



## **Interagency Autism Coordinating Committee (IACC)**

### **Strategic Plan Working Group Meeting**

**July 13-14, 2022**

*July 28, 2022*



This meeting summary was prepared by Rose Li and Associates, Inc., under contract to the National Institute of Mental Health. 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 is gratefully acknowledged: Octavia Martin, Dana Carluccio

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a virtual working group meeting on Wednesday, July 13, 2022, from 1:00 to 5:00 p.m. ET and Thursday, July 14, 2022, from 1:00 p.m. to 5:00 p.m. ET. In accordance with Public Law 92-463, the meeting was open to the public. Susan Daniels, Ph.D., Director, Office of Autism Research Coordination (OARC), National Institute of Mental Health (NIMH) and Acting National Autism Coordinator, chaired the meeting.

## Participants

**Susan Daniels**, Ph.D., *Executive Secretary*, IACC, OARC, NIMH; **Mitchell Berger**, M.P.H., Substance Abuse and Mental Health Services Administration (SAMHSA) (representing Anita Everett, M.D., D.F.A.P.A.); **Alice Carter**, Ph.D., University of Massachusetts, Boston; **Judith Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara Tucci, MD, MS, MBA, FACS); **Sam Crane**, J.D., Quality Trust for Individuals with Disabilities; **Tiffany R. Farchione**, M.D., Food and Drug Administration (FDA); **Courtney Ferrell Aclin**, Ph.D., National Institutes of Health (NIH) (representing Lawrence Tabak, D.D.S., Ph.D.); **Dena Gassner**, M.S.W., Adelphi University; **Dayana J. Garcia**, M.Ed, Administration for Children and Families; **Morénike Giwa Onaiwu**, M.A., Rice University; **Elaine Cohen Hubal**, Ph.D., U.S. Environmental Protection Agency; **Alycia Halladay**, Ph.D., Autism Science Foundation; **Kristina Hardy**, Ph.D., M.D., National Institute of Neurological Disorders and Stroke (NINDS)(representing Walter J. Koroshetz, M.D.); **Craig Johnson**, B.A., Champions Foundation; **Jennifer Johnson**, Ed.D., Administration for Community Living; **Alice Kau**, Ph.D. *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (representing Diana W. Bianchi, M.D.); **Walter J. Koroshetz**, M.D., NINDS; **Cindy Lawler**, Ph.D. National Institute of Environmental Health Sciences (representing Richard Woychik, Ph.D.); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A., Freelance Presenter/Trainer; **Jenny Mai Phan**, Ph.D., Children’s National Hospital; **Joseph Piven**, M.D., University of North Carolina-Chapel Hill; **JaLynn R. Prince**, B.F.A., Madison House Autism Foundation; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration; **Susan Rivera**, Ph.D., University of Maryland; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (DOL)(representing Taryn Mackenzie Williams, M.A.); **Stuart Shapira**, M.D., Ph.D., CDC (representing Karyl Rattay, M.D., M.S., FAAP); **Matthew Siegel**, M.D., Tufts University School of Medicine; **Ivanova Smith**, B.A., University of Washington; **Martine Solages**, M.D., U.S. Food and Drug Administration (FDA) (alternate for Tiffany Farchione, MD); **Teresa Souza**, Ph.D., U.S. Department of Housing and Urban Development; **Hari Srinivasan**, B.A., Vanderbilt University; **Jodie Sumeracki**, B.A., Centers for Medicare and Medicaid Services (CMS); **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna E. Tschiffely**, Ph.D., Department of Defense (DOD)(representing Taryn Mackenzie Williams, M.A.); **Debara Tucci**, M.D., M.S., M.B.A., FACS, NIDCD; **Paul Wang**, M.D., Simons Foundation; **Stephen Whitlow**, J.D., Merakey; **Nicole Williams**, Ph.D., U.S. DOD

## Welcome

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

Members of the IACC convened to discuss the content of the *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy*. Prior to the discussion, Dr. Daniels gave an overview of the *Strategic Plan's* purpose, development process, and content.

The *Strategic Plan* is required by Congress as part of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019. It serves as a guide for federal agencies and private partner organizations, outlining priorities and directions for autism-related research, services, and policy efforts. It is one of the main ways through which the IACC provides advice to the Secretary of Health and Human Services (HHS), and it includes recommendations for research, services, and policy as well as for activity budgeting. The *Strategic Plan* aims to present issues and recommendation in a respectful and inclusive manner.

To develop the *Strategic Plan*, OARC solicited input from both IACC members and the public through full committee meetings, special requests for information, and/or survey. After gathering information, OARC developed a consensus-based draft of the *Strategic Plan*. Although the goal of the working group meeting summarized in this document is to discuss plan content, the final draft of the *Strategic Plan* will be reviewed and accepted by the full IACC by majority vote. Once approved by the IACC, the *Strategic Plan* will be published for use and reference by federal agencies and other community stakeholders.

The *Strategic Plan* consists of seven topic areas, each of which has a dedicated chapter associated with a community-based question. Each chapter provides an overview of recent advances or changes and remaining gaps or opportunities for research, services, and policy. Current chapters include *Screening and Diagnosis, Biology, Genetic and Environmental Factors, Interventions, Services and Supports, Lifespan, and Research Infrastructure and Prevalence*.

The *2021-2023 IACC Strategic Plan* will also include the following sections, the first two of which are new:

- Two cross-cutting themes connected to all seven topics
  - Sex and Gender (previously women and girls, now expanded)
  - Promoting Equity and Reducing Disparities
- Impact of COVID-19 on the autism community, research, services, and policy
- Progress made on previous *Strategic Plan* recommendations
- Budget Recommendations, as required by the Autism CARES Act of 2019

Themes of acceptance and inclusion are interwoven throughout the *Strategic Plan*, and the next draft will include revisions for plain language. An easy-to-read executive summary will also be released.

## Discussion: Introduction

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

Dr. Daniels presented the community-based questions associated with each *Strategic Plan* chapter. Following each question, Dr. Daniels shared a list of related topics covered in the current draft of the *Strategic Plan*. Attendees then provided comments on additional areas that should be included in each chapter. A summary of these discussions is included below.

### Discussion: Question 1 (Screening and Diagnosis)

IACC members shared concerns about insufficient availability of diagnostic service providers and noted that increased compensation for these providers is necessary to expand the workforce and reduce current waitlists for autism screening and diagnostic services. Multiple members emphasized the importance of better workforce training. Many children with autism are not diagnosed in a timely manner because screening is not sufficiently incorporated into training for general providers.

Furthermore, current training emphasizes screening tools and technology rather than techniques for communicating with patients and caregivers. Providers that have limited experience with autistic individuals may be prone to stereotyping or to over-prognosticating (i.e., making assertions about patients' capabilities without considering their individual differences). IACC members agreed that additional work is needed to improve provider training, including education on cultural competency, bias, and interacting with patients and families.

Several IACC members noted that the prevalence of multiple autism co-occurring conditions, such as ADHD or anxiety should be addressed, including the presence of potential parental disability. Diagnoses should also be conducted in stages to allow opportunities for patients and families to ask questions and process new information. However, it can be difficult for providers to distinguish autism from mental health disorders or to determine their co-occurrence. IACC members discussed how improved diagnosis and research of conditions frequently co-occurring with autism, such as substance use disorder, is necessary for autistic individuals to obtain the support they may need.

IACC members agreed that increased access to screening and diagnostic services is needed, but added that standardized reports and assessments have limitations. They noted that autism-related clinician reports should be written with the relevant audience in mind rather than be reduced to a template. For example, a diagnostic report sent to a school should emphasize student strengths, whereas a report included in an application for social security benefits should emphasize functional deficits. Several IACC members also cautioned that standardized assessments such as the Autism Diagnostic Observation Schedule (ADOS) have biases and can fail to detect autism in children and especially in adolescents and adults. Therefore, the *Strategic Plan* should avoid language that refers to these assessments as the diagnostic "gold standard."

Many individuals diagnosed with autism face barriers to obtaining support and services. However, multiple IACC members described a lesser-known gap between the number of individuals who screen positive for autism and the number of individuals who later receive diagnostic testing. Understanding how symptoms of autism change over time is also critical. Some autistic individuals are not diagnosed until adulthood. Therefore, it is important to support research that seeks to understand the trajectories of autism from childhood through adulthood.

More companies are developing screening and diagnostic tools that leverage biomarkers or technology such as eye tracking devices. Coordination among these companies is necessary to optimally support autistic individuals. Effective diagnostic tools could help reduce waitlists. However, IACC members cautioned that these tools have limitations, and their refinement requires further research.

IACC members emphasized that the disparities and delays in diagnosing women and gender-diverse individuals must be addressed. In addition, the field must develop a greater understanding of the experiences of autistic males with low support needs who were not diagnosed in childhood. Inconsistencies in diagnostic criteria used by different types of providers may also lead to disparities in autism diagnosis. For example, providers in urban areas may diagnose autism differently than providers in rural areas. Systems navigators and autistic peer supports can help autistic children, adolescents, adults, and their families overcome barriers to accessing diagnostic and support services.

### **Discussion: Question 2 (Biology)**

During their discussion of Chapter 2, IACC members advocated for expanding research topics in the domain of autism biology and for modifying research ethics training to be more inclusive of autistic individuals.

IACC members commented on the need for greater exploration of the intersection of autism with conditions such as Ehlers Danlos syndrome, postural orthostatic tachycardia (POTS), long COVID, and movement disorders. In addition, the physical and emotional effects of trauma on autistic individuals should be investigated when considering the biology underlying autism.

Autism-related social and emotional deficits are too often emphasized in autism research. Other significant, but understudied, aspects of the condition are difficulties in executive functioning, sensory and sensorimotor processing, and motor development. These aspects may also be affected by individual differences in cognitive and adaptability. The exclusion of executive functioning difficulties from DSM-5 autism spectrum disorder criteria may prevent autistic individuals from obtaining necessary services.

In addition to the neural changes caused by abuse- or discrimination-related trauma and the biological factors that underlie well-being, autism researchers should explore mechanisms of resilience. Multiple IACC members noted that understanding how children learn to adapt to

their environment or mask aspects of their condition could be used to help other autistic children with higher support needs.

Many IACC members agreed that community-based participatory research (CBPR) is an invaluable approach to studying the biology of autism. To equitably engage all members of the autism community, research ethics training should be redesigned for autistic individuals with intellectual disability.

To better encapsulate the topics included in Chapter 2 of the *Strategic Plan*, IACC members suggested headings such as “Biology and Behavior” and “Biology and Development.” Multiple members expressed concern that the word “behavior” has historically negative connotations within the autism community. Multiple members also suggested that the word “differences” is too weak a term to describe autism-related short-comings in the domains of sensorimotor abilities, cognition, and communication.

### **Discussion: Question 3 (Genetic and Environmental Factors)**

The *Strategic Plan* acknowledges the potential association of environmental factors with an increased likelihood of developing autism, but several IACC members noted that such factors may also affect autism progression. When considering environmental chemical exposure, researchers and policymakers should recognize autistic individuals as a particularly vulnerable population.

IACC members stressed that the goals and ethics of genetics research studies should be clear, and that such studies should be designed to improve wellbeing rather than to cure autism. For example, studies could examine genetic factors that predispose certain autistic individuals to anxiety, communication issues, or intellectual disability. When study objectives and ethics are not transparent, autistic individuals may be dissuaded from participating.

### **Discussion: Question 4 (Interventions)**

During their discussion of Chapter 4, IACC members first noted that the phrasing “improve quality of life” may imply that autistic individuals have poor quality of life because of their condition as opposed to the barriers they face in society. Alternative language is needed that acknowledges systemic obstacles to wellbeing and emphasizes supporting autistic individuals.

IACC members next discussed different types of interventions they believed are beneficial and critically needed, including medical interventions for co-occurring conditions, family-based interventions, and peer-support programs.

Several IACC members noted that conditions unrelated to mental health, such as gastrointestinal problems and seizures, may co-occur with autism but are not well understood in the context of developmental disorders. Furthermore, the necessary screening and medical interventions for these conditions are often inaccessible to autistic individuals.

To facilitate access to interventions, IACC members agreed that resources and education should be provided to families of autistic individuals and should extend beyond caregiver support to encompass systems navigation help (e.g., tools for accessing insurance). Furthermore, autism interventions should be culturally and linguistically appropriate.

Multiple members advocated for peer support programs as valuable interventions for autistic individuals. Initiatives such as the Community Autism Peer Specialist (CAPS) program in Pennsylvania may help empower autistic individuals and foster community engagement.

Lastly, IACC members noted that the current lag in implementing evidence-based interventions in the community may exacerbate health disparities. Members agreed that research aimed at more efficient dissemination of evidence-based interventions is needed.

### **Discussion: Question 5 (Services and Supports)**

IACC members discussed a variety of services and supports for autistic individuals with different needs. Many members agreed that autistic individuals with low support needs are often misinterpreted as having no support needs. A resulting lack of support can lead to or exacerbate co-occurring mental health issues such as depression and anxiety. Thus, members advocated for equal access to supports and services across the autism spectrum and at all levels of disability. In schools, it may be helpful to integrate non-academic skill learning into the school day, even for autistic children with no intellectual disability.

To address accidental drowning concerns, multiple members agreed that autistic children should have equal access to swimming and water safety education. Early interventions and services should also promote outdoor recreational activities and opportunities for exploration. In addition, autistic children should be taught how to safely navigate public transportation systems.

Autistic individuals may be at increased risk of homelessness, and additional research is needed to evaluate the prevalence of autism among unhoused populations. Several members stated that supports for housing access should be made available to autistic individuals.

Several IACC members stated that workforce training and education for service providers should include partnerships with autistic individuals. Such partnerships would enable autistic individuals to highlight their lived experiences and help promote best practices for supporting and empowering autistic people.

Multiple IACC members felt strongly that law enforcement should be trained on ways to appropriately interact with autistic individuals. In addition, services should be in place to ensure that autistic individuals receive fair trials and support if incarcerated. They also stressed the importance of trained, qualified professionals who can address the needs of autistic victims of sexual or online harassment.

Multiple IACC members agreed that AAC systems should be made available and acceptable across community settings. Supports such as AAC and captioning could help a variety of autistic individuals, even on an as-needed basis for individuals with low support needs.

Given the communication and sensory processing difficulties that accompany autism, obtaining regular dental care can be a challenge for some autistic individuals. Multiple IACC members agreed that improving access to dental health services, including cosmetic dental services, is important for the autistic community.

A substantial number of autistic children may be attending charter, private, or homeschools. IACC members noted the need to improve understanding of the types and levels of support these children receive. Data indicate that access to services such as speech and language therapy, physical therapy, and occupational therapy often drop off after primary school. These services should be funded throughout K-12 education and included in IEP and 504 plans.

Further contributing to the post-primary school “services cliff,” disability staff at universities and community colleges face an overwhelming workload. Several IACC members expressed that decreasing the ratios of students to support staff is critical for autistic individuals to receive adequate support in college.

### **Discussion: Question 6 (Lifespan)**

Regarding Chapter 6, IACC members discussed supports for autistic children and adults at different life stages. They also highlighted the need for more longitudinal autism research studies.

IACC members noted that autistic adults and other disabled individuals struggle to access social security benefits, and those with access may still live in poverty. Often, covered services and supports are only available in areas with high costs of living, which intersects with issues related to affordable housing.

Multiple IACC members agreed on the lack of postsecondary education support programs for autistic individuals. Existing programs appear to focus on individuals with intellectual disabilities or individuals deemed extremely gifted and talented, leaving those who fall in between with limited support. Furthermore, access to work-based learning and employment supports must be expanded, and in partnership with autistic individuals.

Multiple IACC members emphasized that autistic parents should also receive support and resources. They also advocated for the expansion of services for autistic veterans or active-duty military service members who may have complex support needs and for autistic individuals who may experience abuse, neglect, or other health and safety concerns. IACC members recommended monitoring Home- and Community-Based Services use.

More longitudinal studies are needed that follow autistic individuals into late adulthood. Most autism research focuses on children, and researchers lack knowledge of aging and autism. In



addition to tracking biological aging, studies evaluating the long-term impact of sustained psychotropic drug use should be conducted.

### **Discussion: Question 7 (Research Infrastructure and Prevalence)**

To adequately capture findings that are generalizable to the autism community, several IACC members advocated for oversampling autistic individuals in cohort studies. In addition, autistic research cohorts should be diverse in race, gender, ethnicity, and type of autism.

IACC members also recommended that researchers collaborate with autistic individuals, clinicians, and policymakers when designing studies. Studies should be made accessible to autistic individuals with high support needs who may face barriers to participation. Some data, such as social security information, are inaccessible. IACC members emphasized that data gathering must be improved, including by determining efficient methods for collecting prevalence information.

IACC members noted that some researchers find it difficult to extract data from NDAR, an otherwise valuable tool for collaboration. NDAR should be refined to promote easier data access.

To expand and bolster the diversity of the research workforce, initiatives that incentivize autistic and non-autistic individuals to pursue multidisciplinary research training is critical. In addition, multiple IACC members commented that academic and workplace accommodations (i.e., for interviews and entrance exams) are needed to support autistic researchers.

### **Discussion: Cross-Cutting Objective – Sex and Gender**

IACC members stressed the need to evaluate the gynecological, maternal, and menopausal care provided to autistic individuals. OB/GYNs and other providers should receive training on how to provide care that is sensitive to the needs of autistic individuals. Further, providers should be trained in trauma-informed care.

Several IACC members highlighted that sexual and reproductive health education, including teaching consent and reporting sexual abuse, should be made accessible to autistic individuals. Educational resources should avoid infantilizing autistic adults and adolescents and should be written in plain language and designed to accommodate a range of disability and support needs. Reproductive health should also be studied.

Multiple IACC members noted that the prevalence of transgender and non-binary individuals in the autism community is vastly understudied. Autistic individuals should receive equal access to LGBTQIA+ resources and medical care.

## **Discussion: Cross-Cutting Objective – Reducing Disparities and Promoting Equity**

IACC members first discussed flaws in intelligence quotient (IQ) assessments, which are not designed to index the cognitive abilities of autistic individuals, yet are used to stratify need for supports and services. Autistic individuals with high IQ scores may be deemed ineligible for services that could improve their functioning, while individuals with IQ scores below a certain threshold may be excluded from research opportunities and supports for independent living.

To understand and support diverse groups in the autism community, IACC members stated that racial and ethnic data should be disaggregated in disparities research. Certain disparities may differentially affect subgroups of typically studied populations. Cultural and linguistic barriers should be considered.

Several IACC members noted that research studies have not consistently collected data on income or economic prosperity of autistic individuals, making it difficult to identify socioeconomic disparities within the autistic community. Research funders should mandate that these types of data be included in employment and community living studies. In addition, study samples should include multiple types of autism.

Given the current state of inadequate data disaggregation, multiple IACC members agreed that greater consideration should be given to qualitative research and depictions of lived experiences that may highlight disparities not yet captured in quantitative studies. Mixed-methods studies should also be supported.

Cultural and racial biases, such as assumptions that a child's misconduct is intentional, may result in children being misdiagnosed. Furthermore, some cultural competency training increases bias. IACC members suggested that cultural brokers and community liaisons may help address these issues.

## **Discussion: COVID-19**

IACC members noted that multiple aspects of the COVID-19 pandemic and associated regulations can be distressing to autistic individuals. Disruptions to routine, including transitions between in-person and remote schooling and employment, can be challenging to navigate. For individuals with sensory processing issues, adapting to mask-wearing can be difficult. In addition, some individuals fear being hospitalized for COVID-19 and not receiving adequate support for their autism.

Multiple IACC members agreed that the impact of remote education on autistic children should be investigated. As mask mandates are lifted, autistic children with co-occurring conditions may be unable to return to in-person school. Without access to special education services and education accommodations, they may face important gaps in their learning.

Social security, rehabilitation, and in-home support services have suffered from staff shortages exacerbated by COVID-19. Several IACC members expressed that the loss of family and caregivers has been an important consideration during the ongoing pandemic.

The onset of the COVID-19 pandemic compelled many health and social providers to abruptly switch to providing telehealth services instead of in-person visits. As a result, methods of diagnosing autism and providing supports through virtual platforms were not extensively vetted before they were implemented. IACC members emphasized the need for more research to evaluate the effectiveness of these methods, including in other settings beyond health care, such as in education.

Many members of the autism community are at increased risk of COVID-19 infection and severe disease. As a vulnerable population, autistic individuals are often prioritized for vaccination and preventative care yet frequently face barriers to accessing these services. IACC members advocated for more efforts to increase both risk awareness in the autism community and access to vaccines and prophylactic treatment.

Local government emergency plans must consider people with disabilities. In addition, to better respond to future pandemics, an understanding of the gaps in COVID-19 strategies for this population is needed. IACC members also noted that an understanding of how community systems coordinated efforts to provide care and supports to people with disabilities during the pandemic will help to inform development of future emergency plans and strategies.

Because many conditions co-occur with autism, many IACC members agreed on the importance of investigating whether autistic individuals are more prone to developing long COVID. In addition, research should examine whether long COVID may manifest differently in the autism spectrum disorder population than in other individuals.

Several IACC members noted that autistic individuals, many of whom do not drive, have experienced difficulties using public transportation throughout the pandemic. In addition, people running COVID hotlines did not undergo disability training.

## **Wrap-Up**

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

IACC members discussed seven chapters of the *2021-2023 IACC Strategic Plan*, which focus on autism screening and diagnosis, biology, genetic and environmental factors, interventions, services and supports, lifespan, and research infrastructure and prevalence. They also discussed two new sections focused on (1) promoting equity through consideration of sex, gender, and other disparities in autism diagnosis and support and (2) understanding the impact of COVID-19 on autistic individuals. For each chapter and section, members provided feedback on both *Plan* content and phrasing. Multiple members shared their research findings and personal experiences, which enriched the discussion and will help inform a robust final version of the

*Strategic Plan.* At the conclusion of the meeting, Dr. Daniels reviewed the next steps for the *Strategic Plan*. Committee members will receive a survey to provide further feedback.

The next full Committee meeting is on October 26, 2022.