# IACC Round Robin Updates

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Federal Agency Updates

Department of Health and Human Services

- Last year, Secretary Becerra, Deputy Secretary Palm and Department of Health and Human Services (HHS) Agency Leaders introduced the HHS Roadmap for Behavioral Health Integration. The HHS Roadmap articulated HHS’ commitment to engaging our entire Department in service of the following goal to further advance the President’s vision: The full spectrum of behavioral health care will be integrated into health care, social service, and early childhood systems to ensure all people have equitable access to evidence-based, culturally appropriate, person-centered care. Since launching the HHS Roadmap, HHS has advanced a number of critical policy actions to expand access to and the quality of behavioral health care. A subset of these actions are highlighted here: https://www.hhs.gov/about/news/2024/01/18/hhs-roadmap-for-behavioral-health-integration-fact-sheet-accomplishments.html

- HHS released the 2023 update to its Equity Action Plan, in coordination with the Biden-Harris Administration’s whole-of-government equity agenda. This Equity Action Plan is part of the Department’s efforts to implement the President’s Executive Order on “Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,” which reaffirmed the Administration’s commitment to deliver equity and build an America in which all can participate, prosper, and reach their full potential. Ensuring that all people, including underserved populations, have optimal opportunities for healthy and thriving lives continues to be a priority for HHS. The 2023 Equity Action Plan, with the support of HHS policies and approaches, aids in HHS’ efforts to reach, facilitate, and advance health and well-being for all. See more information here: https://www.hhs.gov/about/news/2024/02/14/hhs-releases-2023-update-equity-action-plan-outlines-new-commitments-advance-equity.html

Administration for Community Living (ACL)

- ACL has announced the launch of the website for The Link Center—a new resource that will help open doors to the world of opportunities for people with intellectual and/or developmental disabilities (I/DD), brain injuries, and/or other cognitive disabilities who also have mental health conditions. The Center was discussed at the October 2023 IACC meeting. The new website was created to serve as a national hub of the most relevant and timely resources—including information about best practices, promising strategies, upcoming events, webinars, and technical assistance opportunities—to support states, communities, and stakeholders in improving the lives of children and adults with these disabilities. It features materials that are intended for a broad audience, including individuals with disabilities and their families, advocates and allies, policymakers, direct support professionals, and clinical professionals. Visit: https://acl.gov/TheLinkCenter

- The U.S. Department of Health and Human Services (HHS), through ACL, announced several new initiatives and resources from ACL’s Direct Care Workforce (DCW) Strategies Center to address the dire shortage of professionals who provide the services many older adults and people with disabilities need to live in the community. These include two technical assistance opportunities to help states strengthen their systems for recruiting, retaining, and developing direct care workers; a national hub to connect states, stakeholders, and communities to best practices and other resources related to the direct care workforce; and a webinar series for states and stakeholders focused on a range of direct care workforce topics. These initiatives will help
sustain the impact of the $37 billion in American Rescue Plan funding invested to date by states in home and community-based services and support the comprehensive set of actions and investments included in the President’s executive order to improve care. See the press release for more information: https://www.hhs.gov/about/news/2024/02/27/hhs-announces-multi-pronged-effort-strengthen-direct-care-workforce.html

• ACL is pleased to announce the release of the 2024–2028 Long-Range Plan (LRP) for the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). As mandated by Congress, NIDILRR’s LRP provides a five-year agenda for advancing the vital work being done in applied research and development to improve the inclusion of people with disabilities into all aspects of society. Shaped by extensive stakeholder input, the new LRP continues to emphasize scientific rigor and the need for research that is highly relevant to the lives of people with disabilities. For more information, visit: https://acl.gov/news-and-events/news/nidilrr-announces-2024-2028-long-range-plan

• ACL has released the FY 2021-2022 Organization Highlights Report for NIDILRR. Every two years, NIDILRR releases this report to provide stakeholders with detailed information on how NIDILRR funding is being used, how NIDILRR research is making a difference, what products are being produced by NIDILRR grants, highlights from former grantees, and how NIDILRR is collaborating across the federal government to achieve its mission. The report highlights key accomplishments from NIDILRR grantees across each of the NIDILRR funding mechanisms and outcome domain areas, illustrating how NIDILRR activities and achievements are improving the lives of people with disabilities. See the report here: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/FINAL%20FY21-22-nidilrr-org-highlights-rpt_508.pdf

• NIDILRR is announcing a new funding opportunity for a Rehabilitation Engineering Research Centers (RERC) program on technologies to enhance independence and community living among people with cognitive disabilities. The purpose of the RERC program is to improve the effectiveness of services authorized under the Rehabilitation Act by conducting advanced engineering research and development of innovative technologies designed to solve particular rehabilitation problems or remove environmental barriers. The RERC on Technologies to Enhance Independence and Community Living Among People with Cognitive Disabilities will conduct research, development, and related activities focused on technologies that support the community living and participation of adults with cognitive disabilities. Applications are due April 24, 2024: https://www.grants.gov/search-results-detail/349389

• During October 2023 to January 2024, the Administration on Disabilities (AoD) Disability Employment Technical Assistance Center (DETAC) partnered with the National Disability Rights Network (NDRN) to host the Strategies to Phase-Out 14(c) Results and Innovation in Systems Excellence (RISE) e-Learning Community. To broaden the reach of this community, DETAC created one-pager with a summary of the community, links to all session recordings, steps you can take to phase-out 14(c), and related resources. Check-out the RISE community summary here: https://aoddisabilityemploymenttacenter.com/wp-content/uploads/2024/02/DETAC_RISE-Summary_Strategies-to-Phase-Out-14c.pdf

• On February 13, 2024, nearly 500 participants joined the DETAC for the February 2024 National Community of Practice (CoP) webinar. This event highlighted the importance of family support for people with disabilities who own their own businesses. The event began with a brief recap of
the work DETAC has done to advance self-employment opportunities for people with disabilities. Then, Sue Babin from the Rhode Island Developmental Disabilities Council (RIDDC) facilitated a panel session featuring three family members of entrepreneurs with disabilities. The panelists offered their perspectives on how to best support loved ones with disabilities who have goals of owning their own business. A recording of the event and slides are available here: https://aoddisabilityemploymenttacenter.com/supporting-self-employment-for-entrepreneurs-with-disabilities-family-perspectives/ 

• On March 12, the AoD DETAC celebrated Developmental Disabilities (DD) and Brain Injury (BI) Awareness month with nearly 400 webinar participants. This webinar highlighted innovative strategies for removing barriers to further advance competitive, integrated employment and economic outcomes for people with DD and BI through small business ownership. Synergies Work, the largest startup hub in the United States for disability-led businesses, shared how people with DD and BI have been successful in launching and maintaining their own businesses. The National Association of State Head Injury Administrators (NASHIA) also shared the latest data and employment trends for people with BI. NASHIA discussed current service gaps and proposed solutions to maximize employment opportunities. The webinar also included perspectives from Angad Sahgal, an entrepreneur with DD, and Kymberlee Baker, an entrepreneur with BI, on key elements needed to establish and operate a business. See the recording of the event and slides here: https://aoddisabilityemploymenttacenter.com/strategies-to-support-people-with-developmental-disabilities-and-brain-injury-to-achieve-employment-goals-through-small-business-ownership/ 

• On April 16, join the AoD Disability Employment Technical Assistance Center (DETAC) for a webinar to increase awareness about National Financial Capability Month. Financial education is a key first step on the pathway towards financial health and wellbeing to live more independently in the community. The Illinois Council on Developmental Disabilities funded a three-year initiative with the National Disability Institute (NDI) called Financial Wellness for People with Intellectual and Developmental Disabilities (I/DD). The panel will highlight how this train-the-trainers model in Illinois provided training to individuals with I/DD and their family members to manage money, reduce debt, and use credit wisely. The training was customized based on individualized needs ranging from a short class to a 10-module curriculum. While we often focus on helping people with disabilities find jobs, this webinar will highlight a model to ensure we also provide a roadmap on the importance of making good financial decisions to further increase independence. For more information, visit: https://aoddisabilityemploymenttacenter.com/national-financial-capability-awareness-month-engaging-diverse-communities-through-financial-education-and-empowerment/ 

• ACL has awarded $3 million in new funding to the University of Southern California, Leonard Davis School of Gerontology (USC) to support implementation of recommendations for addressing Goal 4 (financial and workplace security) in the 2022 National Strategy to Support Family Caregivers. The award will advance the capacity of the aging network and its partner organizations to support and address financial and workplace security challenges faced by family, kinship, and tribal caregivers. See more information here: https://acl.gov/news-and-events/announcements/acl-awards-3m-improve-financial-security-family-caregivers
Centers for Disease Control and Prevention (CDC)

- **Adolescents with Autism Spectrum Disorder—2020 Data from CDC’s ADDM Network**
  - CDC’s most recent report from the Autism and Developmental Disabilities Monitoring (ADDM) Network “Health Conditions, Education Services, and Transition Planning for Adolescents With Autism,” used data collected in 2020 on adolescents with autism spectrum disorder (ASD), building on efforts to monitor 16-year-olds with ASD at multiple ADDM Network sites. In this report, scientists looked at health status and educational services among adolescents with ASD. They found racial and ethnic disparities in the co-occurrence of anxiety and a wide variation in the provision of school-based Individualized Education Program (IEP) services and transition planning by geographic area and intellectual ability, identifying potential areas of focus to improve quality and reduce disparities.
  - ADDM Network: [https://www.cdc.gov/ncbddd/autism/addm.html](https://www.cdc.gov/ncbddd/autism/addm.html)
  - The full article is in *Pediatrics* here: [https://doi.org/10.1542/peds.2023-063672](https://doi.org/10.1542/peds.2023-063672)

- **CDC’s “Learn the Signs. Act Early.” Milestone Tracker App Hits 2 million Downloads and Milestones in Action Photo and Video Library Now Available in Spanish and English**
  - As one of CDC’s priority initiatives, “Learn the Signs. Act Early.” (LTSAE) promotes earlier detection and intervention—both crucial to addressing the developmental and behavioral needs of children. Parents and caregivers have an important role to play. CDC’s *Milestone Tracker* app from the LTSAE program helps parents and caregivers track their child’s developmental milestones from age 2 months to 5 years with easy-to-use illustrated checklists, tips for encouraging child development, steps to take if there are concerns about development, and more. With the help of early childhood professionals across the country, including CDC’s Act Early Ambassadors, pediatricians, Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) providers, early care and education providers, and others, more families are accessing this resource. On January 29, 2024, CDC’s *Milestone Tracker* app reached 2 million downloads. CDC is supercharging dissemination of LTSAE resources to families and the early childhood workforce. Dissemination will occur through several partners, including Federally Qualified Health Centers (FQHCs) and WIC.
  - The “Learn the Signs. Act Early.” program is excited to announce the re-launch of the *Milestones in Action* photo and video library. This resource is now available in English and Spanish to support the program’s new milestones that were released in spring 2022. *Milestones in Action* provides parents and caregivers with images to help understand the developmental milestones that children should reach from 2 months to 5 years. The library is an excellent resource for families to reference as they complete a milestone checklist for their child. For professionals, the free photos and videos can be downloaded for professional development and parent education activities.
  - Browse *Milestones in Action* today and share with your colleagues! The Spanish *Milestones in Action* will be added to CDC’s Milestone Tracker app in spring 2024.
Centers for Medicare & Medicaid Services (CMS)

- On January 5th, 2024, CMS released state spending plan summaries for section 9817 of the American Rescue Plan Act of 2021 (ARP). The state summaries provide information on the amount of planned and reported state spending, as of the quarter ending December 31, 2022, on activities to enhance, expand, or strengthen home and community-based services (HCBS). The state summaries include information on the top categories of each state’s spending and are illustrative examples of activities each state is implementing under ARP section 9817. See the summary here: https://www.medicaid.gov/sites/default/files/2024-01/states-arpa-spending-plan-summaries-ffy2023q1.pdf

- On January 18th, the CMS Innovation Center announced a new model to test approaches for addressing the behavioral and physical health, as well as health-related social needs, of people with Medicaid and Medicare. The Innovation in Behavioral Health (IBH) Model’s goal is to improve the overall quality of care and outcomes for adults with mental health conditions and/or substance use disorder by connecting them with the physical, behavioral, and social supports needed to manage their care. The model will also promote health information technology (health IT) capacity building through infrastructure payments and other activities. The IBH model will launch in Fall 2024 and is anticipated to operate for eight years in up to eight states. CMS will release a Notice of Funding Opportunity for the model in Spring 2024. Please visit the IBH Model webpage for more information: https://www.cms.gov/priorities/innovation/innovation-models/innovation-behavioral-health-ibh-model

- On January 18th, CMS finalized the CMS Interoperability and Prior Authorization Final Rule. The rule sets requirements for Medicare Advantage (MA) organizations, Medicaid and the Children’s Health Insurance Program (CHIP) fee-for-service (FFS) programs, Medicaid managed care plans, CHIP managed care entities, and issuers of Qualified Health Plans (QHPs) offered on the Federally-Facilitated Exchanges (FFEs), (collectively “impacted payers”), to improve the electronic exchange of health information and prior authorization processes for medical items and services. Together, these policies will improve prior authorization processes and reduce burden on patients, providers, and payers, resulting in approximately $15 billion of estimated savings over ten years.

- On January 24th, CMS announced $50 million in grants for states to connect millions more children to critical health care services, particularly for mental health, at school. Made possible by the historic investments of the Bipartisan Safer Communities Act (BSCA), the grants will provide 20 states up to $2.5 million each in funding that can help states implement, enhance, and expand the use of school-based health services through Medicaid and the Children’s Health Insurance Program (CHIP). Along with this $50 million grant announcement, HHS Secretary Xavier Becerra and U.S. Department of Education (ED) Secretary Miguel Cardona issued a joint letter to governors, emphasizing that this grant funding “will make it easier for states to support...
schools in providing critical health care services, especially mental health services, for millions of students across the nation.” More information is available here: https://www.cms.gov/newsroom/press-releases/cms-announces-50-million-grants-deliver-critical-school-based-health-services-children

- On January 29th, CMS released a set of frequently asked questions (FAQs) to supplement the 2021 State Health Official (SHO) letter "Improving Maternal Health and Extending Postpartum Coverage in Medicaid and the Children's Health Insurance Program (CHIP)." The SHO informed state Medicaid and CHIP agencies about the new option for states to provide 12 months of extended postpartum coverage to pregnant individuals enrolled in Medicaid and CHIP. The FAQs provide guidance to state Medicaid programs about what constitutes full benefits during the 12-month extended postpartum eligibility period and clarify whether a state needs to submit a state plan amendment (SPA) to amend its coverage pages. See the FAQs here: https://www.medicaid.gov/sites/default/files/2024-01/postpartum-ext-faqs.pdf

- On February 8th, CMS released an updated State Medicaid & CHIP Telehealth Toolkit that serves as a consolidated and comprehensive compilation of telehealth policies, including related flexibilities and requirements, for states to consider when using telehealth to deliver Medicaid and CHIP benefits and services. The toolkit also includes information about telehealth platforms; billing best practices; best practices from states during and after the COVID-19 Public Health Emergency; strategies to promote the delivery of accessible and culturally competent care via telehealth, including using telehealth in schools; strategies for telehealth in value-based care; evaluation strategies to understand how telehealth affects quality, outcomes, and cost; and strategies for communicating, training, and providing resources on telehealth for providers and for beneficiaries. See the toolkit here: https://www.medicaid.gov/medicaid/benefits/telehealth/medicaid-chip-telehealth-toolkit/index.html

- On February 12th, CMS released an updated State Medicaid, Children's Health Insurance Program, & Basic Health Program Vaccine Toolkit that serves as a consolidated and comprehensive compilation of vaccination policies, including related flexibilities and coverage and payment requirements, for states to consider as they transition away from the COVID-19 public health emergency and implement Inflation Reduction Act coverage requirements. It also includes additional considerations states may make to enhance vaccination coverage and access including provider qualifications, immunization registries, and payment considerations.

- On February 13th, CMS released a set of Quality Improvement (QI) Tools designed to help states improve Behavioral Health follow-up care including: a driver diagram/change ideas table, a measurement strategy, as well as a highlights brief that gives an overview of projects states completed as part of the Improving Behavioral Health Follow-up Care Affinity Group. Visit the webpage on Behavioral Health Follow Up Care to access additional resources: https://www.medicaid.gov/medicaid/quality-of-care/quality-improvement-initiatives/behavioral-health-learning-collaborative/index.html
On February 15th, CMS released updated CCBHC PPS Technical Guidance for states on developing clinic-specific PPS rates, cost reporting, and claiming Medicaid expenditures. The new guidance supports expansion and extension of the CCBHC Demonstration program authorized under section 223 of the Protecting Access to Medicare Act as amended by section 11001 of the Bipartisan Safer Communities Act, and includes additional payments and flexibilities for CCBHCs, most notably new PPS rate options for special crisis services and updated guidance on developing quality bonus payments. All states participating in the CCBHC Demonstration program are expected to come into compliance with the updated PPS guidance by the start of the demonstration year beginning on or after July 1, 2024. See the guidance here: https://www.medicaid.gov/medicaid/financial-management/downloads/section-223-ccbh-pps-prop-updates-022024.pdf

On March 7th, CMS made available the results from the Agency for Healthcare Research and Quality’s (AHRQ) 2024 Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Home and Community-Based Services (HCBS) Survey Database. The HCBS CAHPS Survey asks adult Medicaid beneficiaries about their recent experiences with long-term services and supports (LTSS) furnished through state HCBS programs. The 2024 HCBS CAHPS Survey Database includes 6,053 survey responses submitted by state Medicaid agencies and managed care plans from 24 HCBS programs. Its purpose is to help states and plans to evaluate, compare, and improve the quality of services provided by both fee-for-service HCBS and managed LTSS programs. Among many HCBS measures, the report includes key findings reflecting individuals’ experience with physical safety; availability of staff to help with dressing, showering, or bathing; and ratings of personal assistance and behavioral health staff. For more information, please email the HCBS CAHPS Database at HCBSCAHPSDatabase@westat.com or call the helpline at 1-855-580-4657.

On March 12th, CMS released a report describing best practices in implementing the Money Follows the Person (MFP) Demonstration. Since its authorization in the Deficit Reduction Act of 2005 (P.L. 109-171), the MFP Demonstration has provided nearly $6 billion to 43 states and the District of Columbia to improve access to home and community-based services (HCBS) for Medicaid-eligible individuals and helped more than 107,128 long-term residents transition from institutions to the community. Developed in collaboration with states, providers, and MFP participants, this report identifies effective state strategies for implementing the key components of the MFP Demonstration and features case studies of distinctive state approaches. This report highlights findings across eight areas of interest, identified in Section 204(e) of Division CC of the Consolidated Appropriations Act, 2021.
• On March 15th, CMS released an informational bulletin and slide deck to address questions CMS has received from states, stakeholders, and external partners regarding the permissibility of certain practices during Medicaid and the Children’s Health Insurance Program (CHIP) renewals. To clarify what is permitted under existing federal renewal requirements, both during and beyond unwinding, these resources reiterate some of the relevant federal renewal requirements for state reference, outline policy and operational practices that are not permitted under existing federal Medicaid and CHIP redetermination regulations and provide illustrative examples of processes that are not permitted under federal requirements.

• On March 15th, CMS also released an Informational Bulletin on Medicaid.gov in response to the cyber-attack on UnitedHealth Group’s subsidiary Change Healthcare announcing important flexibilities to help state Medicaid agencies provide needed relief to Medicaid providers and protect access to healthcare coverage. The informational bulletin highlights existing and temporary flexibilities with a focus on providing states with an expedited process for implementing interim payments to affected providers to mitigate disruptions. See the informational bulletin here: https://www.medicaid.gov/federal-policy-guidance/downloads/cib031524.pdf

• On March 27th, CMS released the Streamlining the Medicaid, Children’s Health Insurance Program, and Basic Health Program Application, Eligibility Determination, Enrollment, and Renewal Processes final rule that builds on key lessons learned during Medicaid unwinding and includes a series of provisions to simplify enrollment and renewal processes by standardizing them nationwide and makes it easier for eligible children and adults to stay covered. Provisions include:
  o Eliminating annual and lifetime limits on children’s coverage in CHIP;
  o Ending the practice of locking children out of CHIP coverage if a family is unable to pay premiums;
  o Eliminating waiting periods for CHIP coverage so children can access health care immediately;
  o Improving the transfer of children seamlessly from Medicaid to CHIP when a family’s income rises;
  o Requiring states to provide all individuals with at least 15 days to provide any additional information when applying for the first time and 30 days to return documentation when renewing coverage; and
- Prohibiting states from conducting renewals more frequently than every 12 months and requiring in-person interviews for older adults and those with disabilities.
  - Final rule: [https://www.federalregister.gov/d/2024-06566](https://www.federalregister.gov/d/2024-06566)
- On March 28th, CMS announced additional actions to help people maintain coverage as states continue Medicaid and CHIP eligibility renewals, which restarted across the country last spring following a pause during the COVID-19 pandemic. In addition to extending a temporary special enrollment period (SEP; [https://www.medicaid.gov/resources-for-states/downloads/extn-sep-cnsmrs-lsg-chip-cvrg-adnm-faq.pdf](https://www.medicaid.gov/resources-for-states/downloads/extn-sep-cnsmrs-lsg-chip-cvrg-adnm-faq.pdf)) to help people who are no longer eligible for Medicaid or CHIP transition to Marketplace coverage in states using HealthCare.gov, CMS also released new guidance and other resources to help protect coverage. These include:
  - Guidance on unwinding processes and tools for states reinforcing important federal renewal requirements that states must follow, developed in response to questions from both states and partners;
    - Guidance: [https://www.medicaid.gov/sites/default/files/2024-03/cib03152024.pdf](https://www.medicaid.gov/sites/default/files/2024-03/cib03152024.pdf)
  - New resources for partners to help families navigate their state Medicaid fair-hearing process, such as if someone was determined no longer eligible for Medicaid: [https://www.medicaid.gov/resources-for-states/downloads/mdcid-fair-hrings-prtnr-rsource.pdf](https://www.medicaid.gov/resources-for-states/downloads/mdcid-fair-hrings-prtnr-rsource.pdf)

Food and Drug Administration (FDA)

The FDA is proposing a ban of electrical stimulation devices (ESDs) intended to reduce or stop self-injurious or aggressive behavior, a step rarely taken by the agency. The agency has determined that these devices present an unreasonable and substantial risk of illness or injury. This is the second time the FDA has proposed a ban of these particular devices. The proposed rule, if finalized, will remove ESDs from the market, and the devices will no longer be considered legally marketed. The proposed rule is open for comment until May 28, 2024.

NICHD Director Dr. Diana Bianchi and other NIH leaders attended the **White House Initiative on Women’s Health Research** event on March 18, 2024. NICHD is excited to play a key role in this initiative, which focuses on resources and activities on research to accelerate prevention, diagnosis, and treatment of conditions that affect women uniquely, more often, or differently.

- For more information on the initiative, visit: [https://www.whitehouse.gov/white-house-initiative-on-womens-health-research/](https://www.whitehouse.gov/white-house-initiative-on-womens-health-research/)
- See President Biden’s Executive Order on Advancing Women’s Health Research and Innovation: [https://www.whitehouse.gov/briefing-room/presidential-actions/2024/03/18/executive-order-on-advancing-womens-health-research-and-innovation/](https://www.whitehouse.gov/briefing-room/presidential-actions/2024/03/18/executive-order-on-advancing-womens-health-research-and-innovation/)

NICHD and NIMH co-hosted a workshop on the **Impact of Technology and Digital Media on Child and Adolescent Development and Mental Health** on April 4-5, 2024. The goal of this meeting is to discuss the current state of and future directions for research on the positive and negative effects of technology and digital media on the development and mental health outcomes of infants, children, and adolescents. The recording of this meeting can be accessed via NIH VideoCast: [https://videocast.nih.gov/watch=54538](https://videocast.nih.gov/watch=54538)

**Reproductive Health Care in Adolescents with Autism and Other Developmental Disabilities**

- This NICHD-funded study reported that adults with developmental disabilities often have less access to reproductive health services than adults without these disabilities. Researchers analyzed health records from female adolescents aged 14 to 18 years who sought care in Northern California between 2000 and 2017. They focused on information regarding menstrual conditions, the use of obstetrical-gynecologic care, and prescriptions for contraception across 700 adolescents with autism, 836 adolescents with other developmental disabilities, and 2,187 typically developing adolescents. They found that adolescents with autism and those with other developmental disabilities were more likely to have diagnoses of menstrual disorders, polycystic ovary syndrome, and premenstrual syndrome compared to typically developing peers. Despite the higher prevalence of menstruation-related conditions, these two groups were less likely than typically developing adolescents to visit the obstetrician-gynecologist or use any form of prescription contraception. However, those with autism or other developmental disabilities who did use hormonal contraception did so at an earlier age.


**Scans that chart the distribution of fluid within the brain during infancy could predict the later development of autism spectrum disorder (ASD) and the risk for developing ASD-related sleep problems, suggests a study funded by NIH.** The researchers used magnetic resonance imaging to detect cerebrospinal fluid, which bathes the brain and spinal cord. At 24 months of age, children with enlarged perivascular spaces—fluid-filled spaces surrounding small blood vessels in the brain—had a higher risk for an ASD diagnosis and higher chances for ASD-related sleep problems.

- Children experiencing higher social anxiety may be at greater risk for overeating and weight gain after being socially excluded by their peers, suggests a study from NICHD and other institutions. The researchers found that children who experienced a high stress level after completing an online task that simulates being ostracized and who also reported higher social anxiety were more likely to snack heavily after the simulation and gain weight over the next year and a half. The researchers suggested that efforts to reduce obesity in children may need to consider social stresses, such as ostracism. Read more here: https://www.nichd.nih.gov/newsroom/news/032124-peer-exclusion-weight-gain-children

National Institute on Deafness and Other Communication Disorders (NIDCD)
NIDCD-funded researchers identified how neurons in the human brain encode various elements of speech. The findings might be used to help develop treatments for speech and language disorders. More information is available here: https://www.nih.gov/news-events/news-releases/how-brain-produces-speech

National Institute of Mental Health (NIMH)
- Joshua A. Gordon, M.D., Ph.D., announced his decision to end his tenure as the director of the NIMH on June 14, 2024. Dr. Gordon has served in this role for the past 8 years. Read the full statement here: https://www.nih.gov/about-nih/who-we-are/nih-director/statements/statatement-departure-national-institute-mental-health-director-dr-joshua-gordon
- Fragile X syndrome (FXS) is a genetic disorder caused by the gene FMR1. It is the most common form of inherited intellectual disability and often co-occurs with other conditions like autism and epilepsy. New research has unveiled major insights into genetic mechanisms underlying FXS and related disorders. The study found that the disorders involve extensive silencing of many genes that play key roles in building tissues and making the brain work properly. Read more here: https://www.nimh.nih.gov/news-events/news-releases/researchers-expand-understanding-of-genetic-mechanisms-underlying-fragile-x-syndrome
- Researchers at NIH have found overactivation in many brain regions, including the frontal and parietal lobes and the amygdala, in unmedicated children with anxiety disorders. They also showed that treatment with cognitive behavioral therapy (CBT) led to improvements in clinical symptoms and brain functioning. The findings illuminate the brain mechanisms underlying the acute effects of CBT to treat one of the most common mental disorders. The study, published in the American Journal of Psychiatry, was led by researchers at NIH’s NIMH. Read more here: https://www.nih.gov/news-events/news-releases/cognitive-behavioral-therapy-alters-brain-activity-children-anxiety
- Researchers at NIH have discovered that symptoms of attention-deficit/hyperactivity disorder (ADHD) are tied to atypical interactions between the brain’s frontal cortex and information processing centers deep in the brain. ADHD is a common co-occurring condition in autistic individuals. The researchers examined more than 10,000 functional brain images of youth with ADHD and published their results in the American Journal of Psychiatry. The study was led by researchers at NIH’s National Institute of Mental Health (NIMH) and National Human Genome
Substance Abuse and Mental Health Services Administration (SAMHSA)
HHS, through SAMHSA, announced notices of funding opportunities for grant programs addressing behavioral health across the country. The grant opportunities total $39.4 million and are part of the Biden-Harris Administration’s priorities to beat the overdose epidemic and tackle the mental health crisis – two key pillars of the President’s Unity Agenda for the nation. For more information, visit: https://www.samhsa.gov/newsroom/press-announcements/20240322/biden-harris-administration-announces-39-million-funding-opportunities-unity-agenda

Department of Defense (DoD) – Army
- The FY23 Autism Research Program (ARP) completed its two-tier review cycle; 12 projects (15 separate awards) were recommended for funding. The list of the investigators and their institutions recommended for funding can be found here: https://cdmrp.health.mil/arp/awards/awards
- The ARP just released its FY24 funding solicitations, which includes the Career Development Award, Clinical Trial Award, and the Idea Development Award. Pre-applications are due May 16, 2024. These funding opportunities are available on Grants.gov and the application portal: https://ebrap.org/eBRAP/public/ProgramFY.htm?programFYId=577102
- The Discovery Award, which was a new funding opportunity last year, will be released in the coming weeks.

Department of Education (ED)
- ED’s Office of Educational Technology and the Office of Special Education Programs (OSEP) released a comprehensive guidance package designed to increase understanding of the Individuals with Disabilities Education Act’s (IDEA’s) assistive technology (AT) requirements, dispel common misconceptions regarding AT, and provide examples of the use of AT devices and services for children with disabilities, as well as to highlight the different AT requirements under Part C and Part B of IDEA. This package includes two parts:
- Vice President Kamala Harris announced $6.4 million from ED to address community violence. The funding is being awarded to seven school districts across the country as part of the Project Prevent grant program. The Vice President made the announcement in Charlotte, North Carolina, where she was joined by U.S. Secretary of Education Miguel Cardona to highlight the Biden-Harris Administration’s efforts to reduce gun violence and expand access to mental health services for students. More information is available here: https://www.ed.gov/news/press-
ED released its 2023 Update to its Equity Action Plan, in coordination with the Biden-Harris Administration’s whole-of-government equity agenda. This Equity Action Plan is part of the Department’s efforts to implement the President’s Executive Order on “Further Advancing Racial Equity and Support for Underserved Communities Through The Federal Government,” which reaffirmed the Administration’s commitment to deliver equity and build an America in which all can participate, prosper, and reach their full potential. See the press release here: https://www.ed.gov/news/press-releases/fact-sheet-us-department-education-releases-2023-update-equity-action-plan-outlines-new-commitments-advance-equity

ED’s Office for Civil Rights (OCR) released four new resources with information for students, parents and families, and schools addressing civil rights of students with disabilities, as well as a data snapshot about education access for students with disabilities drawn from OCR’s 2020-21 Civil Rights Data Collection (CRDC). OCR issued these new resources to inform students with disabilities, and their families and schools, about their legal rights under Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination against students with disabilities by institutions that accept federal financial assistance, which includes almost all public schools and public and private institutions of higher education. See more information here: https://www.ed.gov/news/press-releases/us-department-educations-office-civil-rights-releases-new-resources-students-disabilities

ED opened applications for the School-Based Mental Health and Mental Health Service Professional Demonstration grant competitions to help bolster the pipeline of mental health professionals serving in schools and expand student access to school-based mental health services and supports. President Biden named tackling the mental health crisis, particularly among youth, a key pillar in his Unity Agenda for the nation. And, in line with the Administration’s goals, these programs play a key role in doubling the supply of qualified mental health professionals in our nation’s schools. These newly opened applications build on the progress made through the Bipartisan Safer Communities Act to advance the Biden-Harris Administration’s efforts to integrate mental health services into our schools as part of the President’s National Mental Health Strategy. For additional information, see: https://www.ed.gov/news/press-releases/us-department-education-opens-applications-two-k-12-mental-health-programs-increase-number-mental-health-providers-schools

Department of Housing and Urban Development (HUD)

HUD released the 2023 Update to its Equity Action Plan, in coordination with the Biden-Harris Administration’s whole-of-government equity agenda. This Equity Action Plan is part of the Department’s efforts to implement the President’s Executive Order on “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,” which reaffirmed the Administration’s commitment to deliver equity and build an America in which all can participate, prosper, and reach their full potential. As a leading agency that works to support America’s most historically disadvantaged populations, HUD’s Equity Action Plan prioritizes and embeds equity in the work the Department does every single day. HUD’s work, in accordance with the Biden-Harris Administration’s directive, extends to all program offices and departments

- HUD launched a new website detailing protections against Source of Income (SOI) discrimination for families with Housing Choice Vouchers (HCVs). SOI discrimination is the practice where landlords, owners, and real estate brokers refuse to rent to current or prospective qualified tenants with an HCV or other forms of public assistance. The Source of Income Protections website serves as a “one-stop shop” for HUD stakeholders that summarizes existing materials to explain what SOI discrimination looks like, identifies states and local jurisdictions that prohibit it, and provides resources for people who believe they have experienced this form of discrimination. See the press release for more information: [https://www.hud.gov/press/press_releases_media_advisories/HUD_No_24_052](https://www.hud.gov/press/press_releases_media_advisories/HUD_No_24_052)

**Department of Justice (DOJ)**

- The Justice Department’s Antitrust Division, Federal Trade Commission (FTC) and Department of Health and Human Services (HHS) jointly launched a cross-government public inquiry into private-equity and other corporations’ increasing control over health care. Private equity firms and other corporate owners are increasingly involved in health care system transactions, and, at times, those transactions may lead to a maximizing of profits at the expense of quality care. The cross-government inquiry seeks to understand how certain health care market transactions may increase consolidation and generate profits for firms while threatening patients’ health, workers’ safety, quality of care and affordable health care for patients and taxpayers.
  - Comments are due by May 6, 2024, and can be submitted at: [https://www.regulations.gov/docket/FTC-2024-0022](https://www.regulations.gov/docket/FTC-2024-0022)

- DOJ has announced its annual plan for making anticipated grant funding available this fiscal year to advance public safety activities and improve justice system outcomes. The Department is inviting community-based organizations; state, local, tribal, and territorial government agencies, including law enforcement agencies; research institutions; and nonprofit entities to apply for funding from more than 200 grant programs, administered by its Office of Community Oriented Policing Services (COPS Office), Office of Justice Programs (OJP), and Office on Violence Against Women (OVW). As in prior years, the awards will be made later this year and will build on almost $5.8 billion in grants award in FY23. For more information, visit: [https://www.justice.gov/opa/pr/justice-department-announces-plan-administer-grant-funding-opportunities-fiscal-year-2024](https://www.justice.gov/opa/pr/justice-department-announces-plan-administer-grant-funding-opportunities-fiscal-year-2024)

- The DOJ is proposing to revise the regulations implementing Title II of the Americans with Disabilities Act (ADA) that aims to improve access to medical diagnostic equipment (MDE) for people with disabilities. MDE includes equipment like medical examination tables, weight scales, dental chairs, x-ray machines, and mammography equipment. Accessible MDE is essential for people with disabilities to have equal access to medical care. The rule proposes to adopt technical standards that clarify how public entities that use MDE, such as hospitals and health care clinics operated by state or local governments, can meet their existing obligations under the ADA. For more information, see the press release: [https://www.justice.gov/opa/pr/justice-department-advances-proposed-rule-improve-access-medical-care-people-disabilities](https://www.justice.gov/opa/pr/justice-department-advances-proposed-rule-improve-access-medical-care-people-disabilities)
• The Justice Department announced the release of its 2023 Equity Action Plan, which is part of the Department’s broader efforts to implement President Biden’s Executive Order on Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government. The update to the Justice Department’s Equity Action Plan was finalized in December 2023 and will help guide the Department’s equity strategies in Fiscal Year 2024. The Plan memorializes the Department’s commitment to aiding all people – including historically marginalized and underserved communities – in accessing the Department’s programs and resources, navigating complex legal and regulatory hurdles to vindicate their rights, understanding the breadth of the Department’s work, and meaningfully engaging with Justice Department decision-makers. Visit here for more information: https://www.justice.gov/opa/pr/justice-department-releases-update-equity-action-plan

• The Justice Department launched the National Extreme Risk Protection Order (ERPO) Resource Center which will provide training and technical assistance to law enforcement officials, prosecutors, attorneys, judges, clinicians, victim service and social service providers, community organizations, and behavioral health professionals responsible for implementing laws designed to keep guns out of the hands of people who pose a threat to themselves or others. See more information here: https://www.justice.gov/opa/pr/justice-department-launches-national-extreme-risk-protection-order-resource-center

Department of Labor (DOL)
DOL introduced a new resource aimed at boosting the participation of people with disabilities in competitive integrated employment. The Competitive Integrated Employment Transformation Hub brings together resources from across the federal government to provide practical guidance, policy information and evidence-based best practices for people with disabilities, their families, employers, employment service providers and state agencies. Competitive integrated employment ensures that people with disabilities are paid competitive wages and work in environments where the majority of employees do not have disabilities. For more information, see: https://www.dol.gov/newsroom/releases/odep/odep20240321

Department of Veterans Affairs (VA)
The VA released its 2024 Agency Equity Action Plan to help ensure that VA delivers on its promise to provide world-class care and benefits to all Veterans, their families, caregivers, and survivors — regardless of their age, race, ethnicity, sex, gender identity, religion, disability, sexual orientation, or geographic location. More information is available here: https://news.va.gov/press-room/va-announces-2024-equity-action-plan-new-actions-to-ensure-that-all-veterans-receive-the-health-care-and-benefits-they-earned/

Environmental Protection Agency (EPA)
EPA released the 2023 update to its Equity Action Plan, as part of the Biden-Harris Administration’s whole-of-government equity agenda. This Equity Action Plan is part of EPA’s efforts to implement the President’s Executive Order on “Further Advancing Racial Equity and Support for Underserved Communities Through the Federal Government,” which reaffirmed the Administration’s commitment to ensure equity and build an America in which all can participate, prosper, and reach their full potential. For more details, visit: https://www.epa.gov/newsreleases/epa-releases-2023-update-equity-action-plan-outlines-new-commitments-advance-equity
Social Security Administration (SSA)

• SSA is accepting applications for the Interventional Cooperative Agreement Program (ICAP)
  o The ICAP is an exciting research opportunity that allows SSA to enter into cooperative agreements with non-federal entities to conduct interventional research supporting SSA programs. The research interventions funded by ICAP will target five priority research areas:
    ▪ Eliminating the structural barriers for people with disabilities in the labor market, particularly for people of color and other underserved communities, that increase the likelihood of people receiving or applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI);
    ▪ Increasing employment and self-sufficiency of individuals with disabilities, including people in underserved communities;
    ▪ Coordinating planning between private and public human services agencies to improve the administration and effectiveness of the SSDI, SSI, and related programs;
    ▪ Assisting claimants in underserved communities to apply for or appeal decisions on claims for SSDI benefits and SSI; and
    ▪ Conducting outreach to people with disabilities who are potentially eligible to receive SSI.
  o The application is open through Monday, June 3, 2024. Information for ICAP is available on the ICAP funding opportunity page of Grants.gov: [https://www.grants.gov/search-results-detail/353274](https://www.grants.gov/search-results-detail/353274)
  o To learn more about the opportunity and how to apply, please attend the informational session on Thursday, April 25, 2024, from 2:00 pm to 3:00 pm ET. If you would like to participate, please register by Monday, April 22, 2024. After registration, you will receive an email with the Microsoft Teams link; the information session will be recorded. Register here: [https://ocomm.gov1.qualtrics.com/jfe/form/SV_cBnK7ZCVEaHw2Pk](https://ocomm.gov1.qualtrics.com/jfe/form/SV_cBnK7ZCVEaHw2Pk)
  o If you have any questions about ICAP, please email: ICAP.SSA@ssa.gov
  o If you have questions about applying, please email Grants.Team@ssa.gov with “ICAP Inquiry” in the subject line.

• SSA No Longer Including Food in Supplemental Security Income (SSI) In-Kind Support and Maintenance (ISM) Calculations
  o SSI provides monthly payments to adults and children with a disability or blindness, and to adults aged 65 and older, who have limited income and resources. SSI benefits help pay for basic needs like rent, food, clothing, and medicine. People applying for and receiving SSI must meet eligibility requirements, including income and resource limits. Under SSA’s old rules, ISM includes food, shelter, or both that a person receives. Given that the agency counts ISM as an unearned income, this may affect a person’s eligibility or reduce their payment amount. Beginning September 30, 2024, SSA will no longer include food in ISM calculations. The new policy removes a critical barrier for SSI eligibility due to an applicant’s or recipient’s receipt of informal food assistance from friends, family, and community networks of support.
To read the final rule “Omitting Food from In-Kind Support and Maintenance Calculations”, visit: https://www.federalregister.gov/d/2024-06464
For more information on the SSI program, including who is eligible and how to apply, visit: https://www.ssa.gov/ssi

Public Member Updates

Autism Science Foundation (ASF)
ASF has announced the expansion of the ‘Next Gen Sibs’ Project to two additional sites. The University of California at Davis, and the University of Alberta will join Emory University and University of California at Los Angeles in a collaborative research network to identify, evaluate and support the children of typically developing siblings of individuals with autism spectrum disorder (ASD). These second-degree relatives normally do not have access to expert clinical assessments, although research shows that they have a higher probability of an autism diagnosis. The Next Gen Sibs Project was launched in 2021 as an expansion of the Baby Siblings Research Consortium. For more information, visit: https://autismsciencefoundation.org/press_releases/expansion-of-next-gen-siblings-project/

Autism Speaks

- On January 30, the House Small Business Committee’s Subcommittee on Innovation, Entrepreneurship, and Workforce Development held a hearing titled “Pathways to Success: Supporting Entrepreneurs and Employees with Disabilities.” The hearing dove into the challenges that exist for potential employees with disabilities and solutions to ensure their participation in the marketplace. Chairman Marc Molinaro and Ranking Member McGarvey invited three individuals to testify before the committee, including Keith Wargo, President and CEO of Autism Speaks. For more details, visit: https://www.autismspeaks.org/advocacy-news/autism-speaks-ceo-testifies-congress-pathways-employment-individuals-autism-and-other

- The House Energy and Commerce Committee’s Health Subcommittee held a hearing on February 14 titled “Legislative Proposals to Support Patients and Caregivers.” The hearing considered 19 public health bills. Most notably for people with autism and their families, the committee heard about the transformative impact of programs authorized under the Autism CARES Act of 2024 and the bill’s potential to drive further improvements in care and services for the autism community. Autism Speaks Chief Science Officer Andy Shih was one of seven individuals invited by the Health Subcommittee Chair Brett Guthrie and Ranking Member Anna Eshoo to testify before the committee. These witnesses provided expertise on the bills their respective organizations have endorsed and translated to Congress the importance of the legislative proposals in serving patients and caregiver communities. See here for more info: https://www.autismspeaks.org/advocacy-news/autism-speaks-chief-science-officer-speaks-congressional-hearing-autism-cares-act

- Autism Speaks CEO Keith Wargo was also invited to provide remarks at a congressional briefing by House Energy & Commerce Chair Cathy McMorris Rodgers for the Congressional Task Force on Down Syndrome briefing to improve employment outcomes for people with disabilities. This briefing took place on March 21, 2024.

- Autism Speaks is proud to announce its 2023 Local Impact Grant recipients. These grants fund nonprofit 501(c)(3) organizations that provide autistic people with social and educational experiences, enhancing their lives today and accelerating a spectrum of solutions. A combined
$115,000 is being distributed to 23 organizations from 13 states to expand their services which is expected to impact an over 4,000 people in the autism community. Their programs will provide education and training, recreation, athletic and community services, young adult and adult services, assistance with sensory equipment and supportive technology and summer camp scholarships. See the complete list of recipients here: https://www.autismspeaks.org/press-release/autism-speaks-awards-115000-grants-23-organizations-serving-autism-community

Simons Foundation
SFARI (Simons Foundation) continues to offer SEED grants (Supplements to Enhance Equity and Diversity). These grants provide supplements to existing SFARI grants for the recruitment of new lab members from American underrepresented minority groups at the postdoctoral levels. Please direct inquiries to: sciencerfa@simonsfoundation.org

Yetta Myrick
DBPNet is pleased to announce the publication of the first peer-reviewed, interprofessional, and community-engaged consensus statement establishing health care standards for youth with neurodevelopmental disabilities. For more information about the initiative and to register for updates, visit: https://safedbp.org/

- Consensus Statement publication in Pediatrics: https://doi.org/10.1542/peds.2023-063809

Community Updates
Association of University Centers on Disabilities (AUCD)
AUCD is pleased to announce that the University Center of Excellence in Development Disabilities Education, Research, and Service (UCEDD) at Oregon Health & Science University (OHSU), in partnership with CommunicationFIRST, has been selected as the recipient of a subaward to create a national partnership to develop an approach and plan to advance peer-support models for augmentative and alternative communication (AAC) users. This partnership consortium will include individuals who need and use AAC in project leadership as well as self-advocacy organizations, individuals from multiply marginalized communities, and others who also have expertise in AAC and speech disability, disability civil rights, and peer support. The outcomes from this first phase of work will include a set of actionable recommendations for the creation of a nationwide resource for developing peer support models that promote and enhance the field of AAC. Visit here for more information: https://www.aucd.org/template/news.cfm?news_id=16672&parent=39&parent_title=AUCD%20Press%20Releases&url=/template/page.cfm?id%3D3D39
Autistic Self Advocacy Network (ASAN)

- ASAN held a webinar in February on COVID-19 and Mpox. The webinar included information on what Mpox and COVID-19 are and how they’re spread, who is most impacted, and how we can keep each other safer. You can find a recording of the webinar here: https://www.youtube.com/watch?v=QmTFMKmWMZY
- ASAN is excited to announce the new Teighlor McGee Grassroots Mini Grants Program. These mini grants will provide up to $5,000 in funding to projects focused on creating change for people with intellectual and developmental disabilities. We will fund up to six projects during this grant cycle. Created in memory of Teighlor McGee’s legacy of empowering grassroots disability work and uplifting self-advocates of color, this program features two different grant categories: The Affiliates In Action Mini Grant and Self-advocates Transforming Equitable Policy (STEP) Mini Grant.
  - ASAN will hold a webinar on April 18 at 1:00 pm ET about the program. Register here: https://us02web.zoom.us/webinar/register/WN_EHGsWWfNQTG3fHfz9CymQ#
  - For more information on the program, visit: https://autisticadvocacy.org/teighlor-mcgee-grassroots-mini-grants/

The Arc of the United States

In the wake of the police killing of Ryan Gainer, a Black autistic teenager, The Arc of the United States and the DOJ’s Office of Community Oriented Policing Services (COPS Office) are announcing a landmark program to protect the lives and futures of people with disabilities. Just Policing—made possible by a $750,000 grant from COPS Office—will provide disability awareness training to police officers across the country. The program, designed to bridge the gap between law enforcement and people with intellectual and developmental disabilities (IDD), aims to address the high rates of victimization and criminalization this community faces often due to a lack of understanding and support. For more information, visit: https://thearc.org/blog/new-police-training-aims-to-bridge-gap-and-build-safety-with-disability-community/