

April 2024

National Autism Coordinator Update

Committees, News, and Events



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White House and Autism Acceptance Month Updates

White House Updates

[A Proclamation on World Autism Acceptance Day, 2024](#)

- On April 1, 2024, President Biden issued a Proclamation on World Autism Acceptance Day, where he championed the equal rights and dignity of the millions of Americans on the autism spectrum and celebrated the immense contributions of all neurodiverse people. [Read full Proclamation here.](#)

[Biden Calls for Investment In Disability Services](#)

- President Biden is renewing his push to improve support for people with disabilities living in the community. President Biden used his State of the Union address to urge Congress to add funding for Medicaid home and community-based services. The president followed up by including \$150 billion over 10 years “to strengthen and expand Medicaid home and community-based services” in his budget request for the 2025 fiscal year, which begins in October. Additionally, Biden’s budget includes a \$200 million increase in spending on special education services, \$10 million more to train special educators and early intervention providers as well as funding to improve customer service at the Social Security Administration. [View the remarks here.](#)

[Executive Order on Scaling and Expanding the Use of Registered Apprenticeships in Industries and the Federal Government and Promoting Labor-Management Forums](#)

- President Biden recently signed an Executive Order which will help create more Registered Apprenticeship (RA) programs in the federal workforce, encourage agencies to provide preferences on projects to recipients that hire individuals who have participated in RA programs, and increase worker voice for federal programs and contracts. RA programs help meet employer needs while investing in workers’ skills, reducing employment barriers, and promoting job quality, equity, inclusion, and accessibility for the benefit of the Federal Government and the Nation. [View Executive Order here.](#)

United Nations (UN)

[UN World Autism Awareness Day 2024 Virtual Event](#)

- On April 2, 2024, the United Nations held a virtual observance event titled *Moving from Surviving to Thriving: Autistic individuals share regional perspectives*. The event sought to provide a global overview of the state of affairs from the perspective of autistic people themselves. The event featured an all-autistic lineup of panelists from all walks of life, representing six regions: Africa, Asia and the Pacific, Europe, Latin American and the Caribbean, North America and Oceania. The speakers provided their thoughts on the state of affairs in their respective regions, as well as the importance of the implementation of the Sustainable Development Goals (SDGs) for autistic people to be able to thrive. [View event details here](#).

Office of National Autism Coordination (ONAC)

- On April 16, 2024, NIMH and ONAC were pleased to host the 11th Annual Autism Acceptance Month Special Event, *Sound Tracks: An Artistic Journey to Belonging*. This hybrid event featured autistic photographer Blair Bunting, autistic violinist Laura Nadine, and neurodivergent filmmaker John Schaffer. The event included a showing of the film *Sound Tracks*, directed by Mr. Schaffer and featuring Mr. Bunting and Ms. Nadine, as well as Q&A with the artists and remarks from Denise Resnik of First Place AZ, the non-profit organization that sponsored the film. [View event details here](#).
- Throughout the month of April, ONAC will be updating the Autism Awareness Month 2024 webpage on the IACC website with the latest news and events. <https://iacc.hhs.gov/meetings/autism-awareness-month/2024/>

National Institute for Environmental Health Sciences (NIEHS)

- On April 11, 2024, NIEHS held an event commemorating World Autism Month event featuring Eric Garcia, author of *We're Not Broken: Changing the Autism Conversation*. His book is a mix of memoir, history, field interviews, myth-busting, and advice on how to better understand autism. [View event details here](#).

Indian Health Service (IHS)

- On April 2, 2024, IHS posted a message recognizing World Autism Acceptance Day and the month of April as Autism Acceptance Month. IHS highlighted the work of the IHS [Indian Children's Program](#) in equipping health care providers working in the IHS, tribal, and urban Indian health system. Additionally, the IHS held a webinar titled *Applied Behavior Analysis: Love It, or Hate It, but First Understand It* on April 5, 2024. [View the message here](#).

Federal Committees Updates

Interagency Committee on Disability Research (ICDR)

Managed by the Administration for Community Living

- An all-federal committee established under the 1973 Rehabilitation Act to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs.
- Recent activities include:
 - ICDR announced the launch of the Interagency Rehabilitation and Disability (IRAD) [Research Portfolio](#). The IRAD Research Portfolio is a searchable, government-wide inventory of disability, independent living, and rehabilitation research. Its purpose is to enable trend and data analysis across federal agencies, with a goal of aiding collaboration and coordination. The Research Portfolio currently features data from five federal agencies [National Institutes of Health (NIH), National Science Foundation (NSF), Veterans Affairs (VA), Administration for Community Living (ACL), and the Centers for Disease Control (CDC)] from fiscal years 2016 to 2023. The ICDR plans to expand the Research Portfolio to include data from more years and agencies. View [press release here](#).
 - ICDR released a [new toolkit on participatory action research](#). Ensuring that the perspectives of people with disabilities are prioritized in disability and rehabilitation research is critical to moving the field forward, and promoting and funding participatory action research (PAR) is an important way that federal entities can encourage this. This new toolkit from the ICDR provides an overview of PAR and the benefits of using this research orientation within the field of disability and rehabilitation research. This toolkit highlights how PAR can be used to involve people with disabilities across the entire research process and provides federal resources on PAR. The toolkit also highlights best practices and areas for future research using PAR. The toolkit concludes with a variety of resources for disability and rehabilitation researchers and other stakeholders seeking more information about PAR.
 - ICDR has also released a [toolkit on federal funding opportunities for disability and rehabilitation research](#). Research in the area of disability and rehabilitation is essential to understand the challenges faced by people with disabilities to achieving full and inclusive participation in society. Research in disability and rehabilitation also helps to ensure interventions are developed that are evidence based, accessible, and relevant, and that achieve the best possible outcomes. The purpose of this toolkit is to support disability and rehabilitation researchers in identifying potential funding sources for their work. It provides a list of several federal agencies that fund disability and rehabilitation research, information about the topics they fund, links to program funding sites, as well as resources and tips for applicants.

- ICDR's April Lunch & Learn webinar will be a panel discussion on including lived experience perspectives on disability research teams, moderated by ICDR member, Susan Daniels/NIH and featuring James Sulzer/MetroHealth Hospital, Bonnie Swenor/Johns Hopkins University, T.J. Gordon/University of Chicago, and Stephanie Cawthorn, University of Texas, Austin. At the end of the panel discussion, there will be a 15-minute question-and-answer session with the audience. The audience will include a wide range of ICDR stakeholders, federal interagency partners, researchers, practitioners, disability organizations and ICDR Committee members. The webinar will take place on April 30 at 12 pm. [Register for the webinar here.](#)

[RAISE Family Caregiving Advisory Council \(FCAC\)](#)

Managed by the Administration for Community Living

- The RAISE Family Caregivers Act directed the Secretary of HHS to develop a national family caregiving strategy. The RAISE Act also directed the establishment of the FCAC, a federal advisory committee charged with providing recommendations to the HHS Secretary on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs. The [Administration for Community Living](#) (ACL) manages this council.
- No new updates since the joint meeting held September 19, 2023, along with the Advisory Council to Support Grandparents Raising Grandchildren. Meeting summary can be [viewed here.](#)

[National Council on Disability \(NCD\)](#)

- Independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.
- Recent/upcoming activities include:
 - NCD will hold its next council meeting on May 9th, 2024, 1:00pm – 5:00pm ET. Topics to be discussed are TBD. The agenda is linked [here.](#)
 - NCD held a recent council meeting on February 8th, 2024, 1:00pm – 5:30pm ET. Topics discussed included changes to the ACS survey and accessible ground transportation. The agenda is linked [here.](#)
 - NCD Chairman Andres Gallegos passed away on December 1st, 2023. A 14-year veteran of the U.S. Air Force, Gallegos first joined the Council in 2018, and became chairman in 2021. Here is the [press release](#) from his office.

[Federal Partners in Transition \(FPT\)](#)

Managed by U.S. Department of Labor

- An all-federal workgroup that was formed in 2005 with representatives from several federal departments and agencies, including ED, HHS, DOL, and SSA, to support all

youth, including youth with disabilities, in successfully transitioning from school to adulthood.

- Recent activities include:
 - A Steering Committee Meeting was held on March 21st. The Committee is continuing to work on updating the FPT Strategic Plan.
 - A General Assembly meeting was held on March 21st, featuring a presentation titled “Research Findings to Inform Employment Policy and Practice relative to Transition Age Youth (TAY) With Serious Mental Health Conditions (SMHC).”

[Interdepartmental Serious Mental Illness Coordinating Committee \(ISMICC\)](#)

Managed by the Substance Abuse and Mental Health Services Administration

- The ISMICC was established in 2017 by the 21st Century Cures Act. The ISMICC is a federal advisory committee that reports to the Secretary, Congress, and any other relevant federal department or agency on advances in serious mental illness (SMI) and serious emotional disturbance (SED), research related to the prevention, diagnosis, intervention, and treatment and recovery of SMIs, SEDs, and advances in access to services and supports for adults with SMI or children with SED.
- Recent activities include:
 - An [ISMICC Full Committee meeting](#) was held on March 27, 2024. The meeting featured a panel discussion in recognition of the 25th anniversary of the Olmstead decision. View the [agenda topics discussed here](#).

[Disability Advisory Committee \(DAC\)](#)

Managed by the Federal Communications Commission

- The DAC is a federal advisory committee that provides advice and recommendations to the FCC on a wide array of disability issues, including communications and video programming access.
- Recent/upcoming activities include:
 - The DAC will meet next on May 16th, 2024, at 9am ET. The agenda will be available [here](#).
 - The DAC met last on January 30th, 2024. The committee discussed best practices for TRS, and the use of AI for live captioning. The [video and agenda](#) are available online.

[President’s Committee for People with Intellectual Disabilities \(PCPID\)](#)

Managed by the Administration for Community Living

- The PCPID is an advisory committee that aims to provide advice and assistance to the President of the U.S. and the HHS Secretary on a broad range of topics that impact people with intellectual disabilities as well as the field of intellectual disabilities, with the goal of improving the quality of life experienced by people with intellectual disabilities by upholding their full citizenship rights, independence, self-determination,

and lifelong participation in their communities. [Here is a fact sheet](#) detailing the committee's duties to the President.

- Recent activities include:
 - On March 21, the PCPID held their [March 2024 PCPID Meeting](#). Agenda topics can be [viewed here](#).

National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

Managed by the Administration for Strategic Preparedness and Response

- NACIDD is an advisory committee that evaluates issues and programs and provides findings, advice, and recommendations to support and enhance all-hazards public health and medical preparedness, response activities, and recovery related to meeting the unique needs of individuals with disabilities. The NACIDD will advise the Secretary of Health and Human Services (HHS) on actions HHS can take before, during, and after disasters and emergencies to meet the unique needs of individuals with disabilities.
- No new updates since the committee's [September 2023 meeting](#).
- The Charter of the NACIDD was extended under the current continuing resolution until January 19, 2024.

Coordinating Council on Access and Mobility (CCAM)

Managed by the Federal Transit Administration

- Established in 2004, the CCAM is a Federal interagency council that works to coordinate funding and provide expertise on human services transportation for three targeted populations: people with disabilities, older adults, and individuals of low income. The CCAM works at the Federal level to improve Federal coordination of transportation resources and to address barriers faced by States and local communities when coordinating transportation.
- No new updates since the December 2023 webinar on the FY23 [Innovative Coordinated Access and Mobility](#) past funding opportunity.

Children's Interagency Coordinating Council (CICC)

Managed by Office of the Assistant Secretary for Planning and Evaluation

- As part of the Consolidated Appropriations Act, 2023, Congress provided HHS with funding for the Children's Interagency Coordinating Council (CICC). The CICC is charged with fostering greater coordination and transparency on child policy across federal agencies and examining a broad array of cross-cutting issues affecting child poverty and child well-being. On behalf of HHS, ASPE's Office of Human Services Policy has led the effort to stand up and support the CICC.
- As part of this coordination work, ASPE is convening staff-level leadership from active federal interagency groups whose scope overlaps or closely relates to the CICC's focus areas of child poverty and well-being. One of the goals is to encourage communication

and information sharing across all of these groups so that we can learn from each other, build off each other's work, and avoid duplication of efforts.

- The Convening of Federal Interagency Groups by CICC was held on April 1st, 2024.

NSTC Disability Data Interagency Working Group

Managed by the National Science and Technology Council (NSTC), White House

- This working group was convened in March 2024, as a part of the response to President Biden's [Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government \(EO 13985\)](#). The goal of the Working Group is to coordinate activities to strengthen the federal government's use of disability data to advance equity for people with disabilities. This work will allow for rigorous assessment of the extent to which government programs and policies yield consistently fair, just, and impartial treatment of people with disabilities.

Federal Department and Agency Updates

NIH Director statement on the departure of National Institute of Mental Health Director Dr. Joshua Gordon

- Dr. Joshua Gordon is expected to depart from NIMH on June 14, 2024, to return to Columbia University, New York City, as Chair of the Department of Psychiatry at the Vagelos College of Physicians and Surgeons and Psychiatrist-in-Chief of the New York-Presbyterian Hospital campus at Columbia University Irving Medical Center. Dr. Gordon also will serve as director of the New York State Psychiatric Institute (NYSPI). Prior to joining NIMH in 2016, Dr. Gordon served as an associate professor of Psychiatry at Columbia and as a research psychiatrist at NYSPI. As a visionary psychiatrist and neuroscientist, Dr. Gordon brought this perspective to his role as director of NIMH, the lead federal agency for research on mental illnesses. [View statement here.](#)

FDA Proposes New Ban of Electrical Stimulation Devices for Self-Injurious or Aggressive Behavior

- The U.S. Food and Drug Administration (FDA) has proposed a ban of electrical stimulation devices (ESDs) intended to reduce or stop self-injurious or aggressive behavior; a step rarely taken by the agency. The agency has determined that these devices present an unreasonable and substantial risk of illness or injury. This is the second time the FDA has proposed a ban of these particular devices. ESDs deliver electrical shocks through electrodes attached to an individual's skin to attempt to reduce or stop harmful behaviors. This proposed rule proposes to ban ESDs intended for self-injurious and aggressive behaviors, and if finalized, will remove ESDs from the market. [Read press release here.](#)

[Autism Research and Support Services: Federal Interagency Coordination and Monitoring Efforts Could Be Further Strengthened](#)

- A report from the GAO analyzed how the IACC helps to promote the health and well-being of people with autism. It found that NIH has demonstrated 6 of 8 best practices to coordinate agency programs and activities but said that 2 best practices are only partially fulfilled and can be improved. The recommendations were to strengthen tracking and reporting of federal activities related to recommendations of the *IACC Strategic Plan* and the other was to enhance documentation of procedures to prevent duplication of effort. [View report here](#).

[Next Steps on the American Community Survey Disability Questions](#)

U.S. Census Bureau

- The U.S. Census Bureau posted a [Federal Register Notice](#) (FRN) in October 2023, proposing changes to the American Community Survey (ACS) questions on disability to a set of questions based on the Washington Group Short Set (WG-SS) on functioning. That proposal would have aligned the U.S. with international standards from the United Nations and advances in measuring disability. The Census Bureau [received more than 12,000 comments](#) in response to the FRN expressing concerns to all of the proposed changes to the ACS. The Census Bureau decided to postpone changes and engage the community in discussions about this topic.

Non-Governmental Activities and Updates

[INSAR 2024 Annual Meeting](#)

- From May 15-18, 2024, the International Society for Autism Research (INSAR) will be hosting their annual scientific meeting in-person in Melbourne, Australia. This meeting aims to exchange and disseminate new scientific progress among autism scientists and their trainees from around the world. For more information, [please visit the event webpage](#).

[Profound Autism Summit](#)

- On April 5, 2024, the Profound Autism Alliance held the Profound Autism Summit in-person in Burlington, Massachusetts. This was a one day conference bringing together leaders from the areas of research, medicine, treatment, advocacy, education, and human services to discuss the needs of those with Profound Autism across disciplines and throughout the lifespan. For more information, [please visit the event webpage](#).

[AIR-P Presents: Introduction to Plain Language Writing for Academics and Researchers](#)

- On April 16, the Autistic Self Advocacy Network in partnership with the Autism Intervention Research Network on Physical Health (AIR-P) held a webinar providing an overview of plain language writing for people who may be more used to writing in

academic language. Attendees learned the principles of plain language writing and had a chance to put them into practice with interactive exercises. [View webinar details here.](#)

National Coalition Sets Roadmap To Improve Health Care For Those With IDD

- More than a dozen organizations worked alongside individuals with developmental disabilities to develop the new [National Roadmap for Disability-Inclusive Healthcare](#), a set of goals and actions that various stakeholders should take to better prepare doctors, nurses, and dentists to treat those with disabilities. The plan outlines steps for educational associations, regulatory and accrediting bodies, and professional organizations. Most doctors receive little if any training on developmental disabilities while in medical school and residency. As a result, research shows that just 41% of physicians feel prepared to offer people with disabilities a similar quality of care to others. [View the Roadmap here.](#)

Report: The Case for Inclusion: Transforming Temporary Progress into Long-Term Sustainability

- This report from ANCOR and United Cerebral Palsy highlights the state of home and community-based services (HCBS) and trends for direct support professionals (DSPs). This report discusses trends by state with regards to programs such as state-run institutions, Money Follows the Person, and Medicaid waivers, which in totality make-up the push towards high-quality, inclusive services for individuals with IDD. [View Report here.](#)

Legislative Updates

Legislative Hearing to Support Patients and Caregivers

House Energy and Commerce Committee; Subcommittee on Health

- On February 14, 2024, House Energy and Commerce Committee’s Subcommittee on Health held a legislative hearing titled “Legislative Proposals to Support Patients and Caregivers.” Among the legislation discussed, the subcommittee discussed [H.R. 7213](#), Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (co-sponsored by Reps. C. Smith and H. Cuellar). View the [hearing recording here.](#)

Legislative Hearing on Disability Employment

Senate Special Committee on Aging

- On February 29th, the Senate Special Committee on Aging held a hearing titled “All Means All: Empowering People with Disabilities to Thrive in Careers and in the Workplace”. The hearing featured researchers, business owners, and people with lived experience who are working in the community. The expert witnesses provided the Committee with testimony about the importance of people with disabilities working alongside people without disabilities for minimum wage or more. The Transformation to

Competitive Integrated Employment Act (TCIEA) ([S. 533](#) / [H.R. 1263](#)) was introduced by Senator Casey (D-PA), Senator Daines (R-MT), Rep. Scott (D-VA-3) and Rep. McMorris Rogers (R-WA-5) on February 28th, 2023. View the [hearing recording here](#).

[Legislative Hearing to Support Entrepreneurs and Employees with Disabilities](#)

House Committee on Small Business

- On January 30, 2024, the House Committee on Small Business held a subcommittee hearing titled “Pathways to Success: Supporting Entrepreneurs and Employees with Disabilities.” In this hearing, Members heard from various witnesses how entrepreneurs and employees with disabilities are strong contributors to our economy. Witnesses included Mr. Keith Wargo (Autism Speaks), Ms. Iva Walsh (Maeve’s Place), and Mr. Cody Clark (Cody Clark Magic). View the [hearing recording here](#).