

Interagency Autism Coordinating Committee (IACC)

Full Committee Meeting

January 18, 2023

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This meeting summary was prepared by Rose Li and Associates, Inc., under contract to the National Institute of Mental Health (NIMH).

The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a virtual meeting on Wednesday, January 18, 2023, from 10:00 a.m. to 5:00 p.m. 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; **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont, Burlington; **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 A. Cooper**, Ph.D., National Institute on Deafness and Other Communication Disorders (NIDCD) (representing Debara L. Tucci, M.D., M.S., M.B.A., F.A.C.S.); **Sam Crane**, J.D., Quality Trust for Individuals with Disabilities; **Aisha Dickerson**, Ph.D., Johns Hopkins University; **Rebecca Dzubow**, M.P.H., M.E.M., U.S. Environmental Protection Agency (representing Elaine Cohen Hubal, Ph.D.); **Anita Everett**, M.D., D.F.A.P.A., SAMHSA; **Dena Gassner**, M.S.W., Towson University; **Tiffany R. Farchione**, M.D., Food and Drug Administration (FDA); **Courtney Ferrell Aklin**, Ph.D., National Institutes of Health, (representing Lawrence A. Tabak, D.D.S, Ph.D.); **Maria Fryer**, M.S., U.S. Department of Justice; **Morénike Giwa Onaiwu**, Ph.D., Rice University; **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.); **Leah Lozier**, Ph.D., U.S. Department of Housing and Urban Development; **Alison R. Marvin**, Ph.D., Social Security Administration; **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality; **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 (representing Matthew Miller, Ph.D., M.P.H.); **Jenny Mai Phan**, Ph.D., Children’s National Hospital; **Joseph Piven**, M.D., University of North Carolina-Chapel Hill; **Lauren Raskin Ramos**, M.P.H., Health Resources and Services Administration; **Karyl Rattay**, M.D., M.S., FAAP, Centers for Disease Control and Prevention (CDC); **Susan Rivera**, Ph.D., University of Maryland, College Park; **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; **Ivanova Smith**, B.A., University of Washington, Tacoma; **Martine Solages**, M.D., FDA (representing Tiffany Farchione, M.D.); **Hari Srinivasan**, B.A., Vanderbilt University; **Jodie Sumeracki**, B.A., Centers for Medicare & Medicaid Services; **Helen Tager-Flusberg**, Ph.D., Boston University; **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna E. Tschiffely**, Ph.D., Department of Defense (DOD) (representing Nicole Williams, Ph.D.); **Debara L. Tucci**, M.D., M.S., M.B.A., F.A.C.S., NIDCD; **Paul Wang**, M.D., Simons Foundation; **Larry Wexler**, Ed.D., U.S. Department of Education; **Stephen**

Whitlow, J.D., Gateway Transition Center; **Nicole Williams**, Ph.D., DOD; **Taryn Mackenzie Williams**, M.A., DOL

Welcome and Announcements

Joshua Gordon, M.D., Ph.D., Chair, IACC, NIMH

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

Dr. Joshua Gordon introduced the meeting, reviewed the meeting agenda, and welcomed Dr. Karyl Rattay and Dr. Walter Koroshetz as new members of the IACC. Dr. Rattay is Director of the Division of Human Development and Disability at the Centers for Disease Control and Prevention (CDC). Dr. Stuart Shapira will continue to serve as the alternate for CDC. Dr. Koroshetz is Director of the National Institute of Neurological Disorders and Stroke (NINDS) and previously served on the Committee. Dr. Kristina Hardy will serve as the IACC's alternate NINDS representative.

The Committee voted to approve the [October 2022 meeting minutes](#), which will be posted to the IACC website.

National Autism Coordinator Update

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

Dr. Susan Daniels highlighted recent autism-related activities in international and nonprofit organizations and the federal government.

Activities of international and nonprofit organizations include:

- The International Society for Autism Research (INSAR) recently released a [new policy brief](#) on the criminal justice system, which includes recommendations to improve interactions between autistic individuals and the justice system
- The Patient-Centered Outcomes Research Institute (PCORI) announced the approval of \$96 million in funding for 18 new research studies, including a \$4 million study to assess mental health interventions for autistic adults, as summarized in a recent [press release](#).
- The United Nations released the [United Nations Disability Inclusion Strategy](#), which presents a roadmap for advancing the inclusion of people with disabilities in all decision-making processes toward an accessible and equitable world.
- The World Health Organization released the [Global Report on Health Equity for Persons with Disabilities](#), which describes the highest attainable standard of health for persons with disabilities.

There have been several recent activities within the federal government. President Joe Biden issued a [Presidential Proclamation](#) to recognize International Day of Persons With Disabilities

on December 3, 2022, reaffirming his Administration's commitment to health care equity and ensuring that people with disabilities are afforded opportunities, independence, and respect.

Regarding legislative activity, the newly approved [Consolidated Appropriations Act of 2023](#) includes funding for several important programs related to autism and disabilities. In addition, Kevin and Avonte's Law, a program that supports grants to protect children with autism and developmental disabilities (DD) who wander from safety, was reauthorized with the passage of the [National Defense Authorization Act](#) on December 23, 2023. Additional information about these activities and their focus on autism can be found in [Disability Scoop](#), [Autism Speaks](#), and [Autism Society](#).

Other highlights from the federal government include the following:

- On December 2, 2022, the Interagency Committee for Disability Research (ICDR) held an [Executive Committee Meeting](#) to discuss updates from the Government Wide Inventory Work Group and the Disability Data and Statistics Work Group.
 - As a follow-up to its white paper on the [Impact of COVID-19 on Disability Research](#), ICDR published an [updated paper](#) in December 2022 that presents recent information on how the field of disability research has changed and adapted throughout the pandemic.
- The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiving Advisory Council, a Federal Advisory Committee that provides recommendations on effective models of family caregiving to the Health and Human Services Secretary, sought public comments on its [2022 National Strategy to Support Family Caregivers](#).
- The National Council on Disability released a report examining weaknesses in the home- and community-based services ecosystem, titled [Strengthening the HCBS Ecosystem – Responding to Dangers of Congregate Settings During COVID-19](#).
- Federal Partners in Transition, a workgroup that exchanges information between federal agencies on transition-related issues for youth with disabilities, continues to develop a new Strategic Plan. In addition, the workgroup's Steering Committee held a meeting on December 15, 2022.
- The Interdepartmental Serious Mental Illness Coordinating Committee, a federal advisory committee that addresses issues in serious mental illness and serious emotional disturbance, held a [meeting](#) on October 28, 2022.
- The Disability Advisory Committee, a federal advisory committee that provides recommendations to the Federal Communications Commission on a variety of disability issues, held a [meeting](#) on November 1, 2022 (available through [FCC Webcast](#)) and will meet again in 2023 with new membership.
- The U.S. Department of Labor (DOL) released a [blog post](#) on the number of people with disabilities who are re-entering the labor force, which has now surpassed pre-pandemic levels.
- The National Institutes of Health Advancing Prevention Research for Health Equity (ADVANCE) initiative is seeking [public comment](#), due March 1, 2023, on interventions or programs that prevent mental health problems or promote mental health wellness in

populations that experience health disparities. Although not explicitly stated in the announcement, comments related to individuals with disabilities are welcome.

IACC Committee Business

Joshua Gordon, M.D., Ph.D., Chair, IACC, NIMH

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

The Committee discussed upcoming IACC publications. First, Dr. Daniels provided an update on the *IACC Portfolio Analysis Report*, which provides comprehensive information about autism research funding across federal agencies and private research organizations in the United States. The Office of Autism Research Coordination (OARC) is in the final stages of preparing the *2019-2020 IACC Portfolio Analysis Report*, which they plan to release later in 2023. They are currently preparing the 2021 report, which they plan to release in late 2023 to early 2024.

2021-2023 IACC Strategic Plan Discussion

The Strategic Plan outlines priorities for autism research, services, and supports. The IACC has prepared three drafts of the *2021-2023 IACC Strategic Plan for Autism Research, Services, and Policy* based on input from an initial Request for Information, IACC member surveys, and discussion during prior IACC Full Committee meetings. The third and most recent draft was developed with the goal of building a consensus document that addresses the needs of individuals across the autism spectrum, across their lifespan, and from diverse communities. Some of the major themes and topics in the Strategic Plan include the following:

- Major research, services, and policy issues
- Major federal activities and initiatives and interagency coordination
- A commitment to developing solutions to challenges of individuals and their families in health needs, services access, opportunities, and community inclusion
- A commitment to addressing the whole autism spectrum and lifespan, including individuals with high support needs
- Addressing the needs of those from diverse communities
- A commitment to inclusion, acceptance, and equity, and reducing stigma, disparities, and discrimination
- A need for greater inclusion in research, including community-based participatory research
- An update on the research portfolio and budget recommendation

Dr. Daniels thanked IACC members and the general public for sharing their thoughts and feedback regarding development of the *Strategic Plan*.

Ms. Dena Gassner recommended improving the readability and accessibility of the draft by using more lay-friendly language and formatting. Dr. Daniels responded that OARC will review the draft for accessibility and 508-compliance. They are currently developing an “easy read”

version of the *Strategic Plan*. IACC members also suggested forming a working group to discuss how to disseminate information from the *Strategic Plan* to the public.

Dr. Gordon reflected on how this iteration of the plan reflects a greater range of the needs and concerns of the autism community than previous versions. He also stated that the IACC is officially charged with advising the federal government and therefore the plan must be complex and detailed. However, he agreed that the IACC should consider how the Strategic Plan may guide the activities of stakeholders outside of the government.

IACC members suggested that the draft emphasize the utility of large online databases, such as the NIMH Data Archive (NDA), in accelerating autism research and data analysis. Members discussed the need for these databases to be large, user friendly, and accessible in order to be as effective as possible. Dr. Scott Michael Robertson added that international research collaborations may enhance data sharing. Dr. Daniels commented that although the IACC is only charged with developing a domestic Strategic Plan, other countries have expressed interest in developing another *International Portfolio Analysis Report* in the future.

Thirty-seven of 38 IACC members voted to approve the *2021-2023 Strategic Plan*, with any changes agreed upon during this meeting. The final *Strategic Plan* will be sent to Congress and President Biden and may be presented in a poster at the 2023 INSAR annual meeting in May.

2022 Summary of Advances Discussion

The *Summary of Advances* report provides lay-friendly summaries of the 20 most significant advances in autism biomedical and services research selected by the IACC. OARC prepared the 2021 report in fall 2022, which is subject to IACC review before publication in early 2023. For the 2022 report, IACC members nominated articles and discussed nominations at today's committee meeting. The 2022 report is expected to be published in summer 2023.

IACC members discussed the 85 autism-related articles nominated for *the 2022 Summary of Advances*, which span seven topic areas: (1) screening and diagnosis, (2) biology, (3) genetic and environmental factors, (4) interventions, (5) services and supports, (6) lifespan, and (7) infrastructure and prevalence. After OARC compiles a final list of nominated articles, IACC members will vote on the top 20 advances. All other nominated articles will be listed at the end of the report.

IACC members agreed to remove three articles from consideration that were flagged by OARC staff. One study (on telehealth) had a small sample size, and the other studies did not offer original research data or findings. However, multiple IACC members emphasized the importance of research on telehealth's impact on autism diagnosis and behavioral intervention. Dr. Gordon encouraged IACC members to send OARC staff additional telehealth-related articles for nomination, along with nomination justifications.

Multiple IACC members stressed the importance of articles on topics such as service use among Medicaid-enrolled children, barriers to care and adverse outcomes, issues related to sex and gender, disparities in identification and service use among racial and ethnic groups, and more.

In closing out committee business, Dr. Daniels described the work of a working group of the previous IACC that examined co-occurring physical and mental health conditions. The working group began developing a report, summarizing current understanding of these conditions and develop recommendations for future priorities. Dr. Daniels asked the committee if they would be supportive of reconvening the working group to complete that report and present it back to the IACC for approval, as a project to follow the completion of the new IACC Strategic Plan. Multiple members supported reconvening the working group in order to complete this report. Dr. Robertson suggested that the IACC also issue a short brief on the findings from its 2019 workshop on housing. Dr. Daniels agreed that this could be an additional follow-up activity, adding that the U.S. Department of Housing and Urban Development, now that it is represented on the IACC, could be engaged in this effort.

Public Comment Session

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

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

Oral Comments

Mr. Finn Gardiner is a member of the Autistic People of Color Fund, a nonprofit devoted to fostering the inclusion and social integration of autistic people of color. The Fund works with the Autistic Women and Nonbinary Network to direct policy, research, and advocacy to advance healthy outcomes for disabled people (e.g., high-quality, community-based services). The Fund promotes the use of anti-ableist language and anti-ableist practices in autism research. Mr. Gardiner emphasized the importance of including autistic individuals in the planning and execution of research in order to address inequities. He highlighted several research topics of interest to the Fund: (1) investigating mental health of autistic people of color, autistic immigrants, and autistic refugees; (2) improving the short- and long-term outcomes for autistic individuals; (3) understanding the impacts of bias against transgender and cisgender women; (4) understanding the impact of school disciplinary policies and the school-to-prison pipeline on autistic students of color; (5) understanding health care experiences of autistic people of color, LGBTQ+ autistic people, and autistic immigrants and refugees; (6) understanding the impact of unstable housing and homelessness on autistic individuals; and (7) understanding the benefits of and barriers to access for alternative and augmentative communication.

Ms. Stacey Blecher is a board-certified art therapist in Ohio whose husband was recently diagnosed with autism. Ms. Blecher explained that the services that most benefit autistic individuals—art and other expressive therapies—are often not widely available and not covered by insurance. She encouraged efforts to increase accessibility to art therapy and other expressive therapy programs in both urban and rural areas. She also encouraged the use of therapies that employ alternative modes of communication, such as typing, and online therapy. The growth of remote meeting technologies in recent years has increased access to alternative therapies that could greatly benefit the autistic community.

Ms. Areva Martin is the founder and president of Special Needs Network, Inc., a civil rights attorney, and mother of a young adult on the autism spectrum. The Network works to close the gap in services available to lower income and Black, Indigenous, and People of Color (BIPOC) children with autism and other DD. The Network also provides direct services both in clinics and the home. However, the Network is paid for its services at a rate lower than private health insurance carriers are paid for equivalent services, because Medicaid does not recognize board-certified health therapists as licensed providers. Without qualifying for enhanced Medicaid payment or grant funding, centers such as the Network that utilize board-certified therapists cannot financially operate in low-income and underserved neighborhoods. The Special Needs Network requests the IACC's assistance in communicating to the U.S. Department of Health and Human Services the need to expand the definition of Medicaid providers who can receive enhanced payments. This will increase the pool of providers eligible to deliver behavioral health treatment to vulnerable patients and help address long waiting lists. This approach may be cost neutral or lead to long-term cost savings for the government, as it could reduce the burden on emergency departments and increase the levels of employment and independent living among autistic individuals.

Mr. Joseph Joyce provided testimony on behalf of the Autism Society of America and as a father of two adult sons with intellectual and developmental disabilities (IDD). Mr. Joyce described his difficulties in finding direct support professionals and a licensed agency to operate a home in which one of his sons could live independently. He added that millions of families lack access to the resources needed to enable relatives with DD to live independently and depend on public benefits, which often do not adequately pay providers. Mr. Joyce noted that planning for continuous care over the lifespan of people with DD is challenging because states are only required to cover home health and can limit the number of families eligible for waivers. As a result, families often wait an average of 39 months to secure services—a gap that was exacerbated during the COVID-19 pandemic. Mr. Joyce emphasized that these limitations on services must be removed, particularly because the prevalence of autism is expected to increase by at least 15% over the next decade. He asked the IACC to craft recommendations to the current presidential administration and lawmakers to improve the nation's service system for people with autism and other DD.

Dr. Thomas Frazier, board member of Autism Speaks, addressed the importance of proper supports for mental health needs. He noted that the 2018 IACC workshop [Addressing the Health Needs of People on the Autism Spectrum](#) and other resources about lived experiences highlight the gap between the mental health services needed and those received by autistic individuals. The recent Omnibus agreement directs NIMH to develop a “professional judgement” budget estimating the additional funding needed to support research on serious mental illness. The agreement also urges the National Institutes of Health to provide an update on its investment across the priority areas outlined in the IACC Strategic Plan. Dr. Frazier noted that the legislation provides the opportunity for the IACC to articulate a path toward addressing the unmet mental health needs of the autistic community and encouraged the IACC to identify time-limited, goal-driven investments toward these solutions.

Summary of Written Public Comments

Dr. Daniels stated that 118 [written public comments](#) were submitted. Of these comments, 47 focused on research and service needs, resources, and policy implications; 14 on research, services, and supports for adults with autism; 12 on inclusion of autistic perspectives in research; 8 on educational needs and teacher workforce training; 5 on employment; 5 on the role of the IACC and the federal government; 5 on inclusion of underrepresented groups; 4 on mental health research, services, and treatment; 4 on addressing the needs of autistic individuals with high support needs; 4 on increasing autism acceptance and reducing stigma; 4 on language regarding autism; 2 on potential causes of autism; 2 on communication and AAC; and 2 on parent/caregiver support needs. All the comments were provided to the committee ahead of the meeting and are posted on the IACC website for public access.

Committee Discussion

Referring to the comments on gaps in services and the challenges to transitioning care between caregivers, Ms. Gassner shared her own experiences of living separately from her husband for 15 years because of gaps in services in the state where her husband is employed.

Multiple committee members reflected on disparities and inequities experienced by autistic people of color and the importance of understanding intersectionality. Disparities also influence reported prevalence rates, and the increase in diagnoses is due in part to better diagnosis of autism among people of color and women.

IACC members also addressed the difficulty in delineating service needs among the autistic community, and that some difficulties such as self-harm and selective mutism affect people across the spectrum. Many individuals struggle to navigate the health care system and find the right support. Some are continuously referred to one specialist after another, and families should be involved in therapies that their children receive in order to best support them. Therapies should also emphasize child assent to foster self-advocacy skills.

Dr. Robertson referred to the lack of support and empowerment for autistic individuals raising families, which may be a topic for a future IACC meeting. Ms. Ivanova Smith expanded on this topic, emphasizing that autistic individuals develop differently, and that development may change over time. Therefore, research should seek to determine what types and amounts of support autistic individuals need at different stages of life and how co-occurring conditions affect these needs. The research findings will help health care workers and other service providers support autistic individuals across the lifespan.

Several IACC members highlighted the mention of the school-to-prison pipeline. Recent research literature from the UK found that autistic people face substantial barriers in the criminal justice system (e.g., communication and socialization) that may lead to longer sentences. Incarcerated autistic individuals also face gaps in access to needed services.

Ms. Yetta Myrick highlighted a written comment that the social work and mental health fields provide little training on autism, either during schooling or on the job. Training on autism would

be beneficial for both the autistic community and for the doctors and social workers who serve them.

Dr. Morénike Giwa Onaiwu shared a [link](#) to resources on inclusive communication, which are aligned with best practices of researchers, communication specialists, journalists, and multidisciplinary scientists. The resources were also drafted with individuals with various disabilities, including individuals across the autism spectrum and their families.

Support Services Discussion

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

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

Dr. Gordon introduced the discussion on autism services. As evidenced by comments by both Committee members and the public, there is a need to identify which services are most beneficial, where there are gaps in services and research, and what barriers exist. This can help policy and lawmakers work to increase funding and access. Dr. Gordon and Dr. Daniels stated the need to hear from a variety of perspectives, including autistic individuals, family members, and researchers/clinicians/providers.

First, Dr. Gordon asked the IACC members to review a list of evidence-based services for autistic children and adults and suggest others that were not included. In response, several IACC members expressed concern about the term “evidence-based,” because evidence-based services are often developed from studies with that are not generalizable to the autism community. Mr. Hari Srinivasan noted that studies only include individuals who are considered “testable,” which leaves out many people. Dr. Alice Carter and Dr. Alycia Halladay discussed the need for large-scale studies that include moderating variables.

Many IACC members expressed a preference for individualized interventions, given the high heterogeneity of needs across the autism community. Furthermore, IACC members noted that a focus on only evidence-based services overlooks emerging services that remain in the early stages of clinical trial testing or have a small literature (e.g., art therapy, music therapy). Dr. Jennifer Johnson suggested that the list also include emerging or promising therapies and services.

Dr. Gordon acknowledged the IACC members’ contributions and noted that this activity can help to identify barriers and gaps in service delivery. Creating a list of evidence-based services is a starting point for providers to refer patients to therapy that best meets their individual needs. He also noted that no single service will benefit all autistic people.

The following list of available services with some level of evidence was discussed: occupational therapy, physical therapy, speech and language therapy, vocational rehabilitation, music therapy, art therapy, select behavioral interventions (e.g., applied behavioral analysis), independent living skill services, in-home support services, behavioral support services, cognitive behavioral therapy, parent-mediated advocacy and training, and life coaching.

Next, Dr. Gordon asked the IACC members to consider what services are widely accessible, widely available, covered by health insurance, or available at little to no cost. Further, he asked them to consider the barriers to availability for those services not widely available. He reflected on Ms. Gassner's earlier point that vocational rehabilitation is not suitable for everyone and that employment retention is a challenge that needs to be addressed.

Mr. Srinivasan shared his own experiences with state supported services being terminated upon his entry to graduate school, limiting his ability to access needed support. He shared that even though people like him may be able to obtain higher education and employment, that people still may have significant needs for supports and have a difficult time affording them without assistance. He also noted that most autism services are expensive with little accountability. Other members agreed that finances are a large barrier to service access.

Committee members also discussed the availability and flexibility of in-school service. Although Early Intervention Services can include physical, occupational, and communication support services, not all districts or states offer all three. This requires families to seek additional support via Medicaid or private care. However, many families lack the financial resources to access the needed support, which is a time-consuming endeavor. Dr. Maria Mercedes Avila also noted that cultural and linguistic barriers can prevent families from advocating for themselves, accessing services, and participating in research. Areas with racially and ethnically diverse populations are more likely to offer few, or no, service options—including for screening. This barrier could be partially addressed through expansion of Part C Early Intervention Services that serve children with disabilities from birth to age 2. Other members agreed with these points and addressed the need for culturally sensitive interventions.

Dr. Matthew Siegel noted that prescription medications, although not a service, are the most widely available treatment covered by health insurance for two primary reasons. First, the pool of professionals appropriately trained to provide services is small. Further, few of such professionals are trained to treat autistic individuals. Second, payment systems and reimbursement models often provide inadequate coverage of service costs, or inadequate compensation to providers to enable them to extend services to all comers. Medications, however, are more easily covered through health insurance.

Dr. Karyl Rattay addressed the burden of chronic diseases that impact people with disabilities, stating that health promotion and disease prevention programs tend to be designed for the general population. Health promotion and disease prevention programs should be tailored to meet the needs of autistic individuals so they can help support their health and prevent chronic health problems.

IACC members noted that navigating the healthcare and legal system is time consuming and often requires parents, particularly mothers, to leave the workforce. However, parents may not be adequately prepared to navigate the health care or legal settings. Families would benefit from specialists/systems navigators who can provide guidance on services and legal issues.

Ms. Gassner shared the need for a counterpart to child life specialists, who help children struggling with fear and anxiety in hospital settings. Many disabled adults have had negative experiences in healthcare settings and would benefit from the support of an individual who had a similar role. In addition, many physical spaces that provide services to autistic individuals are designed for children. Needed are health care settings that specialize in treating adults, both those newly diagnosed and those diagnosed at an early age. Further, early intervention services are needed for newly diagnosed adults.

The barriers to services that IACC identified included individual and family finances, service availability and flexibility, racial and ethnic disparities, inadequate payment and reimbursement systems, and difficulty navigating healthcare and service systems.

Finally, Dr. Gordon asked the IACC members to consider unmet needs for which services do not exist or do not exist at scale. Dr. Jenny Mai Phan described the need for comprehensive sex and sexuality education, including direct supports and services. Although numerous autistic-friendly sex and sexuality resources exist online, autistic individuals require direct supports and services on a variety of topics (e.g., growth, development, consent, sexuality). Furthermore, when these services are made available, they should be covered by insurance or Medicaid to ensure their wide accessibility.

Several members agreed with Ms. Gassner's remarks on the need for autism for training health providers and for systems navigators, particularly in underserved areas. Mr. Srinivasan said that there is a need for regional centers that can provide supports that are currently siloed, including guidance for navigating health benefits and financial planning tools. Other needs he identified were comprehensive housing supports and training for direct service professionals.

Dr. Rattay noted that individuals with disabilities, including individuals with autism, are often underserved during emergencies. Whether to a pandemic or a natural disaster, the response must attend to all victims. Enhanced disaster preparedness and response services tailored to the needs of people with disabilities would be desirable.

Ms. Gassner said that many autistic people need ongoing in-home support services, rather than training, such as help with cleaning or banking. Training cannot eliminate functional limitations or differences in learning behaviors. Ongoing support is also needed in the workplace to promote employment retention and independent living.

Identified unmet needs included adult-oriented therapies, systems navigators and other hospital support workers, comprehensive sex and sexuality education and support, autism training for healthcare professionals, regional centers with comprehensive support services, caregiver supports, individualized employment and life skills training, ongoing in-home and workplace supports, early intervention services for newly diagnosed adults, and inclusion in planning for emergency response (e.g., pandemics, natural disasters).

Advancing Engaged Research: Highlights Related to Intellectual and Developmental Disabilities Presentation

Nakela Cook, M.D., M.P.H., Executive Director; Patient-Centered Outcomes Research Institute (PCORI)

Meghan Warren, Ph.D., M.P.H., PT, Program Officer, Science; Clinical Effectiveness and Decision Science; PCORI

Dr. Gordon introduced the presenters from the Patient-Centered Outcomes Research Institute (PCORI), a nonprofit organization that is authorized by Congress to fund research on outcomes that matter to patients. Dr. Nakela Cook is the Executive Director of PCORI. Dr. Meghan Warren is a Program Officer at PCORI and manages diverse comparative clinical effectiveness research portfolio, including research on IDD.

Dr. Cook explained PCORI's mission, which is to help people make better informed decisions about their health and health care. They do this by producing and promoting evidence-based information that comes from research guided by patients, caregivers, and the broader health care community. To achieve this mission, PCORI funds comparative clinical effectiveness research (CER) that is stakeholder-centric from conception to study completion. They focus on dissemination of accessible and useful results.

PCORI recently approved a strategic plan that sets forth a holistic approach to generating and promoting the use of evidence designed to enable a more patient-centered system of health. They sought and incorporated stakeholder feedback at every stage of developing the plan. The holistic approach incorporates four essential elements: patient-centered CER funding, engagement, dissemination and implementation, and infrastructure. The strategic plan centers on five national priorities for health:

- Increase evidence for existing interventions and emerging innovations in health
- Enhance infrastructure to accelerate patient-centered outcomes research (PCOR)
- Advance the science of dissemination, implementation, and health communication
- Achieve health equity
- Accelerate progress toward an integrated learning health system

These priorities will drive PCORI-funded research (e.g., clinical trials) and research-related projects (e.g., capacity building projects). PCORI seeks to fund a balanced portfolio of short-term (e.g., horizon scanning reports) and long-term (e.g., phased clinical trials) activities that responds to both a rapidly evolving health care setting and patient concerns and needs. To this end, PCORI developed a framework to further guide funding priorities toward populations (e.g., healthy children and youth, older adults), health behavior (e.g., violence and trauma), and health conditions (e.g., improving mental and behavioral health). Additionally, PCORI works to capture the full range of outcomes, including the impact of economic and other burdens related to use of medical treatments and services.

Dr. Warren described PCORI's current approach to IDD research, which is guided by background research, literature reviews, and stakeholder engagement. Their short- and long-term projects all take a multipronged approach, which includes funding high-priority research, building capacity for PCOR, disseminating and implementing activities, and enhancing efficiency and research design. PCORI identifies topics of interest through background research, literature reviews, and stakeholder engagement in a comprehensive, connected way.

IDD-specific funding announcements from 2020 to 2022 included an engagement award (e.g., building capacity through community engagement for PCOR/CER in IDD) and focused funding to address the needs of individuals with IDD (e.g., caregiver delivered interventions, improving care transitions, mental health interventions). Since 2012, PCORI has awarded \$112 million to 87 projects with a focus on IDD, including 28 CER studies and 56 engagement projects, with the majority of funding (\$101 million) dedicated to the former.

Although all PCORI IDD awards may involve people with autism, PCORI has funded 20 projects specific to autism, including 14 engagement awards, 5 research awards, and 2 other awards, totaling \$32 million, or 30 % of its IDD portfolio. Dr. Warren highlighted three PCORI-funded autism studies: (1) [Building Capacity for CER/PCOR Participation among Black, Indigenous, and other People of Color \(BIPOC\) Adults on the Autism Spectrum](#); (2) [Comparing Cognitive Behavioral Therapy versus Mindfulness-Based Therapy for Autistic Adults](#); and (3) [Improving Classroom Behaviors among Students with Symptoms of Autism Spectrum Disorder or Attention Deficit Hyperactivity Disorder](#). The third study is complete and found autistic students showed improvements in executive functioning behaviors when they participated in an experimental program called Unstuck and On Target versus a regular classroom program. The study received an award to expand the program.

Dr. Warren also shared examples of autism-related, short-term evidence projects, which a topic brief titled [Treatment of Insomnia and Other Sleep Disorders Among Persons with Developmental Disabilities](#) and a workshop on [Methodologic Challenges in Intellectual and Developmental Disabilities Research](#).

Committee Discussion

Multiple IACC members praised PCORI for mandating that awardees include a diversity of stakeholders in their work and dissemination as well as the proper compensation of these individuals for their roles. Ms. Myrick discussed her experiences serving on PCORI's stakeholder advisory board and expressed her strong support for conducting research that impacts communities otherwise excluded from autism research (e.g., low-income, poorly resourced). Dr. Robertson suggested that PCORI compile its practices into a best practices document for conducting autism and other disability-related research. This would enhance public- and private-sector research efforts. Dr. Cook answered that PCORI strives to share its lessons learned with researchers interested in patient- and stakeholder-engaged research. To this end, the PCORI website features several resources and forums for researchers, including a framework for engaging and compensating critical stakeholders in research. PCORI also has a

portfolio of projects around the science of engagement. Dr. Warren added that PCORI's working as a [multi-stakeholder team](#) website is the number one resource that she shares.

Dr. Halladay asked how PCORI-funded projects engage individuals with IDD in projects that require high cognitive functioning (e.g., economic costs, complex emotional issues). Dr. Cook explained that PCORI works to understand lived-experiences and seeks feedback from stakeholder groups during project design to ensure that participation is feasible for all groups, including those with IDD. Dr. Warren added that after an award is issued, researchers submit an engagement plan that PCORI monitors for progress and changes. Should shortcomings emerge in the plan or its execution, PCORI employs individuals with engagement expertise to close gaps, remove barriers, and confirm that the project meets PCORI standards for multistakeholder engagement.

Dr. Halladay clarified that her concern centers on the earliest stages of a study, where letter of intent (LOI) may not meet PCORI's standards for engagement. Individuals with IDD may not be able to participate in stakeholder teams at the same degree as those without intellectual disabilities. She emphasized the need for groups who fund research on IDD or autism, such as PCORI, to communicate and adjust expectations during the competitive submission stage.

Dr. Phan asked if there has been interest in intensive longitudinal studies to study long-term health outcomes. Dr. Cook explained that PCORI's observational studies tend to end follow-up after 3-4 years. PCORI researchers are considering extending the follow-up period of in-progress and upcoming observational studies to 7 years, which is particularly important when studying the transition from adolescence to adulthood. Dr. Paul Wang, Dr. Cook, and Dr. Warren expressed interest in future collaborations between PCORI and IACC.

Round Robin Updates

Dr. Alison Marvin shared that the Social Security Administration (SSA) recently redesigned its [website](#) to improve customer experience and self-service capabilities. In addition, SSA made a second round of awards through the Interventional Cooperative Agreement Program for research related to disability insurance and supplemental security income programs. These awards to Mathematica and Westat will benefit individuals with autism. SSA is seeking a new grant administrator for its small grants program. Lastly, SSA is promoting the ABLE Age Adjustment Act of 2021, which raised the ABLE account qualifying age of onset of disability from 26 to 46 years.

Dr. Judith Cooper shared that the National Institute on Deafness and Other Communication Disorders will be hosting a virtual webinar on January 24-25 on "[Minimally Verbal/Non-Speaking Individuals with Autism: Research Directions for Interventions to Promote Language and Communication](#)." The purpose of the webinar is to identify research needs and opportunities for improving language and communication outcomes for minimally verbal, non-speaking autistic children and adults. The webinar will focus on novel interventions, research designs and methods, and meaningful outcome measures. The planning committee and

attendees include individuals on the spectrum, non-speaking individuals with autism, parents of non-speaking children and adults, and clinicians, educators, and researchers with experience

Dr. Halladay shared that the Autism Science Foundation (ASF) recently announced the [recipients of the Profound Autism Pilots Grants](#). ASF also recently held a meeting of the Baby Siblings Research Consortium, a multidisciplinary, collaborative community of researchers and clinicians who have younger siblings with autism and are dedicated to identifying the early signs and symptoms (biological and behavioral) of autism. Finally, registration for ASF's 10th annual Day of Learning on March 30, 2023 will open in early February.

DC Autism Parents is working with a sexuality educator to plan an online sexuality and DD workshop. The organization is also working with the Family Voices' United to End Racism Against Children and Youth with Special Health Care Needs and their Families project. This project, originally developed for the Family Voices network, has developed a toolkit of resources to support individuals in anti-racism efforts in their states. Related to the PCORI engagement award, Ms. Myrick announced a training for autism researchers to engage the African American community, which will occur in late February or early March.

Dr. Wang shared that the Simons Foundation Autism Research Initiative has three new funding opportunities, two of which are related to diversity, equity, and inclusion. The first is to support the recruitment of members of underrepresented communities as subjects in research related to autism. The second is the recruitment of scientists who are members of underrepresented communities into the autism research community. The third funding opportunity is a new opportunity titled Cross Species Research, which will be especially relevant to sensory, motor, and sleep issues.

Dr. Robertson shared that AskJAN (Job Accommodation Network), which is funded by the DOL Office of Disability Employment Policy (ODEP), is hosting a free training webinar on April 13 focused on [accommodation solutions for neurodivergent workers](#). Also, ODEP partnered with Mathematica to conduct a long-term project on [Research Support Services for Employment of Young Adults on the Autism Spectrum](#). ODEP and Mathematica continue to release new resources and publications available for free to interested parties. ODEP has made available a resource on evidence describing the effectiveness of programs, models, and strategies to support employment outcomes for autistic young adults.

Dr. Jennifer Johnson shared that the Administration for Community Living (ACL) launched a project in 2022 that builds on previous efforts to address the needs of co-occurring IDD and mental health disabilities. ACL has funded the [National Center for Disability, Equity, and Intersectionality](#), to advance its work on health equity to address the ablism and discrimination that occurs in medical decision-making. ACL has also continued work with grantees to assist people with disabilities in getting vaccinated, with a focus on engaging community-based organizations in this effort.

Ms. Gassner commented that she is serving on a Stony Brook University project that received funding to offer free training to health clinicians in the state of New York on intellectual disability and autism without intellectual disability.

Dr. Daniels concluded the session, noting that the complete [Round Robin document](#) is available online.

Closing Remarks and Adjournment

Dr. Daniels and Dr. Gordon thanked the panelists and presenters for their insights.

The next IACC Full Committee Meeting will be held on [April 4, 2023](#).