

# Autism Assessment: What is it and How do I get one?

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# Assessment of Autism Spectrum Disorder

## Objectives

- When to initiate an Autism assessment
- How to initiate and what to expect
- Potential barriers to access
- Impact of cultural/ethnic/socio-economic factors on access
- The importance of research, and barriers to research participation faced by ethnic and cultural minorities





# Prevalence

- ASD is currently estimated to affect 1 in 44 (23/1,000) 8-year-old children in the United States (Centers for Disease Control ADDM data 2018)
- Boys 4 times as likely to be identified with ASD as girls
- Children identified with ASD with available IQ scores, about one-third (35.2%) also had intellectual disability





# Diagnosis and Outcome

- Early diagnosis of ASD often is catalyst for obtaining appropriate intervention and educational services.
- Research shows that early intervention can help children gain developmental skills, so they can reach their potential.
- Early intervention prior to school entry has been found to improve receptive and expressive language, cognitive functioning, and adaptive skills (Reichow et al. 2018)



A black and white photograph showing several hands of different skin tones stacked on top of each other, symbolizing support and unity.

# Diagnosis and Outcome

- Up to 50% of children acquire near normal functioning using the Intensive Behavioral Intervention model; working better with children with language disorders (Couper 2004)
- Early intervention often improves functioning and decreases maladaptive behaviors and symptom severity (Stoelb et al. 2004)



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# Diagnosis and Outcome

- Early detection can ensure appropriate family education, and the provision of services to assist with coping (Bennett, Deluca, & Allen 1996)
- Receiving a diagnosis later in life is often associated with greater emotional and behavioral problems (Liptak Stuart & Auinger 2006)





# What To Do When I Have Concerns?

- Raise your concerns with the child's pediatrician.
- Many pediatricians screen their patients for autism when they are 18-months and 24-months old.
- Based upon a screening, or a parent's concerns, the pediatrician often will refer the child to a specialist for evaluation.
- Specialists who make autism diagnoses include a child psychologist, psychiatrist, or neurologist, a pediatrician who specializes in development and behavior, or a clinic that specializes in autism and developmental conditions.



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# Early Developmental Concerns

- Ignores parents when name is called.
- Speech delays or unusual ways of communicating.
- Plays alone without trying to involve others in play.
- Does not respond or responds too strongly to sound, touch, texture, taste, lights, or other sensory input.
- Becomes very upset by small changes in routine, such as taking a new route to day care.
- Has repetitive movements or behavior, such as rocking, flapping of hands, or spinning.





# Understanding “Typical” Development

- Visit the "[Learn the Signs, Act Early](https://www.cdc.gov/ncbddd/actearly/milestones/index.html)" website and download the [milestone tracker app](https://www.cdc.gov/ncbddd/actearly/milestones/index.html), a program sponsored by the Centers for Disease Control and Prevention (CDC)  
<https://www.cdc.gov/ncbddd/actearly/milestones/index.html>
- SPARKforAutism.org



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# Barriers and Coping Strategies

- Depending on where they live, their insurance, or other factors cause too many families have to wait weeks, months, or even a year or more for an autism evaluation.
- While waiting for an autism evaluation contact your local early intervention program as soon as possible. There, you can receive a free evaluation of your child's development.
- Most importantly, they can provide therapies for the child if they find delays. early intervention can help children gain developmental skills, so they can reach their potential.



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# Barriers and How to Cope

- If your child is under age 3:

<https://www.cdc.gov/ncbddd/actearly/parents/states.html>

1 (an early intervention program list) to find the office for your state or U.S. territory. Children may receive speech therapy, occupational therapy for hand and feeding skills, physical therapy for problems with walking or running, and play groups to help with social skills. Therapies are available at little or no cost, depending on where you live.





# Barriers and How to Cope

- If your child is 3 to 5 years old, contact your local Child Find office and/or as the CDC suggests: "Call any local public elementary school (even if your child does not go to school there) and say: 'I have concerns about my child's development and I would like to have my child evaluated through the school system for preschool special education services.'"
- For students in kindergarten to 12<sup>th</sup> grade, parents may contact their child's school to request an evaluation.



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# Barriers and Coping Strategies

- Unlike clinics and doctors, early intervention and school officials *must* conduct evaluations and provide services within certain timelines as mandated by U.S. Special Education law.





# Understanding the Process

- School systems can “diagnose” autism, in the context of an educational disability, but they often use the "developmental delay" designation until the child is in elementary school, unless a physician or psychologist has already diagnosed the child's autism.
- While early intervention and school evaluations often will not yield an autism diagnosis, what is most important is that the child is having a problem and they need services to address the problem. We can label it later.





# Diagnosing Autism

- While it is now widely believed that autism can reliably be diagnosed by age two (Lord et al. 2006), up to half of children do not receive their first ASD diagnosis until after age six (Sheldrick et al. 2017)
- Black children typically diagnosed with ASD on average 1 ½ years later than White children, and require 3 times the number of visits as White children before receiving an ASD diagnosis (Mandell et al. 2002, 2009)
- White children are systematically diagnosed 1–2 years earlier than non-white children (Fountain et al., 2012; Valicenti-McDermott, et al. 2012)





# Diagnostic Disparities

- On average African American children were almost 5½ years old at the time of diagnosis, despite the fact parents first expressed concerns about their kids' development more than three years earlier (Constantino, J.N., et al 2020)
- Black children, on average, receive their first diagnosis of ASD later than White children (Baio et al. 2018; Shaw et al. 2020)





# Diagnostic Disparities

- Subjects with co-occurring ID tended to be diagnosed earlier than those without ID (Constantino, J.N., et al 2020; Maenner et al. 2020)
- Black children are over-represented among youth with ASD and co-occurring ID and under-represented among youth with ASD without ID, who often are not diagnosed until middle childhood or adolescence (Constantino et al. 2020; Maenner et al. 2020)
- 22% of White children with autism also have intellectual disability. Among Black children, the rate of intellectual disability in those with autism tops 44% (CDC 2020)

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# Diagnostic Disparities

- Those who receive diagnoses later in life often have more subtle symptoms and higher cognitive functioning in early childhood, and therefore get missed by screening protocols that are often only in place until about age three (Mazurek et al. 2014; Ozonoff et al. 2018)



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# Diagnostic Disparity Variables

- Non-white parents more often report the doctor did not spend enough time with their child, did not listen to them carefully, and/or did not make them feel like a partner than non-Latino white parents (Parish et al. 2012)
- Some pediatricians attribute autistic features (e.g., communicative and social deficits) to language and culture rather than to ASD (Begeer et al. 2009)





# Diagnostic Disparity Variables

- Black parents report fewer concerns about social problems, repetitive behaviors and other autism features than White parents (Donohue M.R. et al. 2017)
- Parents in some groups may be less concerned or aware about autism, and may not seek out a diagnosis for their child (Newschaffer C.J. 2017)
- Non-white parents reported fewer ASD concerns before ASD diagnosis than White parents, which suggests different perceptions of similar behaviors based on cultural background (Donohue, et al. 2019)





# Diagnostic Disparity Variables

- Almost a third of 400 Black, African American, and multiracial families reported that their race and ethnicity affected their experience, with some reporting that professionals did not listen to their concerns, or that autism evaluations included activities and toys that were not relevant to their culture (Weitlauf A.S., et al. 2023)



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# Diagnostic Disparity Variables

- When minority children are eventually diagnosed with ASD they are more likely to have initially received a diagnosis other than autism (Mandell et al. 2007)
- Black children with ASD are more likely to be misdiagnosed with another mental health disorder (Pearson & Meadan 2018)
- Having an ID may decrease the likelihood of healthcare professionals assessing for ASD once an ID has been determined, again, delaying an appropriate diagnosis (Mandell et al. 2009)



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# Diagnostic Disparity Variables

- Higher socioeconomic status, and greater parental concern about initial symptoms are associated with earlier diagnoses (Daniels & Mandell 2014; Mandell et al. 2005)
- Children from higher income households are more likely to be diagnosed with ASD than children from lower SES homes (Durkin et al. 2010; Fountain et al. 2010)
- Children whose parents are highly educated are usually diagnosed at a younger age (Fountain et al. 2010)





# Diagnostic Disparity Variables

- Black children were less likely to receive a first-time diagnosis of ASD later in childhood (i.e., older than age six) compared to White children (Habayeb et al. 2021)
- Receiving a diagnosis of ASD later in childhood was related to higher levels of parent-reported autism symptom intensity; particularly for Black children compared to White children (Habayeb et al. 2021)
- For White children, higher levels of emotional problems was related to receiving a diagnosis of ASD later in childhood; opposite finding in Black children (Habayeb et al. 2021)





# Diagnostic Disparity Variables

- Higher cognitive abilities related to a later age of diagnosis in White children while lower cognitive abilities related to a later age of diagnosis in Black children (Habayeb et al. 2021)
- Some studies found that children in older birth cohorts were diagnosed later than children in more recent cohorts, suggesting that the age of ASD diagnosis is decreasing with time (Daniels & Mandell, 2014)
- The distribution of diagnoses by race widened after age 6 (Habayeb et al. 2021)





# Health Disparities and Access to Services

- Significant disparities in the referral rate and clinical diagnosis of autism among racial/ethnic groups (Begeer, et al., 2009; Mandell et al., 2009)
- Racial and ethnic minorities receive lower quality services than nonminority groups and these disparities are related to historical inequalities such as discrimination and contemporary inequalities (e.g., lack of insurance, fewer services offered by Medicaid providers) (Smedley, Stith, & Nelson, 2003)





# Health Disparities and Access to Services

- Overall, fewer children in low SES status communities receive appropriate diagnoses of ASD, and Black children are over-represented in low SES communities (Maenner et al. 2020)
- Even within low SES communities, racial minority children are still less likely to have an ASD diagnosis (Durkin et al. 2017)
- Prevalence of ASD in Medicare higher for Asian and White (1%) than Black beneficiaries (0.6%) (CMS 2016)
- SES a stronger predictor of receipt of state services than symptom severity (Fountain, King, & Bearman, 2011)





# Health Disparities and Access to Services

- Autism prevalence rose almost evenly among high-, middle- and low-socioeconomic groups between 2002 and 2010 (Durkin M.S. et al. 2017)
- White children are about 19 percent more likely than Black children and 65 percent more likely than Latino children to be diagnosed with autism (Durkin M.S. et al. 2017)
- The rate of autism among Black children in the high SES group was higher than that among White or Latino children between 2002 and 2010 (Durkin M.S. et al. 2017)





# The Autism Assessment

- The appointment will likely look different depending on who is conducting the evaluation – a physician, psychologist, or an autism clinic, with these appointments taking part or most of one day, or across several days.
- At Kennedy Krieger's autism clinic, we have specialists (e.g., psychologists, physicians, speech and language pathologists), and often do team evaluations that can take from part of, to an entire day, to several days depending on the makeup of the team involved.





# The Autism Assessment

- A health care provider usually will use an autism diagnostic tool that involves observing and interacting with the child (e.g., ADOS).
- A parent or caregiver also may be asked questions about the child's developmental and health history, behavior, emotional, and adaptive functioning (e.g., ADI).
- A psychologist also may use tests to measure a child's cognitive and learning abilities, memory, and attention.





# Test Performance Differences

## ADOS

- Minority children (relative to majority) have a different symptom profile (i.e., lower scores in language, communication & cognitive composite scores (Chaidez et al. 2012; Landa & Garrett-Mayer 2006; Tek & Landa 2012))
- White children (compared to Black) more likely to have certain ASD symptoms (e.g., inflexible adherence to nonfunctional routines/rituals, persistent preoccupation with parts of objects (Sell et al. 2012))



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# Test Performance Differences

- Holding ADOS subdomain (Social Communication; Repetitive and Stereotyped Behaviors) scores constant, Black children were more likely to have higher (i.e., more atypical) ratings on the ADOS items assessing levels of *Unusual Eye Contact*, *Stereotyped or Idiosyncratic Word Use*, and *Immediate Echolalia*, and Latino children were more likely to have higher ratings on the item assessing levels of *Usual Eye Contact* (Harrison et al. 2017)





# Research

- The design and interpretation of ASD evaluation instruments is largely based on data collected from White/dominant culture participants.
- We need more focused recruitments efforts directed toward nonwhite/underserved communities.





# Research

- Recruitment efforts should include addressing issues related to barriers to research participation including trust and ease of access.
- These efforts can be enhanced by including more non white researchers in the process, creating collaborative partnerships with and providing more resources directly to underserved communities.





# Autism Assessment

Thank You!



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