

INTERAGENCY AUTISM COORDINATING COMMITTEE

2020

SUMMARY OF ADVANCES

in Autism Research



OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

INTERAGENCY AUTISM COORDINATING COMMITTEE

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COVER DESIGN

NIH Medical Arts Branch

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ABOUT THE IACC

The Interagency Autism Coordinating Committee (IACC) is a Federal advisory committee charged with coordinating Federal activities concerning autism spectrum disorder (ASD) and providing advice to the Secretary of Health and Human Services (HHS) on issues related to autism. The Committee was established by Congress under the *Children's Health Act of 2000*, reconstituted under the *Combating Autism Act (CAA) of 2006*, and renewed most recently under the *Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2019*.

Membership of the Committee includes a wide array of Federal agencies involved in ASD research and services. Public stakeholders are also members of the Committee, including self-advocates, family members of children and adults on the autism spectrum, advocates, service providers, and researchers, representing a variety of perspectives from within the autism community. The IACC membership is composed to ensure that the Committee is equipped to address the wide range of issues and challenges faced by individuals and families affected by autism.

Under the CAA and subsequent reauthorizations, the IACC is required to (1) develop and annually update a strategic plan for ASD research, (2) develop and annually update a summary of advances in ASD research, and (3) monitor Federal activities related to ASD.

Through these and other activities, the IACC provides guidance to HHS and partners with other Federal departments, Federal agencies, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of addressing the needs of and improving the quality of life of people on the autism spectrum and their families.

For more information about the IACC, see <http://www.iacc.hhs.gov>.

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INTRODUCTION

THE 2020 IACC SUMMARY OF ADVANCES IN AUTISM RESEARCH

Each year, the IACC releases a list of scientific advances that represent significant progress in the field. The *2020 Summary of Advances* provides short, plain language summaries of the top research breakthroughs selected by the IACC from a pool of research articles nominated by the members. The 20 studies selected for 2020 have provided new insight into disparities in screening, inheritance patterns of autism, and genes associated with autism and early brain development. The advances also include studies that investigated treatments and early intervention, patterns of health care enrollment and usage, and prevalence differences across demographic groups. Articles in the *IACC Summary of Advances* are grouped according to the topics represented by the seven Questions of the 2016-2017 *IACC Strategic Plan for ASD*. Citations for the articles selected for the *Summary of Advances*, as well as a complete listing of those nominated, are included at the end of the document.

Editorial Note on References to Autism: *The terms "person with autism," "person with ASD," "autistic person," and "person on the autism spectrum" are used interchangeably throughout this document. Some members of the autism community prefer one term, while others prefer another. The Committee respects the different opinions within the community on the use of this language and does not intend to endorse any particular preference. In addition, the term "autism" is generally used in this document, and "autism spectrum disorder (ASD)" is used when referring specifically to the DSM defined diagnosis.*

ARTICLES SELECTED FOR THE 2020 SUMMARY OF ADVANCES

SCREENING AND DIAGNOSIS

- Primary Care Autism Screening and Later Autism Diagnosis.
- Timing of the Diagnosis of Autism in African American Children.
- Validation of the Developmental Check-In Tool for Low-Literacy Autism Screening.

BIOLOGY

- Sleep Onset Problems and Subcortical Development in Infants Later Diagnosed With Autism Spectrum Disorder.
- Trajectories in Symptoms of Autism and Cognitive Ability in Autism From Childhood to Adult Life: Findings From a Longitudinal Epidemiological Cohort.

GENETIC AND ENVIRONMENTAL FACTORS

- Inherited Risk for Autism Through Maternal and Paternal Lineage.
- Large-Scale Exome Sequencing Study Implicates Both Developmental and Functional Changes in the Neurobiology of Autism.

INTERVENTIONS

- A Randomized Controlled Trial of Functional Communication Training via Telehealth for Young Children with Autism Spectrum Disorder.
- A Multisite Randomized Controlled Trial Comparing the Effects of Intervention Intensity and Intervention Style on Outcomes for Young Children With Autism.
- Project AIM: Autism intervention meta-analysis for studies of young children.
- Cognitive Behavioral Treatments for Anxiety in Children With Autism Spectrum Disorder: A Randomized Clinical Trial.

SERVICES AND SUPPORTS

- 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.
- Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children.
- Competitive Employment for Transition-Aged Youth with Significant Impact from Autism: A Multi-site Randomized Clinical Trial.

LIFESPAN

- Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder.
- Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study.

RESEARCH INFRASTRUCTURE AND PREVALENCE

- National and State Estimates of Adults with Autism Spectrum Disorder.
- Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults.
- Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016.
- Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016.

SCREENING AND DIAGNOSIS

Primary Care Autism Screening and Later Autism Diagnosis.

Carbone PS, Campbell K, Wilkes J, Stoddard GJ, Huynh K, Young PC, Gabrielsen TP. *Pediatrics*. 2020 Aug;146(2):e20192314. [PMID: 32632024]

Most children in the U.S. are screened for autism, but disparities persist and implementation of screening across medical practices remains inconsistent.

Background: Early identification of autism allows for early intervention, which is associated with improved long-term outcomes. The ASD screening tool most commonly used by pediatricians is the Modified Checklist for Autism in Toddlers (M-CHAT).

Methods & Findings: The goals for this study were to determine the rate of ASD screening at 18- and 24-month visits, identify characteristics associated with completing the screening, and evaluate how the M-CHAT is administered in real-world settings, including the extent to which the M-CHAT improves accurate identification of ASD at earlier ages. The researchers analyzed electronic health records from clinics in Utah for children who attended 18- and 24- month clinical visits between 2013 and 2016. They also contacted the physicians to determine how they administered and scored the M-CHAT, if they adhered to the follow-up recommendation, and the pattern of referrals for children who screened positive. The researchers concluded that ASD screening occurs at most 18- or 24-month visits and that children who screened positive were more likely to be diagnosed with ASD at a younger age.

Implications: There was a high number of false negative screens, which may be related to children receiving only one screen and/or the lack of follow-up interviews. There were also disparities in screening across race, sex, and socioeconomic status. Importantly, unlike the American Academy of Pediatrics, the American Academy of Family Physicians does not recommend universal ASD screening, as was illustrated by the lower likelihood of family physicians administering the M-CHAT than pediatricians. The results of the study support universal ASD screening but indicate a need for more consistent implementation in real-world settings, quick referral for at-risk children, and expansion of ASD screening among family physicians.

SCREENING AND DIAGNOSIS

Timing of the Diagnosis of Autism in African American Children.

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. *Pediatrics*. 2020 Sep;146(3). [PMID: 32839243]

African American children on the spectrum experience delays in diagnosis and have a greater chance of being identified with an intellectual disability.

Background: Despite public health efforts to help families identify and act on early signs of ASD, a significant delay persists between the time at which parents express concern about their child's development and the child's age at ASD diagnosis. This study aimed to better understand delays in ASD diagnosis and the disproportionate rate of co-occurring intellectual disability (ID) in African American children with ASD. The researchers also sought to explore family and social factors that may contribute to differences in IQ among African American children on the spectrum.

Methods & Findings: Researchers used a sample of African American children with ASD enrolled in the Autism Genetics Network study and gathered data from event history calendar interviews, conducted cognitive assessments of the children and their close relatives, compared the prevalence of ASD among their study participants to the wider population, and obtained genetic ancestry data. Across all sites, over 35% of families reported significant wait times. Over 41% reported having to see multiple professionals before receiving an ASD diagnosis, and over 31% indicated a lack of available professionals.

Implications: The researchers concluded that there is a substantial delay in ASD diagnosis among African American children, which occurs despite most families having health insurance. They found that cognitive outcome for African American children with ASD and co-occurring ID were not associated with length of pregnancy, family income, or variation of IQ within the family, which are all associated with cognitive outcome in the general population. Thus, the pronounced co-occurrence of ID in African American children with ASD cannot reasonably be accounted for by these factors. Rather, the disparity may be related to delayed diagnosis (as documented in the present study), disproportionate presumption of ID, and/or reduced access to quality intervention services. This disproportionate burden of ID co-occurrence among African American children with ASD represents a pressing public health concern.

Validation of the Developmental Check-In Tool for Low-Literacy Autism Screening.

Harris JF, Coffield CN, Janvier YM, Mandell D, Cidav Z. *Pediatrics*. 2021 Jan;147(1):e20193659.

[PMID: 33303635]

The Developmental Check-In is a new picture-based autism screening tool that can help to identify autism in children of parents with low literacy levels.

Background: Although early identification of ASD is needed to initiate the early intervention that is critical to improved outcomes, children from poor, racial, or ethnic minority groups are often misdiagnosed and/or receive a later diagnosis than other children—a disparity that is further compounded in families with limited English proficiency. The most commonly used ASD screening tools have decreased sensitivity among underserved populations. There is a need for a comprehensive visual-based ASD assessment that has been validated among racial/ethnic minority, low-income, and/or limited English proficiency families

Methods & Findings: The aim of this study was to validate the Developmental Check-In (DCI) ASD screening tool, which was developed to reduce literacy demands and be easily administered across different settings. The DCI is available in both English and Spanish and consists of 26 pictures grouped by four domains: communication, play, social, and behavior. Researchers recruited children aged 24 to 60 months from Head Start and Early Head Start programs across four low-income communities in New Jersey. Most children were Hispanic (66%) and from families in which English was not the primary language (65%).

Implications: The researchers concluded that the DCI was able to accurately identify ASD among a sample of young children from underserved families who were primarily Hispanic, spoke Spanish as a primary language, were insured through Medicaid or not at all, and had a maternal education of high school or below. Hispanic children are diagnosed with ASD at lower rates than Black and White children; thus the DCI is a promising picture-based screening tool that can be used to help close the gap in age of ASD diagnosis among Hispanic children. Because it is a visually based ASD screener, the DCI may be particularly useful in screening for ASD among low literacy or limited English proficiency groups.

BIOLOGY

Sleep Onset Problems and Subcortical Development in Infants Later Diagnosed With Autism Spectrum Disorder.

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. *Am J Psychiatry*. 2020 Jun 1;177(6):518-525. [PMID: 32375538]

Infants who develop autism are more likely to have sleep challenges in the first year of life and show differences in brain development.

Background: Sleep during the first few years of life is critical for brain development. Sleep challenges have been well-documented in children with autism—with research showing difficulties in falling or staying asleep, reduced sleep duration, and increased night awakenings. Differences in certain brain regions, such as the hippocampus, amygdala, thalamus, and basal ganglia, have also been associated with both ASD and sleep problems. However, no previous studies have examined the link between poor sleep and early brain development in ASD.

Methods & Findings: This study sought to characterize differences in sleep behavior between infants who later develop ASD (N=71), infants who do not develop ASD but are at higher likelihood due to having an older sibling with ASD (N=234), and infants with no family history of ASD (N=127). Parents completed a survey that contained questions such as, “When going to sleep at night, how often did your baby have a hard time settling down to sleep?” Results showed that, in comparison to infants in the other two groups, those who developed ASD had greater difficulty settling to sleep at the beginning or in the middle of the night (i.e., sleep onset problems). Across all groups, infants who had problems falling asleep at 6 and 12 months of age showed reduced social communication skills by 24 months of age. The researchers also found that difficulty with sleep onset was associated with increased volume in the hippocampus between 6 and 24 months of age in the infants who later developed ASD.

Implications: This study contributes new insight about infant sleep behavior and early brain development. The researchers discussed other findings that suggest sleep plays a specific role in processes that occur in the hippocampus, such as learning and memory consolidation, and that this brain region is particularly sensitive to inadequate sleep. Together, these findings indicate a relationship between infant sleep, early brain development, and neurodevelopmental disorders that may lead to targeted interventions for sleep difficulties in infants at higher likelihood of developing ASD.

Trajectories in Symptoms of Autism and Cognitive Ability in Autism From Childhood to Adult Life: Findings From a Longitudinal Epidemiological Cohort.

Simonoff E, Kent R, Stringer D, Lord C, Briskman J, Lukito S, Pickles A, Charman T, Baird G. *J Am Acad Child Adolesc Psychiatry*. 2020 Dec;59(12):1342-1352. [PMID: 31863881]

Improvement in IQ does not consistently reduce challenges faced by children on the autism spectrum, but mainstream school attendance is associated with better outcomes.

Background: ASD is associated with cognitive, social, communication, sensory, and behavioral differences that evolve across the lifespan. One critical milestone is the transition from adolescence into adulthood, when important decisions are made in terms of education, employment, and independent living. However, little is understood about the trajectory of autism characteristics from early childhood into adulthood. Some previous studies have found that patterns of IQ and autism symptoms are related to outcomes in employment and independent living, but overall, research findings on the trajectory of IQ in autism over time are mixed.

Methods & Findings: This longitudinal study examined how IQ and autism symptoms change from late childhood to early adulthood. The study also sought to identify the individual, family, and contextual factors that predict changes in IQ and autism symptoms over time. There was significant variability in initial autism symptoms and IQ across participants. In measuring the trajectory of autism symptoms and IQ over time, the researchers found that IQ increased an average of 7.48 points between 12 and 23 years of age. However, there were no significant changes in the autism symptoms studied over time. In measuring predictors of IQ and autism symptoms, the researchers found that autistic individuals who had a history of early language regression (i.e., loss of verbal and/or nonverbal communication) showed greater increases in IQ over time. Attendance at specialist schools was associated with a relative increase in latent autism symptoms (i.e., developmental delays) over time, and attendance at a mainstream school was associated with significantly fewer autism symptoms at age 23.

Implications: Although previous studies have indicated that higher IQ is associated with improved autism symptoms and better outcomes over time, the results of this study found no such association. The finding of an association with school placement suggests that there may be an underlying mechanism in how IQ affects autism symptoms over the lifespan. Studies of developmental behavior and genetics have highlighted an important link between the environment and IQ. Mainstream schools may provide greater opportunities for different experiences and interactions that might mediate IQ and autism outcomes. This study provides novel insights into the mechanisms that may contribute to autism outcomes in adulthood and suggests potential pathways to interventions for older children with autism.

GENETIC AND ENVIRONMENTAL FACTORS

Inherited Risk for Autism Through Maternal and Paternal Lineage.

Bai D, Marrus N, Yip BHK, Reichenberg A, Constantino JN, Sandin S. *Biol Psychiatry*. 2020 Sep 15;88(6):480-487. [PMID: 32430199]

Patterns of inheritance through the female and male parents of people with autism do not support the hypothesis of a “female protective effect.”

Background: The number of males diagnosed with ASD is approximately three times that of females. To account for this disparity, several recent studies have proposed that there is a “female protective effect” that increases the threshold for ASD in females. This means that females would require a greater accumulation of ASD genetic differences to reach a threshold to be diagnosed with ASD, and males would have a lower threshold to be diagnosed with ASD. If such a female protective effect exists, then females who do not have ASD but have family members with ASD may “silently” carry genetic differences that result in increased likelihood of ASD in their male offspring. This would result in a greater recurrence of ASD in the sons of unaffected mothers than unaffected fathers.

Methods & Findings: To test this hypothesis, this study examined transmission of ASD through female and male parents by comparing the prevalence of ASD among offspring with maternal and paternal aunts and uncles with ASD. Using clinical and developmental data linked from Swedish national databases, the researchers identified 13,103 children diagnosed with ASD, 1,744 aunts with ASD, and 1,374 uncles with ASD. The study results revealed that the presence of ASD in both maternal and paternal aunts or uncles was associated with an increased rate of ASD in children. However, the relative risk of ASD between maternal and paternal lineage was similar. That is, children of unaffected mothers who had a sibling with autism had the same probability of ASD diagnosis compared to children of unaffected fathers who had a sibling with autism. For these children, the possibility of developing ASD was no greater than the prevalence rate in the general population. Additionally, the chance of having ASD was similar in both sons and daughters.

Implications: Given these findings, the researchers concluded that a female protective factor is not a primary mechanism for the difference in ASD prevalence between males and females. There may be other explanations for this disparity that could be examined by similar population-level studies. One possibility is that a female protective factor does exist in combination with other factors, such as a factor that lowers the threshold for ASD in males. Importantly, ASD screening in Sweden does not currently include an evaluation of family history, but the results of this study suggest that children with a family history of ASD may benefit from more robust screening methods to confirm a diagnosis and target with early intervention.

Large-Scale Exome Sequencing Study Implicates Both Developmental and Functional Changes in the Neurobiology of Autism.

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. *Cell*. 2020 Feb 6;180(3):568-584.e23. [PMID: 31981491]

A large-scale genetic sequencing study identified 102 autism-related genes involved in early brain development.

Background: A genetic variant (sometimes called a genetic mutation) is a permanent change in the DNA sequence of a gene. Rare and *de novo* (new) genetic variants significantly contribute to the development of ASD. Despite recent advances in our understanding of the genetic contributions to ASD, there are several unanswered questions about when, where, and in what cell types these genes act to alter neurodevelopment. Studying the sequence of exomes (protein-coding regions of the DNA) can help to answer some of these questions.

Methods & Findings: This paper presents the results of the largest exome sequencing study of ASD to date. In this study, researchers collected 35,583 samples of DNA from 11,986 individuals with ASD, 2,179 unaffected siblings and parents, and 8,809 individuals without ASD. By analyzing the genetic variants in these samples, the researchers identified 102 genes associated with an increased risk of ASD, most of which regulate gene expression in early brain development, including some that affect development broadly and some that are specific to ASD. Of these, 30 genetic variants were considered truly new because they had not been previously implicated in neurodevelopmental disorders. Further characterization of the genetic variants in the 102 ASD risk genes led to new information about how the genes are expressed, the neural processes they affect, and their influence on neurodevelopment.

Implications: When comparing males and females, the researchers found more *de novo* variants in females with ASD than males with ASD. This finding provides support for the theory of a “female protective effect,” which hypothesizes that females require an increased threshold for genetic variants to reach an ASD diagnosis, whereas males require a lower threshold. Additionally, the researchers found that the ASD genes were often expressed in excitatory neurons of the brain. Excitatory neurons promote the transmission of electrical and chemical signals to additional neurons, while inhibitory neurons prevent this transmission. Past research has found that an imbalance in excitatory versus inhibitory neuron activity may contribute to ASD. The findings of this study provide compelling support for both an imbalance in the number and activity of excitatory neurons and inhibitory neurons in the development of ASD.

INTERVENTIONS

A Randomized Controlled Trial of Functional Communication Training via Telehealth for Young Children with Autism Spectrum Disorder.

Lindgren S, Wacker D, Schieltz K, Suess A, Pelzel K, Kopelman T, Lee J, Romani P, O'Brien M. *J Autism Dev Disord.* 2020 Dec;50(12):4449-4462. [PMID: 32300910]

Parents of children with autism can be effectively trained with telehealth support to increase functional communication and reduce challenging behaviors.

Background: Children with ASD are at higher risk for problem behaviors such as self-injury, aggression, verbal outbursts, property destruction, and severe noncompliance, which can significantly disrupt social and learning interactions. Studies have identified several evidence-based approaches for treating these behaviors, including therapy, parent education, and medication. However, among the most researched and utilized treatment approaches is an applied behavior analysis (ABA) method called *functional communication training* (FCT). FCT has been shown to successfully increase functional communication and reduce challenging behaviors across different populations and settings.

Methods & Findings: Access to FCT can be limited by geography, provider availability, and cost. To overcome these barriers to an effective treatment for challenging behaviors, this randomized controlled study sought to examine its effectiveness in a telehealth setting. The researchers compared the effectiveness of FCT to treatment as usual in 38 young children (age 21 to 85 months) with autism. The children were randomly placed in either a group that immediately received FCT for 12 weeks or a waitlist control group that received treatment as usual for 12 weeks followed by delayed FCT for 12 weeks. FCT was administered by parents using real-time support from a telehealth behavioral consultant. The researchers measured the reductions in frequency of challenging behaviors, increases in appropriate requests, and the durability of these effects six months after treatment. Although both groups showed significantly improved behavior after completing FCT, the group of children who received immediate FCT had slightly more behavioral improvement than the group of children who received FCT 12 weeks later. Parents rated the telehealth FCT treatment generally positive, indicating it as highly acceptable.

Implications: The results of this study demonstrate that parents can be effectively trained to apply FCT with live telehealth support. FCT intervention resulted in a 98% reduction (on average) of challenging behaviors and significant increases in functional communication. FCT training delivered remotely to parents can increase access to an evidence-based approach for increasing functional communication and reducing challenging behaviors—improving not only social and learning outcomes, but potentially increasing the benefit of other ASD services.

INTERVENTIONS

A Multisite Randomized Controlled Trial Comparing the Effects of Intervention Intensity and Intervention Style on Outcomes for Young Children With Autism.

Rogers SJ, Yoder P, Estes A, Warren Z, McEachin J, Munson J, Rocha M, Greenson J, Wallace L, Gardner E, Dawson G, Sugar CA, Helleman G, Whelan F. *J Am Acad Child Adolesc Psychiatry*. 2020 Aug 24.

[PMID: 32853704]

While 15-25 hours of high-quality early behavioral/social skills intervention has been shown to have benefits for children on the autism spectrum, there is little evidence that more than 25 hours per week of early intervention leads to better outcomes.

Background: The evidence for early intervention to improve outcomes in young children with ASD is well-established. However, different studies use different intervention styles and levels of intensity, with some studies using a treatment design that is so time-intensive that it would be impractical in a real-life setting. Further, there has not previously been a rigorous effort to compare outcomes across the differing intervention styles and intensities, resulting in a lack of guidance for caregivers and practitioners on optimal delivery.

Methods & Findings: This study conducted a rigorous assessment of two commonly used early intervention styles: the Early Intensive Behavioral Intervention (EIBI), a one-on-one discrete trial training, and the Early Start Denver Model (ESDM), a one-on-one naturalistic developmental behavioral intervention. The researchers evaluated both interventions across two levels of intensity: 15 hours or 25 hours per week, across 12 months. The researchers enrolled 87 children aged 12 to 30 months who met ASD criteria. The children were randomized to four conditions: EIBI for 15 hours a week, EIBI for 25 hours a week, ESDM for 15 hours a week, or ESDM for 25 hours a week. Additionally, all families received two 90-minute coaching sessions each month on the use of their assigned intervention. The researchers found that all interventions improved outcomes over time. There was no difference in outcomes across the EIBI or ESDM and no evidence that initial severity of developmental delay and autism characteristics impacted outcomes from either treatment style. Across most study sites, the researchers found no difference in outcomes across either 15 or 25 hour a week of intervention and no evidence that initial severity of developmental delay and autism characteristics impacted any of the other outcomes from the intensity of either intervention delivered. However, at one study site, they found evidence that initial severity predicted a greater effect from higher intensity intervention (25 hours a week) in improving one outcome: core autism characteristics.

Implications: This study provided some guidance for clinicians in their recommendations for early intervention for ASD. First, the quality and characteristics of early intervention may be more important than its “brand name.” A high-quality early intervention should include a specific, evidence-based approach that provides regular developmental and behavioral intervention integrated with everyday activities. There is evidence that 25 hours of intervention a week may be more effective than 15 hours in improving core autism characteristics for some children, but additional study is needed to support this finding. The researchers reiterated that there is no high-quality evidence for intervention intensity longer than 25 hours.

Project AIM: Autism intervention meta-analysis for studies of young children.

Sandbank M, Bottema-Beutel K, Crowley S, Cassidy M, Dunham K, Feldman JI, Crank J, Albarran SA, Raj S, Mahbub P, Woynaroski TG. *Psychol Bull.* 2020 Jan;146(1):1-29. [PMID: 31763860]

An analysis of research describing seven types of early interventions for children with autism summarizes their benefits and limitations and provides recommendations for more research.

Background: There has been an abundance of research on ASD interventions targeted to young children. In a broad effort to evaluate the effectiveness of early nonpharmacological interventions for ASD, the researchers of this study conducted a comprehensive meta-analysis of seven different intervention types—behavioral approaches, developmental approaches, naturalistic developmental behavioral interventions (NDBIs), Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH), sensory-based interventions, animal-assisted interventions, and technology-based interventions. A meta-analysis is a type of study that systematically gathers data from previous studies and analyzes the outcomes of these studies as a whole.

Methods & Findings: Researchers identified 140 peer-reviewed articles and ten dissertations that met a more rigorous set of criteria than is generally used to evaluate the quality of evidence in ASD interventions. The research team assigned a quality rating to each study according to each intervention type. The research team also assessed whether the outcomes were directly aligned to the intervention (i.e., specific skills that could be observed in the context of the intervention) or not. They then extracted data from all studies to determine how much of a difference the intervention had (i.e., effect size) across each type of outcome within each type of intervention. Of all the intervention types, NDBIs emerged as having strong evidence for the development of social communication, language, and play skills. NDBIs were the most likely to have been conducted in a scientifically rigorous manner to prevent bias and incorporate comparison groups, and they were the least likely to rely on parent or caregiver report.

Implications: Behavioral interventions were the most common intervention studied, which is likely the result of their common use due to the availability of insurance coverage. Of all behavioral interventions, only Early Intensive Behavioral Interventions (EIBI) showed some evidence of effectiveness for cognition and language, but most studies did not meet high standards for quality evidence. The trend towards positive results in behavioral interventions indicate that future studies could improve the confidence of these approaches through use of more scientifically rigorous study designs, such as randomized controlled trials. All other interventions showed little evidence of effectiveness. The researchers of this study suggested that NDBIs and developmental approaches be included in insurance mandates and other policies. Importantly, the results of this meta-analysis suggest that future ASD intervention studies should move toward randomized controlled trials and rely less on parent and teacher reports as outcomes.

INTERVENTIONS

Cognitive Behavioral Treatments for Anxiety in Children With Autism Spectrum Disorder: A Randomized Clinical Trial.

Wood JJ, Kendall PC, Wood KS, Kerns CM, Seltzer M, Small BJ, Lewin AB, Storch EA. *JAMA Psychiatry*. 2020 May 1;77(5):474-483. [[PMID: 31755906](#)]

Cognitive behavioral therapy helps reduce anxiety in children and youth with autism, especially when the therapy is specifically adapted for autism.

Background: Anxiety is common among school-aged youth with ASD. Youth with ASD who experience anxiety commonly react to their fear using coping mechanisms such as meltdowns, aggression, self-harm, or avoidance. These behaviors can significantly interfere with social and learning environments, create family conflict, and result in increased isolation and depression. Several small randomized controlled studies suggest that cognitive behavioral therapy (CBT) may be effective for school-aged youth with ASD and anxiety, but their study designs have not been robust enough to establish evidence. Other studies of CBT that has been adapted to the characteristics of ASD have also shown promise, but these efforts have also been too limited to establish evidence for their effectiveness. It has also been unknown if CBT adapted for youth with ASD differs from standard CBT.

Methods & Findings: This study aimed to evaluate the effectiveness of both standard and adapted CBT for anxiety in children with ASD. The researchers evaluated 145 children aged 7 to 13 years with ASD and anxiety. The children were randomized across three groups: standard CBT, adapted CBT, and treatment as usual. Standard CBT consisted of 16 weekly one-hour sessions targeted for identifying anxiety triggers and developing a plan for appropriate coping strategies. Adapted CBT consisted of 16 weekly 90-minute sessions that included higher levels of parent engagement, personalized strategies to incorporate the child's special interests, a focus on self-regulation and social engagement skills, and increased reappraisal and reinforcement. Treatment as usual included 16 weeks of usual services and no other no specific treatment. Both standard and adapted CBT resulted in positive effects as compared to treatment as usual. However, the adapted CBT was significantly more effective than standard CBT in reducing anxiety and interfering behaviors. Additionally, adapted CBT was shown to further improve emotional dysregulation, social-communication, and adaptive functioning.

Implications: This study provided robust evidence that a CBT protocol adapted for children with ASD was effective for reducing anxiety and coping behaviors and improving social, emotional, and adaptive functioning. The researchers recommended that adapted CBT become available in all clinical settings where children with ASD receive services, suggesting that the protocol can be provided by therapists without specific ASD expertise with modest training and guidance.

SERVICES AND SUPPORTS

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.

Benevides TW, Carretta HJ, Rust G, Shea L. *PLoS One*. 2021 May 25;16(5). [PMID: 34032811]

Disparities in dual eligibility for Medicaid and Medicare benefits across race and ethnicity in autistic adults contribute to disparities in access to services.

Background: Racial and ethnic disparities in diagnosis and access to high-quality autism services and interventions are well-documented for children with ASD. However, to better understand adult disparities, this study investigated racial and ethnic differences in eligibility for public health insurance through Medicare and Medicaid. Individuals may obtain Medicaid by meeting income and asset requirements and Medicare by meeting age or disability requirements. Dual eligibility, in which individuals can be enrolled in both programs, provides beneficiaries with multiple coverage options. People can be eligible for both programs if they meet criteria for disability determination and are enrolled in state Medicaid programs.

Methods & Findings: This study used data from the 2012 Medicare-Medicaid Linked Enrollees Analytical Data Source (MMLEADS) to identify 172,071 adults on the autism spectrum who were insured by Medicare, Medicaid, or both. Almost half (49.87%) of White autistic adults were dual-eligible. In contrast, only 37.53% of Black, 34.65% of Asian/Pacific Island, and 35.94% of Hispanic autistic adults were dual eligible, with most only eligible for state-funded Medicaid. Black beneficiaries were significantly less likely than White beneficiaries to be dual-eligible across all ages. Additionally, in this sample, Black beneficiaries were significantly more likely to have a co-occurring intellectual disability than White beneficiaries. However, the median spending on health care for Black beneficiaries per year was 20% less for dual beneficiaries.

Implications: These results suggest that full-dual beneficiaries were likely to be found eligible based on disability determination criteria rather than income level. Previous studies have found that obtaining a disability determination can depend on privileges such as attorney representation, higher income, or previous employment, which may be criteria that are more limited for members of minority groups. This suggests that the pathway to dual enrollment may not be equal across race/ethnicity since there are barriers to disability determination. The findings also suggest a need for further research on the relationship between co-occurring intellectual disability and costly chronic conditions, race/ethnicity, and health care spending. Overall, this study demonstrates that differences in determination of eligibility and spending on public benefits continues to negatively impact autistic adult beneficiaries of racial and ethnic minority groups. This indicates that policy changes are needed to address these disparities through education, outreach, and reduction of system navigation barriers.

Understanding Racial and Ethnic Disparities in Autism-Related Service Use Among Medicaid-Enrolled Children.

Bilaver LA, Sobotka SA, Mandell DS. *J Autism Dev Disord.* 2020 Nov 21. [PMID: 33219917]

Racial and ethnic disparities persist in Medicaid enrollment and use of services for children with autism.

Background: Medicaid is a public health insurance program that is the largest payer of autism-related health care services among children with autism in the United States. Children are eligible for Medicaid based on disability, income, or foster care. Medicaid also pays for school-based services for eligible children in most states. Research has uncovered racial and ethnic disparities in the use of the Medicaid waiver program, which provides home- and community-based services. However, little is known about racial and ethnic disparities in other Medicaid services and school-based programs.

Methods and Findings: This study used 2012 Medicaid Analytic eXtract (MAX) data to identify 117,848 children (aged 3 to 17) on the autism spectrum. The authors found that among Medicaid-enrolled children with ASD, 64% were White, 18% Black, 14% Latinx, 2% Asian, and 2% Native American/Pacific Islander. Most children were enrolled due to disability and through a waiver program. Black children with ASD were less likely to be enrolled through the waiver program than any other race/ethnicity. Black children on the autism spectrum made up the largest percentage enrolled in Medicaid through foster care. Black, Asian, and Native American/Pacific Islander children with ASD received fewer outpatient services than White children with ASD. Black and Asian children received more autism services in school settings than White children. In comparison to White children with ASD, Black children with ASD living in metro areas were less likely to use outpatient services and were more likely to use school-based services. The results also indicated significant racial and ethnic disparities in case management and care coordination services for Asian, Latinx, and Black children in comparison to White children.

Implications: The researchers suggest that the effects of structural racism may contribute to disparities in Medicaid service use in multiple ways. The most significant disparities were found in case management/care coordination, which would negatively affect the ability to find necessary treatment of health conditions, leading to delays in services and supports. This shows a critical need to address policies that contribute to these disparities. Policy interventions that target geographical differences in service use could also help efforts to achieve equal access, especially for underserved children living in large metropolitan areas.

Competitive Employment for Transition-Aged Youth with Significant Impact from Autism: A Multi-site Randomized Clinical Trial.

Wehman P, Schall C, McDonough J, Sima A, Brooke A, Ham W, Whittenburg H, Brooke V, Avellone L, Riehle E. *J Autism Dev Disord.* 2020 Jun;50(6):1882-1897. [PMID: 30825082]

Project SEARCH is a promising intervention program to improve employment outcomes for young adults on the autism spectrum.

Background: Despite recent legislation mandating transition services for people with disabilities, many young adults with ASD remain at high risk for unemployment and underemployment. Few studies have explored interventions to improve employment outcomes for autistic individuals. Recent studies have demonstrated benefits of supported employment as an intervention for other disabilities. Customized employment is an extension of supported employment that aims to match the strengths of each person with the needs of an employer.

Methods and Findings: Project SEARCH is a transition-to-work internship program that uses supported employment and customized employment to prepare youth and young adults with disabilities for employment. The researchers randomized 156 high school students with ASD (aged 18-21) into two groups. One group was enrolled in the Project SEARCH program and also received ASD-specific supports, including social communication training, provision of visual cues, and behavior support and self-regulation strategies. The control group received services and accommodations as specified in their individualized education plans. Both educational staff and job coaches provided support. The researchers found that 32% of the students in the Project SEARCH group graduated high school having secured competitive employment, while only 5% of those in the control group graduated with employment. After one year, over 73% of students the treatment group had acquired competitive employment, compared to 17% of students in the control group. Participants in the Project SEARCH group reported an average of 18.8 weeks from graduation to employment, while those in the control group reported an average of 43.4 weeks. At one year post-graduation, participants from the Project SEARCH group were working an average of more than 20 hours a week at an average of \$9.67 per hour.

Implications: The Project SEARCH program provided a seamless transition from school-based to adult community-based services for students with ASD, resulting in significantly fewer individuals being unemployed in the year following graduation. The researchers identified six key elements of the program that contributed to improved employment outcomes: internship experience, instruction, receiving personalized vocational support, seamless transition to adult services, high expectations for interns, and developing a resume with examples of successful work. The researchers recognized that Project SEARCH requires a significant investment of time, cost, staffing, and collaboration but highlighted that the intervention provides a solid foundation for students to obtain competitive employment and build a career.

LIFESPAN

Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder.

Hall JP, Batza K, Streed CG Jr, Boyd BA, Kurth NK. *J Autism Dev Disord.* 2020 Aug;50(8):3071-3077.

[PMID: 32056117]

Autistic individuals who belong to sexual and gender minority groups report higher rates of unmet health care needs and negative experiences with providers.

Background: Both individuals with autism and individuals of sexual and gender minority experience multiple, systemic barriers to appropriate health care. Reasons for this include a lack of knowledgeable providers and fear of stigma. Individuals at the intersection of autism and sexual and gender minority may experience cumulative health disparities, but little is understood about their health and access to health care. This study sought to understand the health experiences of individuals with ASD who also identify as LGBTQ+.

Methods & Findings: The National Survey on Health and Disability (NSHD) is an internet-based survey that was implemented between February and June 2018. It provided a snapshot of health outcomes among Americans with disabilities after the implementation of the Affordable Care Act. The researchers extracted data from the NSHD data for 54 adults (aged 18-62) with ASD; of these, 19 individuals also identified as LGBTQ+ (35%). Autistic LGBTQ+ individuals were more likely to have private insurance and straight, autistic cisgender (someone whose gender is the same as their biological sex) individuals were more likely to have Medicare or Medicaid. Data from both the survey and follow-up interviews with five respondents indicated that private insurance was less adequate than Medicare or Medicaid in covering the medical needs of LGBTQ+ individuals on the autism spectrum. LGBTQ+ individuals with ASD reported much higher rates of unmet health care needs and inadequate provider networks than straight, cisgender individuals with ASD.

Implications: This study found evidence that autistic LGBTQ+ individuals lack adequate health care services and experience worse health than straight, cisgender autistic individuals. LGBTQ+ individuals with ASD report higher educational attainment but greater rates of mental illness, smoking, and poor overall health—a finding that is contrary to research of the general population. LGBTQ+ individuals with ASD are also more likely to have post-traumatic stress disorder (PTSD) than straight, cisgender individuals with ASD. The interviews indicated that LGBTQ+ individuals on the autism spectrum were often reluctant to seek health care, which was associated with previous negative experiences and provider attitudes. The results of this study indicate that health care professionals should receive training in the specific needs of LGBTQ+ individuals and LGBTQ+ individuals with ASD.

Anxiety Disorders in Adults with Autism Spectrum Disorder: A Population-Based Study.

Nimmo-Smith V, Heuvelman H, Dalman C, Lundberg M, Idring S, Carpenter P, Magnusson C, Rai D. *J Autism Dev Disord.* 2020 Jan;50(1):308-318. [PMID: 31621020]

Young adults on the autism spectrum are three times more likely to have an anxiety disorder than non-autistic adults.

Background: Anxiety is a common co-existing condition in autistic children; however, less is known about the prevalence and characteristics of anxiety disorder among autistic adults, both with and without intellectual disability (ID). The few existing studies on anxiety in adults with autism have reported inconsistent findings, often fail to document prevalence across distinct types of anxiety disorders, and have not addressed differences between those with and without ID. This study aimed to determine the lifetime prevalence of anxiety disorders in autistic adults and to characterize the risk of co-existing anxiety in autistic adults with and without ID. The study also aimed to determine genetic vulnerability for anxiety amongst full and half non-autistic siblings of autistic individuals.

Methods & Findings: The researchers used data from two large databases of individuals in Sweden that provide information on health and familial linkages. The researchers identified 4,049 autistic adults (aged 18 to 27) with or without ID and a reference population of 217,645 non-autistic adults. Autistic adults were nearly three times more likely to have an anxiety disorder than the reference population. The most commonly diagnosed type of anxiety among autistic adults was a non-specific anxiety or neurotic disorder. Autistic adults without ID were more likely to have been diagnosed with an anxiety disorder than autistic adults with ID. Anxiety was more common among adults on the autism spectrum than their non-autistic full and half siblings. Meanwhile, anxiety was more common among non-autistic full and half siblings than in the reference population. However, genetic distance did not seem to influence the chance of a family member having anxiety (i.e., a sibling versus a half-sibling having anxiety was not significantly different), nor was there any observed difference in risk among family members of autistic adults with or without ID.

Implications: The results of this study indicate a high rate of anxiety disorders among autistic adults, especially among those without ID. The increased prevalence of anxiety in autistic adults without ID compared to those with ID may be related to increased cognitive awareness and verbal ability. There may also be an underestimation of anxiety in those with ID due to “diagnostic overshadowing,” in which anxiety symptoms are attributed to other causes. Anxiety disorders were more common in the non-autistic full and half siblings of autistic adults, suggesting a genetic risk. However, the lack of evidence that non-autistic half siblings are at reduced risk for anxiety indicates that environmental factors may contribute to anxiety. The researchers suggest that mental health professionals who support adults should gain the skills needed to understand co-existing autism and anxiety and the differences in how anxiety is presented between autistic adults with and without ID.

RESEARCH INFRASTRUCTURE AND PREVALENCE

National and State Estimates of Adults with Autism Spectrum Disorder.

Dietz PM, Rose CE, McArthur D, Maenner M. *J Autism Dev Disord.* 2020 Dec;50(12):4258-4266.

[[PMID: 32390121](#)]

An estimated 1 in 45 adults in the United States have autism, indicating a critical need for diagnostic tools and services for adults.

Background: ASD is a developmental disability characterized by social communication challenges and restricted and repetitive behaviors, for which some people may require extensive support across the lifespan. Children diagnosed with ASD may receive school-based supports and services, enabling surveillance for the prevalence, characteristics, and needs of children with ASD. But as children with ASD transition into adulthood, they also transition out of these supports and services. As a result, less is known about the prevalence, characteristics, and needs of adults with ASD. It is critically important to understand national and state-based estimates of adults with ASD to inform development of programs, policies, and services to support them.

Methods & Findings: This study used 2017 data from the National Survey of Children's Health (NSCH) and population mortality rates to estimate the prevalence of ASD in adults. The researchers estimated that there was approximately 2.21% of adults with ASD in the United States in 2017. State prevalence of ASD in adults ranged from 1.97% in Louisiana to 2.42% in Massachusetts. California, Texas, and New York had the greatest estimated number of adults with ASD. There was no obvious geographical pattern for estimated prevalence across the states. The national prevalence of ASD was 0.86% in adult women and 3.62% in adult men.

Implications: There is currently no standardized, validated assessment for ASD in adults. Additionally, some adults with ASD may live independently and not receive services, creating a challenge in accurately determining ASD prevalence in adults. This study estimated that 1 in 45 adults in the United States live with ASD, which indicates a critical need to develop validated ASD assessment tools and provide evidence-based services specific to adults.

Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults.

Hand BN, Angell AM, Harris L, Carpenter LA. *Autism*. 2020 Apr;24(3):755-764. [PMID: 31773968]

Autistic adults older than 65 years have higher rates of nearly all health conditions that typically affect older adults, indicating a need for more supports and services.

Background: Across the general population, older adults (over age 65) have specific health care needs, with differences in the likelihood of co-existing physical and mental health conditions as compared to younger adults. Research has indicated that prevalence of co-existing conditions may further differ among autistic older adults. It is therefore important to determine the prevalence of physical and mental co-existing conditions in autistic older adults to inform the development of the specific services and supports needed to maintain wellbeing.

Methods & Findings: Using a national sample of Medicare beneficiaries between 2016 and 2017, the researchers of this study aimed to compare the prevalence of physical and mental co-existing conditions among older autistic adults and older non-autistic adults. They identified 4,685 autistic older adults and generated a randomized comparison sample of 46,850 non-autistic older adults. Over 43% of autistic individuals had co-existing intellectual disability as compared to 0.2% of the comparison sample. Autistic older adults were significantly more likely to have co-existing physical health conditions such as osteoporosis, cognitive/neurological disorders, heart disease, cancer, cerebrovascular disease, and osteoarthritis. Autistic older adults were also significantly more likely to have co-existing mental health conditions, with the most significant likelihood for schizophrenia/psychotic disorders, attention deficit disorders, and personality disorders. Notably, autistic older adults were 11 times more likely to have sought care for suicidality or intentional self-injury.

Implications: This study provides new and valuable insights into health care needs of autistic older adults. The results of this study indicate that autistic older adults are significantly more likely to have a co-existing physical or mental health condition than non-autistic older adults. These findings highlight a critical need to address the conditions of this older autistic population in health care policies, programs, and services.

Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016.

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. *MMWR Surveill Summ.* 2020 Mar 27;69(4):1-12. Erratum in: *MMWR Morb Mortal Wkly Rep.* 2020 Apr 24;69(16):503. [PMID: 32214087]

CDC data from 2016 estimates that 1 in 54 eight-year-old children are diagnosed with autism.

Background: The Centers for Disease Control and Prevention (CDC) established the Autism and Developmental Disabilities Monitoring (ADDM) Network to report the prevalence of ASD in multiple communities in the United States. ADDM has captured ASD prevalence among eight-year-old children for even-numbered years since 2000. ADDM data indicate that disparities in ASD prevalence across race/ethnicity have decreased in recent years. These data suggest that there has been progress in the detection of ASD among all children.

Methods & Findings: This study reports on the 2016 prevalence of ASD in children born in 2008, as well as demographic characteristics and prevalence of co-existing intellectual disability (ID). Across all 11 ADDM sites, the prevalence of ASD was 1 in 54 eight-year-old children. ASD was 4.3 times more prevalent in boys than girls. ASD prevalence was similar among non-Hispanic White, non-Hispanic Black, and Asian/Pacific Islander children. ASD prevalence was lower among Hispanic children compared to White and Black children. Data showed that 40% of girls with ASD and 32% of boys with ASD had co-existing ID. Co-existing ID was more prevalent among Black children (47%) and Hispanic children (36%) than White children (27%). Although Black children were more likely than White children to have co-existing ID, they were less likely to be evaluated by 36 months of age than White children. Children with co-existing ID were diagnosed with ASD an average of six months later than children without co-existing ID.

Implications: The ASD prevalence in 2016 was approximately 10% higher than in 2014 and approximately 176% higher than 2000 to 2002. This increase could reflect differences ASD screening and diagnosis and/or differences in data availability. Differences in prevalence across states may indicate a need to improve ASD screening and diagnosis in certain communities. Previous ADDM analyses have found that ASD prevalence is positively correlated with socioeconomic status, suggesting that improved screening and diagnosis may be most impactful in lower socioeconomic communities. Although this study found no disparity in ASD prevalence between Black and White children, it did find racial disparities in age of ASD diagnosis, indicating a need to further understand the barriers to timely, accurate diagnosis.

Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Early Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2016.

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. *MMWR Surveill Summ.* 2020 Mar 27;69(3):1-11. [PMID: 32214075]

CDC data from 2016 estimates that 1 in 64 four-year-old children are diagnosed with autism, showing improvements in early identification and evaluation for autism.

Background: The Early Autism and Developmental Monitoring (Early ADDM) Network is a subset of the ADDM Network that estimates ASD prevalence and monitors early ASD diagnoses among four-year-old children. Similar to increased ASD prevalence in eight-year-old children over time, Early ADDM data has shown an increase in ASD prevalence among four-year-old children.

Methods & Findings: This study reports on the 2016 prevalence of ASD among children born in 2012 using the same data collection methods as the ADDM Network across 6 of the 11 ADDM sites. Across all Early ADDM sites, the prevalence of ASD was 1 in 64 four-year-old children. ASD prevalence was 3.5 times higher among four-year-old boys than among four-year-old girls. ASD prevalence was similar among White and Black children. At sites with available information about intellectual disability (ID), 53% of children with ASD had co-existing ID. There was no difference in co-existing ID among four-year-old boys and girls. Approximately 84% of four-year-old children with ASD had their first evaluation before 36 months, with a median age of 26 months for first ASD evaluation and median age of 33 months for diagnosis. The data showed an overall increase of early diagnosis by age 48 months in the Early ADDM 2016 data compared to the 8-year-olds in the 2016 ADDM cohort.

Implications: The disparity in ASD prevalence among Black and White four-year-old children decreased in 2016, and more children were receiving early diagnosis in 2016 than in 2014. Prevalence of co-existing ID was higher in 2016 than in 2014, suggesting that early evaluation increased early identification of ID. Despite this progress, efforts are needed to reduce the disparities in early ASD diagnosis between four-year-old boys and girls. Although 2016 ADDM data showed that eight-year-old girls with ASD were more likely to have co-existing ID than eight-year-old boys with ASD, there was no difference among four-year-old children, suggesting a need to assess how ID is evaluated and if it affects disparities in ASD prevalence across boys and girls.

ARTICLES SELECTED FOR THE 2020 SUMMARY OF ADVANCES

SCREENING AND DIAGNOSIS

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. [PMID: 32632024]

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). [PMID: 32839243]

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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. [PMID: 33219917]

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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. [PMID: 32056117]

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. [PMID: 31621020]

RESEARCH INFRASTRUCTURE AND PREVALENCE

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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. Erratum in: *MMWR Morb Mortal Wkly Rep.* 2020 Apr 24;69(16):503. [PMID: 32214087]

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. [PMID: 32214075]

FULL LISTING OF NOMINATED ARTICLES

(SELECTED ARTICLES APPEAR *RED)

SCREENING AND DIAGNOSIS

*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. [PMID: 32632024]

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