2023 Summary of Advances Nominations IACC Full Committee Meeting January 24, 2024

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Screening and Diagnosis

		Screening and Diagnosis
1	NIMH	Nominated article:
		Herkert D, Sullivan C, Zhu Y, Dawson G. Prevalence and nature of prior
		developmental and medical concerns in toddlers who screen positive for autism in
		primary care. Autism. 2023 Nov;27(8):2361-2371. [PMID: 37838915]
		Justification from IACC member who nominated article:
		Early identification of and intervention for autism can lead to improved outcomes.
		Screening in early childhood leads to earlier referral and diagnosis. This study
		aimed to provide insight into the proportion of children who screened positive for
		autism and did or did not have prior documented caregiver concerns before
		screening was conducted. Analysis of electronic health records of 242 toddlers
		(average 18.69 months old) who screened positive for autism revealed that almost
		80% had prior motor, language, and/or autism concerns. In addition, 23% had
		prior concerns about sleep, and 66% had prior gastrointestinal issues. These
		results show that a positive autism screen often occurs in the context of previous
		concerns and provide an opportunity to reaffirm the issues that caregivers have
		· · · · · · · · · · · · · · · · · · ·
_	NIMH	raised, allowing for a less stigmatizing discussion of autism.
2	INIIVIH	Nominated article:
		James S, Hallur S, Anbar J, Matthews N, Pierce K, Smith CJ. Consistency between
		parent report and direct assessment of development in toddlers with autism
		spectrum disorder and other delays: Does sex assigned at birth matter? <i>Autism</i>
		Res. 2023 Jun;16(6):1174-1184. [PMID: 37009713]
		Justification from IACC member who nominated article:
		This study examined differences between how parents assess and measure their
		autistic child's development versus how diagnosticians (i.e., health providers)
		assess development, particularly language and fine motor abilities in toddlers.
		Also, this study looked at if a child's sex assigned at birth (SAB) influenced the
		parents' or diagnosticians' assessments of development. Results indicate that
		parent-report measures and diagnosticians' assessment may differ when
		measuring receptive language and fine motor skills, and that child SAB appears to
		influence parent and diagnostician assessment for expressive language.
		Understanding how SAB might influence a parent's impression of various aspects
		of development, and how these impressions may differ to pediatric health
		providers' clinical impressions, could help improve early ASD screening, diagnosis,
		and intervention for both boys and girls.
3	Thomas	Nominated article:
	Frazier	Jones W, Klaiman C, Richardson S, Aoki C, Smith C, Minjarez M, Bernier R,
		Pedapati E, Bishop S, Ence W, Wainer A, Moriuchi J, Tay SW, Klin A. Eye-Tracking-
		Based Measurement of Social Visual Engagement Compared With Expert Clinical
		Diagnosis of Autism. <i>JAMA</i> . 2023 Sep 5;330(9):854-865. [PMID: 37668621]
		Justification from IACC member who nominated article:
		Researchers sought to evaluate the performance of eye-tracking measurement of
		social visual engagement (index test) relative to expert clinical diagnosis in young
		children referred to specialty autism clinics. In this study of 16- to 30-month-old
		children enrolled at 6 US specialty centers from April 2018 through May 2019,
		staff blind to clinical diagnoses used automated devices to measure eye-tracking-

		based social visual engagement. Expert clinical diagnoses were made using best
		practice standardized protocols by specialists blind to index test results. Results indicate that in 16- to 30-month-old children referred to specialty clinics, eye-
		tracking-based measurement of social visual engagement was predictive of autism
		diagnoses by clinical experts. Further evaluation of this test's role in early
		diagnosis and assessment of autism in routine specialty clinic practice is
4	NIMH	warranted. Nominated article:
7	TAILVII I	Jones W, Klaiman C, Richardson S, Lambha M, Reid M, Hamner T, Beacham C,
		Lewis P, Paredes J, Edwards L, Marrus N, Constantino JN, Shultz S, Klin A.
		Development and Replication of Objective Measurements of Social Visual
		Engagement to Aid in Early Diagnosis and Assessment of Autism. JAMA Netw
		Open. 2023 Sep 5;6(9):e2330145. [PMID: 37669054]
		<u>Justification from IACC member who nominated article:</u> This study sought to develop an objective performance-based tool to aid in early
		diagnosis and assessment of autism in children younger than 3 years. Researchers
		developed an objective eye-tracking-based index test for children aged 16 to 30
		months, compared its performance with best-practice reference standard
		diagnosis of autism (discovery study), and then replicated findings in an
		independent sample (replication study). Discovery and replication studies were
		conducted in specialty centers for autism diagnosis and treatment. In these studies, objective eye-tracking-based measurements of social visual engagement
		correlated with expert clinical diagnostic status as well as individual levels of social
		disability, verbal ability, and nonverbal ability in autism. These findings suggest
		that objective measurements of social visual engagement can be used to aid in
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5	SSA	autism diagnosis and assessment. Nominated article:
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6	Thomas Frazier	MacKenzie KT, Mazefsky CA, Eack SM. Obtaining a First Diagnosis of Autism Spectrum Disorder: Descriptions of the Diagnostic Process and Correlates of Parent Satisfaction from a National Sample. J Autism Dev Disord. 2023 Oct;53(10):3799-3812. [PMID: 35896863] Justification from IACC member who nominated article: Obtaining an autism spectrum disorder (ASD) diagnosis is often challenging for parents. The purpose of this study was to better understand this process and examine how elements of the process may influence parent satisfaction. A total of 406 parents of autistic children participated. Participants were administered a survey covering the ASD diagnostic process. Parents had developmental concerns early but experienced long wait times and usually attended many appointments. Mean diagnostic age was 3.26 years and overall delay was 1.20 years. Stress and being told there was "no problem" were significantly associated with parental satisfaction with the process. Findings provide insight into challenges experienced by families of autistic children and can help pinpoint areas where the diagnostic
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		Justification from IACC member who nominated article: Autism screening questionnaires have been shown to have lower accuracy when used in real-world settings, such as primary care, as compared to research studies, particularly for children of color and girls. Here researchers report findings from a multi-clinic, prospective study assessing the accuracy of an autism screening digital application (app) administered during a pediatric well-child visit to 475 (17-36 months old) children (269 boys and 206 girls), of which 49 were diagnosed with autism and 98 were diagnosed with developmental delay without autism. The app displayed stimuli that elicited behavioral signs of autism, quantified using computer vision and machine learning. An algorithm combining multiple digital phenotypes showed high diagnostic accuracy. The algorithm had similar sensitivity performance across subgroups as defined by sex, race and ethnicity. These results demonstrate the potential for digital phenotyping to provide an objective, scalable approach to autism screening in real-world settings. Moreover, combining results from digital phenotyping and caregiver questionnaires may increase autism screening accuracy and help reduce disparities in access to diagnosis and intervention.
7	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 <i>Get SET Early</i> program on equitable access to care within the screen-evaluate-treat chain in toddlers with autism spectrum disorder. <i>Autism</i> . 2023 Aug;27(6):1790-1802. [PMID: 36629055] Justification from IACC member who nominated article: Delays in autism identification and access to care could impact developmental outcomes. Children from historically underrepresented minority backgrounds are often identified at older 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 <i>Get SET Early</i> that standardize these steps are effective at addressing disparities. As part of the <i>Get SET Early</i> model, primary care providers administered a parent-report screen at well-baby examinations, and parents designated race, ethnicity, and developmental concerns. Toddlers who scored in the range of concern, or whose primary care provider had concerns, were referred for an evaluation. Age at screen, evaluation, and treatment engagement and quantity was compared across groups. 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. This study suggests 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.
8	NIMH	Nominated article:
		Shuster CL, Sheinkopf SJ, McGowan EC, Hofheimer JA, O'Shea TM, Carter BS, Helderman JB, Check J, Neal CR, Pastyrnak SL, Smith LM, Loncar C, Dansereau LM, DellaGrotta SA, Marsit C, Lester BM. Neurobehavioral and Medical Correlates of

Autism Screening: 2-Year Outcomes for Infants Born Very Preterm. *J Pediatr*. 2023 Sep;260:113536. [PMID: 37271496]

<u>Justification from IACC member who nominated article:</u>

This study sought to identify neonatal characteristics and 2-year neurodevelopmental outcomes associated with positive screening for likelihood of autism. Nine university-affiliated neonatal intensive care units (NICUs) enrolled infants born at <30 weeks of gestation. Infants underwent the NICU Network Neurobehavioral Scale examination before discharge and the Bayley Scales of Infant and Toddler Development, Third Edition, the Child Behavior Checklist, and the Modified Checklist for Autism in Toddlers, revised with follow-up (M-CHAT-R/F). The findings showed that neonatal neurobehavior and medical morbidities were associated with positive M-CHAT-R/F screens at age 2 years in toddlers born very preterm. These findings demonstrate the potential utility of the M-CHAT-R/F as a global developmental screener in infants born very preterm, regardless of whether there is a later autism diagnosis.

Biology

9 NIMH <u>Nominated article:</u>

Buch AM, Vértes PE, Seidlitz J, Kim SH, Grosenick L, Liston C. Molecular and network-level mechanisms explaining individual differences in autism spectrum disorder. *Nat Neurosci*. 2023 Apr;26(4):650-663. [PMID: 36894656]

Justification from IACC member who nominated article:

The biological differences that lead to heterogeneity in autism phenotypes are not well understood. This study analyzed neuroimaging and gene expression data to identify how regional differences in ASD-related gene expression was linked to differences in the functional connectivity of the brain in subsets of individuals. Results from the analysis identified four subgroups. Subgroups 1 and 2 both had more severe core ASD symptoms, but subgroup 1 had above average verbal IQ and <u>low</u> connectivity in language processing areas of the brain. In contrast, subgroup 2 showed the opposite pattern: below-average verbal IQ and high connectivity in the same language areas. Subgroups 3 and 4 both had average verbal IQ scores. Subgroup 3 had high social affect symptoms, low restrictive and repetitive behaviors (RRB), and high connectivity in the anterior cingulate and ventrolateral prefrontal areas of the salience network. In contrast, subgroup 4 showed the opposite pattern: low social affect symptoms, high RRBs, and low connectivity in the same areas of the salience network. For each subgroup, ASDrelated functional connectivity was explained by regional differences in the expression of distinct ASD-related gene sets. These gene sets were differentially associated with molecular signaling pathways involving immune and synapse function, G-protein-coupled receptor signaling, protein synthesis, and other processes. These subgroups provide insight into the biological mechanisms that may underpin differences in autistic behavior and characteristics, which can be further studied in animal models and clinical trials to identify molecular targets for intervention.

10 NICHD <u>Nominated article:</u>

Chari T, Hernandez A, Portera-Cailliau C. A Novel Head-Fixed Assay for Social Touch in Mice Uncovers Aversive Responses in Two Autism Models. J Neurosci. 2023 Oct 25;43(43):7158-7174. [PMID: 37669860]

Justification from IACC member who nominated article:

In humans, autism spectrum disorder is associated with social deficits and atypical sensory processing. Traditionally, it has been difficult to study social touch in rodent models, as most experiments use freely-moving animals, allowing researchers little control over the length, type, and context of the social interactions. This paper introduces a novel behavioral assay to study social touch, in which mice are head-fixed and their interactions are highly controlled and monitored by researchers. In this study, researchers demonstrated the translatability of the new assay by investigating the behavior of mice with two different models of autism: Fmr1 knockout and maternal immune activation. Researchers observed an increase in grimacing, arousal, and avoidance in both autism models in response to social touch when compared with control mice. Interestingly, these differences did not persist when mice were approached by objects instead of other mice -- mirroring social deficits observed in individuals with autism. The new assay could prove highly useful in studying the effects of autism interventions and pharmacological treatments in mice; furthermore, the assay could be easily modified to include simultaneous neural recordings, allowing researchers unprecedented insight into the neuroscience of social touch.

11 NICHD

Nominated article:

Faerman A, Sakallah A, Skiba S, Kansara S, Kopald BE, Lewine JD, Demopoulos C. Language Abilities are Associated with Both Verbal and Nonverbal Intelligence in Children on the Autism Spectrum. *Dev Neuropsychol*. 2023 Jul 4;48(5):248-257. [PMID: 37326312]

<u>Justification from IACC member who nominated article:</u>

Traditional intelligence tests often have high linguistic demands and rely on verbal instructions for test administration, even when designed to measure nonverbal intelligence. As a result, there is concern that such tests may not accurately capture the intellectual abilities of individuals with autism, many of whom experience difficulties in language and communication. In this study, researchers tested 55 young people with autism (ages 6-16), measuring intellectual abilities in addition to general receptive and expressive language ability. Researchers employed two different styles of intelligence test -- one which used verbal instructions, and another which relied on nonverbal, pantomime instructions. Measured language abilities were found to correlate strongly with intelligence scores, but the strength of the correlation did not change with the method of instruction delivery, suggesting that nonverbal instructions may not always be necessary to accurately measure intellectual abilities in individuals with autism. However, in aggregate, the findings underscore both the need to contextualize standardized test results against general language ability, and to further explore the relationship between language abilities and psychological test scores in people with autism.

12 NICHD

Nominated article:

Fountain C, Winter AS, Cheslack-Postava K, Bearman PS. Developmental Trajectories of Autism. *Pediatrics*. 2023 Sep 1;152(3):e2022058674. [PMID: 37615073]

Justification from IACC member who nominated article:

Social and communication challenges are hallmarks of autism spectrum disorder. In children diagnosed with autism, these traits usually improve over time, although the rate and extent of the improvement depend on the child. In this study, researchers analyzed a large sample of over 70,000 individuals with autism to learn more about how communication and social skills change throughout childhood and adolescence. The researchers found that for a small minority of children (about 5 percent of the population), social skills decline during adolescence rather than showing improvement. Children in this group are more likely to be female, to have non-Hispanic white mothers, and to come from zip codes with low median home values. Among children who did show improvement in social and/or communication skills, higher socioeconomic status was generally associated with greater levels of improvement. Furthermore, children of non-Hispanic white mothers also tended to show more improvement compared to other racial and ethnic groups. This research highlights an important and understudied subset of children with autism whose social skills unexpectedly decline during adolescence. Additionally, the study lays the groundwork for future studies to investigate the underlying factors that drive racial, ethnic, and socioeconomic disparities among children with autism.

13 NICHD

Nominated article:

Garic D, McKinstry RC, Rutsohn J, Slomowitz R, Wolff J, MacIntyre LC, Weisenfeld LAH, Kim SH, Pandey J, St John T, Estes AM, Schultz RT, Hazlett HC, Dager SR, Botteron KN, Styner M, Piven J, Shen MD; Infant Brain Imaging Study (IBIS) Network. Enlarged Perivascular Spaces in Infancy and Autism Diagnosis, Cerebrospinal Fluid Volume, and Later Sleep Problems. *JAMA Netw Open*. 2023 Dec 1;6(12):e2348341. [PMID: 38113043]

<u>Justification from IACC member who nominated article:</u>

Previous studies indicate that perivascular spaces are important for clearing waste products from the brain. In older people, malfunction of this clearance process is associated with certain neurological disorders and cognitive decline. Other studies in older adults have linked enlarged perivascular spaces with sleep problems. For the current longitudinal study, researchers sought to determine how early perivascular space enlargement begins in the brain and whether it is associated with a diagnosis of ASD and sleep problems. They analyzed data from an ongoing study of children at increased likelihood for ASD because they have an older sibling diagnosed with ASD. They categorized the participants into three groups, based on their likelihood of developing ASD. The first—those with a sibling with autism and who later developed ASD themselves—were designated high likelihood, positive. Those with a sibling with ASD but who did not develop ASD were high likelihood, negative. The control group—those whose siblings did not have autism and who did not develop ASD—were low likelihood, negative. A total of 311 participants were included in the analysis. Participants with enlarged perivascular spaces had more than double the chance of developing ASD, compared to other participants who also had an older sibling with ASD. Of the high likelihood, positive group, 21 (44.7%) had enlarged perivascular spaces at 24 months, compared to 48 participants (26.7%) in the high likelihood, negative group and 22 participants (26.2%) in the control group. Enlarged perivascular spaces at 24 months were associated with a greater volume of extra axial

		cerebrospinal fluid (between the brain and inner lining of the skull) at 6 to 24 months and a greater likelihood of sleep problems from ages 7 to 12. The researchers hypothesized that the presence of excess cerebrospinal fluid may indicate that the fluid is circulating more slowly than it should, potentially leading the perivascular space to widen. The findings may lead to earlier diagnosis of ASD in children, allowing clinicians to intervene and improving the chances for successful outcomes.
14	NIMH	Nominated article:
		Jourdon A, Wu F, Mariani J, Capauto D, Norton S, Tomasini L, Amiri A, Suvakov M, Schreiner JD, Jang Y, Panda A, Nguyen CK, Cummings EM, Han G, Powell K, Szekely A, McPartland JC, Pelphrey K, Chawarska K, Ventola P, Abyzov A, Vaccarino FM. Modeling idiopathic autism in forebrain organoids reveals an imbalance of excitatory cortical neuron subtypes during early neurogenesis. <i>Nat Neurosci</i> . 2023 Sep;26(9):1505-1515. [PMID: 37563294]
15	NICHD	Despite high heritability and hundreds of known associated genetic factors, there are no known convergent biological pathways that are associated with autism. Macrocephaly (large head circumference) has been linked with increased severity and poorer outcomes in children with autism. The researchers generated single-cell transcriptomic data from forebrain organoids of 13 families to compare differences in gene expression (activity) between boys with autism, with or without macrocephaly (probands), and their non-autistic fathers. The results showed differences in the expression of gene transcription factors that drive cell differentiation during early development in organoids derived from probands with macrocephaly versus those without. Specifically, the researchers observed a relative increase in radial glia and excitatory neurons of the dorsal cortical plate in macrocephalic probands. In contrast, probands without macrocephaly showed an increase in excitatory neurons of the putative preplate. This suggests that the biological mechanisms driving autism with macrocephaly are potentially separate from those driving autism without macrocephaly. Nominated article:
13	NICHD	Mohamed MS, Klann E. Autism- and epilepsy-associated EEF1A2 mutations lead to translational dysfunction and altered actin bundling. <i>Proc Natl Acad Sci U S A</i> . 2023 Sep 19;120(38):e2307704120. [PMID: 37695913]
		Justification from IACC member who nominated article:
		Mutations in the EEF1A2 gene can cause severe autism, epilepsy, and intellectual disability. In this study, researchers focused on three common variants found in patients to investigate the biological mechanisms underlying the association between EEF1A2 and neurological disease. Using cells from both humans and mice, the researchers found that all three EEF1A2 mutations resulted in decreased protein synthesis and altered neuronal morphology. The mutations also induced changes in the actin cytoskeleton a structure critical for healthy neuronal development and function. Overall, the findings suggest that disrupted protein synthesis and cytoskeletal organization may lead to the disease phenotypes associated with EEF1A2 mutations, including autism, providing a target for further research and future therapeutics.
16	NIMH	Nominated article:
		Morton JT, Jin DM, Mills RH, Shao Y, Rahman G, McDonald D, Zhu Q, Balaban M, Jiang Y, Cantrell K, Gonzalez A, Carmel J, Frankiensztajn LM, Martin-Brevet S,

Berding K, Needham BD, Zurita MF, David M, Averina OV, Kovtun AS, Noto A, Mussap M, Wang M, Frank DN, Li E, Zhou W, Fanos V, Danilenko VN, Wall DP, Cárdenas P, Baldeón ME, Jacquemont S, Koren O, Elliott E, Xavier RJ, Mazmanian SK, Knight R, Gilbert JA, Donovan SM, Lawley TD, Carpenter B, Bonneau R, Taroncher-Oldenburg G. Multi-level analysis of the gut-brain axis shows autism spectrum disorder-associated molecular and microbial profiles. *Nat Neurosci*. 2023 Jul;26(7):1208-1217. [PMID: 37365313]

Justification from IACC member who nominated article:

Cellular and biochemical communication between the gut and the brain is referred to as the gut-brain axis (GBA). The GBA can impact brain functioning, including cognition and emotional regulation. This study, which re-analyzed 25 previously published data sets, sought to understand how disruption of the GBA may contribute to autism phenotypes. Researchers found 591 microbes were more common in children with ASD and 169 microbes were more commonly found in neurotypical children. The researchers also found autistic children were less likely to eat foods high in amino acids involved in neurotransmitter biosynthesis, and the metabolites that showed the strongest differences were glutamate and phenylalanine. Re-analysis of data from a prior fecal matter transplant study that had shown improvements in autism phenotypes following treatment revealed that these changes were correlated with a decrease in 91% of these ASD-associated microbes. Together, these results demonstrate clear differences between the gut microbiomes of children with autism and neurotypical controls across multiple studies. Further research is needed to better understand the directionality of cause and effect and how these differences in the microbiome contribute to autism development and phenotypes.

17 NIMH

Nominated article:

Neuhaus E, Santhosh M, Kresse A, Aylward E, Bernier R, Bookheimer S, Jeste S, Jack A, McPartland JC, Naples A, Van Horn JD, Pelphrey K, Webb SJ; ACE GENDAAR Network. Frontal EEG alpha asymmetry in youth with autism: Sex differences and social-emotional correlates. Autism Res. 2023 Dec;16(12):2364-2377. [PMID: 37776030]

Justification from IACC member who nominated article:

In autistic youth, EEG frontal alpha asymmetry (FAA) has been related to ASD diagnostic features and to internalizing symptoms. Among a large, rigorously characterized, sex-balanced participant group, researchers attempted to replicate findings suggestive of altered FAA in youth with an ASD diagnosis, examining group differences and impact of sex assigned at birth. Second, they examined relations between FAA and behavioral variables (ASD features, internalizing, and externalizing) within autistic youth, examining effects by sex. Third, they explored whether the relation between FAA, autism features, and mental health was informed by maternal depression history. In this sample, FAA did not differ by diagnosis, age, or sex. However, youth with ASD had lower total frontal alpha power than youth without ASD. For autistic females, FAA and bilateral frontal alpha power correlated with social communication features, but not with internalizing or externalizing symptoms. For autistic males, EEG markers correlated with social communication features, and with externalizing behaviors. Exploratory analyses by sex revealed further associations between youth FAA, behavioral indices, and maternal depression history. In summary, findings suggest

		that individual differences in FAA may correspond to social-emotional and mental health behaviors, with different patterns of association for females and males with ASD.
18	NIMH	Nominated article:
		Schwartz S, Wang L, Uribe S, Shinn-Cunningham BG, Tager-Flusberg H. Auditory evoked potentials in adolescents with autism: An investigation of brain development, intellectual impairment, and neural encoding. <i>Autism Res</i> . 2023 Sep 21. [PMID: 37735966]
		Justification from IACC member who nominated article:
		Limited research has evaluated neural encoding of sounds from a developmental perspective in individuals with autism, especially among those with intellectual disability. Researchers compared auditory evoked potentials (AEPs) in autistic adolescents with a wide range of intellectual abilities to both age-matched cognitively able neurotypical (NT) adolescents and younger neurotypical children to assess potential developmental delays. Researchers found that peak amplitudes of neural responses were significantly smaller in autistic adolescents compared to neurotypical adolescents. Results suggest that AEPs of autistic adolescents present differently from NTs, regardless of age, and differences cannot be accounted for by developmental delay. Nonverbal intelligence significantly predicted how closely each adolescent's AEP resembled the agenormed waveform. These results support an evolving theory that the degree of disruption in early neural responses to low-level inputs is reflected in the severity
		of intellectual impairments in autism.
19	NICHD	Nominated article: St John T, Estes AM, Hazlett HC, Marrus N, Burrows CA, Donovan K, Torres Gomez S, Grzadzinski RL, Parish-Morris J, Smith R, Styner M, Garic D, Pandey J, Lee CM, Schultz RT, Botteron KN, Zwaigenbaum L, Piven J, Dager SR; IBIS Network. Association of Sex With Neurobehavioral Markers of Executive Function in 2-Year-Olds at High and Low Likelihood of Autism. <i>JAMA Netw Open</i> . 2023 May 1;6(5):e2311543. [PMID: 37140923]
		Justification from IACC member who nominated article:
		This study examined the interaction of sex, family likelihood of autism, and structural brain alterations on executive function (EF) deficits in toddlers (ages 24 months). EF (i.e., a set of high-level cognitive abilities that enable goal-directed behavior) was directly assessed in 110 participants with an older sibling with autism (high family likelihood or HL) and 55 with an older sibling without autism (low family likelihood or LL). Additionally, structural magnetic resonance imaging (sMRI) was performed to determine frontal, parietal, and total cerebral brain volume. Girls and boys at HL were found to have significantly lower EF than girls and boys at LL. In girls this difference persisted even when toddlers with autism were excluded. Also, EF performance deficits were associated with larger frontal lobe volume and smaller parietal volume, although EF was less sensitive to volume differences in girls at LL than in any other group. Future longitudinal studies are warranted to examine the effect of early EF deficits on later developmental outcomes.
20	NIMH	Nominated article:
		Waizbard-Bartov E, Ferrer E, Heath B, Andrews DS, Rogers S, Kerns CM, Wu Nordahl C, Solomon M, Amaral DG. Changes in the severity of autism symptom

domains are related to mental health challenges during middle childhood. *Autism*. 2023 Sep 10:13623613231195108. [PMID: 37691349]

Justification from IACC member who nominated article:

For many autistic children, their autism traits may change during middle childhood. Researchers studied whether these changes are associated with the emergence of other mental health challenges such as anxiety and attention-deficit hyperactivity disorder. Children who had increased social-communication challenges had more anxiety and attention-deficit hyperactivity disorder symptoms and disruptive behavior problems than other children. Children who decreased their restricted and repetitive behaviors, on the contrary, had more anxiety.

21 NIMH

Nominated article:

Wright N, Courchesne V, Pickles A, Bedford R, Duku E, Kerns CM, Bennett T, Georgiades S, Hill J, Richard A, Sharp H, Smith IM, Vaillancourt T, Zaidman-Zait A, Zwaigenbaum L, Szatmari P, Elsabbagh M; Pathways Team. A longitudinal comparison of emotional, behavioral and attention problems in autistic and typically developing children. *Psychol Med.* 2023 Jun 29:1-13. [PMID: 37381780]

Justification from IACC member who nominated article:

Researchers sought to compare the level and growth of anxious-depressed, behavioral and attention problems in an autistic and typically developing (TD) cohort. The results showed that autistic children showed elevated levels of mental health problems, but this was substantially reduced by accounting for IQ and sex differences between the autistic and TD samples. Anxious-depressed problems were particularly elevated at preschool and attention problems at late childhood. Higher IQ predicted lower level of attention problems. Female sex predicted higher level of anxious-depressed and faster decline in behavioral problems. This study suggests that autistic children, especially girls, show elevated mental health problems compared to TD children and there are some differences in predictors. This study has implications for the assessment of mental health in clinical practice for autistic children.

Genetic and Environmental Factors

22 NICHD

Nominated article:

Ames JL, Burjak M, Avalos LA, Braun JM, Bulka CM, Croen LA, Dunlop AL, Ferrara A, Fry RC, Hedderson MM, Karagas MR, Liang D, Lin PD, Lyall K, Moore B, Morello-Frosch R, O'Connor TG, Oh J, Padula AM, Woodruff TJ, Zhu Y, Hamra GB; program collaborators for Environmental influences on Child Health Outcomes. Prenatal Exposure to Per- and Polyfluoroalkyl Substances and Childhood Autism-related Outcomes. *Epidemiology*. 2023 May 1;34(3):450-459. [PMID: 36630444]

Justification from IACC member who nominated article:

Per- and polyfluoroalkyl substances (PFAS) are environmental contaminants associated with numerous adverse health outcomes. Humans are most commonly exposed to PFAS through drinking water, food and its packaging, and indoor dust. This study investigated the connection between prenatal PFAS exposure and autism-related traits observed in early childhood using a large, diverse cohort spanning multiple geographic regions. Scientists used samples collected from 1,429 pregnant women to measure blood concentration of PFAS. Later, their

23	EPA	children were assessed for autism-related traits using the Social Responsiveness Scale (SRS). Increased maternal blood concentration of perfluoronanoic acid (PFNA) was associated with a mild increase in autism-related traits; however, for most other PFAS, blood levels were not strongly linked to any changes in SRS score. Furthermore, exposure to perfluorooctane sulfonate (PFOS) was more strongly associated with the development of autism-related traits in girls than in boys, but the sex difference was not robust. Overall, this study demonstrates the need for further investigation of the link between prenatal PFAS exposure and the development of early childhood traits associated with autism spectrum disorder. Nominated article: Carter SA, Rahman MM, Lin JC, Chow T, Yu X, Martinez MP, Levitt P, Chen Z, Chen JC, Eckel SP, Schwartz J, Lurmann FW, Kleeman MJ, McConnell R, Xiang AH. Maternal exposure to aircraft emitted ultrafine particles during pregnancy and likelihood of ASD in children. Environ Int. 2023 Aug;178:108061. [PMID: 37454628]
		Justification from IACC member who nominated article:
		There is increasing evidence for adverse health effects associated with aircraft-emitted particulate matter (PM) exposures, which are largely in the ultrafine (PM0.1) size fraction, but no previous study has examined neurodevelopmental outcomes. This study sought to assess associations between maternal exposure to aircraft ultrafine particles (UFP) during pregnancy and offspring autism spectrum disorder (ASD) diagnosis. This large, representative cohort study included 370,723 singletons born in a single healthcare system. Demographic data, maternal health information, and child's ASD diagnosis by age 5 were extracted from electronic medical records. Aircraft exposure estimates for PM0.1 were generated by the University of California Davis/California Institute of Technology Source Oriented Chemical Transport model. Increased likelihood of autism was associated with maternal exposure to aircraft PM0.1. The results strengthen the emerging evidence that maternal particulate matter exposure during pregnancy is associated with offspring ASD diagnosis and identify aircraft-derived PM0.1 as novel targets for further study and potential regulation.
24	Aisha	Nominated article:
24	Dickerson	Feinberg JI, Schrott R, Ladd-Acosta C, Newschaffer CJ, Hertz-Picciotto I, Croen LA,
	Dickerson	Daniele Fallin M, Feinberg AP, Volk HE. Epigenetic changes in sperm are associated with paternal and child quantitative autistic traits in an autism-enriched cohort. Mol Psychiatry. 2023 Apr 27. [PMID: 37100868]
		Justification from IACC member who nominated article:
		This study investigates whether paternal autistic traits, and the sperm epigenome,
		were associated with autistic traits in children at 36 months of age. The study identified 94 significant child SRS-associated and 14 significant paternal SRS-
		associated differentially methylated regions (indicating epigenetic mutations).
		Many of the child SRS-associated DMRs were annotated to genes implicated in
		ASD and neurodevelopment. These findings are important because they suggest
		paternal germline methylation is associated with autistic traits.
25	EPA	Nominated article: Rehman MM Carter SA Lin IC Charlet T. Vu V. Martinez MR Levitt R. Chan 7. Chan
		Rahman MM, Carter SA, Lin JC, Chow T, Yu X, Martinez MP, Levitt P, Chen Z, Chen JC, Rud D, Lewinger JP, Eckel SP, Schwartz J, Lurmann FW, Kleeman MJ, McConnell
		R, Xiang AH. Prenatal exposure to tailpipe and non-tailpipe tracers of particulate

matter pollution and autism spectrum disorders. Environ Int. 2023 Jan;171:107736. [PMID: 36623380] Justification from IACC member who nominated article: Traffic-related air pollution exposure is associated with increased likelihood of autism. It is unknown whether carbonaceous material from vehicular tailpipe emissions or redox-active non-tailpipe metals, e.g., from tire and brake wear, are responsible. Researchers assessed autism associations with fine particulate matter (PM2.5) tracers of tailpipe (elemental carbon [EC] and organic carbon [OC]) and non-tailpipe (copper [Cu]; iron [Fe] and manganese [Mn]) sources during pregnancy in a large cohort. This retrospective cohort study included 318,750 children born in Kaiser Permanente Southern California (KPSC) hospitals during 2001-2014, followed until age 5. Results suggest that non-tailpipe emissions may contribute to autism. Implications are that reducing tailpipe emissions, especially from vehicles with internal combustion engines, may not eliminate autism associations with traffic-related air pollution. 26 Aisha Nominated article: Dickerson Song AY, Kauffman EM, Hamra GB, Dickerson AS, Croen LA, Hertz-Picciotto I, Schmidt RJ, Newschaffer CJ, Fallin MD, Lyall K, Volk HE. Associations of prenatal exposure to a mixture of persistent organic pollutants with social traits and cognitive and adaptive function in early childhood: Findings from the EARLI study. Environ Res. 2023 Jul 15;229:115978. [PMID: 37116678] Justification from IACC member who nominated article: This study uses novel statistical methodology to investigate joint exposures of persistent organic pollutants, measured in pregnancy serum samples, and autismrelated symptoms, measure via the SRS and Mullen Scales, and Vineland. The study found greater social deficits in children of mothers with greater PBDE-47 serum concentrations as well as associations between PCB180 and PCB187 and Mullen cognition scores. Several PCBs were also positive associated with Adaptive functioning scores. These results are important because these chemicals have been historically understudied despite that they can exist in the environment for an extended period of time and many stakeholders have expressed concern on how these toxicants impact neurodevelopment. 27 **NICHD** Nominated article: van Jaarsveld RH, Reilly J, Cornips MC, Hadders MA, Agolini E, Ahimaz P, Anyane-Yeboa K, Bellanger SA, van Binsbergen E, van den Boogaard MJ, Brischoux-Boucher E, Caylor RC, Ciolfi A, van Essen TAJ, Fontana P, Hopman S, Iascone M, Javier MM, Kamsteeg EJ, Kerkhof J, Kido J, Kim HG, Kleefstra T, Lonardo F, Lai A, Lev D, Levy MA, Lewis MES, Lichty A, Mannens MMAM, Matsumoto N, Maya I, McConkey H, Megarbane A, Michaud V, Miele E, Niceta M, Novelli A, Onesimo R, Pfundt R, Popp B, Prijoles E, Relator R, Redon S, Rots D, Rouault K, Saida K, Schieving J, Tartaglia M, Tenconi R, Uguen K, Verbeek N, Walsh CA, Yosovich K, Yuskaitis CJ, Zampino G, Sadikovic B, Alders M, Oegema R. Delineation of a KDM2B-related neurodevelopmental disorder and its associated DNA methylation signature. Genet Med. 2023 Jan;25(1):49-62. [PMID: 36322151] Justification from IACC member who nominated article: Epigenetic regulators are naturally occurring cellular proteins with the ability to switch certain genes "on" or "off." Variants in the genes that encode epigenetic regulators have increasingly been identified as a cause of neurodevelopmental

disorders (NDDs). In this study, researchers located individuals carrying disease-causing variants in one such gene: KDM2B. Many of these individuals presented with intellectual or developmental disabilities, autism, attention-deficit/hyperactivity disorder, and/or congenital organ defects. The researchers next analyzed DNA methylation, a measure of epigenetic activity. Disease-causing KDM2B variants were found to have a unique epigenetic "signature" that can be easily detected from a blood sample – providing an easily-accessible tool to diagnose KDM2B-related NDDs, which previously had no known genetic cause. The results from this study will aid in the diagnosis, genetic testing, and treatment for individuals with autism caused by this newly-recognized subset of KDM2B-related NDDs.

28 NIMH

Nominated article:

Yap CX, Henders AK, Alvares GA, Giles C, Huynh K, Nguyen A, Wallace L, McLaren T, Yang Y, Hernandez LM, Gandal MJ, Hansell NK, Cleary D, Grove R, Hafekost C, Harun A, Holdsworth H, Jellett R, Khan F, Lawson LP, Leslie J, Levis Frenk M, Masi A, Mathew NE, Muniandy M, Nothard M, Miller JL, Nunn L, Strike LT, Cadby G, Moses EK; Busselton Health Study Investigators; de Zubicaray GI, Thompson PM, McMahon KL, Wright MJ, Visscher PM, Dawson PA, Dissanayake C, Eapen V, Heussler HS, Whitehouse AJO, Meikle PJ, Wray NR, Gratten J. Interactions between the lipidome and genetic and environmental factors in autism. *Nat Med*. 2023 Apr;29(4):936-949. [PMID: 37076741]

Justification from IACC member who nominated article:

In this study, researchers explored the plasma lipidome in 765 children (485 diagnosed with autism) within the Australian Autism Biobank. They identified lipids associated with autism diagnosis, sleep disturbances, and cognitive function and found that long-chain polyunsaturated fatty acids may causally contribute to sleep disturbances. Researchers then explored the interplay of environmental factors with neurodevelopment and the lipidome, finding that sleep disturbances and unhealthy diet have a convergent lipidome profile that is also independently associated with poorer adaptive function. In contrast, autism lipidome differences were accounted for by dietary differences and sleep disturbances. This study highlights the complex relationship between lipidomics and neurodevelopment, particularly in affecting the quality of life among autistic individuals.

Interventions

29	HRSA	Nominated article:
		Chang YC, Shire S, Shih W, Kasari C. Developmental Play Skills as Outcomes of
		Early Intervention. J Autism Dev Disord. 2023 Oct 5. [PMID: 37796387]
		Justification from IACC member who nominated article:
		Play is critical in the development of cognitive and language skills in young
		children with autism; however, few studies have examined the impact of the
		intervention on the development of play skills. In this study, children who received
		the joint attention, symbolic play, and engagement regulation (JASPER)
		intervention improved significantly in both play diversity and complexity
		compared to children in control conditions. These gains in play skills were
		associated with concurrent improvements in cognition and communication skills.
30	HRSA	Nominated article:

Che X, Gross SM, Wang G, Hong X, Pearson C, Bartell T, Wang X. Impact of consuming a Mediterranean-style diet during pregnancy on neurodevelopmental disabilities in offspring: results from the Boston Birth Cohort. *Precis Nutr.* 2023 Jul 11;2(3):e00047. [PMID: 37744413]

Justification from IACC member who nominated article:

This prospective cohort study assessed the association of a maternal Mediterranean-style diet (MSD) during pregnancy with offspring's' neurodevelopmental disorders (NDD) including autism, ADHD, and other developmental disabilities. A higher maternal MSD score was associated with a lower likelihood of NDD in the offspring. Furthermore, this association of maternal MSD score with offspring NDD was greater in children born to women with overweight and obesity/diabetes mellitus. The findings, if replicated, can lead to broad scale dietary recommendations to reduce the prevalence of neurodevelopmental disorders. Identifying women with low MSD scores can prompt early screening of NDD in offspring and provide an opportunity for early social supports to mothers and children.

31 NIMH

Nominated article:

Clarke KA, Siegel M, Williams DL. The Relationship Between Augmentative and Alternative Communication Use by Pediatric Psychiatric Inpatients With Autism Spectrum Disorder and Interfering Behaviors. *Am J Speech Lang Pathol*. 2023 Sep 11;32(5):2040-2056. [PMID: 37433305]

Justification from IACC member who nominated article:

This study uses retrospective data (i.e., data from a previous study) to investigate the association between verbal ability and augmentative and alternative communication (AAC) use and the presence of interfering behaviors in individuals with autism who have complex behavioral profiles. The sample included 260 autistic inpatients, ages 4-20 years, from six psychiatric facilities, enrolled during the second phase of the previous study when detailed information about AAC use was collected. Measures included AAC use, method, and function; comprehension and production of language; receptive vocabulary; nonverbal IQ; severity of interfering behaviors; and the presence and severity of repetitive behaviors. Lower language/communication abilities were related to increased repetitive behaviors and stereotypies. More specifically, these interfering behaviors appeared to be related to communication in those individuals who were candidates for AAC but who were not reported to have access to it. Although the use of AAC did not predict a decrease in interfering behaviors, receptive vocabulary scores-as measured by the Peabody Picture Vocabulary Test-Fourth Edition-were positively correlated with the presence of interfering behaviors in participants with the most complex communication needs. The communication needs of some individuals with autism may be unmet, prompting the use of interfering behaviors as a form of communication.

32 NIMH

Nominated article:

Day TN, Northrup JB, Mazefsky CA. A PROMIS® ing New Measure for Quantifying Emotion Dysregulation in Toddlers and Preschoolers: Development of the Emotion Dysregulation Inventory-Young Child. *J Autism Dev Disord*. 2023 Jun;53(6):2261-2273. [PMID: 35403207]

Justification from IACC member who nominated article:

		The Emotion Dysregulation Inventory (EDI) was designed and validated to quantify emotion dysregulation (ED) in school-age children, with a particular emphasis on capturing ED in youth with autism. Researchers saw a need to adapt the EDI for use in young children (ages 2-5) given early childhood is a formative time for emotion regulation development. This study discussed the adaptation process for the EDI-Young Child (EDI-YC), including item refinement/generation and cognitive interviews (N = 10 with ASD), consistent with the Patient-Reported Outcomes Measurement Information System (PROMIS®) methodology. The item bank was piloted in a sample of 2-year-olds with and without autism, which provided initial support for the EDI-YC as a valid and reliable measure.
33	HRSA	Nominated article: Hatfield DP, Must A, Kennedy W, Staiano AE, Slavet J, Sabelli RA, Curtin C, Bandini LG, Nauta P, Stuetzle C, Bowling AB. GamerFit-ASD beta test: adapting an evidence-based exergaming and telehealth coaching intervention for autistic
		youth. Front Pediatr. 2023 Sep 5;11:1198000. [PMID: 37732006]
		Justification from IACC member who nominated article:
		Health disparities faced by autistic youth are exacerbated by inadequate physical activity (PA) and sleep, whereas healthy PA and sleep may improve mood and function. Adaptive Game Squad (AGS) is an evidence-based telehealth coaching and exergaming intervention that was adapted to improve PA and sleep for autistic youth ages 10-15 years. This 12-week intervention can be scaled up in a variety of settings to improve the health and well-being of autistic individuals.
34	NIMH	Nominated article:
		Imbiriba T, Demirkaya A, Singh A, Erdogmus D, Goodwin MS. Wearable Biosensing to Predict Imminent Aggressive Behavior in Psychiatric Inpatient Youths With Autism. <i>JAMA Netw Open</i> . 2023 Dec 1;6(12):e2348898. [PMID: 38127348]
		Justification from IACC member who nominated article:
		Aggressive behavior can occur in individuals with autism and can be unpredictable due to communication difficulties. Changes in peripheral physiology (heart rate and sweat gland activity) and motion may be an indicator of upcoming aggressive behavior. This research group previously observed peripheral physiological and motion signals from biosensors worn by 20 autistic youths and, using machine learning, demonstrated that aggressive behavior toward others could be predicted 1 minute before it occurred. The current study seeks to replicate these findings in 70 participants with autism across 4 psychiatric inpatient units. In nearly 500 hours of observation, a total of 6,665 aggressive behaviors were observed, including self-injurious behavior, emotional dysregulation, and aggression towards others. The researchers found that logistic regression was able to predict aggressive behaviors 3 minutes before they occurred. These findings pave the way for further research on adaptive interventions to address aggressive behavior before it is overtly demonstrated.
35	NIMH	Nominated article: Kasari C, Shire S, Shih W, Landa R, Levato L, Smith T. Spoken language outcomes in limited language preschoolers with autism and global developmental delay: RCT of early intervention approaches. <i>Autism Res.</i> 2023 Jun;16(6):1236-1246. [PMID: 37070270]
		Justification from IACC member who nominated article:

This study compared two different early intervention approaches for teaching spoken language to minimally verbal, globally delayed autistic preschoolers. Children were given an hour of therapy daily for 6 months and then reassessed 6 months later. The majority of the 164 participants were from historically excluded populations (low income and minority), and therapy was delivered in school community settings by expert clinicians. Results indicated that the participants made significant progress regardless of intervention approach: 6 months gain in standardized language scores over 6 months, but slower progress during the period after therapy ended. Children who initiated joint attention more frequently, or who had higher language understanding at baseline made more progress if assigned to receive JASPER, a naturalistic developmental behavioral intervention. Children who received Discrete Trial Training made greater language progress during 6-month period after therapy ended. These findings suggest that progress can be made in children with autism who have very little spoken language and who receive targeted early interventions.

36 HRSA

Nominated article:

Mittal S, Bax A, Blum NJ, Shults J, Barbaresi W, Cacia J, Deavenport-Saman A, Friedman S, LaRosa A, Loe IM, Tulio S, Vanderbilt D, Harstad E; DBPNet Steering Committee; DBPNet Steering Committee. Receipt of Behavioral Therapy in Preschool-Age Children with ADHD and Coexisting Conditions: A DBPNet Study. *J Dev Behav Pediatr*. 2023 Dec 1:44(9):e651-e656. [PMID: 37751569]

Justification from IACC member who nominated article:

The American Academy of Pediatrics and the Society for Developmental and Behavioral Pediatrics recommend behavioral therapy (BT) as the first-line treatment for preschool age children with ADHD, before trying medication. This study reviewed records of 497 children under 72 months old that were on medication for ADHD. Of these children, only 45% of these children received any sort of BT prior to beginning ADHD medication. Children with ADHD and Autism Spectrum Disorder or children with disruptive behavioral disorder were more likely to receive BT than children without these conditions (59.3% vs 69% vs 30.6%). This study highlights a universal need to increase receipt and access of BT for young children with ADHD.

Services and Supports

37	Julie	Nominated article:
	Lounds	Adams RE, Lampinen L, Zheng S, Sullivan V, Taylor JL, Bishop SL. Associations
	Taylor	between social activities and depressive symptoms in adolescents and young
		adults with autism spectrum disorder: Testing the indirect effects of loneliness.
		Autism. 2023 May 22:13623613231173859. [PMID: 37212127]
		Justification from IACC member who nominated article:
		This study examined the associations between social participation and depressive
		symptoms among 321 autistic adults. Findings suggested that, overall, whether
		the adults felt that the amount of social activities were meeting their needs was
		more closely associated with depressive symptoms than the actual amount of
		time spent in social activities. Though many studies focus on the amount of social
		activities engaged in by autistic individuals, these findings suggest that a critical

		component to understanding the impact of social activities is whether the
		individual feels the participation is meeting their needs.
38	NIMH, SSA	Nominated article: Brunt S, Sadikova E, Pappagianopoulos J, Mazurek MO. The impact of COVID-19 on receipt of health services among children with and without autism. <i>Autism</i> . 2023 May 26:13623613231176930. [PMID: 37243353] Justification from IACC member who nominated article:
		NIMH: The COVID-19 pandemic disrupted doctor and dental visits, mental health treatments, and other special therapies for children across the United States. Prior research has found that autistic children were more likely to lack these services even before the pandemic, but they experienced more mental health and behavior problems with the onset of the pandemic, increasing the need for these services. This study analyzed data from before (2019) and after (2020) the onset of the pandemic to determine whether autistic children had even more severe disruptions in services after the pandemic started compared to non-autistic children. They found that autistic children were more likely to have unmet medical, dental, and mental health needs in both 2019 and 2020. Overall, children experienced increased disruptions from 2019 to 2020, but this did not differ by diagnosis. The results suggest that there are persisting gaps in autistic children's healthcare regardless of the pandemic.
		SSA: This article comprises of a robust sample and highlights health disparities, particularly unmet health needs among autistic children compared with nonautistic children. Notably, these disparities were further exacerbated during the pandemic, specifically dental services. Furthermore, this article also notes how most participants, 95%, had health insurance, yet still had unmet health needs implying external barriers to receiving care. It also affirms related literature looking at additional disparities among lower income families, females, and non-White children as it pertains to unmet medical needs. Whereby, the authors suggest additional research on the quality of virtual services as it may assist with the unmet health needs of autistic children.
39	NIMH	Nominated article: Constantino JN, Abbacchi AM, May BK, Klaiman C, Zhang Y, Lowe JK, Marrus N, Klin A, Geschwind DH. Prospects for Leveling the Playing Field for Black Children With Autism. <i>J Am Acad Child Adolesc Psychiatry</i> . 2023 Sep;62(9):949-952. [PMID: 37196781]
		Justification from IACC member who nominated article:
		This study sought to examine race-based outcome disparities in autism, particularly around expediting autism diagnosis and implementing appropriate and timely developmental interventions to close the gap in intellectual disabilities (ID) comorbidities across race. Across two sites (St. Louis, MO and Atlanta, GA), black toddlers diagnosed with autism or suspected of having autism were followed for 18 months to track service acquisition and to obtain measurements of autism traits, cognitive outcomes, and adaptive function. Additionally, at the St. Louis site, families were offered autism behavioral interventions if they were unable to access services in the community. Results showed that earlier diagnosis alone did not result in

		more favorable cognitive outcomes for Black children with autism. Additionally, when offered the opportunity for more intensive intervention, most families pursued the opportunity. This study shows the importance of an early diagnosis coupled with timely autism specific services in addressing the prevalence gap for ID between Black and White autistic children.
40	NIMH	Nominated article: Feinberg E, Stransky ML, Augustyn M, Broder-Fingert S, Bennett A, Weitzman C, Kuhn J, Chu A, Cabral HJ, Fenick AM, Blum NJ. Effect of Family Navigation on Participation in Part C Early Intervention. <i>Acad Pediatr</i> . 2023 Jul;23(5):904-912. [PMID: 37004879]
		Part C Early Intervention (EI) services have been shown to promote healthy development among young autistic children. However, EI participation remains low, particularly among children from structurally marginalized communities. Researchers investigated whether family navigation (FN) improved EI initiation following positive primary care screening for autism compared to conventional care management (CCM). Researchers conducted a randomized clinical trial among 339 families of children (ages 15-27 months) who screened as having an increased likelihood for autism at 11 urban primary care sites in 3 cities. Families were randomized to FN or CCM. Families in the FN group received community-based outreach from a navigator trained to support families to overcome structural barriers to autism evaluation and services. El service records were obtained from state or local agencies. Findings suggest that FN improved the likelihood of El participation among urban families from marginalized communities.
41	NIMH	Nominated article: Kenworthy L, Childress D, Armour AC, Verbalis A, Zhang A, Troxel M, Handsman R, Kocher K, Myrick Y, Werner M, Alexander KC, Cannon L, Anthony LG. Leveraging technology to make parent training more accessible: Randomized trial of inperson versus online executive function training for parents of autistic children. Autism. 2023 Apr;27(3):616-628. [PMID: 35916246]
		Justification from IACC member who nominated article: This study compared an online parent training program for executive function intervention for autism to in-person parent training on the same content. Participants were parents of autistic children, who were between 8 and 12 years of age and did not have intellectual disability. Parents were randomized to the inperson or online training conditions. Both trainings were developed with stakeholder (parents and autistic people) guidance. Most parents reported that they liked both trainings and that they were able to implement what they learned with their children. Parents in both groups spent equivalent amounts of time (about 8 hours) with the training materials, but while 94% of parents in the inperson training attended both parent trainings, only 59% of parents in the online group completed all 10 online modules. Parents reported that it was difficult to stay motivated to complete the online trainings over the 10-week trial. Parent and child outcomes did not differ significantly between the groups. Overall, parents reported that the trainings resulted in a reduction in their own parenting strain and improvements in their child's flexibility, emotional control, and global executive function, but not planning and organization. These findings indicated

		brief in-person and online training can help parents learn to support and improve their autistic children's executive function abilities, reducing their own experience of parenting strain. The finding that the online training was equivalent to the inperson trainings is important because it is accessible to parents who encounter barriers to in-person care.
42	NIMH	Nominated article: Koffer Miller KH, Cooper DS, Ventimiglia JC, Shea LL. Feeling intimidated and uncomfortable: Established and exacerbated educational inequities experienced by black parents of autistic children. Autism Res. 2023 May;16(5):1040-1051. [PMID: 36929573] Justification from IACC member who nominated article: To capture the educational experiences of family members of Black autistic children as compared to white autistic children in the United States (US), a mixed methods design was implemented and included semi-structured interviews with family members of children between the ages of 5-12 who participated in a survey. The survey responses were used as attribute data. Twenty-nine interviews were conducted with parents of school-age autistic children. Findings from this study highlight challenges experienced by parents including education service use
		and engagement during the COVID-19 pandemic, engaging with school personnel, and securing accommodations. The findings from this study illuminate the disparities experienced by Black parents of autistic children directly reported by the parents themselves in comparison to white parents. The themes elucidated in this study have implications for policy, practice, and research to ensure equity in educational settings for Black autistic students and their families.
43	HRSA	Nominated article: Rast JE, Fernandes SJ, Schott W, Shea LL. Disparities by Race and Ethnicity in Inpatient Hospitalizations Among Autistic Adults. <i>J Autism Dev Disord</i> . 2023 Feb 9. [PMID: 36757545]
		Justification from IACC member who nominated article:
		This study examined hospitalizations in a large, all-payer, nationally representative sample of inpatient hospitalizations in the US and identified differences in rates of hospitalization for conditions by race and ethnicity in autistic adults. Compared to white, non-Hispanic autistic adults, Black, Hispanic, Asian or Pacific Islander (API), and autistic adults of another race had lower prevalence of admission for a principal diagnosis of a mood disorder. Conversely, Black, Hispanic, API, and autistic adults of another race had higher odds of admission for epilepsy than white autistic adults. Differences in diagnosis prevalence among hospitalized autistic adults may suggest differential access to comprehensive outpatient care that could prevent such hospitalizations, while also pointing to concerns of differential validity of diagnostic tools and treatment approaches. Insurance policy and programs should prioritize optimizing outpatient care to ensure access to care and emphasize the need for equitable treatment.
44	NIMH	This study examined hospitalizations in a large, all-payer, nationally representative sample of inpatient hospitalizations in the US and identified differences in rates of hospitalization for conditions by race and ethnicity in autistic adults. Compared to white, non-Hispanic autistic adults, Black, Hispanic, Asian or Pacific Islander (API), and autistic adults of another race had lower prevalence of admission for a principal diagnosis of a mood disorder. Conversely, Black, Hispanic, API, and autistic adults of another race had higher odds of admission for epilepsy than white autistic adults. Differences in diagnosis prevalence among hospitalized autistic adults may suggest differential access to comprehensive outpatient care that could prevent such hospitalizations, while also pointing to concerns of differential validity of diagnostic tools and treatment approaches. Insurance policy and programs should prioritize optimizing outpatient care to ensure access to care

autistic population are concerning. A web of publicly funded services exists to support the employment, and associated health and well-being, of United States citizens with autism and other intellectual and developmental disabilities, namely through Vocational Rehabilitation (VR) and Medicaid home- and communitybased services (HCBS) waivers. Given an absence of overarching surveillance of employment services, this study aimed to characterize the distribution of autistic service users across Medicaid versus VR, understand the types of employment services utilized within these programs and expenditures, and assess overall capacity to provide employment services as needs continue to increase. This study examined the distribution of employment services among autistic people compared with those with intellectual disability using 2008-2016 data from the Centers for Medicare & Medicaid Services and the Rehabilitation Services Administration. Estimated need for employment services among autistic individuals was compared with capacity derived from VR service counts and a review of HCBS waivers. Although VR appeared to be absorbing short-term employment needs of autistic individuals, Medicaid was severely lacking-and losing ground-in serving those who needed longer-term employment services. VR far outpaced Medicaid in both the number of autistic people served and total expenditures across the study years. However, an estimated 1.98 million autistic adults did not receive employment services that could be critical to improving their health and well-being.

45 NIMH

Nominated article:

Schiltz HK, Clarke E, Rosen N, De La Rosa SG, Masjedi N, Christopher K, Lord C. A Longitudinal Mixed-Methods Characterization of Family Support from Adolescence to Young Adulthood in Autism and Other Developmental Disabilities. *J Autism Dev Disord*. 2023 Sep 5. [PMID: 37668851]

Justification from IACC member who nominated article:

This study used a mixed-methods approach to examine change and stability in formal and informal family support across the transition to adulthood. Caregivers of 126 individuals with autism completed a modified version of the Family Support Scale, including open-ended questions, at five time points from adolescence (age 16) into young adulthood (age 22). Caregivers reported that informal support from family members was the most frequently used, helpful, and valued source of support with relative stability across time. In contrast, the reported helpfulness, use, and value of formal support (e.g., professionals, schools) for caregivers declined over time. Qualitative content analyses revealed characteristics of highly valued support included support type (e.g., instrumental or emotional) and features of the support source (e.g., their understanding). There was a shift to valuing emotional support more than instrumental support over time, especially for caregivers of less able adults. Partnership and dependability emerged as highly valued features of the support source. These findings fit within a social convoy perspective and likely reflect the "service cliff" experienced by autistic individuals or people with developmental disabilities and their families. As social networks shrink over time and formal services are less readily available in adulthood, remaining sources of support, particularly from family members, become increasingly important.

46 NIMH

Nominated article:

Stein Duker LI, Como DH, Jolette C, Vigen C, Gong CL, Williams ME, Polido JC, Floríndez-Cox LI, Cermak SA. Sensory Adaptations to Improve Physiological and Behavioral Distress During Dental Visits in Autistic Children: A Randomized Crossover Trial. *JAMA Netw Open*. 2023 Jun 1;6(6):e2316346. [PMID: 37266941]

Justification from IACC member who nominated article:

Autistic children have poorer oral health and greater oral care challenges, which are often associated with sensory over-responsivity, than neurotypical peers. It is important to identify innovative solutions enabling dentists to successfully perform standard clinic-based procedures for this population. Researchers sought to determine whether a sensory-adapted dental environment (SADE) reduces physiological and behavioral distress in autistic children undergoing dental cleanings, compared with a regular dental environment (RDE). This randomized crossover trial was conducted at a pediatric dentistry clinic in a large urban children's hospital between May 2016 and April 2022. Each child underwent 1 RDE and 1 SADE dental cleaning, administered in randomized and counterbalanced order approximately 6 months apart. SADE included modified visual, auditory, and tactile stimuli. Findings suggest that using SADE was safe and efficacious in decreasing physiological and behavioral distress during dental care. This is important because enhancing oral care is critical for autistic children; this intervention may also be beneficial for populations beyond autism.

47 SSA

Nominated article:

Taylor JL, DaWalt LS, Burke MM, Slaughter JC, Xu M. Improving parents' ability to advocate for services for youth with autism: A randomized clinical trial. Autism Res. 2023 Oct;16(10):1976-1988. [PMID: 37551665]

Justification from IACC member who nominated article:

Youth with autism face challenges accessing services as they transition to adulthood. Improving parents' ability to advocate for services on behalf of their youth may be an effective way to improve service access and ultimately transition outcomes in this group. In this study, researchers tested whether participating in an advocacy intervention improved parents' ability to advocate for services for their transition-aged youth with autism. One hundred and eighty-five parents of youth with autism ages 16–26, recruited across three states in the U.S., were randomized to one of two experimental conditions. The treatment condition received the ASSIST program, a 12-week (24-h) group-based intervention. The control condition received the same written materials as the treatment condition. Primary outcomes for this report—parent advocacy ability—were collected at baseline (prior to randomization) and post-test (immediately after the treatment group finished the 12-week program) by survey. After taking ASSIST, the treatment condition had greater gains than controls in knowledge of adult services (B = -1.62, CI = -2.33 to -0.90) and perceived advocacy skills (B = -0.19, CI = -0.33 to -0.04). Participants who had less knowledge, lower perceived advocacy skills, and less active coping styles at baseline had the greatest treatment gains. Findings suggest that ASSIST is effective in improving parent advocacy ability and may be most beneficial for parents who experience greater challenges advocating for their son/daughter with autism. Future research will examine whether gains in parent advocacy ability leads to improvements in service access and post-school outcomes for transition-age youth with autism.

		Lifesnan
40	A118	Lifespan
48	NIMH	Nominated article:
		Chan DV, Doran JD. Mental health counseling is rated as most helpful by autistic
		adults: Service perspectives in adulthood. <i>Autism</i> . 2023 Sep
		7:13623613231197446. [PMID: 37679948]
		Justification from IACC member who nominated article:
		In this study, autistic adults provided perspectives about service use and
		community participation. They completed surveys, interviews, and carried a global
		positioning system (GPS) tracker. These participants also answered questions
		about which services are most helpful in adulthood, things that make it hard to
		use services, and what services they needed. Most participants used two services
		in the past 2 years: mental health and employment services. Adults who were
		currently seeing a mental health counselor were more likely to be working full-
		time and visit more locations in the community compared to those who were not
		seeing a counselor. Mental health services were reported as the most helpful
		service they received as adults, followed by employment services. These findings
		suggest a need for both mental health and employment services for autistic
40	201	adults, as indicated by the perspectives of autistic adults themselves.
49	DOL	Nominated article:
		Davies J, Heasman B, Livesey A, Walker A, Pellicano E, Remington A. Access to
		employment: A comparison of autistic, neurodivergent and neurotypical adults'
		experiences of hiring processes in the United Kingdom. <i>Autism</i> . 2023
		Aug;27(6):1746-1763. [PMID: 36597955] Justification from IACC member who nominated article:
		This mixed methods study examined the experiences of job hiring in the United
		Kingdom by comparing people on the autism spectrum, other neurodivergent
		people, and neurotypical people. It surveyed 377 participants, including 225
		autistic people, 64 non-autistic neurodivergent people, and 88 neurotypical
		people. Findings emphasized unique social barriers faced by people on the autism
		spectrum, such as pressure to mask, discrimination, and stigma. Participants
		emphasized the need for more practical job recruitment strategies, including work
		trials; greater clarity about what to expect for job duties; and improvements in
		recruiters' understanding of hiring barriers. Participants also stressed their shared
		concerns for more flexible hiring processes, the importance of a supportive
		workplace environment, and frustrations with current focuses on social skills for
		work.
50	SSA	Nominated article:
		Gibbs V, Pellicano E. 'Maybe we just seem like easy targets': A qualitative analysis
		of autistic adults' experiences of interpersonal violence. Autism. 2023
		Oct;27(7):2021-2034. [PMID: 36691297]
		Justification from IACC member who nominated article:
		Research has consistently shown that autistic children are more likely to be
		victimized than non-autistic children. More recently, studies have also found that
		autistic adults report experiencing more violence than non-autistic adults
		however the circumstances surrounding these incidents and the reasons for this
		are not clear. Researchers wanted to learn more about violence during adulthood

for autistic people including what led up to these incidents and what happened afterwards. They spoke to 22 autistic adults who had experienced violence and analyzed what they said to look for common themes. They stated that violence was commonplace in their own lives and in the lives of other autistic people that they know, so much so that they had even come to expect it to happen. They also talked about the negative effect these experiences had on their mental health, the way they felt about themselves and their ability to trust people. This was made worse if people did not believe them when they disclosed what had happened to them. They stated that certain autistic characteristics might make them more vulnerable like being too trusting or going along with people just to please them. They thought that some of these characteristics had been shaped by their experiences, especially being told that that their thoughts, feelings or behaviors were wrong and being pressured to change the way they behaved to 'fit in.' These findings are important in helping to understand how to improve the personal safety of autistic people. DOL 51 Nominated article: Hedley D, Hedley DF, Walkowiak E, Bury SM, Spoor JR, Shiell A. Cost-benefit analysis of a non-government organization and Australian government collaborative supported employment program for autistic people. Autism. 2023 Jul;27(5):1377-1390. [PMID: 36457180] Justification from IACC member who nominated article: This study conducted a cost-benefit analysis of a three-year supported employment program for autistic adults, which was run by the Australian government. It examined direct costs for the program, the benefits for the participants, and avoided costs for government, and the analysis included 56 participants on the autism spectrum. The findings showed that the supported employment program produced a high benefit ratio for the Australian government. Underlying factors included increases in wages and hours worked for people on the autism spectrum and reduced costs for both the social welfare and unemployment benefit systems. Most participants of the supported employment program transitioned into open employment after they had completed the program. 52 NIMH **Nominated article:** Hong J, DaWalt LS, Taylor JL, Haider A, Mailick M. Autism through midlife: trajectories of symptoms, behavioral functioning, and health. J Neurodev Disord. 2023 Nov 3;15(1):36. [PMID: 37919643] Justification from IACC member who nominated article: Using an accelerated longitudinal design with 9 waves of data, developmental trajectories were estimated from adolescence through midlife and into early old age in a community-based cohort (n = 406). The overall aim was to determine whether there were age-related increases or decreases, whether the change was linear or curvilinear, and whether these trajectories differed between those who

have ID and those who have average or above-average intellectual functioning. Subsequently, the slopes of the trajectories were evaluated to determine if they differed depending on age when the study began, with the goal of identifying possible cohort effects. There were significant trajectories of age-related change for all but one of the measures, although different measures manifested different patterns. Most autism symptoms improved through adulthood, while health

worsened. An inverted U-shaped curve best described change for repetitive behavior symptoms, activities of daily living, maladaptive behaviors, and social interaction. For these measures, improved functioning was evident from adolescence until midlife. Then change leveled off, with worsening functioning from later midlife into early older age. Additionally, differences between autistic individuals with and without ID were evident. Although those who have ID had poorer levels of functioning, there were some indications that those without ID had accelerating challenges in their aging years that were not evident in those with ID - increases in medications for physical health problems and worsening repetitive behaviors. Meeting the needs of the increasingly large population of autistic adults in midlife and old age requires a nuanced understanding of life course trajectories across the long stretch of adulthood and across multiple domains.

53 NIMH, CDC

Nominated article:

Hughes MM, Kirby AV, Davis J, Bilder DA, Patrick M, Lopez M, DaWalt LS, Pas ET, Bakian AV, Shaw KA, DiRienzo M, Hudson A, Schwenk YD, Baroud TM, Washington A, Maenner MJ. Individualized Education Programs and Transition Planning for Adolescents With Autism. *Pediatrics*. 2023 Jul 1;152(1):e2022060199. [PMID: 37345494]

Justification from IACC member who nominated article:

NIMH: This study sought to examine the contents of individualized education programs (IEPs) of adolescents with autism, including postsecondary transition goals, services, and changes in special education classification over time. This study involved a longitudinal population-based surveillance cohort from the Autism Developmental Disabilities Monitoring Network from 2002 to 2018 in 3 catchment areas in the United States. Researchers found that 92% of adolescents with autism had an IEP including a transition plan. Those without intellectual disability (ID) were more likely to have postsecondary education and employment goals and have those goals be to pursue higher education or competitive employment compared with those with ID. Forty-one percent of adolescents with autism had a postsecondary living arrangement goal. Although 28% of adolescents with autism received school-based mental health services, none of these adolescents were Black; additionally, 15% of those with ID received mental health services compared with 34% without ID. The percentage of adolescents with autism served under an autism classification increased from 44% at age 8 years to 62% by age 16.

CDC: This study identified potential gaps and disparities in educational services and transition planning among adolescents with autism, helping to guide support for schools and families. The contents of school-based post-high school transition planning are poorly understood among adolescents with autism spectrum disorder.

54 HRSA

Nominated article:

Kahn NF, Sequeira GM, Reyes V, Garrison MM, Orlich F, Christakis DA, Aye T, Conard LAE, Dowshen N, Kazak AE, Nahata L, Nokoff NJ, Voss RV, Richardson LP. Mental Health of Youth With Autism Spectrum Disorder and Gender Dysphoria. *Pediatrics*. 2023 Dec 1;152(6):e2023063289. [PMID: 37909059]

Justification from IACC member who nominated article:

		This study illustrates the increased likelihood for anxiety and depression that youth with co-occurring ASD/GD experience and highlights the need for developmentally appropriate mental health services and interventions for youth
55	SSA	with co-occurring ASD/GD. Nominated article:
	JJA	Kim SA, Baczewski L, Pizzano M, Kasari C, Sturm A. Discrimination and Harassment Experiences of Autistic College Students and Their Neurotypical Peers: Risk and Protective Factors. <i>J Autism Dev Disord</i> . 2023 Dec;53(12):4521-4534. [PMID: 36103077]
		Justification from IACC member who nominated article:
		This study examines autistic and non-autistic college students' experiences of discrimination and harassment. A nationwide survey was used to match autistic students (N = 290) and non-autistic students (N = 290) on co-occurring diagnoses and demographic characteristics. Multiple regression and interaction analysis revealed that faculty support was protective against discrimination and
		harassment regardless of autism status. Habits of mind was particularly protective
		for autistic students against harassment. Any student who engaged in school-facilitated events was more likely to experience discrimination and harassment,
		but the likelihood was heightened for autistic students. Findings highlight the
		importance of faculty support in fostering positive interpersonal experiences on
		campus and demonstrate the need to address deeper college campus issues with
		respect to neurodiversity.
56	NIMH	Nominated article:
		Lai MC, Saunders NR, Huang A, Artani A, Wilton AS, Zaheer J, Ameis SH, Brown HK, Lunsky Y. Self-Harm Events and Suicide Deaths Among Autistic Individuals in Ontario, Canada. <i>JAMA Netw Open</i> . 2023 Aug 1;6(8):e2327415. [PMID: 37552480] Justification from IACC member who nominated article:
		This study sought to examine sex-stratified rates of self-harm events and suicide death among autistic individuals compared with non-autistic individuals, as well as the associated sociodemographic and clinical factors. In this cohort study in Ontario, Canada, autistic females had an 83% increased likelihood and autistic males had a 47% increased likelihood of self-harm compared with non-autistic individuals, when accounting for neighborhood income and rurality, intellectual disabilities, and psychiatric diagnoses. The crude hazard ratio showed that autistic females had a 98% increased likelihood and autistic males had a 34% increased likelihood of suicide death, but these increases were associated with psychiatric diagnoses. This study suggests that psychiatric diagnoses were significantly associated with likelihood of self-harm and especially suicide among autistic females and males.
57	NIMH	Nominated article:
		Liu S, Larsson H, Kuja-Halkola R, Lichtenstein P, Butwicka A, Taylor MJ. Age-related physical health of older autistic adults in Sweden: a longitudinal, retrospective, population-based cohort study. <i>Lancet Healthy Longev</i> . 2023 Jul;4(7):e307-e315. [PMID: 37295448]
		Justification from IACC member who nominated article:
		Research of health outcomes in older autistic adults (≥45 years) is scarce, and little is known about whether intellectual disability and sex affect the health outcomes of this population. The aim of this study was to investigate the association

between autism and physical health conditions in older adults and to examine these associations by intellectual disability and sex. Researchers conducted a longitudinal, retrospective, population-based cohort study of the Swedish population born between Jan 1, 1932, and Dec 31, 1967. Their findings indicate that older autistic adults are at substantially increased likelihood of age-related physical conditions and injuries compared with non-autistic adults. These findings highlight the need for collaborative efforts from researchers, health services, and policy makers to provide older autistic individuals with the necessary support to attain healthy longevity and a high quality of life.

58 NIMH, Julie Lounds Taylor

Nominated article:

Malow BA, Qian Y, Ames JL, Alexeeff S, Croen LA. Health conditions in autism: Defining the trajectory from adolescence to early adulthood. *Autism Res.* 2023 Jul;16(7):1437-1449. [PMID: 37377040]

Justification from IACC member who nominated article:

NIMH: Many medical and psychiatric conditions affecting autistic individuals may begin in childhood, although few longitudinal studies have been conducted to examine prevalence rates of these conditions from adolescence into early adulthood. In this study, researchers analyzed the longitudinal trajectory of health conditions in autistic youth, compared to age and sex-matched non-autistic youth, transitioning from adolescence into early adulthood in a large integrated health care delivery system. The percent and modeled prevalence of common medical and psychiatric conditions increased from age 14 to 22 years, with autistic youth having a higher prevalence of most conditions than non-autistic youth. The most prevalent conditions in autistic youth at all ages were obesity, neurological disorders, anxiety, and ADHD. The prevalence of obesity and dyslipidemia rose at a faster rate in autistic youth compared to non-autistic youth. By age 22, autistic females showed a higher prevalence of all medical and psychiatric conditions compared to autistic males. These findings emphasize the importance of screening for medical and psychiatric conditions in autistic youth, coupled with health education targeted at this population, to mitigate the development of adverse health outcomes in autistic adults.

Julie Lounds Taylor: This study examined frequency of physical and mental health conditions over time for autistic transition-aged youth and a non-autistic comparison group, using electronic health records. The authors examined conditions longitudinally from ages 14 to 22, which is a significant innovation as most of the research on health conditions in autistic individuals uses cross-sectional data. They found that rates of many conditions were higher among autistic youth than non-autistic youth, with increases that were similar between groups over time. Notable exceptions were obesity and dyslipidemia, which started out higher among autistic youth than non-autistic youth at age 14, and increased more rapidly among autistic youth (than non-autistic youth) over the age period under study. Findings suggest that the transition to adulthood may be a particularly pivotal time to address concerns related to obesity and dyslipidemia in autistic populations.

59 Dena Gassner

Nominated article:

McNair ML, Keenan EG, Houck AP, Lerner MD. Seeking contexts that promote neurodiverse social success: Patterns of behavior during minimally-structured

interaction settings in autistic and non-autistic youth. *Dev Psychopathol*. 2023 Aug 18:1-16. [PMID: 37593821]

<u>Justification from IACC member who nominated article:</u>

While peer interaction differences are considered a central feature of autism, little is known regarding the nature of these interactions via directly observed measurement of naturalistic (i.e., minimally structured) groups of autistic and non-autistic adolescent peers. Autistic and non-autistic adolescents participated in a 50-minute, minimally structured, naturalistic peer interactions with activities of varying social demands: eating in a room with peers, playing a physically interactive game, and playing a verbal game. While autistic youth exhibited fewer overall interaction behaviors than non-autistic youth, the two groups did not differ in amount of positive, negative, and low-level interaction behaviors. Within activities, autistic and non-autistic youth only differed in positive interaction behaviors during the context of a verbal social demand. Youth who displayed more positive interaction behaviors during this same activity had less autism symptomatology. These results point toward subtle differences in social demands across naturalistic settings that can either support or impede prosocial interaction for autistic youth, providing a guidepost for identifying settings that best promote social success for neurodiverse populations.

60 SSA <u>Nominated article:</u>

Penton T, Bowling N, Vafeiadou A, Hammond C, Bird G, Banissy MJ. Attitudes to Interpersonal Touch in the Workplace in Autistic and non-Autistic Groups. *J Autism Dev Disord*. 2023 Dec;53(12):4731-4743. [PMID: 36083393]

<u>Justification from IACC member who nominated article:</u>

Unemployment and underemployment have consistently been shown to be higher in autistic adults relative to non-autistic adults. This may be due, in part, to a lack of workplace accommodations being made for autistic people. One factor that may contribute to employment inequalities in autistic people is differences in attitudes towards interpersonal touch. This study acts as a preliminary investigation into whether employed autistic and non-autistic participants differ in their attitudes towards touch in the workplace, and in their loneliness and wellbeing. The current dataset was drawn from a larger online survey (the Touch Test) designed to explore attitudes and experiences towards touch. Researchers found that employed autistic participants had more negative attitudes to general, social and workplace touch relative to non-autistic participants. Autistic participants also experienced greater loneliness and reduced wellbeing. Attachment-related anxiety was the only significant predictor of wellbeing in employed autistic adults. However, attachment-related anxiety, general attitudes to touch and the role of touch in the workplace predicted wellbeing in employed non-autistic adults. With regards to loneliness, general attitudes to touch and the role of touch in the workplace predicted loneliness in autistic participants. Researchers also replicated the finding that a greater proportion of autistic participants were unemployed relative to non-autistic participants. Collectively, this research highlights the importance of considering touch in research investigating employment, and its impact on loneliness and wellbeing, in autistic participants.

61 DOL Nominated article:

Pryke-Hobbes A, Davies J, Heasman B, Livesey A, Walker A, Pellicano E, Remington A. The workplace masking experiences of autistic, non-autistic neurodivergent and neurotypical adults in the UK. *PLoS One*. 2023 Sep 6;18(9):e0290001. [PMID: 37672533]

Justification from IACC member who nominated article:

This qualitative study from the United Kingdom aimed to address the gap in limited research on the social context of workers on the autism spectrum masking in the workplace. It compared the masking experiences of 472 participants, including 285 autistic people, 88 non-autistic neurodivergent people, and 99 neurotypical people. All three groups identified masking as an adaptive response to a range of socially grounded workplace challenges. They also described it as a key strategy to help safeguard against negative employment and social outcomes. Participants on the autism spectrum and other neurodivergent participants reported unique pressures that underlay their masking. Namely, they emphasized limited understanding of neurodiversity in workplaces and greater society on a broader basis. Participants also highlighted the detrimental effects of masking on well-being and the value of openness about identities in the workplace.

62 NIMH

Nominated article:

Ratto AB, Bascom J, daVanport S, Strang JF, Anthony LG, Verbalis A, Pugliese C, Nadwodny N, Brown LXZ, Cruz M, Hector BL, Kapp SK, Giwa Onaiwu M, Raymaker DM, Robison JE, Stewart C, Stone R, Whetsell E, Pelphrey K, Kenworthy L. Centering the Inner Experience of Autism: Development of the Self-Assessment of Autistic Traits. *Autism Adulthood*. 2023 Mar 1;5(1):93-105. [PMID: 36941856]

Justification from IACC member who nominated article:

Current tools for identifying autism are critiqued for their lack of specificity and sensitivity, especially in autistic people who are older, have higher verbal ability or significant compensatory skills, and are not cisgender boys. In this study, researchers attempted to develop a clinical self-report measure of autistic traits as described by autistic people. The measure was developed under the leadership of two autistic researchers and constructed by leveraging descriptions of autism by autistic people to generate items designed to encompass the range of the autistic experience, using strength-based, accessible language. The team utilized iterative feedback from a panel of autistic experts to refine and enhance the measure, called the Self Assessment of Autistic Traits (SAAT). It is intended for people 16 years or older and uses a format that is designed to increase its accessibility and acceptability for autistic respondents. Future work will report on the preliminary psychometrics of the SAAT, with a long-term goal of advancing our understanding of the inner autistic experience and enhancing the clinical and scientific assessment of autism.

63 NIMH

Nominated article:

Schiltz H, Sterrett K, Singer H, Lord C. Anxiety, depression, and well-being in autistic adults and adults with other developmental disabilities: A longitudinal cross-lagged analysis. *Autism Res.* 2023 Jul;16(7):1425-1436. [PMID: 37376983]

<u>Justification from IACC member who nominated article:</u>

This study sought to understand links between anxiety and depression over time in autistic adults and adults with developmental disabilities (DD), and how these conditions impact specific aspects of positive well-being. A sample of 130 adults with autism or other DDs and their caregivers were drawn from a longitudinal

study. Participants complete measures of anxiety, depression, and well-being. Based on caregiver-report, anxiety symptoms predicted later depressive symptoms but depressive symptoms did not predict later anxiety; the opposite pattern was identified for self-report. Aspects of positive well-being (purpose in life, self-acceptance, personal growth) demonstrated differential links with anxiety and depression. These findings highlight the utility of a transdiagnostic approach to mental health services for autistic adults and adults with DDs, and the need to monitor for anxious or depressive symptoms in autistic adults and adults with DDs presenting with depression or anxiety, respectively.

64 HRSA

Nominated article:

Steinberg H, Garfield T, Roux A, Shea L, Shattuck P. Same Transition, Different Perspectives: Comparing Dyadic Interviews with Autistic Young Adults and Parents. *Autism in Adulthood*. 2023 Jul 4. https://doi.org/10.1089/aut.2022.0095

Justification from IACC member who nominated article:

The transition to young adulthood can be a turbulent life stage, and this is often magnified for autistic youth. Young adults frequently profess different goals and values than their parents. While there is some indication in autism research about how parents, and to a lesser extent, autistic young adults, feel about this transition, little research leverages dyadic interviews with both populations or has used this method with Black and/or low-income families. This study explored how autistic youth and their parents thought about and experienced the transition to adulthood out of an urban, low-resourced school district. Most research on autistic people becoming adults is based on White people with more cultural and financial resources and does not ask autistic people themselves or their families with them. Research is needed to improve transition outcomes for these underresearched and underserved groups.

65 Jenny Mai Phan

Nominated article:

Strang JF, Wallace GL, Michaelson JJ, Fischbach AL, Thomas TR, Jack A, Shen J, Chen D, Freeman A, Knauss M, Corbett BA, Kenworthy L, Tishelman AC, Willing L, McQuaid GA, Nelson EE, Toomey RB, McGuire JK, Fish JN, Leibowitz SF, Nahata L, Anthony LG, Slesaransky-Poe G, D'Angelo L, Clawson A, Song AD, Grannis C, Sadikova E, Pelphrey KA, Gendaar Consortium, Mancilla M, McClellan LS, Csumitta KD, Winchenbach MR, Jilla A, Alemi F, Yang JS. The Gender Self-Report: A multidimensional gender characterization tool for gender-diverse and cisgender youth and adults. *Am Psychol*. 2023 Jan 30. [PMID: 36716136]

Justification from IACC member who nominated article:

Given that approximately 13% of autistic individuals experience gender diversity, this study addresses a critical gap in autism research for precision clinical healthcare. This study used a data-driven approach in conducting several validity analyses using the Gender Self-Report (GSR) with 1,654 individuals (>33% autistic; aged 10-77 years). The GSR had been developed and refined though a 12-year community-driven approach. The GSR aims to give voice to individual's experiences of their gender and provides a community-developed gender advocacy tool with 30-self-report items. Results showed that there were two stable factors: Nonbinary Gender Diversity and Female-Male Continuum and found to be internally reliable. The GSR may facilitate more equitable inclusion of gender diverse individuals who do not have, understand, and/or use specialized

self-descriptors for gender; this situation may be more common among autistic individuals and those with less exposure to gender diverse communities.

66 DOL

Nominated article:

Szechy KA, Turk PD, O'Donnell LA. Autism and employment challenges: The double empathy problem and perceptions of an autistic employee in the workplace. *Autism in Adulthood*. 2023 Aug 17.

https://doi.org/10.1089/aut.2023.0046

Justification from IACC member who nominated article:

This study investigated factors that can underly social challenges for people on the autism spectrum in the workplace in the U.S. It compared two competing explanations for key barriers faced by autistic people: assumed impairments in theory of mind and the double empathy problem. The former worldview attributes autistic people's social challenges to their impairments. In contrast, the latter worldview asserts that mutual challenges can arise from differences in cognitive processing styles and perception by autistic and non-autistic people. The study surveyed participants on the autism spectrum (81) and non-autistic participants (173) about how they interpreted a vignette they read about an employee facing challenges in the workplace. The results showed that a significantly greater proportion of autistic participants accurately interpreted the behavior of the story's employee when compared with non-autistic participants. Participants on the autism spectrum who scored higher on the behavioral interpretation of the vignette had a significantly higher mean for self-reported autism traits, when compared with other participants on the autism spectrum. These findings showed support for evidence of the double empathy problem for social barriers that are faced by people on the autism spectrum in the workplace.

67 SSA

Nominated article:

Togher K, Jay S. Disclosing an autism diagnosis: A social identity approach. *Autism Res.* 2023 Oct;16(10):1934-1945. [PMID: 37548311]

Justification from IACC member who nominated article:

Autistic people face a difficult dilemma around whether or not to disclose their diagnosis because autistic people are a stigmatized social group. The central aim of this study was to examine if a social identity approach could be useful in understanding the factors that predict the likelihood of autistic adults disclosing their autism diagnosis in social settings, in the workplace, in educational settings and in the family. The social identity approach predicts that autistic people may cope with this dilemma by using an individualistic strategy to distance themselves from their autistic social identity. Alternatively, they may embrace their autistic social identity and use a collective strategy to resist stigma and advocate for autistic people. Researchers presented a survey based cross-sectional study (n = 175) with autistic adults living in Ireland. Participants completed a series of measures; autism social identification, stigma consciousness, and individualistic and collective strategy use to assess disclosing in the four settings. The overall models in each of the four regressions were significant. Autism social identification positively predicted disclosure in social, workplace and educational settings, while stigma consciousness negatively predicted disclosure in the family and in the workplace. Interestingly, over and above these predictors individualistic strategy use negatively predicted disclosure in each of the four settings, while collective strategy use positively predicted disclosure in social, educational and

		family settings. This approach was useful for explaining autistic adults' strategies to cope with the complex disclosure dilemma.
68	Julie Lounds Taylor	Nominated article: Vincent J, Ralston K. Uncovering employment outcomes for autistic university graduates in the United Kingdom: An analysis of population data. <i>Autism</i> . 2023
		Justification from IACC member who nominated article: This is the first study, to my knowledge, to examine employment outcomes for autistic college students. In the past, people have cited very high unemployment numbers for autistic college graduates (80%), but that doesn't seem to be based in data. In this large survey dataset of college graduates in the U.K., The authors found that rates of full-time employment for autistic college graduates were one-half what they were for graduates without disabilities. They also found higher rates of unemployment for autistic college graduates than graduates without disabilities (15% vs. 6%), and lower pay for those in full-time positions. In contrast
		to previous research that showed high rates of STEM majors and jobs, showed no substantial differences between autistic and non-autistic college students in the academic programs that they were pursuing. Though the data is limited to the U.K, this study finally gives us some estimates of rates of employment and unemployment among autistic individuals who complete a college degree.
69	DOL	Nominated article: Wilson KP, Marsack-Topolewski C, Smith D, Knollman G. Caregiver perceptions and experiences surrounding employment of their adult-aged children on the autism spectrum. Family Relations. 2023 Aug 14;1-17. https://doi.org/10.1111/fare.12932
		Justification from IACC member who nominated article: This qualitative study sought to address the gap in limited research on caregivers' support of employment access for their adult-aged offspring. It conducted 51 semi-structured interviews with caregivers in the U.S. about their experiences and perceptions on employment access for autistic people. Findings described three key themes: a) motivation for employment and independence, b) variability of job training experiences, and c) negative experiences about employment access. Participants stressed key accessibility barriers and their investment in advocacy as caregivers for employment that matched their offspring's interests, strengths, and access needs. Caregivers whose offspring participated in school-based employment training programs perceived those programs to be more effective when compared with perceptions of caregivers whose offspring accessed programs after high school.

Infrastructure and Prevalence

70	CDC	Nominated article:
		Hughes MM, Shaw KA, DiRienzo M, Durkin MS, Esler A, Hall-Lande J, Wiggins L,
		Zahorodny W, Singer A, Maenner MJ. The Prevalence and Characteristics of
		Children With Profound Autism, 15 Sites, United States, 2000-2016. Public Health
		Rep. 2023 Apr 19:333549231163551. [PMID: 37074176]
		Justification from IACC member who nominated article:

In 2021 the Lancet Commission proposed using the term "profound autism" to help identify and support children and adults with autism who are most likely to have the greatest lifetime needs for supports and services based on the presence of co-occurring conditions, such as intellectual disability or being non-verbal. CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network applied this term to its surveillance population from 2000-2016 and in this report present the prevalence of 8-year-old children meeting this definition of profound autism and compare their characteristics to those of children with autism of the same age who did not meet the definition over this period.

71 NIMH

Nominated article:

Kahn NF, Sequeira GM, Garrison MM, Orlich F, Christakis DA, Aye T, Conard LAE, Dowshen N, Kazak AE, Nahata L, Nokoff NJ, Voss RV, Richardson LP. Co-occurring Autism Spectrum Disorder and Gender Dysphoria in Adolescents. *Pediatrics*. 2023 Aug 1;152(2):e2023061363. [PMID: 37395084]

Justification from IACC member who nominated article:

Autism and gender dysphoria (GD) frequently occur together. However, past research has primarily used smaller samples, limiting generalizability and the ability to assess further demographic variation. This study sought to examine the prevalence of co-occurring autism and GD diagnosis in adolescents and to identify any demographic differences. Results showed that a GD diagnosis was more prevalent among autistic youth compared to those without autism. Co-occurring autism/GD diagnoses were more prevalent among youth whose electronic medical record-reported sex was female and those using private insurance, and less prevalent among youth of color, particularly Black and Asian youth. These results could inform services that can help reduce health disparities in this population.

72 NIMH, SSA

Nominated article:

Rubenstein E, Tewolde S, Michals A, Fox M, Wang N. Prevalence of Autism Among Medicaid-Enrolled Adults. *JAMA Psychiatry*. 2023 Dec 1;80(12):1284-1287. [PMID: 37792361]

Justification from IACC member who nominated article:

NIMH: This study sought to estimate the prevalence of adults identified as autistic in Medicaid claims data and to examine the prevalence by year, age, and race and ethnicity to understand enrollment patterns. This cohort study used data from a longitudinal Medicaid claims cohort of enrollees aged 18 years or older with a claim for autism at any point from January 1, 2011, to December 31, 2019, and an approximately 1% random sample of all adult Medicaid enrollees. The data were analyzed between February 22 and June 22, 2023. Across 9 years, 403 028 unique adults had autism claims in their Medicaid records (25.7% female, 74.2% male, 3.3% Asian, 16.8% Black, 12.2% Hispanic, 0.8% Native American, 0.8% Pacific Islander, 74.3% White, and 4.2% of multiple races). Across all ages, autism prevalence increased from 4.2 per 1000 enrollees in 2011 to 9.5 per 1000 enrollees in 2019. The largest increase over the 9 years was in the 25- to 34-year age group (195%), and the smallest increase was in the 55- to 64-year age group (45%). The prevalence of White enrollees was at least 2 times that of the prevalence of every other racial group in all age categories. The study findings suggest that despite difficulties in identifying autism in adults, there is a considerable and growing population of autistic adults enrolled in Medicaid.

		SSA: With Medicaid claims cohort data, the authors provide insight to the increased prevalence of autism in adults, which in turn will have implication on the healthcare system, like increased enrollees within Medicaid in the near future. Furthermore, it affirms related literature regarding demographic information among adults with autism, as most are White (non-Hispanic) males. Moreover, it also highlights disparities in identification, particularly among Black and other minoritized groups.
73	HRSA	Nominated article:
		Schott W, Tao S, Shea L. Prevalence of high-risk conditions for severe COVID-19 among Medicaid-enrolled children with autism and mental health diagnoses in the United States. <i>Autism</i> . 2023 Oct;27(7):2145-2157. [PMID: 36799305]
		Justification from IACC member who nominated article:
		Children are at increased likelihood of varying severity of illness and even death
		from COVID-19. This study included 888,487 autistic children, 423,397 with any
		mental health condition and without autism, and 932,625 children without any of
		these diagnoses. Autistic children had over twice the odds of having any
		underlying conditions, when accounting for age, race, sex, and other
		characteristics. Mitigation measures in schools and other areas could minimize likelihood of short- and long-term impacts from COVID for autistic and all children.
74	NIMH	Nominated article:
		Sterrett K, Magaña MT, Gulsrud A, Paparella T, Kasari C. Predictors of Attrition in a
		Randomized Trial of a Social Communication Intervention for Infant-Toddlers at
		Risk for Autism. J Autism Dev Disord. 2023 Aug;53(8):3023-3033. [PMID:
		<u>35678946</u>]
		Justification from IACC member who nominated article:
		Addressing factors that make it more likely for families to drop out of early
		intervention trials will allow researchers to ensure that families reap the full benefits of participation. This study was an analysis of 78 children participating in
		a university-based randomized controlled trial of two 8-week long early
		intervention programs. Overall, attrition (i.e., dropping out of a study) through 8-
		weeks was low, approximately 13%, however by the one-year follow-up attrition
		rates were approximately 50%. The most consistent predictor of attrition was the
		distance that families had to travel to the university. These data highlight the
		importance of providing services and support (e.g., financial and logistic) during
		follow-up to families to maximize their participation.
75	SAMHSA	Nominated article:
		Yu X, Rahman MM, Carter SA, Lin JC, Chow T, Lurmann FW, Chen JC, Martinez MP,
		Schwartz J, Eckel SP, Chen Z, McConnell R, Xiang AH, Hackman DA. Neighborhood Disadvantage and Autism Spectrum Disorder in a Population With Health
		Insurance. JAMA Psychiatry. 2023 Nov 15:e234347. [PMID: 37966844]
		Justification from IACC member who nominated article:
		This was a retrospective cohort study led by University of Southern California
		authors based on data from Kaiser Permanente Southern California (KPSC) that
		examined electronic medical records of 318 372 children with health insurance,
		including 6357 children with autism spectrum disorder diagnoses, between 2001
		and 2014 and correlated with neighborhood disadvantage based on American
		Community Survey (Census) data. The authors found that neighborhood

		disadvantage as reflected in poverty, unemployment, female-headed households with children, public assistance, less than a high school education, bachelor's degree or greater, and professional occupation, was associated with an autism diagnosis among children with health insurance. This is important because it shows a potential connection between autism and socioeconomic status that has not been explored in depth.
76	NIMH	Nominated article:
		Zahorodny W, Shenouda J, Sidwell K, Verile MG, Alvarez CC, Fusco A, Mars A,
		Waale M, Gleeson T, Burack G, Zumoff P. Prevalence and Characteristics of
		Adolescents with Autism Spectrum Disorder in the New York-New Jersey
		Metropolitan Area. J Autism Dev Disord. 2023 Aug 29. [PMID: 37642865]
		Justification from IACC member who nominated article:
		Studies on autism prevalence have predominantly focused on school-age children.
		This study provides the first population-based data on the prevalence and
		expression of autism among adolescents in a large region of New Jersey. Data
		from 2014 was collected for adolescents aged 16-years using methods from the
		Autism and Developmental Disabilities Monitoring (ADDM) Network. The analysis
		found that ASD prevalence was 17.7 per 1,000 adolescents, with 1 in 55 males and
		1 in 172 females. However, a quarter of the individuals identified did not have a
		formal ASD diagnosis. High socioeconomic status was positively associated with
		ASD identification, and ASD prevalence among white adolescents was higher than
		Hispanic adolescents. A majority of adolescents with autism also had a co-
		occurring neuropsychiatric disorder. These results suggest that additional efforts
		are needed to ensure that all individuals with autism receive a diagnosis and the
		appropriate services and supports to improve health and well-being.
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