Dr. Hemmeter reviewed different employment incentive programs designed to support DI and SSI recipients who are working, which are outlined in the SSA "[Red Book](#)." Continued Payment (Section 301) provides benefits if an individual loses benefits due to continuing disability review (CDR) or aging out. Benefits may continue if the individual participates in an appropriate vocational rehabilitation (VR) program or similar services. Student Earned Income Exclusion (SEIE) provides benefits for individuals under age 22 who regularly attend school. Certain work-related expenses, such as transportation or medical devices, are excluded from the SSI calculation. DI and SSI payment calculations also exclude impairment related work expenses, such as service animals and medical devices. If a person leaves DI or SSI because they returned to work, they can return to the program through Expedited Reinstatement (EXR). Individuals must return within five years under certain conditions to be eligible for EXR. These programs are designed to mitigate concerns about losing benefits.

[Section 1619\(b\)](#) allows an individual to continue receiving Medicaid benefits even if SSI eligibility ends due to work. The [Achieving a Better Life Experience](#) (ABLE) account is not an SSA policy but a savings plan that does not count towards SSI asset limitations. SSA funds external [Work Incentives Planning and Assistance](#) (WIPA) liaisons to provide benefits counseling and supports to those interested in work or who are working. SSA also funds agencies under the [Protection and Advocacy for Beneficiaries of Social Security](#) (PABSS) program to help protect rights related to work. SSA's [Ticket-to-Work](#) program pays employment service providers for successful work outcomes, and the [Vocational Rehabilitation Cost Reimbursement](#) program reimburses state vocational rehabilitation agencies for beneficiaries who achieve nine months at SGA.

There is limited research related to SSI and autism. There is a lack of research on DI and autism. Currently, the only way to apply for SSI and DI is [online](#) or by phone (1-800-772-1213 or TTY 1-800-325-0778). Children under 18 cannot complete the application. There are [resources](#) dedicated to helping

those who help others with the application process. Dr. Hemmeter said that SSA has a new research program called the [Interventional Cooperative Agreement Program](#) (ICAP), which allows SSA to partner with non-federal group and organizations to test or demonstrate a new policy, program, or service. SSA has proposed a number of legislative changes to the SSI and DI payment structures and other complex rules on earning and asset limits. They are also taking lessons learned from the COVID-19 pandemic to make the SSA experience more accessible, such as providing online services and eliminating the need for wet signatures.

## Committee Discussion

Dr. Paul Wang said that the criteria for ASD disability parallels closely with the diagnostic criteria but does not include the latest DSM-V criteria for sensory symptoms. Dr. Hemmeter said that he will take that suggestion to SSA's Office of Disability Policy.

Dr. Gordon read a comment and question from Mx. Morénike Giwa Onaiwu, who shared their family perspective in communicating with SSA. The SSA processes are often intimidating and cognitively inaccessible. Their child was dropped from SSI before the pandemic despite meeting criteria and having the need for benefits. SSA had requested several documents to determine continued eligibility, much of which was not available or applicable to their child. Mx. Giwa Onaiwu is also disabled and has difficulty with executive functioning. Therefore, navigating the SSA system was challenging, especially with no ability to talk to a live person to gain clarification. Instead of providing the requested documents, they felt helpless and their child's SSI and Medicaid both lapsed. Dr. Hemmeter responded that he will share this experience, especially about the inaccessibility of the process for parents with disabilities. He clarified for the Committee that Mx. Giwa Onaiwu was sharing their experience with the age 18 redetermination or medical continuing disability review. Congress has appropriated a significant amount of money for program integrity activities. He encouraged Mx. Giwa Onaiwu to reapply. Even though at one point their child was determined ineligible, there are technical reasons for denials that can be appealed and given a new application. Dr. Hemmeter will also share with the SSA policy office that there is a need for improved communication as well as explanations for why certain documents are needed.

Members of the Committee requested an opportunity to submit additional questions to Dr. Hemmeter. Dr. Alison Marvin suggested that OARC submit the additional Committee questions for SSA so that she and Dr. Hemmeter could provide a response. Dr. Gordon thought this would be a good idea but that the information would have to be shared with and be of interest to the autism community as a whole.

## National Autism Coordinator Update

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

Dr. Daniels provided an update on recent activities. The [2021 HHS Report to Congress on Health and Well-Being of People on the Autism Spectrum](#) was submitted to Congress in Fall 2021 and was required by the Autism CARES Act of 2019. For the purpose of the report, health and well-being were defined as physical and mental health outcomes, access to autism-related services and supports, and access to and inclusion in the community. There were four elements required by Congress including **demographic factors** associated with health and well-being, federal **policies and programs** relevant to health and well-being, current federal **comprehensive approaches** to improving health outcomes and well-being,

and department/agency **recommendations** for improving health outcomes and ensuring coordination between relevant agencies and service providers. There were 22 federal departments and agencies that participated in the development of this report. There were 23 recommendations developed across seven categories set by Congress including interdisciplinary coordination of federal resources; screening and diagnosis of autism in children and adults; behavioral and other therapeutic interventions; primary, preventative, and emergency/acute care; treatment and understanding of co-occurring physical, behavioral, and mental health conditions; caregiver mental health and supports; and quality of life. Dr. Daniels welcomed Committee members to access the report and read the details of each of the 23 recommendations.

Dr. Daniels gave a brief update of activities from the different relevant federal committees, agencies, and entities. President Biden appointed Ms. [Sara Minkara](#) as the U.S. Special Advisor on International Disabilities Rights. He also issued a [Proclamation on the International Day of Persons with Disabilities](#) on December 2, 2021.

The Defense Advanced Research Projects Agency (DARPA) recently funded a study to apply machine learning to early screening to identify children with ASD as early as possible and to potentially reduce disparities.

The National Science Foundation (NSF) recently released funding announcements. The NSF [Convergence Accelerator Program](#) has selected the research topic “Enhancing Opportunities for Persons with Disabilities” this year. The NSF [National Artificial Intelligence Research Institutes](#) also released a call for proposals on augmented learning to expand educational opportunities and improve outcomes using artificial intelligence technologies, including for individuals with disabilities.

The National Council on Disability released the [2021 Progress Report: The Impact of COVID-19 on People with Disabilities](#) and also sent a [letter](#) to leaders at the National Institute on Minority Health and Health Disparities (NIMHD) and the agency for Healthcare Research and Quality (AHRQ) in support of designating people with disabilities as a health disparity population.

[Federal Partners in Transition](#), managed by DOL, is currently working on a new Strategic Plan.

The [Interagency Committee of Disability Research](#) (ICDR) has a new [toolkit](#) on health care access and quality for people with disabilities. ICDR has also identified three new themes for future activities including equity and disability, COVID-19 and disability, and disability statistics. They also host a number of events.

The [RAISE Family Caregiving Advisory Council](#) (FCAC) is holding their first joint meeting with the [Advisory Council to Support Grandparents Raising Grandchildren](#) on January 25, 2022, to develop their National Family Caregiving Strategy.

The [Interdepartmental Serious Mental Illness Coordinating Committee](#) (ISMICC), which is managed by SAMHSA, [recently met](#) on December 16, 2021 to discuss their 2021 ISMICC Report to Congress.

The Federal Communications Commission (FCC) has a [Disability Advisory Committee](#) that recently developed a set of recommendations from their Pandemic Communication Access Working Group called [Concerns and Lessons Learned Regarding Communication Access for People with Disabilities During the Pandemic](#).

Dr. Daniels reviewed three nongovernmental activities. The [Patient-Centered Outcomes Research Institute](#) (PCORI) recently hosted a [workshop](#) on intellectual and developmental disabilities (IDD) on co-occurring mental health conditions and a [webinar](#) on treatment for attention deficit hyperactivity disorder (ADHD). PCORI also released a funding opportunity called [Comparative Effectiveness of Interventions Targeting Mental Health Conditions in Individuals with Intellectual and Developmental Disabilities](#).

The [American Academy of Pediatrics](#) (AAP) published a report called [Promoting the Participation of Children and Adolescents with Disabilities in Sports, Recreation, and Physical Activity](#).

The [National Academies of Science, Engineering, and Medicine](#) hosted a [workshop](#) on challenges and opportunities for creating an optimal care system for individuals with intellectual and developmental disabilities (IDD).

## **IACC Committee Business**

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

### **Autism Research Database (ARD) Demonstration**

Dr. Katrina Ferrara provided a review of the [Autism Research Database](#) (ARD), which is a publicly available resource that provides comprehensive information about the status of autism research funding among federal agencies and private organizations. The ARD currently contains data from 2008 to 2018 and provides advanced capabilities for searching, filtering, and exporting results. The IACC can use the ARD to identify research priorities for the upcoming *Strategic Plan* update.

The ARD contains the complete dataset used for the [ASD Research Portfolio Analysis Report](#). For the year 2018, this includes data from 23 federal agencies and private organizations. Research funding covered over \$394 million and included over 1,500 different projects. The ARD includes details such as funding amount, funder, principal investigator, location, and a description of the project. It aligns projects with the *IACC Strategic Plan* Questions, Objectives, and subcategories; making it possible for the IACC to monitor ASD research, trends, and the proportion of funding aligned with each Question area. The ARD provides breakdown by funder to help determine the historical and current research priorities for different funders. It also provides breakdown by geographic location, both nationally and internationally, to demonstrate where research is taking place. The ARD also allows users to search for projects by keyword and by principal investigator. OARC is currently working on the *2019-2020 Portfolio Analysis Report* and will upload the data from that report into the ARD.

Any questions about the ARD or the *Portfolio Analysis Reports* can be directed to [IACCPublicInquiries@mail.NIH.gov](mailto:IACCPublicInquiries@mail.NIH.gov).

## **Committee Discussion**

Dr. Alycia Halladay asked if the ARD has the capability to select all years at once to track historical funding for grantees. Dr. Ferrara answered that the capability is not currently built into the tool, but they will consider it for the future. Currently, the best way to include data across all years is to export an Excel file for each year and then combine files into one spreadsheet.

Dr. Larry Wexler suggested including an inflation adjustment to help put funding amounts into perspective. Dr. Ferrara said that now there is more than a decade worth of data in the tool, they could consider displaying data as-is and with an inflation adjustment.

## ***IACC Strategic Plan Update***

Dr. Daniels provided an update on the updated *IACC Strategic Plan*. OARC published a request for information (RFI) soliciting input from the public on the updated *Strategic Plan*. They received [responses](#) from 403 individuals and organizations. OARC identified the [major themes](#) from these responses across each Question area. They also identified cross-cutting themes, or themes that aligned across all Question areas. These cross-cutting themes included accessibility to services, treatments, and interventions; disparities in detection/diagnosis and service access and utilization; acceptance of autistic people; inclusion of autistic voices and underserved groups in research and services; lifespan issues, including aging; and personalized approaches to include all autistic individuals, including those with high support needs.

Dr. Daniels highlighted a number of major themes across all Question areas. She also noted themes that had not previously been noted in the *IACC Strategic Plan*. These included: under Question 1, education and stigma; Question 2, inclusion of autistic voices; Question 3, social determinants of health; Question 4, inclusion of the full spectrum of autism and reducing negative effects/experiences associated with some interventions; Question 5, accessibility; Question 6, inclusion of older adulthood in lifespan issues; and Question 7, acceptance and inclusion. OARC also included two supplemental questions in the RFI. One supplemental question was about the COVID-19 pandemic, which resulted in comments related to service disruption, the continuation of remote services and other accommodations post-pandemic, and mental health concerns. The other supplemental question was about disparities and underserved communities, which resulted in comments related to access to services and supports; reduction of disparities in health access and outcomes; and inclusion of autistic people from diverse genders, racial/ethnic groups, and other underserved communities.

Dr. Daniels thanked all who had contributed comments to the RFI and encouraged the Committee to review all of the major themes identified in OARC's review.

## **Committee Discussion**

Dr. Halladay asked how OARC determined novel themes during their review of the RFI responses. Dr. Daniels responded that OARC conducted a qualitative analysis and reviewed previous versions of *IACC Strategic Plans* to determine if themes had been mentioned in the past.

Ms. Dena Gassner asked if there would be an advisory team to contribute insights regarding the use of language throughout the updated *Strategic Plan*. She also asked for clarification on issues related to service accessibility. She wondered if OARC was able to delineate differences in access to different types



of services, such as health, social systems, and diagnostic services. Dr. Daniels answered that OARC has paid careful attention to the use of sensitive, inclusive, and accurate language. They will create a first draft of the *Strategic Plan* and the Committee will then be able to reflect on and respond to language choices. In terms of the definition of accessibility, there was mention of the different accessibility issues in the comments that the OARC staff will consider across different sections of the *Strategic Plan* for consideration by the Committee. Ms. Gassner expressed that access to services is a huge determinant of health and it is important for policy to address those issues.

Dr. Helen Tager-Flusberg suggested that, rather than reflecting on the challenges of the last few years, the Committee should look towards the future in their strategic thinking in order to get ahead of the next pandemic. Dr. Daniels said that she appreciated that perspective and added that some government reports address planning for future emergencies.

Ms. Jalynn Prince appreciated the focus on adulthood and suggested considering the sociological aspects of life, such as how people participate in their community. She also suggested including the impact of autism on families, including the implications of aging parents of adults with autism. For instance, without careful planning, there is the potential for the autistic adult to lose their home and the structures and supports they need. Dr. Daniels said that they plan to address issues related to family, caregiving, and caregiver supports. She is also aware of the homelessness issue and OARC has been working with a partner to understand young autistic people who become homeless. She also hopes to learn about the threat of homelessness on older adults with autism.

Dr. Matthew Siegel asked OARC to consider communication as an additional cross-cutting theme. As one of two core domains in autism, communication drives many aspects of quality of life such as mental and behavioral health and the ability to access education, medical care and services, and employment. Dr. Daniels responded that communication was indeed a recurring theme that will be highlighted and that cross-cutting themes were identified as such in terms of funding and other variables. Communication is tracked in a different way. Dr. Gordon acknowledged that communication was an important issue that should have greater focus and that it might be helpful for Committee members to review how communication is addressed in the current *Strategic Plan*.

Dr. Daniels asked Committee members to respond to opinion poll questions:

Would you like to see a section of the plan devoted to the COVID-19 response?

1. 75 percent indicated yes.
2. 25 percent indicated no.

Would the Committee like to consider a second cross-cutting objective to track activities related to disparities and underserved communities?

1. 95 indicated yes.
2. 5 percent indicated no.

### **Budget Recommendations**

Dr. Daniels said that the *2016-2017 IACC Strategic Plan* called for a doubling of the 2015 ASD research budget to \$685 million by 2020. Comparing their recommended budget to the actual budget from 2015 to 2018 (years 2019 and 2020 were not finalized), the actual budget shows a gentle upward slope that is

still lower than the recommended budget increase. Dr. Daniels asked the Committee to respond to an opinion poll about how to address the next budget recommendation in the updated *Strategic Plan*.

How should the budget recommendation be updated in the upcoming *Strategic Plan*?

1. Option 1: Extend the timeline by five years: The ASD research budget should reach \$685 million by 2025. *59 percent indicated yes*
2. Option 2: Recommend doubling the research funding amount for 2020 (approx. \$480 million): The ASD research budget should reach \$860 million by 2025. *32 percent indicated yes*
3. Option 3: Other, (neither Option 1 nor 2). *9 percent indicated yes*

Dr. Julie Lounds Taylor suggested that it might be sensible to be more conservative than Options 1 and 2 and asked which of the two might be the most impactful. Dr. Gordon explained that Congress requests budget recommendations specifically for research because it is impractical to determine a sum total for cost of autism care and services at the federal level. Congress uses the budget recommendation in a number of practical ways. For instance, authorization bills can be introduced into Congress to authorize the federal government to spend a certain amount in research by a certain year. Authorization bills only provide the authority to spend money; money cannot actually be spent until appropriations have been made. Appropriators have not responded with an increase in appropriations that would enable a budget of this size to research agency. Congress does view a budget recommendation as an advisory opinion with weight, and they use these recommendations to attempt to increase available resources for autism research across a number of federal agencies. How to recommend a budget that is most impactful is a more challenging question. The best approach may be to make an educated guess based on the resources needed to increase research in areas that need more attention, such as communication. The request to double the research budget for autism by 2020 was based on this approach.

Ms. Gassner said that the recommendation to double the budget was a “reach for the stars” request because of the historical underfunding of autism research. Given the number of people who experience negative COVID outcomes, many of which are people with intellectual/developmental disabilities and people of color, a focus on research that can more directly improve outcomes may help justify a recommendation for a larger budget.

Ms. Prince added that previous public comments pushed for increasing the research spending on adults with autism, specifically asking that spending increases from 2 percent of the budget to 4 percent. She asked if their recommendations could include a level of granularity in how research budgets would be allocated, especially in areas that are in dire need. Dr. Gordon said that the Committee is not tasked by Congress to address that level of granularity but that does not mean that the Committee cannot make such recommendations. He reminded the Committee that their role is making recommendations only. From the perspective of Congress and of federal agencies, the most useful approach is to hear general rather than specific recommendations. Very specific recommendations about how a research budget should be allocated may result in competing priorities and may not be very productive.

Dr. Taylor suggested that if the focus of the updated *Strategic Plan* is on engaging underserved and underrepresented communities, there may be justification for Option 2 because increasing diversity is challenging and may need a significant increase in resources. Dr. Gordon agreed that identifying specific areas to expand would be productive and would help justify a budget increase. Dr. Daniels added that the Committee is authorized to make recommendations about autism but there is also an entire body of federal agencies and research resources dedicated to all disabilities—not specifically for autism, but this other funding may be useful for the autism community.

Dr. Susan Rivera suggested that opinion polls be taken again since the discussion had provided Committee members with additional information needed to make informed decisions. Dr. Daniels agreed and suggested conducting the opinion poll a second time because there had been substantial discussion.

How should the budget recommendation be updated in the upcoming *Strategic Plan*?

1. Option 1: Extend the timeline by five years. The ASD research budget should reach \$685 million by 2025. *60 percent indicated yes.*
2. Option 2: Recommend doubling the research funding amount for 2020. The ASD research budget should reach \$860 million by 2025. *40 percent indicated yes.*
3. Other (neither Option 1 or 2). *0 percent indicated yes.*

Dr. Daniels said that the Committee will have an opportunity to provide feedback on changes to priority areas for research in the April 2022 meeting.

## Public Comment Session

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

### Oral Comments

Mr. Russell Lehmann is a motivational speaker and spoken word poet with a platform for autism and mental health. He commented on shock treatment administered as behavioral modification at the Judge Rotenberg Center. Mr. Lehmann has lived through traumatic experiences in inpatient psychiatric settings. Although the school advertises graduated electronic decelerator (GED) shock devices as safe and science-based, the strongest device produces 90 milliamps of electricity lasting two seconds. In contrast, a cattle prod produces 10 milliamps of electricity for a fraction of a second. In his experience, admission to a psychiatric ward can be traumatizing for a child even without the use of GED shock devices. This trauma can last a lifetime and drawings from children in the center are heartbreaking. He requested that the Committee consider taking action to help to individuals with autism and developmental disabilities.

Dr. Karen Heffler is an autism researcher at Drexel University and mother to an autistic adult son. Research indicates an association between early-life digital screen exposure and autism outcomes. There is also a growing number of reports for autism interventions that reduce screen time and increase focus on social engagement strategies. This is associated with rapid improvements in autism symptoms and decreased parental stress. These findings are consistent with child development literature. Digital screens interfere with critical parent-child interactions. Higher screen time is also associated with language delays, social impairments, attention problems, cognitive behaviors, and challenging behaviors. In the U.S., toddlers spend an average of 2.5 hours a day with screens. Dr. Heffler asked the Committee to include a recommendation in their updated *Strategic Plan* to focus research on parent education on digital screen time and social engagement strategies.

Ms. Alison Singer is the President of the Autism Science Foundation and mother of a daughter with profound autism. She also served as a public Committee member for 12 years. In December 2021, *The Lancet* published a special report titled [\*The Lancet Commission on the Future of Care and Clinical\*](#)

[Research in Autism](#). In this report, the commissioners introduced the term “profound autism,” which is defined as autistic people with intellectual disability, who are minimally verbal, and who are likely to require 24-hour support throughout their lives. The goal of introducing this designation was to provide more specificity to the broad spectrum of autism and to equip the community with the language necessary for ensuring that all individuals with autism receive appropriate accommodations and interventions. Ms. Singer stated that concise, meaningful teams can simplify the process of accessing services. It is important to understand that the term is not meant to demean individuals with autism or to invalidate the experiences of those who are not within its definition. It is instead meant to call attention to the unique needs of an underserved population. *The Lancet* report estimated that up to 48 percent of the autism population falls within the category of profound autism. She asked the Committee to increase the number of public Committee members who are parents of individuals with profound autism and to increase their focus on this population in the *Strategic Plan*.

Mr. Michael Ha is father to a four-year-old son with autism who was born into a modern world of technology and social media. Today’s parents often rely on technology and devices that have replaced physical bonding time with parents. Too much time with technology has detrimental effects, as it takes away from naturally occurring communication and social bonding, both of which are core to an autism diagnosis. In his experience with his son, none of the intensive services that were administered early in life significantly increased social response. They joined a pilot study at Drexel University in which they were taught how devices disrupt social interactions between children and parents. They were guided towards strategies for increasing social connection, such as techniques for improving eye contact and obtaining their child’s attention. One suggestion was to remove all technology immediately. Within a week of removing technology time and dedicating time to social interaction, he noticed a difference in his son’s attentiveness to his family and environment. Within three weeks, his receptive skills greatly improved. Within two months, he began to show consistent signs of social engagement, such as playing with peers and vocalizations. He asked the Committee to recommend an increase in funding and focus on this type of intervention so that other families could benefit.

Ms. Nicole Corrado is an autistic individual who has lived experience with wandering and elopement behaviors. She has written an [article](#) based on this experience. She does not agree with the use of a tracking device for wandering unless it can be easily removed and consented to. A tracker should be meant to improve independence and should be a joint decision between the individual and caregiver. Tracking devices should be limited to adults who sign up for one. Tracking devices are one tool to reduce search and rescue time, but they are controversial and do not always prevent elopement or drowning deaths. Funding from Kevin and Avonte’s Law should be used to support swimming lessons, sports programs, and other educational programs to help autistic individuals understand the dangers of elopement and the healthy behaviors they can use as alternatives. There could also be different supports such as an autism-specific crisis line that accommodates spelling for communication, education about sex and consent, safe places for autistic people fleeing abuse, mandatory autism education for first responders, and housing supports for autistic people who want to live independently.

### **Summary of Written Public Comments**

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

The Committee received a number of [written public comments](#). These comments focused on several important topics including addressing the needs of autistic individuals with high support needs and/or

profound autism; concerns about medical practices and potential causes of autism; the role of the IACC and the federal government; research and services needs, resources, and policy implications; comments for the *Strategic Plan*; services and supports for adults with autism; and safety, elopement, and interactions with law enforcement.

### **Committee Discussion**

Ms. Gassner provided clarification regarding the term “profound autism.” Although nearly 60 percent of children with autism have intellectual or borderline disabilities, many are able to enjoy at least part-time employment and positive school experiences when high-quality supports are provided. Not all children in the borderline range are as profoundly affected as the term implies. Additionally, intelligence quotient (IQ) scores and language are not protective factors that prevent self-harm or mitigate functional limitations for many children with autism. Across the spectrum of autism, many autistic individuals engage in non-suicidal, self-injurious behaviors. She encouraged Committee members to view autism as a continuum of challenges. She thanked autistic adults who participate in research. She concluded by stating that requesting that the Committee include representation from a parent of a child with profound autism may demean the Committee members who have high-support needs or who are parents of individuals with high-support needs. Suggesting that the Committee does not represent this community keeps the Committee from doing the important work of unifying the community and advocating for research and policy changes that are critically needed. She hoped the Committee can find a way to unify and move forward for better services and supports for all.

Dr. Martine Solages addressed the comments about the use of electrical stimulation devices (ESDs), also known as GEDs, which have been used as an aversive with people with disabilities in one private center in the U.S. but were partially banned from 2020 to 2021, when the ban was overturned. She said that the issue is currently making its way through the courts. Although she had no update today, she will continue to track the issue and bring updates back to the Committee.

Dr. Robertson addressed the use of ESDs and said that it is important to focus on human rights, self-determination, independence, community living, quality of life, and inclusion to spotlight the broader issue of concerning practices. He hoped to have future discussions on customized, individualized supports for autistic people rather than generalized approaches based on functioning. He suggested the topic be addressed in the updated *Strategic Plan*.

Dr. Daniels read a comment from Mx. Giwa Onaiwu, who stated that being an autistic adult and a parent of an autistic child are not mutually exclusive. It is therefore a broad assumption to state that there needs to be an equal ratio of representation between parents of individuals with profound autism and “high-functioning” individuals with autism. People are intersectional and one individual may fill many roles. A “high-functioning” adult may also be a parent or sibling of someone who meets the criteria for profound autism. Further, the level of functioning for any Committee member is not known.

Dr. Gordon responded to the different perspectives brought forward through the discussion. He agreed that there is subtlety and intersectionality, and that people can represent multiple perspectives. It is also important that all speakers, including the public commenters and current members of the Committee, are respected. He believes that the issue being voiced is the perception that the Committee has been focusing on issues centered on adults with autism and self-advocates. He agreed that the self-advocates on the Committee have wide levels of functioning, and parent advocates are not absent from the Committee. However, there are concerns from some members of the community that issues affecting

individuals with profound autism and their families have not been adequately addressed. He reassured the audience that the Committee will address issues that are important to those with higher support needs. He asked that perspectives from across the community be heard and considered.

Dr. Daniels read a comment from Mx. Giwa Onaiwu, who provided additional thoughts to their original comment. Many individuals are being presumed to be cognitively impaired until they gain the ability to use augmentative and alternative communication (AAC) in late adolescence and adulthood. This will not be the case for everyone, but this supports the idea that a “one size fits all” approach is not useful. They are not necessarily opposed to the term “profound autism,” but rather they are opposed to assuming that such individuals do not matter to those who are different than them. Dr. Gordon read the rest of Mx. Giwa Onaiwu’s comment. If a non-autistic parent can have a profoundly autistic child, there is no reason to assume that an autistic parent cannot also have a profoundly autistic child. When they, or any other individual, shares their perspective, there should not be an assumption that they are only sharing their own experience.

Ms. Sam Crane added that many of the autistic Committee members have consistently brought up the need for more supports, services, and research. There is a need to move beyond the terms “autistic people” and “non-autistic parents” because many are both. The term “profound autism” may obscure issues that the wide spectrum of autistic people experiences, such as self-harm, significant independent living challenges, or AAC use. Many people have different combinations of needs. When debating “high-functioning” versus “profound autism,” there are many individuals who are not being captured in the discussion.

Dr. Wang said that he is a co-author of article in *The Lancet* in which the term “profound autism” was introduced. It is essential that supports and services are developed and made accessible to individuals with extensive needs. There is also a need for appropriate research on this group. The recognition of those with profound autism should be considered part of the neurodiversity perspective because diversity is not restricted to those who are more functional.

Dr. Halladay commented that there may be misunderstanding about the term “profound autism.” She believes that the term may help resolve some of the controversy around topics such as appropriate housing and employment options that have previously been addressed by the IACC. Dr. Halladay also addressed the comment about screen time. There is a program called [Autism Navigator](#) and [Baby Navigator](#), which are projects led by Florida State University. The program provides webinars twice a month to families and professionals about detecting early signs of autism. They also provide one-on-one support for parents to incorporate skills such as social communication, interaction, and following directions.

Ms. Ivanova Smith said that she is concerned that the term “profound autism” may be used to restrict people’s lives and used to justify institutionalization and other restrictions of civil rights. She knows firsthand how a diagnosis can be used to restrict and institutionalize people and segregate them from their communities. She stated that no individual with autism should be institutionalized or restricted in their daily living. She is concerned that the term may be used to hurt those with the most intensive support needs. The limits may not just be institutionalization but also limits on education or placement under guardianship.

Dr. Gordon thanked Ms. Smith for her perspective and agreed that labels should not be used improperly. However, there are a significant number of individuals on the spectrum who need to be in

places where they can access supports that enable them to live their lives. There may be Committee members, including some of the self-advocates, who need or are caring for people who need this intensive level of care, and these voices need to be heard.

Ms. Crane suggested that this may be a political disagreement being recast as a disagreement between people with different experiences. To say that extremely high-level supports have to be delivered in an institution is a policy disagreement, not a disagreement over whose needs are being represented.

Dr. Jennifer Johnson agreed that what is being discussed is a lack of adequate home- and community-based services (HCBS) and supports for individuals with the most intensive support needs to communicate their needs and to live independently. It is important to acknowledge that people who are non-speaking are still communicating in some manner. At this time, the various ways that people communicate are not truly accepted. The services and supports made available for people to live independently varies across states and territories and is very much driven by politics. It is important to be careful when characterizing the needs of individuals, their ability to represent themselves, and the current level of supports they are receiving. Dr. Gordon clarified his comments about institutionalizations were in regard to needing a higher level of care. Dr. Johnson stated that reason some individuals “need” institutional services is because of a current lack of adequate HCBS.

Dr. Siegel provided a research perspective. The purpose of *The Lancet* commission was ultimately to drive more research and services. The autism research landscape has dramatically shifted over the last 20 years. A study that he co-authored analyzed 367 treatment studies published between 1990 and 2013 to determine the inclusion of individuals with either intellectual disability, minimally verbal ability (as it was defined at the time), or lower adaptive functioning (similar to the current definition of profound autism). They found that, over that time period, the inclusion of these individuals went from almost all studies to just one-third. In other words, by 2013, two-thirds of treatment studies did *not* include individuals who would currently fall under the profound autism definition. This is an important context to remember when listening to those calling for more investments in this group. Because it is such an under-researched and underrepresented population, there should be an objective in the updated *Strategic Plan* focused on research for services and policies related to those with profound autism.

Ms. Yetta Myrick said that, as a parent of a young adult with autism and intellectual disability, she may not understand what it is like to be autistic, but the root of the issue is access to services. The public members of the Committee were selected to share their lived experience and support the autism community as a whole. The challenge is ensuring that the research portfolio reflects the needs of all individuals with autism. She does not serve on the Committee to support just her son. She serves on the Committee to ensure that all individuals with autism are safe and feel that they have a meaningful place in society. She asked Committee members to bring their focus back to this purpose.

## Findings and Updates from the Autism and Developmental Disabilities Monitoring Network

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

Dr. Matthew Maenner reviewed two surveillance studies—one on the [prevalence of autism](#) and the other on [early identification of autism](#)—that were published by the [Autism and Developmental Disabilities Monitoring \(ADDM\) Network](#). The ADDM Network is a population-based surveillance system that monitors autism among children living in 11 geographically defined and demographically diverse areas. The ADDM Network has been reporting these data every two years since 2000. It originally monitored autism among eight-year-old children but recently expanded surveillance to include tracking early autism identification among four-year-old children. CDC intends to report follow-up data among 16-year-old children who were previously included at age eight.

The latest reports use a new autism case definition based on information collected from health, education, and service records from multiple community sources. The ASD case definition requires that a child has documentation of a written ASD diagnosis by a qualified professional, a special education classification of autism, or an ASD ICD code obtained from administrative or billing information. For the four-year-old children, the ADDM Network also ascertains instances in which children did not meet the autism case definition but had a documented suspicion of autism in their records. The changes are described in a study published in the *American Journal of Epidemiology* in 2021. The new definition requires considerably less data collection and a simplified method for data review, thus allowing the ADDM Network to disseminate results faster and fund more sites than previously possible. Importantly, the new approach more transparently reflects that children are being evaluated and served in their communities, which aligns with the purpose of the ADDM Network - to inform and improve practices.

Dr. Maenner reviewed findings from their 2018 surveillance data for eight-year-old children. It is currently estimated that 1 in 44 children (2.3 percent) are on the autism spectrum. There has been a general upward trend over time, which may reflect that participating communities change from year to year. Across the 11 sites, there is considerable variability in autism prevalence, ranging from 1.7 percent in Missouri to 3.9 percent in California. Overall, there were few differences across race and ethnicity; however, several communities within the 11 primary communities reported lower prevalence among Hispanic children as compared to White or Black children. The 2018 report included an estimate for American Indian/Alaska Native (AI/AN) children for the first time, which showed a slightly higher prevalence than other groups. It is important to note that the AI/AN population is very small and therefore the prevalence data is less precise than other groups.

The ADDM Network also collects IQ or adaptive test information. Among children that had information on cognitive testing, 35 percent were classified as having intellectual disability (i.e., IQ less than 70). The proportion of boys and girls with intellectual disability were similar. Across race/ethnicity, the proportion of Black children with intellectual disability continued to be higher than White or Hispanic children. The reason for this disparity may be related to inequities in ascertainment or access to services. Across neighborhood-level income, previous ADDM studies reported a robust association between socioeconomic indicators in autism, but the latest ADDM report did not show a consistent pattern, a finding that requires additional analyses.



Over the years, the overall median age of earliest autism diagnosis has not shown much change. Some may interpret this to mean that there has been no progress in early identification. However, this trend may be due to the different metrics used to measure early autism identification. While the median age of diagnosis shows very little change over time, cumulative incidence of identification by 48 months has quadrupled. Additionally, cumulative incidence metrics reveal racial disparities that are masked when using a median age metric.

Dr. Maenner then reviewed data for four-year-old children. Autism prevalence was lower among four-year-old children than eight-year-old children in 10 of the 11 sites (with California as the exception). Overall prevalence was 1.7 percent. Data on eight-year-olds show that many children were not identified with autism until age five or later; therefore, it was surprising that the number of children with suspected autism was too small to make a significant impact on the gap between prevalence estimates. Autism prevalence among four-year-old children showed a different pattern across race/ethnicity than among eight-year-old children. White children showed the lowest autism prevalence as compared to other race/ethnicity groups. There was a higher prevalence among Hispanic four-year-old children in five of the 11 sites. The cumulative incidence of early autism identified by 48 months has increased since 2014. Importantly, some sites show more early autism identification among four-year-old children, but some do not—a trend that will be interesting to monitor in the future.

Dr. Maenner reviewed future activities across the ADDM Network. In addition to their follow-up on 16-year-olds, which includes health and transition data, they are also preparing a report on the estimate of children who might meet the definition of profound autism. They are also conducting a pilot study across some of their sites using data linkages for efficient state-wide autism prevalence estimates. This can help generate estimates for communities that have never had local data. The ADDM Network is also continuing their surveillance for 2020. He welcomed the Committee to review the latest ADDM Network data and [reports](#).

### **Committee Discussion**

Dr. Joseph Piven asked about the potential for confounds and bias when ascertaining data through the school system. Dr. Maenner answered that bias should be a core part of interpretation in any public health surveillance system. Not every child is in an area where they receive school services, which is why it is critical to link multiple sources of medical, educational, and other service data. This is an important step in ensuring every child in a geographic area is included. The ADDM Network collaborates with the ED's Office of Special Education Programs (OSEP) and their privacy office to ensure public health surveillance meets privacy requirements. One challenge has been community services, which vary from site to site. There is variation across wealthy and poor neighborhoods. These variations may reflect who is being identified and the practices being used. Dr. Piven asked if there is a need to do a door-to-door study to validate these rates. Dr. Maenner responded that a study to validate these prevalence rates across sites may be interesting, but also extraordinarily expensive. The more useful question is to determine if the surveillance shows that community providers are effectively identifying children. The goal of the ADDM Network is to use data to inform practice.

Ms. Myrick asked how ADDM sites are selected and if there are plans to expand the network. Dr. Maenner answered that site selection is a competitive process, with four-year cooperative agreements. It is an open competition, and they fund as many sites as they have resources to support. Recent changes to surveillance efficiencies have enabled them to do more than previous years. They would like to expand to all states but would need the resources to do so.

Ms. Gassner asked if the 16-year-old population is the same as the previously identified eight-year-olds. She asked if there have been efforts to reduce selection bias, given that many children who have co-occurring intellectual disability or Down's syndrome may not be given an autism diagnosis. Some children may be given a specialized education plan without being categorized as having a specific type of disability. She also asked if there is any effort to identify those diagnosed in adulthood. Dr. Maenner answered that the new report would include children from the same population. They will be able to identify children who have received an autism diagnosis since age eight. In terms of reducing selection bias, the challenge is that sites vary in their service and education infrastructure and children may receive autism services from different programs. They try to link all available sources. They do track select co-occurring conditions when documented, and it would be interesting to determine if the proportion of children with those conditions changed over time. They are interested in learning more about the prevalence of autism in adults and post-high school outcomes. However, the ability to do this is based on currently available resources. While it is challenging to include adults, there are positive steps in that direction with the inclusion of 16-year-old follow-up data.

Dr. Wexler asked how the ADDM Network uses the ED OSEP publicly accessible state data. Dr. Maenner answered that data is collected from state and local entities and that they collaborated with OSEP's privacy office to outline a data use agreement between entities. They do not get data from a federal source at this point. They do need identifiable information to securely link state data with other data, such as Medicaid services. The identifiable data is subsequently destroyed, and the analytic extract is de-identified. They use OSEP's Child Count data for their data visualization site for different autism data sources. This allows users to compare data for their state, such as autism prevalence Medicaid usage. Dr. Wexler advised Dr. Maenner to be aware that their data on three- to -five-year-old children is oddly skewed because states are allowed to report children as developmentally delayed as opposed to reporting them under a disability category. He offered the support of his team to help facilitate any analyses the ADDM Network would like to explore with ED data.

Ms. Prince addressed the challenge of collecting accurate data on adults with autism. It is hard to advocate for adults on the autism spectrum on the state level without having prevalence data. She asked if there is anything that prevents the CDC from conducting more research on this population. Dr. Maenner said that there is significant interest in expanding the program to include adults, both in surveillance and research programs. Historically, programs have been anchored in a focus on children and they are moving to include adolescents. The [Study to Explore Early Development \(SEED\)](#) research program may have a cohort that is starting to reach adulthood. It is difficult to wait for longitudinal data in real time. The ADDM Network activities are defined by Congressional language. They would take any opportunity given to expand into including adults.

Dr. Robertson concurred that a focus on adults is important. The U.S. is significantly behind the curve as compared to other countries, such as the United Kingdom (U.K.) or Australia, in tracking adults and their needs. He wondered if practices and approaches they are using could be adapted for monitoring adults in the U.S. He asked if there were promising and best practices from the ADDM Network and in the SEED program that could be applied to needs assessments focused on autistic adults. Dr. Maenner said that the idea of looking to international efforts is an excellent idea in terms of becoming familiar with population-level surveillance efforts. In terms of the ADDM Network's program informing needs assessments, the goal of public health surveillance is to inform practice. Surveillance is done at a population-level and to identify disparities or other trends that warrant further investigation. The SEED program pivoted in the last year-and-a-half to conduct a COVID-19 impact study to learn how their families have been affected by the pandemic. There is much that can be done to understand people's

needs. Dr. Robertson clarified that other countries have published their studies on adult autism prevalence and needs assessment. For instance, the U.K. conducted a needs assessment for autistic adults across the entire country, expanding from the local level to the national level, which has driven much of their efforts to improve service systems for autistic adults. Connecting with other countries may be a natural extension of both the ADDM Network and the SEED program as they shift into older children as they age.

## **The Lancet Commission: An International Multi-Disciplinary Group's Perspective on the Future of Healthcare and Clinical Research in Autism**

**Catherine Lord, Ph.D.**, George Tarjan Distinguished Professor of Child and Adolescent Psychiatry, UCLA David Geffen School of Medicine, Semel Institute of Neuroscience and Human Behavior

Dr. Catherine Lord co-chaired *The Lancet* commission on the future of care and clinical research in autism with Dr. Tony Charman. The commission developed the report called [\*An International Multi-Disciplinary Group's Perspective on the Future of Healthcare and Clinical Research in Autism\*](#). The international committee of 32 members reflected a range of different disciplines, countries, ethnicities, and perspectives. They conducted three in-person meetings, including two conferences about international approaches to autism. The committee was divided into subcommittees responsible for outlining certain sections and recommendations of the report. The final draft of the report was then reviewed by three external reviewers, revised, and published in December 2021. There is also an effort to produce a plain language version by spring 2022.

Dr. Lord expressed that the international group recognized the urgency of addressing ways to improve the lives of all people with autism and their families. Current scientific data provides valuable information but has little direct effect on the practical strategies to improve supports and interventions. Part of the challenge is that autism is heterogeneous. Although there is an understanding that autism is a neurobiological condition, the idea that understanding genetic mechanisms would inform practical answers has not been realized. The committee aimed to call attention to the clinical challenges that are unlikely to be solved through biomedical solutions in the near future. Their recommendations were therefore focused on what would make a difference within the next five years. The committee recommends approaches to improve mental and physical health of autistic people through the strengthening of supportive systems. These approaches must include the immediate- and long-term effects on quality of life for both autistic people and their families.

The committee also acknowledged that affecting change within complicated federal systems is a challenge. Differences in how autism manifests both between individuals and across the lifespan also furthers these challenges. People may need different supports across the lifespan. The committee recognized that many autistic people have strengths that contribute to society and that it is important to value autism in neurodiversity.

Across the lifespan, the combination of different experiences and biological risk can result in even greater challenges. For instance, restricted access to employment may increase risk of mental health challenges. There is evidence of approaches that can help improve these challenges, in terms of changing or adapting environments and teaching skills. Strategies include early intervention, naturalistic interventions to promote parent-child interaction, and psychopharmacological treatment for co-occurring conditions.

Research typically compares interventions to treatment as usual rather than comparing different treatments. Therefore, there is a lack of information on which treatments might be the most effective for different populations or for the same population at different timepoints. Understanding this information would save researchers time in developing culturally appropriate interventions that are adapted to the needs of different communities.

One important question that the committee addressed was how to personalize care in autism. In the report, they proposed a stepped care personalized health approach. Most stepped care approaches are created from the point-of-view of a provider, rather than an individual. There has been a push to develop an assessment tool that identifies autism at any age, any level, anywhere. Autism is not a disease, but a condition that causes impairments across a wide range of daily living experiences. They proposed that stepped care should consider the profile of the individual with autism, their family, resources, and community to understand the burden, needs, strengths, and challenges. A diagnosis of autism relays very little about individual needs. The stepped care personalized approach considers individual factors such as safety, age, preferences, symptom severity, and the effect of symptoms on practical life. It considers family factors such as independence, culture, stigma and acceptance, environment, schedules, access to services, and resources. It must identify priorities and preferences for practical interventions.

In terms of research, there is a need to understand which interventions are effective in different populations and environments, at different times, and across different intensities and lengths of time. There is a need for practical solutions. It is necessary to understand the different components involved in implementation and to recognize under what conditions an intervention will support meaningful change. For example, it is important to know how many hours a week of a certain therapy a child really needs. There is also a need to understand what is financially feasible for systems and families and differences in services across schools and areas with different socio-economic profiles.

The committee also addressed inequities in medical and service provisions. Ninety-five percent of children with developmental disabilities under age five live in low-and-middle-income countries (LMIC). Key recommendations included a need for more responsive service systems, integration of evidence-based interventions into care models, high quality research conducted in LMICs, and equitable access to services for underserved and minority groups. Underserved and minoritized populations include girls and women, the LGBTQ population, racial/ethnic minorities, and individuals who are minimally verbal. There is a need for formal medical documentation through governmental health care, education, and social care systems. There is also a need for integration across systems. Research should prioritize clinical practice that increases the understanding of what interventions work for whom and when. Sample sizes need to be large enough to have meaningful results. Furthermore, there is a shortage of service providers, and those without professional training are often called upon to deliver care to autistic individuals.

The committee proposed the term “profound autism” as an administrative term. The term highlights the needs of autistic people with severe intellectual and communication disabilities who cannot speak for themselves, need extensive care throughout their lives, and cannot take care of their adaptive daily needs. IQ or limited language are used as criteria because there are data available from large samples that indicate the complex, extensive needs of this population. The committee also looked at data from three cohorts that showed that the proportion of autistic individuals who would meet these criteria ranged from 18 to 48 percent. The term was suggested to be a voluntary designation intended to spur the clinical and research communities into prioritizing the needs of the most vulnerable and underserved among those with autism.

Forty-eight percent came from an early diagnosis study conducted over 30 years ago and does not reflect who is currently getting diagnosed. One interesting lesson learned from their Scandinavian cohort was that their registries showed very few individuals falling under the criteria for profound autism. These children were not being entered into the registry because it was populated by physicians and the children were receiving services through a different program. The separate early childhood data indicated that the estimated prevalence of profound autism was approximately 18 percent. Importantly, these children are also being lost in research efforts. Therefore, the goal of developing the term “profound autism” was to begin identifying this traditionally excluded population and to determine what can be done to improve the quality of their lives.

Dr. Lord summarized that the committee recommends personalized, developmentally target interventions over the life course; implementation science and community-based effectiveness trials; cost-effectiveness research to support decision making; engagement of stakeholders in intervention development and deployment; culturally adapted and tailored intervention approaches; and the use of more advanced research designs to answer complex questions. Individuals with autism can reach certain levels of independence and how much support they receive will make a difference. Moving to identify all individuals with autism can help improve services and quality of life, and there is a need to work together towards this common goal.

### **Committee Discussion**

Ms. Gassner asked about the representation of autistic researchers and of people of color within the committee. Dr. Lord answered that there were three people on the committee who identified as autistic and were involved in advocacy. There were two African American individuals, two Latinx individuals, and representation from other non-White races/ethnicities. The group particularly benefited from the perspectives of a committee member who is an individual with autism and mother to autistic children.

Dr. Tager-Flusberg commented that there are effective behavioral interventions for treating children with autism. These interventions may not work for all children, but there is an understanding that they work for most. She agreed that the critical questions were exactly how, when, and where these interventions worked best. The last request for applications (RFA) from the Autism Centers for Excellence (ACE) did not mention treatment. The committee’s call for large-scale studies to address behavioral interventions from a personalized approach is a critical recommendation. Much is being invested in personalized interventions that target genetic therapies that will not be realized for a long time.

Ms. Crane added that it is important to include autistic self-advocates, and specifically those with high support needs, in future work. The Committee members who have high support needs have expressed

their concerns that the profound autism designation may obscure their own needs. Dr. Lord said their committee included parents of individuals with severe intellectual disabilities and autism, but not individuals with high support needs.

Dr. Johnson asked to what extent the committee discussed the interaction between the individual and systems. Individuals from diverse backgrounds experience the service system differently and it is important to conduct research through an intersectional lens. Dr. Lord agreed and said that the committee did not end up with representation from the systems perspective.

Dr. Alice Carter said that, in addition to determining the timing of interventions, it is also important to consider *who* is able to conduct the interventions. She appreciated the recommendation to not rely only on developmental psychologists and pediatricians. It is important to examine existing service systems to determine how to do a better job of quickly disseminating evidence-based interventions. Many people in the U.S. in lower-resourced communities cannot access services. Dr. Lord responded that the committee discussed task-sharing in terms of determining who can provide services and supports.

Dr. Halladay asked Dr. Lord to identify a few components of their recommendations that the Committee should include in the updated *Strategic Plan*. Dr. Lord said that large, diverse, multi-site studies are necessary to determine who can benefit from which interventions. There also needs to be support for comparative treatment studies and efforts to determine which factors are most impactful for treatment response at different ages.

Dr. Gordon encouraged Committee members to read *The Lancet* report and to consider which specific, recommendations could be incorporated into the updated *Strategic Plan*. The NIMH can put mechanisms in place to facilitate larger studies that compare treatments. The ACEs currently do this to some extent.

Dr. Wang reiterated that the report did not adequately address issues of intersectionality but there is a key message box on page one of the report that could be used as a springboard for those who would like to continue discussion on it.

## **IACC Committee Business (continued)**

**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

### **Summary of Advances**

Dr. Daniels reminded the Committee that they are working on the *2020 Summary of Advances*. Several Committee members submitted nominations. After a review of those nominations, OARC will send ballots for Committee members to vote on their top 20 articles. The final top 20 articles will then be summarized for the report. The purpose of this discussion is to refine the list of nominations.

Dr. Gordon said that this discussion was to address some nominations that were of concern and to allow nominators to highlight their submissions. The Question areas were taken from the current *Strategic Plan*. The 2021 process will use the revised set of Question areas after the *Strategic Plan* is updated.

## Question 1: Screening and Diagnosis

There were two articles under Question 1 that were of concern because they may not be specific enough to ASD. The first was *Trends in Pediatrician's Developmental Screening: 2002-2016* and the second was *Validation of the NIH Toolbox Cognitive Battery in Intellectual Disability*.

Dr. Gordon highlighted the *Early Detection for Better Outcomes: Universal Developmental Surveillance for Autism across Health and Early Childhood Education Settings* because it was piloted in a very large group of children and showed a higher predictive value than the current Parents' Evaluation of Developmental Status (PEDS) assessment tool. He also highlighted the *Validation of the Developmental Check-in Tool for Low-Literacy Autism Screening*, which was conducted in real-world settings with children from low-income and racial/ethnic minority families in which English was not the primary language.

Dr. Wang asked what merits being designated as an advance. Dr. Gordon responded that ideally it is something addressing what the Committee would like the public (i.e., Congress) to know about because it is either promising or definitive enough to follow-up on. He advised Committee members to avoid articles that are reviews or that are too small to provide definitive answers. Additionally, articles should be specific to autism.

Dr. Carter suggested that, given concerns with sensitivity in screening, they may want to wait for more definitive findings before including these articles. She believes measures can be pushed out too soon and may not work as well as they should. She highlighted the articles that speak to disparities as particularly important, such as *Timing of the Diagnosis of Autism in African American Children*.

A poll was conducted to determine if the two studies of concern should be included in the ballot, given that they are not specific to ASD. There were a significant number of "no" votes (70 percent) for the first study and mixed responses for the second. Dr. Gordon suggested including the second study in the ballot but not the first.

## Question 2: Biology

There were no articles of concern under Question Two.

Dr. Gordon said that there were a number of articles on genes associated with autism and their biological consequences. He highlighted the *Autism-associated SHANK3 Mutations Impair Maturation of Neuromuscular Junctions and Striated Muscles* and the *Trajectories in Symptoms of Autism and Cognitive Ability in Autism from Childhood to Adult Life*.

Ms. Crane agreed that the study on motor function is critical because many who are non-speaking also have significant motor planning concerns. She highlighted the *Sleep Onset Problems and Subcortical Development in Infants Later Diagnosed with autism Spectrum Disorder* for its focus on an important concern for many in the community. She asked for clarification on why the longitudinal study on autism outcomes and cognitive function was under this Question area. Dr. Daniels clarified that it fit the criteria for Question 2.

Dr. Wang also agreed that motor issues and sleep were important areas to study. He generally does not consider any research that focuses on a single gene to have broad significance, especially when those genes account for a small fraction of autism. There are some exceptions, such as the FMR1 gene for Fragile X because it interacts with so many other genes that are also implicated in the underlying biology of autism. Dr. Gordon said that he shared the skepticism about the general relevance of single genes and added that SHANK3 may be similar to FMR1 because it clearly creates a syndrome.

Dr. Daniels clarified that the nominations from OARC were intended to help jump start the process, as the Committee was not in session in 2020.

### **Question 3: Risk Factors**

There were no articles of concern under Question Three.

Dr. Gordon highlighted two articles that involve environmental risk factors: *Environmental Epigenetics of Diesel Particulate Matter Toxicogenomics* and *Gestational Exposures to Phthalates and Folic Acid, and Autistic Traits in Canadian Children*.

Ms. Gassner appreciated the article *Inherited Risk for Autism through Maternal and Paternal Lineage* for its potential to provide more intensive parental support in the early intervention years. Autistic parents may especially struggle with multitasking in the first years of their child's life. Dr. Gordon said that this was helpful insight.

### **Question 4: Treatments and Interventions**

There were three articles of concern under this question area. The first, *Interventions to Address Health Outcomes Among Autistic Adults*, was a systematic review, and the second, *Project AIM: Autism Intervention Meta-analysis for Studies of Young Children*, was a meta-analysis. Systematic reviews are generally not included because they do not address a novel finding. A meta-analysis, however, can reveal a new result or solidify understanding about the impact of a result. Dr. Gordon invited the nominator to discuss the article.

Dr. Halladay nominated the Project AIM study and said that the article looked at vast amounts of data to highlight the proximal and distal factors in behavioral interventions for autism that need more attention. The findings of this article influenced some of her comments on the *Strategic Plan* updates. The article was also considered "outstanding" by the Autism Society for Autism Research.

Dr. Taylor agreed that the Project AIM study brought new information from the studies it included. She also suggested that the systematic review should not be included in the ballot but that the meta-analysis should. Dr. Elaine Cohen Hubal added that systematic reviews may glean new insights, and sometimes studies are labeled as systemic reviews when they are not.

Ms. Gassner nominated the systematic review. The article focused primarily on interventions as experienced by autistic adults and thought the narrowness of the focus may fit under the nomination criteria. However, she does understand the justification for not including systematic reviews in general. She added that this study examines issues related Medicaid/Medicare enrollment of people from ethnic/racial minority backgrounds.



A poll was conducted to determine if the first two studies of concern should be included in the ballot. A significant number of “no” votes (76 percent) were received for the systematic review and a significant number of “yes” (79 percent) were received for the meta-analysis.

The third article of concern under this question area was *Weight Management in Primary Care for Children with Autism: Expert Recommendations*. Dr. Taylor said that this study is a consensus statement on weight management, which is an important issue, however she was not sure if it fits the criteria.

Dr. Gordon suggested that the article *A Multisite Randomized Controlled Trial Comparing the Effects of Intervention Intensity and Intervention Style on Outcomes for Young Children with Autism* may be important. Ms. Crane concurred.

### **Question 5: Services**

There was one article of concern under this question area. *Undocumented Mexican Mothers of Children with Autism: Navigating the Health Care and Educational Service Systems* was of concern because of the small sample size.

Ms. Gassner reiterated her concern for not examining qualitative research as the can be a foundation for building larger studies. Dr. Gordon agreed about the concern and said that its inclusion in the *Summary of Advances* may be problematic.

Dr. Johnson said that another consideration was that there will likely be small sample size with this type of population because not many individuals will fit the inclusion criteria and not many will come forward to participate in research. Dr. Gordon agreed that this was a good point.

A poll was conducted to determine if this study should be included in the ballot. The majority of responses were “no” (65 percent).

Ms. Gassner highlighted the *Competitive Employment for Transition-Aged Youth with Significant Impact from Autism* study for its focus on employment outcomes but is concerned that Project SEARCH tends to choose individuals who are most likely to succeed. Dr. Gordon said that this is a trial that looks at Project SEARCH with ASD supports compared to treatment as usual.

### **Question 6: Lifespan Issues**

There were two articles of concern under this question area. The first, *Listening to the Autistic Voice: Mental Health Priorities to Guide Research and Practice in Autism from a Stakeholder Perspective*, was considered an information-gathering activity to set priorities. The second, *Changes in Access to Educational and Healthcare Services for Individuals with Intellectual and Developmental Disabilities During the COVID-19 Restrictions* was not considered specific to ASD.

Dr. Gordon highlighted the *Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder* article. This article defines an important need. He also highlighted *Defining Positive Outcomes in More and Less Cognitively Able Autistic Adults*, which was interesting because of its focus and may point to important treatment targets.

Ms. Prince asked how other efforts to provide adult services, such as those led by Madison House, may be included in the *Summary of Advances*. Dr. Gordon responded that she may nominate articles for the year that it was published and that they must be peer-reviewed.

Ms. Gassner highlighted *A Comparative Study of Autistic and Non-Autistic Women's Experience of Motherhood*, suggesting that it provided insights about parenting. She also highlighted the *Trends in Supplemental Security Income Payments to Adults with Autism* article, as it highlights issue related to poverty.

Dr. Taylor highlighted the *Social Capital and Autism in Young Adulthood* and the *Development and Psychometric Testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale* articles for their methodology.

A poll was conducted to determine if the two concerning studies should be included in the ballot. There were a significant number of "no" votes (66 percent) for the first article and mixed results for the second article. Dr. Gordon recommended that the second article be included in the ballot.

### **Question 7: Infrastructure and Surveillance**

There were no articles of concern under Question 7.

Dr. Gordon highlighted the three articles nominated by CDC articles because they characterized the latest surveillance data. He also highlighted a *Rhode Island Consortium for Autism Research and Treatment (RI-CART)* that pointed to high co-morbid medical and psychiatric conditions.

Ms. Gassner highlighted the *National and State Estimates of Adults with Autism Spectrum Disorder* article as a good advocacy tool to communicate the needs of autistic people.

Dr. Gordon encouraged Committee members to vote for between one and three articles in each question area, if possible.

Dr. Daniels said that the Committee will discuss the *2021 Summary of Advances* at the next Committee meeting.

Ms. Gassner suggested that a brief orientation meeting for new Committee members would be helpful to clarify what members are charged to do. Dr. Gordon said that a good time for this meeting would be before the next full Committee meeting so that new Committee members would feel more prepared for discussing the *2021 Summary of Advances*.

## Round Robin Updates

Committee members offered Round Robin updates.

Dr. Marvin mentioned that the application for the [ARDRAW Small Grant Program](#) has opened and applications are due February 25, 2022. SSA also held a State of the Science meeting to discuss [Lessons from SSA Demonstrations for Disability and Future Research](#), which is now available for free.

Dr. Halladay said that the [Autism Science Foundation Day of Learning](#) will be on March 30, 2022, and will be a hybrid event. They are also in process of reviewing new grants for post-undergraduates and have released a Request for Applications (RFA) for their undergraduate research program.

Ms. Gassner said that the [International Society for Autism Research](#) (INSAR) community collaborator's requests are set to launch on January 20, 2022.

## Closing Remarks and Adjournment

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

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

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

The next full Committee meeting is on April 13-14, 2022, and will be virtual.