2020 Summary of Advances Nominations

Table of Contents

Question 1: Screening and Diagnosis

NIMH	Carbone PS, Campbell K, Wilkes J, Stoddard GJ, Huynh K, Young PC, Gabrielsen TP. Primary Care Autism Screening and Later Autism Diagnosis. Pediatrics. 2020 Aug;146(2):e20192314. doi: 10.1542/peds.2019-2314. Epub 2020 Jul 6. PMID: 32632024; PMCID: PMC7397730.
	This research study aimed to identify the proportion of children screened by the Modified Checklist for Autism in Toddlers (M-CHAT), characteristics associated with screen completion, and associations between autism spectrum disorder (ASD) screening and later ASD diagnosis. The data were drawn from 36,233 toddlers seen during their 18- and 24-month well-child visits between 2013-2016. Approximately 73% of children were screened, and 1.4% were eventually diagnosed with ASD. Hispanic children and those from lower socioeconomic backgrounds were least likely to be screened. While there was no difference in the age of ASD diagnosis in children who were screened versus those who were not, children who did screen positive were diagnosed 10 months earlier than children who were not screened. The researchers also noted that family physicians rarely screen for ASD, possibly because the American Academy of Family Physicians does not currently recommend universal ASD screening. This represents an important opportunity to increase ASD screening in the U.S. as family physicians account for 16-21% of the provision of pediatric care.
OARC	Carpenter KLH, Hahemi J, Campbell K, Lippmann SJ, Baker JP, Egger HL, Espinosa S, Vermeer S, Sapiro G, Dawson G. Digital Behavioral Phenotyping Detects Atypical Pattern of Facial Expression in Toddlers with Autism. Autism Res. 2021 Mar;14(3):488-499. doi: 10.1002/aur.2391. Epub 2020 Sep 14. PMID: 32924332; PMCID: PMC7920907.
	Behavioral observation as a tool to screen for ASD, while more objective, is expensive, time-consuming, and requires significant expertise. In this study, the authors test a tablet-based behavioral assessment to detect differences in facial expression of 104 toddlers with and without ASD while watching brief movies. Children without ASD more often displayed raised eyebrows and an open mouth, indicative of engagement/interest, while children with ASD more frequently displayed a neutral expression. The results from this study suggest that computational coding of facial movements and expression via a tablet-based assessment can detect differences in affective expression, one of the early core features of ASD, and potentially be scaled for more objective ASD screening.
OARC	Constantino JN, Abbacchi AM, Saulnier C, Klaiman C, Mandell DS, Zhang Y, Hawks Z, Bates J, Klin A, Shattuck P, Molholm S, Fitzgerald R, Roux A, Lowe JK, Geschwind DH. Timing of the Diagnosis of Autism in African American Children. Pediatrics. 2020 Sep;146(3):e20193629. doi: 10.1542/peds.2019-3629. PMID: 32839243; PMCID: PMC7461218.
	African American children affected by ASD experience delays in diagnosis and obstacles to service access, with twice the rate of comorbid intellectual disability (ID) and higher rates of misdiagnosis compared to non-Hispanic white children. This study analyzed data from the largest-available repository of diagnostic and phenotypic information on African American children with ASD to determine the variation of outcomes within the cohort. Researchers found that the average age of ASD diagnosis was around 65 months, which was on average 3 years after parents first had concerns

	about their children's development. Additionally, variation in cognitive outcomes were not explained by sociodemographic or familial factors previously associated with variations in IQ. These findings demonstrate a pressing need to determine if broad implementation of timely diagnosis and high-quality early intervention can reduce the proportion of African American children with autism and co-occurring ID.
OARC	Harris JF, Coffield CN, Janvier YM, Mandell D, Cidav Z. Validation of the Developmental Check-In Tool for Low-Literacy Autism Screening. Pediatrics. 2021 Jan;147(1):e20193659. doi: 10.1542/peds.2019-3659. Epub 2020 Dec 10. PMID: 33303635.
	Significant disparities exist in identification of ASD in children from low-income and racial/ethnic minority families where English is not the primary language. The Developmental Check-In (DCI) is a visual ASD screening tool that has been shown to be effective at discriminating between ASD versus non-ASD in a young, underserved sample at high-risk for ASD. This study tests the DCI among a general sample of 624 underserved children aged 24 to 60 months recruited through Head Start and Early Head Start programs. Parents, primarily Hispanic with reported high school education or less and had public or no insurance, completed the DCI, Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F) and Social Communication Questionnaire. The results demonstrated that 24 of 26 DCI items discriminated ASD from non-ASD, indicating that the DCI is a promising ASD screening tool for young, underserved children, particularly for those with low literacy levels or limited English proficiency.
CDC	Lipkin PH, Macias MM, Baer Chen B, Coury D, Gottschlich EA, Hyman SL, Sisk B, Wolfe A, Levy SE. Trends in Pediatricians' Developmental Screening: 2002-2016. Pediatrics. 2020 Apr;145(4):e20190851. doi: 10.1542/peds.2019-0851. Epub 2020 Mar 2. PMID: 32123018.
	This research study aimed to describe trends in pediatricians' knowledge, attitudes, and practices regarding screening and referring children for developmental problems including autism spectrum disorder. The researchers analyzed American Academy of Pediatrics Periodic Survey data from 2002 (response rate = 58%; N = 562), 2009 (response rate = 57%; N = 532), and 2016 (response rate = 47%, N = 469). In 2016, on average, pediatricians reported referring 59% of their at-risk patients to early intervention (EI), up from 41% in 2002 and pediatricians in 2016 were more likely than in 2002 to report being "very likely" to refer a patient with global developmental delay, milestone loss, language delay, sensory impairment, motor delays, and family concern to EI. To sustain this progress, additional efforts are needed to enhance referral systems, improve EI programs, and provide better tracking of child outcomes.
HRSA	Locke J, Ibanez LV, Posner E, Frederick L, Carpentier P, Stone WL. Parent Perceptions About Communicating With Providers Regarding Early Autism Concerns. Pediatrics. 2020 Apr;145(Suppl 1):S72-S80. doi: 10.1542/peds.2019-1895J. PMID: 32238533.
	Long delays between parents' initial concern about their child's development and a subsequent autism spectrum diagnosis are common. This qualitative study was designed to gain insights from parents of young children with ASD about their experiences communicating with primary care providers with the goal of identifying strategies for improving conversations and decision-making regarding the early detection of ASD. Eight themes related to communication about early ASD concerns emerged: characteristics of the child that caused parental concerns, the response of others when the parent brought up concerns, how concerns were brought up to the

	parent by others, parental responses when others mentioned concerns, information seeking, barriers to and facilitators of acting on concerns, and recommendations to providers. Parent responses suggest the need for increased use of shared decision-making strategies and areas for process improvements.
NICHD	Major S, Campbell K, Espinosa S, Baker JP, Carpenter KL, Sapiro G, Vermeer S, Dawson G. Impact of a digital Modified Checklist for Autism in Toddlers-Revised on likelihood and age of autism diagnosis and referral for developmental evaluation. Autism. 2020 Oct;24(7):1629-1638. doi: 10.1177/1362361320916656. Epub 2020 May 28. PMID: 32466674; PMCID: PMC7541635
	This project was conducted in a primary care clinic where a universal ASD screening policy was implemented for all children seen for 18- and 24-months' well-child visits. This study compared the paper and pencil version of the M-CHAT-R to a tablet or digital version of the M-CHAT-R. Results showed that the likelihood of receiving referral for an ASD developmental evaluation was increased when patients were screened with the tablet screener. While the difference in the age of referral between the two groups was not statistically significant, the mean difference of 4 months (paper group=26.8 months, digital group=23.1) is of high clinical importance. The investigators noted that the primary care physicians benefited from the automatic scoring feature of the tablet and the information provided by the tablet.
ED	Mozolic-Staunton B, Donelly M, Yoxall J, Barbaro J, Early detection for better outcomes: Universal developmental surveillance for autism across health and early childhood education settings. Research in Autism Spectrum Disorders. 2020 Mar;71 101496, ISSN 1750-9467. doi: 10.1016/j.rasd.2019.101496
	The SACS (Social Attention and Communication Surveillance tool) has been developed and validated as a single-step, population-level ASD screening tool for primary health-care professionals. In a study with 125 nurses, 60 early childhood professionals, and over 14,000 children, the researchers investigated whether the SACS could also be used as a universal screening tool by early childhood educational professionals. They compared SACS-R data and data from another screening tool (PEDS Path ASD), from both community heath settings and early childhood education settings. The findings suggest that the SACS has a higher positive predictive value than the PEDS tool and can be employed for universal developmental surveillance by a range of professionals in both health and education settings.
ED	Safer-Lichtenstein J, McIntyre LL. Comparing Autism Symptom Severity Between Children With a Medical Autism Diagnosis and an Autism Special Education Eligibility. Focus on Autism and Other Developmental Disabilities. 2020;35(3):186-192. doi:10.1177/1088357620922162
	Rates of children identified as having autism spectrum disorder (ASD) continue to increase in both medical and school settings. This study included a sample of 73 school-age children with ASD and sought to examine differences in ASD symptom severity, adaptive functioning, and challenging behaviors between those identified in the medical system versus those identified in schools. The results indicated that the children receiving special education in the category of ASD who did not have clinical ASD diagnoses, relative to students with medical ASD diagnoses, were assessed by clinicians as having less severe ASD symptoms but were reported by parents as having similar levels of adaptive functioning and challenging behaviors. These findings call attention to the need for further investigation of a range of questions, including

	whether the special education label of ASD has unintended impacts on expectations or other implications.
NICHD	Shields RH, Kaat AJ, McKenzie FJ, Drayton A, Sansone SM, Coleman J, Michalak C, Riley K, Berry-Kravis E, Gershon RC, Widaman KF, Hessl D. Validation of the NIH Toolbox Cognitive Battery in intellectual disability. Neurology. 2020 Mar 24;94(12):e1229-e1240. doi: 10.1212/WNL.0000000000009131. Epub 2020 Feb 24. PMID: 32094241; PMCID: PMC7274932.
	The research team of the University of California Davis Medical Center adapted the NIH Toolbox Cognitive Battery for people with intellectual disabilities. The researchers validated the battery and its modifications by assessing 242 people ages 6 through 25 with fragile X syndrome, Down syndrome, or other disabilities. They found that the battery produced reliable and valid results for those with a mental age of 5 years and above. Given the dearth of objective and scalable measures that are sensitive to change, the availability of a valid measure, appropriate for use in clinical trials involving individuals with intellectual and developmental disabilities, could move the field forward.
	Question 2: Biology
OARC	Fazel Darbandi S, Robinson Schwartz SE, Pai EL, Everitt A, Turner ML, Cheyette BNR, Willsey AJ, State MW, Sohal VS, Rubenstein JLR. Enhancing WNT Signaling Restores Cortical Neuronal Spine Maturation and Synaptogenesis in Tbr1 Mutants. Cell Rep. 2020 Apr 14;31(2):107495. doi: 10.1016/j.celrep.2020.03.059. PMID: 32294447; PMCID: PMC7473600.
	The transcription factor Tbr1 has been identified as a high-confidence ASD gene, and researchers have previously shown that its function is critical for the maintenance of cortical neurons. In this study, the authors found through single-cell RNA sequencing that additional ASD genes, including *Gsk3β* in the WNT-signaling pathway, are regulated by Tbr1. Additionally, LiCl, a drug approved by the U.S. FDA, and a GSK3β inhibitor rescued neuronal defects in Tbr1 mutants, suggesting that these therapeutic approaches could have relevance for some forms of ASD.
OARC	Gonatopoulos-Pournatzis T, Niibori R, Salter EW, Weatheritt RJ, Tsang B, Farhangmehr S, Liang X, Braunschweig U, Roth J, Zhang S, Henderson T, Sharma E, Quesnel-Vallières M, Permanyer J, Maier S, Georgiou J, Irimia M, Sonenberg N, Forman-Kay JD, Gingras AC, Collingridge GL, Woodin MA, Cordes SP, Blencowe BJ. Autism-Misregulated eIF4G Microexons Control Synaptic Translation and Higher Order Cognitive Functions. Mol Cell. 2020 Mar 19;77(6):1176-1192.e16. doi: 10.1016/j.molcel.2020.01.006. Epub 2020 Jan 29. PMID: 31999954.
	Microexons are short exons of 3–27 nucleotides and result from alternative splicing RNA regulated by the serine/arginine repetitive matrix protein 4 (SRRM4). SRRM4 expression levels are decreased in the brains of individuals with ASD with unknown cause, and mice with lower levels of SRRM4 show microexon misregulation and multiple ASD-like symptoms. In addition to microexon splicing, misregulation of protein translation is known to be associated with ASD. This study investigates the role of microexons in the translation initiation factor eIF4G. Deletion of microexons in eIF4G specifically increased translation of proteins that control neuronal activity, leading to an activated neuronal state. Mice without the eIF4G microexons display altered social behavior, memory, and learning deficits. The results demonstrate a

	critical function for eIF4G microexons in neuronal protein translation and animal behavior and suggest that microexon-controlled disruption of protein production may commonly arise in ASD.
NINDS	Lutz AK, Pfaender S, Incearap B, Ioannidis V, Ottonelli I, Föhr KJ, Cammerer J, Zoller M, Higelin J, Giona F, Stetter M, Stoecker N, Alami NO, Schön M, Orth M, Liebau S, Barbi G, Grabrucker AM, Delorme R, Fauler M, Mayer B, Jesse S, Roselli F, Ludolph AC, Bourgeron T, Verpelli C, Demestre M, Boeckers TM. Autism-associated SHANK3 mutations impair maturation of neuromuscular junctions and striated muscles. Sci Transl Med. 2020 Jun 10;12(547):eaaz3267. doi: 10.1126/scitranslmed.aaz3267. PMID: 32522805.
	Mutations of *Shank3* are associated with ASD and Phelan-McDermid syndrome. Decreased muscle tone is an early clinical symptom in SHANK3-associated ASD. Here, researchers used patient-derived human induced pluripotent stem cells, Shank3 mutant mice, and muscle biopsies from patients with Phelan-McDermid syndrome to analyze the role of SHANK3 on muscle motor unit development. Both patient-derived material and the mouse model show that SHANK3 is important for maturation of neuromuscular junctions. Tirasemtiv, an experimental drug that sensitizes muscle fibers to calcium and in development for amyotrophic lateral sclerosis, resucued motor defects in Shank3 mutant mice. These results suggest that Tirasemtiv may be effective for treating muscle tone defects in ASD patients with *Shank3* mutations.
NICHD	MacDuffie KE, Shen MD, Dager SR, Styner MA, Kim SH, Paterson S, Pandey J, St John T, Elison JT, Wolff JJ, Swanson MR, Botteron KN, Zwaigenbaum L, Piven J, Estes AM. Sleep Onset Problems and Subcortical Development in Infants Later Diagnosed With Autism Spectrum Disorder. Am J Psychiatry. 2020 Jun 1;177(6):518-525. doi: 10.1176/appi.ajp.2019.19060666. Epub 2020 May 7. PMID: 32375538; PMCID: PMC7519575.
	Young children at risk for autism spectrum disorder (ASD) who have difficulty falling asleep and going back to sleep after awakening are more likely to develop ASD than at risk children without these sleep problems. This study found that sleep onset problems were more common at 6–12 months in infants who later developed ASD. Infant sleep onset problems were related to hippocampal volume trajectories from 6 to 24 months only for infants at high risk who developed ASD. These findings provide initial evidence that sleep onset problems in the first year of life can come before ASD diagnosis and are associated with altered neurodevelopmental trajectories in infants at high familial risk who go on to develop ASD.
NICHD	Oztan O, Garner JP, Constantino JN, Parker KJ. Neonatal CSF vasopressin concentration predicts later medical record diagnoses of autism spectrum disorder. Proc Natl Acad Sci U S A. 2020 May 12;117(19):10609-10613. doi: 10.1073/pnas.1919050117. Epub 2020 Apr 27. PMID: 32341146; PMCID: PMC7229671.
	In this study, scientists identified a possible early biological marker of ASD in a unique set of frozen samples of cerebrospinal fluid (CSF) that had been collected from 1,632 infants during hospital treatment for minor fever illnesses. Analysis of the samples found significantly lower concentrations of the so-called “social” neuropeptide, arginine vasopressin (AVP), in the CSF of a subset of infants who were later diagnosed with ASD, compared with CSF from unaffected children. This suggests that a biomarker of autism may be present before behavioral symptoms emerge. If replicated, this approach could be useful for assessing autism risk and facilitating early intervention in high-risk individuals.

OARC	Simonoff E, Kent R, Stringer D, Lord C, Briskman J, Lukito S, Pickles A, Charman T, Baird G. Trajectories in Symptoms of Autism and Cognitive Ability in Autism From Childhood to Adult Life: Findings From a Longitudinal Epidemiological Cohort. J Am Acad Child Adolesc Psychiatry. 2020 Dec;59(12):1342-1352. doi: 10.1016/j.jaac.2019.11.020. Epub 2019 Dec 19. PMID: 31863881.
	IQ and autism symptoms are related to functional adult outcomes, including independent living and employment. This study uses a longitudinal population-based autism cohort to track cognition and autism symptoms from childhood to early adulthood. IQ in 126 participants with ASD increased significantly by an average of 7.48 points between the ages of 12 and 23, but symptoms of autism in the participants remained unchanged. Participants in mainstream schools showed significantly fewer ASD symptoms at 23 years versus those in specialist settings. These findings suggest that identifying the role of educational and social experiences and interventions to promote cognitive development for people with ASD during the second decade of life is an important area of future research.
NINDS	Tai C, Chang CW, Yu GQ, Lopez I, Yu X, Wang X, Guo W, Mucke L. Tau Reduction Prevents Key Features of Autism in Mouse Models. Neuron. 2020 May 6;106(3):421-437.e11. doi: 10.1016/j.neuron.2020.01.038. Epub 2020 Mar 2. PMID: 32126198; PMCID: PMC7210056.
	The neuronal protein Tau is important for neuronal structure and function. Previous research demonstrated that reducing levels of Tau suppressed epilepsy and learning and memory deficits in a mouse model of Dravet syndrome, a treatment-resistant seizure disorder frequently associated with signs of autism. This paper expands upon the previous research and investigated the role of Tau in two mouse models with distinct genetic causes which both exhibit similar behavioral traits associated with autism such as repetitive behavior and defects in social interaction and communication. These ASD-related traits were prevented or diminished by partial or complete genetic removal of Tau. The results suggest a role for Tau in some types of ASD and point to Tau reduction as a potential therapeutic strategy.
OARC	Trakoshis S, Martínez-Cañada P, Rocchi F, Canella C, You W, Chakrabarti B, Ruigrok AN, Bullmore ET, Suckling J, Markicevic M, Zerbi V; MRC AIMS Consortium, Baron-Cohen S, Gozzi A, Lai MC, Panzeri S, Lombardo MV. Intrinsic excitation-inhibition imbalance affects medial prefrontal cortex differently in autistic men versus women. Elife. 2020 Aug 4;9:e55684. doi: 10.7554/eLife.55684. PMID: 32746967; PMCID: PMC7402681.
	Research of rare mutations that cause autism show that autistic individuals have higher levels of excitatory neuronal activity whereas inhibitory neuronal activity outweighs excitatory activity in non-autistic individuals. While most people with autism do not possess these mutations, many of these rare mutations occur on the sex chromosome or are influenced by androgen hormones which regulate development of typically male traits. The authors of this paper use computer modeling of brain scans to ask if neuronal excitation and inhibition occur differently in men and women. Their results demonstrate that, compared with autistic women, autistic men show a greater imbalance between excitatory and inhibitory signaling in brain regions important for social cognition, many of which are strongly affected by androgen hormones. These results may explain why autistic women seem to camouflage autistic traits more commonly than men. These findings suggest that being able to detect imbalances in excitatory versus inhibitory activity using standard brain imaging could be useful for clinical trials.

Question 3: Risk Factors

NICHD	Bai D, Marrus N, Yip BHK, Reichenberg A, Constantino JN, Sandin S. Inherited Risk for Autism Through Maternal and Paternal Lineage. Biol Psychiatry. 2020 Sep 15;88(6):480-487. doi: 10.1016/j.biopsych.2020.03.013. Epub 2020 Apr 2. PMID: 32430199; PMCID: PMC7483301.
	In the current study, researchers analyzed data from Swedish national registers of births and family relationships of children born from 2003 to 2012. Roughly 1.5% of the children were diagnosed with ASD. Offspring of mothers with one or more siblings with ASD were about three times more likely than children in the general population to have ASD. Children of fathers with one or more siblings with ASD were twice as likely as children in the general population to have ASD. These results provide the first population-wide estimate of ASD risk for children of parents who have a sibling with ASD.
NIEHS	Bilinovich SM, Lewis K, Thompson BL, Prokop JW, Campbell DB. Environmental Epigenetics of Diesel Particulate Matter Toxicogenomics. Int J Environ Res Public Health. 2020 Oct 10;17(20):7386. doi: 10.3390/ijerph17207386. PMID: 33050454; PMCID: PMC7650680.
	Building on research that has found exposure to vehicle exhaust and diesel particulate matter (DPM) as a risk factor for autism, this study used data from the Comparative Toxicogenomics Database (CTD), a public database of information on the interactions between genes, diseases, and chemicals, cell culture exposure studies, and phenotypic genetics to study the potential mechanisms and interactions between genes associated with autism risk and exposure to DPM. They identified enhancer/promoter elements with differential chromosome accessibility in response to DPM exposure, including those that target transcription factors associated with both neurodevelopment and responses to environmental stressors. This paper highlights a new strategy to study interactions and associations between genetic factors and environmental exposures that may alter brain development to modify risk for autism.
OARC	Chiang AH, Chang J, Wang J, Vitkup D. Exons as units of phenotypic impact for truncating mutations in autism. Mol Psychiatry. 2020 Oct 27. doi: 10.1038/s41380-020-00876-3. Epub ahead of print. PMID: 33110259.
	An exon is a coding region of a gene that contains the information required to encode a protein. This study found that people with autism who carry truncating mutations in the same exon frequently have strikingly similar cognitive abilities and behaviors. The researchers found that exons biased toward prenatal expression preferentially contribute towards lower IQ phenotypes in ASD, while exons biased towards postnatal expression contribute towards higher IQ phenotypes in ASD. These results have important implications for precision medicine and suggest that exons, rather than genes, often represent a unit of effective phenotypic impact for truncating mutations in autism.
NINDS	Jensen M, Smolen C, Girirajan S. Gene discoveries in autism are biased towards comorbidity with intellectual disability. J Med Genet. 2020 Sep;57(9):647-652. doi: 10.1136/jmedgenet-2019-106476. Epub 2020 Mar 9. PMID: 32152248; PMCID: PMC7483239.
	Intellectual disability (ID) is often comorbid with autism. This presents challenges for diagnosis and for identifying genetic factors specifically associated with autism. In this

	study, researchers analyzed genetic variants in individuals with autism who had either ID or normal cognitive function. The results suggest that de novo variants (new variants not present in either parent) affecting autism-associated genes likely contribute towards autism and ID comorbidity. In contrast, other genetic factors (e.g., missense variants, common variants, variants in regulatory and non-coding regions) likely contribute to cases of autism without comorbid ID.
NICHD	McDonald NM, Senturk D, Scheffler A, Brian JA, Carver LJ, Charman T, Chawarska K, Curtin S, Hertz-Piccioto I, Jones EJH, Klin A, Landa R, Messinger DS, Ozonoff S, Stone WL, Tager-Flusberg H, Webb SJ, Young G, Zwaigenbaum L, Jeste SS. Developmental Trajectories of Infants With Multiplex Family Risk for Autism: A Baby Siblings Research Consortium Study. JAMA Neurol. 2020 Jan 1;77(1):73-81. doi: 10.1001/jamaneurol.2019.3341. PMID: 31589284; PMCID: PMC6784852.
	This longitudinal study of 445 children with multiplex (more than one sibling with ASD) or single-incidence (one sibling with ASD) family history of autism indicated that 68% of children from multiplex families vs 43% of those from single-incidence families had ASD or atypical development at 3-years of age. Children without ASD did not differ in ASD symptoms based on family risk status, but multiplex status was associated with lower cognitive abilities and adaptive skills. This study described heterogeneity in developmental trajectories and outcomes related to different levels of familial risk, suggesting that infants with a multiplex family history of ASD should be monitored early and often and referred for early intervention services at the first sign of concern.
NIEHS	Oulhote Y, Lanphear B, Braun JM, Webster GM, Arbuckle TE, Etzel T, Forget-Dubois N, Seguin JR, Bouchard MF, MacFarlane A, Ouellet E, Fraser W, Muckle G. Gestational Exposures to Phthalates and Folic Acid, and Autistic Traits in Canadian Children. Environ Health Perspect. 2020 Feb;128(2):27004. doi: 10.1289/EHP5621. Epub 2020 Feb 19. PMID: 32073305; PMCID: PMC7064316.
	Phthalates, a class of chemicals that are widely used in consumer products, have been linked to endocrine disruption that has been implicated in neurodevelopmental and altered neurobehavioral outcomes. This study expanded on previous research on prenatal exposure to phthalates and risk of autism. Researchers found that children with higher first trimester exposure to specific phthalate metabolites had higher total Social Responsiveness Scale (SRS) T-scores, which indicate a greater degree of social impairment. They further studied the mediation of these effects by folic acid supplementation and found that the effect of phthalate exposure on child SRS score was significantly attenuated by sufficient (>400ug/d) maternal supplementation with folic acid. This paper is the first study to look at the mediation of the effect of common phthalate exposures on autistic traits by prenatal folic acid supplementation. It contributes to the growing body of literature on prenatal folic acid as a modifier of risks of autism due to environmental chemical exposures.
NINDS	Satterstrom FK, Kosmicki JA, Wang J, Breen MS, De Rubeis S, An JY, Peng M, Collins R, Grove J, Klei L, Stevens C, Reichert J, Mulhern MS, Artomov M, Gerges S, Sheppard B, Xu X, Bhaduri A, Norman U, Brand H, Schwartz G, Nguyen R, Guerrero EE, Dias C; Autism Sequencing Consortium; iPSYCH-Broad Consortium, Betancur C, Cook EH, Gallagher L, Gill M, Sutcliffe JS, Thurm A, Zwick ME, Børglum AD, State MW, Cicek AE, Talkowski ME, Cutler DJ, Devlin B, Sanders SJ, Roeder K, Daly MJ, Buxbaum JD. Large-Scale Exome Sequencing Study Implicates Both Developmental and Functional Changes in the Neurobiology of Autism. Cell. 2020 Feb 6;180(3):568-584.e23. doi: 10.1016/j.cell.2019.12.036. Epub 2020 Jan 23. PMID: 31981491; PMCID: PMC7250485.

	In this landmark study, the international Autism Sequencing Consortium analyzed the DNA of over 35,000 people from around the world. They identified variants in 102 genes associated with increased risk of developing ASD, up from 65 identified previously. Of the 102 genes, 60 had not been previously linked to ASD and 53 were associated more specifically with ASD as opposed to intellectual disability or developmental delay.
NINDS	Trost B, Engchuan W, Nguyen CM, Thiruvahindrapuram B, Dolzhenko E, Backstrom I, Mirceta M, Mojarad BA, Yin Y, Dov A, Chandrakumar I, Prasolava T, Shum N, Hamdan O, Pellecchia G, Howe JL, Whitney J, Klee EW, Baheti S, Amaral DG, Anagnostou E, Elsabbagh M, Fernandez BA, Hoang N, Lewis MES, Liu X, Sjaarda C, Smith IM, Szatmari P, Zwaigenbaum L, Glazer D, Hartley D, Stewart AK, Eberle MA, Sato N, Pearson CE, Scherer SW, Yuen RKC. Genome-wide detection of tandem DNA repeats that are expanded in autism. Nature. 2020 Oct;586(7827):80-86. doi: 10.1038/s41586-020-2579-z. Epub 2020 Jul 27. PMID: 32717741.
	A tandem DNA repeat is a sequence of two or more DNA base pairs that is repeated so that the repeats lie adjacent to each other on the chromosome. The role of tandem DNA repeats in the genetics of ASD is largely unknown. This study investigated tandem repeats in 17,231 genomes of families with individuals with ASD. At 2,588 loci, researchers found gene-associated expansions of tandem repeats that were rare among controls and more prevalent among individuals with ASD than their siblings. Overall, the results estimate that tandem repeat expansions make a collective contribution to the risk of ASD of 2.6%.
HRSA	Raghavan R, Selhub J, Paul L, Ji Y, Wang G, Hong X, Zuckerman B, Fallin MD, Wang X. A prospective birth cohort study on cord blood folate subtypes and risk of autism spectrum disorder. Am J Clin Nutr. 2020 Nov 11;112(5):1304-1317. doi: 10.1093/ajcn/nqaa208. PMID: 32844208; PMCID: PMC7657337.
	This study explored whether specific types of maternal plasma folate in cord blood (cord blood unmetabolized folic acid (UMFA), 5-methyl tetrahydrofolate (THF), and total folate) have differential association with increased risk of autism spectrum disorder (ASD) in children. Findings revealed that cord total folate and maternal supplement intake during second trimester were associated with higher cord UMFA. Higher concentrations of cord UMFA, but not 5-methyl THF or total folate, were associated with a greater risk of ASD in Black children but not in other racial/ethnic groups studied. There was no significant association between cord 5-methyl THF, total folate, *DHFR* genotype, and ASD risk.
	Question 4: Treatments and Interventions
SSA	Andersen AM, Law JK, Marvin AR, Lipkin PH. Elopement Patterns and Caregiver Strategies. Journal of Autism and Developmental Disorders. 2020 Jun;50(6):2053-2063. DOI: 10.1007/s10803-019-03961-x. PMID: 30838492; PMCID: PMC6728233.
	Although a variety of interventions for elopement behaviors (EB) have been studied, studies have typically reported on only one intervention or variations on similar types of interventions, such as ABA therapies, and no studies have compared behavioral therapies and other kinds of interventions, such as environmental or electronic measures. Results from a survey sent to caregivers of children with ASD indicated most families reported multiple interventions for EB and rated interventions overall as effective but burdensome. Several interventions such as fencing, and window locks

	had favorable effectiveness/burden profiles. Tracking devices were used infrequently and rated as having low effectiveness. Behavioral specialists were commonly used, rated as effective, and most often provided by insurance. Medications were rated as having low effectiveness for EB, whether taken off-label for EB or for other reasons
Dena Gassner	Benevides TW, Shore SM, Andresen ML, Caplan R, Cook B, Gassner DL, Erves JM, Hazlewood TM, King MC, Morgan L, Murphy LE, Purkis Y, Rankowski B, Rutledge SM, Welch SP, Wittig K. Interventions to address health outcomes among autistic adults: A systematic review. Autism. 2020 Aug;24(6):1345-1359. doi: 10.1177/1362361320913664. Epub 2020 May 11. PMID: 32390461; PMCID: PMC7787674.
	Autistic adults have more health problems then their same-aged peers. Yet little research has been conducted that focuses on addressing these health problems. In order to guide future research, it is important to know what intervention studies have been done to improve health outcomes among autistic adults. The project team and student assistants read studies that were published between 2007 and 2018 in the online research database, PubMed.
OARC	Lindgren S, Wacker D, Schieltz K, Suess A, Pelzel K, Kopelman T, Lee J, Romani P, O'Brien M. A Randomized Controlled Trial of Functional Communication Training via Telehealth for Young Children with Autism Spectrum Disorder. J Autism Dev Disord. 2020 Dec;50(12):4449-4462. doi: 10.1007/s10803-020-04451-1. PMID: 32300910; PMCID: PMC7572463.
	This randomized controlled trial compares the effects of parent-conducted functional communication training (FCT) for 38 young children with ASD aged 21-84 months. Parents received FCT training from behavioral consultants via telehealth. FCT treatment resulted in a reduction in problem behavior of 98% compared to limited behavioral improvement in children receiving "treatment as usual" during a 12-week period. Social communication and task completion also improved. This study demonstrates that for children with ASD and moderate to severe behavior problems, parent-implemented FCT using telehealth significantly reduced problem behavior, while ongoing interventions typically did not.
NINDS	McCamphill PK, Stoppel LJ, Senter RK, Lewis MC, Heynen AJ, Stoppel DC, Sridhar V, Collins KA, Shi X, Pan JQ, Madison J, Cottrell JR, Huber KM, Scolnick EM, Holson EB, Wagner FF, Bear MF. Selective inhibition of glycogen synthase kinase 3α corrects pathophysiology in a mouse model of fragile X syndrome. Sci Transl Med. 2020 May 20;12(544):eaam8572. doi: 10.1126/scitranslmed.aam8572. PMID: 32434848.
	Fragile X syndrome (FXS) is one of the most common single gene causes of autism. Studies in a mouse model of FXS suggest that the mGluR5 glutamate receptor is a key disease mechanism. However, clinical trials of mGluR5 inhibitors have not been successful, prompting research on alternative treatment strategies. This study shows that when the enzyme glycogen synthase kinase 3 alpha was selectively inhibited, FXS mice showed corrected protein synthesis, improved brain hyperexcitability, and other measures. The results point to this inhibitor as a potential therapeutic approach for FXS.
OARC	Rogers SJ, Yoder P, Estes A, Warren Z, McEachin J, Munson J, Rocha M, Greenson J, Wallace L, Gardner E, Dawson G, Sugar CA, Hellemann G, Whelan F. A Multisite Randomized Controlled Trial Comparing the Effects of Intervention Intensity and Intervention Style on Outcomes for Young Children With Autism. J Am Acad Child

	Adolesc Psychiatry. 2020 Aug 24:S0890-8567(20)31350-2. doi: 10.1016/j.jaac.2020.06.013. Epub ahead of print. PMID: 32853704.
	This study examined the effects of 2 levels of treatment intensity (number of hours) and 2 treatment styles on the progress of young children with autism spectrum disorder (ASD). Study results showed that toddlers performed the same regardless of treatment intensity or teaching approach, and that child characteristics did not predict outcomes. These findings highlight the importance of the rigorous implementation and study of autism intervention science.
Alycia Halladay	Sandbank M, Bottema-Beutel K, Crowley S, Cassidy M, Dunham K, Feldman JI, Crank J, Albarran SA, Raj S, Mahbub P, Woynaroski TG. Project AIM: Autism intervention meta-analysis for studies of young children. Psychol Bull. 2020 Jan;146(1):1-29. doi: 10.1037/bul0000215. Epub 2019 Nov 25. PMID: 31763860.
	In this comprehensive systematic review and meta-analysis of group design studies of nonpharmacological early interventions designed for young children with autism spectrum disorder (ASD), we report summary effects across 7 early intervention types (behavioral, developmental, naturalistic developmental behavioral intervention [NDBI], TEACCH, sensory-based, animal-assisted, and technology-based), and 15 outcome categories indexing core and related ASD symptoms.
OARC	Solish A, Klemencic N, Ritzema A, Nolan V, Pilkington M, Anagnostou E, Brian J. Effectiveness of a modified group cognitive behavioral therapy program for anxiety in children with ASD delivered in a community context. Mol Autism. 2020 May 13;11(1):34. doi: 10.1186/s13229-020-00341-6. PMID: 32404180; PMCID: PMC7218559.
	Youth on the autism spectrum often experience high rates of comorbid anxiety issues. Cognitive behavioral therapy (CBT) has been shown in controlled research settings to be effective in treating anxiety disorders. This study examines the effectiveness of a modified group CBT program (Face Your Fears) delivered in a hospital and across six community-based agencies providing services for youth with ASD. Results showed significant improvements in anxiety levels. Overall, this study demonstrates that community implementation of a modified group CBT program for youth with ASD is feasible and effective for treating anxiety.
ED	Steinbrenner JR, Odom SL, Hall LJ, Hume K. Moving Beyond Fidelity: Assessing Implementation of a Comprehensive Treatment Program for Adolescents With Autism Spectrum Disorder. Exceptional Children. 2020;86(2):137-154. doi:10.1177/0014402919855321
	Comprehensive treatment programs for students with ASD must be implemented with fidelity and careful consideration of ongoing findings and feedback. The researchers describe a thorough process for assessing how a school-based comprehensive treatment program for students with ASD is implemented and received. Through a cluster-randomized trial (60 high schools), they demonstrated that the Center on Secondary Education for Students With Autism Spectrum Disorders (CSESA) Implementation Profile can document a range of implementation features as well as differentiating between intervention and control settings. The CSESA Implementation Profile and Index were shown to support advance planning as well as provide data feedback for continuous, formative monitoring. The results of this study provide the field with resources to support the multilevel documentation and assessment of intervention implementation in school settings.

OARC	Wood JJ, Kendall PC, Wood KS, Kerns CM, Seltzer M, Small BJ, Lewin AB, Storch EA. Cognitive Behavioral Treatments for Anxiety in Children With Autism Spectrum Disorder: A Randomized Clinical Trial. JAMA Psychiatry. 2020 May 1;77(5):474-483. doi: 10.1001/jamapsychiatry.2019.4160. PMID: 31755906; PMCID: PMC6902190.
	Researchers compared the impacts of 2 variants of cognitive behavioral therapy (CBT) on children with ASD and maladaptive and interfering anxiety. Study results showed that CBT adapted for children with ASD led to a greater reduction in anxiety than standard CBT, and both forms of CBT were more efficacious than treatment as usual.
HRSA	Curtin C, Hyman SL, Boas DD, Hassink S, Broder-Fingert S, Ptomey LT, Gillette MD, Fleming RK, Must A, Bandini LG. Weight Management in Primary Care for Children With Autism: Expert Recommendations. Pediatrics. 2020 Apr;145(Suppl 1):S126-S139. doi: 10.1542/peds.2019-1895P. PMID: 32238539.
	The US Preventive Services Task Force and the American Academy of Pediatrics (AAP) have endorsed screening children for overweight and obesity as part of the standard of care for physicians. However, the pediatric provider community has been inadequately prepared to address this issue in children with Autism Spectrum Disorder (ASD). The Healthy Weight Research Network adapted AAP's 2007 guidance for primary care practitioners on managing overweight and obesity for the general population and tailored the recommendations to assist pediatric providers to better meet the unique needs of children with ASD. The significant challenges experienced by this population in both dietary and physical activity domains, as well as the stress experienced by their families, require adaptations and modifications for both preventive and intervention efforts.

Question 5: Services

OARC	Bellesheim KR, Kizzee RL, Curran A, Sohl K. ECHO Autism: Integrating Maintenance of Certification with Extension for Community Healthcare Outcomes Improves Developmental Screening. J Dev Behav Pediatr. 2020 Aug;41(6):420-427. doi: 10.1097/DBP.0000000000000796. PMID: 32735419.
	Recent data shows that most pediatricians often do not meet the American Academy of Pediatrics developmental screening guidelines, leading to delays in diagnosis and interventions for ASD. This study explored if the use of Maintenance of Certification (MOC) Quality Improvement (QI) training improved developmental screening rates in underserved, rural primary care practices. At the end of the 12-months learning module, screening rates went up to 88.6% (versus the initial 53.3%) for general developmental training, and 99% (versus the initial 68.3%) for ASD-specific developmental screenings. At the one-year follow-up, the rates for general and ASD-specific screening were 96.7% and 97.1%, respectively.
Dena Gassner	Benevides TW, Carretta HJ, Rust G, Shea L. Racial and ethnic disparities in benefits eligibility and spending among adults on the autism spectrum: A cohort study using the Medicare Medicaid Linked Enrollees Analytic Data Source. PLoS One. 2021 May 25;16(5):e0251353. doi: 10.1371/journal.pone.0251353. PMID: 34032811; PMCID: PMC8148358.
	Research on children and youth on the autism spectrum reveal racial and ethnic disparities in access to healthcare and utilization, but there is less research to understand how disparities persist as autistic adults age. We need to understand

	racial-ethnic inequities in obtaining eligibility for Medicare and/or Medicaid coverage, as well as inequities in spending for autistic enrollees under these public programs.
OARC	Bilaver LA, Sobotka SA, Mandell DS. Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children. J Autism Dev Disord. 2020 Nov 21:10.1007/s10803-020-04797-6. doi: 10.1007/s10803-020-04797-6. Epub ahead of print. PMID: 33219917; PMCID: PMC8137720.
	This study examined racial and ethnic disparities in the use of nine common autism-related services among Medicaid-enrolled children with autism spectrum disorder (ASD) using 2012 Medicaid Analytic Extract data. Several racial and ethnic disparities were found, varying by geography. Black, Asian, and Native American/Pacific Islanders received fewer outpatient services compared with white children, but there was no disparity for Latinx children. Black and Asian children received more school-based services than white children. Disparities in case management/care coordination services were largest and present in each minority group. Geographic variation in receipt of services suggests targets for policy intervention to improve access for minorities with ASD.
ED	Kim I, Dababnah S, Lee J. The Influence of Race and Ethnicity on the Relationship between Family Resilience and Parenting Stress in Caregivers of Children with Autism. J Autism Dev Disord. 2020 Feb;50(2):650-658. doi: 10.1007/s10803-019-04269-6. PMID: 31667651.
	This research involved analysis of data from the National Survey of Children's Health (including 1,131 parents/guardians of children with ASD) to investigate the relationship between family resilience and parenting stress. As in prior studies of families of children with ASD, family resilience was found to be negatively associated with parenting stress; however, this is the first study to demonstrate that this relationship is significantly different for certain racial/ethnic groups. An increase in family resilience has a proportionally larger impact on parenting stress for African American families than for parents of white children with ASD. The findings suggest the need for more research into family resilience as a protective factor against parenting stress. The researchers' analyses encourage consideration of racial and ethnic nuances in the experiences of resilience and stress, including strategies for building resilience which seem especially effective with African American families.
OARC	Mazurek MO, Parker RA, Chan J, Kuhlthau K, Sohl K; ECHO Autism Collaborative. Effectiveness of the Extension for Community Health Outcomes Model as Applied to Primary Care for Autism: A Partial Stepped-Wedge Randomized Clinical Trial. JAMA Pediatr. 2020 May 1;174(5):e196306. doi: 10.1001/jamapediatrics.2019.6306. Epub 2020 May 4. PMID: 32150229; PMCID: PMC7063545.
	In this large-scale study, the Extension for Community Health Outcomes (ECHO) telementoring model was studied for effectiveness in improving clinical practices for the care of children with autism. Significant changes in autism screening or treatment of comorbidities (other diseases/conditions) were not seen. However, primary care clinicians showed significant improvements in knowledge and self-efficacy immediately following and 3 months after completing the ECHO program.
ED	McClain MB, Shahidullah JD, Mezher KR, Haverkamp CR, Benallie KJ, Schwartz SE. School-Clinic Care Coordination for Youth with ASD: A National Survey of School Psychologists. J Autism Dev Disord. 2020 Sep;50(9):3081-3091. doi: 10.1007/s10803-019-03985-3. PMID: 30877418.

	This study investigated how school psychologists collaborate with other professionals outside of the school setting in the service of students with ASD. Through survey research with 203 practicing school psychologists in the US, the researchers identified patterns in engagement and collaboration between the school psychologists and outside professionals. Respondents were more likely to have referred students with ASD to outside professionals than to have collaborated with outside professionals. The researchers found that school psychologists whose preparation programs had included clinical/practical opportunities to practice collaboration and care coordination were more likely to engage in meaningful collaboration than school psychologists who had not had real-world practice with collaboration as part of their preparation programs. The findings provide important recommendations for the preparation of school psychologists to promote interdisciplinary collaboration and care coordination among school and community/clinic-based service providers for students with ASD.
ED	Pugliese CE, Ratto AB, Granader Y, Dudley KM, Bowen A, Baker C, Anthony LG. Feasibility and preliminary efficacy of a parent-mediated sexual education curriculum for youth with autism spectrum disorders. Autism. 2020 Jan;24(1):64-79. doi: 10.1177/1362361319842978. Epub 2019 May 17. PMID: 31096780; PMCID: PMC6858939.
	This study addresses the complex, and critical challenge of providing supportive, parent-mediated sexual education to students with ASD. Working with 84 youth with ASD and their parents, the researchers provided the Supporting Teens with Autism on Relationships (STAR) program to two intervention groups (facilitator-lead and self-guided) and provided a substance abuse intervention to one control group. The results suggest that the STAR program, either facilitator-led or self-guided, increases both parents' and students' knowledge of sexuality and may improve parents' effectiveness in discussing sexuality with children with ASD.
OARC	Stadnick NA, Lau AS, Dickson KS, Pesanti K, Innes-Gomberg D, Brookman-Frazee L. Service use by youth with autism within a system-driven implementation of evidence-based practices in children's mental health services. Autism. 2020 Nov;24(8):2094-2103. doi: 10.1177/1362361320934230. Epub 2020 Jul 18. PMID: 32686469; PMCID: PMC7541440.
	Autistic youth may receive mental health services in public mental health systems. This case-control study compared 2537 youths with ASD to 2537 matched peers receiving care in the Los Angeles County Department of Mental Health. On average, autistic youth had significantly higher number of claims and received care for significantly longer time than matched peers. In addition, there were differences in the types of mental health services received and the practices that were delivered. For example, behavioral parent training practices were delivered more to autistic youth, but practices to address trauma were delivered more to matched peers. These results demonstrate that it may be valuable to explicitly provide more tailored care recommendations for autistic youth.
HRSA	Luelmo, P, Sandoval, Y, Kasari, C. Undocumented Mexican Mothers of Children with Autism: Navigating the Health Care and Educational Service Systems. International Journal of Developmental Disabilities. doi: 10.1080/20473869.2020.1850159.
	Diagnosis/identification and service gaps persist for low-resourced, underrepresented families of children with autism. This study addresses how one group of families particularly difficult to engage in research and interventions--undocumented Mexican

	immigrant mothers of children with autism--navigate special education and health care systems, the challenges they face in doing so, and the helpers who assist in navigating the process. Findings from semi-structured interviews with the mothers indicated that intervention and services for children with autism are hampered by income, fear of deportation, language limitations, and awareness of autism for undocumented Mexican parents. The study points to the additional barriers that Latinx minority parents face when they are undocumented in the U.S.A. This suggests that health care providers and educators need to approach diverse families with an open mind and cultural sensitivity.
ED	Wehman P, Schall C, McDonough J, Sima A, Brooke A, Ham W, Whittenburg H, Brooke V, Avellone L, Riehle E. Competitive Employment for Transition-Aged Youth with Significant Impact from Autism: A Multi-site Randomized Clinical Trial. J Autism Dev Disord. 2020 Jun;50(6):1882-1897. doi: 10.1007/s10803-019-03940-2. PMID: 30825082.
	Youth with ASD are known to experience many barriers to employment, despite federally-mandated transition services and supports. This research investigated the impact of Project SEARCH plus ASD Supports (PS + ASD) on employment outcomes for transition-age youth with ASD through a multi-site, parallel block randomized clinical trial with 156 transition-aged youth. Researchers found that PS + ASD significantly improved employment outcomes for participants. Although PS + ASD involves investments in time, costs, staff, inter-agency collaboration, and coordination with local businesses, this research suggests that the PS + ASD approach is a significant improvement over traditional community-based employment training programs for transition-aged students with ASD.
CDC	Wiggins LD, DiGuiseppi C, Schieve L, Moody E, Soke G, Giarelli E, Levy S. Wandering Among Preschool Children with and Without Autism Spectrum Disorder. J Dev Behav Pediatr. 2020 May;41(4):251-257. doi: 10.1097/DBP.0000000000000780. PMID: 31977588; PMCID: PMC7505120.
	This is the first study, to our knowledge, that compares wandering among children with autism spectrum disorder (ASD), to those with a previous but unconfirmed diagnosis of ASD, children with other developmental disabilities, and children in the general population. Wandering can compromise child safety and increase parental stress. This paper indicates results of parent report of wandering behavior among about 4000 children aged 4-5 years of age in the Study to Explore Early Development. Among children in the study, 60% of children with ASD wandered, compared with 41% of children with a previous but unconfirmed diagnosis of ASD, 22% of children with developmental disability other than ASD, and 13% of children in the general population. Additionally, mood, anxiety, attention, and oppositional problems were associated with wandering independent of ASD status. These results may inform parents and providers about wandering and facilitate discussions to help improve the safety and lives of children who wander and their families.
	Question 6: Lifespan Issues
OARC	Anderson KA, Hemmeter J, Rast JE, Roux AM, Shattuck PT. Trends in Supplemental Security Income Payments to Adults With Autism. Psychiatr Serv. 2020 Jun 1;71(6):602-607. doi: 10.1176/appi.ps.201900265. Epub 2020 Apr 8. PMID: 32264799.

	This study used Social Security Administration program data to identify population-level trends in Supplemental Security Income (SSI) program participation and payments to adult recipients with autism spectrum disorder (ASD) relative to recipients with intellectual disability and other mental disorders. The authors found that a large and growing number of adults with autism receive SSI benefits. This finding underscores the importance of future research related to the economic security of adults on the autism spectrum.
Dena Gassner	Benevides TW, Shore SM, Palmer K, Duncan P, Plank A, Andresen ML, Caplan R, Cook B, Gassner D, Hector BL, Morgan L, Nebeker L, Purkis Y, Rankowski B, Wittig K, Coughlin SS. Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. Autism. 2020 May;24(4):822-833. doi: 10.1177/1362361320908410. PMID: 32429818; PMCID: PMC7787673.
	Autistic adults commonly experience mental health conditions. However, research rarely involves autistic adults in deciding priorities for research on mental healthcare approaches that might work for them. The purpose of this article is to describe a stakeholder-driven project that involved autistic adults in co-leading and designing research about priorities to address mental health needs. Through a large online survey, two large meetings, and three face-to-face focus group discussions involving over 350 stakeholders, we identified five priorities for mental health research desired by autistic adults. These priorities and preferred outcomes should be used to guide research and practice for autistic adults.
ACL	Hall JP, Batza K, Streed CG Jr, Boyd BA, Kurth NK. Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder. J Autism Dev Disord. 2020 Aug;50(8):3071-3077. doi: 10.1007/s10803-020-04399-2. PMID: 32056117.
	This study explored the health and health care experiences of people with autism spectrum disorder (ASD) who identify as lesbian, gay, bisexual, transgender, or queer (LGBTQ+) using data from a national, internet-based survey of adults with disabilities supplemented by focused interviews. LGBTQ+ respondents had significantly higher rates of mental illness, poor physical health days per month, and smoking compared to straight, cisgender respondents with ASD. LGBTQ+ respondents also reported much higher rates of unmet health care need, inadequate insurance provider networks, and rates of being refused services by a medical provider. Examining the intersection of LGBTQ+ identity and ASD reveals health disparities that insurers and medical providers are not adequately addressing, particularly as individuals transition to the adult medical system.
Alycia Halladay	Jeste S, Hyde C, Distefano C, Halladay A, Ray S, Porath M, Wilson RB, Thurm A. Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions. J Intellect Disabil Res. 2020 Sep 17. doi: 10.1111/jir.12776. Epub ahead of print. PMID: 32939917.
	COVID-19 restrictions have significantly limited access to in-person educational and healthcare services for all, including individuals with intellectual and developmental disabilities (IDDs). The objectives of this online survey that included both national and international families were to capture changes in access to healthcare and educational services for individuals with IDDs that occurred shortly after restrictions were initiated and to survey families on resources that could improve services for these individuals.

NIMH	McCauley JB, Pickles A, Huerta M, Lord C. Defining Positive Outcomes in More and Less Cognitively Able Autistic Adults. Autism Res. 2020 Sep;13(9):1548-1560. doi: 10.1002/aur.2359. Epub 2020 Aug 27. PMID: 32851813.
	Using long-term data from 126 adults diagnosed with ASD (mean age of 26), this study examined how several areas of outcomes, such as autonomy, social relationships, and purpose, were associated with specific aspects of functioning in autistic adults. For more cognitively able adults, outcomes included living independently, having paid employment, and at least one true friend. For autistic adults who were less cognitively able, outcomes included daily living skills above an 8-year-old level, having regular activities outside the home, and having social contacts outside the family. Verbal IQ was a significant predictor of outcomes achieved for individuals within both more and less cognitively able groups. The findings also showed that among adults with less cognitive abilities, having received a formal ASD diagnosis was associated with lower odds of positive outcomes. Among ASD adults with more cognitive skills, there was a higher likelihood of positive outcomes such as increased daily living skills, fewer mental health problems, and self-reported happiness. These findings can provide individuals with ASD, families, and service providers greater insight into important factors to consider when planning the transition to adulthood.
OARC	Moseley RL, Druce T, Turner-Cobb JM. 'When my autism broke': A qualitative study spotlighting autistic voices on menopause. Autism. 2020 Aug;24(6):1423-1437. doi: 10.1177/1362361319901184. Epub 2020 Jan 31. PMID: 32003226; PMCID: PMC7376624.
	There is little information on how autistic individuals go through the transition to menopause and if there are additional challenges faced by autistic versus neurotypical individuals. The authors led an online focus group with seven autistic individuals assigned female at birth and between 49-63 years old. Issues raised include lack of professional knowledge, understanding, and communication about menopause for autistic people, absence of support, and increasing pre-existing as well as generating new cognitive, social, emotional, and sensory difficulties because of menopause. This study demonstrates that additional research is needed about menopause in autistic individuals.
NIMH	Nicolaidis C, Schnider G, Lee J, Raymaker DM, Kapp SK, Croen LA, Urbanowicz A, Maslak J. Development and psychometric testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale. Autism. 2020 Aug 28:1362361320949734. doi: 10.1177/1362361320949734. Epub ahead of print. PMID: 32859135.
	Healthcare systems in the US are underprepared to adequately address the needs and provide the high quality of care that adults with autism require to live independent, healthy, and productive lives. In this paper, researchers developed and tested a measure of healthcare providers' confidence (or "self-efficacy") in providing care to autistic adults, with the aim that this instrument would help researchers better understand the training needs of health care providers in order to serve the adult autistic community. Using a community-based participatory research model the investigators developed a brief survey instrument (AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale) with input from autistic adults, community supporters, and healthcare providers. The instrument was administered to 143 primary care providers from eight primary care clinics in Oregon and California, United States. Overall, results from the showed that healthcare providers acknowledge lack of proper preparedness to serve adults with autism. For example, only 25% a minority of

	respondents expressed high confidence in communicating with adult autistic patients (25%); performing physical exams or procedures (43%); accurately diagnosing and treating other medical issues (40%) and only 14% in identifying accommodation needs (14%). Future research is needed to further validate this scale and to understand how to meet providers' training needs most effectively.
ACL	Nimmo-Smith V, Heuvelman H, Dalman C, Lundberg M, Idring S, Carpenter P, Magnusson C, Rai D. Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study. J Autism Dev Disord. 2020 Jan;50(1):308-318. doi: 10.1007/s10803-019-04234-3. PMID: 31621020; PMCID: PMC6946757.
	Anxiety is common in children with ASD; however, the burden of specific anxiety disorders for adults with ASD is under-researched. Using the Stockholm Youth Cohort, this study compared anxiety disorder diagnoses among autistic adults (n = 4049), with or without intellectual disability, and population controls (n = 217,645). Anxiety disorders were diagnosed in 20.1% of adults with ASD compared with 8.7% of controls, with greatest risk for autistic people without intellectual disability. Rates of almost all individual anxiety disorders were raised, notably obsessive–compulsive disorder and phobic anxiety disorders. Anxiety disorders were more common in full siblings and half-siblings of people with ASD. This is the first large, population-based study which has assessed the rates of PTSD in adults with ASD.
SSA	Pohl AL, Crockford SK, Blakemore M, Allison C, Baron-Cohen S. A comparative study of autistic and non-autistic women's experience of motherhood. Mol Autism. 2020 Jan 6;11(1):3. doi: 10.1186/s13229-019-0304-2. PMID: 31911826; PMCID: PMC6945630.
	Autistic mothers face unique challenges, and the stigma associated with autism may further exacerbate communication difficulties. The study found that autistic mothers were more likely to have experienced additional psychiatric conditions, including pre- or post-partum depression, and reported greater difficulties in areas such as multi-tasking, coping with domestic responsibilities and creating social opportunities for their child. They were also more likely to report feeling misunderstood by professionals, and reported greater anxiety, higher rates of selective mutism, and not knowing which details were appropriate to share with professionals. The study suggests that greater understanding and acceptance amongst individuals who interact with autistic mothers is needed, and autistic mothers would benefit from additional and better-tailored support.
HRSA	McGhee Hassrick E, Sosnowy C, Graham Holmes L, Walton J, Shattuck PT. Social Capital and Autism in Young Adulthood: Applying Social Network Methods to Measure the Social Capital of Autistic Young Adults. Autism Adulthood. 2020 Sep 1;2(3):243-254. doi: 10.1089/aut.2019.0058. Epub 2020 Sep 3. PMID: 32954220; PMCID: PMC7497874.
	Many autistic young adults are disconnected from people, communities, and organizations that could provide them with valuable social resources to support their transition to adulthood. Interpersonal relationships and the resources and support embedded in the social networks of autistic young adults could impact key adult outcomes, including quality of life, mental health, employment, and independence. This study tests the feasibility of using social network methods to measure the resources that autistic young adults gain from their social connections and lays the groundwork for future studies to test whether the social resources young adults on the autism spectrum receive from their networks impact their adult outcomes. The implementation data collected from the study also suggest feasibility of egocentric

	and duocentric approaches, with several important modifications to adapt the measure for the field of autism.

Question 7: Infrastructure and Surveillance

CDC	Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. J Autism Dev Disord. 2020 Dec;50(12):4258-4266. doi: 10.1007/s10803-020-04494-4. PMID: 32390121.
	There is no surveillance system for population-based estimates of the adult autistic population in the US. Using simulation and statistical models, the authors estimated the national and state prevalence of autistic adults 18-84 years. The authors estimate that 2.21% of US adults aged 18 or older, or 5,437,988 adults, have ASD. This estimate can help government officials estimate needs for services.
Julie Lounds Taylor	Hand BN, Angell AM, Harris L, Carpenter LA. Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. Autism. 2020 Apr;24(3):755-764. doi: 10.1177/1362361319890793. Epub 2019 Nov 27. PMID: 31773968; PMCID: PMC7433648.
	Very little is known about the life course of autism – especially as adults age into older adulthood. With increasing numbers of adults who are diagnosed with autism, it is important to understand what types of services and supports they may need as they age. This study used Medicare claims data to compare health conditions of older autistic adults (ages 65+) to a matched sample of older adults who did not have an autism diagnosis. Similar to research in earlier adulthood, the researchers found higher rates of a number of physical health conditions (including conditions related to aging) in the autistic sample. Findings point to the need for innovative solutions to effectively manage co-occurring condition among aging autistic adults within health systems.
CDC	Maenner MJ, Shaw KA, Baio J; EdS1, Washington A, Patrick M, DiRienzo M, Christensen DL, Wiggins LD, Pettygrove S, Andrews JG, Lopez M, Hudson A, Baroud T, Schwenk Y, White T, Rosenberg CR, Lee LC, Harrington RA, Huston M, Hewitt A; PhD-7, Esler A, Hall-Lande J, Poynter JN, Hallas-Muchow L, Constantino JN, Fitzgerald RT, Zahorodny W, Shenouda J, Daniels JL, Warren Z, Vehorn A, Salinas A, Durkin MS, Dietz PM. Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. MMWR Surveill Summ. 2020 Mar 27;69(4):1-12. doi: 10.15585/mmwr.ss6904a1. Erratum in: MMWR Morb Mortal Wkly Rep. 2020 Apr 24;69(16):503. PMID: 32214087; PMCID: PMC7119644.
	The Autism and Developmental Disabilities Monitoring (ADDM) network monitors prevalence of ASD among children aged 8 years. In 2016, ASD prevalence was 1 in 54 children aged 8 years and 4.3 times as prevalent among boys than among girls. Prevalence was lower in Hispanic children compared to other ethnic groups. Differences continue to be seen in early evaluation and diagnosis for black children. This data highlights the ongoing need for services for individuals on the spectrum and their families.
OARC	McCormick CEB, Kavanaugh BC, Sipsock D, Righi G, Oberman LM, Moreno De Luca D, Gamsiz Uzun ED, Best CR, Jerskey BA, Quinn JG, Jewel SB, Wu PC, McLean RL, Levine TP, Tokadjian H, Perkins KA, Clarke EB, Dunn B, Gerber AH, Tenenbaum EJ, Anders TF; Rhode Island Consortium for Autism Research and Treatment (RI-CART), Sheinkopf SJ,

	Morrow EM. Autism Heterogeneity in a Densely Sampled U.S. Population: Results From the First 1,000 Participants in the RI-CART Study. Autism Res. 2020 Mar;13(3):474-488. doi: 10.1002/aur.2261. Epub 2020 Jan 20. PMID: 31957984; PMCID: PMC7060113.
	The Rhode Island Consortium for Autism Research and Treatment (RI-CART) has started a major statewide research registry and summarized findings of its first 1,000 participants. This is the first analysis of a large, population-based U.S. cohort with ASD. The analysis found a high rate of co-occurring medical and psychiatric conditions. Also, researchers found that females received a first diagnosis of ASD at a later age than males, potentially due to more advanced language abilities in females with ASD. This study suggests that new strategies for earlier diagnosis of ASD in females may be warranted.
CDC	Shaw KA, Maenner MJ, Baio J; EdS1, Washington A, Christensen DL, Wiggins LD, Pettygrove S, Andrews JG, White T, Rosenberg CR, Constantino JN, Fitzgerald RT, Zahorodny W, Shenouda J, Daniels JL, Salinas A, Durkin MS, Dietz PM. Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016. MMWR Surveill Summ. 2020 Mar 27;69(3):1-11. doi: 10.15585/mmwr.ss6903a1. PMID: 32214075; PMCID: PMC7119643.
	The Early Autism and Developmental Disabilities Monitoring (Early ADDM) Network is a subset of the larger ADDM Network and estimates ASD prevalence and monitors early identification of ASD among children aged 4 years. Analysis of 2016 Early ADDM data show ASD prevalence is around 1 in 64 children aged 4 years, with higher prevalence among boys than girls. Differences in ASD prevalence between white and black children have decreased. While more children with ASD are receiving earlier diagnosis, the data in this report can continue to be used to improve early identification so services may be accessed as soon as necessary.