

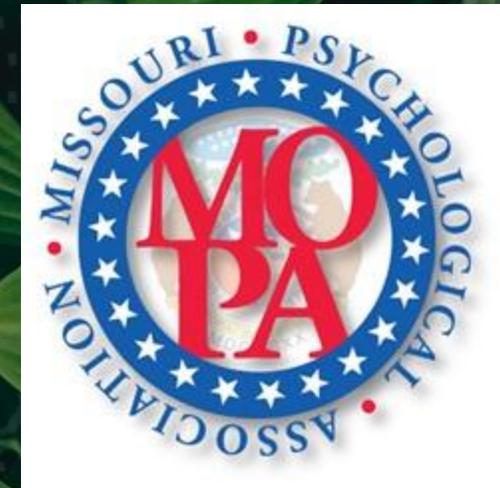
# Diagnosing Autism Spectrum Disorders in Adults: Avoiding iatrogenesis Through Valid Diagnosis

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# Outline

- Basics of autism spectrum disorder
- Core autism symptoms
- Autism across the lifespan
- "Autism" symptoms in the general adult population
- Psychological motivations for autism diagnosis-seeking
- How to address autism diagnosis-seeking with adult therapy clients

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# What is Autism?

- Autism Spectrum Disorder (ASD) is one of a broad group of neurodevelopmental disorders that involve a disruption to brain development.
- Between 2009-2017, prevalence of any DD among children ages 3-17 years was 16.93%:
  - ADHD (9.04%)
  - LD (7.74%)
  - ASD (1.74%)
  - ID (1.10%)

Zablotsky, et al., 2019

# CDC Statistics

## Prevalence

- About 1 in 44 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups.
- ASD is more than 4 times more common among boys than among girls

# Causes/Risks for ASD - Combination of genetic & environmental factors

## Autism's genetic risk factors

Research tells us that autism tends to run in families. Changes in certain genes increase the risk that a child will develop autism. If a parent carries one or more of these gene changes, they may get passed to a child (even if the parent does not have autism). Other times, these genetic changes arise spontaneously in an early embryo or the sperm and/or egg that combine to create the embryo. Again, the majority of these gene changes do not cause autism by themselves. They simply increase risk for the disorder

## Autism's environmental risk factors

Research also shows that certain environmental influences may further increase – or reduce – autism risk in people who are genetically predisposed to the disorder. Importantly, the increase or decrease in risk appears to be small for any one of these risk factors:

### Increased risk

- [Advanced parent age](#) (either parent)
- Pregnancy and birth complications (e.g. extreme prematurity [before 26 weeks], low birth weight, multiple pregnancies [twin, triplet, etc.] )
- Pregnancies spaced [less than one year](#) apart

# Issues that may accompany ASD

- Seizures
- Genetic disorders (e.g., Fragile X)
- GI issues
- Sleep problems
- Other emotional/behavioral disorders
  - 20% have ADHD
  - 30% have anxiety disorder

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# Core Symptoms of ASD

## Impairments in social interaction & communication

- Social-emotional reciprocity (back & forth conversation, sharing, initiation and response to interactions)
- Nonverbal communication (eye contact, gestures)
- Relationships (interest in peers, making friends)

## Restricted, repetitive behaviors and interests

- Repetitive motor movements or speech (lining things up, echolalia, rocking)
- Insistence on sameness, inflexibility
- Restricted, fixated interests
- Hyper/Hypo-reactivity to sensory input and sensory seeking

# Important criteria that don't get as much attention but are vital!

- Symptoms must be present in the early developmental period
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of functioning
- Disturbances are not better explained by another condition (e.g., intellectual disability, social anxiety, ADHD)

# Diagnostic Challenges

- ASD is a behavioral diagnosis
- “When you have met one person with ASD, you have met one person with ASD”
- Developmental delays (speech/language), other disorders (ADHD), and ASD can have overlapping symptoms
- Skill expectations & symptoms change over development (repetitive play to hyperfocused interests)

# How do we assess for ASD?

- Record review
- Parent interview
  - History, current symptoms, impairment
- Parent/Teacher/Self-Report questionnaires
  - Rating scales (SRS-2, SCQ)
- Testing of skills
- Direct observation
  - Informal, ADOS

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# Early Signs of ASD

- Signs and symptoms of autism can be seen from an early age (typically by age 3):
  - Limited eye contact
  - Lack of social smiles and copying facial expressions
  - No response to name or attempts from others to get attention
  - No showing objects
  - Lack of shared enjoyment
  - No lifting arms to be picked up

Video Example: [Center for Autism and Related Disorders | Kennedy Krieger Institute](#)

# School Age Children with ASD

- Approximately 11% of special education students in the United States receive education under the eligibility of Autism [National Center for Education Statistics]
- While there is no specific cognitive phenotype for ASD, individuals often experience executive dysfunction
- According to the Autism and Developmental Disabilities Monitoring (ADDM) Network, about one-third of children with ASD also had intellectual disability

# High School Students on the Autism Spectrum

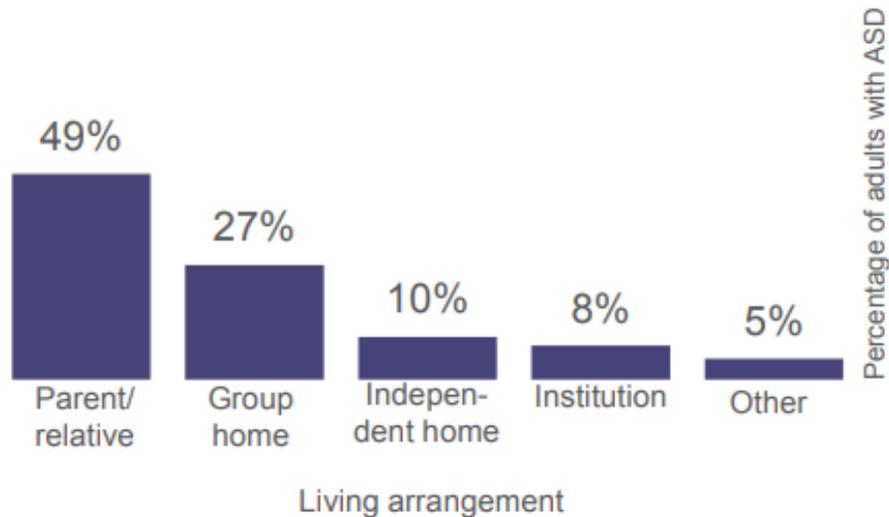
<b>Youth from households with low income</b>	<b>Struggling financially</b> <b>40-46%</b> lived in households with income below 185% of the federal poverty level	<b>Received public benefits</b> <b>1 in 4</b> lived in a home that received at least one form of public assistance 
<b>Minority youth</b>	<b>Highest rate of unmet needs</b> <b>27%</b> of black or African American teens had unmet healthcare needs	<b>Language minority</b> <b>14%</b> lived in a home where a language other than English was regularly used
<b>Special education</b>	<b>Most common therapy</b> <b>47%</b> received speech therapy from special education	<b>Youth participation in transition planning</b> <b>1 in 4</b> did not participate at all 
<b>Mental health</b>	<b>Co-occurring conditions</b> <b>76%</b> were diagnosed with at least one of the following: ADHD, anxiety or depression	<b>Used psychiatric medications</b> <b>55%</b> took medication because of difficulties with emotions, concentration, or behavior
<b>Health care services</b>	<b>Went without health care</b> <b>16%</b> did not receive needed health care	<b>Talked about transition</b> <b>18%</b> of pediatricians talked with families about finding a doctor who treats adults

Shattuck, Paul T., Rast, Jessica E., Roux, Anne M., Anderson, Kristy A., Benevides, Teal, Garfield, Tamara, McGhee Hassrick, Elizabeth, and Kuo, Alice. National Autism Indicators Report: High School Students on the Autism Spectrum. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2018.

# Adults with ASD

Roux, Anne M., Rast, Jessica E., Anderson, Kristy A., and Shattuck, Paul T. National Autism Indicators Report: Developmental Disability Services and Outcomes in Adulthood. Philadelphia, PA: Life Course Outcomes Program, A.J. Drexel Autism Institute, Drexel University, 2017.

## Adults with ASD were most likely to be living with family members.



Source: NCI Adult Consumer Survey 2014-15

## Our key findings

- **Paid, community-based employment was the least common outcome for adults with autism spectrum disorder (ASD). Only 14% held a job for pay in the community.** About one-fourth of adults with ASD had community employment as a goal in their service plan.
- Over half (54%) participated in an unpaid activity in a facility (where most other workers had disabilities).
- One-fourth (27%) had no work or activities, in either community-based or facility-based settings, in the two weeks prior to the survey.

**Over half (54%) of adults with ASD had at least one mental health condition (including anxiety, mood disorder, psychotic disorder, and/or other mental illness) in addition to ASD.**

**Over half (53%) of adults in the ACS with ASD had a limited or full legal (court-appointed) guardian.**

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# "Autism" symptoms in the general adult population



- Poor eye contact
- Social awkwardness
- Difficulty making/keeping friends
- Difficulty in romantic relationships
- Difficulty with subtext
- Difficulty understanding emotions of self or others
- Sensitivities to textures or sounds
- "Nobody understands me"
- "I've always been/felt different"

# "Autism" symptoms in the general adult population

## Base rate

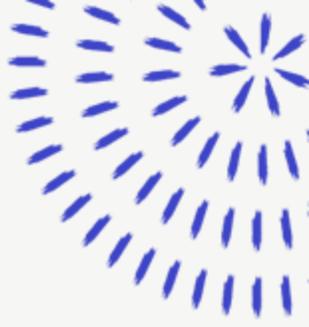
- The percentage of a population of interest that has a certain characteristic

## Autism in the general US population (CDC, 2018)

- 2.3% of 8-year-olds
- 3.7% of 8-year-old boys
- 0.9% of 8-year-old girls

# "Autism" symptoms in the general adult population

- Ubiquitous in typically developed adults
  - Poor eye contact
  - Social awkwardness
  - Difficulty making/keeping friends
  - Difficulty in romantic relationships
  - Difficulty with subtext
  - Difficulty understanding emotions of self or others
  - Sensitivities
  - "Nobody understands me"
  - "I've always been/felt different"



# "Autism" symptoms in the general adult population

- Causes of poor eye contact
  - Social anxiety
  - Submissive posturing
  - Autism
  - Low confidence
  - Low self-esteem
  - Boredom
  - Distraction
  - Cultural norms



# "Autism" symptoms in the general population - "I've always been/felt different"



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# Psychological motivations for autism diagnosis-seeking

Redefining life experiences following trauma

Explanation for behavioral health treatment non-response

Relief of personal responsibility for change

Avoidance of punishment or culpability

Access to benefits, accommodations, or compensation

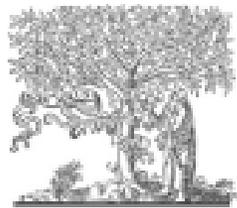
Permission to be different

Social contagion and recent impact of social media

# Social contagion and social media

- Board-certified pediatric neurologists specializing in movement disorders find that the majority of a sample of Tik Tok videos ostensibly depicting tics in Tourette's syndrome are poorly consistent with genuine Tourette's tics

Pediatric Neurology 130 (2022) 14–20



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Research Paper

## The Phenomenology of Tics and Tic-Like Behavior in TikTok

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# Social contagion and social media

- 5.9 billion views on Tik Tok for #autismawareness (2022)
- Benefits of social media
  - Validation and community - "I'm not alone"
  - De-stigmatization of mental health discussion and help-seeking
- Risks
  - No vetting of material for accuracy
  - Can exacerbate symptoms - exposure to displays of exaggerated symptoms result in more symptom endorsement (Nesi, 2020)
  - Implies enough information for self-diagnosis
  - Fosters suspicion of qualified healthcare providers - "I've been misdiagnosed for years!"

# Access to benefits, accommodations, or compensation



## Students With Disabilities Call College Admissions Cheating 'Big Slap In The Face'



## *The College Admissions Scandal: Where Some of the Defendants Are Now*

Dozens of parents and others have pleaded guilty. Here's what happened to a few of them.



## **The most reprehensible part of the admissions scandal: faking disability accommodations**

Why faking disability accommodations is so damaging to disabled students.

By Aditi Juneja | Mar 14, 2019, 3:40pm EDT



EDUCATION

## Why The College Admissions Scandal Hurts Students With Disabilities

March 14, 2019 - 8:02 AM ET  
Heard on All Things Considered

CLARE LOMBARDO

**3-Minute Listen** + PLAYLIST

# Societal Perception of Disability

- "SLD and ADHD are real disorders and can impair life functioning significantly. Accommodations can help students with the essential skills needed for an academic program or work succeed even with the challenges of SLD, ADHD, or mental health disorders. However, we should stop recommending accommodations and medication for students who have relative weaknesses and are not truly disabled. Helping students without disabilities gain a competitive advantage is unfair to disabled students, especially those who have not had the resources that more privileged students have had."

Psychological Injury and Law

<https://doi.org/10.1007/s12207-022-09459-9>



## Have We Loosened the Definition of Disability? The Effects of Changes in the Law and Its Interpretation on Clinical Practice

Robert L. Mapou<sup>1,2</sup>

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### Abstract

Evolving changes in the law and documentation guidelines since the 1990 Americans with Disabilities Act have led to a loosening of the definition of disability, in which relative weaknesses are now interpreted as evidence of a disability. In this paper, after acknowledging my own shortcomings, I trace the evolution of the law and documentation guidelines from the late 1990s to the present. I discuss how this has led to increased pressure from parents and students on evaluating clinicians to diagnose a disorder and confirm that the student has a disability that requires academic accommodations. Rather than recommending effective interventions and compensatory strategies, many stakeholders (parents, students, psychologists, disability support professionals) now seem to preferentially favor provision of accommodations. I conclude by describing how these changes have affected my own practice and make recommendations for best practices for disability documentation.

**Keywords** Documentation guidelines · Disability law · Disability definition · Disability evaluation · Neuropsychological evaluation

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# How to address autism diagnosis- seeking with functional and independent adult therapy clients

- Iatrogenesis – harm brought on by a healer as a result of a treatment; not considered a natural course of illness

# How is an ASD diagnosis harmful in adults without evidence of ASD?

- Iatrogenesis
  - Entrenches pathological beliefs and behavior
  - Encourages accommodating behaviors in loved ones and society
  - Promotes an external locus of control
  - Exacerbates symptoms (Nesi, 2020)
- Other harm
  - Diverts resources away from the autism community
  - Delays treatment of psychopathology
  - Unnecessary medical and behavioral health costs are incurred

# Questions to consider when the issue is raised by your patients

- Why is this diagnosis important now?
- What will be different about your life with this diagnosis?
- If you are evaluated and it is found you don't have autism, what would that mean?





# Responses to resistance

- "But I was able to learn how to successfully use masking to slip by undetected"
- "But autism presents differently in females than it does in males"
- "But that Tik Tok video describes me PERFECTLY"
- "But I had so many problems making friends, I've never fit in, and I was really into dinosaurs as a kid"
- "But my parents were too busy/abusive/stubborn/chaotic/etc. to have me tested when I was younger when it would have been caught"
- "But my RAADS score is off the charts!!"

# "But I was able to learn how to successfully use masking to slip by undetected"

- Masking or "camouflaging" - consciously or unconsciously behaving in a way that minimizes the appearance of an autism trait in a social setting (Hull et al. 2017)
- Hard to study; much research relies on subjective anecdotal accounts
- Camouflaging might result in a missed **autism** diagnosis, but is unlikely to result in complete lack of need for support

# Challenges to Mental Health Providers

- IMMENSE pressure from students, parents, workers, lawyers, etc. on mental health providers to provide a diagnosis
- Mental health providers are natural helpers and advocates for their clients
- Lack of funding and training for objective assessment of ASD may lead to providers testing limits of competence

# Dos and Don'ts to avoid iatrogenesis



- DO only encourage autism assessment conducted by a qualified behavioral healthcare provider - typically this is a clinical psychologist
    - Not from client symptom report alone
    - Not from therapy discussions
    - Not from online symptom questionnaires
    - Not from social media
  - DO explore why an autism diagnosis is important to the client
  - DO validate distress while gently challenging their attribution of distress (for adults without developmental evidence of functional impairment)
    - Teach about base rates
    - Normalize high base rate, nonspecific symptoms (like poor eye contact) without minimizing their lived experience
- 

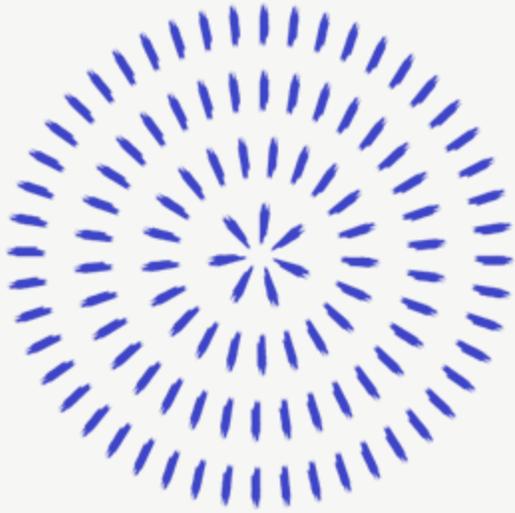
# Dos and Don'ts to avoid iatrogenesis

- DON'T refer a client for an assessment "just to confirm" a diagnosis, or if they are just "curious"
- DO prepare clients for possibility of a negative result (i.e., no evidence of ASD)
- DON'T encourage or reference media or social media portrayals of ASD in therapy
- DON'T rely on online symptom checklists (e.g., RAADS) as diagnostic tools – most just ask about same nonspecific symptoms, high base rate symptoms clients are already endorsing

# When to refer for formal autism assessment

- When there is developmental evidence of significant functional impairment
- When client is genuinely open to the results of an autism assessment
- When the client intends to act on results of the assessment





# Questions? Ideas?

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