

IACC Round Robin Updates



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Federal Agency Updates

Administration for Community Living (ACL)

- ACL is pleased to announce four new cooperative agreements for ACL's 2023 grant initiative in support of the 2022 National Strategy to Support Family Caregivers. The project period for these new grants is September 30, 2023 – September 29, 2027. The collective award amount is over \$3.6 million. Through these four-year awards, grantees will develop, test, and disseminate new approaches for supporting family caregivers, using the Strategy as a roadmap. At this time, no project has been funded to address Goal 4: Ensure financial and workplace security for family caregivers. To address this important priority, ACL will be issuing a Notice of Funding Opportunity in October 2023 requesting applications that will increase awareness of and access to the resources available to address financial and workplace security for family caregivers, as well as identify unmet needs. For more information: <https://acl.gov/news-and-events/announcements/acl-awards-36-million-improve-support-family-caregivers>
- ACL is seeking input on a proposed rule to establish the first-ever federal regulations for adult protective services (APS) programs. The proposed rule aims to improve consistency and quality of APS services across states and support the national network that delivers APS services, with the ultimate goal of better meeting the needs of adults who experience or are at risk of maltreatment. The deadline for comments is November 13, 2023: <https://acl.gov/APSrule>

Centers for Disease Control and Prevention (CDC)

- In January, the Autism and Developmental Disabilities Monitoring (ADDM) Network began its sixth funding cycle, with CDC investing more than \$20 million over 4 years (2023-2026) to continue autism surveillance activities among 4-, 8-, and 16-year-old children across 10 funded sites, while also continuing autism surveillance activities among 4-, 8-, and 16-year-old children at the CDC-managed site in Georgia (Metropolitan Atlanta Developmental Disabilities Surveillance Program: <https://www.cdc.gov/ncbddd/autism/maddsp.html>). The Consolidated Appropriations Act, 2023 provided CDC with support for the expansion of the ADDM Network. CDC worked quickly to award additional funding to create new ADDM Network sites and expand surveillance among 16-year-olds. The newly awarded sites were selected and approved through an objective review process under funding opportunity CDC-RFA-DD23-2301 in fall 2022. We are pleased to announce the following ADDM Network expansion updates:
 - The ADDM Network has expanded from 11 sites to **16 sites**.
 - Newly awarded ADDM Network sites include **Arizona, Indiana, Pennsylvania, Texas (Austin), and Texas (Laredo)**.
 - **All ADDM Network sites will track autism among 4- and 8-year-olds.**
 - **Nine ADDM Network** sites will now track transition planning and co-occurring conditions among 16-year-old children with autism; this is an increase from five sites.
 - Shortly after announcing the addition of five new ADDM Network sites in April, CDC funded a supplemental award (CDC-RFA-DD23-2301) to support new cerebral palsy surveillance activities at four existing sites (**Minnesota, Utah, Tennessee, and Missouri**). All funded ADDM Network sites had the opportunity to apply for these supplemental funds, and awardees were selected through an objective review process.

- For more information related to these updates, please visit: <https://www.cdc.gov/ncbddd/autism/addm-network-sites.html>
- CDC's *Learn The Signs. Act Early.* program is partnering with the Health Resources and Services Administration's (HRSA's) Bureau of Primary Health Care. This partnership will help support the 151 federally qualified health centers that recently received HRSA's Early Childhood Development grant to improve developmental screening and appropriate follow-up referral and care among young children in the primary healthcare setting. CDC will offer technical assistance to encourage ongoing family-engaged developmental monitoring in addition to screening, referral, and follow-up as part of this initiative.
- In summer 2023, CDC began data collection on the latest phase of its Study to Explore Early Development (SEED), known as SEED Follow-Up, to address the information gap in our understanding of how people with autism develop from childhood to adolescence to adulthood. The goal of SEED Follow-Up is to better understand the experiences and challenges faced by children, adolescents, and young adults with autism. This information can help determine the services and supports people with autism may need to thrive. To accomplish this goal, SEED Follow-Up is currently inviting families of children who were in one of the three previous phases of SEED to take part in a follow-up survey. Over the next 3 years, CDC plans to enroll more than 4,000 families and their children in this follow-up study, including more than 1,000 with autism. As of September 2023, more than 1,000 families from Colorado, Georgia, Maryland, North Carolina, and Pennsylvania have been invited to participate in SEED Follow-Up. Recruitment at Missouri and Wisconsin SEED sites will begin in early 2024. For more information about the SEED Follow-Up visit: <https://www.cdc.gov/ncbddd/autism/SEED-Follow-Up.html>

Centers for Medicare & Medicaid Services (CMS)

- On June 5, 2023, CMS released a set of resources designed to support state Medicaid and partner agencies that play critical roles in designing and delivering supports and services that meet the current and future needs of adults with intellectual and developmental disabilities (I/DD) and their aging parents and caregivers. An estimated one million households in the United States include an adult with I/DD living with and supported by aging caregivers, and this number is growing. As adults with I/DD and their caregivers age and experience life transitions, they may need new or additional supports. The series of resources can be all found here:
 - How State Agencies Can Anticipate and Meet the Needs of Adults with I/DD and Their Aging Caregivers describes strategies that state Medicaid and partner agencies can leverage to anticipate and meet the needs of adults with I/DD and their caregivers, including strategies related to services, data management, and partnerships. This resource is available here: https://www.medicaid.gov/sites/default/files/2023-05/3.1_State_Agencies-508%5B22%5D.pdf
 - State Policies and Practices to Support Person-Centered Planning Across the Lifespan for Individuals with I/DD and Their Aging Caregivers highlights ways that states can design and implement person-centered planning processes to support adults with I/DD and their caregivers throughout their lives. This resource is available here: https://www.medicaid.gov/sites/default/files/2023-05/3.2_Person_Centered_Planning-508%5B87%5D.pdf

- State Policies and Practices to Support Aging Caregivers of Adults with I/DD discusses strategies states are using to address the needs of aging caregivers, including assessment, training, and navigation support. This resource is available here: https://www.medicaid.gov/sites/default/files/2023-05/3.3_Support_for_Aging_Caregivers-508%5B18%5D.pdf
- State Spotlights: Supporting Adults with I/DD and Their Aging Caregivers highlights innovative strategies states are using in four areas of focus: building interagency partnerships and relationships, providing engagement and navigation supports, implementing person- and family-centered systems of support, and planning for the future. This resource is available here: https://www.medicaid.gov/sites/default/files/2023-05/3-1_Adults_with_IDD_State_Spotlights-508%5B95%5D.pdf
- On June 12, 2023, HHS announced new flexibilities to help keep Americans covered as states resume Medicaid and CHIP renewals. These flexibilities were announced in a letter Secretary Becerra sent to the nation’s governors urging them all to adopt available flexibilities to minimize avoidable coverage losses among children and families. For more information, please see the press release here: <https://www.cms.gov/newsroom/press-releases/hhs-takes-additional-action-keep-people-covered-states-resume-medicaid-chip-renewals>
 - HHS, through the Centers for Medicare & Medicaid Services (CMS), has worked extensively with state Medicaid agencies to provide guidance on federal requirements, develop strategies to make Medicaid and CHIP renewals easier for people, and troubleshoot operational issues. This has included partnering with health plans, health care providers, federally qualified health centers, home visiting programs, early childhood providers, advocates, and civil rights, faith-based, health industry, employers, and other community-organizations.
 - A full list of all available flexibilities HHS is offering states is here: <https://www.medicaid.gov/resources-for-states/downloads/state-strategies-to-prevent-procedural-terminations.pdf>
 - An “All Hands On Deck” fact sheet is here: https://www.medicaid.gov/sites/default/files/2023-06/renewals-all-hands-on-deck-fact-sheet_0.pdf
 - An “All Hands on Deck” partner call-to-action is here: <https://www.medicaid.gov/sites/default/files/2023-06/renewals-call-to-action.pdf>
- On June 28, 2023, CMS announced that it is making additional ownership data, including names of affiliated owners, available for the first time on Nursing Home Care Compare: <https://www.medicare.gov/care-compare/?providerType=NursingHome>
 - Aggregate data on the safety, staffing, and quality for groups of nursing homes sharing ownership/operatorship is also now available on <https://data.cms.gov/>, part of the Biden-Harris Administration’s ongoing initiative to increase the transparency of corporate ownership and operation of nursing homes: <https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/>

- CMS remains committed to the American public by providing residents, families, caregivers, and stakeholders with as much information as possible about nursing homes in order to support consumers in making informed decisions about their healthcare and to promote safety and quality in nursing homes. This will increase the transparency of nursing home safety and quality data among nursing homes with shared ownership and operatorship structures. This information can also be used by states to gain more information about prospective owners and operators of nursing homes prior to certification of new nursing homes and during change of ownership requests.
- CMS noted that feedback from users and stakeholders for how to improve the utility of the data published is welcome at: NH_Affiliation_Inquiries@cms.hhs.gov
- On July 10, 2023, CMS posted an expanded Report to Congress for Non-Emergency Medical Transportation (NEMT) in Medicaid: <https://www.medicaid.gov/sites/default/files/2023-07/nemt-rtc-2018-2021.pdf>
 - This report provides T-MSIS data from 2018-2021, an additional year from the previous report, which is available here: <https://www.medicaid.gov/sites/default/files/2022-07/nemt-rtc.pdf>
 - The new report also includes an extensive analysis of Medicaid coverage of NEMT, such as the types of medical services accessed when using NEMT by beneficiary subgroup, monthly trends in the use of NEMT versus telehealth services, and a comparison by delivery model of the volume of NEMT services used by states.
 - Learn more about NEMT here: <https://www.medicaid.gov/medicaid/benefits/assurance-of-transportation/index.html>
- On July 27, 2023, CMS released the Medicaid and CHIP Mental Health (MH) and Substance Use Disorder (SUD) Action Plan Overview and Guide, which outlines the agency's strategies for improving treatment and support for enrollees with these conditions.
 - Areas of focus include improving coverage and integration to increase access to prevention and treatment services, encouraging engagement in care through increased availability of home and community-based services (HCBS) and coverage of non-traditional services and settings, and improving quality of care for MH conditions and SUDs.
 - Overview: <https://www.medicaid.gov/sites/default/files/2023-07/cmcs-mntl-helth-substnce-disrdr-actn-plan-overview.pdf>
 - Guide: <https://www.medicaid.gov/sites/default/files/2023-07/cmcs-mntl-helth-substnce-disrdr-actn-plan.pdf>
- On July 31, 2023, HHS, through CMS, announced its Guiding an Improved Dementia Experience (GUIDE) Model, which aims to improve the quality of life for people living with dementia, reduce strain on unpaid caregivers, and help people remain in their homes and communities through a package of care coordination and management, caregiver education and support, and respite services: <https://www.cms.gov/priorities/innovation/innovation-models/guide>
 - The GUIDE Model will be tested by the Center for Medicare and Medicaid Innovation and is a key deliverable from President Biden's April 2023 Executive Order on Increasing Access to High-Quality Care and Supporting Caregivers (available here: <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/18/executive-order-on-increasing-access-to-high-quality-care-and->

[supporting-caregivers/](#)), as well as key goals of the National Plan (National Plan) to Address Alzheimer's Disease.

- Through the GUIDE Model, CMS will test an alternative payment for participants who deliver key supportive services to people with dementia, including comprehensive, person-centered assessments and care plans, care coordination, and 24/7 access to a support line. Under the model, people with dementia and their caregivers will have access to a care navigator who will help them access services and supports, including clinical services and non-clinical services such as meals and transportation through community-based organizations.
- For more information, see the press release: <https://www.cms.gov/newsroom/press-releases/biden-harris-administration-announces-medicare-dementia-care-model>
- CMS issued guidance on August 2, 2023, to states detailing actions they can take to extend flexibilities, such as the use of telehealth, that were authorized as part of the COVID-19 public health emergency under 1915(c) HCBS waivers beyond the November 11, 2023, expiration date. Since January 2023, CMS has consistently provided states with information to prepare for the May 11 end of the COVID-19 national emergency and public health emergency declarations, including key dates certain flexibilities are set to expire.
 - The guidance is available here: <https://www.medicaid.gov/sites/default/files/2023-08/smd23004.pdf>
 - Key flexibility expiration dates are here: <https://www.medicaid.gov/sites/default/files/2023-08/cib050823.pdf>
- CMS released an informational bulletin on August 15, 2023, notifying states that mandatory financial eligibility rules (spousal impoverishment provisions) for married applicants and beneficiaries eligible for HCBS in Medicaid are extended to September 30, 2027, consistent with the Consolidated Appropriations Act, 2023. Under the Medicaid spousal impoverishment provisions, a certain amount of the couple's combined resources is protected for the spouse living in the community. The extension helps married individuals seek coverage of certain long-term services and supports they need to stay healthy. The informational bulletin can be found here: <https://www.medicaid.gov/sites/default/files/2023-08/cib08152023.pdf>
- On August 28, 2023, CMS released a final rule to require reporting of standardized quality measures in Medicaid and CHIP. The data on these quality measures will help CMS identify opportunities to improve the provision of high-quality, person-centered health care and reduce health disparities among the millions of people enrolled in Medicaid and CHIP. This rule finalizes requirements for mandatory annual state reporting of three different quality measure sets starting in federal fiscal year 2024:
 - Core Set of Children's Health Care Quality Measures for Medicaid and CHIP;
 - Behavioral health measures on the Core Set of Adult Health Care Quality Measures for Medicaid; and
 - Core Sets of Health Home Quality Measures for Medicaid.

The purpose of the Child and Adult Core Sets is to measure the overall national quality of care for beneficiaries, monitor performance at the state level, and improve the quality of health care. The purpose of the Health Home Core Sets is to measure the overall national quality of health home care for Medicaid beneficiaries, monitor the impact of this optional state plan benefit, monitor performance of this benefit at the state and program levels, and improve the quality of

health care. States will be required to report stratified data for an increasing number of measures over time, with potential stratification factors including geography and race/ethnicity. For more information, or to review the rule in its entirety, visit the Federal Register:

<https://www.federalregister.gov/d/2023-18669>

- On August 30, 2023, as part of its ongoing work to make sure all Americans have access to health care coverage, CMS sent a letter to all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands requiring them to determine whether they have an eligibility systems issue that could cause people, especially children, to be disenrolled from Medicaid or the Children’s Health Insurance Program (CHIP) even if they are still eligible for coverage, and requiring them to immediately act to correct the problem and reinstate coverage. CMS is prepared to work with states to provide technical assistance as they evaluate and address these issues. CMS’ top priority remains making sure everyone has access to affordable, quality health coverage. For more information, see this Press Release: <https://www.cms.gov/newsroom/press-releases/cms-takes-action-protect-health-care-coverage-children-and-families>
- On September 1, 2023, HHS, through CMS, issued a proposed rule that seeks to establish comprehensive staffing requirements for nursing homes—including, for the first time, national minimum nurse staffing standards—to ensure access to safe, high-quality care for the over 1.2 million residents living in nursing homes each day. This proposed rule builds on the President Biden’s historic Action Plan for Nursing Home Reform launched in the 2022 State of the Union. This action is one among many advanced by the Biden-Harris Administration to build a long-term care system where all older Americans can age with dignity, where people with disabilities can receive high quality services in the setting of their choice, where family caregivers are adequately supported, and where there is a pipeline of direct care workers into good-paying jobs with the free and fair choice to join a union. Included among the proposals are provisions that would promote transparency related to the percent of Medicaid payments for services in nursing facilities and intermediate care facilities for individuals with intellectual disabilities (ICF/IID) that are spent on compensation to direct care workers and support staff.
 - Fact Sheet on President Biden’s Action Plan for Nursing Home Reform: <https://www.whitehouse.gov/briefing-room/statements-releases/2022/02/28/fact-sheet-protecting-seniors-and-people-with-disabilities-by-improving-safety-and-quality-of-care-in-the-nations-nursing-homes/>
 - The press release is available at: <https://www.cms.gov/newsroom/press-releases/hhs-proposes-minimum-staffing-standards-enhance-safety-and-quality-nursing-homes>
 - The proposed rule is available at: <https://www.federalregister.gov/d/2023-18781>
 - The CMS fact sheet is available at: <https://www.cms.gov/newsroom/fact-sheets/medicare-and-medicaid-programs-minimum-staffing-standards-long-term-care-facilities-and-medicaid>
- Additionally, CMS announced a national campaign to support staffing in nursing homes. As part of the HHS Workforce Initiative (information available here: <https://www.hhs.gov/about/news/2023/07/06/new-hhs-initiative-aims-strengthen-nations-health-workforce.html>), CMS will work with the Health Resources and Services Administration (HRSA) and other partners to make it easier for individuals to enter careers in nursing homes, investing over \$75 million in financial incentives, such as scholarships and tuition reimbursement. This staffing campaign builds on other actions by HHS and the Department of

Labor to build the nursing workforce. The ASPE report is available at:
<https://aspe.hhs.gov/reports/dcw-wages>

Department of Education (ED)

- ED's Rehabilitation Services Administration (RSA) announced recently that it will fund 20 model demonstration projects focused on improving economic self-sufficiency for children and youth with disabilities by creating systemic approaches to enhance post-school outcomes. The nearly \$199 million in funding for the Pathways to Partnerships innovative model demonstration project supports collaborative partnerships between state vocational rehabilitation agencies, state and local educational agencies, and federally funded centers for independent living to help individuals with disabilities seamlessly transition to life after high school, preparing them for independent living, competitive integrated employment, and community integration. Pathways to Partnerships is the largest discretionary grant ever administered by RSA. Additional information is available here: <https://www.ed.gov/news/press-releases/us-department-education-awards-nearly-199-million-improve-career-opportunities-students-disabilities-through-partnerships>

Environmental Protection Agency (EPA)

- America's Children and the Environment (ACE), an online tool for evaluating children's environmental health, will be updated in October 2023 with the latest data. ACE offers interactive graphs and figures for indicators covering a wide range of topics including neurodevelopmental disorders. Using data from the National Health Interview Survey (NHIS), the autism indicator was updated with data through 2021. Key findings are summarized as follows:
 - Since 1999, the percentage of children reported to have autism in the United States has increased by 14-fold.
 - For the years 2018-2021, the rates of autism reported were approximately 4 times higher for boys than for girls, at 4.6% and 1.5%, respectively. This difference is statistically significant.
 - The highest prevalence of autism was for Black or African American non-Hispanic children (3.8% in 2018-2021), followed by children of "All Other Races/Ethnicities" (3.4%), and White non-Hispanic children (3%). Autism prevalence was lower among Hispanic children (2.8%) and Asian non-Hispanic children (2.5%).
 - For 2018-2021, the prevalence of autism was higher for children living below the poverty level (4.2%) than those living at or above the poverty level (2.8%).
- The ACE autism indicator can be found here:
<https://www.epa.gov/americaschildrenenvironment/health-neurodevelopmental-disorders>

National Institutes of Health (NIH)

- On September 26, 2023, Dr. Eliseo J. Pérez-Stable, director of the National Institute on Minority Health and Health Disparities (NIMHD), designated people with disabilities as a population with health disparities for research supported by the NIH. The decision was made in consultation with Dr. Robert Otto Valdez, director of the Agency for Healthcare Research and Quality (AHRQ), after careful consideration of a report delivered by an NIMHD advisory council, input from the disability community, and a review of the science and evidence. The designation is one of

several steps NIH is taking to address health disparities faced by people with disabilities and ensure their representation in NIH research. See this news release for additional information: <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>

- NIH issued a Notice of Funding Opportunity (Health and Health Care Disparities Among Persons Living with Disabilities) calling for research applications focused on novel and innovative approaches and interventions that address the intersecting impact of disability, race and ethnicity, and socioeconomic status on healthcare access and health outcomes. Additional information is available here: <https://grants.nih.gov/grants/guide/pa-files/PA-23-309.html>
- NIH has published a Notice of Funding Opportunity (Understanding and Mitigating Health Disparities Experienced by People with Disabilities Caused by Ableism) to encourage research to understand the impact of ableism on health outcomes. Research on the underlying mechanisms by which ableism adversely influences the health of persons with disabilities, as well as developing and/or testing interventions at a community or health systems level to mitigate adverse health effects of ableism are high priority. Additional information can be found here: <https://grants.nih.gov/grants/guide/rfa-files/RFA-HD-24-007.html>
- NIH is inviting comments and suggestions on updating the agency's mission statement.
 - The NIH's Advisory Committee to the Director (ACD) Working Group on Diversity, Subgroup on Individuals with Disabilities issued a report in December 2022 that contains several recommendations, including updating the NIH mission statement: https://acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf
 - The ACD adopted the Working Group's recommendations and provided them to the NIH Director.
 - The report stated: "One immediate action for the NIH to support disability inclusion is to remove the language of 'reducing disability' from the NIH mission statement. The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be 'fixed'."
 - To address this suggestion and following discussions among NIH Leadership and with NIH subject matter experts, a proposed revised mission statement was developed: "To seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to optimize health and prevent or reduce illness for all people."
 - NIH invites input from interest groups throughout the scientific research, advocacy, and clinical practice communities, those employed by NIH or at institutions receiving NIH support, and the public, on the proposed revised mission statement.
 - Comments must be received by 11:59:59 p ET on November 24, 2023, at: <https://rfi.grants.nih.gov/?s=64caaa8bb1112e46ad0a1d52>
 - For additional information, see the Federal Register Notice: <https://www.federalregister.gov/d/2023-18989>

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

- Dr. Amanda Alise Price joined NICHD as the Office of Health Equity Director and Chief Scientific Officer on April 9, 2023. She presented at the National Institute of Mental Health (NIMH)-

sponsored Diversifying the Autism Research Workforce conference in Washington, D.C., on June 2, 2023.

- NICHD funded a multiple-principal investigator (PI) R01 (HD110542; PIs: Fidler, Baumer, and Bishop), addressing the need for developing an ASD screening measure for infants and toddlers with Down syndrome (DS). The investigators will achieve this goal by first assessing ASD symptoms and examine two areas of potential risk in a cohort of 225 young children (18-45 months) with DS: 1) developmental profile in multiple domains including cognition, communication, motor skills, and adaptive behavior, as well as 2) the presence of co-occurring biomedical risk conditions including premature birth and low birth weight, infantile spasms, congenital heart defects, sleep dysregulation, and gastrointestinal conditions. Data will be analyzed to determine the strongest early predictors of ASD. Results will inform early screening procedures in young children with DS. This study is responsive to one of the NIH INCLUDE (Investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) priorities of improving health and well-being for people with DS. For more information about the project, see: <https://reporter.nih.gov/project-details/10735533>
- Results from a study funded by NICHD, NIMH, and other organizations suggests that a tablet-based screening application for ASD may improve early detection. To address the need for more accurate ASD screening tools, researchers developed the SenseToKnow app, which records and analyzes children's responses to short movies designed to elicit a range of behavioral patterns. The app can track many early signs of ASD, including differences in social attention, facial expressions, head movements, response to name, blink rates, and motor skills. The work was led by Geraldine Dawson, Ph.D., and Guillermo Sapiro, Ph.D., of the Autism Center of Excellence at Duke University, Durham, North Carolina. For additional information, see the news release here: <https://www.nih.gov/news-events/news-releases/digital-autism-screening-tool-shows-promise-nih-funded-study>

National Institute on Deafness and Other Communication Disorders (NIDCD)

- NIDCD recently published a Notice of Special Interest (NOSI) on Promoting Language and Communication in Minimally Verbal/Non-Speaking Individuals with Autism. The purpose of the NOSI is to encourage applications for research to promote language and communication in autistic individuals who are minimally verbal/non-speaking. Further research is needed to evaluate and tailor existing interventions, develop novel interventions, develop and apply new research designs and methods to intervention efforts, and identify meaningful outcome measures. Additional information can be found here: <https://grants.nih.gov/grants/guide/notice-files/NOT-DC-23-009.html>
- NIDCD published a Request for Information (RFI) Inviting Input Regarding NIDCD/s Research Directions to Support Communication in Minimally Verbal/Non-Speaking People. Responses were welcome from all from July 10 – September 15, 2023. Additional Information on the RFI is available here: <https://grants.nih.gov/grants/guide/notice-files/NOT-DC-23-013.html>

National Institute of Environmental Health Sciences (NIEHS)

- NIEHS hosted the thirteenth annual Environmental Epidemiology of Autism Research Network (EEARN) meeting on May 4, 2023, in Stockholm, Sweden. The meeting was held as a satellite meeting to the International Society for Autism Research (INSAR) meeting. EEARN was initiated in 2010 as a partnership with Autism Speaks to bring together environmental epidemiologists

studying autism to share ideas and information about ongoing and planned studies. This year's meeting featured a panel on Diversity, Equity, and Inclusion (DEI) in autism research; a presentation on existing large studies/data resources and how to access them; a broad discussion on the needs of junior researchers entering the field, and a trainee/early career investigator poster session. The meeting was the first in-person meeting post-COVID-19 and a great success based on the broad interest and lively discussions from all ~60 participants.

National Institute of Neurological Disorders and Stroke (NINDS)

- NINDS, along with the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD); National Heart, Lung, and Blood Institute (NHLBI); National Institute on Aging (NIA); National Institute of Mental Health (NIMH); and NIDCD are hosting a workshop on Remote Neuropsychological Assessments in Research: Present and Future Needs. The workshop will bring together a multidisciplinary group of clinician-scientists and patient advocates from academic, regulatory, and pharmaceutical groups to discuss gaps, needs, and opportunities in remote assessment of cognition. The virtual event will take place on Thursday, November 2, 10:00 am to 4:15 pm ET, and Friday, November 3, 10:00 am to 4:00 pm ET. For registration and agenda, see this link: <https://event.roseliassociates.com/remoteassessments/>

Social Security Administration (SSA)

- Supported Employment Demonstration (SED) Concluded
 - SED represents another approach to SSA's continuing efforts to reduce the growing dependence on the disability rolls. The goal of this multi-year (2017-2022) project was to provide integrated mental health and vocational services (using the Individual Placement and Support [IPS] model) to individuals with behavioral health challenges who were declined for SSI or SSDI disability assistance in the previous 30-60 days. Twenty states and thirty community mental health sites in those states carried out the study with 3,000 participants, aged 18 to 50, with diagnosed or probably mental health conditions, including people with autism and autistic-spectrum conditions. SSA contracted with Westat, Inc. (a research firm in Rockville, MD) to test the relative impact of the intervention services on key outcomes.
 - Given the central feature of the intervention, employment was the primary outcome of interest, and the study also analyzed participants' status related to disability benefits before, during, and after the study (i.e., whether participants appealed denials, re-applied for benefits, or were allowed for SSI or DI disability benefits).
 - The SED findings showed significantly higher employment rates (i.e., more work hours and higher earnings) for participants who received IPS and integrated behavioral and medical health care services compared to the control group; documented significantly higher employment rates for African American/Black and Hispanic individuals compared to White individuals who engaged in IPS services; but found no significant differences in the allowance (or application) rates for SSI/DI disability claims for the intervention and control groups. Many more outcomes and areas were analyzed and documented in the final reports for the SED (a process report and an impact and cost-benefit report).
 - These reports are now available online at: https://www.ssa.gov/disabilityresearch/supported_employment.html

- The SED Public Use File (PUF) is now available at:
https://www.ssa.gov/disabilityresearch/sed_puf.html
- Retirement and Disability Research Consortium (RDRC) Awards Announced
 - The RDRC is an interdisciplinary extramural research program funded by SSA through 5-year cooperative agreements. All RDRC research and activities must be relevant to one of SSA's program areas or populations. In addition, each fiscal year SSA provides the centers with research focal areas. \$12 million per year is split between the partner centers. Additional information about the RDRC can be found here:
<https://www.ssa.gov/policy/extramural/index.html>
 - Congratulations to the following applicants which have been selected (September 2023) for the five-year agreements covering activities for FY 2024-2028:
 - Boston College and University of Massachusetts-Boston
 - CUNY Baruch College, CUNY Hunter College, and The New School
 - National Bureau of Economic Research, Spelman College, and Howard University
 - University of Maryland Baltimore County, University of Baltimore, and Brandeis University
 - University of Michigan
 - University of Wisconsin-Madison, Howard University, and Montana State University
- Social Security Services for the Hispanic Community
 - SSA strives to deliver great customer service and helpful information to everyone, including people who are more comfortable reading and speaking Spanish:
<https://blog.ssa.gov/social-security-services-for-hispanic-community/>
 - SSA's Spanish-language website provides information about SSA programs and services. You can learn how to get a Social Security card, plan for retirement, apply for benefits, and much more: <http://www.segurosocial.gov/>
 - You can learn more about why Social Security is important to the Hispanic community at: <https://www.ssa.gov/espanol/personas/hispanos/>
 - SSA provides many publications in Spanish on popular topics such as retirement, disability, and survivor benefits; Medicare; and Supplemental Security Income (SSI). These publications can be found here: <https://www.ssa.gov/espanol/publicaciones/>
 - Spanish-speaking customers who need to speak with a representative can call SSA at 1-800-772-1213 and press 7.
 - Please share these resources with friends and family who may need them.
 - Follow SSA on their Spanish-language Facebook page (<https://www.facebook.com/segurosocial>) and on Twitter/X (<https://twitter.com/segurosocial>).
- SSA is seeking input on a proposal to revise the time period that is considered when determining whether an individual's past work is relevant for purposes of making disability determinations and decisions. Specifically, the past relevant work period would be reduced from 15 to 5 years. This change would allow individuals to focus on the most current and relevant information about their past work, better reflect the current evidence base on changes over time in worker skill decay and job responsibilities, reduce processing time and improve customer service, and

reduce burden on individuals. The deadline for comments is November 28, 2023:

<https://www.federalregister.gov/d/2023-21557>

- Social Security's National Disability Forum on *Youth Transitioning to Adulthood and Preparing for an Age-18 Redetermination* will be held on Wednesday, October 18, 2023, from 1:00 pm to 3:00 pm ET via Microsoft Teams. The purpose of the forum is to learn from social service advocates, educators, foster care agencies, and the public about youth transitioning to adulthood; Achieving a Better Life Experience (ABLE) accounts; continued payments under a qualifying program (Section 301); and determining capability and the need for representative payees. This is a listen and view only forum. If you would like to participate, please register by Monday, October 16, 2023, at:

https://ocomm.gov1.qualtrics.com/jfe/form/SV_263YLOsJyCH6SUu

Substance Abuse and Mental Health Services Administration (SAMHSA)

- The Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) will be meeting on October 18, 2023, from 10:00 am to 4:00 pm ET. The meeting is open to the public and can be accessed virtually. For access and additional information, please see the Federal Register Notice: <https://www.federalregister.gov/d/2023-19449>

Public Member Updates

Autism Science Foundation (ASF)

- ASF announced in June 2023 that it would join the Health Resource Alliance Open Science program, which will enable ASF-funded researchers to publish in open access journals at no cost to the researcher. This program will allow more research to be disseminated to the broader autism community sooner. For more information, see the press release here: https://autismsciencefoundation.org/press_releases/asf-joins-new-program-to-make-all-its-funded-research-available-open-access/
- In July, ASF announced a second request for proposals for research on individuals with "profound autism." ASF is interested in supporting projects that will either a) increase the opportunity for people with profound autism to participate in research, b) identify and characterize the underlying biological mechanisms of profound autism, or c) develop treatments specifically for those with profound autism. Applications were due on September 15. For more information, see here: <https://autismsciencefoundation.org/apply-for-a-profound-autism-pilot-grant/>
- ASF has announced a request for proposals for early career researchers to study critical issues in autism. One-year pre-doctoral and post-doctoral and two-year post-undergraduate fellowships are available for qualified applicants interested in autism research. Applications are due on December 8th at 5:00 pm ET. For additional information, visit: <https://autismsciencefoundation.org/grants-awards-fellowships/>

Julie Lounds Taylor, Ph.D.

- Dr. Julie Lounds Taylor has recently taken on the role of Co-Director of the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities. The Center conducts interdisciplinary research to better understand developmental disabilities and human development; offers services to people with disabilities, families, educators, and healthcare and

other service providers; trains clinicians, students, and researchers; and engages with the disability community to learn more about the needs and strengths of people with developmental disabilities. More information about the Center can be found here:

<https://vkc.vumc.org/vkc/ucedd>

Simons Foundation Autism Research Initiative (SFARI)

- SFARI is pleased to announce that SPARK (Simons Foundation Powering Autism Research for Knowledge) has released new phenotypic data for use in research studies. Approved investigators can request the data via SFARI Base. More information is available here:

<https://www.sfari.org/2023/08/15/spark-july-2023-update-new-phenotypic-data-available/>

Yetta Myrick, B.A.

- For the past two years, Dr. Allysa Ware, Executive Director of Family Voices, and Ms. Myrick co- led the “Building Capacity in the African American ASD Community for Patient Centered Outcomes Research” project. This project was funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EASC-IDD-00251). As a result of this work, “A Patient-Centered Autism Research Agenda to Engage the African American Community” was recently published. The research agenda provides a blueprint to change the culture of the autism research space by building a community of African American self-advocates, family stakeholders, and researchers who will work to improve trust and ensure equitable representation of the African American community in autism research. It outlines three key strategies for researchers to ensure their research is culturally responsive and relevant to the African American community, provides equal opportunity for African Americans to participate, and considers how research results will be shared back with the community in ways that are accessible and actionable. The recommendations reflect the expertise and lived experience of a diverse community of more than 200 autistic self-advocates, parent/family caregivers, researchers, providers, and funders. Learn more by visiting:

<https://familyvoices.org/araprogram/resources/>

Community Updates

Association of University Centers on Disabilities (AUCD)

- AUCD is a membership organization that supports and promotes a national network of university-based interdisciplinary programs. AUCD welcomes Network members, organizational partners, experts from across the disability field, individuals with disabilities, family members, students, and trainees to learn and grow together during this year's AUCD 2023 Conference. The AUCD Conference provides an opportunity to share with and learn from colleagues and peers. This premiere event features four engaging large group plenaries from high-level leaders, more than 220 concurrent and poster presentations covering a broad spectrum of disability topics, as well as innovative research, programming, and advocacy efforts. Additional information on the Conference, including how to register, is available here:

<https://www.aucd.org/conference/index.cfm/2023>

Autism Society of America

- The Autism Society of America has released an Applied Behavior Analysis (ABA) resource that provides information to help families and caregivers understand their options when making decisions about whether ABA is right for them. This resource can be found here: <https://autismsociety.org/autism-society-applied-behavior-analysis-aba-resource/>
- The Autism Society of America has also released a Building College Success resource that offers practical advice, information, and strategies for autistic students to support a successful college transition. This resource is available here: <https://autismsociety.org/navigating-college-life-with-confidence-a-resource-for-autistic-students/>

Autism Speaks

- In collaboration with the National Autism Data Center at Drexel University, Autism Speaks launched Autism by the Numbers Dashboard that centralizes autism data across the United States to foster insights into the systems that serve autistic individuals, spotlight accessibility of supports and services, and enable advocacy in key areas for the autistic community. The dashboard can be accessed here: <https://nationalautismdatacenter.org/autism-by-the-numbers/>

Autistic Self Advocacy Network (ASAN)

- ASAN has released two resources on sex education for people with intellectual and developmental disabilities. “A Self-Advocate’s Guide to Safer Sex” and “What Do I Need to Know About Sexual Assault” are available in Easy Read and plain language here: <https://autisticadvocacy.org/2023/06/proud-supported-2023/>
- ASAN also has new accessible resources on COVID-19, including information about long COVID, vaccine cards, and vaccine mandates. These resources are available in Easy Read and plain language, in both English and Spanish, here: <https://autisticadvocacy.org/2023/07/new-accessible-covid-19-resources-on-vaccine-cards-long-covid-and-more/>

BRAIN Foundation

- The BRAIN Foundation is focused on supporting translational research that will lead to the development of FDA-approved interventions and improved standard of care for co-occurring conditions in individuals with autism. The BRAIN Foundation will be hosting the Synchrony Symposium 2023 on October 20-22 at the Asilomar Conference Grounds in California. This international symposium on translational research in autism will bring together academia, biotech, pharmaceutical companies, venture partners, and community stakeholders to catalyze scientific research that can improve the health and quality of life for people with autism and neurodevelopmental disorders. Additional information about the symposium, including how to register, is available here: <https://brainfoundation.org/synchrony-symposia/>

First Place – Phoenix

- First Place – Phoenix offers supportive housing and a residential transition program for individuals with autism and other neurodiverse populations, as well as sites for education, training, and creative inspiration. First Place – Phoenix is hosting its 2023 symposium titled “All Aboard! On Track to Drive Change” on October 18-20 in Phoenix, Arizona. The symposium will

include sessions related to housing and community living; Dr. Susan Daniels, HHS National Autism Coordinator, will be speaking about how the IACC has championed federal efforts to improve housing, transportation, employment, and services across the lifespan. For registration and more information, visit: <https://www.firstplaceaz.org/leadership-institute/2023-symposium/>

Ohio Center for Autism and Low Incidence (OCALI)

- OCALI uses data, research, and evidence-based strategies to shape policy and practice designed to inspire change and promote access and independence for people with disabilities. OCALI is hosting OCALICONLINE 2023, the premier autism and disabilities conference. The conference will bring together a cross-section of professionals and parents who utilize a variety of products and services at home, work, and in the community. The conference offers sessions which target a range of disabilities, including autism, deaf/hard of hearing, blind/visual impairments, and other low-incidence disabilities. Dr. Susan Daniels, HHS National Autism Coordinator, will be speaking about the new IACC Strategic Plan. IACC member Lindsey Nebeker will be speaking on double empathy and sibling relationships. The conference will be held online November 14-17. For registration and other information, visit: <https://conference.ocali.org/>

The Arc of the United States

- The Arc is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities to ensure access to information, advocacy, and skills needed to support full inclusion and participation in the community. The Arc's 2023 National Convention will take place November 6-8 in New Orleans, Louisiana, and provides an opportunity to connect and learn with advocates, professionals, people with intellectual and developmental disabilities and their families on topics around employment, education, advocacy, housing, criminal justice, and more. Registration and other information about the convention is available here: <https://convention.thearc.org>