Overdiagnosis or Underdiagnosis? Considerations for Diagnosing ADHD and Autism

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Dr. Ulbricht completed her undergraduate studies at the University of Virginia and earned her Ph.D. in Clinical and Community Psychology at George Washington University. She completed a two-year postdoctoral fellowship at Kennedy Krieger Institute/Johns Hopkins, where she received further training in Autism and diagnostic assessment of neurodevelopmental disabilities.

Dr. Ulbricht spent ten years as the Service Chief for the outpatient Child and Adolescent Psychiatry Service at Fort Belvoir Community Hospital. At Fort Belvoir, she continued her work in psychodiagnostic assessment and child/family therapy while leading a multidisciplinary team.

Dr. Ulbricht joined DHA's Behavioral Health Clinical Management Team at Defense Health Headquarters in July 2023, stepping in as the Program Lead for Child and Family Behavioral Health. She is currently working with other leaders to integrate Child and Family Behavioral Health programs across Navy, Army, and Air Force into an effective, cohesive, standardized DHA program.

Disclosures

- Dr. Jennifer Ulbricht has no relevant financial or non-financial relationships to disclose relating to the content of this activity
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Learning Objectives

At the conclusion of this activity, participants will be able to:

1. Distinguish three contributing factors for overdiagnosis and underdiagnosis of attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD).
2. Describe possible consequences of overdiagnosis and underdiagnosis.
3. Identify best practices to avoid over and underdiagnosis.

Developmental Disabilities and ADHD/ASD

- The Centers for Disease Control and Prevention (CDC) defines Developmental Disabilities as: **“a group of conditions due to an impairment in physical, learning, language, or behavior areas”**
- Another definition (Handbook of Developmental Disabilities): **“a set of abilities and characteristics that vary from the norm in the limitations they impose on independent participation and acceptance in society”**

- The CDC reports 17% of children ages three through 17 have a Developmental Disability/Delay (DD)
- 6.7% of children have two or more
- Kids with DDs are likely to benefit from interventions across fields (medical, education, physical therapy, occupational, speech, mental health)
- The entry-point for support is often diagnosis and referral

Over-diagnosed or Under-diagnosed?

- ADHD and Autism Spectrum Disorder are two of the most common Developmental Disabilities

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- Both have increased in prevalence, leading to questions regarding possible overdiagnosis
- Both have shown gender, racial, cultural, and socioeconomic differences in prevalence, leading to questions regarding possible underdiagnosis

Increasing Prevalence

ADHD Prevalence History (Gascon, 2022)

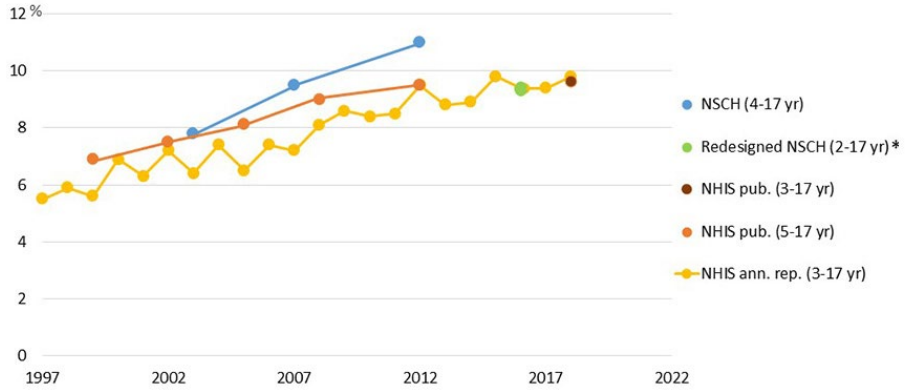
- North America has shown an increasing number of individuals diagnosed with ADHD over the past 25 years with numbers rising from 6.1% to 10.2% between 1997 and 2016. Studies have revealed prevalence of ADHD in school aged children as high as 15.5% in a US study and 23% of students in a Canadian study. Global prevalence from meta-analysis is about 7.2%.

ADHD Prevalence Snapshot

(https://www.cdc.gov/ncbddd/adhd/timeline.html)

- Diagnosis increases across age span- most kids diagnosed 6-11
  - 2% of children ages 3-5
  - 10% of children ages 6-11
  - 13% of children ages 12-17
- ADHD is more common in boys (13%) than girls (6%)
- Six in ten children with ADHD had at least one other mental, emotional, or behavioral disorder diagnosis

- ADHD diagnosis throughout the years: Estimates from published nationally representative survey data (parent-reported ADHD diagnosis)



Autism Prevalence History in US

(https://www.cdc.gov/ncbddd/autism/data.html)

- 2002, 6.6 per 1000, 1 in 150
- 2004, 8.0 per 1000, 1 in 125
- 2006, 9.0 per 1000, 1 in 110
- 2008, 11.3 per 1000, 1 in 88
- 2010, 14.7 per 1000, 1 in 68
- 2012, 14.5 per 1000, 1 in 69
- 2014, 16.8 per 1000, 1 in 59
- 2016, 18.5 per 1000, 1 in 54
- 2018, 23.0 per 1000, 1 in 44

- 2020, 27.6 per 1000, 1 in 36
- Eight-year-old children identified as having Autism
- Percentage varied across geographic areas (from 2.3% in MD to 4.5% in CA)
- Boys nearly four times as likely to be diagnosed as girls
- Children with Intellectual Disability (about 30%) diagnosed about a year earlier than those without

Factors Contributing to Increased Prevalence

- Increased awareness
- Diagnostic criteria update – DSM 5 published in 2013
- Increased universal screening
- Some decreased stigma (anecdotal – Poll)
- Tying of services and supports to diagnosis

Poll Questions

- Experience: Have you had parents or patient seeking specific diagnoses that may have been seen more negatively a few years ago?
  - Yes
  - No
- Opinion: Where are patients (children/adolescents/parents) getting their diagnostic information?
  - TikTok
  - WebMD
  - Pharmaceutical Companies
  - Other

Increased Awareness

- In the 1950s, only mention of Autism in DSM was in relation to symptoms of children with schizophrenia; Autism added for the first time in 1994 (30 years ago) as a spectrum disorder
- In the 1960s, ADHD symptoms were “hyperkinetic reaction of childhood” and “minimal brain dysfunction”; Formally recognized as attention deficit disorder in 1980s
- Study found increase in Google searches for “ADHD”, “ADHD treatment”, “ADHD medication”, and “ADHD therapy” from 2004-2020, with medication searches having a more-substantial increase (Zhao, 2021). Also saw decreases in searches during holiday breaks, increases directly post-break, increases during ADHD Awareness Month (October), and some increases with celebrity events and pharmaceutical campaigns

Differences in ADHD Criteria for DSM-5 (2013)

- Changed category from “first diagnosed in childhood” to Neurodevelopmental Disorders (reflecting improved recognition of brain developmental correlates)
- Symptom threshold changed for adults
- Cross-situational requirement strengthened to “several” symptoms in each setting
- Subtypes changed to specifiers
- Onset criterion changed from “symptoms that caused impairment present before age seven years” to “several inattentive or hyperactive-impulsive symptoms were present prior to age 12”
- “Impairment” changed to “symptoms interfere with or reduce quality of social, academic, or occupational function”
- Comorbid diagnosis with ASD now allowed (previously was excluded)

Differences for Autism Diagnosis in DSM5 (2013)

- Collapses four previously separate disorders (Autistic Disorder, Asperger Syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified) into Autism Spectrum Disorder
- Includes “new” diagnosis: Social (pragmatic) communication disorder which does not have restricted, repetitive behaviors (RRB)
- DSM IV TR (2000) had three symptoms categories (Qualitative impairment in social Interaction (2), Qualitative impairment in communication (1), Restricted interests and repetitive behaviors (1)) requiring six symptoms total

DSM 5 Symptom Categories

- DSM 5 has two symptom categories and allows for specifying severity in each category separately (rather than globally)
  - **Persistent deficits in social communication and social interaction** current or by history; Need deficits in each of three areas (social emotional reciprocity; nonverbal communicative behavior; developing, maintaining, and understanding relationships)
  - **Restrictive, repetitive patterns of behavior, interests, or activities; need at least two types** (stereotyped or repetitive motor movements including echolalia/idiosyncratic phrases; insistence on sameness, inflexibility, adherence to routine or ritualized patterns of verbal or nonverbal behavior; highly restricted, fixated interests abnormal in intensity or focus; hyper or hyporeactivity to sensory input or interest in unusual sensory aspects of the environment)

Over-Pathologizing Typical Behaviors

- Morrow et al., (2012) In British Columbia the cutoff to start school is December 31 – kids born in December are the youngest in the grade and those born in January are the oldest
- Researchers calculated the relative risk and absolute risk of receiving diagnosis of ADHD and of receiving prescription for medication to treat ADHD for one million children
- Boys born in December were 30% more likely to receive a diagnosis of ADHD and 41% more likely to be prescribed medication than boys born in January.
- Girls born in December were 70% more likely to be diagnosed with ADHD and 77% more likely to be prescribed medication.
- Even kids born within three days of the cutoff showed the increase in relative risk. Study replicated in American groups.

A Relative Age Effect (Morrow et al., 2012)

- This is relative age effect – researchers interpreted as overdiagnosis and overtreatment due to relative immaturity of the youngest children in the cohort - the medicalization of normative behaviors.
- They report that teachers' opinions of children are the key mechanisms driving the relationship between school starting age and ADHD diagnosis

- Other explanations:
  - underdiagnosis of older children in the cohort
  - social pressures on younger children that amplify the symptoms

Increased Prevalence due to Overdiagnosis?

- Kazda et al., (2021) conceptualized three drivers of overdiagnosis:
  - Broader diagnostic category catches more “gray area” with phrases like “now or in the past” (over-definition); intervention with milder cases has not been studied enough to know if it is effective
  - Over-detection through screening younger children
  - Medicalization of behavior patterns that may be typical – what is the “norm” for behavior in a prekindergarten class? Is normative behavior now medicalized because of increased performance requirements? Are we medicalizing social/economic disadvantage? (Gascon, 2022)

Additional Considerations for Overdiagnosis

- Pressure from parents and schools related to increased environmental stressors and expectations (**anecdotal - poll**)
- Self-diagnosis
- Resources linked to diagnosis
- More diagnoses dependent on Primary Care where shorter appointment times may limit ability for detailed evaluation; Fewer specialty care evaluations/consultations available and/or covered by insurance

Poll Question

- Experience: Have you seen (in personal or professional life) increases in demands/expectations for kids/families?
  - Yes
  - No
- Opinion: Do you see it coming more from society or parents?
  - Society
  - Parents

Sociocultural Differences in Diagnosis

Contributing Factors to Underdiagnosis

- Unconscious bias
- Awareness/stigma
- Availability of resources including specialized diagnosing providers
- Differential presentation or developmental course
- Diagnostic criteria informed by studies without appropriate diversity

Sociocultural Differences in ADHD (Coker, 2016)

- Black/African-American and/or Latino children are less likely to have a parental report of ADHD diagnosis or taking ADHD medication in the last year compared to white children
- Disparity in medication use was present for those with either ADHD diagnosis or ADHD symptoms
- Disparity was absent between racial groups when no need for medication was present (diagnosis or ADHD symptoms), **suggesting difference is under-identification rather than overtreatment**
- Very few children without ADHD diagnosis or symptoms reported taking medication

Unconscious Bias in ADHD (Fadus, 2020)

- There is some evidence that ethnic and racial minority youth are more likely to be diagnosed with disruptive behavior disorders like Oppositional Defiant Disorder or Conduct Disorder rather than ADHD
- Oppositional Defiant Disorder or Conduct Disorder diagnosis *instead* (not concurrent) of ADHD diagnosis has significant implications for treatment – limits access to medication, accommodations at school, therapy, etc.
- Among several contributing factors (systemic/structural racism), unconscious biases of diagnosing providers may lead to less exploration of potential explanations of behavior

Bias in ASD Measures (Kalb, 2022)

- Examined item-level biases in Autism Diagnostic Observation Schedule (ADOS-2) for race and sex (N=6296); overall, they found few (11%) systematic biases among the items of the 16 with statistically significant differences, only two had moderate to large effect sizes (RRB items).
- Differential item functioning did demonstrate some interesting patterns regarding race: when present, differences were most frequently observed in the Social Affect domain and in the direction leading to underestimation of ASD severity for Black/African American children; these items had poorer discrimination as well, suggesting these items are not as effective at detecting ASD in these children
- However, only one item is included in the scoring algorithm; this suggests a small impact on the overall result of the ADOS-2

Gender Differences – Autism (Hus & Segal, 2021)

- Boys are nearly four times as likely to be diagnosed with ASD than girls
- More girls with ASD than boys have IQ <70
- This persistent difference was thought to relate to hormonal and neurobiological factors: fetal testosterone as a risk factor; different neural connectivity
- Acceptance of neurobiological explanation has led to acceptance of studies with many more boys than girls (often exclusively male)
- More recent studies have suggested differences in diagnostic distribution may reflect biases in perception, assessment and diagnosis

Gender-Relative Deficits (Wood-Downie, 2021)

- Meta-analysis indicated that autistic females demonstrated significantly better social interaction and communication skills than autistic males, which reflected the pattern found for nonautistic individuals
- Non-ASD girls>Non-ASD boys >/= (not significant) ASD girls > ASD boys for social interaction and communication
- With age, difference between Non-ASD and ASD becomes more pronounced for females (not males) supporting the idea that ASD social and communication symptoms “emerge” in adolescence for females
- These differences are most noted on narrowly defined symptoms, not broad assessments like Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised

Gender Differences in ADHD Diagnosis (Attoe, 2023)

- ADHD is diagnosed in boys at 3:1 ratio in childhood, but diagnosis in adulthood is close to 1:1
- Girls/women are more likely to be diagnosed in adolescence or adulthood
- Diagnostic criteria are gender biased (same research issue as ASD)
- Girls exhibit more emotional symptoms and more likely to be treated for anxiety/depression before finally identifying ADHD
- Girls more likely to have subtle externalizing symptoms (e.g., excessive talking/impulsivity) that still have impact on social-emotional well being
- Gender bias is not just in clinic setting, but also parents and teachers are less likely to refer for evaluation and treatment
- Late diagnosis (underdiagnosis) has been linked to underachievement and maladjustment in adulthood

Possible Consequences of Underdiagnosis of ADHD

- Arnold et al., (2020): Meta-analysis of 176 studies with long term (>2 years) outcome measures
  - Found both long-term achievement test scores and academic performance are adversely impacted in untreated ADHD
  - Found that both pharmacological and nonpharmacological treatment improved outcomes (with a stronger improvement in achievement test scores)
  - The strongest improvement in performance and scores was with multimodal intervention
- Attoe et al., (2023): Reviewed studies of women diagnosed in adulthood with ADHD and found:
  - Impacts on social/emotional well-being including low self-esteem, poor emotional control, maladaptive coping strategies
  - Difficult relationships including romantic and family
  - Lack of control (locus of control) and gaining control and self-acceptance with diagnosis

Possible Consequences of Underdiagnosing ASD

- Lupindo et al., (2021) surveyed men diagnosed with ASD in adulthood. Found missed opportunities and significant impact on life experiences overall due to lack of understanding of their difficulties and development of maladaptive coping strategies (avoidance, masking)
- French et al., (2023) completed a meta-analysis regarding risks of undiagnosed/late diagnosed ASD and ADHD and found increased risks for **substance abuse**, **accidents**, and **offending behavior**. They also found increased risk for **lower levels of income and education**, as well as impact on **mental wellbeing**

Possible Consequences of Overdiagnosis

- Stigma for individual and family (loneliness, isolation, difficulties with education and employment, bullying); though stigma can often be triggered by behavior, not just diagnostic label (Turnock, 2022)
- Limits to future careers (military)
- Unnecessary interventions and treatments – increased burden on taxed system
- Extensive and expensive evaluations and treatments – increased burden on taxed families

Benefits of Early Diagnosis

- ASD (Okoye, 2023)
  - Early intervention enhances development outcomes and improves adaptive skills
  - Enables families to access specialized support services and community resources
  - Greater understanding of individual and their needs
- ADHD
  - Eligibility for accommodations at school
  - Access to medication and behavioral interventions
  - Greater self-understanding and improved self-esteem (Attoe, 2023)

So what can we do about over- and underdiagnosis?

First, we need to acknowledge that ADHD and ASD are genuine clinical conditions that can cause significant impact on an individual's ability to function in society.

Second, ADHD and ASD are complex spectrums of diverse strengths and difficulties.

Challenges to Accurate Diagnosis

- ADHD and ASD are both frequently comorbid with other developmental disorders/delays
- ADHD and ASD have numerous “associated” symptom patterns that are not part of diagnostic criteria (e.g., sensory integration)
- Many neurodevelopmental disorders share executive dysfunction as a symptom (Gascon, 2022)
- ASD is particularly heterogeneous in symptomology, severity, and phenotypes (Hus, 2021)
- Both change in presentation and impact over development and presenting symptoms may be highly dependent on context
- No clear quantitative diagnostic tool (e.g., blood test)

Best Practices for Accurate Diagnosis

- Consider the factors addressed today: unconscious bias, relative age, difference in gender
- Consider variety of sources for symptoms (trauma, sleep)- is this a normal reaction to abnormal context?
- Universal screening for ASD
- Compare like-to-like, with gender and age/developmental level
- Recognize limitations of diagnostic tools
- Collect information from several sources including observation
- Multi-disciplinary evaluations or consultations (Extension for Community Healthcare Outcomes)
- Review school and/or “outside” evaluation
- Reflect on impact of parent/ patient and motivations (Poll 3)
- Balance of starting support as soon as possible while making as accurate a diagnosis as possible

Poll Question 3

- Opinion: Is it ok to delay a diagnosis due to parent reluctance?
  - Yes
  - No

Resources for Providers

- Center for Deployment Psychology's Department of Defense Child Collaboration Study: **on-demand training,** expanding telehealth, digital tools, collaboration events and working groups: https://deploymentpsych.org/DoDKidsStudy (upcoming Extension for Community Healthcare Outcomes)
- Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD): https://chadd.org/for-professionals/continuing-education-on-adhd/
- OneOp: Free and open-access resources developed in collaboration with the DOD and university SMEs: https://oneop.org/series/youthresilience/
- Thrive Clearinghouse for Military Family Readiness: https://thrive.psu.edu/for-professionals/resources/
- Autism Research Institute: https://autism.org/webinars/

Resources for Families

- CHADD empowers people effected by ADHD: https://chadd.org/for-parents/overview/
- Thrive for Parents: videos on parenting topics, handouts, newsletters, blogs, and access to additional resources: https://thrive.psu.edu/for-parents/resources/
- Military One Source Podcasts: EFMP/Office of Special Needs on topics related to exceptional families: https://www.militaryonesource.mil/resources/podcasts/efmp/
- Tricare's Autism Care Demonstration https://tricare.mil/autism
- Services and advocacy for individuals with Intellectual and Developmental Disabilities (IDD): https://thearcofnova.org/
- Child Mind Institute Family Resource Center with guides on ADHD, ASD, Behavior, Screen time, etc. https://childmind.org/resources

Key Takeaways

- Autism and ADHD are two of the most diagnosed neurodevelopmental disabilities and they have increased in prevalence over the past decades.
- Increases in prevalence have been linked to increased awareness, changes in diagnostic criteria, and improved access to resources. Overdiagnosis has been related to relative age and increases in pathologizing normative behavior
- Autism and ADHD demonstrate sociocultural differences in prevalence suggesting systematic underdiagnosis of girls with ASD and Black/Latino children with ADHD, as well as late diagnosis of girls with ADHD
- Sociocultural differences have been traced to unconscious bias, availability of resources, stigma, lack of research on different groups (different presentations), and bias in measures
- Providers should be aware of the bias patterns discussed, collect information from multiple sources, and keep the best interest of the patient in mind when diagnosing

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Questions?

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