January 2023

IACC Round Robin Updates

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FEDERAL AGENCY UPDATES

Administration for Community Living (ACL)

- In September 2022, ACL awarded a cooperative agreement totaling an estimated $3.25 million over five years to create a national technical assistance and resource center that will improve support for people with co-occurring intellectual and developmental disabilities and mental health needs so they can live and participate in their communities. Details about the agreement can be found here: https://acl.gov/news-and-events/announcements/acl-launches-center-improve-support-people-who-have-both-intellectual

- ACL awarded a grant to the Cincinnati University Center of Excellence in Developmental Disabilities, which will lead a coalition of national partners, including Morehouse School of Medicine, the National Cultural Competency Center, the Kennedy Krieger Institute, and the Autistic Self Advocacy Network, in a five-year project to create the National Center for Disability, Equity, and Intersectionality (the Center for DEI). The Center for DEI aims for greater equity for people with disabilities through disability-led initiatives targeting ableism and racism with an intersectional lens. The goal of the Center for DEI is to lead the nation's charge to identify and reduce life-limiting inequities in healthcare, community living, and justice for people with disabilities. Additional information about the Center for DEI, as well as other ACL grants to advance equity and inclusion for people with disabilities and older adults, can be found here: https://acl.gov/news-and-events/announcements/acl-awards-nearly-173-million-advance-equity-and-inclusion-people

- ACL recently awarded two grants totaling $125 million to rapidly increase the number of older adults and people with disabilities who have received the updated COVID-19 vaccine and annual flu vaccine. These programs will distribute funding and leverage partnerships across the aging and disability networks to host community vaccine clinics, provide in-home vaccinations, provide transportation to vaccination sites, conduct outreach and education to older adults and disabled people, and more. More information about the grants can be found here: https://acl.gov/news-and-events/announcements/acl-awards-125-million-grants-vaccination-programs-older-adults-and

- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) is funding a new project (Parents Taking Action eHealth Adaptation and Pilot for Latinx, Black, and Chinese Families of Young Children with Autism Spectrum Disorder) that will study the intersection of race and ethnicity with the experiences of families with young children with ASD. The goal of this project is to address the disparities facing underserved racial and ethnic minority families by adopting an innovative microlearning concept in delivering bite-sized parent training content. The objectives are to adapt three culturally tailored versions of Parents Taking Action for Black (in English), Latinx (in Spanish), and Chinese (in Simplified Chinese) into bite-sized online learning content and to evaluate the feasibility, acceptability, and preliminary

evidence of efficacy of the adapted intervention. The researchers published several manuscripts in 2022 for similar NIDILRR-funded work:

- Dababnah, S., Kim, I., Magaña, S., & Zhu, Y. (2022). Parents taking action adapted to parents of Black autistic children: Pilot results. Journal of Policy and Practice in Intellectual Disabilities, 1– 15. https://doi.org/10.1111/jppi.12423
- Zeng W, Magaña S, Lopez K, Xu Y, Marroquín JM. Revisiting an RCT study of a parent education program for Latinx parents in the United States: Are treatment effects maintained over time? Autism. 2022 Feb;26(2):499-512. doi: 10.1177/13623613211033108. Epub 2021 Jul 28. PMID: 34320853: https://pubmed.ncbi.nlm.nih.gov/34320853/
- Marie Tejero Hughes, Sandra Magaña, Wendy Gonzales, Giselle Núñez, Marisol Moreno-Angarita; Colombian parents of children with autism spectrum disorder: Perceptions, experiences, and expectations. Journal of International Special Needs Education 1 January 2022; 25 (1): 25–36. doi: https://doi.org/10.9782/JISNE-D-20-00051

- A NIDILRR grantee at the University of Kansas has received funding through several of NIDILRR's funding mechanisms over many years to build capacity among parents to provide interventions for their children with ASD. This year, they received new funding for one project to further these efforts. The overall goal of this project is to fully develop and test the Online and Applied System for Intervention Skills - Supervision (OASIS-S), an online platform designed to build professional capacity for individuals pursuing the Board-Certified Behavior Analyst (BCBA) credential to primarily to serve individuals impacted by autism spectrum disorders (ASD). During this phase, this project develops and integrates a within-system video review feature to ensure HIPAA/FERPA compliance, expands the content to match the current professional supervision requirements, and fully develops/deploys the supervision hours tracking feature.
- NIDILRR began funding two other new Small Business Innovation Research Projects in 2022. These include:
  - **SkillTalk: Using Streaming Video for Young Adults with Autism Spectrum Disorder to Build Microskills to Develop and Sustain Relationships for Healthy and Independent Living.** dfusion, Inc. Scotts Valley, CA https://search.naric.com/research/redesign_record.cfm?search=1&type=all&criteria=autism&phrase=no&rec=3850
  - **Leveraging Self-Management Technology to Augment Social Skills for Employment for Individuals with Autism.** Cognitopia. Eugene, OR https://search.naric.com/research/redesign_record.cfm?search=1&type=all&criteria=autism&phrase=no&rec=3926

Agency for Healthcare Research and Quality (AHRQ)
- AHRQ is updating the 2015 report on Psychosocial and Pharmacologic Interventions for Disruptive Behavior in Children and Adolescents (available here: https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/disruptive-behavior-

disorder_research.pdf). The Agency is accepting comments on six Key Questions and two Contextual Questions for the report through January 31, 2023. The questions and more information on the report is available here: https://effectivehealthcare.ahrq.gov/products/disruptive-behavior, and comments can be submitted here: https://effectivehealthcare.ahrq.gov/products/form/disruptive-behavior

Centers for Disease Control and Prevention (CDC)
- CDC has awarded funding for the sixth funding cycle of the Autism and Developmental Disabilities Monitoring (ADDM) Network and is beginning surveillance activities in January with new and returning sites. The 11 ADDM Network sites will track early identification, prevalence, and characteristics of children with ASD among 4- and 8-year-olds; a subset of the sites (five) will also track co-occurring conditions and educational transition planning among 16-year-old adolescents. Information about ADDM Network sites can be found here: https://www.cdc.gov/ncbddd/autism/addm-network-sites.html
- Planning is also underway for the additional $5 million in funding for the ADDM Network in the recently passed budget to expand ASD tracking activities and re-establish cerebral palsy surveillance in at least two sites.
- ASD prevalence and early identification findings for 2020 from the ADDM Network are expected to be published in Spring 2023.
- CDC's "Learn the Signs. Act Early." (LTSAE) program has released an updated Milestones in Action – a FREE, online library of photos and videos to reflect the revised English-language developmental milestones: https://www.cdc.gov/ncbddd/actearly/milestones/milestones-in-action.html
- The LTSAE program continues working to collect images for its Spanish-language collection and expects to release them in the coming year.
- The English-language Milestone Tracker app will soon be updated with the new photos and videos. The app can be downloaded here: https://www.cdc.gov/ncbddd/actearly/milestones-app.html
- CDC's Milestone Tracker app has been downloaded more than 1.5 million times. The LTSAE program has developed surveys for app users in order to learn what impact the app has on behaviors and outcomes related to early identification of developmental delay. The surveys might be launched by Fall 2023, pending approval.

Department of Defense (DOD)
- The FY22 program cycle for the Autism Research Program (ARP) will be completing its two-tiered review process in the coming weeks. Investigators will be notified of funding recommendations within the next month. A list of those recommended for funding will be available on our website in early spring: https://cdmrp.health.mil/
- The ARP received a Congressional appropriation of $15 million for FY23. Funding solicitations will be made available to the public in early spring on both https://cdmrp.health.mil/ and https://www.grants.gov/

Department of Housing and Urban Development (HUD)

- In January 2023, HUD awarded $24.7 million to provide affordable housing to support community living for non-elderly people with disabilities. Please see the press release for more information: https://www.hud.gov/press/press_releases_media_advisories/hud_no_23_001

Department of Labor (DOL)

- ODEP's project on Research Support Services for Employment of Young Adults on the Autism Spectrum (REYAAS) has released new resources from its listening sessions and literature review.
- One REYAAS resource discusses Barriers and Facilitators to Employment and Careers for autistic young adults as summarized from its listening sessions held in spring 2022: https://www.mathematica.org/publications/barriers-and-facilitators-to-employment-and-careers-for-young-adults-on-the-autism-spectrum
- Another REYAAS resource describes Evidence on the Effectiveness of Programs, Models, and Strategies to Support Employment Outcomes for young adults on the autism spectrum: https://www.mathematica.org/publications/evidence-on-the-effectiveness-of-programs-models-and-strategies-to-support-employment-outcomes
- The Job Accommodation Network (JAN) supported by ODEP is hosting a free training webinar on Accommodation Solutions for Neurodivergent Workers on April 13 at 2 pm Eastern Time.
    - More information on the webinar is here: https://askjan.org/events/index.cfm?calview=eventdetails&dtid=A8FC7F4B-F08E-3D0C-6468F1CC056CEF3E
    - To attend the training, register here: https://askjan.org/events/register/2023-webcast-series.cfm?regEventID=A8F9E83C-EB93-53D7-B7A10FD685C6F769
    - Access JAN's webpage on accommodations for workers and job seekers on the autism spectrum here: https://askjan.org/disabilities/Autism-Spectrum.cfm

Social Security Administration (SSA)

- **Redesigned www.SSA.gov Website**
    - In December 2022, the Social Security Administration has launched a redesigned website at www.SSA.gov. The reimagined website prioritizes customer experience. SSA.gov is visited by over 180 million people per year, and it is one of our most important tools for providing efficient and equitable access to service. Improved self-service capability allows people to skip calling or visiting an office, which helps Social Security staff focus on those visitors who need in-person assistance. Visitors to SSA.gov can use interactive tools to:
        - ***Check eligibility for benefits:*** The new benefit eligibility screener is a convenient and simple way for people to learn if they might be eligible for benefits.
        - ***Save time on Social Security Number (SSN) and card online services:*** To request a replacement card, request an SSN for the first time, or make

changes to your record, visit www.ssa.gov/ssnumber/. Note that the Social Security Administration now offers people the choice to self-select their sex on their SSN record.

- **■** ***Start an application for Supplemental Security Income (SSI):*** People can start the application process online and request an appointment to apply for SSI benefits by answering a few questions at www.ssa.gov/benefits/ssi/

- **■** ***Apply for Social Security benefits and other online services:*** For most benefits, people can apply online or start an application online. In many cases, there are no forms to sign. The agency will review the application and reach out with questions or for more information. Visit www.ssa.gov/onlineservices to apply for retirement, disability, or Medicare.

- o Using a *my* Social Security account, a personalized online service, people can start or change direct deposit, or request a replacement SSA-1099. Individuals already receiving Social Security benefits can print or download a current Benefit Verification Letter if they need proof of their benefits. People not yet receiving benefits can use their online account to get a personalized Social Security Statement, which provides their earnings information as well as estimates of their future benefits. The portal also includes a retirement calculator and links to information about other online services. The agency encourages people without a *my* Social Security account to create one today at www.ssa.gov/myaccount/

- **ICAP Round 2 Awards Announced**
  - o On December 22, 2022, SSA made the second round of awards for the Interventional Cooperative Agreement Program (ICAP). Projects under ICAP are collaborative cooperative agreements with States, foundations, and other non-federal groups and organizations who have the interest and ability to identify, operate, and evaluate research related to the Disability Insurance and Supplemental Security Income programs. ICAP is an ongoing program that will accept new applications for award every year. This year, ICAP made awards to Mathematica and Westat for research that will include participants on the autism spectrum. Mathematica will conduct a randomized controlled trial to assess the impact of an employment intervention for youth with disabilities who are transitioning into the adult workforce. Westat will conduct a randomized controlled trial to assess the impact of combining supportive housing with Individual Placement and Support (IPS) supported employment services for recently homeless people experiencing a range of disabilities and mental health conditions. If anyone is interested in reading more about ICAP, they may review SSA's ICAP project page: https://www.ssa.gov/disabilityresearch/icap.html

- **Upcoming Funding Opportunity – New competition for ARDRAW Grand Administrative Organization**
  - o SSA is preparing to post the solicitation for a new grant administrator for the Analyzing Relationships between Disability, Rehabilitation, and Work (ARDRAW) Small Grant Program this quarter. ARDRAW consists of two parts: 1) a grant to an

organization to serve as grant administrator, and 2) subgrants to graduate students to perform research of interest to SSA's disability program. Graduate students who have previously been awarded ARDRAW subgrants have produced some excellent research relating to autism.

- o ***Eligible types of entities for the grant administrator role include:*** research organizations; universities; associations of research organizations and universities; and University Centers for Excellence in Developmental Disabilities (UCEDDs); Leadership Education in Neurodevelopmental Disabilities (LEND) programs; Eunice Kennedy Shriver Intellectual and Developmental Disability Research Centers (IDDRCs); and similar programs. Only organizations in the United States are eligible to apply. For more information, please see the ARDRAW forecast on Grants.gov: https://www.grants.gov/web/grants/view-opportunity.html?oppId=343104

- **Achieving a Better Life Experience (ABLE) Age Adjustment Act Signed**
  - o Achieving a Better Life Experience (ABLE) accounts are tax-advantaged savings accounts that are available to certain people with disabilities. One advantage of an ABLE account is that the first $100,000 in an ABLE account is exempted from the SSI individual resource limit.
  - o The bipartisan ABLE Age Adjustment Act was signed into law in December 2022. This bill will raise the ABLE account qualifying age of onset of disability from 26 to 46 as of January 1, 2026, thus making an estimated six million more Americans eligible for an ABLE account.
  - o For more information about ABLE accounts and how to open one, visit https://choosework.ssa.gov/blog/2022-04-21-2022-able-update.html and https://www.ssa.gov/ssi/spotlights/spot-able.html

Substance Abuse and Mental Health Services Administration (SAMHSA)

- SAMHSA has issued an announcement seeking comments on standards for Certified Community Behavioral Health Clinics (CCBHCs). These are specially designated clinics that provide a comprehensive range of mental and substance use services. (See: https://www.samhsa.gov/section-223 and https://www.thenationalcouncil.org/program/ccbhc-success-center/ccbhc-overview/). There are roughly 500 CCBBHCs in 46 states. CCBHCs treat both adult and pediatric populations, and, as proposed, the draft certification criteria require that "[w]hen treating individuals with developmental or other cognitive disabilities, level of functioning is considered and appropriate evidence-based treatments are provided. These treatments are delivered by staff with specific training in treating the segment of the population being served." Comments will be accepted through January 20, 2023, and instructions about how to comment are at this link: https://www.samhsa.gov/certified-community-behavioral-health-clinics/ccbhc-criteria-update-announcements
- The next virtual Interdepartmental Serious Mental Illness Coordinating Committee (ISMICC) meeting will be March 14, 2023, at 11AM-4PM EST. Additional information,

including how to register for the meeting, is available on the Federal Register Notice: https://www.federalregister.gov/d/2023-00916

PUBLIC MEMBER UPDATES

Autism Science Foundation (ASF)

- ASF announced the recipients of our most recent pilot grant mechanism on January 10th, calling for ways to improve inclusion of individuals who are either minimally verbal or have extreme cognitive disability or both. They include a study on a new non-invasive way to detect brain activity during sleep, an understanding of who is using AAC devices and what sorts of training or support they use when they in fact access a device, an examination of self-injury in a large community-based setting across the state of Pennsylvania, and also an examination into the predictors and possible treatment of a phenomenon known as "neuropsychiatric regression". This has been documented in the Phelan McDermid Syndrome community but in fact probably is not limited to that community. You can learn more about the studies we funded as well as the PI's and summaries on the ASF website: https://autismsciencefoundation.org/asf-funded-research/

- We were also very happy to help organize a meeting of the Baby Siblings Research Consortium, held in early November 2022 in Minneapolis before it got too blistering cold. This is a group of 50 and growing scientists from around the world that are able to study families with autism as early as birth, and sometimes pregnancy, to understand not just the early origins of autism, but early detection and diagnosis. At this meeting we talked about both biological and behavioral signs of ASD that are present even before the diagnosis can be made, how to support families to improve outcomes of these siblings in a variety of ways and how to better communicate with health care providers so that accurate detection is possible across the community, not just experts in clinical psychology, and can help those across the spectrum.

- We are happy to announce our 10th Day of Learning will be on March 30th in NYC, again, hybrid. It will be followed by a short celebratory cocktail hour for those that are able to attend in person. Save the date, registration will begin very soon and sign up for updates to get notified when that registration site goes live: https://autismsciencefoundation.org/day-of-learning/

Simons Foundation Autism Research Initiative (SFARI)

- Sensory function, motor function, and sleep: SFARI is offering a new RFA in 2023 for cross-species research, with particular interest in these topics. The autistic community has highlighted the need for helpful interventions in these domains. These areas also may be most amenable to translational research, given the conservation of their neural mechanisms across species. https://www.sfari.org/grant/cross-species-studies-of-asd/

- DEI in the community of autism scientists: SFARI continues to offer SEED grants (Supplement to Enhance Equity and Diversity), which provide up to $100,000 per 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/

Yetta Myrick

- If you are a researcher focused on autism and you are seeking to improve equity in your work, please join us for this virtual program to help autism researchers reach and engage African American families and self-advocates in research. Learn to develop processes and practices that improve equity. If you are selected for the Autism Research Equity Training and complete both sessions for your group, you will receive a stipend of $125 for your time. Apply by February 15, 2023: https://www.surveymonkey.com/r/autismequity

COMMUNITY UPDATES

Autism Speaks

- Data from Autism Speaks MSSNG database was used in a recently published study in *Cell*. The team of researchers from The Hospital for Sick Children found 134 genes linked with autism, as well as various genetic changes, including copy number variations (CNVs) likely associated with autism. The study can be found at: https://doi.org/10.1016/j.cell.2022.10.009

Autism Society of America

- In collaboration with the Institute for Community Inclusion at the University of Massachusetts Boston, the Autism Society of America has released a new toolkit for employment professionals, autistic individuals, and families titled "Creating a Path: How to Support Families and Young Adults with Autism to Prepare for Competitive Integrated Employment." The toolkit explores four primary predictors of future employment success for youth with autism: 1) career exploration and work-based learning, 2) building the young adult's soft skills, 3) developing the young adult's self-determination skills, and 4) family involvement in employment planning. A link to download the toolkit can be found in the press release here: https://autismsociety.org/press-release-autism-society-of-america-and-icis-thinkwork-collaborate-to-promote-integrated-employment-for-youth-with-autism/
- The Autism Society of America partnered with Immunize.org to provide a webinar titled "Improving the Vaccination Experience: Accessible Vaccination for Neurodiverse People at Any Age." The webinar includes practical tips to improve vaccine confidence by employing strategies to reduce stress when vaccinating neurodiverse patients. A

recording of the webinar as well as vaccination resources can be found here: https://www.immunize.org/webinars/cdc4/

Association of University Centers on Disabilities

- The Association of University Centers on Disabilities (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

- Applications are now open for the Autistic Self Advocacy Network (ASAN)'s 2023 Autism Campus Inclusion (ACI) Leadership Academy. The program will be held July 10th through 19th. Applications are due by midnight on Sunday, March 5th, 2023. Applications and more information can be found here: https://autisticadvocacy.org/aci/