

October 2022

National Autism Coordinator Update

Committees, News, and Events



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Non-Governmental Updates

Launch of Black Feathers Podcast (Disability Conversation for All)

- Crystal Hernandez, Psy.D., M.B.A. and Shauna Humphreys, M.S., LPC launched a new podcast, Black Feathers, to discuss disability-related topics of interest to Tribal communities. They connect to listeners through sharing data, storytelling, and innovative content as well as providing resources. The podcast embraces diversity, equity, and honor within Tribal Nations. Dr. Hernandez is the mother to a child on the autism spectrum.

ASF Launches Novel 'Participate in Research' Website Directory

- The Autism Science Foundation (ASF) has launched a new directory of research participation opportunities to help individuals on the autism spectrum and their families find and more easily enroll in autism research studies. The directory is free and searchable.

Autism Speaks: Thought Leadership Summit on Autism and Aging

- In June 2022, Autism Speaks hosted a virtual Summit bringing together families, self-advocates, researchers and policymakers to discuss the issues facing autistic adults as they age. Over two days of sessions, presenters shared the top challenges faced by aging autistic adults, discussed policy considerations, provided an overview of the existing research and identified opportunities for further action to support this community.

Stanford Neurodiversity Summit 2022

- The Stanford Neurodiversity Summit is a virtual forum where neurodiverse/neurodivergent people, their family members and friends, educators, clinicians, researchers, and all other stakeholders and professionals will share visions, innovations, and inspirations about how neurodiversity can make our society better. The theme of this year's summit is "How do you contribute to the Neurodiverse Community? Education, Service, Research, and/or Advocacy." Event details and registration can be found [here](#).

[AUCD 2022 Conference: “Health Equity: Serving the Whole Person”](#)

- The annual AUCD Conference provides opportunities to share with and learn from colleagues and peers. This year, from November 13-16, AUCD will celebrate accomplishments and take a deeper dive into health equity, the social determinants of health, and the steps needed to ensure that every person is provided the best opportunities possible. Conference schedule and registration details are available [here](#).

Updates from Federal Entities and Committees

White House

- President Joseph R. Biden issued a proclamation to celebrate National Disability Employment Awareness Month (NDEAM). He honors the contributions of individuals with disabilities to the workplace and recommits to equal opportunity for all. [View proclamation here](#).
- The Office of Autism Research Coordination (OARC) aggregates federal and private news, resources, and events related to NDEAM 2022. [View webpage here](#).

Federal Interagency Workgroup on Autism (FIWA)

Managed by the HHS National Autism Coordinator/NIMH/NIH

- This all-federal working group includes multiple federal agencies and departments with programs related to autism and disabilities.
- Departments and agencies on the working group assist with the development of Reports to Congress required under the Autism CARES Act and other cross-agency reports.
- The group fosters interagency collaborations to enhance implementation of IACC Strategic Plan recommendations.
- Recent activities:
 - The NAC is keeping the FIWA updated on progress on the IACC Strategic Plan and planning for future reports to Congress on autism (e.g., the next Autism CARES Act Report to Congress) and other cross-agency activities.

[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:
 - Members are continuing to work on developing a new Strategic Plan for transition age youth with disabilities. The FPT Steering Committee met on September 15th, 2022 and the next meeting is planned for December 15th, 2022.

- My Future Matters Symposium: Held in-person on October 20 in honor of [National Disability Employment Awareness Month](#) and held jointly by ODEP, The Center for Advancing Policy on Employment for Youth (CAPE-Youth), and the National Working Group on Youth Transition's Youth Members. The topic of focus was future policy considerations for youth and young adults with disabilities transitioning into the workforce.

[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:
 - The ICDR held a Stakeholder Meeting on [June 23, 2022](#). The meeting included an interagency panel discussion on disability research with the U.S. Department of Transportation, National Science Foundation, and U.S. Access Board; and presentations on the impact of COVID-19 on people with disabilities, disability data and statistics, and disability equity. Meeting materials available [here](#).
 - The ICDR released a new toolkit called [Getting the Most Out of Stakeholder Engagement: A Toolkit to Better Understand and Measure Engagement](#). The toolkit is designed to give Administration for Community Living (ACL) staff and leadership guiding principles, promising practices, and resources to help enhance ACL's stakeholder engagement efforts. It includes practical information about stakeholder engagement – how and when to do it and why it is important – as well as interviews and case studies with examples from across ACL. The toolkit also focuses on the importance of measuring and analyzing stakeholder feedback, an area often lacking in engagement planning.
 - The NIDILRR-sponsored [State-of-the-Science on Disability Statistic Conference](#) took place on October 6-7, 2022. During this two-day hybrid event, experts in disability statistics provided, described, and discussed the latest advancements in disability statistic science and provided insights to new research and methods in disability data collection, analytical techniques, and advanced statistical analyses of key topics. Presentation slides are available online.
 - The ICDR held four recent Lunch and Learn webinars:
 - [Children and Youth with Disabilities in the Context of the COVID-19 Pandemic](#) with Emily Lund, Ph.D., C.R.C.
 - [Understanding Post-COVID Conditions \(Long COVID\)](#) with Elizabeth Unger, Ph.D., M.D.
 - [The Pathogenesis of Long COVID and Its Implication for Treatment](#) with Steven Deeks, M.D.

- [Understanding and Responding to the Cultural and Linguistic Differences in the Conduct of Disability Research](#) with Tawara Goode, M.A.

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:
 - NCD held a Quarterly Business Meeting on July 25th. The agenda is available [here](#). The Council heard public comment on the April Supreme Court decision *Cummings v. Premier Rehab Keller, P.L.L.C.* The Council also discussed proposed additions to its [Health Equity Framework](#). NCD is currently planning their [next Quarterly Meeting](#) to be in-person October 27-28th in Providence, RI. The agenda is coming soon.

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:
 - ACL is making the [2022 National Strategy to Support Family Caregivers](#) (the Strategy) available for public comment through November 30, 2022 via this [online form](#).. Public comments received will be used to inform the ongoing work of the Family Caregiving Advisory Council and the Advisory Council to Support Grandparents Raising Grandchildren, as well as to inform future updates to the Strategy.
 - Recently held their second joint meeting with the Advisory Council to Support Grandparents Raising Grandchildren on September 21, 2022. Meeting featured the announcement of the National Strategy publication. Meeting [agenda](#) available online.

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:
 - The ISMICC will meet on October 28th at 10:00 a.m. ET. The full agenda for the meeting and the Zoom link are available [at this link](#).

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 will hold its [next meeting](#) on Tuesday, November 1st at 1:00 p.m. ET. The meeting will be available online through [FCC Webcast](#).

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.
- Recent activities include:
 - The recently reconvened PCPID held their first meeting on July 28, 2022, and discussed Home and Community Based Services, employment, education, housing, and the direct support professional workforce crisis. The meeting [agenda](#), [minutes](#), [slides](#), and [recording with captions](#) are all available online.

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.
- Recent activities include:
 - The National Advisory Committee on Seniors and Disasters and the NACIDD conducted a joint virtual public meeting on August 4, 2022. The two committees

provided a status update on their work since March on topics related to national public health and medical preparedness, response, and recovery, specific to the needs of older adults and people with disabilities in disasters. Meeting [agenda](#) available online.

Agency for Healthcare Research and Quality (AHRQ)

- The Agency for Healthcare Research and Quality (AHRQ) is seeking public input about person-centered care for people at risk for, or living with, multiple chronic conditions (MCC). Comments will inform the agency's work and research agenda. Specifically, they are looking for comments on the current state of care and comments about innovative models, strategies, and approaches. Comments are due November 15. More [information](#) available online.

[NIH Awards \\$100 Million for Autism Centers of Excellence Program](#)

- The National Institutes of Health (NIH) [awarded a total of \\$100 million](#) over the next five years to support nine Autism Centers of Excellence (ACEs). Each ACE will include a Plan for Enhancing Diverse Perspectives (PEDP), which outlines strategies to increase the participation of women and people from underrepresented groups. Additionally, each ACE will have an advisory board that includes autistic people and/or parents of individuals with autism. The *Eunice Kennedy Shriver* National Institute of Child Health and Development also issued a [press release](#).

[Improving Data Infrastructure for Patient-Centered Outcomes Research for People with Intellectual and Developmental Disabilities](#)

Developed by the Assistant Secretary for Planning and Evaluation (ASPE)

- This report describes insights gained from key informant interviews and an ASPE-hosted listening session on short-term opportunities for improving patient-centered outcomes research (PCOR) data infrastructure that addresses the needs of individuals with intellectual and developmental disabilities (ID/DD). Report can be downloaded [here](#).