

January 2022

## National Autism Coordinator Update

*Committees, News, and Events*



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### **Non-Governmental Updates**

#### **Patient-Centered Outcomes Research Institute (PCORI)**

- As part of the 2019 legislation that reauthorized PCORI's funding for 10 years, Congress included research on intellectual and developmental disabilities as a priority topic for PCORI. In July 2021, PCORI's Board of Governors approved [two awards](#) totaling \$12 million to support studies assessing ways to deliver mental health care to young people with intellectual and developmental disabilities (IDD). Recent events include:
  - On October 21, 2021, PCORI hosted a [workshop](#), during which a panel of clinical and research professionals discussed the topics of IDD and co-occurring mental health conditions.
  - On November 10, 2021, PCORI hosted a [stakeholder webinar](#) on diagnosis and treatment for attention deficit hyperactivity disorder in children and adolescents.
  - Current funding opportunity announcement: [Comparative Effectiveness of Interventions Targeting Mental Health Conditions in Individuals with Intellectual and Developmental Disabilities -- Cycle 1 2022](#)
  - PCORI is inviting [Public Comments](#) on its [Proposed Research Agenda](#) until January 31, 2022.

#### **American Academy of Pediatrics**

- The American Academy of Pediatrics published a [new report](#) highlighting guidance which encourages pediatricians to include children with disabilities in the physical activities of their peers, instead of focusing solely on the child's disability as a barrier. The report also discusses how families should talk about fitness goals, likes, and dislikes in order to develop a movement plan to help with social inclusion and physical wellness.

#### **National Academies**

- The National Academies of Sciences, Engineering, and Medicine recently hosted a [workshop](#) exploring the challenges and opportunities for creating an optimal care system for individuals with intellectual and developmental disabilities (IDD). It explored

questions related to three areas of focus: models of care that deliver holistic, tailored, and coordinated care; the development of a competent workforce; effective financing and payment approaches. The workshop was sponsored by the Lucille Packard Foundation for Children's Health.

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

### **White House**

- On October 28, 2021 President Biden [appointed Sara Minkara](#) to be the U.S. Special Advisor on International Disability Rights – a role critical to ensuring that U.S. diplomacy and foreign assistance promote and protect the human rights of persons with disabilities around the world.
- On December 2, 2021, President Biden issued a [Proclamation on the International Day of Persons with Disabilities](#) affirming the human rights of people with disabilities.

### **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. Slate of 2022 meetings to be scheduled shortly.
- 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.

### **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.

### **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 the [Health Care Access and Quality for People with Disabilities Toolkit](#). The toolkit includes resources for future federal research for addressing health care access and quality challenges faced by people with disabilities and

provides an overview of federal programs and research, best practices, and areas for future research on health care access and quality for people with disabilities.

- The committee has adopted three new themes for future activities:
  1. Equity and Disability
  2. COVID-19 and Disability
  3. Disability Statistics
- The Lunch & Learn Webinar Series highlights a variety of topics related to disability and rehabilitation research. Recent Lunch & Learn Webinars have covered workplace disability and inclusion ([August 2021](#)) and how national health surveys can be used to better understand HUD-assisted adults living with disabilities ([September 2021](#)).

### **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 recently responded](#) to the Centers for Medicare & Medicaid Services' (CMS) Request for Information (RFI) on rural emergency hospitals. In the response, NCD highlighted the high usage of emergency room services due to lack of preventative care; the high risk of falls during transportation due to sensory, cognitive, and physical disabilities; lack of needed accommodations such as ASL interpreters during care; and need for additional staff training and accessible equipment.
- In December, NCD [sent a letter](#) to the leaders of the National Institute on Minority Health and Health Disparities (NIMHD), as well as the Agency for Healthcare Research and Quality (AHRQ), supporting designating people with disabilities as a health disparity population. NCD noted the wealth of literature on health disparities among the over 64 million people with disabilities in the U.S.
- In October, NCD released the [2021 Progress Report: The Impact of COVID-19 on People with Disabilities](#), which highlights how people with disabilities are at a higher risk of facing negative impacts of COVID-19 in areas related to indoor congregate settings, chronic co-occurring medical conditions, as well as the direct care workforce. The report provides recommendations in areas such as healthcare, education, employment, and communication access for people with disabilities.

### **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:
  - The RAISE Family Caregiving Advisory Council and the [Advisory Council to Support Grandparents Raising Grandchildren](#) will hold their first joint meeting on January 25, 2022, from 12:30 pm to 4:30 pm ET, to begin the development of the National Family Caregiving Strategy. Agenda and webinar information to be developed soon.

### [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 recently met on December 16, 2021. The Committee discussed the 2021 ISMICC Report to Congress, potential for working groups, and an overall planning session. The full agenda is available [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. Recent activities include:
  - Committee meeting on [September 9, 2021](#).
  - Resource: [Concerns and Lessons Learned Regarding Communication Access for People with Disabilities During the Pandemic](#)

### [Defense Advanced Research Projects Agency \(DARPA\)](#)

- As a part of their The Physics of Artificial Intelligence program, DARPA funded research by a [University of Chicago team](#), led by Dr. Ishanu Chattopadhyay, to investigate, develop, and implement tools that augment current machine learning tools and capabilities. They identified a need for tools to help identify children with ASD as early as possible.
  - In one of their [studies](#), they developed and validated machine inferred digital biomarkers for autism using individual diagnostic codes already recorded during medical encounters, referred to as the Autism Co-morbid Risk Score (ACoR). They concluded that if adopted in practice, ACoR could significantly reduce the

median diagnostic age for ASD and reduce long post-screen wait-times experienced by families for confirmatory diagnoses and access to evidence based interventions.

### **National Science Foundation (NSF)**

The following updates pertain to NSF funding opportunities related to disability research:

- “Enhancing Opportunities for Persons with Disabilities” was selected as a research topic for 2022 for the NSF [Convergence Accelerator](#) Program. This theme includes communication and assistive technologies, workforce accommodations, and robotics. Announcement can be [found here](#).
- NSF is calling for proposals for their [National Artificial Intelligence Research Institutes](#), a joint program of NSF and the following collaborators: U.S. Department of Agriculture (USDA) National Institute of Food and Agriculture (NIFA), U.S. Department of Education (ED) Institute of Education Sciences (IES), U.S. Department of Homeland Security (DHS) Science & Technology Directorate (S&T), National Institute of Standards and Technology (NIST), Department of Defense (DOD) Office of the Under Secretary of Defense for Research and Engineering (OUSD (R&E)), and IBM Corporation (IBM). This program solicitation expands upon the nationwide network established by the first 18 AI Research Institutes to pursue transformational advances in a range of economic sectors, and science and engineering fields.
  - Six new themes have been identified for the new solicitation. Theme #6 focuses on AI technology to enhance education and outcomes, including those for people with disabilities: “Theme 6: AI-Augmented Learning to Expand Education Opportunities and Improve Outcomes”