

April 2023

## National Autism Coordinator Update

### *Committees, News, and Events*



Susan Daniels, Ph.D.

Acting HHS National Autism Coordinator

Office of the NIMH Director

National Institute of Mental Health

## **White House and Autism Awareness Month Updates**

### **White House Updates**

- During Black History Month, the Biden-Harris Administration released [a fact sheet on the administration's work to support Black disabled Americans](#). Across the whole of the federal government, agencies are examining their policies and programs for disparities that have made it difficult for Black Americans and people with disabilities to thrive in their communities – at work, at school, and at home. Topics covered included employment, financial empowerment, education, family support, healthcare, etc. Read more [here](#).
- On March 31<sup>st</sup>, President Biden issued a proclamation on World Autism Awareness Day, 2023. The proclamation called upon all Americans to learn more about autism to improve early diagnosis, to learn more about the experiences of autistic people from autistic people, and to build more welcoming and inclusive communities to support people with autism. Read the [full proclamation here](#).

### **United Nations (UN)**

- On March 28<sup>th</sup>, UN Secretary General António Guterres issued a statement to mark World Autism Awareness Day 2023. The statement called on additional efforts to promote inclusive education, equal employment opportunities, self-determination, and an environment where every person is respected. The statement also recognizes the role of families, caregivers, and support networks in the lives of people with autism. Read the [full statement here](#).
- The United Nations will observe World Autism Awareness Day (April 2<sup>nd</sup>) with a global virtual event on the theme “Transformation: Toward a Neuro-Inclusive World for All”. The event will take place virtually, on Sunday April 2, 2023, from 10 am to 1 pm EST. With four moderated panel discussions, this year's event will specifically explore the contributions autistic people make at home, at work, in the arts and in policymaking. It will also shed light on how the transformation in the narrative around neurodiversity can continue to be furthered in order to overcome barriers, improve the lives of autistic people everywhere and achieve the Sustainable Development Goals. Registration is

open via the United Nations World Autism Awareness Day webpage, at <https://www.un.org/en/observances/autism-day>.

### **Office of Autism Research Coordination (OARC)**

- On April 14, 2023, from 2:00-3:30 pm EST, the National Institute of Mental Health (NIMH) and OARC are pleased to host their 10th Annual Autism Awareness Month Special Event titled “A Portrait of Autism: Artists and Their Works.” The virtual event will feature 4 artists, who will talk about how their experiences as autistic individuals have shaped their artistic expression. The event will include a sampling of their artwork and a Q&A with the artists. For more information, including registration, please visit the [event webpage](#).
- Throughout the month of April, OARC will be updating the Autism Awareness Month 2023 webpage on the IACC website with the latest news and events. <https://iacc.hhs.gov/meetings/autism-awareness-month/2023/>

### **Indian Health Service (IHS)**

- In celebration of Autism Awareness Month, IHS will host a webinar titled “American Indian/Alaska Native Parents of Children with Autism Panel” on April 12, 2023, at 12 pm EST. The purpose of this webinar is to provide American Indian/Alaska Native (AI/AN) parents the opportunity to share their stories as parents of children with Autism. This webinar will serve as a safe place for healthcare providers and community members to become more aware of the unique experiences of AI/AN families and to ask questions. Additional information can be found [here](#).
- On April 27, 2023 at 2 pm EST, IHS will be hosting a webinar titled “The Importance of Screening for Autism Spectrum Disorder and Use of the M-CHAT.” This webinar will focus on developing providers’ skills in the early identification of ASD markers, understanding of ASD-specific screening tools, with an in-depth discussion on the Modified Checklist for Autism in Toddlers (M-CHAT) and utilizing ASD screening tools in clinics. Focus will also include discussion of follow-up steps to take when a child is identified as “at risk.” Teaching tools will include a resource page, decision tree charts and quick facts for providers. Additional information can be found [here](#).

### **National Institute of Environmental Health Sciences (NIEHS)**

- On April 20, 2023 from 1:00-2:00 pm EST, NIEHS will be hosting a special virtual event for World Autism Awareness Month titled “Identifying Early Brain Markers in Infancy in Autism and Associated Developmental Disabilities.” His event will feature Dr. Mark Shen Ph.D. from the University of North Carolina at Chapel Hill. For more information, including registration, please visit the [event webpage](#).

## **Updates from Federal Entities and Committees**

### **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:
  - On March 22, 2023, ICDR held a Lunch & Learn Webinar on “[COVID-19 Data on Individuals with Intellectual and Developmental Disabilities](#).” The webinar featured Emma Plourde, Public Health Analyst from the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, and William Haltermann III, Program Specialist, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. HHS issued a [final report](#) on this topic in July 2021.

### **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.
- No new updates since their September 21, 2022 meeting. Details on a 2023 meeting are forthcoming.

### **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 recently held their quarterly business meeting on February 16, 2023 at 12:00pm ET. [Here is the agenda](#).
  - NCD issued a [Notice of Funding Opportunity](#) titled “The Absence of People with Disabilities in Clinical Trials” to address the explicit and implicit exclusion of people with disabilities in clinical trials and the legal implications and impact of exclusion on the disability community. The final report issued by the awardee will provide recommendations and promising practices to increase the

acceptance and participation rates of people with disabilities in clinical trials. Proposals were due March 22, 2023.

- On March 27, 2023, NCD issued an [update](#) on its [Health Equity Framework](#) published last year.
- NCD and the [National Indian Council on Aging](#) recently released a toolkit — “[Understanding Disabilities: In American Indian & Alaska Native Communities](#)” — to share resources and recommendations on disability services and protections for Tribal Nations.

### **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:
  - The FPT held a General Committee meeting on March 16<sup>th</sup> and is continuing development of a new Federal Youth Transition Plan.

### **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 21<sup>st</sup> 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 held a meeting on March 14, 2023. [The full agenda and link are 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.
- No new updates since the November 1, 2022 meeting. The DAC will meet again this year in 2023 with new membership. This iteration will last until 2024.

## **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.
- No new updates since the July 28, 2022, meeting. [Here are the minutes from the July 2022 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.
- No new updates since the August 4, 2022, joint [meeting with National Advisory Committee for Seniors with Disabilities \(NACSD\)](#).

## **NIH/NICHD Workshop: [Ableism in Medicine and Clinical Research Workshop](#)**

### **Sponsored by the National Center for Medical Rehabilitation Research at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development in collaboration with the NIH Medical Rehabilitation Coordinating Committee**

- From April 27-28, 2023, NICHD will host a two-day, virtual workshop focused on awareness and research opportunities to mitigate the impact of Ableism in both clinical care and the biomedical and behavioral research enterprise. This workshop is intended to inform future research areas in this complex area of public health. For more information, including registration, please visit the [event webpage](#).

## **Non-Governmental Updates**

### **Autism Science Foundation Presents 10th Annual Day of Learning**

- On March 30, 2023, the Autism Science Foundation held its 10<sup>th</sup> Annual Day of Learning. ASF’s Days of Learning are TED-style science conferences that bring top researchers together with autism stakeholders to share cutting-edge research findings and to discuss the issues that matter most to our families. These events take place in person and online. More information [found here](#).

### **[Autism Science Foundation Awards First Round of Profound Autism Pilot Grants](#)**

- The Autism Science Foundation has awarded four grants to researchers for projects examining sleep, neuropsychiatric regression, self-injurious behaviors, and methods for improving access to communications systems. These new grants were launched in response to The Lancet Commission on the Future of Care and Clinical Research in Autism call for use of the term “profound autism.” Awardees include Dimitrios Mylonas, Ph.D., Massachusetts General Hospital; Sheng-Nan Qiao, Ph.D., Yale University; Giacomo Vivanti, Ph.D., Drexel University; and Charlotte DiStefano, Ph.D., Children’s Hospital of Los Angeles. This project is co-sponsored by CureShank and the Phelan-McDermid Syndrome Foundation.

### **Kennedy Krieger Research Institute: [Neurodiversity in the Workplace Conference](#)**

- From March 22-24, 2023, Kennedy Krieger Institute hosted a conference in DC that brings together employers, stakeholders and policymakers who are committed to improving employment outcomes for the neurodiverse workforce. More information can be found [here](#).

### **AJ Drexel Autism Research Institute: [National Autism Indicators Report Explores Autistic Individuals’ Use of Medicaid Across the Lifespan](#)**

- In the [latest edition](#) of the [National Autism Indicators Report series](#), researchers at Drexel University’s [A.J. Drexel Autism Institute](#) explore how autistic individuals use Medicaid and how their service use changes across the lifespan – from infants to older adults – using data from the Centers for Medicaid and Medicare Services (CMS) from 2008-2016. This is the first report in the Autism Institutes’ new Policy Insight series of National Autism Indicators Reports. The user-friendly series will deliver statistics about policy-relevant issues pertinent to the lives of autistic people and those with other developmental disabilities. For more information, including an [at-a-glance edition](#) of the report, please [visit here](#).

### **[INSAR 2023 Annual Meeting](#)**

- From May 3-6, 2023, the International Society for Autism Research (INSAR) will be hosting their annual scientific meeting in-person in Stockholm, Sweden. 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](#).