

July 2024

National Autism Coordinator Update

Committees, News, and Events



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White House Updates

Biden-Harris Administration Partners with States and Releases Data Recommendations to Strengthen the Direct Care Workforce

- HHS announced recently that 20 states have been selected to participate in two separate technical assistance programs that together will help participating states better recruit, train, and retain direct care workers, who provide home and community-based services (HCBS) for older adults and people with disabilities. Both programs are offered through the ACL's Direct Care Workforce (DCW) Strategies Center. [Read the press release here](#). Read President Biden's [Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers here](#).

Biden-Harris Administration Builds on the Success of the Affordable Care Act by Streamlining Enrollment in Medicaid and CHIP Coverage

- The Biden-Harris Administration recently unveiled a final rule that will 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 Streamlining the Medicaid, Children's Health Insurance Program, and Basic Health Program Application, Eligibility Determination, Enrollment, and Renewal Processes rule will remove red tape and barriers to enrollment, update and build on the Affordable Care Act's (ACA's) coverage protections and ensure that millions of Americans can get and keep their coverage. With this rule, millions of Americans will benefit from a modernized, less cumbersome enrollment process with reduced red tape, helping more people keep coverage. [Read more 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 has released an updated [Federal Statutory Definitions of Disability](#) white paper. This paper includes a collection of federal statutory definitions of disability as contained in the United States Code and is organized by topic area (e.g., Civil Rights, Education, Employment, Housing, etc.). This paper also provides a cross-reference guide that illustrates the overlap in definitions across various acts or programs in the U.S. Code. This resource is designed for federal agencies to be able to examine where federal definitions of disability overlap or differ across their programs and guiding legislation.
 - ICDR has recently released the [Surveying the Landscape of Disability Data and Statistics](#) toolkit. Collecting complete and accurate data on disability is essential to addressing the many disparities that people with disabilities face across multiple facets of daily life (e.g., health, housing, employment) compared to people without disabilities. Improving data on disability will provide a strong evidence base for how to tailor policies and programs to address the equity challenges people with disabilities face. This toolkit provides an overview of the current federal landscape of disability data collection to help people with disabilities and those supporting them, disability researchers, and federal agency staff better understand current research and resources on disability data and statistics and where improvements and additional collaboration are needed. The toolkit discusses current resources and research conducted by or funded by federal agencies and provides recommendations and resources from the field for next steps to improve disability data collection efforts.
 - ICDR's May Lunch & Learn webinar featured a series of presentations by representatives of federal agencies that provide funding for disability and rehabilitation research. A recording of the webinar is available [here](#).
 - ICDR's [Annual Stakeholder Meeting](#) took place on June 27. This year's virtual stakeholder meeting focused on the conduct of disability research against the evolving digital landscape. This interactive meeting included presentations, panel discussions, and breakout groups for participants to engage around the theme of digital accessibility and inclusion.

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.
- Recent updates:
 - Joint Meeting of the RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren was held on June 13, 2024. Agenda items included federal agency progress towards implementing the national strategy and a presentation on the 2024 Joint Update Report to Congress. Meeting recording will be available soon, access the [agenda 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 held its recent council meeting on June 27th over Zoom. The agenda is available [here](#).

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 May 16th. The Committee is continuing to work on updating the FPT Strategic Plan.
 - A General Assembly meeting was also held on May 16th, featuring a presentation titled “AI & Disability Employment,” by Bryna Helfer, Ed.D., Director of the Employment Resource Support Team, ODEP, and Lydia Parenteau, Policy Advisor, ODEP
 - Next Steering Committee and General Assembly meetings are scheduled for September 19, 2024.

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:
 - No new updates since [ISMICC Full Committee meeting](#) on March 27, 2024.

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 activities include:
 - The DAC most recently met on May 16th, 2024, at 9am ET. The agenda is available [here](#).

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:
 - No updates since [March 2024 PCPID Meeting](#).

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.
- The Charter of the NACIDD was extended under the current continuing resolution until December 31, 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.
- Recent updates include:
 - FTA announced that [17 projects in 15 states](#) will receive funding to improve public transportation for people with disabilities, older adults, and individuals with low-incomes.
 - The approximately \$7.8 million in grants represents the next round of funding from the [Innovative Coordinated Access & Mobility \(ICAM\) Pilot Program](#). The grant selections support organizations that coordinate public transportation for underserved groups, allowing them to access healthcare, community services, education, and jobs by building partnerships among health, transportation, and human services providers.

[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.
 - On July 22nd, 2024, from 12-1:30pm ET, the CICC is holding a public event to explore issues and opportunities related to benefit access and utilization for children and their families experiencing poverty. This event will feature presentations from lived experts, researchers, and leaders from state and community initiatives. Presenters will highlight resources and current initiatives that address issues related to benefit access and utilization, including stigma, administrative burden, and benefit cliffs. The event will be held virtually and will be limited to the first 500 registrants. [Register here](#).

- 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 develop a Federal Evidence Agenda on Disability Equity, which will help 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. The working group also conducted interviews with federal and non-federal disability data subject matter experts (SMEs).
- Recent activities include:
 - The working group has published a Request for Information (RFI) to collect input from the public to help inform the development of the Federal Evidence Agenda on Disability Equity. [Access the RFI here](#). Deadline for comments is July 15.
 - The working group is held a series of eight invite-only virtual listening sessions with individuals and organizations from the disability community in order to obtain input to inform the creation of the Federal Evidence Agenda.

Federal Department and Agency Updates

HHS Releases FY 2019-2023 Report to Congress on Federal Autism Activities

- The report is required by the Autism CARES Act of 2019 and was prepared by the HHS National Autism Coordinator and the Office of National Autism Coordination (ONAC), on behalf of the Office of the HHS Secretary, with contributions from multiple federal departments and agencies. The report describes the autism-related activities of over 25 federal departments, agencies, divisions, and offices between fiscal years 2019 to 2023. This includes descriptions of federal programs on biomedical and services research, education, health, employment, housing, disability benefits, justice, and disability services. The report provides updates on progress made by federal departments and agencies in implementing the recommendations of the IACC Strategic Plan, as well as information on topics requested by Congress, including the prevalence of autism, progress on diagnosis and interventions, and home and community-based services (HCBS). Read [full report here](#). View [press release here](#).

Release of the 2019-2020 IACC Autism Research Portfolio Analysis Report

- The [2019-2020 IACC Autism Research Portfolio Analysis Report](#) analyzes funding progress made towards the Objectives of the IACC Strategic Plan. For the first time, the full report is accompanied by an "[At-a-Glance](#)" summary document that provides an

overview of key findings in the report. The [Autism Research Database](#) has been updated with 2019 and 2020 data. This report represents the twelfth and thirteenth years of data collected. It is the ninth comprehensive report of U.S. autism research funding across both the federal and private sectors. Read [full report here](#).

HHS Leadership Marks One-Year Anniversary of President Biden's Care Executive Order

- Senior officials at the U.S. Department of Health and Human Services (HHS) released several statements recently marking the one-year anniversary of President Biden's Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers. [Read the statements here](#).

ACL Announces Nearly \$2 Million To Support State Implementation of the National Strategy to Support Family Caregivers

- The Administration on Community Living (ACL) recently announced about \$2 million to support statewide implementation of the [National Strategy to Support Family Caregivers](#). ACL will award four cooperative agreements to state units on aging to undertake a range of activities. Each project will be fully funded for a period of 24 months with one, 24-month budget of up to \$490,000. Each grantee will be expected to focus on implementing at least three of the five goals of the Strategy, as determined by the state's needs and priorities. Successfully implementing the actions and recommendations contained in the Strategy will require the grantees to break down siloes that exist through close collaboration by multiple agencies in the state. [Read more here](#).

Celebrating the 25th Anniversary of Olmstead v. L.C.

- On June 20th, the U.S. Department of Justice's Civil Rights Division and the U.S. Department of Health and Human Services' Administration for Community Living and Office for Civil Rights held an event marking the 25th anniversary of the Supreme Court's landmark decision in Olmstead v. L.C. In that case, the Court held that unjustified segregation of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act and that states are required to ensure that people with disabilities can receive services in the most integrated setting appropriate to their needs, opening the doors to community inclusion and integration for even more people with disabilities. The event featured people with disabilities, federal leaders, and national experts talking about the impact of Olmstead, barriers to community living and true inclusion that people with disabilities still face 25 years later, and what is needed to fully realize the promise of this landmark decision. View the [recording here](#). Read [ACL's blog post here](#).

HHS Finalizes Rule Strengthening Protections Against Disability Discrimination

- The U.S. Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), finalized a rule that prohibits discrimination on the basis of disability. This

rule, titled Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, advances equity and bolsters protections for people with disabilities under Section 504 of the Rehabilitation Act (Section 504). This important Final Rule is HHS's latest action in furtherance of Executive Order 14091, entitled Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. The Section 504 Final Rule clarifies and strengthens civil rights protections for people with disabilities and advances the promise of the Rehabilitation Act and helps protect people with disabilities from experiencing discrimination in any program or activity receiving funding from HHS because of their disability. Read [press release here](#).

NIMH Disability, Equity, and Mental Health Research Webinar Series

- The National Institute of Mental Health's (NIMH) Office for Disparities Research and Workforce Diversity is hosting a Disability, Equity, and Mental Health Research Webinar Series, which focuses on exploring the health disparities experienced by people with disability. These include disparities in mental health outcomes, which can be further compounded for those with intersecting identities. The series explores the notion of mental health conditions as a disability and considers the viewpoints of those with lived experience. Upcoming webinars include:
 - **Transforming Mental Health Disability Research Through Lived Experience Leadership and Co-Production**
 - **Date/Time:** August 8, 2024, 1:00–2:30 p.m. ET
 - This webinar will introduce a range of approaches to meaningfully integrate individuals with lived experiences of psychiatric disabilities into mental health research. [Nev Jones, Ph.D.](#), will discuss proven methods of integration and co-creation, including co-production, integration, and co-leadership, and highlight ways in which the NIMH research portfolio would benefit from greater emphasis on and high standards for meaningful inclusion. [Register here](#).
 - **Framework for Understanding Structural Ableism in Health Care**
 - **Date/Time:** September 9, 2024, 2:00–3:30 p.m. ET
 - In this webinar, [Dielle Lundberg, M.P.H.](#), and [Jessica Chen, Ph.D.](#), will introduce a conceptual framework outlining pathways through which structural ableism in public health and health care may contribute to health inequities for “people who are disabled, neurodivergent, chronically ill, mad, and/or living with mental illness” (Lundberg & Chen, 2023). In doing so, they will draw on writing by disability studies and disability justice scholars and activists, which provides much of the basis for current understandings of ableism and related systems. [Register here](#).

Additional Updates

17th Session Of The Conference Of States Parties To The UNCRPD (COSP17)

United Nations

- The seventeenth session (COSP17) of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (CRPD) took place June 11-13, 2024 at the United Nations Headquarters in New York. The overarching theme focused on rethinking disability inclusion in the current international juncture and ahead of the Summit of the Future. Subthemes include international cooperation to promote technology innovations and transfer for an inclusive future, persons with disabilities in situations of risk and humanitarian emergencies, and promoting the rights of persons with disabilities to decent work and sustainable livelihood. View the [event page for more information](#). View the [list of associated side events](#). Autism-related events include:
 - Wed Jun 12 2024, 12:30pm - 2:00pm: ["Listening the voices of autism self-advocates in the Global South: Ubuntu, "stories from Africa""](#) (Government of South Africa, Commonwealth Disabled Peoples Forum)
 - Wed Jun 12 2024, 1:15pm - 2:30pm: [Development of Australia's National Autism Strategy: Achieving a vision of an inclusive society for all Autistic people of all ages living in Australia](#) (Australian Government Department of Social Services)
 - Thu Jun 13 2024, 1:15pm - 2:30pm: [Autism; innovation for disability inclusion](#) (Permanent Mission of Ireland to the UN)
 - IACC Member Dena Gassner spoke on disability employment at the side event: Promoting the rights of persons with disabilities to decent work and sustainable livelihood: lessons from the front line and what this means for states, the UN and civil society, sponsored by the Government of Malta, UN ESCWA, and the Leprosy Mission International.
 - IACC Executive Secretary Susan Daniels served on the U.S. Delegation to the conference along with officials from the U.S. Department of State, USAID, ACL, CDC, and US Access Board, providing support to the delegation on issues related to autism, neurodiversity, and intellectual and developmental disabilities.

Neurodiversity @ Work Playbook: Federal Edition

- The Neurodiversity@Work Playbook Federal Edition is the product of a collaborative research project, the *Neurodiversity and Employment Initiative: Initiating and Scaling Neurodiversity@Work Initiatives across Private and Public Organizations*, led by Dr. Hala Annabi, an associate professor at the University of Washington Information School. Federal agencies interested in establishing neurodiversity employment programs or general practices will benefit from understanding the policies and mechanisms that encourage and enable such programs within the U.S. Federal Government employment structures. While Federal sector recruitment and employment processes may differ from

those in the private sector, they certainly share the challenge of a scarcity of talent. [Read the report here.](#)

Legislative Updates

Full Committee Markup of 13 Health Bills

House Energy and Commerce Committee

- On June 12th, the House Energy and Commerce Committee held a markup for 13 health related bills, including the Autism CARES Act of 2024 ([H.R 7213](#)). The bill passed through the Energy and Commerce Committee with a vote of 42-0. View the [markup recording here](#).

FY25 Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Act Subcommittee Markup

Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Subcommittee; House Committee on Appropriations

- On June 11th, the House Appropriations Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Subcommittee met to consider its Fiscal Year 2025 bill. The measure was approved by the Subcommittee. Section 722 of the bill includes language on the use of electric shock devices, noting continued use of the ESDs if they “are authorized or ordered for an individual by a court of competent jurisdiction.” The Appropriations Committee is expected to mark-up and vote on the bill on July 10th. Read [text here](#). View [press release here](#).