2021
SUMMARY
OF ADVANCES

in Autism Research

IAcc
INTERAGENCY AUTISM
COORDINATING COMMITTEE

OFFICE OF
AUTISM RESEARCH
COORDINATION
NATIONAL INSTITUTES OF HEALTH

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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 autism research and services, as well as public stakeholders, including autistic adults, family members of those on the autism spectrum, advocates, service providers, and researchers, who represent a variety of perspectives. The IACC membership is composed to ensure that the Committee is equipped to address the wide range of issues and challenges experienced by individuals and families in the autism community.

Under past and present authorizing legislation, the IACC was and is currently required to (1) develop and annually update a strategic plan for autism research, (2) develop and annually update a summary of advances in autism research, and (3) monitor federal activities related to autism.

Through these and other activities, the IACC provides guidance to HHS and partners with other federal departments, research and advocacy organizations, and the broader autism community to accelerate research and enhance services with the goal of positively impacting the lives of people on the autism spectrum and their families.

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

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THE 2021 IACC SUMMARY OF ADVANCES IN AUTISM RESEARCH

Each year, the IACC releases a list of scientific advances that represent significant progress in the field of autism research. The *2021 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 2021 have provided new insight into disparities in screening, medication use in autism, and the biology associated with communication outcomes. The advances also include studies that investigated early interventions and family navigation, service needs across the lifespan, and updated prevalence estimates across demographic groups. Articles in the *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 2021 SUMMARY OF ADVANCES

SCREENING AND DIAGNOSIS

- Race/ethnic inequities in conjoint monitoring and screening for U.S. children 3 and under: Disparities in Monitoring and Screening.
- Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial From DBPNet.
- Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis.

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- Early social communication development in infants with autism spectrum disorder.
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- Children with ASD and Communication Regression: Examining Pre-Loss Skills and Later Language Outcomes Through the Preschool Years.

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- Impact of autism genetic risk on brain connectivity: a mechanism for the female protective effect.
- Developmental vitamin D and autism spectrum disorders: findings from the Stockholm Youth Cohort.

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- Medication Use in Youth With Autism and Attention-Deficit/Hyperactivity Disorder.
- Intranasal Oxytocin in Children and Adolescents with Autism Spectrum Disorder.
- Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis.

SERVICES AND SUPPORTS

- Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services.
- Who gains and who loses? Sociodemographic disparities in access to special education services among autistic students.
- Healthcare Costs of Pediatric Autism Spectrum Disorder in the United States, 2003-2015.

LIFESPAN

- Self-reported parkinsonism features in older autistic adults: A descriptive study.
- Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services.
- The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder.
- Identifying School-Based Factors that Predict Employment Outcomes for Transition-Age Youth with Autism Spectrum Disorder.

INFRASTRUCTURE AND PREVALENCE

- Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018.
- Early Identification of Autism Spectrum Disorder Among Children Aged 4 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018.

SCREENING AND DIAGNOSIS

At-a-Glance:

Hispanic and Black children are less likely to receive combined screening and monitoring for developmental disabilities.

Background: The American Academy of Pediatrics (AAP) encourages pediatricians to conduct developmental monitoring (i.e., ongoing assessment of developmental progress) and screening (i.e., a formal process conducted at specific ages to aid diagnosis) for autism at well-child visits for all infants and young children. Compared to either monitoring or screening alone, this combined strategy is associated with children with autism and other developmental disabilities receiving appropriate early intervention services. Notably, non-White children with autism or other developmental disabilities are often identified later than White children. This study aims to determine whether there are racial or ethnic inequities in children's receipt of combined developmental monitoring and screening.

Methods & Findings: Researchers analyzed results of the National Survey on Children's Health, a caregiver survey that collects data on the physical and emotional health of children under age 18 in the United States (U.S.). Overall, approximately 23% of caregivers reported receiving monitoring and screening in combination with one another, 14% receiving screening alone, 13% monitoring alone, and 50% receiving no monitoring or screening. White children were more likely to receive combined monitoring and screening than Hispanic and Black children. Conversely, caregivers of Hispanic and Black children reported that they received *neither* monitoring *nor* screening at higher rates than White children. The researchers also used the survey data to identify other characteristics that may influence how likely a child is to receive monitoring and screening. Racial and ethnic differences were explained by some of these other characteristics, such as having an established healthcare provider, insurance status, and English-speaking status. Having an established healthcare provider was an especially strong factor in likelihood of receiving combined monitoring and screening.

Implications: Because having a consistent source of healthcare is strongly associated with race and ethnicity, researchers concluded that this factor may be the primary cause of lower rates of combined monitoring and screening in non-White children. In turn, this factor likely contributes to later identification and lower rates of receipt of intervention and community-based services, which has been found in previous studies. These findings underline that equitable access to consistent sources of healthcare is an important precursor to effective screening/ monitoring and interventions for autism.

Effect of Family Navigation on Diagnostic Ascertainment Among Children at Risk for Autism: A Randomized Clinical Trial from DBPNet.

Feinberg E, Augustyn M, Broder-Fingert S, Bennett A, Weitzman C, Kuhn J, Hickey E, Chu A, Levinson J, Ellenberg JS, Silverstein M, Cabral HJ, Patts G, Diaz-Linhart Y, Fernandez-Pastrana I, Rosenberg J, Miller JS, Guevara JP, Fenick AM, Blum NJ. *JAMA Pediatr*. 2021;175(3):243-250. [*PMID: 33427861*]

At-a-Glance:

Family navigation services can help reduce racial and ethnic disparities in autism evaluation and diagnosis.

Background: Low-income families and families of racial or ethnic minorities have reduced rates of accessing autism diagnostic services, compared to higher-income and White families. A way to potentially reduce these disparities is family navigation, which is an individually tailored, culturally informed care management strategy. Navigators are community health workers that engage an entire family to coordinate care services when a screening result indicates a potential ASD diagnosis. This study aimed to determine the effect of family navigation on the length of time between an initial positive screening for ASD and clinical diagnostic evaluation.

Methods & Findings: The study included 250 children who were identified as potentially having ASD during routine well-child visits at 11 primary care sites that were part of three different large integrated healthcare systems in Massachusetts, Pennsylvania, and Connecticut. The children were randomly assigned into one of two groups: family navigation or conventional care management. The two groups were demographically similar, and both were ethnically and racially diverse, including Hispanic, Black, White, and ethnically diverse non-U.S. born children. To support this diverse study population, researchers trained navigators who were predominantly bilingual and bicultural community members. The proportion of children who received ASD diagnoses was similar whether family navigation or conventional care management was used. However, the study found that more children in the family navigation group received a clinical diagnostic evaluation for ASD within one year compared to children whose care was conventionally managed. Family navigation had a greater positive impact for Hispanic families than non-Hispanic families. This greater level of impact was attributed to the additional barriers that may be faced by non-English speaking families and how those barriers were reduced by bilingual assistance. In addition, having bicultural navigators who share common experiences and values with families in the study may have been more important for the engagement of Hispanic families than for non-Hispanic families.

Implications: Results from this study indicate that family navigation has the potential to reduce disparities in ASD diagnosis. Family navigation may be more likely to help certain groups, especially Hispanic and immigrant groups. The researchers hypothesize that these groups may face language and cultural barriers that limit their ability to take advantage of services when offered through conventional care. Thus, these groups are more likely to benefit from the language and cultural support provided by the family navigation program. Future studies can further evaluate the contextual factors that contribute to the effectiveness of family navigation.

Sex differences in scores on standardized measures of autism symptoms: a multisite integrative data analysis.

Kaat AJ, Shui AM, Ghods SS, Farmer CA, Esler AN, Thurm A, Georgiades S, Kanne SM, Lord C, Kim YS, Bishop SL. *J Child Psychol Psychiatry*. 2021;62(1):97-106. [*PMID: 32314393*]

At-a-Glance:

Autism screening tests do not need to be scored differently for boys versus girls.

Background: Among people diagnosed with autism, boys are overrepresented relative to girls. However, this imbalance may be more dramatic than the actual sex-based difference in autism rates. One factor driving this imbalance may be commonly used ASD diagnostic tools, which may be less attuned to detecting autism in girls. Girls may also have less pronounced or different signs of autism or might be better than boys at masking or camouflaging (i.e., hiding) autism-related behaviors. Notably, according to current statistics, girls diagnosed with ASD are more likely to have very low intelligence quotient (IQ), which suggests that high-IQ autistic girls may be camouflaging their autistic traits and therefore not diagnosed. Thus, this study aimed to determine whether scores on ASD diagnostic tests differ between girls and boys after accounting for factors such as age, nonverbal intelligence quotient (i.e., scores on an IQ test that does not use words), and language level.

Methods & Findings: Researchers assessed clinical data representing 8,985 individuals gathered from 20 different autism-focused studies and clinics. Researchers' analyses indicated that scores on certain assessments did differ by sex. Specifically, young boys had higher raw scores on tests measuring restricted and repetitive behaviors, based on both parents' reports and researchers' direct observations of behavior. During adolescence, however, girls showed these behaviors more frequently or intensely. Although social communication scores on some tests did not differ by sex, girls were less effective at social communication on one such test in adolescence. All these observed sex differences, however, were very small.

Implications: The small sex differences observed in this study suggest that existing diagnostic tests can identify ASD regardless of sex. In addition, researchers suggested that even observed sex differences on ASD diagnoses during adolescence may result from parents having higher expectations for the social capacity of girls compared to boys. Overall, although girls may experience different autism-related challenges than boys, this study does not support a need to develop sex-specific diagnostic scoring. However, the results do suggest that less sensitive diagnostic tests should be checked for their ability to capture all relevant autism-related traits.

BIOLOGY

Early social communication development in infants with autism spectrum disorder.
Bradshaw J, McCracken C, Pileggi M, Brane N, Delehanty A, Day T, Federico A, Klaiman C, Saulnier C, Klin A, Wetherby A. *Child Dev.* 2021 Nov;92(6):2224-2234. [*PMID: 34786700*]

At-a-Glance:

Infants that are later diagnosed with autism exhibit differences in social communication skills at 9 to 12 months of age.

Background: Differences in social communication are a key feature of autism but can be difficult to detect at early ages. Such effects might be expected at 9 to 12 months of age, when infants begin developing observable social communication skills such as gesture, eye gaze, and facial expression. However, while ASD can be diagnosed as early as 14 months, few studies have assessed communication skill development from 9 to 12 months. Understanding differences in social communication skill development could support potential ASD diagnosis in even younger infants.

Methods & Findings: This study aimed to determine whether 9- to 12-month-old infants who were later diagnosed with ASD displayed differences in social communication skills during this key stage of early communication development. A group of 124 infants enrolled in a prospective longitudinal study (i.e., a study design that follows the same people over a period of time) were given a special standardized communication assessment at 9 months and again at 12 months of age by a speech-language pathologist with expertise in autism. Each infant received a score based on categories including emotion and eye gaze, gesture, vocalization, understanding, and object use. Later, at 24 months of age, all participating infants received diagnostic evaluation for ASD by a licensed clinical psychologist and speech-language pathologist. The 30 infants who were diagnosed with ASD scored significantly lower on most areas of social communication at 9 months and on all but one area at 12 months compared to typically developing children (i.e., no ASD diagnosis). Race, maternal education, and family income did not significantly impact the findings of this study.

Implications: These results demonstrate how autism can affect the development of communication skills in early infancy. Furthermore, this study identifies a small but foundational set of skills (e.g., eye gaze, facial expression, and sounds) that distinguish 9- and 12-month-old infants who go on to be diagnosed with autism from typically developing infants. This may help inform the development and improvement of early ASD screening tests and interventions. Because this study successfully detected communication differences in infants later diagnosed with ASD, future studies can explore the relationship between brain activity and these differences during early stages of communication development to aid in the design of new diagnostic and screening tools.

Infant vocalizing and phenotypic outcomes in autism: Evidence from the first 2 years.
Plate S, Yankowitz L, Resorla L, Swanson MR, Meera SS, Estes A, Marrus N, Cola M, Petrulla V, Faggen A, Pandey J, Paterson S, Pruett JR Jr, Hazlett H, Dager S, St John T, Botteron K, Zwaigenbaum L, Piven J, Schultz RT, Parish-Morris J; IBIS Network. *Child Dev.* 2021 Oct 28. [*PMID: 34708871*]

At-a-Glance:

Among infant siblings of children with autism, those later diagnosed with autism vocalize less at 12 months than their neurotypical peers.

Background: Clinicians often assess children for autism because of parental concerns about their child's language development. However, infants who are eventually diagnosed with ASD show a wide range of vocal communication differences at 12 to 24 months of age. Some previous studies have found that infants later diagnosed with ASD vocalize less than those not diagnosed with ASD, while studies that include infant siblings of children with autism, who may be more likely to receive an ASD diagnosis, have generated more mixed results. This mixed evidence base has made it difficult to pursue the use of vocalizations as a diagnostic indicator.

Methods & Findings: This study aimed to assess vocalization differences between infants who have an older sibling with autism (higher likelihood of a later diagnosis of ASD) and infants who do not have an older sibling with autism (lower likelihood of an ASD diagnosis). Specifically, the researchers focused on measuring speech-like vocalizations (sounds that are found in adult speech and are precursors to language, such as single consonants and vowels, babbles, and words). Video recordings were taken of infants at 6, 12, and 24 months of age as they interacted with their caregiver and a clinician. The infants were screened for ASD at 24 months of age. The researchers compared the vocalizations of infant siblings later diagnosed with ASD, infant siblings not diagnosed with ASD, and infants who do not have a sibling with ASD. The study found that at 12 months, the infant siblings who did not later receive an ASD diagnosis produced more vocalizations than the infant siblings who were later diagnosed with ASD. Infants without a sibling with ASD did not exhibit a distinctive vocalization pattern. At 24 months, the neurotypical infant siblings produced more vocalizations and more speech-like vocalizations than both the infant siblings later diagnosed with ASD and the infants without a sibling with ASD. However, neurotypical infant siblings did not exhibit above-average language skills overall, as measured by a standardized language test.

Implications: Findings from this study provide support that video-based assessments of vocalizations can be a promising tool for future studies of infant siblings of children with ASD. In addition, this study provides evidence that identifying decreased vocalization in infant siblings of children with ASD can help diagnose ASD earlier and guide early intervention efforts. The researchers plan to develop techniques that can identify more detailed aspects of speech-like and non-speech-like vocalizations.

Children with ASD and Communication Regression: Examining Pre-Loss Skills and Later Language Outcomes Through the Preschool Years.
Prescott KE, Weismer SE. *J Autism Dev Disord.* 2022;52:1956-1970. *[PMID: 34061309]*

At-a-Glance:

Regression in early communication skills does not have a long-term impact on the future language skills of children with autism.

Background: Early in life, many children with autism appear to lose certain skills in a process called regression. Language and communication regression is particularly common and is not well understood. To date, no studies of language regression have focused on *receptive* language skills (i.e., the ability to understand language), and few studies have addressed loss of preverbal communication skills (such as cooing, babbling, vocal imitating) and their relationship to later language skills in children who experience regression. This study aimed to fill this gap by examining how language regression may differ depending on pre-verbal and verbal communication skills attained prior to regression and how regression impacts later language skills in preschool.

Methods & Findings: The researchers used data from 129 preschool-aged children with autism to study language outcomes. First, caregivers were interviewed to obtain information about children's communication skills and number of words used. Beginning at approximately 2.5 years of age, children completed multiple diagnostic, cognitive, and language assessments during three to four visits with a psychologist over the course of about four years. The researchers found several differences at Visit 2 (when children were an average age of 3.7 years) between children who previously had lost communication skills and those who had not lost skills. Children who had previously lost fewer communication skills had better receptive language skills than children who had previously lost more communication skills. In addition, the children who used more words before experiencing regression had stronger receptive and expressive language skills at Visit 2. However, in all cases, these differences were small in magnitude and had disappeared by Visit 4 (when children were an average age of 5.5 years).

Implications: Children in this study demonstrated different levels of pre-verbal and verbal communication skills prior to regression. Given this range, these children likely experience different rates of language development. Importantly, the reduction of differences by Visit 4 suggest that regression does not cause long-term effects on language skills (although longer-term longitudinal follow up is needed to confirm this). This finding suggests that autistic children who experience language regression would likely benefit from specialized speech-language interventions individualized to their unique language learning profile.

GENETIC AND ENVIRONMENTAL FACTORS

Impact of autism genetic risk on brain connectivity: a mechanism for the female protective effect.

Lawrence KE, Hernandez LM, Fuster E, Padgaonkar NT, Patterson G, Jung J, Okada NJ, Lowe JK, Hoekstra JN, Jack A, Aylward E, Gaab N, Van Horn JD, Bernier RA, McPartland JC, Webb SJ, Pelphrey KA, Green SA, Bookheimer SY, Geschwind DH, Dapretto M, GENDAAR Consortium. *Brain*. 2022;145:378-387. [*PMID: 34050743*]

At-a-Glance:

Genes associated with autism impact activity in certain parts of the brain more in boys than in girls.

Background: Autism is diagnosed 3 to 4 times more often in boys than in girls, but the biological reasons for this difference are unclear. One potential explanation is that the gene differences associated with autism impact brain function more strongly in boys than girls. As a result, girls might need to accumulate a higher number of genetic differences to be develop autism—a hypothesis known as the female protective effect. This study explored specifically whether a subset of genes associated with autism may have effects on the brain's "functional connectivity," meaning how well brain regions communicate with one another. In particular, some genes associated with autism affect the connectivity of parts of the brain called the salience network, which plays a central role in determining what to pay attention to in an environment. This study compared functional connectivity in this network in both autistic and neurotypical boys and girls.

Methods & Findings: This study used a brain imaging technique called magnetic resonance imaging (MRI) to study functional connectivity in the brains of boys and girls (ages 8–17 years old) with and without autism. Researchers used DNA from either blood or saliva samples to determine the number of genetic differences associated with autism that each participant had. Brain imaging of autistic boys who had more gene differences associated with autism revealed increased communication between the salience network of the brain and regions involved in processing sensations, such as temperature, vibration, touch, and pain. Brain imaging in autistic girls did not show this relationship. The researchers also looked at boys and girls who had some gene differences associated with autism but did not have enough autistic traits to receive an autism diagnosis. The same distinction between sexes was observed: boys who had more genetic differences associated with autism but did not meet the criteria for ASD showed greater connectivity between the salience network and sensory regions of the brain in scans, but girls with some autism-associated genetic differences but without an ASD diagnosis did not exhibit this relationship.

Implications: These results suggest that some of the genes related to both autism and the functional connectivity of the salience network might have more influence on boys' brains than on girls' brains. Moreover, the increased connectivity between the attention and sensory regions of the brain may explain autistic boys' greater tendency to show repetitive movements compared to autistic girls. These repetitive behaviors are a key part of ASD diagnosis. Thus, these functional connectivity differences may be an illustration of the female protective effect and could play a role in the higher rate of ASD diagnosis in boys than in girls.

Developmental vitamin D and autism spectrum disorders: findings from the Stockholm Youth Cohort

Lee BK, Eyles DW, Magnusson C, Newschaffer CJ, McGrath JJ, Kvaskoff D, Ko P, Dalman C, Karlsson H, Gardner RM. *Mol Psychiatry*. 2021;26:1578-1588. [*PMID: 31695167*]

At-a-Glance:

Low vitamin D levels in pregnancy may be a contributing factor in the development of autism.

Background: Vitamin D, commonly referred to as the "sunshine vitamin," is a hormone that is important for brain development early in life. Vitamin D deficiency is common in pregnant women, and occurs more often in winter, northern countries, urban settings, and in dark-skinned individuals. A baby's brain may develop differently if concentrations of vitamin D are low prenatally (i.e., during pregnancy). This study investigated whether low levels of vitamin D during pregnancy and early in life can influence the likelihood of a later autism diagnosis.

Methods & Findings: This study used data from Sweden, which has several large, population-wide sources of data on maternal and child health. The researchers began by using a database containing health information for all children living in Stockholm County in Sweden. They examined health data from 3,006 children born between 1996 and 2000. To connect this health data to vitamin D levels, the researchers analyzed blood samples that are collected from all pregnant women and their newborns in Sweden. To avoid confusing the influence of familial factors (e.g., genetics) with maternal vitamin D levels, researchers also did an analysis comparing vitamin D levels in sibling pairs where one sibling has ASD and the other does not, reducing the chance that results could be affected by genetic and other shared family factors. The results of the study overall showed that children were 1.75 times more likely to be diagnosed with autism if their mothers had lower levels of vitamin D in the first trimester of pregnancy and if the children themselves had low vitamin D levels in their first month of life (the researchers considered vitamin D levels to be "low" if they were in the lower half of all the measured vitamin D levels in the study sample population). In addition, children with low vitamin D in the first month of life (i.e., neonates) were more likely to be diagnosed with autism regardless of their mothers' vitamin D levels during pregnancy.

Implications: Vitamin D is involved in a range of processes that are relevant to early brain development. This study found that higher concentrations of prenatal/neonatal vitamin D are associated with lower likelihood of ASD later in life. These results suggest a possible connection between autism and low levels of vitamin D during early brain development, especially during pregnancy and infanthood. However, it is not clear based on these data whether low vitamin D can cause autism. Randomized trials of vitamin D supplementation would be necessary to definitively determine this possibility. Researchers also noted that low vitamin D levels in pregnancy and early life are associated with other neurological conditions (e.g., attention-deficit/hyperactivity disorder, schizophrenia), so some of the same factors may be involved in all these cases.

INTERVENTIONS

INTERVENTIONS

Medication Use in Youth With Autism and Attention-Deficit/Hyperactivity Disorder.
Rast JE, Anderson KA, Roux AM, Shattuck PT. *Acad Pediatr.* 2021 Mar;21(2):272-279. [*PMID: 32492579*]

At-a-Glance:

Children with both autism and ADHD take more medication than those with only autism or only ADHD and may have distinct care needs.

Background: No clear guidelines are available for how and when to provide prescription medications to treat common co-occurring conditions in children on the autism spectrum. Children with autism often have co-occurring conditions such as anxiety and attention-deficit/hyperactivity disorder (ADHD). There are well-established protocols for the use of brain-chemical altering medications, known as psychotropic medications, for treatment of these conditions in the neurotypical population. The utility of these medications in children with autism, however, is not clear. While there are no FDA-approved medications that address the core traits of autism, two drugs are approved for use in individuals with ASD to modify challenging behaviors that can occur with autism (e.g., aggression, irritability). Despite the limited number of medications approved for individuals on the autism spectrum, previous studies indicate that children with ASD commonly take psychotropic medications. This study aimed to explore how many children with autism are currently taking psychotropic medications using recent, nationally representative data.

Methods & Findings: This study compared the use of medication in three groups: children with autism only, children with autism and ADHD, and children with ADHD only. Researchers used 2016 and 2017 data from the National Survey of Children's Health, which provides information about children's medication usage based on reports from their caregivers. The researchers focused on children aged 6-11 and 12-17. They analyzed medication usage for autism, for ADHD, and/or more generally for emotion regulation, concentration, or behavior. The study found that 68% of children ages 6-11 with autism *and* ADHD and 76% of youth ages 12-17 with autism *and* ADHD were taking at least one psychotropic medication. In comparison, this was 73% and 70% for children and youth with ADHD alone, respectively, and 13% and 22% for children and youth with autism alone. Although some children and youth with autism alone took a medication to improve emotion regulation, concentration, or behavior, children and youth with autism *and* ADHD were more likely to take these medications, and youth with autism *and* ADHD were more likely to take these medications than youth with ADHD alone.

Implications: This study provides up-to-date national estimates on psychotropic medication usage in children and youth with autism. In particular, the results suggest a surprisingly high use of medications by children with autism *and* ADHD. This finding requires further investigation to understand what drives the high rates of medication use in this group and to determine whether children and youth with both autism *and* ADHD have unique medication or other support needs.

Intranasal Oxytocin in Children and Adolescents with Autism Spectrum Disorder.
Sikich L, Kolevzon A, King BH, McDougle CJ, Sanders KB, Kim SJ, Spanos M, Chandrasekhar T, Trelles MDP, Rockhill CM, Palumbo ML, Witters Cundiff A, Montgomery A, Siper P, Minjarez M, Nowinski LA, Marler S, Shuffrey LC, Alderman C, Weissman J, Zappone B, Mullett JE, Crosson H, Hong N, Siecinski SK, Giamberardino SN, Luo S, She L, Bhapkar M, Dean R, Scheer A, Johnson JL, Gregory SG, Veenstra-VanderWeele J. *N Engl J Med*. 2021 Oct 14;385(16):1462-1473. [*PMID: 34644471*]

At-a-Glance:

Use of an oxytocin nasal spray in children and adolescents with autism does not result in improved social interactions or behavior.

Background: Individuals on the autism spectrum experience various challenges related to social behaviors and may often display increased irritability and hyperactivity. Some studies have suggested that reduced levels of a hormone called oxytocin, which is known for its role in promoting social bonding, may be responsible for difficulties in social interactions in autism. Oxytocin therapy has been used off-label in some individuals on the autism spectrum as a potential intervention to improve social behavior, but previous studies have not been able to confirm its efficacy. Earlier clinical trials examining oxytocin in autism have shown widely varying results. This large randomized controlled trial sought to resolve the previous contradictory findings and determine whether extended use of oxytocin can help to improve social behaviors in children and teenagers on the autism spectrum.

Methods & Findings: This study evaluated whether a nasal oxytocin spray could affect social interactions and other behaviors (e.g., irritability, social withdrawal, and hyperactivity) in children and adolescents on the autism spectrum during a 24-week clinical trial. Individuals between the ages of 3 and 17 were assessed by trained researchers and were selected for participation if they met the criteria for autism. Participants were then randomly assigned to receive either a nasal oxytocin spray or a placebo (i.e., a comparison nasal spray that did not contain oxytocin) every day at a series of gradually increasing doses. Participants received social interaction scores every 4 weeks based on multiple assessments that were completed by caregivers or the participant. Separate analyses were performed in groups of individuals with minimal verbal fluency and high verbal fluency. This study found no difference in social interaction scores between the oxytocin group and the placebo group and no difference between the groups with differing levels of verbal ability.

Implications: The findings of this study demonstrate that extended use of a nasal oxytocin spray over a 24-week period does not make a detectable difference in measured social interactions or behaviors in children and adolescents with autism. While this study showed no observable social benefit with the use of intranasal oxytocin, there are remaining questions around issues such as the ideal dose, whether current formulations are able to penetrate the blood-brain barrier, and whether a longer intervention time course could reveal effects. In addition, future studies that use techniques such as brain imaging may reveal new information on how oxytocin might be used in autism.

INTERVENTIONS

Effect of Preemptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis.
Whitehouse AJO, Varcin KJ, Pillar S, Billingham W, Alvares GA, Barbaro J, Bent CA, Blenkley D, Boutrus M, Chee A, Chetcuti L, Clark A, Davidson E, Dimov S, Dissanayake C, Doyle J, Grant M, Green CC, Harrap M, Iacono T, Matys L, Mayberry M, Pope DF, Renton M, Rowbottam C, Sadka N, Segal L, Slonims V, Smith J, Taylor C, Wakeling S, Wan MW, Wray J, Cooper MN, Green J, Hudry K. *JAMA Pediatr.* 2021;175(11):e213298. [*PMID: 34542577*]

At-a-Glance:

An intervention teaching parents how to encourage social skills in infants showing early behaviors associated with autism can reduce their child's future likelihood of an autism diagnosis.

Background: Signs of autism generally emerge early in development, but clinical diagnosis often does not occur until a child is at least 3 years old, and interventions are typically offered only after that point. One early intervention, the iBASIS Video Interaction to Promote Positive Parenting (iBASIS-VIPP), involves training parents to use a sequence of positive social interaction strategies, videotaping caregiver-infant interactions using those strategies, and then meeting with a therapist to receive feedback and support on how to enhance parent-infant interactions. The goal of the intervention is to teach the parent to understand and actively engage in increasing their infant's social engagement. Previous research evaluations of the iBASIS-VIPP have had significant shortcomings due to relatively small numbers of participants and short durations of follow-up observation. The present study aimed to resolve these flaws by enrolling more participants and lengthening the study duration to two years.

Methods & Findings: This study gave one of two interventions to 104 one-year-old infants who showed early potential signs of autism. The infants received either usual care or usual care plus iBASIS-VIPP for five months. Between the end of the intervention and by the time participants reached 3 years of age, a difference gradually emerged between the usual care group and usual care plus iBASIS-VIPP group. The infants who received iBASIS-VIPP showed fewer traits associated with autism when tested, and fewer children in the iBASIS-VIPP group were later diagnosed with ASD compared to those in the usual care group. In addition, caregiver sensitivity to infant needs was higher in the iBASIS-VIPP group.

Implications: These results show that an early intervention targeted to infants and caregiver interactions can improve developmental outcomes and reduce the likelihood of meeting criteria for an ASD diagnosis for at least 18 months. The findings suggests that some early life interventions may be able to influence the brain and social developmental processes associated with autism. To fully assess the impact of interventions such as the iBASIS-VIPP, researchers need to analyze longer-term child- and adulthood outcomes. Furthermore, there is a need to assess the cost-effectiveness of this intervention to determine its feasibility and value. Still, given the evidence of some impact and the absence of adverse effects, these findings support the use of iBASIS-VIPP or similar early interventions for infants showing early signs of autism.

SERVICES AND SUPPORTS

Analysis of the SPARK study COVID-19 parent survey: Early impact of the pandemic on access to services, child/parent mental health, and benefits of online services.
Bhat A. *Autism Res.* 2021;14:2454-2470. [*PMID: 34591364*]

At-a-Glance:

Early COVID-19 service disruptions affected children on the autism spectrum and their families to varying degrees, showing the need for in-person, virtual, or hybrid healthcare and family support services based on family preferences and needs.

Background: At the beginning of the COVID-19 pandemic, school and clinic closures dramatically decreased families' access to services for their autistic children. Some services temporarily disappeared, while others transitioned to a virtual-only model that did not work well for all autistic children. In addition, family caregiving demand increased as children lost opportunities for in-person socialization. This study examined the early impacts of these service changes on autistic children and their families. It identified which groups of autistic children experienced the greatest loss in services and the greatest negative impact on emotional and mental health.

Methods & Findings: Parents of autistic children participating in the Simons Foundation Powering Autism Research for Knowledge (SPARK) study completed a questionnaire between March and April of 2020. Responses received revealed that the three most severely impacted support services during the COVID-19 pandemic were speech-language therapies, special education, and physical or occupational therapy. Low-income families experienced greater reductions in care compared to higher income families. For approximately half of children and three-quarters of caregivers, the early weeks of the pandemic had a moderate to severe impact on mental or emotional health. In addition, parents reported that their children experienced more intense emotional and behavioral challenges when only online support services were available. Parents expressed mixed feelings about these virtual services: approximately equal numbers reported that online services were very helpful (14%) or not helpful (19%). Families with older children and children with fewer support needs benefited more from online services, as did children with more repetitive behaviors who had not previously received online services.

Implications: These results provide data supporting a need for improved care access for autistic children, especially in the event of future COVID-19-related closures or other public health emergencies. This study provides evidence of the negative impact of reduced access to services and provides motivation for further research on this issue. In addition, it suggests that clinicians should assess children and families' needs and circumstances prior to recommending virtual or hybrid healthcare models. When possible, virtual services and supports should be used for those children who are most likely to benefit, and in-person services should be employed with effective safety precautions (e.g., mask wearing, surface and toy sanitization) when deemed more likely to be beneficial. To ensure that families can access the care that best suits their needs, parents and caregivers require greater education about and access to insurance coverage for family support services such as respite care – especially parents whose children have high support needs.

Who gains and who loses? Sociodemographic disparities in access to special education services among autistic students.

Sturm A, Williams J, Kasari C. *Autism Res*. 2021;14:1621-1632. [*PMID: 33904253*]

At-a-Glance:

Autistic students experience racial and income-based disparities in special education eligibility and school-based services.

Background: In areas with majority White and high-income families, students accessing special education services are more likely to have a diagnosis of autism than a diagnosis of intellectual disability or a specific learning disability, such as dyslexia. The opposite is true in areas with mostly non-White and low-income students (i.e., students are more likely to have a diagnosis of intellectual disability or specific learning disability than autism). Notably, these demographics are also correlated with differences in school funding and accessibility of health-related services (e.g., speech and language, occupational therapy). This study examines how school-based special education service use differs based on diagnosis, race, and income.

Methods & Findings: Researchers used data from administrative records of a large, predominantly Hispanic/Latino school district in Southern California. The researchers considered students who were eligible for special education services based on a diagnosis of either autism, a specific learning disability, or an intellectual disability. Of those students, autistic children received the most school-based services on average, as well as the greatest variety and frequency of services. Children with specific learning disabilities were most likely to be mainstreamed (schooled in general education classrooms alongside students without disabilities) at least half of each school day. Lower-income children received fewer school-based services on average than higher-income students. White students who were eligible for services due to autism received more services on average than students of any other race/ethnicity. Hispanic/Latino students received the fewest services, even though they made up most of the student population in the school district being studied. Race- and income-based differences in service use were greater among autistic students than among those with learning or intellectual disabilities.

Implications: The results from this study suggest that students who are from lower income families or who are racial or ethnic minorities have a harder time accessing school-based special education services. Students from underrepresented, under-resourced, and underserved backgrounds likely have access to fewer resources such as advocates and information to aid in navigating the processes of identification, referral, and service allocation. In addition, the scale of inequities differs based on the specific diagnosis children receive. Autistic students experience the highest proportion of racial inequities. Inequities in accessing special education services and supports may depend in part on families having both the resources and knowledge to successfully navigate the complexity of the education system. These resources and knowledge are less common among families of color and families with lower income. The findings of this study suggest the need for additional focus and enhanced services and supports for under-resourced students of color.

Healthcare Costs of Pediatric Autism Spectrum Disorder in the United States, 2003-2015

Zuvekas SH, Grosse SD, Lavelle TA, Maenner MJ, Dietz P, Ji X. *J Autism Dev Disord*. 2021;51:2950-2958. [*PMID: 33113106*]

At-a-Glance:

Autistic children have between $3,930 to $5,621 more in annual health care costs than non-autistic children.

Background: Previous research studies have worked to identify healthcare cost estimates for autistic children. These estimates have varied widely, from $3,398 to $7,454 per year in 2018 dollars (i.e., adjusted to the value of the dollar in 2018). Estimates have varied in part due to different data sources and different inclusion criteria. Few studies have evaluated the differences in healthcare expenses between children with autism and those without autism. The current study provides updated estimates for the difference in healthcare costs between U.S. children on the autism spectrum compared to non-autistic children.

Methods & Findings: The researchers used 2003-2015 data from two ongoing federal surveys (the Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey(NHIS)) to determine the annual healthcare costs of autistic children aged 3-17 years. Annual estimated costs were determined for children ever diagnosed with ASD (based on parent response to the NHIS) and children with ASD-related costs in the year of interest (based on responses to the MEPS). The researchers found that the estimated healthcare cost difference between autistic and non-autistic children was $5,621 using MEPS data and $3,930 using the NHIS-derived measure of ever being diagnosed with ASD (in 2018 dollars). These estimates were lower than those that have been reported in other previous studies but still represent substantial costs to the healthcare system. The researchers calculated that, from 2013 through 2015, Americans spent approximately $3.9 billion in 2018 dollars annually on childhood autism-related costs.

Implications: This study calculated two estimates for the healthcare costs of autistic children. Both estimates support the conclusion that children with autism incur substantially greater healthcare costs than children not on the autism spectrum. It is important to note that the datasets used in this study do not take into account funding for school-based services and supports that students with autism may receive. Furthermore, family members may reduce their workforce participation to care for their child. Additionally, some children with autism may be in long-term care settings or in foster care and likely incur higher healthcare costs, but these cases are not fully captured by the datasets used in this study. This combination of significant cost considerations highlights the need for improved policies surrounding funding for autism services, supports, and interventions to improve the health and wellbeing of individuals with autism and their families.

LIFESPAN

Self-reported parkinsonism features in older autistic adults: A descriptive study.
Geurts HM, McQuaid GA, Begeer S, Wallace GL. *Autism.* 2021 Jun 21:13623613211020183. [*PMID: 34154378*]

At-a-Glance:

Many older autistic adults without intellectual disabilities report having more symptoms associated with Parkinson's disease, such as stiffness and slow movements.

Background: Parkinson's disease affects the nervous system (i.e., the body's "command center") and parts of the body controlled by the nerves. Some studies have suggested that adults with autism may have motor symptoms similar to Parkinson's disease—such as stiffness, tremors, and unstable posture—more often than adults without autism. This set of symptoms is known as "parkinsonism." However, it can be difficult to distinguish parkinsonism from the effects of medications that some adults with autism take. This study sought to evaluate how often adults with autism report having parkinsonism and to identify any distinguishing features in those who do have parkinsonism.

Methods & Findings: This study examined two groups of autistic adults between 50 and 83 years of age. One group of 296 adults was from the Netherlands and the other group of 209 adults was from the U.S. The study used a self-report questionnaire to ask participants whether they were experiencing symptoms related to parkinsonism, such as "Do you have trouble buttoning buttons or dressing?" and "Have you ever noticed stiffness in your legs?" Adults with autism in both the Netherlands and U.S. groups reported experiencing notably more rigidity, stiffness, and slowness compared to adults without autism. Autistic adults from the Netherlands group indicated that these motor issues were not present in childhood but rather developed later in adulthood. The researchers also found that autistic adults with parkinsonism in the Netherlands group, but not the U.S. group, had more medical health issues and fewer cognitive issues. In both countries, there were no differences between adults with and without parkinsonism in terms of educational level, income level, or medication use. Specifically, there were no differences in the use of psychotropic medications (e.g., antidepressants, anti-anxiety medications, stimulants, antipsychotics, and mood stabilizers).

Implications: Findings from this study suggest that middle-aged and older adults with autism may be more likely to have symptoms of parkinsonism. However, it is important to note that the study did not include a standardized autism assessment to confirm the self-reported clinical diagnoses of each participant. Future research could use this study's methods to screen individuals quickly and cost-effectively for parkinsonism features and track aging individuals with autism to observe whether and when they develop Parkinson's disease. Overall, this study adds to the knowledge base around aging-related concerns among older autistic adults.

Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services.

Schott W, Nonnemacher S, Shea L. *J Autism Dev Disord*. 2021 Apr;51(4):1188-1200. [*PMID: 32671666*]

At-a-Glance:

In one state-wide study, over half of adults with autism on waiting lists for HCBS had unmet service needs, with levels of need particularly high among African Americans, Hispanics, and adults over the age of 21.

Background: Once they have aged out of the educational system, many adults with autism face additional barriers to accessing services and have significant unmet service needs in areas such as self-care, household activities, and vocational supports. This problem is particularly pressing for adults seeking Medicaid-funded home- and community-based services (HCBS), for which there are often long waiting lists. Medicaid currently provides over 2.5 million people with HCBS through state waiver programs, yet nearly half a million individuals with intellectual and developmental disabilities, such as autism, are currently on waiting lists for HCBS. This study sought to better understand the service needs of adults with autism who are on waiting lists for HCBS.

Methods & Findings: This study examined data from the Pennsylvania Autism Needs Assessment, a survey that was sent to individuals with autism and their caregivers living in the state who were on a waiting list for Medicaid-funded HCBS programs. In total, 227 individuals with autism responded to the survey, as well as 396 caregivers. Although many individuals waiting for Medicaid-funded HCBS were receiving some services, the researchers found that over half of autistic adults reported unmet needs for mental health services and more than 60% reported unmet needs for functional supports (e.g., physical therapy, occupational therapy, social skills therapy, and speech therapy) and employment support services. There were also important age and racial disparities in levels of unmet needs and services received. African American adults were more likely to report unmet needs of all kinds. Both African Americans and Hispanics had substantially higher odds of having unmet employment support needs and reported lower service receipt. Adults aged 22 and over received fewer services than people aged 18-21. In addition, adults living independently were more likely to report unmet physical health needs, suggesting a need for increased case management or service navigation support. Adults enrolled in school and adults who were employed were less likely to report unmet employment support needs.

Implications: This study highlights the unmet support needs of adults with autism who are on waiting lists for HCBS. These findings provide actionable information on what services are most needed and may assist in policy and program planning for Medicaid HCBS waiver programs and other service systems, including the education system. These results are also important to policymakers aiming to improve access to services for vulnerable groups, such as minority racial/ethnic groups and autistic adolescents transitioning into adulthood.

The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder.

Vivanti G, Tao S, Lyall K, Robins DL, Shea LL. *Autism Res.* 2021 Oct;14(10):2189-2199. [*PMID: 34378867*]

At-a-Glance:

Medicaid data suggests early-onset dementia is more prevalent among adults with autism compared to the general population.

Background: It is unclear whether older adults with autism have a higher risk of being diagnosed with early-onset dementia (i.e., those who are diagnosed with dementia before age 65) compared to older adults without autism. In addition, many individuals with autism have co-occurring intellectual disability, which is a risk factor for early-onset dementia. Although previous research has highlighted the importance of understanding dementia in people with autism, studies have generated inconsistent findings.

Methods & Findings: This study used Medicaid data to examine the nationwide rate of early-onset dementia in individuals with autism and intellectual disability. The sample included over 1.2 million individuals aged 30 to 64 years divided into four groups: the general population, individuals with autism, individuals with intellectual disability, and individuals with both autism and intellectual disability. Individuals with autism only (4.04%), autism and intellectual disability (5.22%), and intellectual disability only (7.1%) all had higher rates of early-onset dementia compared to the general population (0.97%). Individuals with autism, regardless of the presence of intellectual disability, were approximately 2.2 times more likely to be diagnosed with early-onset dementia than the general population. Across all groups, risk factors associated with the increased prevalence of dementia were older age, depression, and cardiovascular disease. However, after adjusting for these risk factors, individuals with autism were still 2.6 times more likely to be diagnosed with early-onset dementia than the general population.

Implications: This study provides evidence that early-onset dementia is more prevalent in adults with autism and/or intellectual disability compared to the general population. Although people with only intellectual disability had the highest risk of early-onset dementia, people with autism and people with both autism and intellectual disability had higher rates of early-onset dementia than the general population. These findings do not support previous hypotheses that autism serves as a "safeguard" against dementia and related issues. It is possible that autistic individuals have an increased risk of early-onset dementia due to biological factors related to autism and/or a lack of services and supports. These findings point to the importance of understanding and addressing specific needs in older individuals with autism and dementia, including the need for long-term care resources and appropriate support programs.

Identifying School-Based Factors that Predict Employment Outcomes for Transition-Age Youth with Autism Spectrum Disorder.

Wong J, Coster WJ, Cohn ES, Orsmond GI. *J Autism Dev Disord.* 2021 Jan;51(1):60-74. [*PMID: 32356081*]

At-a-Glance:

Various factors, including daily living skills, family, and school-based supports can influence employment outcomes for transition-age youth on the autism spectrum.

Background: Youth with autism often encounter difficulties transitioning from school to the work force. Previous studies have found that adults with autism have the lowest employment rates compared to their peers with other disabilities. Because of these challenges and the growing population of youth with autism, there is an increasing need to provide appropriate services that help them transition to employment. However, limited research has investigated what employment-related services and interventions are most important during the high school years. Identifying specific factors that contribute to later employment outcomes (e.g., employment status, weekly wages, length of employment, job satisfaction) can help strengthen and improve these school-based transitional support services.

Methods & Findings: This study measured various characteristics of students and their families, as well as the school-based employment transition supports students received, to determine which characteristics and types of supports predicted later employment outcomes for youth with autism. This study used a secondary analysis (i.e., analyzing existing data from a previous study) of a nationally representative dataset composed of data from school programs as well as surveys of youth, parents, students, and teachers. Based on these data, researchers analyzed a group of students receiving special education services, ages 13 to 16 years and again later at 21 to 25 years. Daily living skills were measured using a parent survey, in which parents considered their child's ability to accomplish different tasks, such as using public transportation to get around town and reading and understanding signs. The study identified two distinct pathways that were related to later employment success for youth with autism. For young people with more adaptive skills (e.g., activities of personal care and daily living), academic performance most strongly influenced future employment. For young people with less adaptive skills, school-based employment transition supports, such as transition planning services, job shadowing, and work exploration, had the most influence on future employment. In both cases, parents' expectations for their children's future employment and parents' participation in future planning and school activities also played an important role in employment outcomes.

Implications: This study highlights the importance of identifying the specific kinds of employment supports that are most relevant for youth with autism. Individuals may have different support needs, and thus require different kinds of services in achieving their employment goals. The study also shows the complex relationships between student factors, family-related factors, school-based transition supports, and employment outcomes for youth with autism. In particular, it highlights the role of academic success, parent participation in special education, and school support services, all of which future research can explore in greater detail.

INFRASTRUCTURE AND PREVALENCE

At-a-Glance:

CDC data from 2018 estimated that 1 in 44 eight-year-old children in the U.S. have a diagnosis of autism.

Background: Every two years, the Autism and Developmental Disabilities Monitoring (ADDM) Network estimates how prevalent autism is among children who are 4- and 8-years-old. Through this monitoring program, the Centers for Disease Control and Prevention (CDC) can evaluate how well early identification programs are functioning, how these programs are being used by different groups of people, and whether there are demographic changes in the population of individuals identified with ASD. Over time, the ADDM Network has reported decreasing prevalence differences between groups, suggesting more equitable identification (e.g., similar rates of autism detected among Black and White children), but other disparities remain. This study focuses on the ADDM Network's monitoring of 8-year-old children.

Methods & Findings: In 2018, the ADDM Network had sites in 11 states. The data from these sites was used to estimate the local autism prevalence of children born in 2010. These sites found that 1 in 44 children who were 8 years of age had documented autism (meaning they either received formal diagnosis, were eligible for school services, or their medical records were coded for autism). Boys were more than 4 times as likely to have an ASD diagnosis than girls. Rates of autism were similar among White, Black, Hispanic, and Asian/Pacific Islander children. Not enough data were available to determine the prevalence of autism among American Indian/Alaskan Native children. Thirty-five percent of children identified with autism were also documented as having an intellectual disability. Black autistic children were more likely to be classified as having an intellectual disability than White autistic children. Nearly half (47%) of children with documented autism had been evaluated by 3 years of age, and the median age at earliest diagnosis was 50 months. Autistic children who had intellectual disability were diagnosed earlier than autistic children without intellectual disability. Findings from some—but not all—states suggested that children from lower-income neighborhoods were more likely to have documented autism than children from higher-income areas.

Implications: These findings indicate an overall higher prevalence of autism than was reported in previous years, suggesting an overall improvement in identification. The findings also suggest, however, that disparities in access to autism identification services continue among certain groups, in addition to geographic differences in prevalence. For example, while overall rates of autism across all ADDM sites is similar, in certain states, autism in Hispanic children is evaluated and identified less frequently than in other children. Some recorded disparities (e.g., the high rate of intellectual disability among autistic Black children) suggest a need for increased research into how race and other demographic factors intersect with autism diagnosis and characteristics. Increased work is needed to reduce disparities in identification of and support for children with autism.

At-a-Glance:

CDC data from 2018 estimate that 1 in 59 four-year-old children in the U.S. have a diagnosis of autism and that children are being identified earlier.

Background: Every two years, the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network estimates how prevalent autism is among children who are 4- and 8-years-old. This network also monitors the earliest age these children were first documented as or suspected of having autism. By comparing children of different ages, this program can track historical trends, including potential improvements in early identification of autism. In addition, this approach allows the CDC to determine whether access to autism-related evaluation and care is similar among different demographic groups. This study focuses on the ADDM Network's monitoring of 4-year-old children.

Methods & Findings: In 2018, the ADDM Network had sites in 11 states. The data from these sites was used to estimate the local autism prevalence in children born in 2014. Four-year-old boys were almost 3.5 times more likely to be documented as having autism than girls. Asian/Pacific Islander children were the most likely to have autism, followed by Hispanic, Black, White, and American Indian/Alaskan Native children. Children living in lower-income areas were also more likely to have autism. Approximately half of children identified with autism were also classified as having intellectual disability. Children whose records contained a qualified professional's statement indicating a possibility of autism but were not formally diagnosed were less likely to have a documented intellectual disability. Intellectual disability was higher among Black autistic children than among White, Asian/Pacific Islander, and Hispanic autistic children, all of whom had similar rates. Approximately 72% of children with a formal ASD diagnosis had their first evaluation by age 36 months. The prevalence was similar among boys and girls and by racial and ethnic groups but did vary by site. Early identification improved relative to the previous year of analysis in 2016. Moreover, compared to children born in 2010, children born in 2014 were 1.5 times more likely to be diagnosed with autism by 4 years of age. In addition, this study finds that for the first time, ASD prevalence was higher among Asian/Pacific Islander, Hispanic, and Black children than among White children.

Implications: Given the increased likelihood of early evaluation among children born in 2014 relative to those born in 2010, it appears that early autism identification is improving over time. This was found to be particularly true among populations that historically were less likely to receive appropriate evaluation, such as low-income and non-White groups. The year 2018 was also the first time in which enough data were recorded for Asian/Pacific Islander and American Indian/Alaskan Native children to be included in the analyses. In addition, identification rates increased among Asian/Pacific Islander, Black, and Hispanic children and children from families with lower income. However, autistic children with intellectual disability were more likely to be identified than autistic children without intellectual disability, particularly among Black children. Additionally, the differences in prevalence of autism in four-year-old children compared to eight-year-old children suggest that many children are identified with autism later than four years of age. Therefore, more work is needed to provide timely and equitable access to early autism identification services.

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INFRASTRUCTURE AND PREVALENCE

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