

# Interagency Autism Coordinating Committee (IACC)

## Full Committee Meeting

*July 10, 2024*

*Revised on November 5, 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: Christy Huffman, Erica Schipper, Nancy Tuveson.

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The Interagency Autism Coordinating Committee (IACC, also referred to as “the Committee”) convened a hybrid meeting on Wednesday, July 10, 2024, from 10:00 a.m. to 5:00 p.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; **Thyria Alvarez**, M.S.W., U.S. Department of Housing and Urban Development (HUD) (representing Leah Lozier, Ph.D.); **Deirdra Assey**, M.A., U.S. Department of Justice (DOJ); **Maria Mercedes Avila**, Ph.D., M.S.W., M.Ed., University of Vermont Larner College of Medicine; **Bryan Bloomer**, Ph.D., Environmental Protection Agency (EPA) (representing Elaine Cohen Hubal, Ph.D.); **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; **Allyson Dean**, Ed.D., Administration for Children and Families (ACF); **Thomas Frazier**, Psy.D., Autism Speaks; **Dena Gassner**, M.S.W., Adelphi University; **Kristi Hardy**, Ph.D, M.D., National Institute of Neurological Disorders and Stroke (NINDS) (representing Walter Koroshetz, M.D.); **Craig Johnson**, M. Ed., Champions Clubs Foundation; **Jennifer Johnson**, Ed.D., Administration for Community Living (ACL); **Christy Kavulic**, Ed.D., U.S. Department of Education (ED); **Cindy Lawler**, Ph.D., National Institute of Environmental Health Sciences (NIEHS)(representing Richard Woychik, Ph.D.); **Leah Lozier**, Ph.D., HUD; **Alison Marvin**, Ph.D., Social Security Administration (SSA); **Kamila Mistry**, Ph.D., M.P.H., Agency for Healthcare Research and Quality (AHRQ); **Yetta Myrick**, B.A., DC Autism Parents; **Lindsey Nebeker**, B.A.; **Sunny Patel**, M.P.H., SAMHSA; **Scott Patterson**, Ph.D., HSSP, Department of Veterans Affairs (VA); **Jenny Mai Phan**, Ph.D., Children’s National Hospital; **JaLynn Prince**, B.F.A., Madison House 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); **Amanda Reichard**, Ph.D., ACL (representing Jennifer Johnson, Ed.D); **Susan Rivera**, Ph.D., University of Maryland; **Scott Michael Robertson**, Ph.D., U.S. Department of Labor (representing Taryn Mackenzie Williams, M.A.); **Barbara Roland**, M.B.S., LPC, Indian Health Service (IHS); **Stuart Shapira**, M.D., Ph.D., CDC; **Matthew Siegel**, M.D., Boston Children’s Hospital; **Jane Simoni**, Ph.D., National Institutes of Health (NIH) (representing Monica Bertagnolli, M.D.); **Ivanova Smith**, B.A., University of Washington; **Martine Solages**, M.D., U.S. Food and Drug Administration (FDA) (representing Tiffany Farchione, M.D); **Julie Lounds Taylor**, Ph.D., Vanderbilt University Medical Center; **Anna Tschiffely**, Ph.D., U.S. Department of Defense (DOD)(representing Nicole Williams, Ph.D.); **Paul Wang**, M.D, Simons Foundation; **Emily Weaver**, ED (representing Christy Kavulic, Ed.D.); **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; HHS National Autism Coordinator; Director, Office of National Autism Coordination (ONAC), NIMH*

Dr. Shelli Avenevoli welcomed participants to the meeting. Dr. Avenevoli thanked Dr. Joshua Gordon for his service as the previous IACC Chair and Dr. Susan Daniels for her continued service as IACC Executive Secretary. Dr. Daniels welcomed Ms. Deirdra Assey, the newest IACC member from the Department of Justice (DOJ).

Dr. Daniels noted that this meeting was the last IACC meeting under the current iteration of the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act. Under the current act, the Committee will sunset on September 30, 2024. The Autism CARES Act is currently in the reauthorization process.

The IACC voted to approve the [April 2024 minutes](#).

## National Autism Coordinator Update

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

Dr. Daniels began with relevant White House updates. First, in support of the [Executive Order \(EO\) on Increasing Access to High-Quality Care and Supporting Caregivers](#), the U.S. Department of Health and Human Services (HHS) selected 20 states to participate in two separate technical assistance programs. These programs will help participating states to better recruit, train, and retain direct support professionals who provide home- and community-based services (HCBS) for older adults and people with disabilities.

The Biden-Harris Administration also unveiled a [final rule](#) to protect and improve how millions of eligible people apply for, renew, and maintain health care coverage through Medicaid, the Children's Health Insurance Program (CHIP), and the Basic Health Program (BHP).

The Disability Data Interagency Working Group for the National Science and Technology Council, within the White House Office of Science and Technology Policy, coordinates activities across multiple federal departments and agencies to strengthen the federal government's use of disability data to advance equity for people with disabilities. This working group plans to create a Federal Evidence Agenda on Disability Equity by Fall 2024. As part of the development of the Federal Evidence Agenda on Disability Equity, the working group issued a [request for information \(RFI\)](#) to solicit responses on considerations for collecting data on disabilities and ensuring these data are inclusive and publicly accessible. Dr. Daniels encouraged IACC members and attendees to respond to this RFI to ensure representation of people with autism and intellectual and developmental disabilities (IDD).

Dr. Daniels then provided relevant legislative updates. The next iteration of the Autism CARES Act will reauthorize IACC funding through September 2029. On June 12, the House Committee on Energy and Commerce voted unanimously to advance the bill to the full House of Representatives. Updates related to this legislation can be found on the [IACC website](#).

On June 11, 2024, the House Appropriations Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Subcommittee of the House Committee on Appropriations held a hearing on its fiscal year (FY) 2025 appropriations bill. Section 722 of that bill includes a proposed amendment that would prevent the U.S. Food and Drug Administration (FDA) from banning devices, including electric shock devices (ESDs), that have been ordered for an individual by a court. The House Committee on Appropriations will vote on this proposed amendment on July 10. This amendment was rejected.

Next, Dr. Daniels provided federal committee updates:

- Interagency Committee on Disability Research (ICDR) released an updated [Federal Statutory Definitions of Disability](#) white paper as well as a [Surveying the Landscape of Disability Data and Statistics](#) toolkit. ICDR recently held a Lunch & Learn webinar that featured a series of presentations from agencies that fund disability and rehabilitation research. ICDR also held its annual stakeholder meeting on June 27.
- RAISE Family Caregiving Advisory Council (FCAC) held a joint meeting with the Advisory Council to Support Grandparents Raising Grandchildren on June 13 to discuss support for grandparent caregivers. Meeting information is available on [the FCAC website](#).
- National Council on Disability (NCD) held its [recent council meeting](#) on June 27.
- Disability Advisory Committee (DAC) held its [recent meeting](#) on May 16, which included a discussion on digital accessibility.
- Coordinating Council on Access and Mobility (CCAM)'s Federal Transit Administration (FTA) recently announced [17 projects in 15 states](#) that will fund improvements to public transportation for people with disabilities, older adults, and individuals with low incomes.
- Federal Partners in Transition (FPT) held a Steering Committee Meeting and a General Assembly Meeting on May 16.
- Children's Interagency Coordinating Council (CICC) held an [event](#) on July 22 that explored issues and opportunities related to benefit access and utilization for children and families experiencing poverty.

Dr. Daniels then provided federal department and agency updates:

- HHS released a [statement](#) to mark the 1-year anniversary of the [EO on Increasing Access to High-Quality Care and Supporting Caregivers](#). To support implementation of this EO, the Administration for Community Living (ACL) announced nearly \$2 million to support implementation of the *National Strategy to Support Family Caregivers*.
- DOJ, ACL, and the HHS Office for Civil Rights (OCR) held an [event](#) celebrating the 25th anniversary of the U.S. Supreme Court decision in *Olmstead v. L.C.*, which was also the

subject of an ACL [blog post](#). HHS OCR also [finalized a rule](#) strengthening protections against disability discrimination under Section 504 of the Rehabilitation Act of 1973.

- Two upcoming NIMH webinars will explore the notion of mental health conditions as disabilities. On August 8, Nev Jones, Ph.D. will present on “[Transforming Mental Health Disability Research Through Lived Experience Leadership and Co-Production.](#)”

Dr. Daniels concluded her presentation with updates regarding nongovernmental organizations (NGOs):

- The 17th Session of the Conference of States Parties (COSP17) to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) met on June 11-13 at United Nations (UN) headquarters in New York City. The overarching theme of this meeting was rethinking disability inclusion in preparation for the Summit of the Future. Dr. Daniels served on the U.S. Delegation to this conference and advocated for greater inclusion across multiple aspects of life for individuals with autism and IDD. IACC member Ms. Dena Gassner spoke about employment and family support. Three side events at COSP17 focused on autism: (1) an Australian event on its upcoming National Autism Strategy; (2) a South African event on autistic voices in Africa; and (3) a joint event managed by Ireland, New Zealand, Hungary, and the World Health Organization (WHO) on supporting autistic people in society.
- To aid neurodivergent employees in the federal workplace, the University of Washington recently developed the [Neurodiversity @ Work Playbook: Federal Edition](#). This report details how federal agencies can establish neurodiversity employment programs and inclusive workplaces.

## Discussion

Ms. Yetta Myrick expressed concern that the Disability Data Interagency Working Group’s RFI will stop accepting responses 5 days after this meeting (i.e., July 15), which may not provide sufficient time for responses from many NGOs. She suggested that IACC provide additional notice to nonfederal IACC members regarding future RFIs. Dr. Daniels responded that IACC is considering potential approaches (e.g., biweekly or monthly emails) to notifying IACC members about RFIs and similar feedback opportunities.

## Round Robin Updates

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

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

Ms. JaLynn Prince described the [Stop the Stigma Together](#) project, which focuses on reducing stigma around mental health conditions and substance use disorders. The project addresses co-occurring mental health conditions (e.g., depression, anxiety) that are often experienced by autistic people and their caregivers, and stresses the importance of supporting caregiver health.

Ms. Ivanova Smith provided two updates:

- The [University of Washington Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\) Self-Advocate Discipline](#) recently celebrated its 10th anniversary.
- Washington state recently passed the “Nothing About Us Without Us” Act, which requires state work groups, advisory committees, and task forces focused on issues that affect underrepresented communities (e.g., people with disabilities) to include those with lived experiences on their rosters.

Dr. Paul Wang provided updates from the Simons Foundation Autism Research Initiative (SFARI):

- [SFARI website](#) offers multiple resources for autism researchers.
- SFARI’s annual grant program, “Fellows to Faculty Award,” aims to support the transition from senior postdoctoral to first independent faculty positions. The program focuses on candidates from groups that are underrepresented in science (e.g., racial and ethnic minorities, individuals with autism).
- SFARI is expanding its [Autism in the Workplace initiative](#), which provides funding to nonprofit employers to create infrastructure and training to support autistic individuals in the workplace.

Dr. Thomas Frazier provided updates on Autism Speaks:

- The next iteration of the Autism CARES Act includes language related to creating a new Autism Intervention Research Network for communication needs, increasing research focus on aging and autism, and increasing the number of developmental and behavioral pediatricians.
- Autism Speaks is advocating for passage of the Autism Family Caregivers Act. This bill would create a new pilot program at the Health Resources and Services Administration (HRSA) to fund 25 local caregiver skills training (CST) sites in 15 states.
- Autism Speaks also recently joined a coalition of 167 stakeholders that signed a letter requesting the creation of an Office of Caregiver Health within HHS. Additionally, Autism Speaks’ MSSNG genomic database has been updated.
- The Early Childhood Development Action Network (ECDAN) will host a webinar on July 30 titled “Toward Better, Inclusive ECD: Addressing the needs and rights of young children with developmental disabilities in policy design and service delivery.” The webinar will discuss the [2023 Global Report on Children with Developmental Disabilities](#), which was co-authored by WHO and the United Nations Children’s Fund (UNICEF).

Dr. Bryan Bloomer shared updates from the Environmental Protection Agency (EPA). The director of their Office of Civil Rights developed a multiyear initiative to ensure that the EPA is a safe and welcoming workplace for people with disabilities.



Ms. Myrick shared that the Centers for Disease Control and Prevention (CDC) [Learn the Signs. Act Early](#) program celebrated its 20th anniversary. To help bridge the gap between initial autism diagnosis and the initiation of support for parents and caregivers of autistic children, Ms. Myrick created a document that helps parents and caregivers identify relevant post-diagnosis goals (e.g., social and emotional development, speech therapy) for their child.

Dr. Scott Robertson provided updates from the U.S. Department of Labor (DOL). The theme for this year's National Disability Employment Awareness Month in October will be "[Access to Good Jobs for All.](#)" Additionally, DOL recently held webinars on cognitive disabilities and neurodiversity and mental health. DOL also recently [announced](#) cooperative agreements to help youth and young adults with disabilities overcome obstacles to employment.

## **Federal Interagency Workgroup on Autism (FIWA) Presentations**

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

Dr. Daniels introduced FIWA, which is a group of federal officials who coordinate federal efforts regarding autism, including implementation of the IACC Strategic Plan and other activities required under the Autism CARES Act. This session focused on presentations from FIWA representatives who did not present during the January IACC meeting.

## **Health Resources and Services Administration**

*Lauren Raskin Ramos, M.P.H., Director, Division of Maternal and Child Health Workforce Development, Maternal and Child Health Bureau, HRSA*

Ms. Ramos outlined HRSA's autism programs, which focus on three programmatic areas: (1) training healthcare and other professionals to screen, refer, and provide services for children with autism or other developmental disabilities (DD); (2) promoting evidence-based interventions for individuals with autism or other DD; and (3) ensuring implementation of best practices in transition for youth with autism.

For training, HRSA supports the [LEND](#) program, which provides interdisciplinary training for health care and other professionals who address the needs of individuals with autism and other DD. The training provides academic, clinical, leadership, and community based opportunities. Participants learn to screen for autism and other DD, refer to services, and care for patients with autism/DD. LEND funds 60 training programs across the United States. Each year LEND programs reach nearly 18,000 trainees in more than 25 disciplines and provide continuing education to more than 380,000 practicing healthcare professionals.

HRSA also supports the [Developmental-Behavioral Pediatrics \(DBP\) program](#), which increases access to evaluation and services for children with developmental and behavioral concerns. DBP funds 13 training programs that support 3-year fellowships to pediatricians. They also provide continued education and have expanded training to include mini-fellowships and intensive training experiences. The program reaches 1,900 trainees and 38,000 practicing



professionals each year. HRSA also supports an Interdisciplinary Technical Assistance Center that is housed at the [Association of University Centers on Disabilities \(AUCD\)](#).

To promote research on evidence-based interventions, HRSA supports three types of research portfolios, all of which align with the IACC Strategic Plan:

- Autism Research Networks, which focus on physical and behavioral health aspects of autism: (1) Autism Intervention Research Network on Physical Health (AIR-P), (2) Autism Intervention Research Network on Behavioral Health (AIR-B), (3) Developmental Behavioral Pediatrics Research Network (DBPNet), and (4) Healthy Weight Research Network for Children with Autism & DD (HWRN).
- Autism Single Investigator Innovation Programs (SIIPs), which focus on emerging and understudied issues relating to autism: (1) Autism Longitudinal Data Project (ALDP) and (2) Autism Transitions Research Project (ATRP).
- Investigator-Initiated Programs, which enable investigators to test interventions in underserved populations or perform secondary data analyses on interventions: (1) Autism Field-Initiated Innovative Research Studies (FIRST) and (2) Autism Secondary Data Analysis Research (SDAR).

HRSA recently redesigned their Best Practices Program and created the [Transition for Youth with Autism and/or Epilepsy \(YAES\)](#) program. This program develops and advances national-, state-, and community-level frameworks that support successful transition from child- to adult-serving systems for youth with autism and/or epilepsy who have complex health and social needs and require a higher level of family support and coordination. Transition services under this program include healthcare, postsecondary education, employment, and independent/daily living activities.

HRSA also supports the Supporting Access for Everyone (SAFE) Initiative, which is an inter-professional and stakeholder-driven initiative to establish a standard of practice in healthcare for supporting youth with neurodevelopmental disabilities. In collaboration with health professionals and advocates, SAFE developed 10 inter-professional consensus statements for healthcare practices across five areas: (1) training; (2) communication; (3) access and planning; (4) diversity, equity, inclusion, belonging, and anti-ableism; and (5) policy and structural change. SAFE published the [consensus statement](#) in *Pediatrics*, which is also available on the [SAFE website](#), along with an executive summary and plain language summary.

### **Congressionally Directed Medical Research Programs (CDRMP)**

*Nicole Williams, Ph.D., Program Manager, CDRMP, U.S. Department of Defense*

CDMRP funds medical research across 35 different diseases and disorders, including many types of cancer, spinal cord injuries, Alzheimer's disease, traumatic brain injury, and autism. CDMRP's Autism Research Program (ARP) seeks to promote innovative research that advances the understanding of autism and leads to improved outcomes for Service Members, their families, and the American public. ARP was launched in 2007 with an annual appropriation of \$7.5

million, which doubled to \$15 million by 2020 and has remained level since then. Between FY 2007 and FY 2024, ARP has received almost \$165 million in total which has translated to 220 awards.

The ARP strategic plan identifies four goals: (1) advance effective treatments and interventions for autism; (2) address needs of persons with autism into adulthood; (3) support those caring the autism community; and (4) understand causes, mechanisms, and signs of autism. CDMRP also encourages researchers to involve autistic individuals, caregivers, and family members in research teams and projects.

FY 2024 funding opportunities span different types of autism research, from initial discovery research to clinical trials. They introduce four new areas of interest: (1) community-supported and participatory research interventions; (2) factors impacting quality of life for current and former military families with an autistic family member; (3) gender identity and sexual health, including puberty and sexual education for autistic individuals; and (4) new advances in autism interventions using a strength-based model. In addition, they support early career investigators, including autistic researchers, through their Career Development Award and the Clinical Trial Award: Early Career Investigator Option.

### **Administration for Children and Families (ACF)**

*Allyson Dean, Ed.D., Inclusion and Disabilities Services Specialist, Office of Head Start, ACF*

The ACF promotes the economic and social well-being of families, children, individuals, and communities. Toward this overall goal, ACF supports early childhood care and education initiatives that relate to autism, including programs that assist with screening for autism and other development differences. To achieve this, they partner with other governmental agencies, such as CDC and the U.S. Department of Education (ED)' Office of Special Education Programs (OSEP), to promote their materials for families and training programs for providers.

ACF supports autistic children and their caregivers through multiple support programs, including Head Start, childcare programs, and other ACF pre-kindergarten programs. ACF partners with Individuals with Disabilities Education Act (IDEA) stakeholders to deliver Parts B and C services locally. ACF also recently partnered with ED to release a [joint policy statement](#) on the inclusion of children with disabilities in early childhood programs.

ACF also provides resources for early childhood education (ECE) and childcare providers, particularly under the Head Start program. ACF developed the [Head Start Center for Inclusion](#) website, which provides many resources (e.g., fact sheets, training modules) on autism. ACF also launched the [Head Start Inclusion Lab app](#), which helps ECE and childcare providers ensure that children with autism and other DD have appropriate and tailored support services. They also issue policy and guidance to states, territories, and tribal leaders on important topics such as early childhood behavioral mental health. Finally, last year ACF provided \$1.4 million in funding for children to receive early childhood services.

**Indian Health Service (IHS)**

*Barbara Roland, M.B.S., L.P.C., Supervisory Healthcare Administrator (Mental Health Chief), Division of Behavioral Health, Office of Clinical and Preventative Services, IHS*

The IHS provides clinical assessment services for autism as well as other mental health conditions (e.g., depression, anxiety) to American Indian and Alaska Native (AI/AN) populations. Patients may be referred to outside health care providers for these services. The Pediatric Neurodevelopmental & Behavioral Health Clinical Consultation program enables health care providers to seek expert advice in order to provide care for AI/AN youth with autism and other neurodevelopmental conditions.

IHS supports autistic youth through its [Indian Children's Program](#). As part of this program, IHS offers webinars and technical support for healthcare providers through the IHS Telebehavioral Health Center of Excellence (TBHCE). TBHCE offers multiple webinars on autism, including how autism interacts with other co-occurring mental health conditions (e.g., disruptive disorders, anxiety disorders, attention-deficit/hyperactivity disorder [ADHD]).

**Administration for Strategic Preparedness and Response (ASPR)**

*Maxine Kellman, D.V.M., Ph.D., P.M.P.; Senior Public Health Analyst; Office of Strategy, Policy, and Requirements; ASPR*

ASPR leads the nation's medical and public health preparedness for, response to, and recovery from disasters and public health emergencies. As part of this public health preparedness, ASPR includes two advisory committees that develop recommendations relevant to older adults and people with disabilities:

- [National Advisory Committee on Seniors and Disasters \(NACSD\)](#) provides advice and consultation to the HHS Secretary and ASPR regarding medical and public health activities as they pertain to the unique needs of older adults in preparation for, response to, and recovery from all-hazards emergencies and disasters.
- [National Advisory Committee on Individuals with Disabilities and Disasters \(NACIDD\)](#) provides advice and consultation to the HHS Secretary and ASPR regarding medical and public health activities as they pertain to the unique needs of individuals with disabilities in preparation for, response to, and recovery from all-hazards emergencies and disasters.

Both committees fall under the authority of the Federal Advisory Committee Act (FACA) and the Pandemic and All-Hazards Preparedness and Advancing Innovation Act (PAHPAIA) of 2019. Under FACA, both committees are required to each have seven non-Federal voting members who serve 3-year terms as well as 10 Federal non-voting ex-officio members.

NACSD and NACIDD offer recommendations that focus on community readiness, disaster preparedness infrastructure, and behavioral health considerations. These recommendations focus on serving these populations before, during, and after disaster events.

NACSD developed its first recommendations in May 2023:

- Advance the dissemination of accessible, available, and usable emergency preparedness, response, recovery, and mitigation information and communication support services.
- Expand trained community disaster partners.
- Establish and sustain Disaster Care Centers of Excellence for older adults as a model of care for regional collaboration, virtual support, and specialized guidance.
- Capitalize upon the opportunity to expand the existing Long-Term Care Ombudsman (LTCO) Program with dedicated resources and additional employees to advocate for disaster preparedness, response, and recovery planning across the long-term care continuum.

In September 2023, NACSD completed another set of recommendations, advising that HHS should seek funding through the Older Americans Act Title VII for an Office of State LTCO Program to:

- Develop and provide an emergency preparedness training curriculum targeted for teaching resident and family councils in long-term care facilities about emergency preparedness, response, and recovery.
- Provide and require grant funding through HHS for emergency management and health coalitions to integrate advocates, including representatives of the LTCO program, into local coordination for disaster and health emergencies planning.
- Encourage state, local, tribal, or territorial (SLTT) emergency responders to include long-term care ombudsman in their regularly scheduled prep meetings and drills related to issues of long-term care advocacy.

Additional recommendations focused long-term care, such as requiring nursing homes to be certified in disaster preparedness and developing supports and technical guidance for patients, staff, and families.

In September 2023, NACIDD developed three recommendations related to disaster preparedness and disabilities:

- Review and correct HHS's use of blanket waivers under Section 1135 of the Social Security Act to ensure appropriate care and legal protections during public health emergencies (PHEs).
- Include timely development and distribution of videos, press releases, press conferences, and all other communication in American Sign Language and regional or locally used sign languages appropriate for the populations affected by a PHE.
- Develop, require, and frequently update brief just-in-time training for all PHE responders on disaster-related accessibility, equity, inclusion, and health maintenance needs of people with disabilities, and the requirement for compliance with all applicable disability laws.

**Federal Emergency Management Agency (FEMA)**

*Sherman Gillums, Jr., Ed.D., Director, Office of Disability Integration and Coordination, FEMA, Department of Homeland Security*

The mission of FEMA is to help people before, during, and after disasters. Further details can be found in the [2022-2026 FEMA Strategic Plan](#). As part of this mission, the Post-Katrina Emergency Management Reform Act of 2006 established the FEMA Disability Coordinator. The coordinator accounts for the needs of people with disabilities, older adults, and other people with access and functional needs during and after disasters. This position was established due to data that found that approximately 80% of people who died due to Hurricane Katrina and subsequent disasters were older adults and people with disabilities. [EO 13985 on Advancing Racial Equity and Support for Underserved Communities Through The Federal Government](#) sought to further support people who disproportionately suffer during disasters by establishing the FEMA Office of Disability Integration and Coordination. This EO specified measures and approaches to ensure equity in disaster planning.

Research conducted by the FEMA Office of Disability Integration and Coordination identified 14 points of inequity in disaster preparedness, response, and recovery for people with disabilities:

1. Inclusive planning that preemptively accounts for the needs of people with disabilities through inclusion.
2. Disaster alerts and warnings through multiple channels and across a range of communication pathways.
3. Information that is clear, complete, consistent, certain, and accurate for the broadest audience and accessibility types.
4. Evacuation and transportation that is accessible and accounts for all functional needs.
5. Available emergency contact network and culturally aware search and rescue operations.
6. Sheltering that allows for sustained family and caregiver unification that meets a variety of needs in an accessible, integrated setting.
7. Communication aids and assistive services, including availability of sign language and certified deaf interpreters, accessibility kits, and Section 508-compliant web-based content.
8. Recovery/mitigation plans that account for whole-of-community access and functioning in rebuilding and “pro-building” opportunities.
9. Medical care, including access to primary, emergency, and mental health care as well as prescription medication points of distribution.
10. Accounting for power dependency for critical life-sustaining medical devices (e.g., dialysis, oxygen, and feeding tube equipment).
11. Ensuring access to special diets (e.g., medically necessary meals and appropriate dietary options) and timely access to potable water.
12. Registration for disaster services and timely access to the full range of FEMA support for disaster recovery.

13. Accessible housing options that account for the full range of needs of people with disabilities.
14. Full community reintegration, including home, work, and school life.

Dr. Sherman Gillums illustrated the importance of these factors using case studies from Hurricane Ian. First, a mother with two autistic sons sheltered in their car rather than a congregate shelter because of concerns about stigma and lack of understanding regarding her sons' behaviors. This case study demonstrates how autistic people, and their families often must cope with societal attitudes and perceptions, even during a disaster.

Second, during the hurricane, a 6-year-old boy with autism and his older brother both died by drowning after the little boy wandered off alone. This case study demonstrates the importance of educating first responders on autism as well as common issues (e.g., tendency to wander off, attraction to water). These considerations may impact where families are sheltered to prevent children from wandering off.

Third, a 7-year-old autistic boy wore a Bendy & The Ink Machine costume during the hurricane to cope with the noise, uncertainty, and darkness during the hurricane. This demonstrates how unique factors can help children with autism cope with stressful events, and how families know about these unique factors.

Dr. Gillums concluded the presentation by describing how the needs of the autistic community were considered during disaster responses in Guam following Typhoon Mawar. The FEMA Disability Integration Workforce collaborated with the autistic community to develop messaging and instructions regarding power outages. FEMA also released a free training entitled [IS-368.A: Including People with Disabilities in Disaster Operations](#), which describes how FEMA assists people with disabilities during and after disasters.

### **Discussion**

Dr. Wang noted that he is an alum of the HRSA LEND program and emphasized the importance of LEND's interdisciplinary approach to training. He also highlighted the importance of the SAFE Initiative and suggested that future IACC meetings explore this initiative in more detail.

Ms. Myrick asked Dr. Gillums for additional details on how FEMA supported parents and caregivers of autistic people in Guam during and after Typhoon Mawar. Dr. Gillums described working with experts on the ground, such as helping the American Red Cross coordinate with local autism advocacy organizations (e.g., Autism Speaks). FEMA also coordinated with these groups develop culturally messaging that accounted for unique challenges these families experience. Because internet availability was limited during and immediately after the typhoon, FEMA undertook a radio campaign to transmit important information.

Ms. Gassner expressed concern that many of the FIWA presentations focus mainly on families of children with autism and did not describe supports for adults or parents on the autism spectrum with autistic children. She asked how autistic adults are involved in the decision-

making processes for policies and protocols. Dr. Williams stated that autistic advocates are involved in all CDMRP programs and processes, such as peer and programmatic review processes. The participation of autistic researchers has also increased. Dr. Allyson Dean noted that ACF recently launched a website to support adults and family members with disabilities. This site focuses on autism, learning differences, and cognitive disabilities. ACF also partners with the Parent Training Information Center to support families with disabilities.

Dr. Gillums also described how FEMA, in collaboration with the National Association of Councils on Development Disabilities (NACDD), is educating first responders on autism and identifying ways to best help autistic people during and after disasters. FEMA representatives recently participated in a podcast with Robin Troutman, Chief Executive Officer of NACDD, on the intersection of disaster responses and autism and DD. Dr. Jenny Mai Phan suggested that IACC develop a working group to collaborate with FEMA on disaster response approaches, especially with the increase in the frequency of natural disasters. Dr. Gillums stated that they usually collaborate with stakeholders living in affected areas, and suggested that IACC can help FEMA coordinate with disability and disaster preparedness leaders in each state.

## **IACC Committee Business**

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

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

Dr. Daniels provided an overview of IACC accomplishments under the current iteration of the Autism CARES Act. Dr. Daniels thanked the 80 different individuals who have served in various capacities (e.g., members, alternates) on the Committee since 2021. Additionally, many members of the public regularly attended IACC meetings, responded to RFIs, and provided public comments.

Between January 2021 and July 2024, IACC held 11 Full Committee meetings and 1 working group meeting on the IACC Strategic Plan. These meetings covered a variety of topics, including housing, employment, mental health, needs across the autism spectrum, justice and law enforcement interactions, impacts of the COVID-19 pandemic, and family caregiving. During this period, IACC completed six reports (1 strategic plan, 3 Summary of Advances, 2 Portfolio Analysis Reports), with three reports pending (1 strategic plan, 1 portfolio analysis, and 1 Summary of Advances).

A draft reauthorization of the Autism CARES Act is currently under consideration. HHS and Office of National Autism Coordination (ONAC) will solicit nominations for new members after the new legislation passes. If the Autism CARES Act is reauthorized by September 30, then current IACC member terms will be extended 180 days to finish current projects.

Multiple IACC members expressed appreciation for the provision of disability accommodations and support during meetings.



ONAC has prepared the draft *2023 IACC Summary of Advances* report, which will be sent to IACC members for review and comments. Following comments from members, IACC will prepare the final report, with publication anticipated in late summer 2024.

The article by [Jones et al. \(2023\)](#) that was selected for the 2023 Summary of Advances has a [companion article](#), and the author requested that both articles be included in the report. IACC members voted to ask ONAC to review both articles and decide whether both articles must be included to demonstrate the scientific advance. If so, ONAC will create a single summary of both articles; otherwise, ONAC will include a brief note about the companion article in the summary of the selected article.

For the *2024 IACC Summary of Advances*, IACC members can nominate articles through the end of 2024. In early 2025, ONAC will contact current IACC members to vote on nominated articles for inclusion in the 2024 report.

In October 2023, IACC voted to focus its *2024 IACC Strategic Plan Update* on co-occurring physical and mental health conditions and their impacts on health outcomes among autistic people. ONAC is currently completing a draft of this report and will send this draft to committee members for review. The draft will be published on the IACC website along with a description of activities used to develop the report (e.g., RFI and workshops on co-occurring conditions). ONAC will revise the Strategic Plan Update based on feedback from IACC members with the goal of publishing the final report by December 2024.

Dr. Daniels provided an overview of the 2024 Strategic Plan Update chapters and the topics included in each:

- Introduction
  - Epidemiology of co-occurring conditions
  - Health disparities
  - Recent IACC activities and interest that relate to co-occurring conditions
  - Community perceptions of research and services need, including summary of RFI responses
- Chapter 1: Co-occurring Physical Health Conditions
  - Epilepsy
  - Gastrointestinal issues and disorders
  - Sleep issues and disorders
  - Sensory and motor challenges
  - Ehlers-Danlos syndromes and dysautonomia
  - Health in older adulthood and aging-related health conditions
- Chapter 2: Co-Occurring Mental Health Conditions
  - Anxiety disorders
  - ADHD
  - Depression
  - Obsessive-compulsive disorder (OCD)

- Self-injurious behavior (SIB), aggression, and emotional dysregulation
- Suicidality
- Additional mental health conditions identified by RFI respondents, including feeding and eating disorders, gender dysphoria, Pathological Demand Avoidance (PDA), tic disorders (e.g., Tourette syndrome), and trauma
- Chapter 3: Co-Occurring Intellectual, Communication, and Other DD
  - Intellectual disabilities
  - Communication challenges
  - Related DD, including Fragile X syndrome, Rett syndrome, Phelan-McDermid syndrome, Tuberous Sclerosis Complex, and Down syndrome
- Chapter 4: Health Care Service Provision
  - Accessibility
  - Patient-provider interactions
  - Considerations for individuals with high support needs
  - Reducing disparities
  - Impact of COVID-19

Ms. Gassner emphasized that communication challenges should be framed as a complex spectrum rather than as a dichotomy between “speaking” and “non-speaking.” Many autistic people who can verbally communicate may still experience intermittent or context-specific communication challenges (e.g., speaking on a telephone).

Multiple IACC members expressed concern about including PDA in the list of co-occurring conditions because PDA is not an officially recognized diagnosis in the *Diagnostic and Statistical Manual, 5th Edition* (DSM-5) or standard medical coding classifications (e.g., ICD-11). PDA remains a contentious topic within the autism community. Ms. Sam Crane suggested including PDA in the Strategic Plan Update alongside a description of the need for more research to investigate whether PDA is a valid psychological diagnosis. IACC members agreed to sharing the report with the previous working group before publication.

## Public Comments Session

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

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

*Oni Celestin, Ph.D., Deputy Director, ONAC, NIMH*

## Oral Comments

Ms. Jackie Kancir spoke on behalf of the National Council on Severe Autism (NCSA) on the critical issue of caregiving for people with “profound autism.” She described how many family caregivers live in a persistent state of crisis due to intense behaviors that require support from an entire family. Caregivers and families often face these burdens due to inadequate support provided under Medicaid HCBS waivers.

NCSA recommends that IACC authorize a report on autism caregiver burden across the lifespan and develop a strategic plan outlining solutions to secure the wellbeing of family caregivers, including distinct analyses for caregivers of people with “profound autism.” This strategic plan should also explore caregiver physical and mental health, financial stability, educational and vocational opportunity opportunities, and food and housing security. NCSA also encourages IACC to include family caregivers of people with autism who have high support needs.

Ms. Amanda Lopez is a speech language pathologist from Sam’s Sibs Stick Together, a group that supports sibling caregivers of autistic people. Sam’s Sibs Stick Together collaborated with Dr. Alycia Halladay and the Autism Science Foundation to launch a webinar series on the experiences of sibling caregivers, research on sibling caregiver relationships, transition planning, and changes in needs of caregivers over time. Ms. Lopez facilitates a separate adult sibling caregiver support group with multiple goals for group participants to share joys and concerns, provide a safe space, learn how to be caregivers, and share resources and information.

To help sibling caregivers prepare to be the primary caregiver, the Sam’s Sibs Stick Together website has resources on stress management, transition information, and research about the sibling experience. Ms. Lopez also welcomed any adult sibling caregivers to join her support group.

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

IACC received a total of 58 written [public comments](#). Comments focused on the following topics: the experiences of family caregivers and the needs of autistic individuals with high-support needs (47); research and service needs, resources, and policy implications (6); the inclusion of autistic perspectives in research (1); the role of IACC and the federal government (2); and potential causes of autism (2).

### **Committee Discussion**

Ms. Gassner emphasized that perspectives related to high support needs autism are represented on the IACC. Several IACC members, as well as panelists, have experience as parental caregivers for autistic people with high support needs. She noted that IACC also frequently considers the experiences of autistic parents, who face challenges posed by their own disabilities as well by their role as caregiver for their autistic children. This situation can create additional burdens for these autistic parents, requiring them to navigate complex assistance systems both for themselves and for their children.

Ms. Crane noted the lack of legal protections for non-speaking autistic people in home- and community-based (HCBS) settings. Protection & Advocacy Systems (P&As) can monitor potential signs of neglect and abuse in institutional settings if contacted by a disabled person. However, many non-speaking autistic people may be unable to contact P&As on their own, creating a potential gap in oversight of HCBS settings. Dr. Robertson also noted that access to HCBS enhances health and well-being and can lead to greater independence and employment.

He also emphasized the need to ensure access to alternative augmented communication (AAC) and other forms of communication for non-speaking individuals.

Dr. Julie Lounds Taylor emphasized the shortage and high turnover of direct support professionals for all people with disabilities, including autistic people. These shortages and turnover can be very disruptive to autistic people and their families and may hinder the ability of many autistic people to fully live in and engage with their communities. Multiple IACC members noted the impact of this crisis on families. They recommended that IACC focus on the shortage of direct support professionals, including ways to support these professionals and reduce turnover.

IACC members discussed potential non-family sources (e.g., employers, educators) of support for people with autism other than direct support professionals. Autistic individuals and their families also need additional support for the transition to adulthood, which could reduce parents' concerns about their child's future. Families of autistic people need more education on different assistance programs and how to navigate them. Supports should also be person-directed, where individuals can choose their own caregivers. These supports are often unavailable to people with the highest needs.

Ms. Gassner asserted that many assistance programs (e.g., Supplemental Security Income [SSI], Supplemental Nutrition Assistance Program [SNAP]) are often managed by agencies that have a hidden curriculum and may aim to deny coverage. She advocated for the recruitment of system navigators who are independent of these agencies to help families navigate these complex systems. Ms. Crane agreed and noted that the Quality Trust for Individuals with Disabilities provides similar services to District of Columbia (DC) residents, and these services could be expanded to other states and localities.

## **Perspectives on Family Caregiving**

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

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

This session was designed to acknowledge the work family caregivers perform on behalf of their loved ones and to highlight available resources. The panel provides the opportunity to learn about the work of ACL and other organizations related to family caregiving. This session can help identify areas for potential synergy and collaboration with ACL.

## **Resources for Family Caregivers from the Administration for Community Living**

*Jennifer Johnson, Ed.D., Deputy Director, Administration on Disabilities, ACL*

ACL's mission is to ensure that all people, regardless of age and disability, can live and fully communicate in their community. Family caregivers fill major gaps in support for older adults and people with disabilities, helping them remain in the community and avoid

institutionalization. The significance of family caregivers is recognized by a [recent EO on Increasing Access to High-Quality Care and Supporting Caregivers](#).

The United States faces an increasing shortage of direct support professionals, with an estimated 1 million additional direct support professionals needed by 2030. As a result, families are assuming greater caregiving responsibilities. Currently approximately 53 million people act as family caregivers in the United States, about 2.7 million of whom are grandparents. These numbers lead to an estimated \$600 billion in unpaid care and \$500 billion in lost income annually. Caregiving involves many roles, including navigating assistance programs, assisting with transportation, and acting as personal care attendants.

To address the issue of caregiver stress, ACL provides support to family caregivers through various programs and projects. The [Developmental Disabilities Assistance and Bill of Rights Act of 2000](#) authorized funding for several programs overseen by ACL's Administration on Intellectual and Developmental Disabilities which work to support families and improve state policies, including the [State Councils on Developmental Disabilities](#), [University Centers for Excellence in Developmental Disabilities \(UCEDD\)](#), and the [Protection and Advocacy \(P&A\) systems](#). ACL funds national projects to build stronger family support systems, such as the [Charting the LifeCourse tools](#) used in numerous states and local communities. ACL also funds a [National Association of Councils on Developmental Disabilities \(NACDD\)](#) project called [Bridging the Aging and Disabilities Networks](#), which aims to create coordinated services to address individual needs, plans, and preferences for both aging caregivers and adults with IDD across the lifespan. ACL oversees and supports the [President's Committee for People with Intellectual Disabilities](#), which is currently drafting a report on the importance of high-quality HCBS in supporting people with IDD. Although not specifically centered on family caregiving, the committee's recommendations could positively impact families.

ACL is involved in multiple activities to address the direct support professional shortage. For example, ACL supports the [Direct Care Workforce Strategies Center](#), which provides resources, technical assistance, and training to 20 states to recruit and retaining direct support professionals. The [Center for Youth Voice, Youth Choice](#) addresses the school-to-guardianship pipeline by informing youth about alternatives to guardianship as they become legal adults. This center recruits and trains youth ambassadors, and also develops resources for families to support their youth and understand alternatives to guardianship. Finally, [The Lifespan Respite Care Program](#), administered by ACL since 2009, awards grants to eligible agencies in 38 states and DC to develop accessible community-based respite care services for caregivers of children and adults of all age groups and abilities. The program aims to elevate the quality, availability, dissemination, and coordination of respite care programs. As part of this work, ACL has funded the [ARCH National Respite Network and Resource Center](#) since 2009 to provide technical assistance to Lifespan Respite Care Program grantees.

**Resources for Family Caregivers from the Administration for Community Living (ACL)**

*Jonathan Westin, J.D., M.P.A., Aging Services Program Specialist, Office of Supportive and Caregiver Services, ACL*

Dr. Johnson gave introductory remarks about resources for family caregivers from ACL, then Mr. Westin spoke about the National Caregiving Strategy as a Catalyst for Change. The Recognize, Assist, Include, Support, and Engage (RAISE) Act aims to improve federal, state, and local systems that support family caregivers. It established the FCAC, which is charged with developing a report to Congress and a National Family Caregiving Strategy.

To inform development of its Initial Report to Congress, the National Family Caregiving Strategy, and public listening sessions, ACL [issued an RFI](#) in 2019 to learn about the concerns of family caregivers. Of the 1,613 responses, 75% were from family caregivers. To ensure receipt of feedback from all stakeholders, ACL also conducted 17 key informant interviews and 22 listening sessions between December 2020 and December 2021, engaging 145 organizations such as state entities, counties, employers, healthcare providers, and faith-based organizations.

The National Family Caregiving Strategy consists of four components: (1) [the 2022 National Strategy to Support Family Caregivers](#) report, which details strategic goals and intended outcomes; (2) [First Principles](#), which outlines cross-cutting considerations for family caregivers; (3) nearly 350 [federal actions](#) by 15 agencies to implement the strategy; and (4) approximately 150 [actions for states, counties, and other entities](#). The strategy serves as a vision and roadmap for change, and a framework for all caregiving situations, and is meant to be actionable and practical for stakeholders. The strategy takes a whole of society approach and provides a unifying structure for collaboration and planning for the caregiving community. Toward the strategy's goals, ACL facilitates the National Caregiver Support Collaborative, which consists of five grantees that have specific goals related to research, family caregiver coordination and support, education and outreach, coordination of care, and financial security.

To support grandparents who are caregivers for their grandchildren, ACL will submit the *Joint RAISE/Supporting Grandparents Raising Grandchildren Act (SGRG) Act Council Report* to Congress in fall 2024 following clearance reviews. To facilitate their work, member federal agencies will start to meet more routinely to better coordinate efforts to support caregivers. These meetings will focus on ensuring that these agencies are meeting their respective goals and adapting these goals over time. Subcommittees will play a crucial role in this process by gathering information, reviewing research and data, and crafting ideas for non-federal sector updates to the strategy, which are planned for 2025.

## **Supporting Autistic Adults and their Family Caregivers Across the Lifespan**

*Christina Marsack-Topolewski, Ph.D., L.M.S.W., Associate Professor, School of Social Work, Eastern Michigan University*

Dr. Christina Marsack-Topolewski conducts research on family caregiving, caregiver quality of life, social support, future planning, service delivery, and service utilization. She has identified three overarching themes for support services and networks for autistic adults and their caregivers: (1) tailored, accessible services, (2) support with service navigation, and (3) advanced care planning.

Many health care professionals and service providers may implicitly view autism as a condition mainly among children and adolescents rather than one that continues into adulthood. Thus, most current services for autistic people focus on children and adolescents rather, which often leads to a “services cliff” when autistic people transition from juvenile to adult services. In addition, many services employ a uniform approach for all service participants, often leading to mismatches between individual needs and service offerings. Many services also have long waitlists and limited or no availability in many geographic areas (e.g., rural areas)

To be more accessible, services should be designed according to the “four 4 As” of service:

1. Accommodation (e.g., are available options organized in an accessible way?)
2. Acceptability (e.g., what are the attitudes of autistic people and their caregivers regarding available service options?)
3. Availability (e.g., do services consistently exist in different geographic areas?)
4. Affordability (e.g., are services affordable?)

Services should also be designed to account for bidirectional benefits between autistic adults and their caregivers (e.g., benefits to a caregiver can also benefit the autistic person).

Navigating many existing support services can be laborious, cumbersome, and time-consuming. Family navigators can help individuals and families access unconnected services. For example, the Family Support Navigation Program (FSN) in Michigan provided training to individuals with adult children with disabilities who were familiar with local services. These trained individuals then helped empower their peers to navigate complex systems and overcome barriers to service access. These peer navigators were familiar with services for both aging and disabled populations, which helps address the needs of autistic adults. Overall, however, coordinated systems are needed to simplify navigation and reduce the burden on families.

Finally, advanced care planning should be incorporated into person-centered service plans. The needs of autistic adults and their caregivers change over time. Proactive planning in anticipation of future needs will help to ensure smoother transitions and greater continuity of care for autistic people.

Caregiving can carry in length, duration, and intensity. Caregivers require support to balance their own needs and the needs of their loved one.



**Voices of Resilience: Black Families and Autism Advocacy**

*Elizabeth Morgan, Ph.D., Interim Director and Assistant Professor in the Doctorate in Educational Leadership Program, College of Education, California State University Sacramento*

Dr. Elizabeth Morgan described the unique challenges she and other Black families often face in advocating for their autistic children. These challenges include cultural and social stigmas and systemic inequalities that hinder access to necessary resources. Compared to their White peers, Black children with autism are more likely to be misdiagnosed, diagnosed later in life, and have limited access to services after diagnosis.

Addressing these challenges requires identifying and leveraging the strengths and assets of Black families. Many of these assets are described in two papers authored by Dr. Morgan. The first, [\*Addressing the Intersectionality of Race and Disability to Improve Autism Care\*](#), explores how the intersection of race and disability status affects service delivery systems as well as the historical impact of Black activists on the disability rights movement. The second study, [\*Narratives of Single, Black Mothers Using Cultural Capital to Access Autism Interventions in Schools\*](#), examines the experiences of Black mothers navigating school systems. Findings showed that when schools engaged in family-centered practices, mothers were able to use their advocacy strategies to better support their children. Their advocacy strategies proved to be powerful assets that improved their children's experiences.

The assets of many Black families of autistic children can be conceptualized using the Community Cultural Wealth Model. Community cultural wealth refers to assets that communities of color particularly have that are translatable to resources and support for their communities. These assets are often unrecognized. One of the six types of community cultural wealth is resistance capital, which refers to the skills that are fostered through oppositional behavior, challenges, and inequity. Navigational capital refers to the skills of maneuvering through systems and institutions that are built around the exclusion of one's community, such as modern schools. The other types of capital are aspirational, familial, social, and linguistic. Other theorists have looked at Black Cultural Capital and Motherhood Capital.

Dr. Morgan explored forms of community cultural wealth that Black mothers of autistic children use when navigating service systems. Interviewees shared that their children were placed in the most restrictive disability-specific classrooms rather than offered opportunities to be included in less restrictive classroom environments. Interviewees exemplified resistance capital when advocating for their children in the face of these barriers. Similarly, one interviewee's efforts to seek the best resources and support for her child serves as an example of navigational capital.

These examples of community cultural wealth are best leveraged when families can share their knowledge, experience, expertise, and strategies. The Sankofa Family Support Network is an evidence-based model that was developed for and by Black families and providers. Sankofa provides support and culturally-relevant resources and trainings to Black families with children who have DD. They also have monthly support group meetings for families and strive to eradicate stigma and bias associated with disability in the Black community. Together with

UCEDD, this group published a [paper](#) on these efforts. The Sankofa framework was first implemented at the University of California Davis Medical Investigation of Neurodevelopmental Disorders (MIND) Institute in 2015 and replicated in Wisconsin. Testimonies from parents who participate in the Sankofa network reflect increased confidence in advocating for their families, as well as increased social support among the families.

Dr. Morgan concluded her presentation presenting a video from Sankofa member Diane Millner. Ms. Millner talked about the importance of peer supports and learning from each other. Dr Morgan stressed the importance of including Black communities' perspectives in the disability advocacy movement. The current disparities that exist in diagnoses and access to support are products of the systemic of racism, sexism, and ableism. Solidarity with the Black community and advocacy for inclusivity in every facet of society are necessary in the advocacy movement.

### **Discussion**

Dr. Taylor began the discussion by describing a new 12-week program that her team at Vanderbilt has developed to help family caregivers understand and navigate the "hidden curriculum" of adult service system. The program focuses on how the different pieces fit together and how to determine which service is appropriate for your son or daughter. They are wrapping up a large trial where the program was tested in Wisconsin, Tennessee, and Illinois. This program has shown effectiveness in increasing caregivers' knowledge about adult services and improving their access to these services. The program should become available through the Vanderbilt UCEDD in the upcoming months.

Ms. Gassner stressed that agencies that support parents in navigating these systems must also provide additional support to parents with disabilities. Additionally, given the inherent power dynamics in many support services, many family caregivers and students require ongoing advocacy in addition to training programs on their rights and responsibilities.

Dr. Bloomer asked about the establishment and expansion of social support networks, seeking insights into how these networks could be developed into policy. Dr. Johnson noted that [Parent and Training Information Centers](#) under IDEA offer a family-to-family peer support model that are funded in every U.S. state and territory. She also mentioned past funding for Family Support 360s, which aimed to provide ongoing peer support for families. She acknowledged the challenge of raising awareness about available resources for families.

Dr. Marsack-Topolewski emphasized the importance of both formal and informal support networks for family caregivers. Social workers and other professionals can help families augment their existing social support by guiding them on how to build an informal support network that can adapt to evolving needs across the lifespan. These professionals could also help people navigate formal support systems. Dr. Bloomer suggested further exploration of culturally aware support mechanisms for caregivers. He noted that informal support networks provide support for communities who may mistrust government services.

## Panel Discussion: Family Caregivers

*Joe Joyce, Parent of an autistic adult; Board member, Autism Society of America; Board member, Autism Science Foundation*

*Vontril McLemore, Grandparent of an autistic adult*

*Yetta Myrick, IACC member; Parent of an autistic adult; Founder and President, DC Autism Parents*

*Lindsey Nebeker, IACC member; Autistic adult and sibling of an autistic adult; Marketing Consultant, Independent Contractor*

*Nancy Richey, Parent of an autistic adult; member, RAISE FCAC member*

Panelists began by introducing themselves and their backgrounds:

- Ms. Lindsey Nebeker explained that she and her brother were diagnosed with autism at age 2. Her brother requires 24/7 care, is non-speaking, and does not use an AAC device. Her mother helped create a small, English-speaking school in Japan for students with IDD. Her brother has lived in a community-based residential housing program since age 16 and attended a public school for students with disabilities until age 22. Ms. Nebeker acknowledged that describing the challenges of caregiving for family with high support needs with compassion and humanity can sometimes be difficult.
- Ms. Myrick's 20-year-old son has autism, ADHD, and an intellectual disability. To help her son, Ms. Myrick has learned how to navigate different support systems in DC and Montgomery County, Maryland for different types of support (e.g., speech and art therapy). She experienced barriers and delays to getting her son's autism diagnosis. She now uses her experiences in her role as a CDC Act Early ambassador. She also acknowledged the invaluable support she has received from her parents, brother, and grandmother.
- Ms. Nancy Richey is the mother of an autistic son with an intellectual disability. Her son had to change school districts due to lack of support. She described the Autism Society's key support to her family following her son's diagnosis, including navigating different systems (e.g., schooling, healthcare). She also learned from other parents and caregivers. Her son now works in a grocery store as part of a self-directed employment program.
- Mr. Joe Joyce has an adult son with high support needs autism. His son is non-verbal and has severe SIB, sometimes hitting himself as often as 8,000 times per day. Mr. Joyce's son was the first non-speaking person with high support needs autism to present during an IACC meeting (in 2019). Mr. Joyce has another son with Down syndrome and an intellectual disability, as well as a neurotypical daughter.
- Ms. Vontril McLemore is a caregiver to her grandson who was diagnosed with autism and IDD at age 3. He was vocal when he was born but lost his ability to speak as a toddler. Her grandson can understand speech and communicate using other means. The Texas Workforce Commission and Quest Employment helped him obtain a job at Five Below. Because her grandson is an autistic Black man, Ms. McLemore expressed concerns about potential intersections of racism, ableism, and classism (e.g., negative

interactions with law enforcement). Her grandson also wants to socialize and date but finding online safe spaces to meet other people is difficult.

Ms. Nebeker described the challenge of her unique role, where two siblings have the same diagnosis but very different presentations. She talked about the loneliness and the pressure of these roles. She also noted that non-speaking people with untranslatable communication methods are particularly vulnerable to neglect and abuse, even within institutional settings. This concern about potential neglect and abuse can be stressful for family members of non-speaking autistic people as a result.

Mr. Joyce stated that placing an autistic family member with high support needs in residential care can be a painful but necessary decision to ensure their family members' safety (e.g., preventing severe SIB). Ms. Nebeker said many caregivers still feel as though they have abandoned their family member. Caregivers face difficult decisions related to the balance between safety and autonomy.

Panelists also described the resources they need.

Ms. Myrick stated that there needs to be more training for educators on how to support transition-aged youth across the spectrum. Transition-aged youth and their families also need better access to information as well as additional resources. Additional support is also needed for students who may be labeled as "difficult" or "incurable" in school due to undiagnosed autism, IDD, or other neurodevelopmental conditions.

Ms. Richey described the need for resources for transitioning caregiving responsibilities (e.g., when caregivers age and another person assumes the role of primary caregiver) are relatively scarce, leaving many caregivers unsure about the best approach to follow. Many people may be the caregiver for multiple family members for different reasons (e.g., disabilities, old age), creating more transitions for the family to navigate.

The shortage of qualified direct support professionals has increased the number of caregivers who have left the workforce to focus on caregiving. Mr. Joyce noted that a single wage creates financial stress and uncertainty for the family. The availability of respite services are also limited. In addition, a single caregiver may not be able to fully attend to all needs, especially when caring for more than one individual (e.g., preventing severe SIB). Direct support professionals can attend to some needs, but not all (e.g., transportation). They also have limited hours. All of these factors contribute to caregiver burnout.

Ms. McLemore said navigating the complex web of support and assistance programs (e.g., Medicaid programs) can be complicated, and information about these programs is not centralized in a single source. Currently, many family caregivers receive information about resources through organizations such as [Texas Parent to Parent](#) and [Family Voices](#), but more centralization and integration is needed. Also needed is greater collaboration among different sources of support (e.g., federal, SLTT, nonprofit, and school-based programs) to reduce gaps in support and prevent incarceration.

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## **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 panelists and presenters for their insights. Future updates about IACC, including completion of current IACC projects and updates on the next iteration of the IACC, will be posted on the IACC website.