

October 2023

National Autism Coordinator Update

Committees, News, and Events



Susan Daniels, Ph.D.

HHS National Autism Coordinator

Office of the NIMH Director

National Institute of Mental Health

Dr. Susan Daniels Appointed National Autism Coordinator

- Dr. Susan A. Daniels, Ph.D. has been appointed as the HHS National Autism Coordinator and Director of the Office of National Autism Coordination (ONAC). In this position, Dr. Daniels will play a vital role in ensuring the implementation of national autism research, services, and support activities across federal agencies. This role will complement Dr. Daniels's continuing work as the Executive Secretary of the Interagency Autism Coordinating Committee (IACC), a federal advisory committee composed of federal officials and public members that focuses on gathering public input, coordinating federal autism activities, and providing advice to the HHS Secretary on issues related to autism. [View press release here.](#)

White House Updates

- President Biden announced his intent to nominate Dr. Monica Bertagnolli as Director of the National Institutes of Health (NIH), the world's preeminent biomedical research organization. Dr. Bertagnolli is a world-renowned surgical oncologist, cancer researcher, educator, and physician-leader who has the vision and leadership needed to deliver on NIH's mission to seek fundamental knowledge and promote human health. [Read announcement here.](#)
- The Biden-Harris Administration is announcing new tools to lower prescription drug costs for low-income people with Medicare through the Extra Help program, which provides eligible seniors and disabled people with help paying for their Medicare Part D premiums and cost-sharing. These resources complement forthcoming expansions in Extra Help benefits and will ensure more people eligible for benefits are enrolled in this vital program. Beginning January 1, 2024, eligible seniors and people with disabilities will benefit even more through the expansion of the Extra Help program. Nearly 300,000 low-income people with Medicare currently enrolled in the Extra Help program stand to benefit from the program's expansion. [Read more here.](#)
- President Biden issued several proclamations and statements recently, including:
 - During National Disability Employment Awareness Month (NDEAM), the Administration recognizes the immense contributions of disabled Americans,

and they recommit to delivering America’s full promise of equal dignity, respect, and opportunity for every American. President Joe Biden reflects on his history of supporting legislation that protects the rights of people with disabilities and how his Administration continues to promote job opportunities for Americans with disabilities. [Read more here.](#)

- On the 50th anniversary of the Rehab Act, President Joe Biden restates his commitment to ensuring the rights of Americans with disabilities. As part of this commitment, he signed an Executive Order to advance opportunities for people with disabilities in the Federal workforce. President Biden was also a co-sponsor of the Rehab Act in his early days as a Senator. [Read more here.](#)
- To commemorate the 33rd Anniversary since the passing of the Americans with Disabilities Act (ADA), President Biden issued a proclamation reflecting on the history, impact, and opportunities for continued work on this landmark legislation in the lives of individuals with disabilities across our Nation. [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’s monthly Lunch & Learn webinars cover a range of topics relevant to individuals with autism and other disabilities. Recent Lunch & Learns include:
 - [April 2023](#): Disability Cultural Competence in Healthcare
 - [May 2023](#): How Did the COVID-19 Recession Impact People with Disabilities in Rural America?
 - [June 2023](#): Emergency Preparedness and the Impact of Climate Change on People with Disabilities
 - [July 2023](#): Disparities in Health Care in Medicare Advantage Associated with Dual Eligibility
 - [August 2023](#): Participatory Action Research with People with Disabilities
 - ICDR’s State of the Science Conference on Disability Statistics was conducted on February 9 and 10, 2023. A document highlighting key points of the conference, as well as a full summary and recording, is now available [online](#).
 - The 2023 annual virtual stakeholder meeting focused on the theme of inclusion of people with disabilities across all facets of the disability and rehabilitation research landscape. This meeting included a stakeholder panel discussion, presentations on emerging topics in disability and rehabilitation research,

concurrent breakout groups for participants to discuss topics related to the ICDR's core focus areas (COVID-19, equity, and disability data and statistics), and a federal agency panel discussion. A recording of the meeting and a research report is available [here](#).

RAISE Family Caregiving Advisory Council (FCAC)

Managed by the Administration for Community Living

- The RAISE Family Caregivers Act directs 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 activities include:
 - On Thursday, July 27, 2023, ACL held a swearing in and kick-off meeting for the new RAISE Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren. The council discussed potential next steps towards building on the 2022 National Strategy to Support Family Caregivers previously developed by the first council. Meeting summary and materials can be [accessed here](#).
 - A follow-up meeting was held September 19, 2023, focused on an analysis of public comments on the *2022 National Strategy to Support Family Caregivers* and updates from federal agencies about their progress in implementing the strategy. Meeting agenda can be [viewed here](#), with summary to be released soon.

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 activities include:
 - The next NCD Council meeting will be held on November 16-17, 2023, in Providence, Rhode Island, and virtually on Zoom. The meeting will focus on housing and transportation issues. Additional information, including registration and agenda, is [available here](#).
 - NCD recently held a two-day, in-person quarterly business meeting July 12-13, 2023. [Here is the agenda](#).
 - NCD held a celebratory event for the Americans with Disabilities Act (ADA) titled "On the Threshold of Independence" on July 12th at 6:00 p.m. The recording of the livestream is available on [Youtube](#).

- In May 2023 NCD released a report on [The Impacts of Extreme Weather Events on People with Disabilities](#) offering findings and recommendations to bring about policy and systems change to advance national disability policy goals and reduce casualties. (View [press release 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 8/17. This meeting focused on federal resources to support competitive integrated employment
 - A General Committee Meeting was held on 8/21. This meeting focused on resources for Native American communities.

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.
- The Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) will be meeting on October 18, 2023, from 10:00 am to 4:00 pm ET. The meeting is open to the public and can be accessed virtually. For access and additional information, please see the [Federal Register notice](#).

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.
- The DAC met recently on September 7th at 9:00 a.m. ET. Topics discussed included disability rights, A.I. accessibility, and the use of audio descriptions. 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.
- The committee met on May 1, 2023, and discussed needs associated with various aspects of home- and community-based services (HCBS), including workforce challenges of direct support professionals, employment services for individuals with intellectual disabilities, community living services, and federal support programs. A full recording of the meeting is available [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.
- The committee held a joint public meeting with the National Advisory Committee on Seniors and Disaster (NACSD) on September 19, 2023, to discuss their respective reports, [Recommendations from the NACIDD](#) and [Recommendations from the NACSD](#), detailing the specific needs of people with disabilities and older adults, respectively, related to disaster preparedness and response. Additional information is available [here](#).

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 activities include:
 - In October 2022, the CCAM convened and officially adopted the [2023-2026 CCAM Strategic Plan](#).

- On November 30, 2022, the CCAM hosted a public webinar to learn about the recently adopted 2023 - 2026 CCAM Strategic Plan, resource commitments, and next steps for implementation. The presentation can be [accessed here](#), along with the [recording](#).

[Interagency Task Force on Trauma-Informed Care \(TIC Task Force\)](#)

Managed by the Substance Abuse and Mental Health Services Administration (SAMHSA)

- The TIC Task Force was established on October 13th, 2018 of the Public Law 115-271, the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Act of 2018. The purpose is to identify, evaluate, and make recommendations regarding: (1) best practices with respect to children and youth, and their families as appropriate, who have experienced or are at risk of experiencing trauma; and (2) ways in which Federal agencies can better coordinate to improve the Federal response to families impacted by substance use disorders and other forms of trauma.
- In 2021, the TIC Task Force published the [National Strategy for Trauma-Informed Care Operating Plan](#). Through the Operating Plan, the Task Force identifies childhood trauma, including substance misuse, as a serious public health problem in the United States with potentially long-lasting negative impacts compounded by racial and historical trauma. To address this, communities need support to build infrastructure and capacity to prevent trauma, respond to those impacted by trauma, and enhance resilience. A robust evidence base for a continuum of interventions at the individual, system, and community levels are needed to promote the provision of best practices. The Task Force subsequently sunset after the publication of this final report.

Federal Department and Agency Updates

[NIH Designates People with Disabilities as a Population with Health Disparities](#)

- In September 2023, the National Institute on Minority Health and Health Disparities (NIMHD) designated people with disabilities as a population with health disparities for research supported by NIH.
- NIMHD is the lead NIH institute on monitoring minority health and health disparities research.
- The designation is one of several steps NIH is taking to address health disparities faced by people with disabilities and ensure their representation in NIH research.
- The NIH also issued a [notice of funding opportunity](#) calling for research applications focused on novel and innovative approaches and interventions that address the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and health outcomes.

NIH Requests Public Input on Proposed Update to Mission Statement

- The NIH has proposed an update to its mission statement to make it more inclusive and replace the current portion of the mission that includes the goal of “reducing disability.”
- The proposed language is “To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people.”
- The public is invited to submit input on this proposed change. Deadline is November 24. [Read more here.](#)

I/DD Counts National Summit Report Highlights Health Data as Equity Issue

Report by the Administration for Community Living (ACL)

- Reliable health data is important to supporting people with intellectual and developmental disabilities (I/DD). Being counted is a health equity and civil rights issue. Although data collection about people with disabilities generally has improved in recent decades, there is still not enough information on how many people with I/DD live in the U.S. In 2022, the Administration for Community Living (ACL), organized a national summit that included people with I/DD, representatives from federal agencies, advocacy groups, researchers, and health care providers. The group discussed progress on its 2030 roadmap for health data equity, remaining gaps, and priorities for the future. This [report](#) summarizes the key ideas from the summit and actions recommended by and for the I/DD Counts initiative.

HHS Issues New Proposed Rule to Strengthen Prohibitions Against Discrimination on the Basis of a Disability in Health Care and Human Services Programs

- The Department of Health and Human Services (HHS), through its Office for Civil Rights (OCR), announced a proposed rule that strengthens Section 504 of the Rehabilitation Act of 1973 to prohibit discrimination on the basis of disability in federally funded health programs. This Notice of Proposed Rulemaking (NPRM) clarifies the application of Section 504 to several critical areas. The proposed rule:
 - Ensures that medical treatment decisions are not based on biases or stereotypes about individuals with disabilities, judgments that an individual will be a burden on others, or beliefs that the life of an individual with a disability has less value than the life of a person without a disability;
 - Clarifies obligations for web, mobile, and kiosk accessibility;
 - Establishes enforceable standards for accessible medical equipment;
 - Clarifies requirements in HHS-funded child welfare programs and activities;
 - Prohibits the use of value assessment methods that place a lower value on life-extension for individuals with disabilities when that method is used to limit access or to deny aids, benefits, and services.
 - Clarifies obligations to provide services in the most integrated setting appropriate to the needs of individuals with disabilities.

- Read the [press release here](#). Public comments on the NPRM are due November 13, 2023 and can be [submitted here](#).

[U.S. Department of Labor Announces \\$7.5M Cooperative Agreement to Continue Support for Disabled Youth Employment Initiatives](#)

- The Department of Labor (DOL) announced the award of a \$7.5 million, five-year cooperative agreement to continue support for a policy center aimed at boosting disabled youth employment. Administered by the department's Office of Disability Employment Policy (ODEP), the agreement will provide \$1.5 million annually for the agency's Center for Advancing Policy on Employment for Youth (CAPE-Youth). ODEP created the center in 2019 to enhance national, state and local workforce systems, focusing on improved outcomes for youth with disabilities, especially those from underserved communities. The center's development and management will be overseen by the Council of State Governments, a nonpartisan organization that fosters collaboration between elected and appointed officials across the country and the six U.S. territories.

[CMS Takes Action to Protect Health Care Coverage for Children and Families](#)

- The Centers for Medicare & Medicaid Services (CMS) [sent a letter](#) to all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands requiring them to determine whether they have an eligibility systems issue that could cause people, especially children, to be disenrolled from Medicaid or the Children's Health Insurance Program (CHIP) even if they are still eligible for coverage. CMS is requiring states to immediately act to correct the problem and reinstate coverage. Following the end of pandemic-era conditions for Medicaid coverage, states across the country have resumed regular processes for renewing individuals' Medicaid and CHIP enrollment. CMS believes that eligibility systems in a number of states are programmed incorrectly and are conducting automatic renewals at the family-level and not the individual-level, even though individuals in a family may have different eligibility requirements to qualify for Medicaid and CHIP.

[Justice Department Advances Proposed Rule to Strengthen Web and Mobile App Access for People with Disabilities](#)

- The U.S. Department of Justice (DOJ) submitted a [FRN](#) on a proposed rule that aims to improve web and mobile applications access for people with disabilities and clarify how public entities can meet their existing Americans With Disabilities Act (ADA) obligations as many of their activities shift online. The proposed rule, which falls under existing under Title II of the ADA, is particularly significant in the wake of the pandemic, as public entities have significantly increased the scope of essential services and programs offered through the web and mobile apps. It is critical for these technologies to be

accessible for people with disabilities. Ensuring that people with disabilities have equal access to these same services is essential. Written public comments were requested before October 3, 2023.

Non-Governmental Activities and Updates

16th Session Of The Conference Of States Parties To The CRPD

- The Convention on the Rights of Persons with Disabilities (CRPD) was adopted by the General Assembly by its resolution 61/106 of December 13, 2006. The 16th session of the Conference of States Parties to the CRPD (COSP16) was held at the United Nations Headquarters, New York, from June 13 to 15, 2023. The theme of the Conference was harmonizing national policies and strategies with the CRPD: achievements and challenges, with subthemes centering on ensuring equal access to and accessibility of sexual and reproductive health services for persons with disabilities, digital accessibility for persons with disabilities, and reaching the under-represented groups of persons with disabilities.
- On June 15, the Autism Alliance of Canada hosted a side event titled “Challenges, Best-Practices, and a Way Forward: Looking at National Autism Strategies through the lens of the CRPD.” This event aimed to discuss and showcase the successes and challenges of State Parties to the CRPD in developing and implementing national autism policies that are in alignment with the CRPD, focusing on the critical articles of accessibility, education, and work and employment. Dr. Susan Daniels, Executive Secretary of the IACC, was a featured panelist and shared the role of the IACC and its Strategic Plan in coordinating U.S. federal autism efforts, and the Strategic Plan’s alignment with the UNCRPD. [Read more about this event here.](#)

Recent conference: International Society for Autism Research (INSAR) Annual Meeting

- [The annual INSAR meeting](#) featured research presentations on a broad range of topics. The meeting was held in May 2023 in Stockholm, Sweden.
- Keynote presentations from the following speakers:
 - Wendy Chung, M.D., Ph.D. (advances in autism genetics research)
 - Gauri Divan, M.B.B.S., M.R.C.P.C.H. (adapting interventions for low-resource settings)
 - Patricia Howlin, Ph.D. (autism in older age)
- Also featured a roundtable discussion about precision health for neurodiverse communities.
- For more information, visit the [meeting archive link here.](#)

Recent conference: Stanford Neurodiversity Summit 2023

- [Annual meeting](#) bringing together neurodiverse/neurodivergent individuals, employers, service agencies, educators and students, parents, and professionals from all areas of the disability field. This Summit was held from October 1-3, 2023.
- Topics included:
 - Employment
 - Mental Health
 - Higher Education
 - K-12 Education
 - Human Rights
- For more information, visit the [Summit archive link here](#).

Upcoming conference: OCALICONLINE 2023 Autism and Disabilities Conference

- OCALI is hosting OCALICONLINE 2023, the premier autism and disabilities conference. The conference will bring together a cross-section of professionals and parents who utilize a variety of products and services at home, work, and in the community. The conference offers sessions which target a range of disabilities, including autism, deaf/hard of hearing, blind/visual impairments, and other low-incidence disabilities. Dr. Susan Daniels, HHS National Autism Coordinator, will be speaking about the new IACC Strategic Plan. IACC member Lindsey Nebeker will be speaking on double empathy and sibling relationships. The conference will be held online November 14-17. For registration and other information, visit: <https://conference.ocali.org/>

National Autism Indicators Report: Health Care Experiences During the COVID-19 Pandemic

- Autistic people often have greater health care needs than non-autistic peers. According to the National Autism Indicators Report: Health Care Experiences During the COVID-19 Pandemic, the pandemic-related changes in access to health care may have been an extra burden on autistic individual's health and, ultimately, quality of life. Researchers at A.J. Drexel Autism Institute's Policy and Analytics Center examined changes in access and disruptions to health care services for autistic children and adults during the beginning of the COVID-19 pandemic. These findings will inform better evidence-based practices for future public health emergencies to improve policies and programs for autistic individuals. [Read report here](#).