2023 Summary of Advances Nominations

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Screening and Diagnosis

SSA	**Nominated article:** Dahl E, Moody EJ, Barger B, Rosenberg S, DiGuiseppi C, Fallin MD, Lee LC, Wiggins L. Differential Performance of Social Communication Questionnaire Items in African American/Black vs. White Children. *J Autism Dev Disord*. 2023 Mar 10. [PMID: 36897518]
	Justification from IACC member who nominated article: Although the historical disparity in ASD prevalence for African American/Black children has recently become less prominent, variation still exists between geographic sites, which suggests racial disparities may persist. Screening is a critical first step in identifying children with ASD and ensuring equitable opportunities for diagnosis, services, and supports; thus, this study, which explores differential item response patterns in the Social Communication Questionnaire (SCQ) – a major screening measure – by racial and ethnic group, is important in understanding racial disparity in diagnosis, and highlights the need to develop ASD screening tools that are psychometrically sound across all racial and demographic groups.
NIMH	**Nominated article:** Engelhard MM, Henao R, Berchuck SI, Chen J, Eichner B, Herkert D, Kollins SH, Olson A, Perrin EM, Rogers U, Sullivan C, Zhu Y, Sapiro G, Dawson G. Predictive Value of Early Autism Detection Models Based on Electronic Health Record Data Collected Before Age 1 Year. *JAMA Netw Open*. 2023 Feb 1;6(2):e2254303. [PMID: 36729455]
	Justification from IACC member who nominated article: Researchers examined the ability of machine-learning tools to predict and identify early signs of autism in children as young as 30 days of age. In a retrospective study using Electronic Health Records (EHRs) from 45,080 children (30 – 360 days-of-age), researchers at Duke University developed a machine-learning algorithm that examined a wide range of factors across the infant's entire health profile, such as medications, vital signs, inpatient and outpatient visits, etc. In comparisons between children who would later go on to receive a diagnosis of autism, to those without ASD, the researchers found that different machine-learning algorithms and models showed strong ability to specifically and accurately predict and autism diagnosis at 30 and 360 days of age. These findings suggest the potential of using large-scale analyses of EHR to improve capabilities for early screening of ASD among very young children.
NIMH	**Nominated article:** Pham C, Bacon EC, Grzybowski A, Carter-Barnes C, Arias S, Xu R, Lopez L, Courchesne E, Pierce K. Examination of the impact of the Get SET Early program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder. *Autism*. 2023 Jan 11:13623613221147416. [PMID: 36629055]
	Justification from IACC member who nominated article: Delays in autism spectrum disorder identification and access to care could impact developmental outcomes. Although trends are encouraging, children from historically underrepresented minority backgrounds are often identified at later ages and have reduced engagement in services. It is unclear if disparities exist all along the screen-evaluation-treatment chain, or if early detection programs such as *Get SET Early* that standardize, these steps are effective at ameliorating disparities. As part of the *Get SET Early* model, primary care providers administered a parent-report screen at well-baby

	examinations, and parents designated race, ethnicity, and developmental concerns. No differences were found in the mean age at the first screen, evaluation, or initiation or quantity of behavioral therapy between participants. However, children from historically underrepresented minority backgrounds were more likely to fall into the range of concern on the parent-report screen, their parents expressed developmental concerns more often, and pediatricians were more likely to refer for an evaluation than their White/Not Hispanic counterparts. Overall results suggest that models that support transparent tracking of steps in the screen-evaluation-treatment chain and service referral pipelines may be an effective strategy for ensuring equitable access to care for all children.
NIMH	**Nominated article:** Pierce K, Wen TH, Zahiri J, Andreason C, Courchesne E, Barnes CC, Lopez L, Arias SJ, Esquivel A, Cheng A. Level of Attention to Motherese Speech as an Early Marker of Autism Spectrum Disorder. JAMA Netw Open. 2023 Feb 1;6(2):e2255125. [PMID: 36753277]
	Justification from IACC member who nominated article: *Motherese*, a form of infant-directed speech that's characterized by exaggerated intonation, simple grammar, high pitch, and slow tempo, is a well-established form of caregiver interaction that effectively elicits infant and toddler engagement. In this study, researchers examined the dynamic of motherese among 653 toddlers (ages 12-24 months), both with and without an ASD diagnosis. They utilized eye-tracking methods to gauge toddlers' fixation on motherese speech versus other distractors such as noise or visual shapes. The findings revealed a significantly lower level of fixation on motherese speech among children with ASD, such that a level of fixation on motherese that was 30% or lower, was associated with a 94% predictive probability of a child's ASD diagnosis. Future research on the impact of motherese may have important implications for efforts to improve early screening and diagnosis of ASD
	Biology
NIMH	**Nominated article:** Bozhilova N, Welham A, Adams D, Bissell S, Bruining H, Crawford H, Eden K, Nelson L, Oliver C, Powis L, Richards C, Waite J, Watson P, Rhys H, Wilde L, Woodcock K, Moss J. Profiles of autism characteristics in thirteen genetic syndromes: a machine learning approach. *Mol Autism*. 2023 Jan 13;14(1):3. [PMID: 36639821]
	Justification from IACC member who nominated article: Phenotypic studies have identified distinct patterns of autistic characteristics in genetic syndromes associated with intellectual disability (ID), leading to diagnostic uncertainty and compromised access to autism-related support. Previous research has tended to include small samples and diverse measures, which limits the generalizability of findings. In this study, researchers generated detailed profiles of autistic characteristics in a large sample of > 1500 individuals with rare genetic syndromes. The findings demonstrated that genetic syndromes were associated with different but overlapping autism-related profiles, indicated by the substantial accuracy of the entire, multiclass SVM model (55% correctly classified individuals). Syndrome groups such as Angelman, fragile X, Prader-Willi, Rubinstein-Taybi and Cornelia de Lange showed greater phenotypic specificity than groups such as Cri du Chat, Lowe, Smith-Magenis, tuberous sclerosis complex, Sotos and Phelan-McDermid. These findings replicate and extend

	previous work, demonstrating syndrome-specific profiles of autistic characteristics in people with genetic syndromes compared to autistic individuals without a genetic syndrome. This work calls for greater precision of assessment of autistic characteristics in individuals with genetic syndromes associated with ID.
NIMH	**Nominated article:** Mattern H, Cola M, Tena KG, Knox A, Russell A, Pelella MR, Hauptmann A, Covello M, Parish-Morris J, McCleery JP. Sex differences in social and emotional insight in youth with and without autism. *Mol Autism*. 2023 Mar 4;14(1):10. [PMID: 36871073]
	Justification from IACC member who nominated article: The study examines sex differences in language-based markers of social and emotional insight in girls and boys with autism and non-autistic peers during semi-structured clinical interviews. Sixty-four participants aged 5 to 17 years were individually matched on chronological age and full-scale IQ to form four groups: autistic girls, autistic boys, non-autistic girls, and non-autistic boys. Results revealed the main effects of diagnosis, such that youth with autism exhibited lower insight than non-autistic youth on scales indexing social cognition and object relations, emotional investment, and social causality. With regards to sex differences, across diagnoses, girls were rated higher than boys on the social cognition and object relations, emotional investment, and social causality scales. Examined within each diagnosis separately, clear sex differences emerged: both autistic and non-autistic girls demonstrated better social cognition and understanding of social causality than boys in their respective diagnostic groups. No within-diagnosis sex differences were found on the emotional insight scales, however. These results suggest that relatively enhanced social cognition and understanding of social causality in girls may be a population-level sex difference that is preserved in autism, despite the core social challenges that characterize this condition. The current findings reveal new information about insight into social and emotional thinking and relationships in autistic girls versus boys that have important implications for improving identification and designing effective interventions.

Genetic and Environmental Factors

Interventions

NIMH	**Nominated article:** Guthrie W, Wetherby AM, Woods J, Schatschneider C, Holland RD, Morgan L, Lord CE. The earlier the better: An RCT of treatment timing effects for toddlers on the autism spectrum. *Autism*. 2023 Mar 15:13623613231159153. [PMID: 36922406]
	Justification from IACC member who nominated article: Behavioral interventions that incorporate naturalistic, developmental strategies have been shown to improve outcomes for young children who receive an ASD diagnosis. Although there is broad consensus that children on the spectrum should begin supports as soon as possible, the empirical evidence for this is relatively limited and little is known about the optimal age to start autism-specific interventions. This team conducted a randomized controlled trial (RCT) to test the effects of starting intervention at different ages, using the Early Social Interaction (ESI) model, a parent-implemented intervention for toddlers on the spectrum. Results revealed that children who received Individual-ESI earlier showed greater gains than those who received this intervention later. Gains were demonstrated in several areas, which included the use

	and understanding of language, social use of communication skills, and self-help skills. Importantly, these findings were specific to the intensive and individualized parent coaching model compared to group-based treatment, allowing researchers to rule out the possibility that these timing effects were due to children getting older rather than the intervention itself. These results suggest that even a narrow window of 18 versus 27 months may have an impact on outcomes and underscore the importance of screening and evaluation as young as possible.

Services and Supports

SSA	**Nominated article:** Hinkle KA, Lerman DC. Preparing Law Enforcement Officers to Engage Successfully with Individuals with Autism Spectrum Disorder: An Evaluation of a Performance-Based Approach. *J Autism Dev Disord*. 2023 Mar;53(3):887-900. [PMID: 34255235]
	Justification from IACC member who nominated article: Violent encounters between law enforcement officers and individuals on the autism spectrum continue to make headlines. Although many police departments have added some form of training on how to better interact with those on the spectrum, there little literature on what such training should look like or how well such trainings work. This study – although small – demonstrates the efficacy of a behavioral skills training program that trains law enforcement officers how to interact more effectively with individuals on the spectrum.
NIMH	**Nominated article:** Ishler KJ, Berg KA, Olgac T, Obeid R, Biegel DE. Barriers to service and unmet need among autistic adolescents and young adults. *Autism*. 2023 Feb 5:13623613221150569. [PMID: 36740742]
	Justification from IACC member who nominated article: Prior studies have described the roadblocks, or barriers, to needed services experienced by families with young autistic children, but less research has focused on those faced by autistic adolescents and young adults. In this study, researchers aimed to understand the barriers to service experienced by autistic adolescents and young adults and their families. They surveyed 174 caregivers of autistic youth between 16 to 30 years old. Researchers found that caregivers who felt more caregiving burden had more difficulty accessing services for their youth. Specifically, caregivers who felt more strongly that their daily lives had been disrupted, felt more financial strain, and worried more about their youth well-being experienced more roadblocks to getting services for the youth. Male caregivers also reported fewer difficulties related to service access. Importantly, the older the youth was when they had been diagnosed with autism, the more service barriers their caregivers reported. No differences were observed in the level of barriers experienced by youth who lived in urban versus suburban settings, or between white and non-white families. However, when youth lived with their caregivers (rather than, for example, in a group home), fewer quality-related barriers to services were reported. Finally, greater access (but not quality) barriers were linked to youth having more unmet service needs. These findings can help to reduce the barriers to service experienced by autistic adolescents and young adults and their families.
NIMH	**Nominated article:** Liu BM, Paskov K, Kent J, McNealis M, Sutaria S, Dods O, Harjadi C, Stockham N, Ostrovsky A, Wall DP. Racial and Ethnic Disparities in Geographic Access to Autism

	Resources Across the US. *JAMA Netw Open*. 2023 Jan 3;6(1):e2251182. [PMID: 36689227]
	Justification from IACC member who nominated article: While research has identified racial and ethnic disparities in access to autism services, the size, extent, and specific locations of these access gaps have not yet been characterized on a national scale. In this study, researchers aimed to evaluate differences in access to autism health care services among autistic children of various races and ethnicities within precisely defined geographic regions encompassing all serviceable areas within the US. Researchers found that autistic children from several minoritized racial and ethnic groups, including Black and Hispanic autistic children, had access to significantly fewer autism resources than White autistic children in the US. This study pinpointed the specific geographic regions with the greatest disparities, where increases in the number and types of treatment options are warranted. These findings suggest that a prioritized response strategy to address these racial and ethnic disparities is needed.
	Lifespan
NIMH	**Nominated article:** Charlton RA, McQuaid GA, Bishop L, Lee NR, Wallace GL. Predictors of sleep quality for autistic people across adulthood. *Autism Res*. 2023 Jan 13. [PMID: 36639914]
	Justification from IACC member who nominated article: Poor sleep can have a significant impact on physical health and well-being. Sleep problems are common among autistic children, but less is known about sleep across the autistic adult lifespan. Autistic adults (n = 730, aged 18-78 years) were recruited via Simons Powering Autism Research for Knowledge Research Match. Participants completed online surveys asking about demographics, health problems, social support, symptoms of anxiety and depression, and overall and specific aspects of sleep quality. Physical health, assigned female sex at birth and self-reported anxiety symptoms significantly contributed to models for all aspects of sleep. Perceived stress contributed to models of overall and subjective sleep quality, and daytime dysfunction. Depression symptoms did not contribute significantly to any of the models of sleep quality. However, utilizing government support mechanisms (such as social security) contributed to the model of sleep efficiency. Age contributed little to models of sleep quality, whereas perceived stress and psychotropic medication use contributed to some but not all aspects of sleep. Given known impacts of poor sleep on health, cognition and quality of life, attention should be paid to sleep and its possible everyday effects for autistic people of all ages.
NIMH	**Nominated article:** Kopp S, Asztély KS, Landberg S, Waern M, Bergman S, Gillberg C. Girls With Social and/or Attention Deficit Re-Examined in Young Adulthood: Prospective Study of Diagnostic Stability, Daily Life Functioning and Social Situation. *J Atten Disord*. 2023 Mar 13:10870547231158751. [PMID: 36915033]
	Justification from IACC member who nominated article: This study aimed to investigate diagnostic stability, daily life functioning and social situation in women diagnosed with ADHD and/or ASD in childhood. Results found that at follow-up, 89% of women with ADHD or ASD in childhood still met the criteria for either of these diagnoses. Very few women were "in remission." In 34% of study

	participants, the main diagnosis shifted from ADHD to ASD. Women with ADHD and ASD had significantly more reported challenges and unfavorable social situation than comparison women.
NIMH	**Nominated article:** Torenvliet C, Groenman AP, Radhoe TA, Agelink van Rentergem JA, Van der Putten WJ, Geurts HM. A longitudinal study on cognitive aging in autism. *Psychiatry Res*. 2023 Mar;321:115063. [PMID: 36709700]
	Justification from IACC member who nominated article: Longitudinal studies on cognitive aging in autism are scarce, and largely underpowered, yet essential to obtain more conclusive results on cognitive changes in autism during adulthood. In the largest longitudinal study on cognition thus far, researchers aimed to get more insight into cognitive aging in autism. Participants were tested on 15 outcome measures, covering verbal memory, visual (working) memory, prospective memory, theory of mind, fluency, response speed, inhibition, planning, and switching. Results showed no significant differences between groups (autism/no-autism) in changes over time. Using multilevel models, most tasks showed sensitivity to cross-sectional age-related effects, and/or longitudinal changes, with worse performance at older age, and later timepoints. However, effects were not significantly different between the autism and no-autism group. This lack of group differences was substantiated by additional Bayesian analyses. In sum, the current study provides evidence for parallel (similar) cognitive aging in autism. Specifically, autistic individuals diagnosed in adulthood, without intellectual disability, do not seem at risk for accelerated cognitive decline.
NIMH	**Nominated article:** Warreman EB, Nooteboom LA, Terry MB, Hoek HW, Leenen P, van Rossum E, Ramlal D, Vermeiren R, Ester WA. Psychological, behavioural and biological factors associated with gastrointestinal symptoms in autistic adults and adults with autistic traits. *Autism*. 2023 Feb 16:13623613231155324. [PMID: 36794469]
	Justification from IACC member who nominated article: Little is known about factors related to the increased risk for gastrointestinal symptoms in adults with an autism, while the negative impact of gastrointestinal symptoms is evident. Especially, the relationship between gastrointestinal symptoms and psychological, behavioral, and biological risk factors in adults with autism is unclear. This study found that not only adults with autism but also adults with higher levels of autistic traits were at increased risk for gastrointestinal symptoms. Adults with autism who experienced psychological conditions (psychiatric conditions, worse perceived health, chronic stress) had a higher risk for gastrointestinal symptoms than adults with autism without these psychological problems. Moreover, adults with higher levels of autistic traits were less physically active, which was also associated with gastrointestinal symptoms. In conclusion, this study highlights the relevance of identifying psychological conditions and evaluating physical activity when trying to help adults with autism or autistic traits and gastrointestinal symptoms. This suggests that healthcare professionals should be more aware of behavioral and psychological risk factors when evaluating gastrointestinal symptoms in adults with autism.

Infrastructure and Prevalence

NIMH	**Nominated article:**

	Casseus M, Kim WJ, Horton DB. Prevalence and treatment of mental, behavioral, and developmental disorders in children with co-occurring autism spectrum disorder and attention-deficit/hyperactivity disorder: A population-based study. *Autism Res*. 2023 Jan 16. [PMID: 36644987]
	Justification from IACC member who nominated article: There is a lack of nationally representative studies examining the co-occurrence of autism and attention-deficit/hyperactivity disorder (ADHD) in children. This study examines comorbid mental, behavioral, and developmental disorders (MBDDs) and associated treatment modalities for children with co-occurring autism and ADHD. Results found that compared to children with autism without co-occurring ADHD, children with autism + ADHD had higher prevalence of most MBDDs, including anxiety, depression, behavior or conduct problems, and other mental health conditions. Similarly, compared to children with ADHD without autism, children with autism + ADHD had higher odds of anxiety, depression, behavior or conduct problems, and other mental health conditions. A multidisciplinary approach is necessary to support the complex needs of these children.
CDC	**Nominated article:** Hughes MM, Shaw KA, Patrick ME, DiRienzo M, Bakian AV, Bilder DA, Durkin MS, Hudson A, Spivey MH, DaWalt LS, Salinas A, Schwenk YD, Lopez M, Baroud TM, Maenner MJ. Adolescents With Autism Spectrum Disorder: Diagnostic Patterns, Co-occurring Conditions, and Transition Planning. *J Adolesc Health*. 2023 Feb 25:S1054-139X(23)00001-0. [PMID: 36849336]
	Justification from IACC member who nominated article: CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network released its first-ever report looking at data on adolescents aged 16 years in 2018 with autism spectrum disorder (ASD). This report marks an expansion of CDC's ASD surveillance system to help communities identify healthcare needs and gaps in transition planning for adulthood among youth with ASD
CDC	**Nominated article:** Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-2):1–14. DOI: http://dx.doi.org/10.15585/mmwr.ss7202a1
	Justification from IACC member who nominated article: This is the 11th surveillance summary published in MMWR and marks a period of 20 years of monitoring ASD in multiple U.S. communities. This report describes ASD prevalence and characteristics among children aged 8 years from 11 ADDM Network sites in 2020, including prevalence by site and demographic characteristics, median ages when children with ASD were first evaluated or identified, and the co-occurrence of intellectual disability. These data can be used by service providers, educators, communities, researchers, and policymakers to track trends and support efforts to ensure the equitable allocation of needed services and support for all children with ASD.
CDC	**Nominated article:** Shaw KA, Bilder DA, McArthur D, et al. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-1):1–15. DOI: http://dx.doi.org/10.15585/mmwr.ss7201a1

	Justification from IACC member who nominated article: This report provides data on early ASD identification among children aged 4 years in 11 U.S. communities, including prevalence and characteristics of children with ASD and suspected ASD in 2020, and comparisons with children aged 8 years to show patterns in identification and emergence of possible impacts of the COVID-19 pandemic. These data can be used for ongoing monitoring of trends and to support efforts to ensure early and equitable identification of children with ASD.
CDC	**Nominated article:** Shaw KA, Williams S, Hughes MM, Warren Z, Bakian AV, Durkin MS, Esler A, Hall-Lande J, Salinas A, Vehorn A, Andrews JG, Baroud T, Bilder DA, Dimian A, Galindo M, Hudson A, Hallas L, Lopez M, Pokoski O, Pettygrove S, Rossow K, Shenouda J, Schwenk YD, Zahorodny W, Washington A, Maenner MJ. Statewide county-level autism spectrum disorder prevalence estimates-seven U.S. states, 2018. *Ann Epidemiol*. 2023 Mar;79:39-43. [PMID: 36669598]
	Justification from IACC member who nominated article: The infrastructure to track statewide autism spectrum disorder (ASD) prevalence varies from state to state and depends on the availability of resources. Seven existing 2018 Autism Developmental Disabilities Monitoring (ADDM) Network sites (Arizona, Arkansas, Minnesota, New Jersey, Tennessee, Utah, and Wisconsin) linked statewide health and education data for the first time to calculate statewide and county-level ASD estimates and compare results towith more resource-intensive record review methods. The manuscript shared tradeoffs and lessons learned from the approach.
SAMHSA	**Nominated article:** Shenouda J, Barrett E, Davidow AL, Sidwell K, Lescott C, Halperin W, Silenzio VMB, Zahorodny W. Prevalence and Disparities in the Detection of Autism Without Intellectual Disability. *Pediatrics*. 2023 Feb 1;151(2):e2022056594. [PMID: 36700335]
	Justification from IACC member who nominated article: This cross-sectional study used 2000-2016 data from the New Jersey Autism Study, which is part of the CDC - Autism and Developmental Disabilities Monitoring (ADDM) Network, to identify the prevalence of autism spectrum disorder (ASD) with (ASD-I) and without (ASD-N) intellectual disability in a four-county New Jersey area. The study also identifies ASD-I and ASD-N disparities based on sex, race, ethnicity and social economic status. Importantly, the study reflects that many of those with ASD among all groups examined can occur without intellectual disability. However, significant disparities exist and persons with lower income/SES are more likely to have substantial disability (ASD-I) and reside in areas where they may have decreased access to needed services.