

IACC Round Robin Updates



Federal Agency Updates

Administration for Community Living (ACL)

- U.S. Equal Employment Office Commission (EEOC) Chair Charlotte Burrows issued a statement on October 25, 2021 to commemorate National Disability Employment Awareness month. Ms. Burrows explains the importance of including people with disabilities in the workforce and the work of the EEOC. The full statement is available here: <https://acl.gov/news-and-events/announcements/statement-eEOC-chair-national-disability-employment-awareness-month>
- ACL will receive \$150 million to bolster the public health workforce. This critical funding will go directly towards wages and benefits for direct support professionals within the disability and aging networks. Additional information is available here: <https://acl.gov/news-and-events/announcements/acl-investing-150-million-expand-public-health-workforce-respond>
- ACL funds the Mental Health and Developmental Disabilities (MHDD) National Training Center (<https://www.mhddcenter.org/>), a collaboration between the University Centers for Excellence in Developmental Disabilities at the University of Kentucky, University of Alaska Anchorage, and Utah State University. The MHDD National Training Center work to improve mental health services and supports for people with developmental disabilities. MHDD's Project ECHO is a network with real-time access to a team of experts in the field of mental health and developmental disabilities. The Winter/Spring 2022 webinar series is open for registration and begins on January 20, 2022. Additional information is available in this online flyer: <https://www.mhddcenter.org/wp-content/uploads/2022/01/MHDD-Flyer-Winter-Spring-2022-Final-Accessible.pdf>

Centers for Disease Control and Prevention (CDC)

- CDC recently released two new reports on the prevalence and early identification of autism spectrum disorder in children. The two *MMWR Surveillance Summaries* (titles below) and accompanying *Community Report* can be accessed online: https://www.cdc.gov/ncbddd/autism/new-data.html?s_cid=ncbddd_dhdd_addm21_data_part_2021-12
These data will be described in more detail during a presentation at the January IACC meeting.
- CDC re-contacted 1,029 parents who previously completed the Study to Explore Early Development (SEED) to assess the impact of COVID-19 on the health, behaviors, and

services received by their children, and the impact of the COVID-19 pandemic on families. The data provide a unique resource to inform public health strategies during public health emergencies by providing pre-post measures and comparisons among children with and without developmental disabilities. Preliminary analyses indicate children with ASD are more likely to report delays in general health services and much more likely to report delays in specialty services compared with children with other disabilities or in the general population.

- CDC’s “Learn the Signs. Act Early.” program is celebrating a milestone of its own—having reached over ONE MILLION total downloads of its Milestone Tracker app: <https://www.cdc.gov/ncbddd/actearly/milestones-app.html>
- CDC’s “Learn the Signs. Act Early.” program continues to make strides in promoting the integration of ongoing developmental monitoring (<https://wicworks.fns.usda.gov/resources/learn-signs-act-early>) into Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) visits, despite the COVID-19 pandemic forcing WIC to transition to nearly 100% virtual engagement with families. To date, 19 states have opted to integrate CDC’s Milestone Tracker app into their WICShopper app, facilitating over 560,000 visits to CDC’s app. Since July 2021, over 17,000 WIC clients have completed an online training about developmental milestones that prompts them to complete a checklist for their child. Further, since November, over 287 WIC staff have completed a training for WIC providers about early child development, and a few states have made this a required training. CDC has collaborated with the Association of State Public Health Nutritionists to advance these efforts, and both the U.S. Department of Agriculture’s Food and Nutrition Service and the National WIC Association have been supportive partners. Note: WIC serves about half of all infants in the United States.
- Building off the successful Learn the Signs. Act Early Ambassador (<https://www.cdc.gov/ncbddd/actearly/ambassadors-list.html>) model and through a cooperative agreement with the Association of University Centers on Disabilities, CDC is supporting Children’s Mental Health Champions in 10 states (California, Colorado, Connecticut, Georgia, Kentucky, Maine, Montana, New Mexico, New Hampshire, and South Dakota) and one territory (American Samoa).
 - Children’s Mental Health Champions address the mental health needs of children and families by supporting one or more pillars of this work:
 - Partnerships to address silos in care.
 - Screening, early identification, and referral for care of mental disorders.
 - Prevention of mental disorders, promotion of mental health through resources, and implementation of evidence-based programs.
 - The current pilot projects represent diversity in both target ages and populations served. However, the projects in several states (Georgia, Colorado, New Mexico, and Montana) specifically address the mental health of children with co-occurring autism or developmental disabilities.

- Children’s Mental Health Champions – AUCD's National Center on Disability in Public Health: <https://nationalcenterdph.org/our-focus-areas/wellness-and-mental-health/mental-health-champions/>
- CDC collaborated with the American Academy of Pediatrics to improve delivery of essential health services, such as developmental surveillance, screening, referral, and follow-up, during the COVID-19 pandemic and response. Promising practices were identified and a free PediaLink course describing them was released in December 2021: <https://shop.aap.org/innovative-strategies-for-improving-developmental-surveillance-and-screening/>
- Significant Publications (Since October 2021)
 - DiGuseppi C, Crume T, Van Dyke J, Sabourin KR, Soke GN, Croen LA, Daniels JL, Lee LC, Schieve LA, Windham GC, Friedman S, Robinson Rosenberg C. Peri-Pregnancy Cannabis Use and Autism Spectrum Disorder in the Offspring: Findings from the Study to Explore Early Development. J Autism Dev Disord. 2021 Nov 12. doi: 10.1007/s10803-021-05339-4. Epub ahead of print. PMID: 34767135. <https://pubmed.ncbi.nlm.nih.gov/34767135/>
 - Maenner MJ, Shaw KA, Bakian AV, Bilder DA, Durkin MS, Esler A, Furnier SM, Hallas L, Hall-Lande J, Hudson A, Hughes MM, Patrick M, Pierce K, Poynter JN, Salinas A, Shenouda J, Vehorn A, Warren Z, Constantino JN, DiRienzo M, Fitzgerald RT, Grzybowski A, Spivey MH, Pettygrove S, Zahorodny W, Ali A, Andrews JG, Baroud T, Gutierrez J, Hewitt A, Lee LC, Lopez M, Mancilla KC, McArthur D, Schwenk YD, Washington A, Williams S, Cogswell ME. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill Summ. 2021 Dec 3;70(11):1-16. doi: 10.15585/mmwr.ss7011a1. PMID: 34855725; PMCID: PMC8639024. <https://pubmed.ncbi.nlm.nih.gov/34855725/>
 - Rice CE, Carpenter LA, Morrier MJ, Lord C, DiRienzo M, Boan A, Skowrya C, Fusco A, Baio J, Esler A, Zahorodny W, Hobson N, Mars A, Thurm A, Bishop S, Wiggins LD. Defining in Detail and Evaluating Reliability of DSM-5 Criteria for Autism Spectrum Disorder (ASD) Among Children. J Autism Dev Disord. 2022 Jan 4. doi: 10.1007/s10803-021-05377-y. Epub ahead of print. PMID: 34981308. <https://pubmed.ncbi.nlm.nih.gov/34981308/>
 - Shaw KA, Maenner MJ, Bakian AV, Bilder DA, Durkin MS, Furnier SM, Hughes MM, Patrick M, Pierce K, Salinas A, Shenouda J, Vehorn A, Warren Z, Zahorodny W, Constantino JN, DiRienzo M, Esler A, Fitzgerald RT, Grzybowski A, Hudson A, Spivey MH, Ali A, Andrews JG, Baroud T, Gutierrez J, Hallas L, Hall-Lande J, Hewitt A, Lee LC, Lopez M, Mancilla KC, McArthur D, Pettygrove S, Poynter JN, Schwenk YD, Washington A, Williams S, Cogswell ME. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. MMWR Surveill

- Summ. 2021 Dec 3;70(10):1-14. doi: 10.15585/mmwr.ss7010a1. PMID: 34855727; PMCID: PMC8639027. <https://pubmed.ncbi.nlm.nih.gov/34855727/>
- Shaw KA, McArthur D, Hughes MM, Bakian AV, Lee LC, Pettygrove S, Maenner MJ. Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016. J Am Acad Child Adolesc Psychiatry. 2021 Nov 24:S0890-8567(21)02000-1. doi: 10.1016/j.jaac.2021.11.019. Epub ahead of print. PMID: 34838692. <https://pubmed.ncbi.nlm.nih.gov/34838692/>

Centers for Medicare & Medicaid Services (CMS)

- CMS launched a new “one-stop shop” (<https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html>) on October 21, 2021, for state Medicaid agencies and stakeholders on Medicaid.gov to advance transparency and innovation for home and community-based services. Home and community-based services allow people enrolled in Medicaid to receive services and supports in a preferred setting outside of an institution, such as in their own home. Through this new webpage, state Medicaid agencies and stakeholders can access information about states’ plans to enhance, expand, and strengthen home and community-based services across the country using new Medicaid funding made available by the American Rescue Plan Act of 2021 (ARP).
- On December 7, 2021, CMS released a State Medicaid Director Letter (SMDL) (<https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/smd21004.pdf>) that provides guidance to states on a provision of the Sustaining Excellence in Medicaid Act of 2019 that allows them to adopt special financial methodologies for Medicaid applicants and beneficiaries who need home and community-based services (HCBS). The provision permits states to only apply certain income and/or asset disregards to individuals who need home and community-based services. This authority is currently in effect, and CMS is available to provide technical assistance to any state wishing to adopt the authority.
- CMS is partnering with the Administration for Community Living and the U.S. Department of Housing and Urban Development on a Housing and Services Resource Center (<https://acl.gov/HousingAndServices>) launched in December 2021. The Center was created for people who work in the organizations and systems that provide housing resources and homelessness services, behavioral and mental health services, independent living services and other supportive services, and others who are working to help people live successfully and stably in the community.
- As part of the Biden-Harris Administration’s effort to work with states to promote access to Medicaid services for people with mental health and substance use disorder

(SUD) crises, on December 28th CMS issued a State Health Official (SHO) letter (<https://www.medicaid.gov/federal-policy-guidance/downloads/sho21008.pdf>) on the scope of, and payments for, a new Medicaid state option authorized under President Biden's American Rescue Plan (ARP), to provide coverage for qualifying community-based mobile crisis intervention services. Mobile crisis intervention services are essential tools to meet people in crisis where they are and rapidly provide critical services to people experiencing mental health or substance use crises by connecting them to a behavioral health specialist 24 hours per day, 365 days a year. This new option will help states integrate these services into their Medicaid programs, a critical component in establishing a sustainable and public health-focused support network.

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

- Funding recommendations for the FY2021 ARP have recently been posted to our website: <https://cdmrp.army.mil/arp/awards/awards>
 - Projects include clinical trials, translational and basic science studies, along with several projects being conducted by early career stage independent investigators.
 - The FY2022 program has not been announced as we are under the Continuing Resolution until next month.

Department of Education (ED)

- The Office of Special Education and Rehabilitative Services' (OSERS) Rehabilitation Services Administration (RSA) issued over \$134.9 million to fund programs to support vocational rehabilitation and other employment services for people with disabilities. Information about the new grants can be found here: <https://sites.ed.gov/osers/2021/11/new-rsa-2021-discretionary-grant-awards/>
- RSA also released a new FAQ document for vocational rehabilitation agencies and community rehabilitation providers on what qualifies as competitive integrated employment for people with disabilities. The updated guidance states that integrative employment opportunities must provide at least minimum wage and that compensation must be on par with workers without disabilities doing the same jobs and the jobs must be within the community. The document (RSA-FAQ-22-02) can be downloaded at this link: <https://rsa.ed.gov/sites/default/files/2021-10/RSA-FAQ-22-02.docx>
- OSERS' Office of Special Education Programs (OSEP) awarded \$70.3 million to state and local programs that provide educational services to children and youth with disabilities. Information about these grants is available here: <https://sites.ed.gov/osers/2021/11/new-osep-2021-discretionary-grant-awards/>
- OSERS released two new Q&As to clarify states' and early intervention service providers' obligations under the IDEA Part C during the ongoing pandemic. The Department noted that referrals to early intervention services dropped when the coronavirus emerged and

have not returned to pre-pandemic levels. The two new documents complete OSERS Return to School Roadmap series. Additional information is available here:

<https://sites.ed.gov/idea/new-qas-address-child-find-referral-and-eligibility-and-the-provision-of-early-intervention-services-under-idea-part-c-amidst-the-covid-19-pandemic/>

- ED released a new resource titled *Supporting Child and Student Social, Emotional, Behavioral, and Mental Health* to promote the mental health and social and emotional well-being among children and students. This resource highlights seven key challenges to providing school- or program-based mental health support across early childhood, K-12 schools, and higher education settings, and presents seven corresponding recommendations. The resource can be found here:
<https://www2.ed.gov/documents/students/supporting-child-student-social-emotional-behavioral-mental-health.pdf>

Department of Justice (DOJ)

- BJA, the University of Cincinnati and their partners, established the Academic Training to Inform Police Response Initiative: <https://www.informedpoliceresponses.com/> to (1) raise awareness in the policing community about the nature and needs of people with Behavioral Health (BH) conditions and Intellectual and Developmental Disabilities (IDD); (2) provide training and resources on BH, IDD, and crisis response; and (3) support the use of evidence-informed, best practices in these responses. A handout about the program is available here:
<https://www.theiacp.org/sites/default/files/MHIDD/AT%20Project%20One%20Pager%200508%20Nov%202021%20FINAL.pdf>
- BJA has published a style guide for staff and contractors who produce printed or online content for BJA and BJA grantees and training and technical assistance providers who develop content that will include the BJA logo. It contains guidelines for content related to criminal justice and behavioral health and intellectual and developmental disabilities, including concepts, terminology, and definitions. The style guide is available online at this address: https://iacc.hhs.gov/meetings/iacc-meetings/2022/full-committee-meeting/january19/justice_style_guide_2021.pdf
- Forthcoming Publications:
 - Law Enforcement Response to People with Developmental Disabilities: 4 Steps for Diversion
 - Understand Developmental Disabilities for Criminal Justice Professionals
- Forthcoming Funding Opportunities for FY 2022
 - For more information about forthcoming funding opportunities for FY 2022, please attend the upcoming funding webinar. Please visit this link for information on BJA's website about our upcoming Grant Applicant Education Series: <https://bjaojp.gov/news/grant-applicant-education-series-webinars-announced>. Please feel free to share with partners. Also know that we will

announce program specific applicant webinars once that info becomes available covering all solicitations that support: 1) LE, 2) courts, 3) corrections, and 4) behavioral health.

- The Kevin and Avonte Program supports local jurisdictions' efforts to reduce the number of deaths and injuries of individuals with forms of dementia such as Alzheimer's disease or developmental disabilities such as autism who, due to their condition, wander from safe environments. It provides funding to law enforcement and public safety agencies to implement locative technologies to track missing individuals, and it funds such agencies and partnering nonprofit organizations to develop or operate programs to prevent wandering, increase individuals' safety, and facilitate rescues.
- This program seeks to fund the implementation of transdisciplinary crisis response training to educate, train, and prepare law enforcement officers so that they are equipped to appropriately interact with people who have behavioral health conditions (including mental health and substance use) and intellectual and developmental disabilities (IDD) in the course of completing their job responsibilities. It seeks applications from states, local law enforcement, and correctional entities to plan and implement training, engage in organizational planning to deploy trained officers in times of crisis, and sustain a best practice crisis response program.

Department of Labor (DOL)

- DOL launched an initiative to protect professional caregivers' wages and rights and ensure that industry employers comply with the law. Additional information about the initiative can be found here:
<https://www.dol.gov/newsroom/releases/whd/whd20211123>
- Launched in 2021, DOL's Office of Disability Employment Policy (ODEP)'s project on Research Support Services for Employment of Young Adults on the Autism Spectrum (<https://www.mathematica.org/projects/research-support-services-for-employment-of-young-adults-on-the-autism-spectrum>) will hold listening sessions with key stakeholders, including young adults on the autism spectrum, in the coming months.
- ODEP's Partnership on Inclusive Apprenticeship (PIA) (<https://inclusiveapprenticeship.org/>) has produced 10 episodes of its podcast series (<https://inclusiveapprenticeship.org/resources/apprenticeship-for-all-podcast/>) and released several resource guides for employers and industry intermediaries (<https://inclusiveapprenticeship.org/resources/>); it has also issued resource guides for job seekers on how to become an apprentice (<https://inclusiveapprenticeship.org/becoming-an-apprentice/>), advance careers (<https://inclusiveapprenticeship.org/advancing-your-career-through-inclusive-apprenticeship/>), and disclose disabilities and request accommodations and supports

[\(https://inclusiveapprenticeship.org/disclosing-your-disability-and-requesting-an-accommodation/\)](https://inclusiveapprenticeship.org/disclosing-your-disability-and-requesting-an-accommodation/)).

- ODEP's Employer Assistance and Resource Network on Disability Inclusion (EARN) (<https://askearn.org/>) will host a webinar on February 16, 2022, on Expanding Your Talent Pool: Disability Inclusion in Advanced Manufacturing (<https://askearn.org/event/expanding-your-talent-pool-disability-inclusion-in-advanced-manufacturing>). This webinar will discuss how pre-employment training and community partnerships can help expand talent pipelines; it will also spotlight thriving workers, including people on the autism spectrum and other neurodivergent people.

Department of Housing and Urban Development (HUD)

- HHS and HUD announced the expansion of a partnership established in 2021 to improve access to affordable, accessible housing and the critical services that make community living possible for people with disabilities and older adults. The partners also announced the launch of a national Housing and Services Resource Center (HSRC) as the hub of this coordinated federal effort.
 - Press release: https://www.hud.gov/press/press_releases_media_advisories/HUD_No_21_201
 - Housing and Services Resource Center Website: <https://acl.gov/HousingAndServices>

Environmental Protection Agency (EPA)

- EPA announced Stronger Protections from Lead in Drinking Water: Next Steps for the Lead and Copper Rule. The fact sheet is available: https://www.epa.gov/system/files/documents/2021-12/lcrr-review-fact-sheet_0.pdf
- EPA announced that the Lead and Copper Rule Revisions will go into effect to support near-term development of actions to reduce lead in drinking water.
- At the same time, EPA has released a Federal Register Notice announcing the intent to develop and finalize Lead and Copper rule Improvements prior to October 16, 2024.
 - Here is the press release: <https://www.epa.gov/newsreleases/epa-announces-intent-strengthen-lead-and-copper-regulations-support-proactive-lead>
 - To see additional actions that EPA is taking under the President's action plan, visit: <https://www.whitehouse.gov/briefing-room/statements-releases/2021/12/16/fact-sheet-the-biden-harris-lead-pipe-and-paint-action-plan/>
 - For more information on EPA's Lead and Copper Rule, visit: <https://www.epa.gov/ground-water-and-drinking-water/review-national-primary-drinking-water-regulation-lead-and-copper>.
 - For more information on estimated 2022 Drinking Water State Revolving Fund allotments to remove lead service lines through the Bipartisan Infrastructure Law, visit: www.epa.gov/infrastructure/water-infrastructure-investments

Health Resources and Services Administration (HRSA)

- AIR-P will host a webinar in collaboration with AUCD on January 18th, 2022, at 4pm EST, entitled: Bolstering Autistic College Student's Mental Health and Wellness (https://www.aucd.org/template/event.cfm?event_id=9050&id=379&parent=379). This talk is presented by Brett Ranon Nachman, PhD, a Postdoctoral Research Scholar at NC State Belk Center. Dr. Nachman will discuss findings from his dissertation on how autism-specific college support programs assist students in processing issues related to their mental health.
- HRSA announced two new funding opportunities to help build the evidence base and research infrastructure for children with special health care needs. Applications are due in March 2022 for the "Enhancing Systems of Care for Children with Medical Complexity Demonstration Projects and Coordinating Center" (<https://www.grants.gov/web/grants/view-opportunity.html?oppld=334401> and <https://www.grants.gov/web/grants/view-opportunity.html?oppld=334392>) and April 2022 for the "Children and Youth with Special Health Care Needs Research Network" (<https://www.grants.gov/web/grants/view-opportunity.html?oppld=334381>).

National Institutes of Health (NIH)

- **National Institute of Environmental Health Sciences (NIEHS)**
 - NIEHS supports a broad range of research on how environmental exposures impact human health including how early life exposures influence neurodevelopmental outcomes, such as ASD. NIEHS funded investigators are currently studying the association of a wide range of exposures, such as air pollution and pesticides with the development of autism. NIEHS supported researchers are also investigating the mechanisms by which these exposures contribute to the development of autism and autistic traits, including epigenetics, inflammation, and the microbiome.
 - Dr. Youssef Oulhote, at the University of Massachusetts Amherst, was awarded an NIEHS Outstanding New Environmental Scientist (ONES) R01 to study the interplay between multiple environmental chemical exposures, folate levels, and folate-related genetic polymorphisms and their contribution to autistic traits (1R01ES032552-01: <https://reporter.nih.gov/project-details/10360836>). This research can inform our understanding of the mechanisms contributing to autism and strategies for modifying risks of debilitating aspects. The ONES program (<https://www.niehs.nih.gov/research/supported/training/ones/index.cfm>) is a highly competitive R01 that supports early-stage investigators in launching their independent research career through support of innovative environmental health research and career enhancement.

- **National Institute of Mental Health (NIMH)**
 - **Study Update: Autism Biomarkers Consortium-Clinical Trials**
The Autism Biomarkers Consortium for Clinical Trials (ABC-CT) (<https://fnih.org/our-programs/biomarkers-consortium/autism-biomarkers>), a multi-site study initiated in 2015 to test and refine a set of biomarkers to serve as reliable, objective measures of variation in social impairment in ASD, received NIH funding in Fall 2020 to conduct a second phase of research. The next phase of the project will involve a) a follow-up study of the original cohort to examine the longer-term stability of these biomarker measures, b) administering measures from phase 1 of the study with a new cohort of children to see if the original findings can be replicated and confirmed, and c) conducting a feasibility study of its EEG N170 and eye tracking measures in children ages 3 to 5, both with and without ASD. Overcoming the challenges posed by the ongoing COVID-19 pandemic, the investigators have begun re-contacting and re-assessing participants from phase 1 of the study. The project also continues to make progress on its EEG N170 and eye tracking measures which were both accepted as ASD biomarkers for the FDA Biomarker Qualification Program (<https://www.fda.gov/drugs/drug-development-tool-ddt-qualification-programs/biomarker-qualification-program>).
 - **NIH Autism Centers of Excellence (ACE)**
Grant applications for the next phase of the Autism Centers of Excellence (ACE) Program, a trans-NIH initiative that supports large-scale studies on ASD, were received in November of last year. There was a very robust response to both the Center (P50) and Network (R01) requests for applications. Scientific Review Officers from the NIH Center for Scientific Review (CSR) are currently planning the peer review panels for early Spring. Institutes that fund ACE Centers are the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), National Institute of Environmental Health Sciences (NIEHS), National Institute of Mental Health (NIMH), and National Institute of Neurological Disorders and Stroke (NINDS).
 - **NIH Crisis Intervention Research in ASD**
For individuals on the autism spectrum, the difficulties of dealing with the COVID pandemic and the daily adjustments needed to stay safe and healthy can present added stresses and strains which can increase the risk for experiencing unanticipated medical and/or mental health crises. NIMH has funded a number of research projects that have studied crisis intervention efforts aimed at helping individuals with ASD and their families. One such study used a retrospective, longitudinal design to examine the Emergency Department (ED) experiences and of individuals with and without ASD who sought care for suicidal ideation or suicidal behavior (1R21MH125262-01: <https://reporter.nih.gov/project->

[details/10302533](#)). The study also utilized nationwide medical claims records from over 100 million publicly and privately insured individuals. The researchers also conducted interviews with key stakeholders about ways to improve ED-based suicide prevention practices and increase post-ED mental health treatment engagement for individuals with ASD, in order to better understand critical points of prevention and intervention for suicidal individuals with ASD.

Another study is seeking to develop a behavioral intervention to improve social function and health outcomes and decrease victimization risk for young adults with ASD (1R03MH113966-01A1: <https://reporter.nih.gov/project-details/9528771>). Some key goals of the study are to determine the social cognitive factors that individuals with ASD need to appropriately access and assess information about adult relationships and intimate behaviors and to conduct a needs assessment of the goals and preferences for an intervention program geared toward independent functioning and reduction of victimization risks, gathered through input from with young adults on the spectrum, their parents, and education, health, and social service providers. In addition, the study team developed an initial treatment manual that integrates critical stakeholder perspectives and goals with evidence-based information about methods and content.

A third project examined the epidemiologic patterns of injuries treated at emergency departments and hospitals in children with ASD, across different stages of development (1R21HD098522-01A1: <https://reporter.nih.gov/project-details/9891178>). Using data from a nationwide database of Emergency Departments, the study examined the time trends of injuries among individuals with ASD (ages 0-20 years old) in hospitals and Eds; characterized the patterns of treated injuries according to injury mechanism, intent, severity, and other demographic characteristics; and assess the excess risk of injuries. Findings from the study can help inform preventive strategies and facilitate the development of effective interventions to reduce injuries in children with ASD.

- **Telemedicine Tools for ASD Diagnoses/TAP (Tele-ASD-PEDS)**

During the past 3 years, NIMH has funded 3 sequentially staged studies focused on the development and validation of tele-assessment tools to detect autism in young children. The first study tested and validated a tele-assessment tool “the TAP” for virtual use in clinics with young toddlers (ages 18-36 months). Findings yielded high levels of diagnostic agreement of autism compared to the blinded comprehensive evaluation with gold standard measures. The second study expanded the scope of the previous study by testing the tele-assessment TAP tool for in-home use with toddlers – with the TAP activities being delivered by parents and guided remotely by clinicians. This study was funded in 2021 and is

ongoing. A third study funded in 2022 will develop and validate a modified TAP tool for in-home use focused on an older cohort of pre-school children (ages 36-72 months). Together, these three studies will provide the needed scientific foundation that will lead to future virtual implementation of two psychometrically sound tele-assessment tools for early autism detection that can be delivered by clinicians in both clinics and in-home use with toddlers and preschool children.

- **Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities**

While early autism detection and intervention among young children is considered crucial, research suggests that several groups of children – the poor, racial and ethnic minorities, and non-English speakers – are more likely to be diagnosed with autism spectrum disorder (ASD) later in life.

A new study published in JAMA Pediatrics (cited below) found that a multistage screening protocol for autism correctly diagnosed these children with autism at a younger age, and increased the number of boys diagnosed with the condition, especially Spanish speakers. The research was supported by NIMH and conducted by Drs. Alice Carter from the University of Massachusetts Boston and R. Christopher Sheldrick from Boston University.

This study tested the implementation of a multistage screening intervention in Massachusetts at three Early Intervention (EI) programs, which provided autism screening to children who are referred by pediatricians or parents. Overall, 33,326 children aged 14-36 months were assessed by EI providers. Researchers found that diagnoses of ASD were more common in the intervention sites vs. comparison sites and noted that these children experienced higher levels of poverty (66.9%), were more likely to be Black (30.7%), Spanish speakers (28.9%), and male (64%).

ASD multistage screening in EI was associated with a 60% increase in ASD diagnoses compared with standard care. Furthermore, improvements were greater among Spanish-speaking families compared with English-speaking families. Overall, multistage screening for autism in EI may improve early ASD detection and reduce in health disparities.

Sheldrick RC, Carter AS, Eisenhower A, Mackie TI, Cole MB, Hoch N, Brunt S, Pedraza FM. Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities. JAMA Pediatr. 2022 Jan 4. doi: 10.1001/jamapediatrics.2021.5380. Epub ahead of print. PMID: 34982099. <https://pubmed.ncbi.nlm.nih.gov/34982099/>

- **National Institute on Deafness and Other Communication Disorders (NIDCD)**
 - NIDCD remains actively involved in trans-NIH issues related to autism, including the Autism Coordinating Committee and planning of the Autism Centers of Excellence program. A priority area related to autism remains research involving minimally verbal individuals, and we are exploring possible ways to address and increase such research.

Social Security Administration (SSA)

- SSA has announced it will include a 5.9% cost-of-living adjustment for benefit recipients beginning either December 2021 or January 2022, depending on the type of benefits received. More information is available at this link:
<https://www.ssa.gov/news/press/releases/2021/#10-2021-2>
- **The Social Security Administration (SSA) is excited to announce the release of a new book: Nichols, Austin, Jeffrey Hemmeter, and Debra Goetz Engler, eds. 2021. Lessons from SSA Demonstrations for Disability Policy and Future Research. Rockville, MD: Abt Press.**
This volume compiles papers and discussion by over 30 leading disability and social policy researchers and experts originally presented at a “State of the Science Meeting” held on June 15, 2021, and synthesizes lessons about which policies, programs, and other operational decisions could provide effective supports for disability beneficiaries and recipients who want to work. The book is available for free download using the following link
https://www.ssa.gov/disabilityresearch/demonstrations/documents/SSALessons_Final.pdf, and available in hardcopy form at online booksellers (at cost--no profit is made by purchasing the book).
- **The application period for the ARDRAW Small Grant Program has opened. Applications are due by Friday, February 25, 2022.**
The Social Security Administration’s (SSA’s) Analyzing Relationships between Disability, Rehabilitation and Work (ARDRAW) Small Grant Program is a one-year \$10,000 stipend program awarded to graduate-level students to conduct supervised independent research designed to foster new analysis of work, rehabilitation, and disability issues, which may develop innovative and fresh perspectives on disability. ARDRAW focuses on research relevant to SSA’s work incentives and employment supports – specifically rehabilitation, work, and the disability program. For more information, please visit <https://ardraw.policyresearchinc.org/>
- **Social Security Administration (SSA) staff, in collaboration with Mathematica, released the following paper: *Changing Stays? Duration of Supplemental Security Income Participation by First-Time Child Awardees and the Role of Continuing Disability Reviews.***

This article provides new evidence of the changing role of the Supplemental Security Income (SSI) program for low-income children, including children on the autism spectrum, since 1997. The authors use administrative records from the Social Security Administration to identify new SSI awardees and track their histories in SSI and in the Social Security Disability Insurance program. The full report can be found at <https://www.ssa.gov/policy/docs/ssb/v81n2/v81n2p17.html>

Substance Abuse and Mental Health Services Administration (SAMHSA)

- The Interdepartmental Substance Use Disorders Coordinating Committee (ISUDCC) met in December 2021. Additional information about the ISUDCC is available online: <https://www.samhsa.gov/about-us/advisory-councils/isudcc>
- SAMHSA’s Mental Health Technology Transfer Center Network holds trainings that may be relevant to some members of the autism community. Information about these trainings is available here: <https://mhttcnetwork.org/centers/global-mhffc/training-and-events-calendar>
- The Supplemental Security Income (SSI)/SAMHSA’s Social Security Disability Insurance (SSDI) Outreach, Access, and Recovery (SOAR) program is “designed to increase access to Social Security Administration (SSA) disability benefits, Supplemental Security Income and Social Security Disability Insurance (SSI/SSDI), for eligible adults who are experiencing or at risk of homelessness and have a mental illness, medical impairment, and/or a co-occurring substance use disorder.” Information is available online: <https://soarworks.samhsa.gov/>
- SAMHSA also works with the HHS Office of Civil Rights and others to support implementation following the Supreme Court’s 1999 ruling in Olmstead that persons with disabilities, including mental health conditions and substance use disorders, should be able to live in the most integrated community settings feasible. More information is provided in the links below:
 - <https://www.hhs.gov/civil-rights/for-providers/compliance-enforcement/examples/olmstead/index.html>
 - <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>
- SAMHSA also periodically develops publications focused on disabilities (see e.g., Mental and Substance Use Disorder Treatment for People With Physical and Cognitive Disabilities, 2016, https://store.samhsa.gov/sites/default/files/d7/priv/pep19-02-00-002_508_022620.pdf).
- SAMHSA supports the Disaster Technical Assistance Center which helps ensure behavioral health for first responders and members of the public is addressed during disasters and emergencies (<https://www.samhsa.gov/dtac>). As well, SAMHSA supports the disaster distress hotline for people to seek behavioral health care during and following emergencies (<https://www.samhsa.gov/find-help/disaster-distress-helpline>).

- The Protection & Advocacy for Individuals with Mental Illness Program (PAIMI; <https://www.samhsa.gov/paimi-program>) is a SAMHSA grant program that supports legal advocacy for persons with serious mental illness, generally in institutional settings (such as reducing the use of restraints and seclusion). PAIMI is one part of the federally supported protection and advocacy system that also includes programs to support Protection and Advocacy for Individuals with Developmental Disabilities (<https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>), the Protection and Advocacy of Individual Rights Program (<https://rsa.ed.gov/about/programs/protection-and-advocacy-of-individual-rights>), the Client Assistance Program (<https://rsa.ed.gov/about/programs/client-assistance-program>), and other protection and advocacy efforts.
- SSI/SSDI Outreach, Access, and Recovery (SOAR, <https://www.samhsa.gov/homelessness-programs-resources/grant-programs-services/soar>) is a joint SAMHSA/SSA program that has been phenomenally successful in training providers who work with SMI individual on how to fill out the SSA forms for disability. This program focuses on ensuring that providers understand the meaning of the terms as defined by SSA so that application forms can be filled out properly. This program has been extremely successful in helping applicants file successful applications and not be denied access to SSI/SSDI benefits.

Public Member Updates

Autism Science Foundation (ASF)

- Save the date! Our 2022 Day of Learning will be March 20th, 2022. You can view the list of speakers here: <https://autismsciencefoundation.org/day-of-learning-evening-of-celebration/day-of-learning/2022-2/>. Stay tuned for registration details.
- ASF received our annual pre-, post-doctoral fellowship submissions as well as applications for the new post-undergraduate mechanism. We are reviewing them and look forward to announcing the recipients before the next IACC meeting.
- We also started the “Next Gen Siblings” study, which aims to investigate the early signs and features of ASD in children born to undiagnosed siblings of autistic people. Studies have shown there is an increased likelihood of a diagnosis, but little is known about the early signs, and even the specific questions families are interested in. The first phase will involve interviews with siblings to better understand their questions, concerns, and priorities for research.
- ASF published a year end summary of research. While it does not cover everything that happened in 2021, it highlights many issues of importance that the IACC has identified. You can read it here: <https://autismsciencefoundation.wordpress.com/2021/12/16/the-year-in-review-2021/>

Simons Foundation Autism Research Initiative (SFARI)

- To address DEI in the community of autism scientists, SFARI continues to offer SEED (Supplement to Enhance Equity and Diversity) grants, which provide up to \$100,000/year for 3 years, for the recruitment of post-doctoral lab members from American under-represented minority groups. <https://www.sfari.org/grant/sfari-seed-rfa/>
- To address historic disparities in the participation of Black or African American autistic subjects in research, SFARI continues to offer grants to support incentive payments to Black or African American autistic study subjects, in studies that focus strongly on this group. <https://www.sfari.org/grant/spark-research-match-diversity-equity-and-inclusivity-request-for-applications/>
- SFARI's funding highlights for 2021 included new focuses on sex differences in autism, human cognitive and behavioral research on autism, and research on the potential influence of maternal COVID-19 infection on the development of autism in children born from those pregnancies.