

July 2024

# IACC Round Robin Updates



## Table of Contents

Federal Agency Updates .....	2
Department of Health and Human Services (HHS).....	2
Administration for Children and Families (ACF).....	2
Administration for Community Living (ACL).....	3
Centers for Disease Control and Prevention (CDC).....	6
Centers for Medicare & Medicaid Services (CMS).....	7
National Institutes of Health (NIH).....	9
Substance Abuse and Mental Health Services Administration (SAMHSA) .....	10
Department of Education (ED).....	11
Department of Housing and Urban Development (HUD) .....	11
Social Security Administration (SSA) .....	12
Public Member Updates .....	13
Autism Science Foundation (ASF).....	13
Autism Speaks .....	13
Camille Proctor .....	14
Simons Foundation Autism Research Initiative (SFARI).....	14
Community Updates .....	14
Association of University Centers on Disabilities (AUCD) .....	14
The Arc of the United States .....	15

## Federal Agency Updates

### Department of Health and Human Services (HHS)

- **Final Rules**
  - **Nondiscrimination in Health Programs and Activities:** On April 26, 2024, the HHS Office for Civil Rights (OCR) and Centers for Medicare & Medicaid Services (CMS) issued a final rule under Section 1557 of the Affordable Care Act (ACA) advancing protections against discrimination in health care. By taking bold action to strengthen protections against discrimination on the basis of race, color, national origin, sex, age, and disability, this rule reduces language access barriers, expands physical and digital accessibility, tackles bias in health technology, and much more.
    - **Final Rule:** <https://www.federalregister.gov/d/2024-08711>
    - **Press Release:** <https://www.hhs.gov/about/news/2024/04/26/hhs-issues-new-rule-strengthen-nondiscrimination-protections-advance-civil-rights-health-care.html>
  - **Nondiscrimination on the Basis of Disability in Programs or Activities Receiving Federal Financial Assistance:** On May 1, 2024, HHS, through OCR, finalized a rule that prohibits discrimination on the basis of disability. This rule advances equity and bolsters protections for people with disabilities under Section 504 of the Rehabilitation Act (Section 504). This important Final Rule is HHS's latest action in furtherance of Executive Order 14091, entitled Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.
    - **Final Rule:** <https://www.federalregister.gov/d/2024-09237>
    - **Press Release:** <https://www.hhs.gov/about/news/2024/05/01/hhs-finalizes-rule-strengthening-protections-against-disability-discrimination.html>
    - **Website:** <https://acl.gov/504rule>
    - **Fact Sheet:** <https://www.hhs.gov/civil-rights/for-individuals/disability/section-504-rehabilitation-act-of-1973/part-84-final-rule-fact-sheet/index.html>
- **Announcement:** On April 25, 2025, HHS announced that 20 states have been selected to participate in two separate technical assistance programs that together will help states better recruit, train, and retain direct care workers who provide home and community-based services (HCBS) for older adults and people with disabilities. In addition, HHS and the Department of Labor released key recommendations for building data infrastructure to support development of policies and initiatives to strengthen the HCBS direct care workforce. Read more here: <https://www.hhs.gov/about/news/2024/04/25/biden-harris-administration-partners-states-and-releases-data-recommendations.html>

### Administration for Children and Families (ACF)

#### New Resources:

- On May 10, 2024, ACF announced new policy guidance and resources for states, Tribes, territories, and local early childhood programs to promote the mental health and wellness of children, families and the early care and education workforce. These materials support President Biden's Unity Agenda priority to tackle the mental health crisis and are in line with his

strategy for transforming mental health in the United States. For more information, visit:  
<https://www.acf.hhs.gov/media/press/2024/new-early-childhood-behavioral-health>

- ACF recently launched a new webpage to engage parents with disabilities and learning differences. Engaging parents with disabilities and learning differences strengthens family well-being and supports the healthy growth and development of their children. Like all caregivers, parents with disabilities and learning differences partner with family, friends, and professionals to care for their children. Engaging parents with disabilities and learning differences is a big part of providing equitable and inclusive services. This resource provides information, suggests strategies, and includes links to additional resources that support Head Start staff to engage parents thoughtfully and intentionally. Visit the webpage at:  
<https://eclkc.ohs.acf.hhs.gov/family-engagement/engaging-parents-disabilities-learning-differences/engaging-parents-disabilities-learning-differences>

#### Administration for Community Living (ACL)

- **Funding Opportunity:** ACL recently announced about \$2 million to support statewide implementation of the National Strategy to Support Family Caregivers. ACL will award four cooperative agreements to state units on aging to undertake a range of activities. Each project will be fully funded for a period of 24 months with one, 24-month budget of up to \$490,000. Each grantee will be expected to focus on implementing at least three of the five goals of the Strategy, as determined by the state's needs and priorities. Successfully implementing the actions and recommendations contained in the Strategy will require the grantees to break down siloes that exist through close collaboration by multiple agencies in the state. Applications are due August 6, 2024. Read more here: <https://acl.gov/news-and-events/announcements/acl-announces-nearly-2-million-support-state-implementation-national>
- **New Initiative:** USAging invites the aging services network and its partners to join the National Caregiver Champion Collaborative (CCC). The CCC will facilitate peer networking and engagement among professionals who lead caregiver services and supports. Participants will gather regularly to share successful strategies and best practices, discuss lessons learned, explore new partnerships, and get insight into the latest research and emerging evidence-based caregiver programs. Caregiver champions are likely to be leaders and managers from organizations that administer caregiver services and supports such as state units on aging, area agencies on aging, Title VI programs, aging services providers, and caregiving service providers. The CCC is administered by USAging through a cooperative agreement with ACL as part of ACL's \$20 million initiative to support implementation of the National Strategy to Support Family Caregivers. For more information, visit:  
<https://www.usaging.org/content.asp?admin=Y&contentid=1607>
- **Final Rule:** On May 7, 2024, HHS, through the ACL, announced a final rule to establish the first federal regulations for Adult Protective Services (APS). The new regulations promote high quality APS and will improve consistency in services across states. With the final rule, ACL aims to support the national network that delivers APS, with the ultimate goal of better meeting the needs of adults who experience, or at risk of, maltreatment and self-neglect.
  - **Final Rule:** <https://www.federalregister.gov/d/2024-07654>
  - **Press Release:** <https://acl.gov/news-and-events/announcements/final-rule-establish-first-ever-regulations-adult-protective-services>

- **Website:** <https://acl.gov/APScrule>
- **Fact Sheet:** <https://acl.gov/sites/default/files/2024-05/APS%20Regs%20-%20Long%20Fact%20sheet.pdf>
- **Upcoming Webinar: National Caregiver Support Collaborative Webinar on Caregiver Assessments**
  - Join ACL’s National Caregiver Support Collaborative (NCSC) on **Tuesday, July 16, 2024, at 3:00 pm ET** for a webinar on caregiver assessment best practices and state efforts to implement assessments in the National Family Caregiver Support Program (NFCSP), Native American Caregiver Support Program (NACSP), and related programs. During this webinar, participants will learn about:
    - Key considerations in assessing and meeting the needs of family caregivers.
    - Federal efforts to promote the use of caregiver assessments.
    - Successful strategies, tools, and resources for implementing and administering caregiver assessments and reassessments, as well as training and follow-up activities.
  - Featured speaker Kathy Kelly, executive director of the Family Caregiver Alliance, and panelists who will discuss their successful strategies and lessons learned from the field regarding caregiver assessments in their respective programs.
  - This webinar is free and open to the public. ASL and CART services will be provided during the webinar. Registration is required: <https://us06web.zoom.us/meeting/register/tZ0vf-gggDMrHN1YRgPXICK6Ci7whaLGjd9#/registration>
- **Disability Employment TA Center (DETAC) Webinars:**
  - Webinars are recorded and posted with supporting materials on the DETAC website: <https://aoddisabilityemploymenttcenter.com/detac-events/>
  - **How Job Accommodations Make a Difference**
    - On July 9, 2024, at 3:00 pm ET, a panel of researchers from the Rehabilitation Research and Training Center (RRTC) on Employment for People with Physical Disabilities will share insightful data on how providing job accommodations for people with disabilities does make a difference in performing their job duties and enjoying equal employment opportunities. Presenters will highlight their current research projects and latest observations that will support grantees, federal and state policymakers, job seekers with disabilities, and employers to improve employment outcomes for people with disabilities.
    - For more information, including about the speakers, visit: <https://aoddisabilityemploymenttcenter.com/job-accommodations-make-a-difference-data-points-and-implications/>
    - Register for the webinar here: [https://us06web.zoom.us/webinar/register/WN\\_3n3bkg-iSFeklgyN9CkqFA](https://us06web.zoom.us/webinar/register/WN_3n3bkg-iSFeklgyN9CkqFA)
  - **Ensuring Equal Access to Benefits Counseling to Maximize Community Inclusion**
    - On June 11, DETAC celebrated the Olmstead anniversary milestone with a webinar focused on ensuring equal access to financial education resources and benefits counseling for people with disabilities searching for employment. During the webinar, the panel discussed how people with disabilities and their

families can access tools for financial education through Centers for Independent Living (CIL). The panel also shared how state agencies, Hispanic and Latino community organizations, and the local Association of People Supporting Employment First (APSE) chapter in Colorado partnered on benefits counseling outreach to help maximize community inclusion and independent living for people with disabilities.

- To access the recording and slides, visit:  
<https://aoddisabilityemploymenttcenter.com/ensuring-equal-access-to-benefits-counseling-to-maximize-community-inclusion/>
- **Examining How Historically Black Colleges and Universities Serve Students with Intellectual Disabilities in Higher Education Programs**
  - The DETAC May 2024 National Community of Practice (CoP) Webinar featured presenters from Think College, Alabama A&M University, and Arkansas State University. Presenters provided a roadmap for developing, maintaining, and expanding post-secondary education (PSE) programs for students with intellectual disabilities at Historically Black Colleges and Universities (HBCUs). The webinar reviewed key elements in three segments:
    - Review national trends in PSE programs for students with intellectual disabilities at HBCUs.
    - Provide an overview of the Southeast Postsecondary Education Alliance (SEPSEA) HBCU Committee.
    - Discuss how the first program in the nation at an HBCU was established, including an overview of program structure, partners involved and employment outcomes for students with intellectual disabilities.
  - To access the recording and slides, visit:  
<https://aoddisabilityemploymenttcenter.com/maycopwebinar-inclusivehighered/>
- **Announcements:**
  - Self Advocates Becoming Empowered and ACL’s Administration on Disabilities are pleased to announce the **2024-2025 Self Advocacy Resource and Technical Assistance Center (SAR-TAC) award fellows**. Seven fellows were chosen based on the policy or leadership project they wanted to do to help the self advocacy movement. See the list of fellows here: <https://acl.gov/news-and-events/announcements/sar-tac-announces-2024-2025-fellows>
  - ACL is awarding grants to three University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) to begin a new five-year cycle to further generate knowledge to support the independence and inclusion of people with intellectual and developmental disabilities (I/DD) in all aspects of community life. These three centers are part of the 67 federally designated UCEDDs located nationwide in states and territories. UCEDDs are interdisciplinary education, research, and public service units of universities — or public or nonprofit entities associated with universities. They are authorized by the Developmental Disabilities Assistance and Bill of Rights Act. For more information, visit: <https://acl.gov/news-and-events/announcements/new-core-grants-awarded-three-ucedds>

## Centers for Disease Control and Prevention (CDC)

- **Announcements:**

- **CDC.gov Relaunch:** The relaunch of CDC.gov is part of CDC's Digital Communication Modernization and Moving Forward Initiative. This multidisciplinary effort was based on years of web metrics, usability data, industry standards, and consumer research. The goal is to improve digital communication by providing clear and easily understandable information for CDC.gov visitors. The official relaunch happened on May 15, 2024. Check out CDC's updated autism spectrum disorder (ASD) website at: <https://www.cdc.gov/autism/index.html>
- **Act Early Ambassador Training:** As one of CDC's priority initiatives, "Learn the Signs. Act Early." (LTSAE) promotes earlier detection of and developmental services for children with developmental delays—both crucial to addressing the developmental and behavioral needs of children. In March 2024, the program hosted its annual Act Early Ambassador Training, with more than 50 Act Early Ambassadors participating from many states, territories, and tribal communities. During the training, Act Early Ambassadors shared progress and brainstormed new ways to integrate LTSAE resources into programs serving young children and families. The Act Early Ambassadors support the work of LTSAE in their states to improve early identification of developmental delays and disabilities. For more information and to find your Act Early Ambassador, visit: <https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>

- **Research Articles:**

- **Community Testing Practices for Autism within CDC's Autism and Developmental Disabilities Monitoring Network**
  - A new CDC study looked at population-level testing practices among 8-year-old children identified with ASD within CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network in 2018. Information about ASD test use in community practice is lacking. While there is no specific test or biomarker to diagnose ASD, an ASD test can support a diagnosis.
  - Findings from CDC's ADDM Network showed that ASD testing practices varied widely by ADDM site and differed by race and the presence of co-occurring intellectual disability. Across 11 ADDM Network sites, more than 60% of 8-year-old children identified with ASD had an ASD test in their records. Fewer than half of the children with ASD received an Autism Diagnostic Observation Schedule (ADOS) or Autism Diagnostic Interview-Revised (ADI-R).
  - Information on ASD testing practices may help standardize and improve ASD identification to ensure all children with ASD are identified and receive the services and support they need.
  - **Read the abstract for free here:** <https://pubmed.ncbi.nlm.nih.gov/38531639/>
- **Autism Spectrum Disorder (ASD) Diagnoses and Congenital Cytomegalovirus**
  - A new CDC study examined the risk of ASD among nearly 3 million US children between ages 4 and 7 years, with or without congenital cytomegalovirus (cCMV). This study used Medicaid or Children's Health Insurance Program (CHIP) claims data. Children born with cCMV were 2.5 times as likely to also have an ASD diagnosis than children without cCMV. While this work cannot establish a

causal relationship, it highlights the importance of monitoring children with a diagnosis of cCMV, especially in children with hearing loss, for early signs of ASD.

- **Read the abstract for free here:** <https://pubmed.ncbi.nlm.nih.gov/38808409/>

## Centers for Medicare & Medicaid Services (CMS)

- **New Informational Resources**

- **Frequently Asked Questions (FAQs):**

- On April 10, CMS published the first set of **Medicaid School-Based Services (SBS) Technical Assistance Center (TAC) frequently asked questions**. The questions were among the most commonly received by the SBS TAC, which is available to support state Medicaid agencies, state educational agencies, and local education agencies in operationalizing Medicaid SBS. Additional questions will be added over time. Access the FAQ here:

<https://www.medicaid.gov/resources-for-states/medicaid-state-technical-assistance/medicaid-and-school-based-services/medicaid-school-based-services-frequently-asked-questions-faqs/index.html>

- On June 5, CMS released **FAQs on Medicaid and the Children’s Health Insurance Program (CHIP) coverage of peer support services**. These FAQs were developed in close collaboration with the Substance Abuse and Mental Health Services Administration (SAMHSA) to provide clarification regarding federal policy on coverage of peer support services outlined in the State Medicaid Director (SMD) letter #07-011 issued on August 15, 2007, which established that states “have the option to offer [p]eer [s]upport services as a component of a comprehensive mental health and substance use service delivery system.” Access the FAQ here: <https://www.medicaid.gov/federal-policy-guidance/downloads/faq06052024.pdf>

- On April 11, CMS released three resources to promote quality improvement efforts within Medicaid-funded HCBS:

- **2024 HCBS Quality Measure Set (QMS):** Informational Bulletin updating the 2022 HCBS QMS; available here: <https://www.medicaid.gov/federal-policy-guidance/downloads/cib041124.pdf>
- **Home and Community-Based QMS Reporting Requirements for Money Follows the Person (MFP) Demonstration Grant Recipients:** Informational Bulletin addressing requirements and expectations for reporting populations, timeframes, required measures, stratification, and sampling; available here: <https://www.medicaid.gov/federal-policy-guidance/downloads/cib04112024.pdf>
- **2024 Long-Term Services and Supports (LTSS) Quality Measures Technical Specifications and Resource Manual:** Introduces a set of measures for Medicaid fee-for-service (FFS) delivery systems that correspond with measures for Medicaid managed care programs; available here: <https://www.medicaid.gov/license/form/8586/3396>

- On June 12, CMS released **Medicaid and CHIP Managed Care Monitoring and Oversight Tools, including States’ Responsibility to Comply with Medicaid Managed Care and**



**Separate CHIP Mental Health and Substance Use Disorder Parity Requirements.** This Informational Bulletin will help states to improve the monitoring and oversight of managed care in Medicaid and CHIP by providing additional tools for the states. Additionally, this bulletin reminds states of Medicaid managed care and separate CHIP mental health and substance use disorder parity requirements. This is the fourth in a series of bulletins on increasing states' monitoring and oversight of managed care. Access the Information Bulletin here: <https://www.medicaid.gov/federal-policy-guidance/downloads/cib06122024.pdf>

- **Final Rules:** On April 22, CMS issued three final rules to support family caregivers, boost compensation and job quality for care workers, expand and improve care options, and improve the safety and quality of care in federally funded nursing homes:
  - **Ensuring Access to Medicaid Services:** This rule addresses critical dimensions of access across both Medicaid FFS and managed care delivery systems, including for HCBS. These improvements seek to increase transparency and accountability, standardize data and monitoring, and create opportunities for states to promote active beneficiary engagement in their Medicaid programs, with the goal of improving holistic access to care.
    - **Final Rule:** <https://www.federalregister.gov/d/2024-08363>
    - **Fact Sheet:** <https://www.cms.gov/newsroom/fact-sheets/ensuring-access-medicaid-services-final-rule-cms-2442-f>
    - **Applicability Dates Table:** <https://www.medicaid.gov/medicaid/access-care/downloads/applicability-date-chart-ac.pdf>
  - **Medicaid and Children's Health Insurance Program Managed Care Access, Finance, and Quality:** This rule strengthens standards for timely access to care and states' monitoring and enforcement efforts; enhances quality and fiscal and program integrity standards for state directed payments (SDPs); specifies the scope of in lieu of services and settings (ILOSs) to better address health-related social needs (HRSNs); further specifies medical loss ratio (MLR) requirements; and establishes a quality rating system (QRS) for Medicaid and CHIP managed care plans.
    - **Final Rule:** <https://www.federalregister.gov/d/2024-08085>
    - **Fact Sheet:** <https://www.cms.gov/newsroom/fact-sheets/medicaid-and-childrens-health-insurance-program-managed-care-access-finance-and-quality-final-rule>
    - **Applicability Dates Table:** <https://www.medicaid.gov/medicaid/managed-care/downloads/applicability-date-chart-mc.pdf>
  - **Minimum Staffing Standards for Long-Term Care Facilities and Medicaid Institutional Payment Transparency Reporting:** This rule establishes, for the first time, national minimum staffing requirements for nursing homes to improve the care that residents receive and support workers by ensuring that they have sufficient staff. It also requires states to report annually, at the facility level, on the percent of Medicaid payments for certain institutional services (nursing facility services and services in Intermediate Care Facilities for Individuals with Intellectual Disabilities [ICF/IDD]) that are spent on compensation for direct care workers (such as nurses and therapy staff) and support staff (such as housekeepers and workers providing transportation for residents).



- **Final Rule:** <https://www.federalregister.gov/d/2024-08273>
- **Fact Sheet:** <https://www.cms.gov/newsroom/fact-sheets/medicare-and-medicaid-programs-minimum-staffing-standards-long-term-care-facilities-and-medicaid-0>

National Institutes of Health (NIH)

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

- **Research Funding Opportunity:** In June 2024, NIH published **RFA-HD-25-002: Centers for Collaborative Research in Fragile X and FMR1-Associated Conditions (P50 Clinical Trial Optional)**. Fragile X Syndrome (FXS) is the most common genetic cause of autism; it is estimated that half of males and 1 in 5 females with FXS meet the diagnostic criteria for autism. Successful Fragile X Centers will be composed of multidisciplinary teams of basic, translational, clinical, and/or data science investigators collaborating to address complex, difficult-to-solve problems within specific research priorities identified in the NIH FMR1 Strategic Plan. The application due date is August 20, 2024. For more information, visit: <https://grants.nih.gov/grants/guide/rfa-files/RFA-HD-25-002.html>
- **Announcement:** NICHD is one of the Institutes that leads the **NIH INCLUDE (Investigation of Co-occurring conditions across the Lifespan to Understand Down syndrome) Project**, that was launched in June 2018. One of the goals of the INCLUDE project was to build a large cohort of people with Down syndrome (DS) across the lifespan to better understand the epidemiology of the condition and how the co-occurring conditions impact lifespan and outcomes for those with DS. In October 2023, NIH issued a series of competitive funding opportunities to support cohort research sites (RFA-OD-24-003) with an emphasis on diverse sampling, a clinical cohort coordinating center (RFA-OD-24-005), and a federated biobanking resource (RFA-OD-24-004). NIH expects to announce the grant awards of these funding opportunities in August 2024. For more information about the INCLUDE Project, visit: <https://www.nih.gov/include-project>

**National Institute on Deafness and Other Communication Disorders (NIDCD)**

**Research Article:** Differences in regional brain structure in toddlers with autism are related to future language outcomes

- **Brief Summary:** Language and social symptoms improve with age in some autistic toddlers, but not in others, and such outcome differences are not clearly predictable from clinical scores alone. This study demonstrates that autistic toddlers show differentially larger or thicker temporal and fusiform regions; smaller or thinner inferior frontal lobe and midline structures; larger callosal subregion volume; and smaller cerebellum. These brain alterations improve accuracy for predicting language outcome at 6-month follow-up beyond intake clinical and demographic variables. Among autistic toddlers, brain alterations in social, language and face processing areas enhance the prediction of the child’s future language ability. This article highlights important predictors of future language ability as well as important underpinnings for language growth.
- **This work was supported by:** NIDCD grant R01DC016385; NIMH grants R01MH118879 and R01MH104446
- **Read the article for free here:** <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC11176156/>

## **National Institute of Environmental Health Sciences (NIEHS)**

### **Upcoming Workshop (hybrid): A Web-Based Tool for Autism Research and the Environment (aWARE)**

On September 5-6, 2024, NIEHS will be hosting a Workshop: A Web-Based Tool for Autism Research and the Environment (aWARE). The aWARE tool is a web-based project led by the Division of Extramural Research and Training (DERT) and the Division of Toxicology and Technology (DTT). Its purpose is to address the challenge of understanding environmental contributors to ASD by creating an interactive and visual tool. The aWARE tool aims to aggregate and assess data from published research on environmental factors related to ASD, using a systematic evidence map (SEM) approach. SEMs allow users to identify and display relevant published evidence as well as to explore research questions within the available evidence. Prior to tool development, listening sessions engaged the broader autism community to gather perspectives. The upcoming workshop will discuss objectives, scope, tool entities, and user experiences, aiming to create a valuable resource that resonates with diverse perspectives within the ASD community.

- For registration information please visit: <https://www.niehs.nih.gov/news/events/aware>
- For more detailed information about the aWARE project, please refer to the research article titled “Becoming aWARE: The Development of a Web-Based Tool for Autism Research and the Environment”, available for free here: <https://www.mdpi.com/2039-4713/13/3/31>

## Substance Abuse and Mental Health Services Administration (SAMHSA)

### • **New Reports:**

- **2024 National Strategy for Suicide Prevention:** On April 23, 2024, Biden Harris Administration, through the U.S. Department of Health and Human Services (HHS) released the *2024 National Strategy for Suicide Prevention* and accompanying Federal Action Plan. SAMHSA and CDC, in partnership with the National Action Alliance for Suicide Prevention, led the development of these critical deliverables which support the Biden-Harris Administration’s priorities to address the overdose and mental health crises, key pillars of the Biden-Harris Unity Agenda. For more information, visit: <https://www.samhsa.gov/newsroom/press-announcements/20240423/biden-harris-administration-releases-national-strategy-suicide-prevention-first-ever-federal-action-plan>
- **National Strategy to Improve Maternal Mental Health Care:** On May 14, 2024, HHS announced the release of a national strategy, with recommendations developed by the Task Force on Maternal Mental Health, a subcommittee of the SAMHSA Advisory Committee for Women’s Services, to address the urgent public health crisis of maternal mental health and substance use issues. For more information, see: <https://www.samhsa.gov/newsroom/press-announcements/20240514/maternal-mental-health-task-force-national-strategy-improve-maternal-mental-health-care>
- **Services Funding Opportunity:** On May 8, 2024, HHS through SAMHSA, announced \$46.8 million in notices of funding opportunities to promote youth mental health, grow the behavioral health workforce, improve access to culturally competent behavioral care across the country, and strengthen peer recovery and recovery support. President Biden made tackling the mental health crisis and beating the opioid epidemic key pillars in his Unity Agenda for the nation. Visit here for more information: <https://www.samhsa.gov/newsroom/press->

[announcements/20240508/biden-harris-administration-announces-46-million-behavioral-health-funding-opportunities](https://www.samhsa.gov/newsroom/press-announcements/20240508/biden-harris-administration-announces-46-million-behavioral-health-funding-opportunities)

- **Services Resource:** SAMHSA introduced a new resource in June 2024, *Guidance to States and Communities on Using Federal Funding to Support Mental Health Services for LGBTQI+ Youth*. This guidance outlines how states and communities can use SAMHSA funding to support mental health services for lesbian, gay, bisexual, transgender, queer, intersex, and other gender diverse youth (LGBTQI+) with examples from BSCA grantees. See the resource here: <https://store.samhsa.gov/product/guidance-funding-support-mental-health-lgbtqi-youth/pep24-06-002>
- **Announcement:** On June 4, 2024, HHS, through CMS in partnership with SAMHSA, welcomed 10 new states into the Certified Community Behavioral Health Clinic (CCBHC) Medicaid Demonstration Program, after they successfully developed the necessary state-level infrastructure and worked with providers in their states to develop programs that meet CCBHC standards: Alabama, Illinois, Indiana, Iowa, Kansas, Maine, New Hampshire, New Mexico, Rhode Island and Vermont. Visit here for more information: <https://www.samhsa.gov/newsroom/press-announcements/20240604/biden-harris-administration-expands-access-mental-health-substance-use-services-addition-10-new-states-ccbhc-medicare-demonstration-program>
- **Committee Meeting:** On June 10, 2024, Interdepartmental Substance Use Disorders Coordinating Committee (ISUDCC) held full committee meeting. Agenda topics included discussion of SAMHSA's Overdose Prevention and Response Toolkit, Naloxone Saturation Policy Academies, and Harm Reduction Framework. See additional meeting information here: <https://www.samhsa.gov/meetings/isudcc-meeting-june-2024>

## Department of Education (ED)

**Announcement:** May 9, during Mental Health Awareness Month, the Biden-Harris Administration announced new actions to increase access to school-based mental health services, including: (1) nearly doubling investments in the U.S. Department of Education's (Department's) School-Based Mental Health Services (SBMH) and Mental Health Service Professionals (MHSP) grant programs in the current Fiscal Year; (2) making additional investments through the Bipartisan Safer Communities Act (BSCA) to improve the mental health and wellbeing of students and educators; and (3) offering new mental health and wellbeing trainings and resources for schools and educators. Read more here:

<https://www.ed.gov/news/press-releases/during-mental-health-awareness-month-u-s-department-education-announces-new-actions-increase-access-school-based-mental-health-services>

## Department of Housing and Urban Development (HUD)

**New Report:** *Housing Search Assistance for Non-Elderly People with Disabilities*

The study identified barriers that people with disabilities face accessing and using housing assistance—including navigating program eligibility requirements, searching for housing, and coordinating services and supports up to the point of moving into an assisted unit—and successful strategies to address those challenges. The study included a literature review, interviews with a small number of key stakeholders, and nine case studies of programs that serve people with disabilities and connect them to housing assistance programs. The results of the study are documented in the subject report and a brief that addresses Participant Experiences with Housing Search Assistance and Implications for Service Providers

that Serve People with Disabilities. The report is available here:

<https://www.huduser.gov/portal/publications/Housing-Search-Assistance.html>

## Social Security Administration (SSA)

- **Final Rule:** SSA recently published a final rule that announced one of several updates to Supplemental Security Income (SSI) regulations that will help people receiving and applying for SSI. Under the final rule, beginning September 30, 2024, the agency will expand the definition of a public assistance household to include households receiving Supplemental Nutrition Assistance Program (SNAP) payments and households where not all members receive public assistance. The expanded definition will allow more people to qualify for SSI, increase some SSI recipients' payment amounts, and reduce reporting burdens for individuals living in public assistance households.
  - **Final Rule:** <https://www.federalregister.gov/d/2024-08364>
  - **Press Release:** <https://www.ssa.gov/news/press/releases/2024/#5-2024-3>
- **Announcements:**
  - **Social Security Updates Occupations List Used in Disability Evaluation Process:** In determining disability claims for adults, Social Security may have to evaluate whether a person can adjust to other work that exists in significant numbers in the national economy. To make this determination, the agency considers a person's capacity to do work-related activities, as well as consider their age, education, and work experience. The agency has identified 114 occupations with jobs that exist in very limited numbers, if at all, in each of the nine U.S. Census divisions of the country. Based on this finding, the agency will not use these occupations to support a "not disabled" finding at the last step in the evaluation process for disability determinations. The agency also identified 13 occupations where federal courts have questioned supporting evidence of a "not disabled" finding. The agency is implementing additional evidence requirements for these occupations. Read more here: <https://www.ssa.gov/news/press/releases/2024/#6-2024-2>
  - **Social Security to Simplify Disability Evaluation Process:** In response to President Biden's Executive Order on Transforming Federal Customer Experience and Service Delivery to Rebuild Trust in Government, the agency is proud to announce changes that will reduce administrative burdens for applicants and help more people with disabilities receive government benefits and services if they are eligible. Beginning June 22, 2024, when determining past relevant work, the agency will review only five years of past work. This change makes it easier for people applying for benefits by focusing on their most recent relevant work activity while still providing enough information to continue making accurate determinations. Read more here: <https://www.ssa.gov/news/press/releases/2024/#6-2024-3>

## Public Member Updates

### Autism Science Foundation (ASF)

- **Research Funding Opportunity:** On July 1, ASF published the Request for Applications for the Suzanne Wright Memorial Accelerator Award. This funding is earmarked for research ideas that build upon, speed up, or enhance an existing research project. For more information, visit: <https://autismsciencefoundation.org/apply-for-a-research-accelerator-grant/>
- **Research Participation Opportunity:** ASF announced the relaunch of the Participate in Research Directory, which is a tool used to match families and individuals with autism to research projects based on their interest, location, and age. This tool has been desperately needed by the community who would like to participate in research, as well as the research community whose studies sometimes fail because of recruitment issues. Following extensive interactions with the community (surveys and focus groups), each study will have a visual graphic of the goals and highlights that the community recommended. Any study in the world can submit their project to the directory, and anyone can access the directory at: <https://autismsciencefoundation.org/participate-in-research/>
- **New Initiative and Upcoming Webinar:** Siblings play a critical role in the autism family but are underrecognized and underappreciated. ASF and Els for Autism have joined together to organize “Sam’s Sibs Stick Together”, an initiative that provides mental health supports as well as the opportunity to discuss the newest science and research about siblings with siblings. On July 23, at 2:00 pm ET, we will be hearing from supersibling Amy Ursitti, who will provide her perspectives on being a sibling to her profound brother Jack. Learn more at: <https://www.samssibssticktogether.com/>

### Autism Speaks

- **Research Resource:** On May 15, 2024, MSSNG, the world’s largest autism whole-genome dataset was expanded. Genomic data is now available for 13,801 individuals, including over 6,000 autistic people and over 7,000 of their family members. The data are freely available for autism researchers. For more information, see: <https://www.autismspeaks.org/science-news/worlds-largest-autism-genome-database-expands>
- **Services Initiative:** Autism Speaks launched an initiative to expand Caregiver Skills Training (CST) in underserved communities in the United States. Autism Speaks is actively recruiting Parent Training and Information Center (PTIC) and Head Start sites. Please contact Autism Speaks if you are aware of any agencies or organizations that may be interested. To learn more about the CST Program, visit: <https://www.autismspeaks.org/caregiver-skills-training-program>
- **Report and Upcoming Webinar:** In September 2023, WHO-UNICEF released the *2023 Global Report on Children with Developmental Disabilities*. The Early Childhood Development Action Network (ECDAN) will be holding a webinar on July 30, 8:30-10:00 am, to further disseminate the report. The webinar "Toward better, inclusive ECD: Addressing the needs and rights of young children with developmental disabilities in policy design and service delivery" is a collaboration of the WHO, Partnership for Early Childhood Development & Disability Rights (PECDDR), Autism Speaks, UNICEF, and ECDAN.
  - **2023 Global Report on Children with Developmental Disabilities:** <https://www.unicef.org/documents/global-report-children-developmental-disabilities>

- **Registration Link for Webinar:**  
[https://us02web.zoom.us/webinar/register/WN\\_sxNQaIJLSjmkmszcwpTtSA](https://us02web.zoom.us/webinar/register/WN_sxNQaIJLSjmkmszcwpTtSA)

## Camille Proctor

**New Research Project:** Racial disparities continue to exist in autism research, negatively impacting Black autistic children. They are misdiagnosed, receive access to inferior quality services, and are almost twice as likely as white autistic children to have a co-occurring intellectual disability. To examine this void, NIMH funded the "Racism and Resilience among Black Autistic Children and Caregivers" project. This Multiple Principal investigator (MPI) and R01-funded project launched April 1, 2024. Researchers at Drexel will partner with the University of North Carolina-Chapel Hill Frank Porter Graham Child Development Institute and IACC member Camille Proctor will serve as their lead community partner. Read more here: <https://drexel.edu/news/archive/2024/April/New-Project-Examines-Racism-and-Resilience-Among-Black-Autistic-Children-and-Caregivers>

## Simons Foundation Autism Research Initiative (SFARI)

- **Research Funding Opportunity:** SFARI Fellows to Faculty Award (DEI) grants (previously known as BTI awards) facilitate the transition of senior post-doctoral researchers into independent faculty positions. Candidates should have backgrounds and experiences that are underrepresented in science. Applications will open in October 2024.
- **Research Resource:** SFARI continues to offer multiple research resources (biospecimens, iPSCs, post-mortem brain tissue, genotype and phenotype data, cohorts for recruitment, etc.) by application to qualified researchers from academia or industry.
- **Services Initiative and Funding Opportunity:** The Simons Foundation is expanding its Autism in the Workplace initiative and has launched a grant program that provides funding to non-profit employers to build the infrastructure and training they need to launch inclusive internship programs for autistic candidates.
  - **For more information, visit:** <https://www.simonsfoundation.org/science-society-culture/autism-in-the-workplace/>
  - **Inquiries can be directed to:** [aitw@simonsfoundation.org](mailto:aitw@simonsfoundation.org)
- For more information about SFARI updates, visit: <https://www.sfari.org/>

## Community Updates

### Association of University Centers on Disabilities (AUCD)

- **New Resources:**
  - **How Families Can Empower Youth with Intellectual and Developmental Disabilities (IDD) from Racially and Ethnically Diverse Backgrounds:** This brief shares the perspectives and experiences of culturally and linguistically diverse family members of four youth who shared their employment and community engagement stories. It outlines the pivotal role these families played to support youth with IDD to find and maintain competitive integrated employment and to meaningfully engage with their communities. It draws from in-depth, semi-structured interviews with youth with IDD, their family members, and job coaches. Find the full brief here: [https://www.thinkwork.org/sites/default/files/files/RP62\\_R.pdf](https://www.thinkwork.org/sites/default/files/files/RP62_R.pdf)



- **Cognitive Behavioral Strategies for Autistic Students Toolkits:** The Vanderbilt Kennedy Center (TN IDDRC, UCEDD, LEND)'s Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) and the Vanderbilt Consortium LEND Training Program have produced two toolkits and online courses. The two newest toolkits share the theme of Cognitive Behavioral Strategies for Autistic Students and is broken into two specific age groups, one for elementary-age students and the other for adolescent students. Find out more and access the toolkits here: <https://www.aucd.org/news/vanderbilt-kennedy-center-lead-program-introduces-two-new-toolkits-for-educators>
- **Upcoming Webinar: Leveraging the AIR-P for Collaborative Research Through the LEND Program**
  - This webinar on Tuesday, July 16, 2024, at 4:00 pm ET will provide an overview of the intersection between two initiatives funded by the Health Resources and Services Administration (HRSA): The Autism Intervention Research Network on Physical Health (AIR-P) and The Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) Program. Panelists will describe how they leverage the AIR-P to further the mission of the LEND program. They will discuss successful research projects their trainees have worked on that align with the goals of these programs. Panelists will also discuss challenges with instituting collaborative research and training projects and potential strategies for addressing these challenges. Finally, they will discuss ongoing work within the AIR-P LEND committee.
  - CART captioning will be provided. There is no cost for this webinar. CEUs are not offered for this webinar.
  - For more information, including featured speakers, visit: <https://www.aucd.org/event/leveraging-the-air-p-for-collaborative-research-through-the-lead-program>
  - Register for the webinar here: <https://us06web.zoom.us/meeting/register/tZAude-qrD8rHdVXbLiWgZxkVnvTANUYwWA1>

## The Arc of the United States

### Announcements:

- **Improving Mental Health Care for People with Intellectual and Developmental Disabilities:** The United Health Foundation, the philanthropic foundation of UnitedHealth Group (NYSE: UNH), has awarded The Arc of the United States a three-year, \$2.5 million grant to improve mental health care for people with intellectual and developmental disabilities (IDD). Up to 40% of people with IDD have co-occurring mental health conditions, and this critical funding will help address their unmet mental health needs. Read more here: <https://thearc.org/blog/the-arc-and-united-health-foundation-launch-2-5m-partnership-to-tackle-mental-health-crisis-for-people-with-disabilities/>
- **Transforming The Arc's Data, Tech Training, and Spanish Education Resources:** The Arc of the United States and Comcast NBCUniversal announced a major expansion of their long-standing partnership that will break down barriers and create more equity and opportunity for people with IDD. Comcast is providing a \$1 million grant over two years to The Arc to modernize its data infrastructure, deepen the impact of its digital literacy programs, and give Spanish-speaking families access to special education advocacy. This funding is a part of Project UP, Comcast's \$1 billion commitment to advance digital equity and help create a future of unlimited possibilities.



Read more here: <https://thearc.org/blog/comcast-grants-1m-to-transform-the-arcs-data-tech-training-and-spanish-education-resources/>