

April 2022

## National Autism Coordinator Update

*Committees, News, and Events*



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### **Non-Governmental Updates**

#### **United Nations World Autism Awareness Day Observance**

- The theme of the 2022 observance is “Inclusive Quality Education for All.” This is in accordance with [Sustainable Development Goal 4 \(SDG 4\)](#) that focuses on ensuring inclusive and equitable quality education and promoting lifelong learning opportunities for all, as the foundation for improving people’s lives and reducing inequalities.
- This year’s event will take place [April 8, 2022, 10-11:15am ET](#) and is organized by the UN Department of Global Communications and UN Department of Economic and Social Affairs, with the support of civil society partners including the Autistic Self Advocacy Network, the Global Autism Project and the Specialisterne Foundation. The virtual event will include a moderated panel discussion, along with brief presentations by self-advocates, educators and other experts.

#### **World Health Organization (WHO)**

- In advance of World Autism Awareness Day, the World Health Organization released an [online version of its training program for caregivers of children with developmental delays or disabilities \(DD\)](#) such as autism. This program has been piloted in more than 30 countries and teaches skills that can be used to promote the well-being and development of children. The online training includes recorded information sessions on a variety of topics. Sessions also help caregivers improve their own well-being. In April, WHO will launch companion manuals for facilitators of in-person trainings. The program was developed in collaboration with Autism Speaks.

#### **Canadian Autism Spectrum Disorder Alliance (CASDA)**

- CASDA is an organization focused on the creation and implementation of a comprehensive national autism strategy addressing funding and policies for the autistic community in Canada. They recently held their [Canadian Autism Leadership Summit](#) on April 4-5, 2022, focused on themes such as: equity, diversity, and social inclusion in policy development; evolution of evidence-informed supports across the lifespan; and

progress in employment programs and disability supports. Dr. Susan Daniels was a featured panelist during a panel discussion of plans for a national Canadian autism strategy & perspectives and lessons from around the world. She shared the role of legislation, the IACC, and the IACC Strategic Plan in shaping federal autism policy in the U.S.

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

### **White House**

- In March 2022, [President Biden appointed 21 key citizen members to the President's Committee for People with Intellectual Disabilities \(PCPID\)](#). The Committee advises the President and the Secretary of the U.S. Department of Health and Human Services on issues related to people with intellectual disabilities. The members of PCPID reflect the diversity of America and includes self-advocates, family members, researchers, service providers, business representatives, and other advocates.
- In his [2022 Presidential Proclamation for World Autism Awareness Day](#), President Joseph R. Biden reaffirms his Administration's commitment to equity for people on the autism spectrum across all races, ethnicities, genders, cultures, and geography in access to services, inclusion of people with lived experience in research, opportunities for competitive integrated employment, and the ability to pursue their life interests free of discrimination.
- President Joe Biden recently signed a [\\$1.5 trillion spending bill](#) that sends \$14.5 billion for special education and \$6 million for home and community-based services (HCBS). The bill is the first federal spending bill to be approved since President Biden took office and funds the government through September 2022.

### **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 recently completed their contribution to the [2021 HHS Report to Congress on the Health and Well Being of Individuals with Autism Spectrum Disorder](#).
- The group fosters interagency collaborations to enhance implementation of IACC Strategic Plan recommendations.

### **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.
- Members are continuing to work on developing a new Strategic Plan for transition age youth with disabilities.
- Recent activities include:
  - The FPT held a meeting on March 17, 2022. The meeting featured presentations from the Department of Labor’s Office of Disability Employment Policy (ODEP) and representatives of the [Center for Advancing Policy on Employment for Youth \(CAPE-Youth\)](#), a collaboration between ODEP, The Council of State Governments, and the Yang-Tan Institute on Employment and Disability at Cornell University.

### **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:
  - Publication of [FY 2021 ICDR Accomplishments Report](#). In 2021, ICDR promoted and optimized interagency coordination and collaboration through its activities and continued to implement the government-wide strategic plan required by the Workforce Innovation and Opportunity Act. ICDR also engaged with stakeholders and continued its ongoing activities to support its overall mission, goals, and objectives. Details of specific ICDR accomplishments and research highlights throughout FY 2021 are included in the report.
  - The ICDR Executive Committee held a meeting on February 24, 2022. The Disability Data and Statistics Subcommittee provided an update on recent activities, including plans for an upcoming Roundtable event. The Executive Committee provided feedback on and brainstormed ideas on the new ICDR focus areas of Equity, Disability Data and Statistics, and COVID-19 and Disability Rehabilitation Research. Detailed meeting notes are available on the [ICDR website](#).

### **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.
- NCD published the [Health Equity Framework for People with Disabilities](#) in February 2022 and held a virtual session to discuss the details of the Framework.

- The Framework outlines the inequities faced by people with physical, intellectual, and developmental disabilities and gives guidelines for how federal agencies can reduce inequities and what areas to focus on.
- The Framework is a blueprint for policy makers to address disparities and inequities and included input from national disability advocacy organizations.
- The Framework is made up of four core components:
  - Designation of people with disabilities as a Special Medically Underserved Population (SMUP)
  - Standardize and implement Comprehensive Disability Clinical-Care Curricula on all disability across the lifespan
  - Ensure Accessibility of Medical Diagnostic Equipment
  - Improve Data Capturing by including indicators of disability status in all public health surveillance systems and capture data across the lifespan.
- NCD will next conduct one-on-one meetings with federal partners and Congressional offices to move the framework from paper to reality and work with the Association of American Medical Colleges (AAMC) and medical schools/board to design and adopt standardized, comprehensive disability clinical-care curricula.
- NCD published a report on [\*Medicaid Oral Health Coverage for Adults with Intellectual & Developmental Disabilities – A Fiscal Analysis\*](#) in March 2022. The report examined how state Medicaid dental benefits and state waiver programs impacted the receipt of dental care among adults with intellectual and developmental disabilities (I/DD) and strategies for expanding dental care for adults with I/DD.

### **[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 seeking nominations for this council](#). Up to 15 non-federal voting members from the following groups will be appointed for three-year terms: family caregivers; older adults who need long-term services and supports; individuals with disabilities; health care and social service providers; providers of long-term services and supports; employers; paraprofessional workers; state and local officials; accreditation bodies; veterans; and as appropriate, other experts and advocates engaged in family caregiving.

## 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.
- The ISMICC will meet on April 13, 2022. The full agenda for the meeting, along with meeting minutes and other materials, will be 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 announced two programs: the [Affordable Connectivity Program](#), which will replace Emergency Broadband Benefit in providing various communication discounts. In addition, the [Emergency Connectivity Fund](#) is a \$7.2 billion program which has provided emergency funding for schools and libraries since May 2021.
  - Updates to text-in services include an expanded “text-to-911” registry to show where real time text (RTT) is available to communicate with emergency personnel. In effect July 2022, “text-to-988” will supplement the 1-800 number suicide hotline.
  - The DAC is currently [seeking public feedback](#) on the implementation of the Twenty-First Century Communications and Video Accessibility Act. The bi-annual report is due in October 2022.
  - Related to TRS and RTT: The DAC discussed technical challenges of using Telecommunications Relay Services (TRS) for accessing video conferencing and ways to address those challenges. As well, the Real-Time Text (RTT) Working Group recommended the FCC consider ways to educate the public about RTT updated capabilities to ensure consumers understand the services are widely available, about how RTT works, its benefits, and its limitations.