

**IACC October 2021 Meeting
Round Robin Updates**

FEDERAL AGENCY UPDATES

Centers for Disease Control and Prevention (CDC)

- In response to COVID-19, CDC has initiated a number of collaborations:
 - Collaborated with the American Academy of Pediatrics (AAP) to improve delivery of essential health services, such as developmental surveillance, screening, and referrals. Promising practices to continue developmental surveillance, screening, referral, and follow up during COVID-19 response have been identified, and a Pedialink course is in development (potential release during Winter, 2021-2022).
 - Continues to collaborate with Association of University Centers on Disabilities to support 42 state/territorial Act Early Ambassador-led teams to enhance early childhood systems' ability to identify children with developmental delay and autism spectrum disorder (ASD) during the COVID-19 pandemic and recovery.
 - Will collaborate with the AAP and Family Voices to improve capacity among pediatric healthcare providers to increase COVID-19 vaccination among children, youth, and families with developmental disabilities, including ASD.
 - Will collaborate with Research Triangle Institute (RTI) International to develop and disseminate Spanish-language resources with important COVID-19 information, including but not limited to prevention, symptom identification, vaccination, testing, and treatment. These resources are designed for Hispanics with intellectual and developmental disabilities (IDD) who also have extreme low literacy (ELL), Spanish-speaking caregivers of Latinos with IDD and ELL, disability-serving partner organizations, and healthcare providers.
- CDC is also supporting one new program: The Tribal Act Early Ambassador Project provided \$75K awards to fund Tribal Act Early Ambassadors from the Southern Plains Health Board and Wabanaki Public Health and Wellness; they have just received the notice of award and will be kicking off this project in the next few weeks.
- CDC has been working with AAP and a panel of subject matter experts to revise and update the developmental milestones and parenting tips included on the Learn the Signs. Act Early. milestone checklists; a paper describing the process is under review (at *Pediatrics*) and the updated materials (app, web, and print materials) will be released this Winter, 2021-2022.
- Through collaboration with the National Institutes of Health, CDC leveraged a new partnership with the Autism Sequencing Consortium to promote analyses of laboratory specimens and genetic discovery for children with ASD. Whole genome sequencing, and genotype data have been generated from Study to Explore Early Development (SEED) samples using funding from the Autism Sequencing Consortium. Because of this collaboration, the number of SEED participants with genetic data available has increased by 150%.
- Significant Publications (Since July 2021)
 - Abercrombie J, Pann J, Shin F, Taylor E, Brisendine AE, Holm RS, James C, Viehweg S, Chodron G. [Evaluation of the Feasibility and Perceived Value of Integrating Learn the Signs. Act Early. Developmental Monitoring Resources in Early Head Start.](#) *Early Childhood Education Journal*, 2021 Aug 16 [Online ahead of print].
 - Grosse SD, Nichols P, Nyarko K, Maenner M, Danielson ML, Shea L. Heterogeneity in Autism Spectrum Disorder Case-Finding Algorithms in United States Health

Administrative Database Analyses. J Autism Dev Disord. 2021 Sep 28. Epub ahead of print. [PMID: 34581918]

- Matias SL, Pearl M, Lyall K, Croen LA, Kral TVE, Fallin D, Lee LC, Bradley CB, Schieve LA, Windham GC. Maternal prepregnancy weight and gestational weight gain in association with autism and developmental disorders in offspring. Obesity (Silver Spring). 2021 Sep;29(9):1554-1564. Epub 2021 Aug 4. [PMID: 34347372]
- Ryerson AB, Rice CE, Hung MC, Patel SA, Weeks JD, Kriss JL, Peacock G, Lu PJ, Asif AF, Jackson HL, Singleton JA. Disparities in COVID-19 Vaccination Status, Intent, and Perceived Access for Noninstitutionalized Adults, by Disability Status - National Immunization Survey Adult COVID Module, United States, May 30-June 26, 2021. MMWR Morb Mortal Wkly Rep. 2021 Oct 1;70(39):1365-1371. [PMID: 34591826]
- Tinker SC, Cogswell ME, Peacock G, Ryerson AB. Important Considerations for COVID-19 Vaccination of Children With Developmental Disabilities. Pediatrics. 2021 Oct;148(4):e2021053190. Epub 2021 Jul 16. [PMID: 34272340]

Department of Defense (DoD) – Autism Research Program (ARP)

- For the FY 2020 program cycle, 10 projects were funded including those focused on preclinical, translational, and clinically focused studies. Award information including both technical and public abstracts for these projects can be found at <https://cdmrp.army.mil/search.aspx>.
- The FY 2021 cycle is ongoing. We anticipate that projects recommended for funding will be made public in January/February 2022.

Department of Housing and Urban Development (HUD)

- HUD awarded a research contract to identify successful approaches and programs to assist people with disabilities overcome challenges encountered when using housing rental assistance and searching for and successfully leasing housing in the community. The study includes a literature review, an environmental scan, and nine case studies. Results are expected in late 2023.

Environmental Protection Agency (EPA)

- On October 6, EPA Administrator Michael S. Regan announced an update to [EPA's Policy on Children's Health](#). The 2021 policy updates the 1995 version and cements the protection of children by including an improved definition of children's environmental health to reflect and be consistent with scientific findings from the last 25 years. It also clarifies that childhood includes not only the period from conception through infancy, early childhood, and adolescence until 21 years of age, but also the effects of early life exposure that may become evident in adulthood and later generations.
- The Office of Children's Health Protection is the only office in the federal government focused on the protection of children's environmental health. The office, including regional children's health coordinators, stands ready to assist all programs and regions, and works with stakeholders to enhance our efforts in this area. For more information, please see www.epa.gov/children and www.epa.gov/schools.

National Institutes of Health (NIH)

- The Autism Centers of Excellence (ACE) Network is a trans-NIH initiative that supports large-scale studies on ASD. Institutes that fund ACE Centers are the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), National Institute of Environmental Health Sciences (NIEHS), National Institute of Mental Health (NIMH), and National Institute of Neurological Disorders and Stroke (NINDS). Applications are now open for ACE Centers from institutions that support major multidisciplinary research programs of ASD research. The deadline for submission is November 9, 2021. More information can be found at the following links:
 - NOT-HD-21-045: <https://grants.nih.gov/grants/guide/notice-files/NOT-HD-21-045.html>
 - RFA-HD-22-007: <https://grants.nih.gov/grants/guide/rfa-files/RFA-HD-22-007.html>
 - RFA-HD-22-008: <https://grants.nih.gov/grants/guide/rfa-files/RFA-HD-22-008.html>
- **National Institute of Environmental Health Sciences (NIEHS)**
 - We continue to fund studies to better understand the association of environmental exposures and risk for autism, focusing on how these exposures are modifiable factors that may be targets for ameliorating negative health outcomes associated with autism.
 - NIEHS is excited by the continued growth of environmental health research related to autism. In FY 2021, three of our new awards were for post-doctoral fellows or early-stage investigators, who are bringing new perspectives and ideas to both epidemiology and lab-based mechanistic research on environmental contributors to autism.
 - Dr. Debbie Cory-Slechta was awarded a RIVER R35 to continue her research on the mechanisms underlying alterations in neurodevelopment in response to early life exposure to air pollution that may contribute to autism, schizophrenia, and other neurodevelopmental disorders. The Revolutionizing Innovative, Visionary Environmental Health Research (RIVER) R35 is a “people, not projects” award for outstanding environmental health sciences researchers who demonstrate a broad vision and potential for continuing their impactful research by providing them with increased scientific flexibility, stability in funding, and administrative efficiency.
- **National Institute of Mental Health (NIMH)**
 - **Autism Biomarkers Consortium – Clinical Trial: Study Update:** The [Autism Biomarkers Consortium for Clinical Trials \(ABC-CT\)](#), a multisite study established in 2015 to test and refine a set of biomarkers to serve as reliable, objective measures of variation in social impairment in ASD, received NIH funding in fall 2020 to conduct a second phase of research. The next phase of the project will involve a) a follow-up study of the original cohort to examine the longer-term stability of these biomarker measures, b) administering measures from phase 1 of the study with a new cohort of children to see if the original findings can be replicated and confirmed, and c) conducting a feasibility study of its EEG N170 and eye tracking measures in children ages 3 to 5, both with and without ASD. Overcoming the challenges posed by the ongoing COVID-19 pandemic, the investigators have begun re-contacting and re-assessing families and participants from phase 1 of the study. The project also continues to make progress on its EEG N170 and eye tracking measures which were both accepted as ASD biomarkers for the FDA Biomarker Qualification Program.

- **Telemedicine Tools for ASD Diagnoses:** Telemedicine tools have the potential to address significant disparities in accessing autism diagnostics services for many families impacted by the disorder. The NIMH recently awarded a grant to conduct a rigorous evaluation of [TAP \(TELE-ASD-PEDS\)](#), a previously validated tool of a parent-administered and clinician guided tele-assessment for autism diagnosis. The newly awarded grant will conduct a randomized clinical trial (RCT) at Vanderbilt University and the University of California, Davis, and will recruit 360 toddlers (ages 18-42 months) to participate in the home-based TAP telemedicine assessment. This large-scale RCT evaluation of TAP will have the potential to demonstrate the efficacy and effectiveness of a telemedicine diagnostic tool that can improve access to autism diagnostic care, eliminate the time lag between ASD symptom emergence and diagnosis, and reduce disparities for underserved populations.
- **2021 Annual ACE Investigator Meeting:** In early June, NIH convened the annual Autism Centers of Excellence (ACE) Investigators Meeting which brought together over 200 autism researchers taking part in the ACE Centers and Networks research programs. In addition to research progress presentations from early career scientists, ACE investigators also held panel discussions on the impact of COVID-19 pandemic restrictions on conducting ACE research, as well as methods and adaptations they adopted to keep their research activities moving forward. A group of early-stage ACE researchers also led a panel discussion on efforts to address issues regarding diversity, equity, and inclusion in autism research. They discussed their current efforts to promote racial and ethnic diversity among participants and families taking part in autism studies, as well as increasing diversity in the training of future generations of autism researchers.

Social Security Administration (SSA)

- **The Social Security Administration remains committed to providing timely and accurate information during the COVID-19 pandemic. Please visit <https://www.ssa.gov/coronavirus/> (or <https://www.ssa.gov/espanol/coronavirus/> for Spanish) to view COVID-19 questions and answers.** An example of an answer to an oft asked question: “We determined that, under our rules, COVID-related financial assistance would not affect eligibility for SSI or the monthly SSI payment amount”.
- **The Social Security Administration encourages everybody to create their free and secure “my Social Security” account at <https://www.ssa.gov/myaccount>.** A “my Social Security” account provides personalized tools for everyone, whether they receive benefits or not, and can be used to request a replacement Social Security card, check the status of an application, estimate future benefits, or manage benefits already received. You can also access your redesigned Social Security Statement (new as of October 2); for samples of the redesigned Social Security Statement and a collection of new fact sheets to accompany the online Social Security Statement (in English and Spanish), please visit <https://www.ssa.gov/myaccount/statement.html>.
- **The Social Security Administration has listed an open “Request for Information on Potential Disability Insurance and Supplemental Security Income Demonstrations” in the Federal Register (see <https://www.federalregister.gov/documents/2021/09/17/2021-20158/request-for-information-on-potential-disability-insurance-and-supplemental-security-income>); we welcome recommendations that focus on ASD!** The Commissioner of Social Security is authorized to test new program rules to promote attachment to the labor force and increase

the employment and self-sufficiency of individuals receiving or applying for DI or SSI benefits, including children and youth; and to coordinate planning between private and public welfare agencies to improve the administration and effectiveness of the DI, SSI, and related programs. This request for information seeks public input on potential services, supports, or DI and SSI policy changes that could achieve these goals. The input we receive will inform our deliberations about possible future demonstrations and tests. We will also use the responses as reference material as we provide Congress technical advice regarding any potential renewal of the section 234 authorization. To ensure that your comments are considered, we must receive them no later than November 16, 2021.

- To follow up the discussion on the first day of the October 2021 meeting relating to the presentation from Assistant Secretary Williams of the Department of Labor, SSA would like to share that they have previously worked and are continuing to work with the Department of Labor, particularly the Office of Disability Employment Policy (ODEP) on a number of initiatives. Assistant Secretary Williams and SSA Commissioner Kijakazi met last month to discuss ways to address common goals and are meeting again this month with a broader group. At the staff level, ODEP and SSA have collaborated on a number of projects over the last decade (and SSA has also worked with other agencies) to find ways to promote employment and well-being for all people with disabilities, including people with autism spectrum diagnoses. SSA would be happy to present information about our collaborative work and other efforts at a future IACC meeting.

Substance Abuse and Mental Health Services Administration (SAMHSA)

- The [Interdepartmental Serious Illness Coordinating Committee \(ISMICC\)](#) reports to Congress and federal agencies on issues related to serious mental illness (SMI) and serious emotional disturbance (SED). The next meeting of the ISMICC is [October 27, 2021, from 1:00 pm – 5:00 pm](#).
- The [Interdepartmental Substance Use Disorders Coordinating Committee \(ISUDCC\)](#) is focused on substance use disorder treatment and coordination among federal agencies. The ISUDCC held their [first meeting on August 26, 2021](#), and will meet again on [December 9, 2021, from 1:00 pm – 5:00 pm](#).

ADDITIONAL REFERENCES

- Wang Z, Chan AYL, Coghill D, Ip P, Lau WCY, Simonoff E, Brauer R, Wei L, Wong ICK, Man KKC. Association Between Prenatal Exposure to Antipsychotics and Attention-Deficit/Hyperactivity Disorder, Autism Spectrum Disorder, Preterm Birth, and Small for Gestational Age. *JAMA Intern Med.* 2021 Oct 1;181(10):1332-1340. [[PMID: 34398171](#)]