

July 2021

Updates from the National Autism Coordinator

Committees, News, and Events



Susan Daniels, Ph.D.

Acting HHS National Autism Coordinator
Office of the NIMH Director
National Institute of Mental Health

International Society for Autism Research (INSAR)

- Scientific and professional organization devoted to advancing the knowledge about autism by promoting the highest quality of research.
- The [2021 Virtual Annual Meeting](#) was held May 3 – May 7, 2021.
- This summer's [INSAR 2021 Institute: Autism and Intersectionality](#) focuses on understanding autism research and autistic people's experiences across multiple identities and groups (e.g., race, gender, sexual orientation, neurodiversity, culture, poverty).
- [INSAR Policy Briefs](#) are published on the INSAR website. They provide an overview of the scientific research, an implications statement, and recommendations for next steps or actions.
 - The INSAR Policy Brief [Autism Community Priorities for Suicide Prevention](#) was published in April 2021.
 - Longer version of the policy brief aimed at researchers and research funders: [Where Do We Go from Here? Autism Community Priorities for Future Suicide Research](#)

Updates from Relevant Federal Committees

Federal Interagency Workgroup on Autism

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.
- Currently working on the *Report to Congress on the Health and Well-Being of Individuals on the Autism Spectrum* in collaboration with OARC/NIMH.
- The workgroup allows for cross-agency exchange of information on projects and programs related to ASD and consideration of IACC Strategic Plan recommendations.

National Advisory Committee on Individuals with Disabilities and Disasters (NACIDD)

Managed by the HHS Office of the Assistant Secretary for Preparedness and Response

- This new federal advisory committee is currently being established and will evaluate issues and programs and provide 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. It 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.
- Up to seven new voting non-federal members with expertise in disability accessibility, medical disaster planning, preparedness, response, or recovery will be selected for the Committee. The nomination period closed on July 12, 2021.

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.
- The FPT developed the [2020 Federal Youth Transition Plan: A Federal Interagency Strategy](#), which outlines how the partner agencies will enhance interagency coordination through the identification of a shared vision, compatible outcome goals, and policy priorities, ultimately leading to improved outcomes for youth with disabilities by 2020.
- The *Federal Youth Transition Plan* is due for an update in the near future.
- This group facilitates exchange of information between federal agencies on transition related issues for 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:
 - ICDR Virtual Stakeholder Event (June 2021)
 - Event on [Recruitment Strategies for Hiring Individuals with Disabilities](#) (July 21, 2021)
 - White paper entitled [The Impact of COVID-19 on Disability Research: New Challenges and Widening Disparities](#) (January 2021)

- Published [Health Information Technology Toolkit: A Compendium of Accessible and Usable Health IT Resources](#) (January 2021)
- Published [Aging with Disability: A Toolkit for Interagency Collaboration](#) (May 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.
- Recent activities include:
 - Conducting comprehensive study to examine effects of the pandemic on people with disabilities across a range of policy topics
 - [NCD makes recommendations to National Governors Association on COVID-19 vaccination equity](#) (February 2021)
 - Report: [Enforceable Accessible Medical Equipment Standards](#) report (May 2021)
 - [Letter to HHS Secretary Becerra](#) Concerning Health Equity (June 2021)
 - [Quarterly meetings](#)
- Upcoming meetings: July 22nd, 2021 & October 7th-8th, 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 first meeting of the FCAC was held in August 2019. The [Administration for Community Living](#) (ACL) manages this council.
- Recent activities include:
 - FCAC adopted [26 recommendations](#) aimed at establishing a national approach to addressing the needs of family caregivers of all ages and circumstances. These recommendations will be included in the Council's initial Report to Congress in 2021 and serve as the foundation for the National Family Caregiving Strategy.
 - [Council meeting](#) in April 2021 included discussion with the Older Adults Equity Collaborative on access and equity in aging services programs, particularly when working with caregivers.
 - The development of a Family Caregiving National Strategy was further discussed during the Council's three subcommittee's meetings in May 2021.
 - The Council voted to move the Report to Congress through the official government clearance process.