

# IACC Round Robin Updates



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## **FEDERAL AGENCY UPDATES**

### **Centers for Disease Control and Prevention (CDC)**

- CDC is reviewing applications submitted in response to the Notice of Funding Opportunity “Enhancing Public Health Surveillance of Autism Spectrum Disorder through the Autism and Developmental Disabilities (ADDM) Network”. The goal of the ADDM Network is to provide estimates of the prevalence and characteristics of children with autism spectrum disorder (ASD), monitor disparities by race/ethnicity and socioeconomic status, provide data to inform planning for resource and service needs, and foster activities to increase ASD awareness and reduce barriers to ASD identification. Funding will be offered through two components: one focused on activities among 4-year-old and 8-year-old children and the other focused on activities among 16-year-old children. This will be the sixth funding cycle for ADDM Network activities; the new funding cycle will begin in January 2023.
- CDC has received data from surveillance year 2022 and will publish prevalence and early identification findings in spring 2023.
- CDC and the Study to Explore Early Develop (SEED) sites are preparing the SEED Follow-up Study to better understand the development of ASD as children become adolescents and young adults. Families of children who previously participated in SEED Phases 1, 2, and 3 (when they were 2-5 years of age) will be contacted beginning in 2023 when they are 8-21 years of age. The Follow-up Study will include a number of important topics, such as healthcare needs and utilization, community and social supports, bullying and discrimination, safety and risk of suicide, everyday living skills, transition from high school, employment and vocational training, quality of life and interpersonal relationships, and family and financial support needs.
- CDC has been conducting analyses of data from more than 1,000 participants (including children with ASD, other developmental disabilities, and population control children) from SEED who were recontacted during the COVID-19 pandemic to assess changes in their health, behaviors, and services received. Additional ongoing analyses will address changes during the pandemic in daily living skills and behavior problems, factors associated with childhood resiliency, response to mitigation strategies and infection among children, and parental mental health.
- CDC’s *Learn the Signs. Act Early.* program recently selected a new cohort of 58 Act Early Ambassadors. The 2022-2024 cohort includes 44 returning Ambassadors and 14 new Ambassadors and represents 47 states and the District of Columbia (including two Ambassadors each in California, Florida, Illinois, Louisiana, New York, and Texas), three territories (Guam, Northern Mariana Islands, and Puerto Rico), and one Freely Associated State (Federated States of Micronesia). The Ambassadors gathered in Atlanta on September 13-14 for orientation and training. CDC looks forward to continuing to support Ambassador efforts to increase family-engaged developmental monitoring and other activities to improve early identification of ASD and other developmental disabilities.

- CDC and other members affiliated with the *Learn the Signs. Act Early.* program have articles describing the new Milestones in the September issues of the *Zero to Three Journal* (available here: <https://www.zerotothree.org/resources/zero-to-three-journal/>), including: Abercrombie, J. Wiggins, L., Green, K.K. CDC’s “Learn the Signs. Act Early.”: Developmental Milestone Resources to Improve Early Identification of Children With Developmental Delays, Disorders, and Disabilities.
- The *Learn the Signs. Act Early.* webpage at <https://www.cdc.gov/ncbddd/actearly/milestones/index.html> has important key points to help answer questions related to the revisions to the developmental milestones checklists: <https://www.cdc.gov/ncbddd/actearly/about.html#points>

### **Centers for Medicare & Medicaid Services (CMS)**

- On August 1, 2022, the U.S. Department of Health and Human Services (HHS), through CMS, released guidance on a new Medicaid health home benefit for children with medically complex conditions. This new optional benefit helps state Medicaid programs provide Medicaid-eligible children who have medically complex conditions with person-centered care management, care coordination, and patient and family support. CMS anticipates that the new benefit will help these children receive the care they need, including across state lines. Children with medically complex conditions – including serious health concerns like cerebral palsy, cystic fibrosis, blood diseases, and mental health conditions that can severely impact a child’s ability to function – often require tremendous care coordination and highly specialized treatment. Finding needed services often requires traveling well beyond a family’s home, and often care is only available for these children out-of-state. The new health home services are expected to give these children and their families help in coordinating and managing care. The guidance can be found here: <https://www.medicaid.gov/federal-policy-guidance/downloads/smd22004.pdf>
- On August 18, 2022, HHS, through CMS, announced three key actions to strengthen and expand access to high-quality, comprehensive health care for children across the country. These actions are part of HHS’s ongoing efforts (<https://www.hhs.gov/about/news/2022/05/03/fact-sheet-celebrating-mental-health-awareness-month-2022.html>) to support President Biden’s call to address the nation’s mental health crisis, including its impact on children.
  - Leveraging Medicaid, CHIP, and Other Federal Programs in the Delivery of Behavioral Health Services for Children and Youth. In this guidance document to states, CMS is reinforcing Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) statutory mandates for children’s health coverage, in particular mental health coverage. The EPSDT benefit is a requirement for all states and provides comprehensive and preventive health care services, including mental health services, for most children under age 21 who are enrolled in Medicaid. CMS is urging state agencies and stakeholders to use every possible tool offered by Medicaid and CHIP, alone or in tandem with funding

from other federal programs, to provide high-quality behavioral health services to eligible children and youth. The guidance includes strategies to improve prevention, early identification, and treatment; expand provider capacity; and increase the integration of behavioral health and primary care. This guidance represents one of the many steps CMS will take to strengthen behavioral health services for children in the Medicaid program. The guidance document is available here: <https://www.medicaid.gov/federal-policy-guidance/downloads/bhccib08182022.pdf>

- School-based Health Services in Medicaid: Funding, Documentation, and Expanding Services. In this guidance document to states, CMS is prompting states to work with schools to deliver on-site health care services to children enrolled in the Medicaid program – covering nine essential policy areas related to benefits and payment. Providing essential health care in schools, including mental health services, better positions providers to reach children and youth where they are to get them the care they need. Medicaid covers many services that may be provided through schools, including immunizations, health screenings, oral health care, substance use disorder treatment, and mental health care. This guidance represents one of several steps CMS is taking to support access to Medicaid school-based health services – including actions it will take to implement provisions of the Bipartisan Safer Communities Act – and to promote the availability of Medicaid-covered services, including mental health treatment, in schools. The guidance document can be found here: <https://www.medicaid.gov/federal-policy-guidance/downloads/sbscib081820222.pdf>
- The Mandatory Medicaid and CHIP Core Set Reporting Proposed Rule. This proposed rule, which includes a Core Set of Children’s Health Care Quality Measures for Medicaid and CHIP, details proposed mandatory reporting requirements that would standardize quality measures across Medicaid and CHIP for children nationally – helping to promote health equity and strengthen the quality of Medicaid and CHIP services across the country. The Child and Adult Core Sets include a range of measures key to determining how well Medicaid and CHIP meet their mission of providing affordable, high-quality, person-centered health care coverage to low-income people, including children and families. The proposed rule will mandate reporting of the Core Set for children, and behavioral health quality measures for adults. In doing so, the Core Set can help CMS and stakeholders evaluate Medicaid and CHIP across the 54 programs run by states and territories. Specifically, the mandatory Core Sets would evaluate how Medicaid and CHIP coverage is meeting the needs of individuals and communities, including where health disparities persist, and how the quality of care can be improved. This proposed rule would also mandate national reporting of behavioral health metrics for adults, and details quality metrics for the Medicaid “health home” model. The proposed rule is available on the

Federal Register:

<https://www.federalregister.gov/documents/2022/08/22/2022-17810/medicaid-program-and-chip-mandatory-medicaid-and-childrens-health-insurance-program-chip-core-set>

- The 2022 National Strategy to Support Family Caregivers was delivered to Congress and posted by the Administration for Community Living (ACL) on September 21, 2022: <https://acl.gov/CaregiverStrategy>. The Strategy includes nearly 350 actions the federal government, including CMS, will take to support family caregivers in the coming year and more than 150 actions that can be adopted at other levels of government and across the private sector to begin to build a system that ensures family caregivers – who provide the overwhelming majority of long-term care in the United States – have the resources they need to maintain their own health, well-being, and financial security while providing crucial support for others. The strategy was developed jointly by the advisory councils established by the Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (<https://acl.gov/sites/default/files/about-acl/2018-10/PLAW-115publ119%20-%20RAISE.pdf>) and the Supporting Grandparents Raising Grandchildren (SGRG) Act (<https://acl.gov/programs/support-caregivers/supporting-grandparents-raising-grandchildren-0>), with extensive input from family caregivers, the people they support, and other stakeholders. CMS is a member of the RAISE Family Caregiving Advisory Council.

#### Department of Education (ED)

- New OSEP 2022 Discretionary Grant Awards – In fiscal year 2022, ED’s Office of Special Education and Rehabilitative Services (OSERS) Office of Special Education Programs (OSEP) provided over \$101 million to fund new programs that help educate children and youth with disabilities to assist states and local districts to improve results for infants, toddlers, children, and youth with disabilities ages birth through 21. The list of all funded programs can be found here: <https://sites.ed.gov/osers/2022/09/new-osep-2022-discretionary-grant-awards/>
- The New Rhonda Weiss National Technical Assistance Center to Improve State Capacity to Collect, Report, Analyze, and Use Accurate IDEA Data in Accessible Formats
  - **Purpose:** The Rhonda Weiss Center for Accessible IDEA Data focuses on providing necessary supports to improve dynamic accessibility options for IDEA Data nationally. This center will increase the overall awareness, understanding, knowledge base, tools, and resources available to IDEA Data stakeholders in the area of equitable accessibility. The expected outcomes of the Center include increased equitable access to data by those with blindness, visual impairments, motor impairments, and intellectual disabilities as well as an increased knowledge among state staff to apply practices and processes to make data more accessible.
  - **Abstract:** The Center will be led by co-directors, an expert in IDEA data and an expert in accessibility. The directors will manage leads in accessibility, technical

assistance, technology, dissemination and communication, and evaluation. The primary activities of the Center include developing and implementing an open license, accessible software program to make data more accessible to individuals with disabilities. In addition, the Center will create tools and products and provide technical assistance to develop state capacity to make IDEA 616 and 618 data more accessible.

- New Guidance Helps Schools Support Students with Disabilities and Avoid Discriminatory Use of Discipline: <https://www.ed.gov/news/press-releases/new-guidance-helps-schools-support-students-disabilities-and-avoid-discriminatory-use-discipline>
  - New guidance released from ED’s Office for Civil Rights (OCR) and OSERS helps public elementary and secondary schools fulfill their responsibilities to meet the needs of students with disabilities and avoid the discriminatory use of student discipline.
  - These newly released resources are the most comprehensive guidance on the civil rights of students with disabilities concerning student discipline and build on the Department’s continued efforts to support students and schools through pandemic recovery.
- New Grants with an ASD Concentration
  - Project SMART: Equipping Low-Incidence Scholars for Service, Mentoring, Advocacy, Research & Teaching – Vanderbilt University
  - Low-Incidence Interdisciplinary Scholars Building Reading Opportunities for Social-Emotional Resilience – Portland State University
- OSEP monitors states’ compliance with the Individuals with Disabilities Education Act (IDEA) to ensure that states provide early intervention services for infants and toddlers with disabilities and the free appropriate public education (FAPE) of children with disabilities. ED and OSEP are seeking comments by October 31, 2023, to examine how the 2023 determinations process can promote equity, particularly whether and how to use data from the current State Performance Plan/Annual Performance Report that can be seen in the Part B and Part C measurement table, data from the current IDEA 618 data collections, and other publicly available data. Additional information on how to submit feedback is available here: <https://sites.ed.gov/idea/office-of-special-education-programs-seeking-input-prioritizing-equity/>

#### **Department of Housing and Urban Development (HUD)**

- In March 2022, HUD awarded FY 2021 Continuum of Care Program grants totaling \$1.749 billion to 4,056 permanent supportive housing projects, totaling 66.1% of all competition funding, assisting individuals with disabilities exit homelessness and achieve housing stability. Additional details are available here: [https://www.hud.gov/press/press\\_releases\\_media\\_advisories/HUD\\_No\\_22\\_121](https://www.hud.gov/press/press_releases_media_advisories/HUD_No_22_121)

- In July 2022, HUD awarded over \$36 million in mainstream vouchers and fees to support community living for people with disabilities. More information can be found here: [https://www.hud.gov/press/press\\_releases\\_media\\_advisories/HUD\\_No\\_22\\_138](https://www.hud.gov/press/press_releases_media_advisories/HUD_No_22_138)
- Since April 2021, HUD, alongside HHS, has provided technical assistance to help public housing agencies (PHAs) that administer Mainstream Vouchers for non-elderly persons with disabilities to strengthen their partnerships with state agencies that assist persons with disabilities to transition from institutional settings to the community. More details are included here: [https://www.hud.gov/press/press\\_releases\\_media\\_advisories/HUD\\_No\\_22\\_121](https://www.hud.gov/press/press_releases_media_advisories/HUD_No_22_121)

### **Department of Justice (DOJ)**

- The DOJ's Civil Rights Division recently updated its webpage on Combating Improper Seclusion in Schools. The webpage includes information on what seclusion is, DOJ's efforts to combat improper seclusion, how to report cases of improper seclusion, and additional resources: <https://www.justice.gov/schoolseclusion>
- The *Exploring Locative Technology: What You Need to Know to Address Wandering* webinar includes perspectives from law enforcement, family members, and disability advocates about locative technology as a strategy to address wandering by individuals with intellectual or developmental disabilities. The advantages and disadvantages of locative technology and possible alternatives are also explored. Webinar can be accessed [here](#).

### **National Institutes of Health (NIH)**

#### **NIH Awards \$100 Million for Autism Centers of Excellence Program**

- The National Institutes of Health (NIH) [awarded a total of \\$100 million](#) over the next five years to support nine Autism Centers of Excellence (ACEs). Each ACE will include a Plan for Enhancing Diverse Perspectives (PEDP), which outlines strategies to increase the participation of women and people from underrepresented groups. Additionally, each ACE will have an advisory board that includes autistic people and/or parents of individuals with autism. The *Eunice Kennedy Shriver* National Institute of Child Health and Development also issued a [press release](#).

### **National Institute of Mental Health (NIMH)**

- Research evidence has consistently shown that providing access to services and treatments as early as possible can lead to significant improvements in developmental outcomes among young children diagnosed with autism spectrum disorder (ASD). However, inequalities associated with differences in socioeconomic status, as well as race and ethnicity, contribute to disparities in accessing early ASD diagnoses and vital services and treatment interventions. Drawing on data from an NIMH-funded study as part of the ASD Pediatric, Early Detection, Engagement and Services Research (PEDS) Network, researchers published finding which showed how incorporating a multi-stage screening process for ASD in federally funded services may reduce disparities in early ASD diagnoses. In partnership with the Massachusetts Department of Public Health, the

researchers implemented a three-stage screening procedure system at three early intervention sites in Boston. In the first stage, early intervention specialists administered two screening questionnaires that assessed children's social and emotional development and autism symptoms. In the second stage, the specialists administered an observational ASD screening tool designed for young children. If a child had positive screening scores or the specialist or family expressed concerns about ASD, the family continued to the third stage which included a comprehensive ASD evaluation by a licensed psychologist. Implementation of the multi-stage screening process in three study sites showed an increased rate of ASD diagnosis (i.e., an additional 8.1 ASD diagnoses per 1,000 children per study quarter). Additionally, data showed an increase in diagnoses among Spanish-speaking families (15.4 additional ASD diagnoses per 1,000 children per study quarter), which was more than double the increase observed among non-Spanish-speaking families (6.9 additional ASD diagnoses per 1,000 children per study quarter).

- Research Highlights: <https://www.nimh.nih.gov/news/research-highlights/2022/multistage-autism-screening-in-early-intervention-settings-may-reduce-disparities>
- Reference Paper: PMID 34982099; <https://pubmed.ncbi.nlm.nih.gov/34982099/>
- Despite the significant advances made in developing standardized assessment tools to screen and diagnose children with autism, recent research has also highlighted how the diagnostic validity of the most commonly used instruments vary as a function of child characteristics (e.g., biological sex, language level, cognitive ability, behavior problems). To address this important issue, a recently awarded NIMH grant to Dr. Somer Bishop at the University of California, San Francisco will utilize assessments from over 17,500 children to optimize use of standardized instruments, either alone or in combination, for determining autism (ASD) diagnosis in specific subgroups of children using quantitative measures and machine learning algorithms. The investigators will test questions about what diagnostic and screening tools, or combination of tools, works best for identifying ASD in subgroups of children. The newly funded study has the potential to significantly help individualize the diagnostic process for gains in both research and clinical settings and could lead to a more tailored and accurate approach to diagnosis of autism in children. (1R01MH128288-01A1: <https://reporter.nih.gov/project-details/10522317>)

### **Social Security Administration (SSA)**

- The Social Security Administration now offers people the choice to self-select their sex on their Social Security number (SSN) record. The agency has implemented this policy change and the new option is now available. For more information, please visit [www.ssa.gov/news/news/press/releases/2022/#10-2022-3](http://www.ssa.gov/news/news/press/releases/2022/#10-2022-3)
- Approximately 70 million Americans who receive monthly Social Security and/or Supplemental Security Income (SSI) benefits will see an 8.7% cost-of-living adjustment (COLA) for 2023. The COLA takes effect with SSI payments paid on December 30, 2022, and Social Security benefits paid in January 2023. Many beneficiaries may want to find out exactly what their new benefit amount will be. The fastest way is through their *my*

**Social Security** account. In early December, customers can log in to their **my Social Security** account and check the Message Center. For beneficiaries who do not have a **my Social Security** account, they will need to create their account by November 15 to see their notice online. Beneficiaries can also opt to receive a text or email alert when there is a new message from us – such as their COLA notice – rather than receiving a letter in the mail. The Social Security Act ties the annual COLA to the increase in the Consumer Price Index (CPI-W), as determined by the Department of Labor’s Bureau of Labor Statistics. You can learn more about the new COLA at [www.ssa.gov/cola](http://www.ssa.gov/cola).

- There is still time to claim your 2021 Child Tax Credit! Thanks to the American Rescue Plan, the Child Tax Credit was increased and expanded for 2021. Most families are eligible to receive the credit for their children. For families with qualifying children who did not turn 18 before the start of this year, the 2021 Child Tax Credit is worth \$3,000 to \$3,600 per child, depending on their age. Visit the SSA blog at <https://blog.ssa.gov/theres-still-time-claim-your-2021-child-tax-credit/> for more information. Get the money your family deserves by filing for the credit right away.

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

- SAMHSA supported two recent articles on persons with intellectual and developmental disabilities in the mental health system:
  - Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations: <https://pubmed.ncbi.nlm.nih.gov/34346730/>
  - Persons With Intellectual and Developmental Disabilities in the Mental Health System: Part 2. Policy and Systems Considerations: <https://pubmed.ncbi.nlm.nih.gov/34346727/>
- The Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) will be meeting virtually on October 28<sup>th</sup>, from 10:00 am to 4:30 pm. Information on attending can be found at this address: <https://snacregister.samhsa.gov/>

### **PUBLIC MEMBER UPDATES**

#### **Autism Science Foundation (ASF)**

- ASF released an RFA to generate proposals for improving inclusion of individuals with autism with minimal verbal ability, cognitive disability, and severe and challenging behaviors into research studies. This group is often excluded from science because of logistical reasons and measurement challenges, and this RFA will be focused on ways to improve research around this group and creating infrastructure and tools to do this for future studies. More information on this RFA is available here: <https://autismsciencefoundation.org/apply-for-a-profound-autism-pilot-grant/>
- ASF also recently launched a Participate in Research dashboard. Problems in recruitment for autism research has always been challenging, leading to underpowered research and delays in finding answers for families. Since the age of the Interactive

Autism Network, there has not been a place where the entire community can search for studies that may be of interest to them or they be eligible to participate. We now have that system, under the “Participate in Research” page on the ASF website. You can enter in the age of yourself, child, your relation to autism, where you live, or just scientific areas that you are interested in participating. Virtual and online studies are also included so you can participate from your home. We encourage the community to go to the site: <https://autismsciencefoundation.org/participate-in-research/>

- The Consortium for Autism, Neurodevelopmental Disorders and Digestive Disorders presented a two-day set of presentations around the range of issues that people with autism experience with their GI system and, most importantly, testimonials from families about how they have impacted the quality of life of their child. We also heard from clinicians who talked about procedures done to diagnose these problems and why they need to be changed, adapted, and then validated. In fact, we also learned that the interview/question and answers need to be improved as well. All of the presentations are now online, including the survey of over 600 families: <https://www.candidgi.com/>

#### **Simons Foundation Autism Research Initiative (SFARI)**

- SFARI’s SEED program promotes diversity in the community of autism scientists by offering post-doctoral funding to American underrepresented minority scientists. This and other SFARI funding opportunities are detailed at: <https://www.sfari.org/funding-opportunities/>

#### **Yetta Myrick**

- New Developmental Milestone Book Created to Support Black and African American Families: The annual block party in Mr. Marshall's Neighborhood is underway! Everyone in the neighborhood is pitching in, even the children Mr. Marshall has watched grow over the years. Follow Mr. Marshall and his community as they prepare for the biggest celebration of the year! ***Mr. Marshall's Block Party*** was co-written by Yetta Myrick, (Centers for Disease Control and Prevention’s (CDC) Act Early Ambassador to the District of Columbia), and Morgan Cruise with illustrations by Jennifer Price Davis for [Act Early DC](#), the District of Columbia's local campaign of the national CDC’s ["Learn the Signs. Act Early."](#) Program, to support Black and African American families in monitoring their child's development. Act Early DC, a project of DC Autism Parents in partnership with the DC Developmental Disabilities Council, is funded by the CDC through the Association of University Centers on Disabilities. Act Early DC aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. Download [Mr. Marshall's Block Party E-Book!](#) Check out this short interview about the book: [Mr. Marshall's Block Party Interview](#)
- Community Autism Research Ambassador Program: Family Voices, in partnership with a dynamic group of stakeholders, conducted a two-day Community Autism Research Ambassador Program (ARAP), which engaged African American autistic self-advocates and families of children with autism. During the convenings, stakeholders provided critical information to guide the development of a research agenda for the African

American autism community. The findings from the convenings indicate the need to focus on life after diagnosis and integration into the community across the lifespan. Furthermore, additional information is needed to understand the unique experiences of self-diagnosed autistic self-advocates. More information about the ARAP program and Stakeholder Collaborative can be found at <https://familyvoices.org/araprogram/>.

- Supporting Access for Everyone (SAFE) Initiative: Many children with neurodevelopmental disabilities experience extreme stress and behavioral dysregulation in medical settings. These challenges can result in delayed and foregone care, reduced access to care, as well as increased risk for injury and avoidable restrictive practices. Currently, there is no mechanism to share strategies and limited research to inform practice. There has been a growing awareness across many institutions and advanced by many community advocates of the urgent need to improve medical care for youth with disabilities. Despite the work that has been done, the field has had no unifying guidance to pull together research, community-informed practices, and the perspectives of community stakeholders. Through the generous support of DBPNet, funded by HRSA, and the technical support by the incredible team at Association of University Centers on Disabilities and Interdisciplinary Technical Assistance Center on Autism and Developmental Disabilities, Drs. Carol Weitzman, Marilyn Augustyn and Cy Nadler formed Supporting Access for Everyone (SAFE), ([www.safedbp.org](http://www.safedbp.org)) an interprofessional and stakeholder-driven initiative to establish best practices for supporting youth with neurodevelopmental disabilities in medical settings. This program has 2 components, a 2-day public forum where diverse stakeholders can expand testimony that they had submitted and answer critical questions from a consensus panel as well as the audience that will help the consensus panel consolidate their knowledge in preparation for drafting a consensus statement. The consensus panel, which is comprised of a breadth of stakeholders across professional disciplines as well as family and self-advocates who will be meeting in early November to synthesize the information from the public forum and existing research and begin to draft this consensus statement. There is more information about each consensus panel member on the SAFE website. The SAFE Initiative team believes this consensus statement will lay the groundwork for disseminating and evaluating SAFE practices and developing SAFE certification, all with the overarching goal of improving health outcomes for all children. Stakeholders are invited to [submit testimony](#) on how to support SAFE medical care for children with neurodevelopmental disabilities (deadline October 31).

## **COMMUNITY UPDATES**

### **Autism Speaks**

- Autism Speaks hosted the Thought Leadership Summit on Autism and Aging in June 2022. The virtual summit brought together families, self-advocates, researchers, and policymakers to discuss the issues facing autistic adults as they age. Recordings of the presentations and more information is available here:

<https://www.autismspeaks.org/science-news/autism-speaks-hosts-thought-leadership-summit-autism-and-aging>

- Five additional academic medical centers in the U.S. were added to the Autism Speaks Autism Care Network, for a total of 25 sites within the network. Locations of the new sites and additional information can be found here:

<https://www.autismspeaks.org/science-news/autism-speaks-welcomes-five-new-sites-autism-care-network>

- Autism Speaks is launching a new resource for providers developed at the Autism Speaks Thought Leadership Summit on Challenging Behavior by a group of 65 expert clinicians, parents, and policy makers. The Provider Guide: Program Development and Best Practices for Treating Severe Behaviors in Autism resource is available here:

<https://www.autismspeaks.org/clinician-guide-program-development-best-practices>

### **Autism Society of America**

- The Autism Society of America recently released its 2021 Annual Report, available here: <https://autismsociety.org/autism-society-of-america-releases-2021-annual-report/>
- The Autism Society of America also released a State Disability Advocacy Toolkit to guide individuals to effectively advocate at both the state and local levels. Additional information and a link to the toolkit is available here: <https://autismsociety.org/state-advocacy-toolkit/>
- The Autism Society of America and Nickelodeon co-created a Back-to-School resource pack to help support students on the autism spectrum and their teachers. The resource pack is available for free and a download link can be found here: <https://autismsociety.org/autism-society-x-nickelodeon-back-to-school-resources/>
- Through the Vaccine Education Initiative (VEI), ASA has made tremendous strides in improving COVID vaccine uptake in the Autism community. The three pillars of the VEI are to promote vaccine confidence, education, and accessibility. Applying a universal design framework, our programming reduces barriers at every stage of the vaccination process, with tailored support for healthcare providers, Autistic individuals, and families/caregivers. Additional information can be found here:

<https://autismsociety.org/resources/covid-19-support/>

### **Association of University Centers on Disabilities**

- Registration for the Association of University Centers on Disabilities (AUCD) 2022 Conference is now open through November 3, 2022. The conference will take place in person at Washington, D.C., from November 13-16, 2022, and a virtual registration option for livestreaming is available. Additional information on the conference can be found here: <https://www.aucd.org/conference/index.cfm/aucd-2022-conference2022>
- AUCD holds multiple events related to autism and disabilities throughout the year. Links to event registration, as well as past recordings, are available here:

<https://www.aucd.org/template/page.cfm?id=965>

### **Autistic Self Advocacy Network**

- The Autistic Self Advocacy Network (ASAN) released a new guide for LGBTQ+ autistic people called “Rights and Respect!” to help autistic LGBTQ+ individuals figure out what to do if they are not being respected. The guide is available as an easy read edition or a plain language version; both versions are available here:

<https://autisticadvocacy.org/resources/respect/>

### **The National Alliance to Advance Adolescent Health**

- The National Alliance to Advance Adolescent Health received funding from the Lucile Packard Foundation for Children’s Health to address the services cliff that low-income youth with special health care needs face as they age into adulthood. The funds will be used to examine disruptions and barriers to service needs to identify state and federal policy and program strategies that will ensure access to adult public program benefits. Additional information can be found in the full press release:

<https://www.thenationalalliance.org/publications/2022/5/24/the-national-alliance-receives-new-funding-to-address-barriers-inequities-and-policy-options-for-yshcn-aging-out-of-public-programs>