2022
SUMMARY OF ADVANCES

in Autism Research

IACC
INTERAGENCY AUTISM
COORDINATING COMMITTEE

OFFICE OF
NATIONAL AUTISM
COORDINATION
NATIONAL INSTITUTES OF HEALTH

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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 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 broad 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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INTRODUCTION

THE 2022 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 *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 2022 provide new insight into social communication and language, early intervention services, and co-occurring conditions across the lifespan. The advances also include studies that investigated telehealth diagnostic interventions adopted during the COVID-19 pandemic, genetic factors associated in brain development, and updated estimates for the number of children receiving early identification across demographic groups and with or without co-occurring intellectual disability. Articles in the *Summary of Advances* are grouped according to the topics represented by the seven Questions of the *IACC Strategic Plan*. 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 IACC supports the use of accessible language around autism in its publications. The terms "person with autism," "person with autism spectrum disorder (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 "ASD" is used when referring specifically to the DSM-5-TR defined diagnosis.*

ARTICLES SELECTED FOR THE 2022 SUMMARY OF ADVANCES

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- A Data-Driven Approach in an Unbiased Sample Reveals Equivalent Sex Ratio of Autism Spectrum Disorder-Associated Impairment in Early Childhood.
- Provider and Caregiver Satisfaction with Telehealth Evaluation of Autism Spectrum Disorder in Young Children During the COVID-19 Pandemic.
- Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities.

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- Infant Visual Brain Development and Inherited Genetic Liability in Autism.
- Mapping the time course of overt emotion dysregulation, self-injurious behavior, and aggression in psychiatrically hospitalized autistic youth: A naturalistic study.
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- Mental health screening in pediatric primary care for children with autism.

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- How do autistic people fare in adult life and can we predict it from childhood?
- Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research.
- Vocational Outcomes in ASD: An Examination of Work Readiness Skills as well as Barriers and Facilitators to Employment Identified by Autistic Adults.
- Co-occurring conditions and racial-ethnic disparities: Medicaid enrolled adults on the autism spectrum.
- Medicaid Disruption Among Transition-Age Youth on the Autism Spectrum.

INFRASTRUCTURE AND PREVALENCE

- Progress and Disparities in Early Identification of Autism Spectrum Disorder: Autism and Developmental Disabilities Monitoring Network, 2002-2016.

SCREENING AND DIAGNOSIS

Clinician Diagnostic Certainty and the Role of the Autism Diagnostic Observation Schedule in Autism Spectrum Disorder Diagnosis in Young Children

At-a-Glance:

The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) test may not be necessary for clinicians to diagnose autism in most children.

Background: ASD is diagnosed according to traits described in the Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition) (DSM-5), including challenges in social communication and social behavior and the presence of restricted, repetitive behaviors or interests. Autism can be diagnosed during a clinical evaluation solely using the DSM-5. However, another assessment called the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) is also frequently used to diagnose autism in young children. The ADOS is an activity-based assessment of communication skills, social interaction, and imaginative use of materials. ADOS diagnoses are often required to obtain insurance coverage for interventions and services. ADOS assessments take 45-60 minutes and must be done by trained specialists. Limited access to specialists, long waitlists, and high appointment costs can hinder diagnosis and access to support programs, particularly among racial and ethnic minorities, families living in rural areas, and families of lower socioeconomic status. Furthermore, evaluation of the ADOS tool has been limited to research settings. Given limited information on the use of ADOS in clinical settings, the authors of this paper sought to examine the consistency of diagnoses using the ADOS and the DSM-5.

Methods & Findings: Participants in this study included 349 children, ages 18 months to 6 years, who were referred for ASD diagnostic evaluation. Children were evaluated by developmental behavioral pediatricians (DBPs) trained in diagnosing autism. For each child, the DBPs first assessed potential autism according to DSM-5 diagnostic criteria, using all available information (medical and developmental history; direct clinician assessment and physical examination; interaction with the child and family; and information from all available assessments of language, cognitive, and adaptive function). The ADOS was then administered to all participating children, after which the clinician again recorded their diagnostic conclusion (this time incorporating information from the ADOS). The DBPs also self-rated how certain they were about their diagnosis, both before and after administration of the ADOS. The study results revealed 90% agreement between diagnoses made with versus without the ADOS. The most significant predictor of consistency between the two diagnoses was the degree of clinician diagnostic certainty at the time of the first diagnosis (i.e., without the ADOS). The two diagnoses were also more likely to be consistent for children who had more pronounced behavioral or social traits that are common among autistic children.

Implications: ASD diagnostic assessments that do not include the ADOS are less expensive and less time consuming. The findings from this study suggest that, in most cases, the ADOS is not necessary for DBPs and potentially other highly trained specialist clinicians to diagnose autism. The authors suggest that to streamline assessments and reduce barriers to services access, the ADOS should not be required by insurers, early intervention programs, school intervention programs, or behavioral health providers. However, the ADOS may still be helpful in certain cases, for example, when DBPs or other highly trained clinicians are unsure about a diagnosis or when assessing older children for autism.

A Data-Driven Approach in an Unbiased Sample Reveals Equivalent Sex Ratio of Autism Spectrum Disorder-Associated Impairment in Early Childhood.

Burrows CA, Grzadzinski RL, Donovan K, Stallworthy IC, Rutsohn J, St John T, Marrus N, Parish-Morris J, MacIntyre L, Hampton J, Pandey J, Shen MD, Botteron KN, Estes AM, Dager SR, Hazlett HC, Pruett JR Jr, Schultz RT, Zwaigenbaum L, Truong KN, Piven J, Elison JT; IBIS Network. *Biol Psychiatry.* 2022 Oct 15;92(8):654-662. [*PMID: 35965107*]

At-a-Glance:

Measurement bias may contribute to underdiagnosis or late diagnosis of autism in girls, highlighting the need to improve detection methods for girls and ensure access to interventions based on need, regardless of formal diagnosis.

Background: Tools used to diagnose ASD were largely developed based on how autism presents in boys. ASD is diagnosed in approximately four times as many boys as girls, but it is unclear if this difference is due to biases in diagnostic criteria or true differences in biology. Among children who have a sibling with autism, the ratio of boys to girls with ASD is lower at 3 to 1. In this study, researchers examined children with autistic siblings to assess potential sex-based diagnostic biases.

Methods & Findings: Children with older siblings with ASD were assessed for early indicators of autism using multiple measures at ages 6-9, 12-15, 24, and 36-60 months. Researchers used statistical modeling to correct for sex-based measurement bias and then grouped children based on changes over time in social communication (SC) and restricted and repetitive behaviors (RRB). For both SC and RRB, they identified a group of "higher concern" and a group of "lower concern". In the higher concern group, the ratio of boys to girls was approximately 1 to 1. However, the ratio of boys to girls diagnosed with autism at the 24-month visit was closer to 3 to 1. Among the girls who were in the group of higher concern but did not receive an ASD diagnosis, the researchers noted that many had average or above average language skills but had difficulties conversing and some RRBs. The clinicians conducting the assessments often recommended monitoring girls in this group but were more likely to ascribe behavioral differences to factors such as emotion regulation or shyness instead of autism.

Implications: Findings from this study suggest that sex-based differences in autism diagnoses are likely influenced by differences in social skills and measurement bias. Differences in nonverbal social behavior (such as eye contact) may also be interpreted differently in girls. Using current diagnostic tools, girls who may show autism-related concerns may never meet the threshold for diagnosis. This may contribute to disparities in diagnoses and access to support programs and behavioral health supports. Enhanced focus on subtle RRBs and social differences may help improve detection and diagnosis of autism in girls. This study further demonstrates the need for better assessment tools for use in girls and underscores the importance of ensuring that interventions to improve social interaction and emotion regulation are accessible without the need for a formal ASD diagnosis.

Provider and Caregiver Satisfaction with Telehealth Evaluation of Autism Spectrum Disorder in Young Children During the COVID-19 Pandemic.

Reisinger DL, Hines E, Raches C, Tang Q, James C, Keehn RM. *J Autism Dev Disord.* 2022 Dec;52(12):5099-5113. [*PMID: 35579789*]

At-a-Glance:

Telehealth evaluations for autism diagnoses in young children showed high satisfaction rates among providers and caregivers, indicating their potential to increase access and reduce wait times.

Background: Families may face difficulties accessing diagnostic evaluations for autism in young children for many reasons, including shortages of trained specialists, long wait lists, and limited access in rural and under-resourced areas. The COVID-19 pandemic increased these difficulties but also presented the potential for telehealth to increase access to diagnostic evaluations. Initial studies of remote autism diagnostic evaluations suggested that most providers and caregivers were satisfied with the process, but some healthcare providers and caregivers expressed concerns about technology barriers (e.g., limited broadband internet access), distractions in home environments, and audio/video distortions. However, published data on telehealth diagnostic evaluations remains limited, particularly regarding whether provider and caregiver satisfaction with telehealth evaluations differs based on diagnostic outcome, demographics (e.g., child race/ethnicity, household income), and degree of technology issues encountered.

Methods & Findings: Researchers surveyed provider and caregiver satisfaction for autism telehealth diagnostic evaluations of 308 children between the ages of 14 and 78 months who were referred to Riley Hospital for Children in Indianapolis, IN, between May 2020 and June 2021. These parents were offered the telehealth diagnostic evaluation after the hospital canceled in-person evaluations due to the COVID-19 pandemic. Participating providers included seven psychologists and four pediatricians with neurodevelopmental training, who evaluated signs of potential autism using the TELE-ASD-PEDS assessment and adaptive functioning using the Vineland Adaptive Behavior Scale. Most providers (94%) and caregivers (88%) rated their overall satisfaction as "Satisfied" or "Very satisfied." Caregivers of children with more pronounced traits of autism and lower adaptive functioning were more satisfied with telehealth evaluations compared to caregivers of children with less pronounced traits. Caregiver satisfaction did not differ based on race/ethnicity, age, household income, type of insurance, or travel time saved. Provider and caregiver satisfaction were both higher in cases where children were diagnosed during the evaluation compared to cases where the child was not diagnosed or when the physician was uncertain about the diagnosis. Finally, providers who did not encounter technical difficulties were more satisfied than providers who did.

Implications: These results suggest that telehealth evaluations are a viable option for diagnosing autism in young children, which can increase access and reduce wait times for diagnostic evaluations. However, providers should account for caregiver preferences for telehealth appointments. One possible approach is an initial telehealth evaluation followed by an in-person assessment in cases when providers are less certain about the diagnosis. Furthermore, these results illustrate the importance of telehealth training, including technical training (e.g., equipment setup), to increase the confidence of providers in telehealth diagnostic evaluations.

Effectiveness of Screening in Early Intervention Settings to Improve Diagnosis of Autism and Reduce Health Disparities.

Sheldrick RC, Carter AS, Eisenhower A, Mackie TI, Cole MB, Hoch N, Brunt S, Pedraza FM. *JAMA Pediatr.* 2022 Mar 1;176(3):262-269. [*PMID: 34982099*]

At-a-Glance:

Incorporating autism screening into early intervention settings may improve early detection, which is required for access to services and supports.

Background: Research has shown that universal screening in pediatric primary care settings is not sufficient to identify all children with ASD. Furthermore, children who are racial or ethnic minorities, non-English speaking, or from low-income families are less likely to receive a timely ASD diagnosis. However, for children under 3 years old who may be at risk for or experiencing developmental delays, the Individuals with Disabilities Education Act (IDEA) Part C ensures access to early intervention services in all U.S. states and territories. Early intervention specialists, with their expertise in early childhood and disabilities, may be well equipped to provide ASD screening. This study evaluated whether a screening protocol for ASD implemented in early intervention settings can increase rates of ASD diagnosis.

Methods & Findings: This study utilized a large data set maintained by the Massachusetts Department of Public Health that includes records of all children receiving early intervention services. Data were included from 33,326 children who received services from 12 early intervention sites in low-income neighborhoods. At nine of the sites, children received standard care. At the other three sites, an ASD screening protocol was administered, including parent questionnaires in English or Spanish and an interactive assessment to evaluate children's social and communication behavior. By analyzing administrative records containing children's demographic information, individualized service plans, insurance claims for early intervention services, and ASD diagnoses, researchers compared rates of ASD diagnosis before and after implementation of the ASD screening protocol. They also compared the rates of diagnosis at the three sites using the ASD screening protocol to the rates at standard care sites. Implementation of the ASD screening protocol was associated with a significant increase in the rate of ASD diagnosis compared to the other standard care sites. This increase was larger among children from Spanish-speaking families versus other families and among boys versus girls.

Implications: This study represents the first comprehensive evaluation of ASD screening in early intervention settings. These results demonstrate that incorporating ASD screening into these settings may help improve autism detection and diagnosis early in life, especially among children from Spanish-speaking families. Improving detection will enable more children to receive a diagnosis, which is a prerequisite for many important autism services and supports.

BIOLOGY

At-a-Glance:

There are significant differences in the gene activity of autistic versus neurotypical brains, particularly in brain regions involved in sensory and language processing.

Background: Previous research indicates that complex interactions among hundreds of genes contribute to autism. In the brain, these genes regulate immune responses, neuronal communication, and the activity (also called the "expression") of other genes. However, exactly how these changes may lead to autism remains unknown, including whether they are confined to one area of the brain or occur throughout. Transcriptomic analysis is a method used to detect changes in the activity of thousands of genes, rather than focusing on specific genes. This method can be used to help identify patterns of gene expression and biological underpinnings of autism by determining where changes in gene activity occur in the brain, even in genes not previously linked to autism.

Methods & Findings: Researchers conducted analyses of gene activity in 725 post-mortem brain samples from 49 autistic people and 54 neurotypical people. These samples examined 11 distinct regions within the cerebral cortex. The cerebral cortex is the part of the brain involved in sensory processing as well as language, memory, emotion, learning, and decision-making. Researchers identified 4,223 genes that were expressed differently in autistic versus neurotypical brains, and these differences were found across the cerebral cortex. The largest number of differences were observed in the brain regions responsible for vision, space perception and hand-eye coordination, and hearing and language processing. Furthermore, while neurotypical brain regions could be distinguished based on differences in gene expression, gene expression in autistic brain regions showed less variation. Of the 11 brain regions compared, this effect was most prominently observed in the regions responsible for vision, language processing and body image, and speech processing and sensation.

Implications: The differences between neurotypical versus autistic brain regions involved in sensory and language processing correspond with the sensory and language processing difficulties commonly experienced by autistic people. The reduced variation between brain regions in autistic individuals also suggests differences in the development and function of these regions, which may contribute to cognitive differences (e.g., problem-solving). These results illustrate the complexity of autism biology and the importance of continued research to better understand how autism genes contribute to variations in brain connectivity and function.

Quantifying social skill deficits and strengths profiles in autistic youth.
Gates JA, Gerber AH, Miller CE, Lerner MD. *Child Dev.* 2023 May;94(3):659-673. Epub 2022 Dec 27.
[*PMID:* 36573397]

At-a-Glance:

Autistic youth exhibit considerable social strengths and struggle more with performing social skills than with learning them.

Background: Social difficulties are common for autistic youth. It has been long assumed that autistic children experience these difficulties due to atypical social learning and that interventions are best focused on helping them acquire social skills. However, recent evidence suggests social difficulties may instead arise from autistic children not consistently performing behaviors that they have already learned or due to having fewer social skill strengths, or both. Existing assessment tools have been unable to examine the distribution of individuals' challenges and strengths. However, researchers have developed a new method to disentangle and capture the different kinds of social skills challenges (in acquisition of new skills or performance of skills previously acquired) and social strengths of autistic youth. This method can be used to create a Social Skill Deficits and Strengths Profile (SSDSP) for autistic youth that are descriptive of these nuances.

Methods & Findings: The researchers used the SSDSP to examine social functioning in 150 autistic and 61 non-autistic youth ages 7-17 years. Participants' parents ranked the frequency and importance of 46 social behaviors for their children. The researchers divided the behaviors into one of three categories: acquisition, performance, and strength. Behaviors ranked as "never occurring" (that the child had not been observed doing previously) and "important or critical" were categorized as social *acquisition* challenges. Behaviors ranked as "seldomly occurring" (they had been observed before, but not often or consistently) and "important or critical" were categorized as social *performance* challenges. Behaviors ranked as "almost always occurring" (observed consistently) and "important or critical" were categorized as social skill *strengths*. After categorizing all ranked behaviors, the researchers calculated participants' percentage of behaviors in each category. Autistic youth exhibited significantly more acquisition and performance challenges and fewer social skill strengths than non-autistic youth but more social strengths than expected. Among autistic youth, social performance challenges were three times more common than social acquisition challenges and twice as common as social skill strengths.

Implications: Results from this study indicate that while autistic youth exhibit more challenges acquiring and performing social skills than do non-autistic youth, social performance challenges and social strengths were both more common than social acquisition challenges. This indicates that performance challenges may be a core feature of social function in autism, which has long been thought to be dominated by social acquisition issues. It also highlights the presence and importance of substantial social strengths in this population. This study supports the need for interventions that help autistic youth perform the social skills they already know and nurture and foster their existing social strengths.

At-a-Glance:

Social communication challenges in older autistic siblings are associated with altered brain development in younger siblings who are eventually diagnosed with ASD.

Background: ASD has a genetic component, and younger siblings of individuals with ASD are more likely to develop ASD themselves. This likelihood is increased if the older sibling with ASD shows high levels of social communication challenges. Thus, social communication traits within families may serve as early markers for inherited, autism-associated genetic factors. Neuroimaging studies have shown that autistic children have different patterns of brain development compared to their neurotypical peers. However, the relationships between these brain development patterns and the inherited genetic factors of autism are unclear. This study aimed to investigate the relationship between the level of ASD traits in the older sibling and the brain development of the younger sibling.

Methods & Findings: This study included 384 pairs of siblings (89 pairs where both siblings had ASD) and looked at how the ASD traits in the older sibling were related to brain development in the younger sibling at 6, 12, and 24 months. Researchers analyzed brain scans of participants to identify differences in the size and function of certain regions of the brain. In a subset of sibling pairs, researchers also examined the functional connectivity (how effectively brain regions communicate with one another) of the younger siblings' visual system. Among sibling pairs in which both children were ultimately diagnosed with ASD, greater social communication challenges among the older siblings were associated with increased total brain volume, total brain surface area, and visual system surface area in the younger siblings at multiple timepoints. Greater social communication challenges among the older siblings were also associated with altered structural and functional connectivity in the visual systems of the younger siblings at 6 months. These associations were not observed in the younger siblings who were not eventually diagnosed with ASD.

Implications: This study suggested that brain features observed in the MRI scans in early development are related to the level of ASD traits in the family. The results point to a convergence of structural and functional differences in areas of the brain involved in visual processing, indicating that genetic factors influence the early development of the visual circuitry in ASD. As the visual processing of social stimuli (e.g., eyes, faces) is critical early in life, this may shape infants' experiences of the environment around them and contribute to the development of autism.

Mapping the time course of overt emotion dysregulation, self-injurious behavior, and aggression in psychiatrically hospitalized autistic youth: A naturalistic study.

Northrup JB, Goodwin MS, Peura CB, Chen Q, Taylor BJ, Siegel MS, Mazefsky CA. *Autism Res*. 2022 Oct;15(10):1855-1867. [*PMID: 35751466*]

At-a-Glance:

There is a potential link between emotional dysregulation, self-injurious behavior (SIB), and aggressive behavior among autistic youth in psychiatric hospitals, emphasizing the need for mental and behavioral health support programs and interventions that focus on regulating emotions.

Background: Aggression, self-injurious behavior (SIB; e.g., skin picking), and emotional dysregulation (difficulty managing emotions) are more common among autistic people than the general population. However, few studies have examined whether these are related or whether SIB and aggression are more common during times of emotional dysregulation. SIB and aggression are the most common reasons for psychiatric hospitalization among autistic people. Identifying potential links between emotional dysregulation, SIB, and aggression may help improve mental and behavioral health support for people on the autism spectrum.

Methods & Findings: In this study, researchers observed 53 autistic youth admitted to psychiatric hospitals and recorded when individuals displayed emotional dysregulation, SIB, and/or aggressive behavior. This allowed for natural, real-time observation of behavior. Emotional dysregulation was defined as behaviors indicating agitation or clear negative emotion (e.g., crying, yelling, thrashing). SIB and aggressive behaviors were defined as behaviors likely to harm oneself (e.g., hitting self, pulling one's own hair) or others (e.g., hitting or throwing objects). These behaviors varied greatly between participants. In the study, 51 participants displayed emotional dysregulation, 42 displayed SIB, and 39 displayed aggressive behaviors. Emotional dysregulation was observed during 49% of instances of SIB and 36% of instances of aggressive behavior. Emotional dysregulation was more likely to come after SIB and aggressive behaviors than to occur before episodes of these behaviors.

Implications: Emotional dysregulation may play a role in the onset and continuation of SIB and aggressive behaviors in some autistic people. These individuals may benefit from behavioral and mental health support programs and interventions that focus on regulating emotions. For other autistic individuals, the results of this study suggest that some instances of SIB and aggression may not be associated with outward indications of emotional dysregulation. Instead, they may be caused by other things, such as a desire for a specific outcome. Alternatively, it is possible that the person could be experiencing an internal state of emotional dysregulation but not showing observable signs externally. Further research could investigate methods of measuring emotional dysregulation that do not rely on observable signs of distress, such as elevated heart rate. Additionally, given the correlation in the literature between restricted and repetitive behaviors and SIB and aggression, future research could explore the relationships between these behaviors.

At-a-Glance:

Autistic children with early word loss exhibit a slight delay in some language skills, but the delay does not worsen over time and overall language development is comparable to autistic children without early word loss.

Background: Not all autistic children have the same patterns of language development, and some may experience language regression (the loss of previously acquired words). However, little is known about what causes language regression. Some studies have associated language regression with delayed speech, but others indicate that children with language regression eventually achieve typical language development milestones. This study examined autistic children over time to assess predictors and long-term outcomes of autistic children who experienced language regression early in life.

Methods & Findings: Researchers analyzed data from 408 children diagnosed with ASD. They evaluated parent interviews collected over multiple timepoints to examine the frequency, age of onset, and other factors associated with language regression. The researchers also examined how children with and without language regression developed expressive communication skills (using words to convey ideas; for example, asking questions) and receptive communication skills (using words to understand ideas; for example, following directions). The data revealed that 22% of children in the study experienced language regression. Children with language regression walked and learned their first words before children without language regression, but both groups began using phrases of multiple words at similar ages. Children with language regression exhibited a 3-month delay in skills related to expressive, but not receptive, communication. This delay remained consistent over time. Sociodemographic factors such as biological sex, maternal education, and family income did not differ for children with and without language regression.

Implications: This study shows that although autistic children with language regression experienced a slight delay in expressive communication, the delay did not increase over time and therefore likely became less consequential as children aged. The overall pattern of communication development was the same between children who did and children who did not experience language regression. This indicates that language regression does not predict worse long-term developmental outcomes for children with autism.

GENETIC AND ENVIRONMENTAL FACTORS

Associations Between Pregnancy-Related Predisposing Factors for Offspring Neurodevelopmental Conditions and Parental Genetic Liability to Attention-Deficit/Hyperactivity Disorder, Autism, and Schizophrenia: The Norwegian Mother, Father and Child Cohort Study (MoBa).

Havdahl A, Wootton RE, Leppert B, Riglin L, Ask H, Tesli M, Bugge Askeland R, Hannigan LJ, Corfield E, Øyen AS, Andreassen OA, Tilling K, Davey Smith G, Thapar A, Reichborn-Kjennerud T, Stergiakouli E. *JAMA Psychiatry*. 2022 Aug 1;79(8):799-810. [*PMID: 35793100*]

At-a-Glance:

Genes associated with ADHD, autism, and schizophrenia may also affect prenatal factors such as maternal depression and anxiety during pregnancy, highlighting the need to consider genetic factors when studying effects of the prenatal environment on brain development.

Background: Numerous studies have investigated how maternal behavior and health during pregnancy relate to the development of attention deficit/hyperactivity disorder (ADHD), ASD, and schizophrenia, but it remains uncertain whether prenatal exposures directly cause these conditions or if they are influenced by shared genetic factors. One way to explore this is to examine whether mothers with genetic predisposition for ADHD, ASD, or schizophrenia are also more likely to be exposed to pregnancy-related factors that are associated with those conditions, which would imply that prenatal factors alone may not be the sole cause ADHD, ASD, or schizophrenia.

Methods & Findings: This study included genetic, lifestyle, and health data from 14,539 mothers who participated in a Norwegian pregnancy study. Researchers examined the relationship between mothers' genetic predisposition for ADHD, ASD, and schizophrenia and certain factors that were present during pregnancy. Higher likelihood of maternal anxiety or depression during pregnancy was associated with genetic predispositions for schizophrenia, ADHD, and ASD. Genetic predisposition for ASD was not significantly associated with other prenatal factors. However, mothers with genetic predispositions for either ADHD or schizophrenia were more likely to smoke and gained more weight during pregnancy. Mothers with a genetic predisposition for ADHD were also more likely to be younger and more likely not to take supplements during pregnancy, while mothers with a genetic predisposition for schizophrenia were more likely to drink coffee during pregnancy.

Implications: The results of this study suggested that maternal genetic predispositions for ADHD, ASD, and schizophrenia are associated with certain factors such as depression and anxiety during pregnancy. These shared genetic predispositions imply that the prenatal exposures alone likely do not cause these neurodevelopmental conditions. Additional research is needed to understand which exposures during pregnancy may impact children's developmental outcomes, taking into account any shared genetic predisposition of the mother. Studies that fail to consider genetic factors for different conditions may lead researchers to draw false conclusions about the effects of environmental exposures on child brain development.

INTERVENTIONS

Super responders: Predicting language gains from JASPER among limited language children with autism spectrum disorder.

Panganiban J, Kasari C. *Autism Res*. 2022 Aug;15(8):1565-1575. [*PMID: 35437928*]

At-a-Glance:

Behaviors such as use of gesture, fine motor skills, and play can help predict how autistic children will respond to an intervention to improve social communication and language, suggesting a strategy to match interventions to those who will benefit the most.

Background: Early interventions can significantly improve outcomes for autistic children. However, responses to these inventions can vary from one child to another. Predicting how different children may respond to a given type of intervention will allow customization of an intervention plan to a child's unique needs. In this study, researchers analyzed behavioral data from autistic children with limited language (single or no words) to predict which of the children would respond best to a social communication intervention called JASPER (Joint Attention, Symbolic Play, Engagement, and Regulation).

Methods & Findings: Researchers analyzed data previously collected from 99 autistic children across five separate intervention studies. The children were 3 to 5 years old, had limited language, and underwent a two- to six-month JASPER intervention. Before and after the intervention, the children were tested on various behaviors, including expressive language (i.e., the ability to convey one's ideas using words). Using results from the expressive language testing, researchers categorized the children as "super responders" (improvement beyond what would be expected during typical development) or "slow responders" (less improvement than would be expected during typical development). The researchers then used machine learning and statistical methods to develop a prediction model that characterizes each type of responder based on the behaviors assessed. Three specific factors were potential predictors of responder type: use of requesting gestures, diversity in play, and level of fine motor skills. Diversity in play was the strongest predictor, and children who played with a wider variety of toys had an approximately 70% chance of being super responders.

Implications: These findings demonstrate that a child's response to the JASPER intervention may be affected by a combination of the child's unique characteristics. The findings in this study can help match this intervention, or similar interventions, to children who will benefit the most. In addition, future efforts to develop other interventions should consider using similar statistical and machine learning methods to identify which populations of children would most benefit.

SERVICES AND SUPPORTS

Disparities in Early Intervention Program Participation by Children With Autism Spectrum Disorder in a US Metropolitan Area, 2006 to 2016.
Shenouda J, Barrett E, Davidow AL, Sidwell K, Halperin W, Silenzio VMB, Zahorodny W. *JAMA Pediatr*. 2022 Sep 1;176(9):906-914. [*PMID: 35849409*]

At-a-Glance:

Less than half of the children in New Jersey diagnosed with autism between 2006 and 2016 received early intervention services, and significant socioeconomic and racial/ethnic disparities were observed, underscoring the urgency to address disparities and increase access to early intervention.

Background: Signs of autism may be observable by 18 months, and ASD can be reliably diagnosed by 24 months. Research has shown that earlier receipt of services and supports is associated with better outcomes for children diagnosed with ASD. In the United States, Part C of the Individuals with Disabilities Education Act (IDEA) guarantees infants and toddlers with developmental delays and disabilities access to Early Intervention Programs (EIPs). This study investigated the extent to which children diagnosed with ASD accessed EIP services between 2006 and 2016 across four New Jersey counties and whether access was influenced by certain sociodemographic factors.

Methods & Findings: Researchers analyzed special education and medical records collected from multiple cohorts of 8-year-old children included in the New Jersey Autism Study, a part of the Autism and Developmental Disabilities Monitoring (ADDM) Network, between 2006 and 2016. A total of 4,050 children with ASD were identified across cohorts, of whom 46.6% received EIP services. Receipt of these services increased from 39.3% in the 2006 cohort to 55.5% in the 2016 cohort and varied based on socioeconomic status, race, level of disability, and age of developmental delay diagnosis. Among White children with autism, 49.1% received EIP services versus 45.2% of Hispanic and 43.3% of Black children with autism. Further, 49.0% and 53.1% of children living in census regions associated with middle and high socioeconomic status, respectively, received early intervention services, versus only 41.7% of children living in low socioeconomic status regions. Among children classified by expert clinicians as having significant disability, 57.3% received early intervention services versus 40.1 to 46.6% of children with less significant disability. Furthermore, statistical modeling showed that children who were diagnosed with a developmental delay before 36 months of age were 2.64 times as likely to receive early intervention services if born in 2008 versus 1998.

Implications: Although the use of early intervention services is on the rise, this study demonstrates that a significant proportion of children with autism still are not receiving these services. Furthermore, race and socioeconomic-based disparities in the receipt of early intervention services persist. Future research should further investigate these disparities to improve early intervention access and outcomes for all children diagnosed with autism.

At-a-Glance:

Pediatricians can identify early mental health concerns in school-age children with autism through screening during well-child appointments, and opportunities exist to refine screening and linkage efforts across pediatric care settings.

Background: Children with autism experience high rates of co-occurring mental health needs. Many of these conditions require long-term interventions, and earlier detection may lead to better mental health outcomes. As primary points of contact for children's healthcare, pediatricians are well positioned to identify children's mental health needs early and connect them to necessary mental health services. This study evaluated the use and impact of mental health screening in pediatric primary care clinics for children with autism.

Methods & Findings: Researchers analyzed demographic and mental health screening data from 166 children with autism, aged 4 to 16 years, who attended well-child appointments at one of two Southern California healthcare systems. Across both organizations, study patients were 8 to 9 years old on average, predominantly male, and approximately half identified as Hispanic/Latino. Primary care providers screened patients for mental health concerns using the Pediatric Symptom Checklist-17 (PSC-17), a short questionnaire used by providers to identify psychosocial challenges in children. The screening rates at both organizations were similar (53% and 55%, respectively), and the rates at which children were identified as having potential co-occurring mental health concerns was high, ranging from 36 to 47%. Children who screened positive for potential mental health concerns tended to score highest on checklist items measuring attention challenges and challenging behaviors. Following their positive screen, 45 to 57% of these children were referred to mental health services by their primary care provider. Researchers observed no significant demographic differences in screening or referral rates.

Implications: The high rates of positive mental health screening reported in this study align with previous findings indicating high rates of co-occurring mental health needs in children with autism. Furthermore, given that slightly over half of the eligible patients received mental health screening, this study demonstrated the feasibility of mental health screening in pediatric primary care settings. However, because many eligible children were not screened and many who screened positive were not referred to mental health services, future studies should investigate how to increase screening rates and post-screening referrals, including optimal timing of mental health referrals, to improve engagement in needed mental health services.

LIFESPAN

Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study.

At-a-Glance:

International survey results indicate several barriers, particularly communicating with providers and sensory challenges in waiting rooms, that may affect autistic adults in scheduling and completing primary care visits, leading to worse health outcomes.

Background: Many autistic adults have poorer health outcomes than their non-autistic peers, including reduced life expectancy, higher likelihood of chronic medical conditions, and higher likelihood of emergency room use and inpatient admission. Although autistic adults may have increased health needs, they often report that these needs are not adequately met. To examine autism-specific healthcare barriers, this international study including respondents from the United Kingdom, Ireland, and North America surveyed autistic adults about the challenges they face in accessing primary care and their associated adverse health outcomes.

Methods & Findings: An autistic-led research team created and administered a 52-item online survey to 507 autistic and 157 non-autistic adults. The survey included questions about specific barriers to accessing healthcare; reasons for delaying or avoiding primary care visits; and difficulties booking, planning, or waiting for primary care visits. The survey also asked about challenges people may encounter during their primary care visits, like difficulties with communication or sensory processing or a lack of available social supports. Lastly, the survey explored the impact of these barriers by asking study participants to report on the health consequences of their experiences. Eighty percent of the autistic adults surveyed reported barriers to visiting a primary care provider, primarily related to communication and sensory processing difficulties, compared to only 37% of the non-autistic adults. Significantly more autistic adults than non-autistic adults struggled with telephone calls to book appointments, delayed or avoided their appointments due to feeling misunderstood by their providers, and had difficulty communicating with their providers and reception staff. In addition, significantly more autistic adults felt uncomfortable in waiting rooms due to noise from other patients, crowding, bright lights, and other sensory challenges. Most adults surveyed reported that online or text-based appointment booking systems would improve their experiences, but autistic adults also reported that they preferred the option to email in advance their reason for consultation, the first or last appointments of the day, and quiet waiting rooms. Autistic adults who encountered difficulties reported that they often went untreated for physical and mental health conditions and were less likely to follow up on referrals to specialists.

Implications: These findings indicate that reducing health disparities may require adapting primary care practices to the unmet needs of autistic adults. For example, autism-friendly practices may employ a personalized approach to healthcare that includes administering staff autism training and providing patients with a healthcare access needs assessment. Offering flexible online booking and taking into consideration the sensory sensitivities of autistic individuals by increasing appointment lengths and making changes to reduce waiting room noise and crowding may improve the experiences of autistic patients.

How do autistic people fare in adult life and can we predict it from childhood?
Forbes G, Kent R, Charman T, Baird G, Pickles A, Simonoff E. *Autism Res.* 2022 Dec 15. [*PMID: 36519265*]

At-a-Glance:

Factors measured in childhood such as IQ, adaptive functioning, and degree of autistic traits may predict levels of independence, employment and education, and, to a lesser extent, physical health in autistic adults.

Background: Compared to their non-autistic peers, autistic young adults are less likely to live independently and more likely to have anxiety and depression. However, these outcomes vary significantly among autistic people. Identifying factors in childhood (e.g., cognitive function, adaptive behavior skills) that may predict adult outcomes (e.g., employment) can help identify which children will benefit most from interventions and support programs to help them succeed in adulthood. Longitudinal studies, which collect the same data on participants over long periods of time, can best identify these factors. Thus, this group of researchers sought to examine potential childhood factors and adult outcomes from longitudinal study data that followed autistic people from childhood into young adulthood.

Methods & Findings: Researchers examined data from the Special Needs and Autism Project (SNAP), a longitudinal study that follows outcomes among autistic people born between 1990 and 1991 in England. Childhood data from participants were collected between 2001 and 2003 on degree of autistic traits, adaptive functioning, IQ, language development, overall mental health, maternal mental health, and quality of life. Adult outcome data were collected from the same individuals between 2013 and 2015 on close friendships, employment status, education, living situation (e.g., living with family), anxiety, depression, and quality of life. Sixty-eight percent of autistic adults reported close friendships, while only 14% reported very little social interaction. Compared to their non-autistic peers, autistic adults were twice as likely to not be employed or pursuing education, and 29% were employed in supported or sheltered employment programs. Only 5% lived independently from family compared to 54% of their non-autistic peers, and 37% were receiving high levels of support (10+ hours of care, including overnight care). A lower degree of autistic traits and higher IQ during childhood were strongly associated with higher likelihood of living independently as a young adult and somewhat associated with likelihood of employment or education. However, other childhood measures (e.g., language development, maternal mental health, parental education level) did not predict adult outcomes. Once adjusted for childhood IQ and degree of autistic traits, higher childhood adaptive functioning was associated with multiple improved outcomes in adulthood (e.g., higher likelihood of employment and living independently).

Implications: These results suggest that autistic children with lower IQ and higher degree of autistic traits may particularly benefit from support programs and behavioral health support to assist them in becoming independent and pursuing adult employment or education. However, the results also show that commonly used measurements of autistic traits and childhood IQ may not be effective in predicting social or mental health difficulties in adulthood. Instead, adaptive functioning scores may better predict certain adulthood outcomes.

At-a-Glance:

Autistic people diagnosed as adults are more likely to have co-occurring psychiatric conditions than those diagnosed as children, highlighting the importance of mental health supports for autistic people across the lifespan and the need for further research on how timing of autism diagnosis affects well-being.

Background: Research on autism has traditionally focused mostly on people diagnosed as children, with significantly fewer studies among people diagnosed with autism as an adult. Some studies suggest that people diagnosed with autism in adulthood are more likely to have other psychiatric conditions (e.g., anxiety, depression) than autistic people who were diagnosed in childhood. However, many of these studies had relatively few participants or focus on adults who depend on family or residential care. In contrast, the Simons Powering Autism Research Knowledge (SPARK) database has data from more than 100,000 autistic people, including more than 7,300 independent adults (i.e., without a conservator or guardian) and adults who were diagnosed later in life. Thus, the authors used the SPARK database to examine whether the prevalence of co-occurring psychiatric conditions differs based on age of diagnosis.

Methods & Findings: Researchers examined data from 4,567 adult (age 18 or older) participants in the SPARK database who are legally independent and previously completed medical and background questionnaires. These questionnaires provided data regarding sex at birth, age and types of diagnoses, and demographic data. Slightly more than half (52.5%) of participants were diagnosed with autism in childhood (prior to age 21). Compared to 48.4% of female participants, 58.2% of male participants were diagnosed with autism during childhood. Many participants were also diagnosed with other health conditions, including developmental delays and disorders (30.0%), sleep disorders (31.5%), and at least one psychiatric condition (86.8%). Mood disorders (e.g., depression, bipolar disorder) and anxiety were the most common co-occurring psychiatric conditions. Participants diagnosed with autism during adulthood were more likely to have other psychiatric conditions, particularly anxiety (59.7%) and depression (60.5%).

Implications: These results demonstrate that co-occurring psychiatric conditions are common among all autistic adults, and prevalence varies based on the age of autism diagnosis, suggesting that lifelong outcomes may be impacted by self-understanding and/or the presence or absence of appropriate supports in childhood and adolescence. More research is needed on whether differences in psychiatric conditions based on age of autism diagnosis is due to previous misdiagnoses (e.g., attributing autistic traits to social anxiety) or differences in risk for co-occurring conditions. Furthermore, undiagnosed children may face multiple difficulties during childhood (e.g., bullying, low self-esteem), and not having knowledge of autism as context for these difficulties may put them at greater-than-average risk of depression and anxiety. Given these health differences noted, it may be helpful to include age of autism diagnosis in the description of adult autistic samples for future studies.

Vocational Outcomes in ASD: An Examination of Work Readiness Skills as well as Barriers and Facilitators to Employment Identified by Autistic Adults.

At-a-Glance:

Work readiness skills (e.g., adaptability, success in daily routines) may improve employment outcomes for autistic adults.

Background: Autistic adults are at higher risk of unemployment and underemployment compared to their neurotypical peers. Recent research suggests that difficulties in certain work readiness skills (e.g., teamwork, organization) may be greater barriers to obtaining and retaining employment for autistic people than education or relevant experience. Autistic people may have strengths in some work readiness skills (e.g., persistence) but struggle with other skills (e.g., adaptability). Vocational rehabilitation and career support services can assist autistic adults in improving specific skills, thus helping to reduce employment disparities among autistic adults. Researchers sought to examine whether work readiness skills are associated with employment outcomes among autistic adults.

Methods & Findings: Researchers examined work readiness skills and employment outcomes among 281 autistic adults between the ages of 21 and 39. Participants completed a questionnaire which asked about five sets of relevant skills: (1) adherence to rules and requirements (e.g., meeting deadlines); (2) work style (e.g., adjusting to work environment); (3) ability to work independently; (4) routine daily activities (e.g., hygiene, driving or using public transportation); and (5) interpersonal skills (e.g., asking for help when needed). Participants also answered questions about potential sensory challenges in employment (e.g., discomfort with textures or types of lighting) and answered two qualitative questions exploring reasons for poor employment outcomes. Nearly half (49%) of participants were employed for more than 10 hours a week, while 8% received some form of economic assistance or sheltered employment and 43% were unemployed. Participants who were fully employed had higher scores for work style (e.g., skilled at adapting to change) and routine daily activities (e.g., effectively managing daily tasks) compared to unemployed participants. Responses to qualitative questions regarding work challenges identified three themes: (1) personal difficulties associated with autism (e.g., physical and mental health); (2) difficulties finding and keeping desired and fulfilling jobs; and (3) lack of autism-friendly workplaces and associated burnout. Recommended improvements included education for employers regarding autism, career and job training support for autistic adults, and autism-friendly accommodations (e.g., flexible scheduling).

Implications: These results suggest that workplace skills, particularly daily routines and adapting to workplace demands (including sensory challenges), can present barriers to employment for autistic adults. Vocational programs that address these challenges may improve employment outcomes among autistic people. Solutions to workplace challenges highlight the importance of education and empathy among employers to accommodate the needs of autistic employees rather than putting the onus solely on autistic people.

Co-occurring conditions and racial-ethnic disparities: Medicaid enrolled adults on the autism spectrum.

Schott W, Tao S, Shea L. *Autism Res.* 2022 Jan;15(1):70-85. [*PMID: 34854249*]

At-a-Glance:

Medicaid data suggest that co-occurring health conditions among autistic adults, which occur more often than in non-autistic peers, differ based on race and ethnicity.

Background: Multiple studies suggest that autistic adults are at higher odds than their non-autistic peers of co-occurring medical and psychiatric conditions (e.g., epilepsy, anxiety), premature death, and poor physical health. Less is known about whether these co-occurring conditions differ based on race and ethnicity. Studies have previously identified racial and ethnic disparities in autism diagnosis and support, including age of diagnosis, access to support services, and quality of care. Medicaid serves as one of the largest insurers for mental health services in the United States and as one of the primary insurers for adults with disabilities, including autistic adults. Thus, analyzing Medicaid records can provide key insights into whether co-occurring conditions in autistic adults differ based on race and ethnicity.

Methods & Findings: Researchers analyzed claims data for adults ages 18-64 from the Medicaid Analytic eXtract (MAX) database for 2008 through 2012. The data included Medicaid claims among 155,617 adults with autism as well as 466,581 non-autistic adults with similar characteristics (e.g., age, prevalence of intellectual disabilities) for comparison. Claims data were analyzed for race, ethnicity, and multiple co-occurring physical and psychiatric conditions. Compared to adults without autism, autistic adults were four times as likely to have obsessive compulsive disorder (OCD), twice as likely to have attention deficit/hyperactivity disorder (ADHD), and twice as likely to have anxiety. Autistic adults also had higher odds than non-autistic adults for multiple other health conditions, including Parkinson's disease, endocrine disorders, and epilepsy. The prevalence of co-occurring conditions among autistic adults differed based on race and ethnicity. Compared to White autistic adults, Black autistic adults were more likely to have schizophrenic disorder, drug abuse/dependence, and hypertension, and were less likely to have OCD, anxiety, cancer, and migraines. Hispanic autistic adults were more likely than their White counterparts to have schizophrenic disorder, obesity, diabetes, liver disease, hypertension, asthma, and autoimmune disorders. Compared to White autistic adults, Asian and Pacific Islander autistic adults were more likely to have gout, diabetes, Down syndrome, and hypertension, and were less likely to have alcohol and drug use/dependence, bipolar disorder, ADHD, and migraines.

Implications: Compared to their White counterparts, autistic adults from other racial and ethnic groups may face different physical and mental health challenges. Many of the racial and ethnic disparities among autistic adults (e.g., hypertension, cardiovascular disease) have also been observed in the general population. Racial and ethnic differences in co-occurring conditions – particularly for psychiatric conditions such as ADHD and anxiety – among autistic adults may be due to biases in diagnoses and access to mental health care. Addressing and reducing these disparities is crucial for improving health equity and providing holistic healthcare and support to autistic adults from all racial and ethnic groups.

Medicaid Disruption Among Transition-Age Youth on the Autism Spectrum.
Shea L, Tao S, Marcus SC, Mandell D, Epstein AJ. *Med Care Res Rev.* 2022 Aug;79(4):525-534. [*PMID: 34632834*]

At-a-Glance:

Lack of lifelong Medicaid coverage for autistic adults in many states leads to higher rates of coverage loss and lower re-enrollment compared to non-autistic peers with intellectual disabilities.

Background: Medicaid is a crucial source of support for autistic adolescents and young adults as they transition from school-based support programs to adult care and assistance programs. However, while most state Medicaid programs support people with intellectual disabilities throughout their lifespans, fewer states provide lifespan support for people with an autism diagnosis. Autistic young adults without intellectual disabilities may be at particular risk of losing coverage because many states require that autistic adults demonstrate cognitive impairment to be eligible. The loss of Medicaid coverage can hinder access to key supports, such as occupational therapy, speech therapy, and social skills training that can help autistic adults achieve success in adult activities such as postsecondary education and work. Thus, continuous Medicaid coverage of support programs like those for adults with intellectual disabilities could be important for improving economic and employment outcomes among autistic young adults.

Methods & Findings: Researchers examined data from 2008 to 2012 in the Medicaid Analytic eXtract (MAX) database. Researchers analyzed Medicaid enrollment, disenrollment, and re-enrollment rates for people between the ages of 14 and 22 who had at least two outpatient or one inpatient claim associated with an autism or intellectual disability diagnosis. This dataset included 67,520 participants with autism (ASD-only), 120,804 participants with intellectual disabilities (ID-only), and 19,085 participants with both autism and intellectual disabilities (ASD+ID). Unlike their ID-only peers with, ASD-only adolescents and young adults were more likely to be enrolled in Medicaid under "poverty" or "other" categories rather than the "disability" category. From 2008 to 2012, 19.5% of ASD-only young adults disenrolled from Medicaid, compared to 16.0% of ID-only individuals and 8.5% of ASD+ID individuals. Among ASD-only young adult, most disenrollments occurred at age 19, with a second peak at age 21. Re-enrollment rates also differed between ASD-only young adults (34.6%), ID-only young adults (43.7%), and ASD+ID young adults (38.5%). For all three groups, re-enrollments peaked at age 18 and then declined with age.

Implications: These results demonstrate that autistic young adults without intellectual disabilities are at greater risk of losing Medicaid access compared to their peers with intellectual disabilities, with or without autism. Increased disenrollment at age 19 corresponds to when many states begin assessing eligibility (e.g., household income) as an adult rather than based on parental eligibility. Similarly, the second disenrollment peak at age 21 corresponds to when most states terminate the right to support through educational programs. Furthermore, the large number of autistic young adults enrolled in Medicaid under the "poverty" or "other" categories suggests that autism does not qualify as a disability under many state Medicaid programs, particularly in the absence of cognitive impairment. Ensuring that autistic young adults retain coverage may require changes to state Medicaid programs to expand accessibility for autistic people across the spectrum.

INFRASTRUCTURE AND PREVALENCE

At-a-Glance:

The number of autistic children identified early increased substantially between 2002 and 2016 in the United States, though racial and ethnic disparities remained; analyses suggest median age should not be used to measure progress.

Background: Many autistic children experience social and communication challenges, and early interventions may improve outcomes for these children. To ensure that all autistic children receive the supports they may need, researchers have sought to understand the reasons for delays and disparities in autism identification. Importantly, the statistical measures used in such research can lead to different interpretations of progress and disparities in early autism detection. This study compared different measures to assess progress in early autism identification over time and by geographic region, race/ethnicity, and presence of co-occurring intellectual disability.

Methods & Findings: Researchers analyzed data collected between 2002 and 2016 for 31,393 8-year-old autistic children in the Autism and Developmental Disabilities Monitoring (ADDM) Network. ADDM Network clinicians reviewed health and education records to determine if a child should be considered to have ASD for the purposes of determining prevalence. Children with a documented ASD diagnosis or special education eligibility were considered "identified" as having autism; "unidentified" autistic children included those whose health and/or education records met criteria for autism but did not have a formal autism diagnosis. Researchers compared median age at identification and cumulative incidence of identified ASD. The median age of autism identification is the age at which 50% of children received an ASD diagnosis or special education eligibility. The cumulative incidence of identified autism is calculated by dividing the number of children identified at or before a given age by the total population, including unidentified children. From 2002 to 2016, the cumulative incidence of children identified with ASD by age 48 months quadrupled. Although children of every race and ethnicity were more likely to be identified over time, Black and Hispanic autistic children without co-occurring intellectual disability were 30% less likely to be identified than were White autistic children without a co-occurring intellectual disability. By contrast, in 2016, Black children with a co-occurring intellectual disability were 50% more likely to be identified with autism than White children with a co-occurring intellectual disability. Both the progress in early identification as well as these striking disparities were masked by the most commonly used measure of early identification, median age of autism identification.

Implications: Significant progress has been made in identifying autism in early childhood, but disparities in early identification by race/ethnicity and co-occurring intellectual disability remain. In particular, race/ethnicity appears to affect the likelihood that children without co-occurring intellectual disability will receive timely diagnoses. Thus, additional research examining these disparities is needed to equitably improve early identification of autism. These findings were not seen using median age of identification, suggesting median age is not useful for measuring public health priorities of progress and disparities in early identification of ASD.

ARTICLES SELECTED FOR THE 2022 SUMMARY OF ADVANCES

SCREENING AND DIAGNOSIS

Barbaresi W, Cacia J, Friedman S, Fussell J, Hansen R, Hofer J, Roizen N, Stein REK, Vanderbilt D, Sideridis G. **Clinician Diagnostic Certainty and the Role of the Autism Diagnostic Observation Schedule in Autism Spectrum Disorder Diagnosis in Young Children.** *JAMA Pediatr.* 2022 Dec 1;176(12):1233-1241. [*PMID: 36251287*]

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FULL LISTING OF NOMINATED ARTICLES
(SELECTED ARTICLES APPEAR *RED)

SCREENING AND DIAGNOSIS

*Barbaresi W, Cacia J, Friedman S, Fussell J, Hansen R, Hofer J, Roizen N, Stein REK, Vanderbilt D, Sideridis G. **Clinician Diagnostic Certainty and the Role of the Autism Diagnostic Observation Schedule in Autism Spectrum Disorder Diagnosis in Young Children.** *JAMA Pediatr.* 2022 Dec 1;176(12):1233-1241. [*PMID: 36251287*]

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