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**Interagency Autism Coordinating
Committee (IACC)
Strategic Plan Update Meeting**

September 23, 2024



This meeting summary was prepared by Rose Li and Associates, Inc., under contract to the National Institute of Mental Health (NIMH). The views expressed in this document reflect both individual and collective opinions of the meeting participants and not necessarily those of NIMH. Contributions to this summary by the following individuals are gratefully acknowledged: Joshua Elmore, Christy Huffman.

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The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a virtual meeting on Monday, September 23, 2024, from 9:00 a.m. to 11:00 a.m. In accordance with Public Law 92-463, the meeting was open to the public. Shelli Avenevoli, Ph.D., Acting Director, National Institute of Mental Health (NIMH), chaired the meeting.

Participants

Shelli Avenevoli, Ph.D., Chair, IACC, NIMH; **Susan Daniels**, Ph.D., IACC, NIMH; **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont Larner College of Medicine; **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara Tucci, M.D., M.S., M.B.A., FACS); **Sam Crane**, J.D., Independent Consultant; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Rebecca Dzubow**, M.P.H., Environmental Protection Agency (EPA); University Bloomberg School of Public Health; **Thomas Frazier**, Psy.D., Autism Speaks; **Dena Gassner**, M.S.W., Adelphi University; **Morénike Giwa Onaiwu**, Ph.D., Autistic Women & Nonbinary Network; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Kristi Hardy**, Ph.D., M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.); **Elaine Cohen Hubal**, Ph.D., EPA; **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); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS)(representing Richard Woychik, Ph.D.); **Leah Lozier**, Ph.D., U.S. Department of Housing and Urban Development (HUD); **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Matthew Miller**, Ph.D., M.P.H., U.S. Department of Veterans Affairs (VA); **Justin Mills**, M.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A.; **Amber Parker**, M.J.M., U.S. Department of Justice (DOJ); **Sunny Patel**, M.P.H., SAMHSA; **JaLynn Prince**, B.F.A., Madison House Autism Foundation; **Camille Proctor**, The Color of Autism Foundation; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration (HRSA); **Karyl Rattay**, M.D., M.S., FAAP, Centers for Disease Control and Prevention (CDC); **Scott Michael Robertson**, Ph.D., U.S. Department of Labor; **Stuart Shapira**, M.D., Ph.D., CDC; **Ivanova Smith**, B.A., University of Washington; **Hari Srinivasan**, B.A., Vanderbilt University; **Jodie Sumeracki**, B.A., Centers for Medicare & Medicaid Services (CMS); **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna Tschiffely**, Ph.D., U.S. Department of Defense (DOD); **Paul Wang**, M.D., Simons Foundation; **Emily Weaver**, U.S. Department of Education; **Nicole Williams**, Ph.D., U.S. DOD

Welcome, Roll Call, and Announcements

Shelli Avenevoli, Ph.D., Acting Director, NIMH; Chair, IACC

Susan Daniels, Ph.D., Executive Secretary, IACC; U.S. Department of Health and Human Services (HHS) National Autism Coordinator; Director, Office of National Autism Coordination (ONAC), NIMH

Dr. Shelli Avenevoli welcomed participants to this special meeting of the IACC. Dr. Avenevoli noted that the purpose of the meeting was to discuss and receive feedback on the draft *2024 IACC Strategic Plan Update*, which focused on conditions that co-occur with autism. She noted that IACC members will vote at the end of the meeting on whether to approve the report.

Dr. Susan Daniels thanked the many people who contributed to the draft, including over 1,200 members of the public who submitted responses to [the Request for Information \(RFI\) on co-occurring conditions](#), the physical and mental health working group of the prior IACC, and the previous IACC itself.

Legislative Update

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

Dr. Daniels provided relevant legislative updates. The Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019, which authorizes the IACC, expires on September 30, 2024. The House of Representatives and Senate currently each have their own version of a bill, the Autism CARES Act of 2024, which would reauthorize IACC funding.

Dr. Daniels explained how the timing of the reauthorization impacts the Committee. If reauthorization occurs prior to expiration of the current IACC, the terms of current IACC members will be extended for 180 days to allow for the completion of pending reports. If reauthorization does not occur until after the current IACC sunsets, IACC efforts will pause until reauthorization occurs. If this delay is brief, then member terms would be extended to allow for the completion of pending reports following reauthorization. Dr. Daniels noted that funding for most federal autism research and services will not be impacted by the delay, including efforts by the Office of National Autism Coordination (ONAC) and the Federal Interagency Workgroup on Autism (FIWA). Following reauthorization, ONAC will post a call for nominations for new IACC members.

Current IACC members who have only served one term are eligible to be nominated again. Following the nomination process, the Secretary of Health and Human Services (HHS) will select a combination of new and previous members to form the new Committee.

2024 IACC Strategic Plan Update Discussion

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

The *2024 IACC Strategic Plan Update* presents information on a variety of conditions that commonly co-occur with autism and identifies gaps in research and services for improving health outcomes. The previous IACC identified these conditions as an area of importance for further consideration and convened a working group to hold workshops and begin drafting a report. This work was paused in 2019 after the members' terms expired. In October 2023 the current IACC voted to focus the 2024 IACC Strategic Plan on co-occurring conditions, building on the work of the previous committee. To inform the plan update, IACC issued the RFI in January 2024 to collect public feedback on the topic of conditions that co-occur with autism. This report also highlights IACC activities that provided the committee with information on research and services. ONAC completed an initial draft report in August 2024. ONAC implemented feedback from the IACC and circulated a revised draft report in September 2024. This is the document being discussed in this meeting.

If the IACC approves the draft report, ONAC will work to prepare the final report with an anticipated publication in December 2024. If the IACC does not approve the report, ONAC will continue to revise and will share the revised draft at a later date depending on when the Autism CARES Act is reauthorized.

Feedback from IACC members to the report was highly positive. Dr. Daniels requested throughout the discussion that IACC members send her and ONAC references related to the additional content that they were recommending be included in the draft report. She also stated ONAC will seek out additional literature to support suggestions made by Committee members.

Chapter 1: IACC Interest in the Impact of Co-Occurring Conditions

Chapter 1 details the activities of the IACC Working Group for Improving Health Outcomes for Individuals on the Autism Spectrum. It also highlights recent IACC activities related to co-occurring conditions.

Discussion

Ms. Ivanova Smith reiterated the importance of considering co-occurring conditions as related to autism, as there may be a tendency to overlook these conditions among autistic people.

Chapter 2: Community Perceptions of Research and Services Needs

Chapter 2 focuses on responses to the RFI. It includes information on respondent demographics, types and impacts of co-occurring conditions, perceived needs in the research space; services and supports needs; and the impact of COVID-19 on the autism community.

Discussion

Ms. Gassner, Dr. Julie Taylor, and Ms. Yetta Myrick noted that, in addition to the information on systems navigation in the report, a statement should be included which explicitly states that systems navigators are needed only because systems are so inaccessible to patients and family members. Dr. Morénike Giwa Onaiwu noted that systems navigation needs to be implemented in a culturally appropriate manner.

Chapter 3: Co-Occurring Physical Health Conditions

Chapter 3 focuses on physical conditions that often co-occur with autism or have important consequences on the health of those with autism, including epilepsy, gastrointestinal disorders, sleep disorders, sensory and motor challenges, Ehlers-Danlos Syndrome, dysautonomia, immune system dysfunction, and impacts of co-occurring physical health conditions (e.g., epilepsy, sensory and motor challenges) during midlife and older adulthood.

Discussion

Mr. Hari Srinivasan noted that a section on movement disorders that frequently co-occur with autism should be added to the draft report. Dr. Daniels suggested that movement disorders could be added to the sensory and motor challenges section of Chapter 3. Mr. Srinivasan suggested that movement disorders should have its own section, as there may be underlying motor issues. Dr. Giwa Onaiwu suggested additional content needed for the section on Alzheimer's disease and related dementias.

Dr. Giwa Onaiwu suggested that polycystic ovary syndrome (PCOS) be added to the report. Dr. Daniels noted that she did not believe that reproductive health issues were included in the draft, but that a section on reproductive health issues among autistic people might be warranted.

Mr. Srinivasan suggested that the draft should include more information about chronic health issues prevalent among autistic people such as obesity and diabetes. He also noted that some medications (e.g., risperidone) commonly used to manage aspects of autism can cause weight gain and increased blood sugar. Dr. Daniels noted that epidemiological studies highlighting the relationship between autism and chronic health conditions were included in the draft report, but that she was unsure if obesity and diabetes were explicitly mentioned. Ms. Sam Crane suggested that polypharmacy be discussed in both physical and mental health chapters. Ms. Gassner noted that it may also be prudent to add information about the inconsistent and unexpected ways in which individuals with autism respond to medications. She noted that polypharmacy in those with autism often arises from taking secondary medications to treat side effects from primary medications.

Dr. Scott Robertson noted that the references in the sleep conditions section of the report appear to be limited to studies of children. He asked if any literature addressed these conditions in adults. Dr. Daniels stated that she believed that the report included available literature on the topic, but that ONAC would check to make sure nothing relevant was missed.

Ms. Smith suggested including co-occurring birth defects, such as club feet and Fetal Alcohol Spectrum Disorders (FASD). Dr. Giwa Onaiwu suggested that ONAC might consider adding information about HIV exposure in utero, as some antiretroviral drugs increase the risk of having a child with developmental disabilities.

Dr. Giwa Onaiwu also noted that skin conditions such as eczema, dermatosis, and psoriasis can exacerbate skin picking and some self-injurious behaviors (SIB) and should thus be added to the draft report. Dr. Daniels said that ONAC will examine what has been included in the section on immune system dysfunction and can add these conditions.

Ms. Lindsey Nebeker and Dr. Giwa Onaiwu suggested that misophonia and osmophobia be added to the draft report. Ms. Gassner recommended that light sensitivity also be added.

Chapter 4: Co-Occurring Mental and Behavioral Health Conditions

Chapter 4 focuses on mental and behavioral health conditions that often co-occur with autism or have important consequences on the health of people with autism. These include: anxiety disorders, attention-deficit/hyperactivity disorder (ADHD), catatonia, depression, obsessive-compulsive disorder (OCD), SIB, aggressive behavior, emotion dysregulation, suicidality, bipolar disorders, feeding and eating disorders, gender dysphoria, pathological demand avoidance (PDA), schizophrenia, substance use disorder (SUD), Tourette syndrome and other tic disorders, trauma and post-traumatic stress disorder (PTSD), and wandering and elopement behaviors (WAEB).

Discussion

Ms. Gassner noted that the content in the draft report related to trauma focused mostly on adverse childhood experiences (ACEs). She stated that many adults with autism experience repeated exposure to traumatic events in adulthood, and thus that information about these repeated exposures should be added to the report. Dr. Daniels affirmed that this is an important area that should be explored in more depth. Ms. Prince noted the need for adult diagnostic services, which Dr. Daniels states is covered in another chapter. Dr. Jennifer Johnson discussed the importance of differential diagnosis and ensuring that autistic individuals are also able to receive diagnoses for co-occurring mental health issues.

Ms. Crane noted that cognitive behavioral therapy (CBT) is mentioned in several places in the draft report. She stated that some evidence suggests that CBT may be less effective among autistic people compared to neurotypical people. She suggested that the report acknowledge that further research may be needed to identify modified CBT approaches or new treatment models that are effective autistic people.

Ms. Crane also noted that the use of the phrase “transgender female” in the gender dysphoria section is ambiguous. She cited past examples from the literature wherein “transgender female” referred to people who were assigned female at birth, whereas modern usage of transgender female refers to those who were assigned male at birth. She suggested use of transgender women or transgender girls to add clarity. Dr. Daniels stated that the report was

likely using whatever language had been used in the references that were being cited, but that ONAC would go back to this section and edit to ensure clarity.

Chapter 5: Co-Occurring Intellectual, Communication, Developmental, and Learning Disabilities

Chapter 5 focuses on intellectual, communication, developmental, and learning disabilities, as well as high support needs.

Discussion

Dr. Alycia Halladay noted that although a table on genetic conditions that are associated with autism was included in Chapter 5, many of these genetic conditions have effects on both physical health (Chapter 3) and mental health (Chapter 4). She stated that this should be highlighted in the report. Dr. Daniels asked Dr. Halladay and Dr. Paul Wang how much information the table on genetic conditions should capture. Dr. Halladay and Dr. Wang stated that attempts to be entirely comprehensive would likely be futile due to the number of conditions in the literature and the constant updates that occur in the field. IACC members agreed to have the report link to outside resources for additional information such as [Simons Foundation Autism Research Initiative \(SFARI Base\)](#), [Alliance for Genetic Etiologies in Neurodevelopmental Disorders and Autism \(AGENDA\)](#), and [Combined Brain](#).

Dr. Helen Tager-Flusberg noted that the report should include more information on receptive language difficulties, as these difficulties are common in those who are minimally speaking or non-speaking. Dr. Daniels stated that ONAC will confer with Dr. Tager-Flusberg to ensure that this topic is addressed adequately. Dr. Alice Carter added that toddlers with both receptive and expressive communication delays have increased mental health challenges.

Ms. Smith suggested that more information about body language and non-speaking communication be added to the draft report. She stated that the attempts of non-speaking individuals to communicate are sometimes misinterpreted as challenging behaviors. Dr. Daniels noted that this potential misinterpretation is included in the section on SIB, but stated that more information could be added to Chapter 5 if relevant references can be found. Ms. Gassner also suggested including information about selective mutism, as verbal autistic people may have trouble communicating when under duress.

Dr. Giwa Onaiwu noted that the report should highlight the historic use of labels such as intellectual disability and conduct disorders to marginalize and segregate people of color. Additionally, she stated assessing cognition without spoken language is challenging. Dr. Daniels affirmed the importance of including this information.

Mr. Srinivasan suggested that the draft report recommend further research into noninvasive brain computer interfaces (BCI) for aiding in communication. Current BCI technology only focuses on requesting basics.

Ms. Crane appreciated the careful balance in the section on high support needs.

Dr. Daniels notes that ONAC was surprised to find the lack of available data on the prevalence of learning disabilities in those with autism. She requested that IACC members send any references that they may know of related to this topic.

Chapter 6: Health Care Service Provision

Chapter 6 focuses on accessibility of health care, patient-provider interactions, considerations for individuals with complex and high support needs, promoting equity and reducing disparities, the impact of COVID-19, and the activities and initiatives of relevant federal agencies.

Discussion

Ms. JaLynn Prince noted that the report should recommend that more providers be trained to diagnose adults with autism, as she has observed a large surge in the need for such services. Dr. Jennifer Johnson also noted the importance of differential diagnosis between autism and co-occurring mental health disorders. Dr. Daniels stated that information about diagnosis and recommendations for further training for adult diagnosis and differential diagnosis could be added to this chapter.

Dr. Giwa Onaiwu noted that in addition to highlighting provider training, the report should address provider compensation. She stated that direct support professionals (DSPs) are often cited as being incredibly helpful for many families, but the wages for DSPs are not competitive enough to offset the high attrition for these roles. Dr. Daniels noted that the Administration for Community Living (ACL) and Health Resources and Services Administration (HRSA) provided comments on the draft report; ONAC will seek further guidance from ACL and HRSA related to this topic.

Ms. Gassner suggested that information related to autistic burnout and its associations with poverty and reporting mandates be added to the draft report.

Ms. Gassner also suggested that the report include information on trauma-informed dental care. Many autistic people require nitrous oxide or sedation to receive dental care, and the cost of this anesthesia is not always covered by insurance. Dental procedures that are often considered cosmetic may also impact on social and physical health; and such cosmetic procedures are often not covered by insurance. Ms. Prince noted that rural areas often lack dental providers with specialized training in working with autistic people. She suggested that the report recommend further research into services that can help serve this need, such as mobile dentistry services, training opportunities, or patient navigators that specialize in dentistry.

Dr. Johnson discussed the importance of trauma-informed care. She also suggested that the draft report recommend further research on tools that individuals with autism with intellectual and developmental disabilities can use to communicate their health needs to their providers. She has been working with a program that has developed related materials and will determine if her team has published in this area.

Dr. Robertson suggested including literature about additional challenges autistic people and parents face in systems interactions.

Introduction and Conclusion

The goal of the introduction is to provide background on why the IACC considers co-occurring conditions to be an important area for research. It also addresses any themes that run across multiple chapters. The conclusion provides a summary of the report content and lays out a path for future research in this area.

Discussion

Ms. Gassner noted that all co-occurring conditions discussed can impact employment and education outcomes, but the report currently limits this discussion to physical conditions. She noted that because access to many subsidized services is based on income, many individuals with autism who do seek full time employment lose access to these services. She also suggested further emphasizing the costs of lack of supports for daily living (e.g. financial, physical, cognitive). Dr. Daniels noted that the draft report does include some information about the impacts of social determinants of health on health outcomes, but this information could be expanded.

Ms. Prince noted that the framework of neurodiversity and associated terminology are important to many members of the autistic community. She stated that the report currently does not define or use this term, which may be interpreted as a significant omission. Dr. Daniels suggested that neurodiversity and associated terminology will be covered in the introduction.

Dr. Carter suggested that the report clearly state that it is not intended to be comprehensive and should link to additional information and resources.

Dr. Daniels stated that this is the first time so many conditions have been included in one document, and expressed hope that it will be a useful reference for the autism community.

2024 IACC Strategic Plan Update Vote

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

IACC members voted on the approval of the *2024 IACC Strategic Plan Update*. The first question was: "Given today's discussion, are you comfortable with voting to approve the *2024 IACC Strategic Plan Update* today?" 78% of members voted yes. The second question for the vote was: "Do you approve the *2024 IACC Strategic Plan Update* (with any revisions discussed today)?" 86% of members voted to approve the report (pending the edits discussed during this meeting).

Dr. Daniels noted that a strong majority approved of the report, and thus this iteration of the report would move forward. She also noted that, depending on when the Autism CARES Act is

reauthorized, ONAC may reach out to individuals who provided comments during this meeting to make sure that edits made to the report address member feedback.

Closing Remarks and Adjournment

Shellie Avenevoli, Ph.D., Acting Director, NIMH; Chair, IACC

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

Drs. Avenevoli and Daniels thanked the past and current IACC, the Improving Health Outcomes Working Group, and ONAC staff for their instrumental work on this draft report. IACC plans to publish the report in December of 2024. IACC will place a call for nominations for the new IACC committee within 4-6 weeks after reauthorization of the Autism CARES Act.