Autism and Gender Diversity:
A Neurodiversity-Affirming Approach

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SFDPH / UCSF / Private Practice

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Disclosures

- No relevant financial disclosures

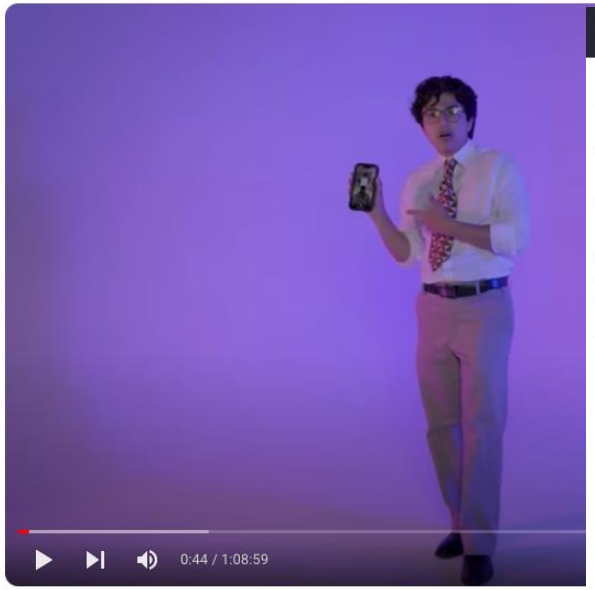
Learning objectives

- Describe autism using the neurodiversity paradigm and social model of disability, and contrast with the pathology paradigm and medical model of disability
- Recognize how autism may present differently from stereotypic presentations of autism, and how this impacts the use of common autism assessment tools
- Identify 3 ways to make your practice more neurodiversity-affirming

- Note: in this presentation I focus primarily on autistic individuals without co-occurring intellectual disability

Road map

- Background
- Terminology and paradigms
- Intro to autism
- Autism assessment
- Making your practice more neurodiversity-affirming



TikTok Gave Me Autism: The Politics of Self Diagnosis

Alexander Avila
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Teens Are Diagnosing Themselves With Autism, ADHD

Published on December 06, 2023

Written by S. Nicole Lane

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Reports of young teens self-diagnosing the and agoraphobia after watching TikTok vide

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ou are currently using **Ad Blocking software**. What are the consequences?

Home / Autism spectrum disorders

AUGUST 30, 2023 Editors' nc

Is TikTok helping autistic people self-diagnose? New research show role app plays in diagnosis

by Northeastern University

The Atlantic My Account Give a G

HEALTH

The Link Between Autism and Trans Identity

Confusion over why autism is so prevalent among transgender people may be limiting their access to medical care.

By Bryony White

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HEALTH

Transgender and nonbinary people are up to six times more likely to have autism

JANUARY 15, 2023 · 8:02 AM ET

HEARD ON WEEKEND EDITION SUNDAY

By Lesley McClurg

5-Minute Listen + PLAYLIST

Transgender and nonbinary people are up to six times more likely to also have autism. This intersection has researchers trying to understand the connection and how society views these identities.

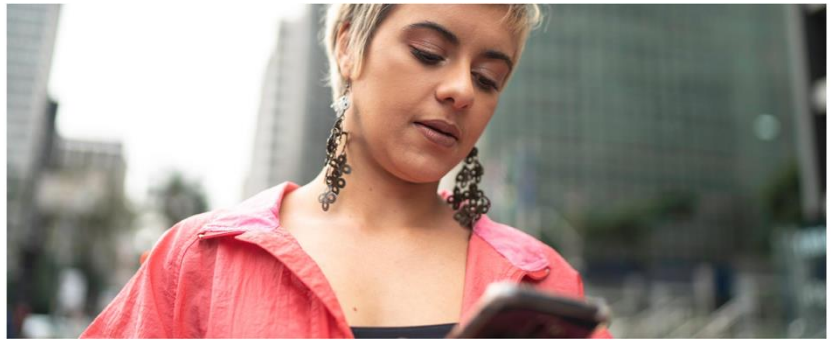
PsychCentral Conditions Discover Quizzes Resou

Is There a Link Between Autism Spectrum Disorder and Transgender Identity?

Causes | Importance | Necessity of sensitivity | Recap

Autistic people report higher rates of noncisgender identities, and gender diverse folks self-report higher rates of autistic traits.

HENRY FORD HEALTH FeelWell EatWell MoveWell ParentWell



The Social Media Influence On Diagnosing Autism In Adults And Adolescents

Posted on October 10, 2022 by *Henry Ford Health Staff* 6873

Case: “Jackie”

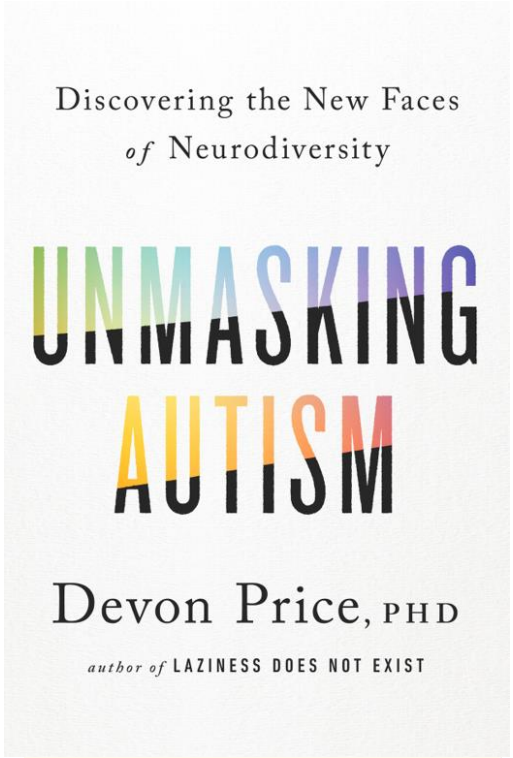
- 18yo transmasculine/nonbinary teenager (they/he) with a history of depression, anxiety, trauma, asks to be evaluated for autism
  - First learned about autism from social media

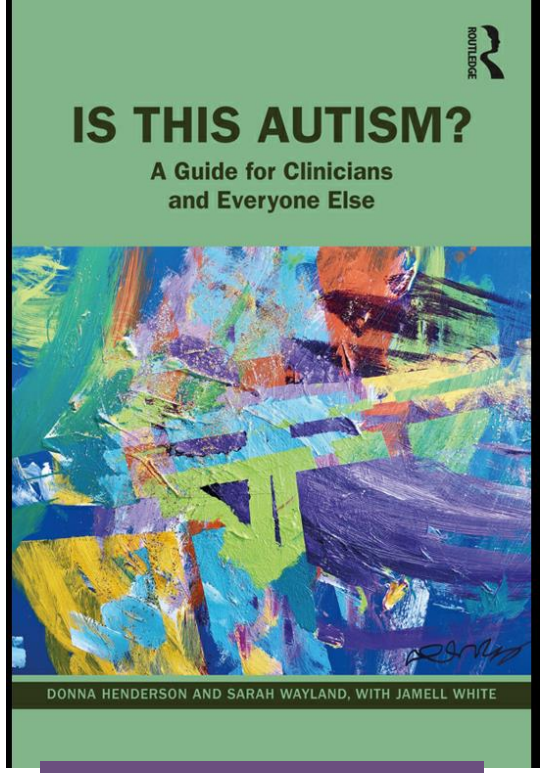
Clinical observation at a youth clinic

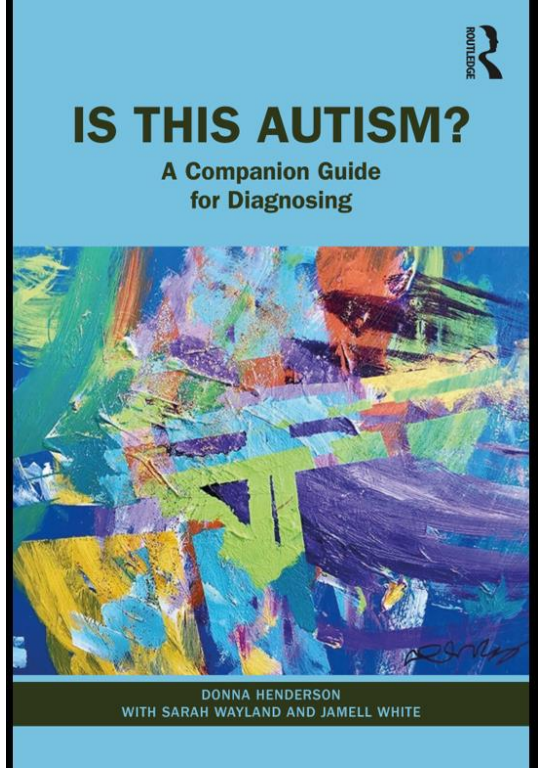
- Increasing requests among youth wanting to explore autism diagnosis
- Presentations differ from the stereotypic presentations of autism taught in medical training

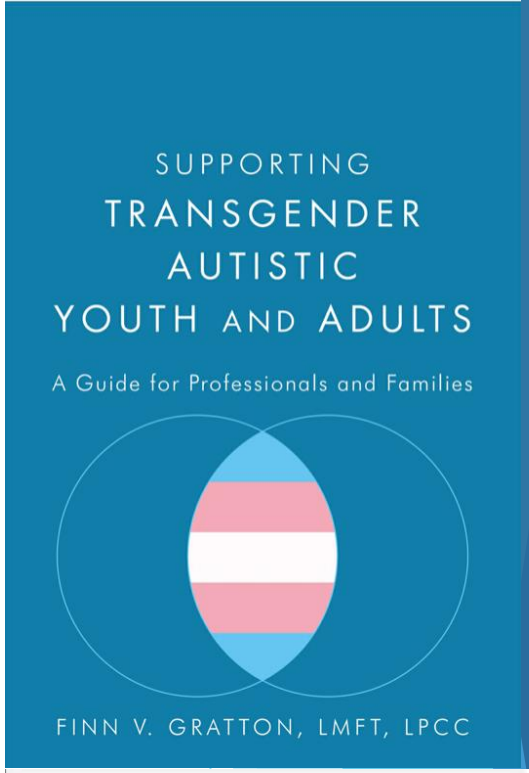
My journey

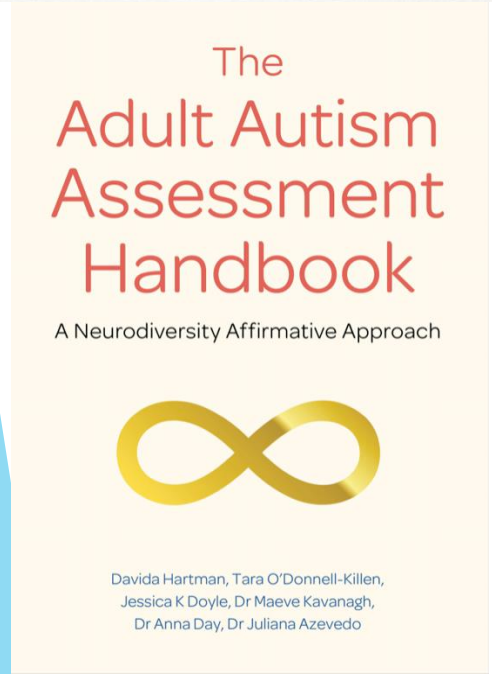
- Multiple trainings/conferences from WPATH, USPATH, UCSF, SFDPH
- Trained to administer MIGDAS-2 (for children/adolescents and adults)
- Self-learning
  - Unmasking Autism by Devon Price
  - Is this Autism? A guide for Clinicians and Everyone Else & A Companion Guide for Diagnosing
  - The Adult Autism Assessment Handbook: A Neurodiversity-Affirming Approach
  - Supporting Transgender Autistic Youth and Adults by Finn Gratton, LMFT, LPCC
  - Neuroqueer Heresies by Nick Walker
  - Neurodivergent Insights
  - Divergent Conversations podcast
  - Dr. Donna Henderson podcast episode on diagnosing autism in girls and women
  - Reading various academic papers and articles from autistic individuals
  - Finn Gratton's ND-affirming consult group
  - Neurodivergent Insights Learning Nook Clinician Community
  - Neurodiversity in Psychiatry group

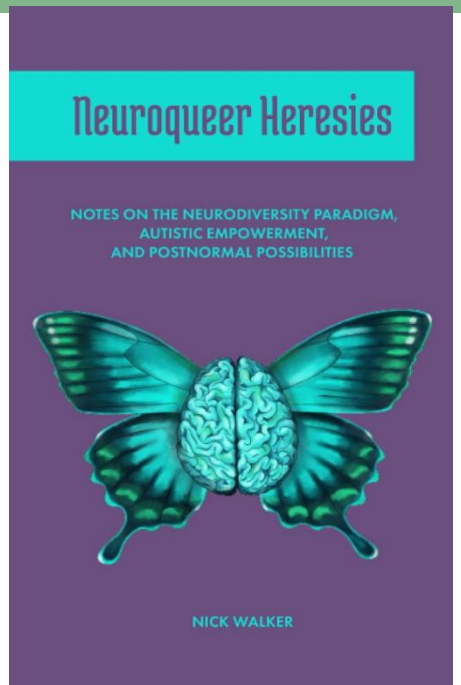




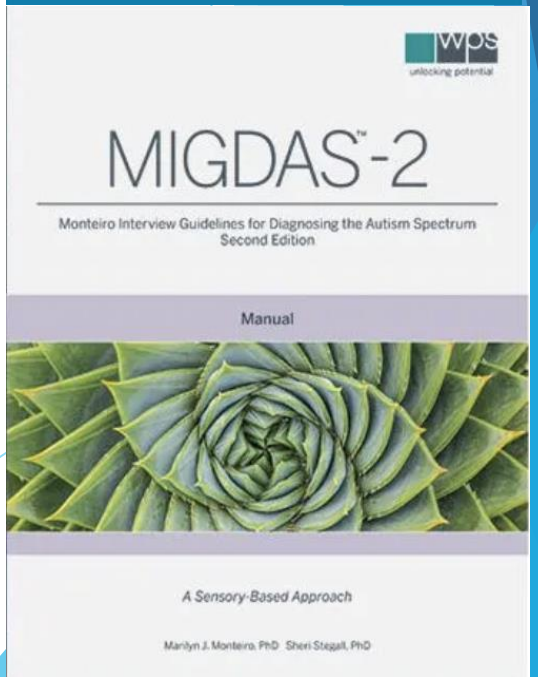








Neurodivergent
insights
Dr. Neff



Clinical experience

- Experience with ~65 autistic youth and adults
  - ~40 – I assessed and diagnosed
  - Other cases: external historic/new diagnoses, cases from trainees I supervise
  - Note: primarily without intellectual disability
- Community and private practice settings

Terminology

Terms related to neurodiversity

- **Neurodiversity:** the diversity of human minds, the infinite variation in neurocognitive functioning within our species (originally coined by Judy Singer)
- **Neurotype:** one's style of neurocognitive functioning
- **Neurodivergent (ND):** having a mind that functions in ways which diverge significantly from the dominant societal standards of "normal." (originally coined by Kassiane Asasumasu)
- **Neurotypical (NT):** having a style of neurocognitive functioning that falls within the dominant societal standards of "normal."
- **Neurodiverse:** multiple neurocognitive styles are represented, including neurodivergent and neurotypical
  - Note: a single person is not diverse / neurodiverse
- **Neuroqueer:** the practice of queering (subverting, defying, disrupting, liberating oneself from) neuronormativity and heteronormativity simultaneously

https://neuroqueer.com/neurodiversity-terms-and-definitions/

Paradigms

- **Pathology paradigm**
  - Assumption there is one “right” style of neurocognitive functioning
  - Variations that diverge are framed as pathologies, deficits, disorders
  - Dominance of pathology paradigm in medical literature
- **Neurodiversity paradigm**
  - Neurodiversity is natural and valuable form of human diversity
  - Idea of one “normal” or “healthy” type of brain or mind is a cultural constructed fiction (like ethnicity, gender, culture) → dynamics of social power inequities

https://neuroqueer.com/autism-and-the-pathology-paradigm/

Models of disability

- **Medical model of disability**
  - Disability attributed to medicalized defects located within the disabled individual
  - Assumption that status quo societal norms are “right” and “natural”
  - Having traits and needs that are incompatible with those norms constitutes a personal deficiency
- **Social model of disability**
  - Disability is the result of failures of accommodation, societal attitudes, and systemic barriers, which conflict with the needs, traits, and abilities of specific groups and individuals

https://neuroqueer.com/autism-and-the-pathology-paradigm/

Universal design

- Designing an environment so that it can be accessed, understood, and used to the greatest extent possible by all people regardless of their age, size, ability, or disability.
- An environment should be designed to meet the needs of all people who wish to use it. It is a fundamental condition of good design.

https://universaldesign.ie/about-universal-design

Intro to autism

You will likely encounter autistic patients

- Undiagnosed autism is prevalent in adult outpatient psychiatric clinics (Nyrenius et al 2022)
  - ~18.9% prevalence of autism (possibly up to 35%)
  - Additional 5-10% with subthreshold symptoms
  - ~6% already had a diagnosis

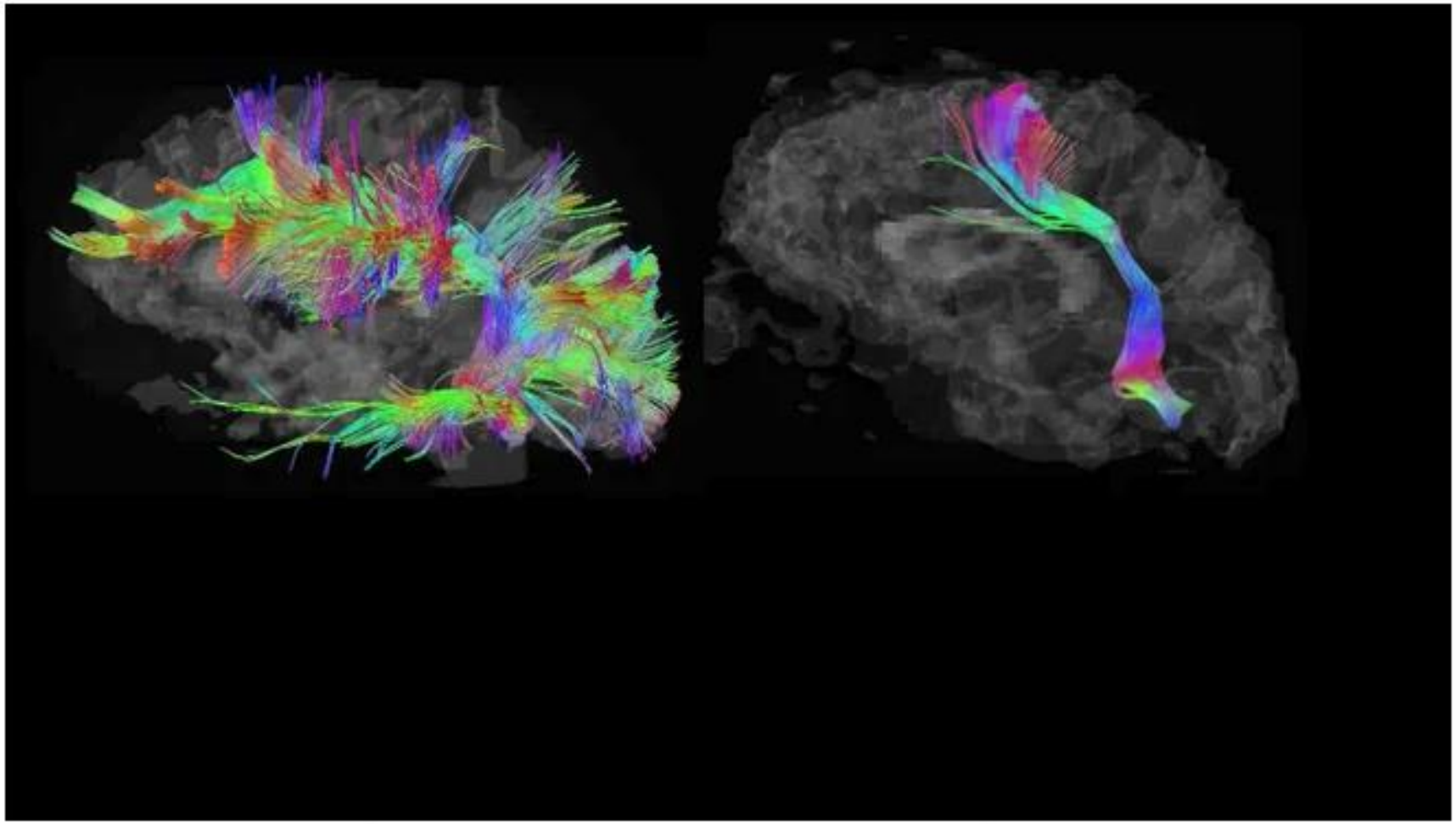
Nyrenius, J., Eberhard, J., Ghaziuddin, M., Gillberg, C., & Billstedt, E. (2022). Prevalence of Autism Spectrum Disorders in Adult Outpatient Psychiatry. *Journal of Autism and Developmental Disorders*, *52*(9), 3769–3779. https://doi.org/10.1007/s10803-021-05411-z

Autism definition from Nick Walker, PhD (she/her)

"Autism is a genetically-based human neurological variant. The complex set of interrelated characteristics that distinguish autistic neurology from non-autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual's subjective experience more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable…One analogy that has often been made is that autistic individuals have a different neurological "operating system" than non-autistic individuals."

https://neuroqueer.com/what-is-autism/

Brain scan differences of Temple Grandin



This is a brain scan of Temple Grandin, left, compared to someone without autism. Grandin's visual output area is much larger than a typical person's. *Walt Schneider, University Of Pittsburgh*

https://www.usatoday.com/story/news/nation/2013/05/01/autism-temple-grandin-brain/2122455/

- 4x connections in visual system
- Fewer connections auditory/speech areas

DSM-5 criteria

- Social communication differences (all 3, currently or by history)
  - Reciprocity
  - Nonverbal communication
  - Relationships
- Specific patterns of behavior/experience (at least 2, currently or by history)
  - Movements/mannerisms (repeating movements/behaviors that are calming/soothing, e.g. stimming)
  - Flexibility (e.g. sameness, routines, transitions)
  - Passions and special interests
  - Sensory experiences (hyper or hypo responsivity)
    - 5 senses + interoception, proprioception, vestibular

A note on language

- I will use autism rather than autism spectrum disorder/ASD
- Identity-first language over person-first language*
  - e.g. autistic person, instead of person with autism/ASD
- Allistic = non-autistic
- Needing less/more support, instead of high/low functioning
- Disabled, instead of differently abled, special needs

*respect the language that the patient uses for themself

The double empathy problem

- When people with very different experiences of the world interact with one another, they will struggle to empathize with each other (Milton 2012)
  - E.g. a non-autistic person having difficulty feeling empathy for an autistic person, and vice versa
- The challenge is cross-neurotype communication
  - Autistic people effectively communicate with each other (Crompton et al 2020[1])
    - Autistic chains equal to non-autistic chains, mixed chains performed the worst
  - Autistic pairs rated more highly in interactional rapport than non-autistic pairs, with mixed pairs rated lowest (Crompton et al 2020[2])
  - Thus, autistic people have a distinct way of communicating, not deficits

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem.' *Disability & Society*, *27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

[1]Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. Autism, 24(7), 1704–1712.

[2]Crompton, C. J., Sharp, M., Axbey, H., Fletcher-Watson, S., Flynn, E. G., & Ropar, D. (2020). Neurotype-Matching, but Not Being Autistic, Influences Self and Observer Ratings of Interpersonal Rapport. *Frontiers in Psychology*, *11*, 586171. https://doi.org/10.3389/fpsyg.2020.586171

Autistic strengths

- Sensory differences (attend more to visual, auditory info, etc)
- Strong sense of morals/justice (e.g. Greta Thunberg)
- Strong sense of integrity (e.g. consistent behavior when not being watched)
- Clear, direct communication
- Special interests, passions, hyperfocus
- Cognitive/thinking styles
- Grit, perseverance, strong work ethic
- Creativity and artistic talents

Henderson, D. A., Wayland, S. C., & White, J. (2023). *Is this autism? A companion guide for diagnosing*. Routledge.

Woods, S. E. O., & Estes, A. (2023). Toward a more comprehensive autism assessment: The survey of autistic strengths, skills, and interests. *Frontiers in Psychiatry*, *14*, 1264516. https://doi.org/10.3389/fpsyt.2023.1264516

Co-occurring chronic health conditions

https://allbrainsbelong.org/all-the-things/

Autism and gender diversity

Co-occurrence of autism and gender diversity

- Depending on the study, 5-20% of trans and gender diverse people are also autistic (Gratton 2020)
- TGD people are 3-6x as likely to be autistic (Warrier et al 2020)
- Theories about the overlap:
  - Autistic TGD youth may feel less need to conform to social norms (and less impacted by binary gender socialization)
  - Sensory sensitivities may intensify the experience of gender dysphoria

Gratton, F. V. (2020). *Supporting transgender autistic youth and adults: A guide for professionals and families*. Jessica Kingsley Publishers.

Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M.-C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. *Nature Communications*, *11*(1), 3959. https://doi.org/10.1038/s41467-020-17794-1

Issues with diagnosis and current assessment tools for autism

- Original studies included few girls and likely no trans and nonbinary folks, so the diagnostic criteria is centered on boys
- Overall ratio of boys to girls is 3 to 1 (Loomes et al 2017)
  - About 2:1 for those with intellectual disability (Yeargin-Allsopp et al 2003)
  - About 7-9:1 for those without intellectual disability
  - 3:4 when mathematically correcting for errors (80% undiagnosed at age 18) (McCrossin 2022)
- ADOS-2 was normed on cisgender white boys from privileged backgrounds
  - Misses girls/women, trans/nonbinary folks, people of color, people with co-occurring mental health problems
  - Behavioral observation only, misses people who camouflage
  - Of those diagnosed in the community, only 81% men and 50% women met ADOS cutoff score required for inclusion in autism studies (D'mello et al 2022)

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466–474. https://doi.org/10.1016/j.jaac.2017.03.013
Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). *Prevalence of Autism in a US Metropolitan Area*.
McCrossin, R. (2022). Finding the True Number of Females with Autistic Spectrum Disorder by Estimating the Biases in Initial Recognition and Clinical Diagnosis. *Children*, *9*(2), 272. https://doi.org/10.
D'Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline. *Autism Research*, *15*(10), 1929–1940. https://doi.org/10.1002/aur.2795

Gender differences in autism diagnosis

- AFAB, female gender, gender-diverse, and high IQ people were diagnosed significantly later (McQuaid et al 2023)
  - Later autism diagnosis associated with increased mental health risks, lower quality of life, and increased self-harm
- ”Extreme male brain theory” (Baron-Cohen)
  - High levels of systemizing abilities and difficulties with cognitive empathy and emotional expression represent masculine characteristics”
- “Female autism phenotype” (Hull et al 2020)
  - Differences in social difficulties, interests are more relational, co-occurrence of internalizing disorder, camouflaging/compensation strategies

McQuaid, G., Ratto, A. B., Jack, A., Khuu, A., Smith, J. V., Duane, S., Clawson, A., Lee, N. R., Verbalis, A., Pelphrey, K., Kenworthy, L., Wallace, G., & Strang, J. (2023). *Gender, assigned sex at birth, and gender diversity: Windows into diagnostic timing disparities in autism* [Preprint]. PsyArXiv. https://doi.org/10.31234/osf.io/kc6ax

Hull, L., Petrides, K. V., & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: A Narrative Review. *Review Journal of Autism and Developmental Disorders*, *7*(4), 306–317. https://doi.org/10.1007/s40489-020-00197-9

Challenges to autism diagnosis in gender diverse people

- Gender-diverse people diagnosed later than cisgender people (McQuaid et al 2023)
  - Nonbinary folks diagnosed significantly later than people of binary genders
- Greater gender diversity is associated with polygenic scores predicting higher IQ (Thomas et al 2022)
- Gender diversity may overshadow autism-related signs when social and behavioral differences are attributed to gender minority stress
  - However, default mode functional connectivity supports true developmental autism (Strang et al 2023)
- Trans youth with autistic traits not meeting the threshold of diagnosis
  - Experienced clinical level autism-related problems and challenges, similar levels of mental health concerns (e.g. internalizing sx)
  - Broad autism grouping had worse suicidality compared to strict autism grouping

McQuaid, G., Ratto, A. B., Jack, A., Khuu, A., Smith, J. V., Duane, S., Clawson, A., Lee, N. R.,Verbalis, A., Pelphrey, K., Kenworthy, L., Wallace, G., & Strang, J. (2023). *Gender, assigned sex at birth, and gender diversity: Windows into diagnostic timing disparities in autism* [Preprint]. PsyArXiv. https://doi.org/10.31234/osf.io/kc6ax

Thomas, T. R., Tener, A. J., Pearlman, A. M., Imborek, K. L., Yang, J. S., & Michaelson, J. J. (2022). *Dimensional gender diversity is associated with greater polygenic propensity for cognitive performance and interacts with other genetic factors in predicting health outcomes*.

Strang, J. F., McClellan, L. S., Li, S., Jack, A. E., Wallace, G. L., McQuaid, G. A., Kenworthy, L., Anthony, L. G., Lai, M.-C., Pelphrey, K. A., Thalberg, A. E., Nelson, E. E., Phan, J. M., Sadikova, E., Fischbach, A. L., Thomas, J., & Vaidya, C. J. (2023). The autism spectrum among transgender youth: Default mode functional connectivity. *Cerebral Cortex*, *33*(11), 6633–6647. https://doi.org/10.1093/cercor/bhac530

Strang, J. F., Anthony, L. G., Song, A., Lai, M.-C., Knauss, M., Sadikova, E., Graham, E., Zaks, Z., Wimms, H., Willing, L., Call, D., Mancilla, M., Shakin, S., Vilain, E., Kim, D.-Y., Maisashvili, T., Khawaja, A., & Kenworthy, L. (2023). In Addition to Stigma: Cognitive and Autism-Related Predictors of Mental Health in Transgender Adolescents. *Journal of Clinical Child & Adolescent Psychology*, *52*(2), 212–229. https://doi.org/10.1080/15374416.2021.1916940

Mental health of autistic trans/gender diverse youth

- Based on data from 919,898 pts aged 9-18 yrs
- Odds ratios compared to non-autistic, cisgender youth

	Autistic	Gender diverse	Autistic + Gender diverse
Anxiety	4.5	6.0	19.3
Depression	1.9	11.5	18.8
Eating disorder	5.2	4.7	6.0
Suicidality	2.2	8.5	11.2
Self-harm	4.3	9.6	11.3

50-70% autistic people are also diagnosed with ADHD (Hours et al 2022)

Kahn, N. F., Sequeira, G. M., Reyes, V., Garrison, M. M., Orlich, F., Christakis, D. A., Aye, T., Conard, L. A. E., Dowshen, N., Kazak, A. E., Nahata, L., Nokoff, N. J., Voss, R. V., & Richardson, L. P. (2023). Mental Health of Youth With Autism Spectrum Disorder and Gender Dysphoria. *Pediatrics*, *152*(6), e2023063289. https://doi.org/10.1542/peds.2023-063289

Hours, C., Recasens, C., & Baleyte, J.-M. (2022). ASD and ADHD Comorbidity: What Are We Talking About? *Frontiers in Psychiatry*, *13*, 837424. https://doi.org/10.3389/fpsyt.2022.837424

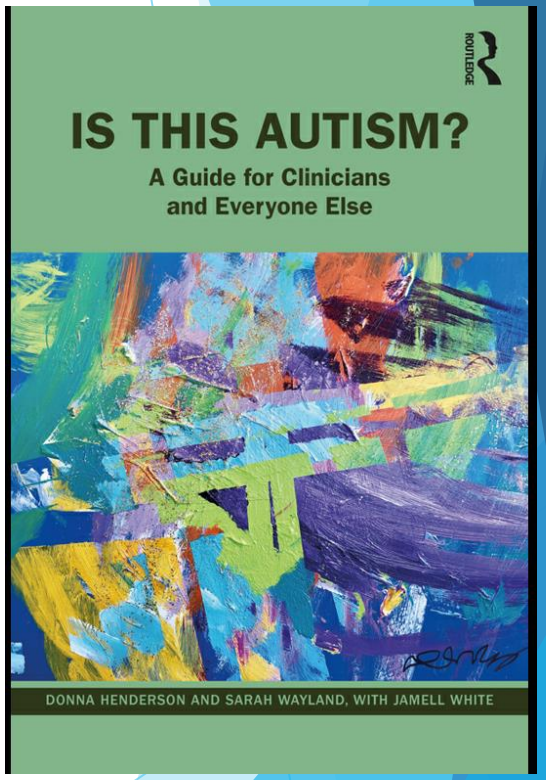
Considerations when working with autistic TGD people

- Do not assume that autistic people do not know their gender and are unable to provide informed consent/assent about their treatment
  - May have a lot of clarity around their gender identity and embodiment goals
  - Are able to consent/assent
- Communication and language differences do not mean an individual is unable to communicate clearly who they are
- Use a variety of strategies and approaches to assess and obtain information
- When appropriate, collaborate with family system and other treatment providers
- Consider risks/benefits of both treatment and non-treatment
- Gender-affirming care should not be held merely because someone is autistic
- May benefit from supports around communication, presenting info in multiple formats, navigating sensory sensitivities, and executive functioning related to medical tasks (planning, making appointments, etc)

Autism Assessment

Is this Autism? A Guide for Clinicians and Everyone Else

- Very helpful resource in understanding the diagnostic criteria and how it may present/manifest in people with more subtle/less stereotypic presentations of autism
- Main author: Donna Henderson, PsyD, neuropsychologist, along with 100 autistic people who whare their personal experiences
- 2nd book: Is This Autism: A Companion Guide for Diagnosing is tailored for clinicians who may diagnose autism



DSM-5 criteria

- Social communication differences (all 3, currently or by history)
  - Reciprocity
  - Nonverbal communication
  - Relationships
- Specific patterns of behavior/experience (at least 2, currently or by history)
  - Movements/mannerisms (repeating movements/behaviors that are calming/soothing, e.g. stimming)
  - Flexibility (e.g. sameness, routines, transitions)
  - Passions and special interests
  - Sensory experiences (hyper or hypo responsivity)
    - 5 senses + interoception, proprioception, vestibular

Reciprocity

- Back and forth conversation, small talk
  - Initiating conversation, responding to conversation, building on what the other person says, show curiosity about the other person
  - Difficulty greeting or responding to greetings
  - Talking too much, interrupting, making space for others to speak
  - Having specific scripts for small talk, not knowing how to handle when people go off script
- Social skills, understanding the hidden social rule book
- Understanding jokes, sarcasm, metaphors
- Direct style of communication

Nonverbal communication

- Eye-contact and gaze
  - Feeling eye-contact is very intense, uncomfortable, may force self to do it
  - Some have learned to look at nose or in general direction to appear to be giving eye-contact
- Observing and understanding body language & gestures, reading others, getting a sense of what they are thinking
- Body positioning, walking alongside another person
- Volume, prosody/tone, rate of speech, facial expressions, gestures
- Watching and mirroring people in videos/TV's/movies, copying others' behaviors

- Impact of culture: Asian culture – speak more softly, use indirect forms of expression, not maintain eye-contact since too much eye-contact may be considered disrespectful

Relationships

- Developing, maintaining, and understanding relationships (e.g. any challenges with making friends, keeping friends)
- Ask about current challenges and past challenges when people were younger (e.g. children)
  - Social communication is more simple during childhood, so some people may not have difficulties until adolescence where social communication becomes more complex
  - Some have an easier time making friends as adolescents and adults with other neurodivergent people
  - More difficulty with same-aged peers, easier time making friends with people who are older or younger
- Easier time making friends in structured settings (e.g. school)
- Common pattern of one intense friendship at a time

Repeating patterns of behavior and experience

- E.g. “stimming” - shaking, fidgeting, rocking, pacing
- Listening to same play list, reading same book, watching same movie over and over again
- Collecting items, organizing/sorting
- Making sounds, saying words/phrases repeatedly (e.g. “well, actually” “thank you very much” “I love that”).
- Has a calming/soothing effect, promotes focus, helps with overwhelm, release of emotion.
- Distinguish with compulsions and tics
- Do not try to stop unless pt wants to and/or there is safety risk

Flexibility

- Insistence on sameness, routines, difficulty with last minute changes to plans, transitions
- Routines and rituals, having particular way of doing things
- Strong reactions to small changes
- Difficulty coping with transitions
- Black-and-white thinking
- Strong moral compass, passionate about social justice
- Rule following
- Literal interpretations

Special interests and passions

- Can be fully absorbed, hyperfocus, spend hours on special interest
- May forget to eat/drink, use bathroom, go to sleep, interfere with completing other tasks/behaviors
- May align with a job or something the individual can get paid for, or it might not
- May have developed shame due to talking too much about interests and receiving negative feedback from others
- Girls interests are different (e.g. animals, boy bands), may not stand out as notable.
- Interests can change over time. Special interests may last days, weeks, years, or decades, and may come and go

Sensory experiences

- Hyper- or hypo- responsivity
- 5 senses (vision, hearing, touch, taste, smell)
  - Vision: bright lights, overhead fluorescent lights, screens too bright, learned to wear sunglasses
  - Hearing: loud noises, cacophony of voices/music, sound of chewing, learned to wear noise-cancelling headphones
  - Smell: strong fragrances, perfumes, cologne
  - Texture: certain fabrics, tags, inseams, food textures
  - Taste: ”picky eater,” don’t like foods mixing
- 3 additional
  - Interoception: sense of internal states, e.g. hunger, thirst, need to use bathroom, emotions
  - Proprioception: position in space, e.g. walking together, parallel parking
  - Vestibular: balance, e.g. carsick, seasick, or craving rocking, pacing, spinning
- Sensory craving/enjoyment

DSM-5 criteria

- Symptoms present currently or by history
- Symptoms present in early developmental period
  - But may not become fully manifest until **social demands exceed capacities**, or
  - May be **masked** by learned strategies in later life
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning
  - Can include emotional impairment (i.e. anxiety, depression), or being exhausted when forced to camouflage, with a significant need for recovery time (Henderson et al 2023)
  - Can differ depending on context, holding it together in public and breaking down while at home
  - Burnout, school or work avoidance, difficulty launching into adulthood

Henderson, D. A., Wayland, S. C., & White, J. (2023). *Is this autism? A companion guide for diagnosing*. Routledge.

Additional considerations

- Camouflaging/masking
- Sensory shutdowns/meltdowns
- Demand avoidance/PDA (pathological demand avoidance vs pervasive drive for autonomy)
- Alexithymia (low interoceptive awareness)
- Affective empathy vs cognitive empathy

Barriers to assessment/diagnosis

- Long wait times for assessment at autism clinics (months to > 1-3 yrs)
  - From UCSF Center for ASDs and NDDs website:
    - ***Please note we're currently not accepting new patients for diagnostic evaluations at this time due to high demand. Please continue to check our website for updates.***
  - Often focused on children, inaccessible to older adolescents and adults
- Financial barriers
- Lack of trained/qualified providers
- Long testing appointments (hours of assessment) which makes it inaccessible for many, some can't tolerate the process

Screening

- Listen for autism diagnostic criteria,
  - e.g. history of social challenges (making/keeping friends, social skills, etc), sensory sensitivities, difficulty with flexibility
- Standardized questionnaires

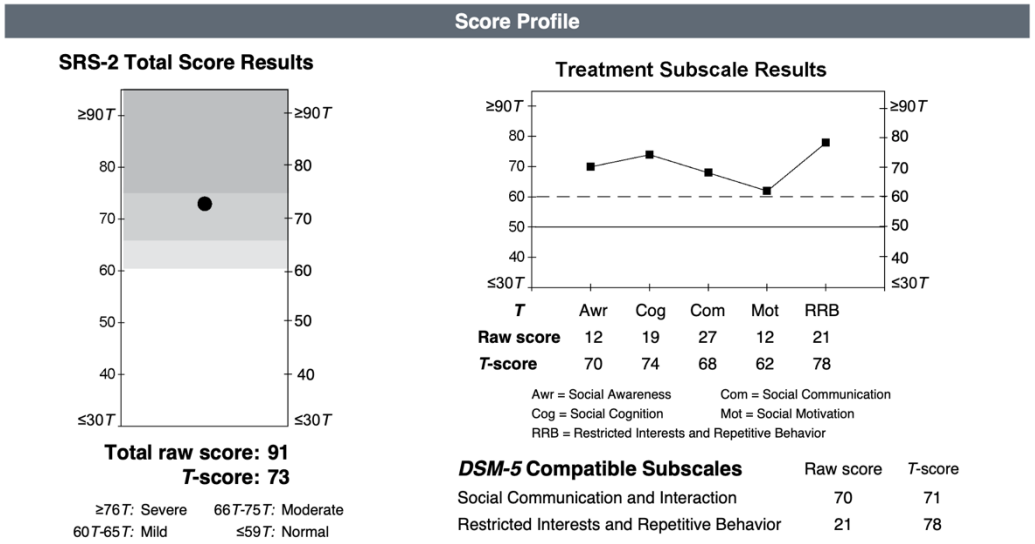
Free tools

- Self-report questionnaires (age 16 and older)
  - Autism Quotient (AQ, adolescents 12-15, children 4-11)
    - 50 questions
    - Threshold score > 26.
  - Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R)
    - 80 questions
    - Threshold score >65
  - Camouflaging Autistic Traits Questionnaire (CAT-Q)
    - Does not measure core autistic traits, but rather the camouflaging and compensation efforts that people engage in
    - Threshold score >100

https://embrace-autism.com/

Proprietary tools

- Social-Responsiveness Scale, 2nd edition (SRS-2)
- Child Autism Rating Scale (CARS-2)
- Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, 2nd edition (MIGDAS-2)



Score Profile

SRS-2 Total Score Results

≥90*T* 80 70 60 50 40 ≤30*T*

Total raw score: 91
***T*-score: 73**

≥76*T*: Severe
66*T*-75*T*: Moderate
60*T*-65*T*: Mild
≤59*T*: Normal

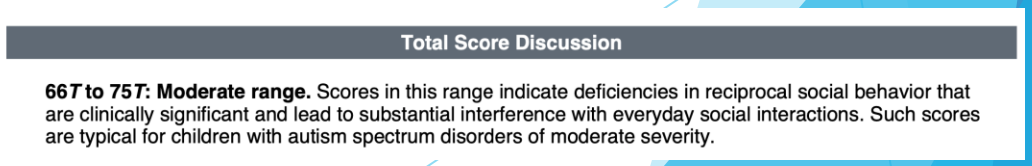
Treatment Subscale Results

≥90*T* 80 70 60 50 40 ≤30*T*

T	Awr	Cog	Com	Mot	RRB
Raw score	12	19	27	12	21
***T*-score**	70	74	68	62	78

Awr = Social Awareness
Com = Social Communication
Cog = Social Cognition
Mot = Social Motivation
RRB = Restricted Interests and Repetitive Behavior

***DSM-5* Compatible Subscales**	Raw score	*T*-score
Social Communication and Interaction	70	71
Restricted Interests and Repetitive Behavior	21	78



Total Score Discussion

66*T* to 75*T*: Moderate range. Scores in this range indicate deficiencies in reciprocal social behavior that are clinically significant and lead to substantial interference with everyday social interactions. Such scores are typical for children with autism spectrum disorders of moderate severity.

My approach

- Standardized measures:
  - Youth under 16:
    - Parent/guardian: SRS-2
  - Age 16+ (or mature teenager under age 16)
    - Patient: AQ, RAADS-R, CAT-Q
    - Parent/guardian: SRS-2
- Qualitative interview with youth and parents/guardians. Consider autism criteria, as well as: sensory shutdowns/meltdowns, demand avoidance, strengths
- Assess co-occurring conditions
- Autism is a clinical diagnosis, which does not require any specific instrument/tool (though insurance may have requirements)
- Consider neuropsych testing to better understand full cognitive capacities, strengths/challenges
  - Make sure the testing psychologist is familiar with autism, and it's more subtle presentations
  - Be wary of those who only use ADOS-2 and not MIGDAS-2

Considerations

- Prioritize the patient's history above your own observations, rating scales, self-report measures, and test scores
- Interpret scores/data in the context of the whole clinical picture
- Patients who believe they are autistic have often done a great deal of research and should be taken seriously
  - Some have done so much research they may be more knowledgeable about autism than some clinicians
- Check your own bias that autism is categorically bad
- Do not rule out autism because you see some "non-autistic" traits or behaviors (e.g. masking/camouflaging)

Henderson, D. A., Wayland, S. C., & White, J. (2023). *Is this autism? A companion guide for diagnosing*. Routledge.

To diagnose or not diagnose?

- Goal of assessment and diagnosis: self-understanding
- I discuss pros/cons of having a formal diagnosis in the medical chart, and support the patient/family in making an informed choice
  - Pros
    - Medical record accurately reflects diagnosis, share with providers
    - Easier to advocate for accommodations, supports
  - Cons
    - Stigma within healthcare settings
    - Potential challenges with accessing gender-affirming care in states with restricted access
    - Risks: life insurance, medical, immigration, legal

https://devonprice.medium.com/seeking-an-autism-diagnosis-heres-why-you-might-want-to-rethink-that-530e79c272a0
https://www.instagram.com/p/CqiSu3NuW08/?utm_source=ig_web_copy_link&igsh=MzRlODBiNWFlZA==

Power of diagnosis

- Getting a proper diagnosis (in a neurodiversity-affirming manner) can be a life-changing experience
- Concrete benefits
  - Access to supports, accommodations, appropriate intervention
- Less tangible benefits (may be more powerful)
  - Protection from inaccurate or pejorative labels
  - A sense of community with other people who share the neurotype
  - Greater understanding from family, educators, and healthcare professionals

Henderson, D. A., Wayland, S. C., & White, J. (2023). *Is this autism? A guide for clinicians and everyone else*. Routledge.

- “The most powerful benefit of proper diagnosis of autism is the gift of nonjudgmental self-understanding. Only an accurate and neurodiversity-affirmative self-understanding can free an individual from a lifetime of self-blame and shame.”

  – Donna Henderson, PsyD

Henderson, D. A., Wayland, S. C., & White, J. (2023). *Is this autism? A guide for clinicians and everyone else*. Routledge.

Self-diagnosis

- Embraced in the community due to the inaccessibility of a formal diagnosis
- Risk of being invalidated/harmed by clinicians who have a narrow view of autism traditionally taught in medical/mental health settings
- Several studies show that self-diagnosed autistic people report similar results to formally diagnosed autistic people (Overton et al 2023)
  - Both were similar in reported stigma, self-esteem, quality of life, struggling with employment (McDonald 2020)
- Benefits of lived experience awareness, self-understanding, connection to community and resources outweigh the risks (Divergent Conversations podcast, episode 17)
- Recommend a ”smorgasbord” approach
  - Screeners, family/friends, social media, meet with doctor, etc. Get multiple data points

Overton, G. L., Marsà-Sambola, F., Martin, R., & Cavenagh, P. (2023). Understanding the Self-identification of Autism in Adults: A Scoping Review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1

McDonald, T. A. M. (2020). Autism Identity and the “Lost Generation”: Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum. *Autism in Adulthood*, *2*(1), 13–23. https://doi.org/10.1089/aut.2019.0069

Case: “Jackie” continued

- Functional impact
  - Takes days to recover after going to school → school avoidance
  - Exhaustion after social interactions
  - Difficulty maintaining friendships
- School IEP assessment
  - Found NOT to meet autism criteria per ADOS-2
- On my assessment (qualitative/quantitative), found to meet criteria
  - High masking, able to camouflage autistic traits
  - Provided psychoed about diagnosis
  - After shared-decision making, decided to add formal diagnosis to chart

Case: “Jackie” continued

- After autism diagnosis:
  - Learning to regulate sensory experiences with sensory toys/objects, preparing for stressful situations
  - Making friends with other neurodivergent people, unmasking
  - Making time for special interests/passions
  - Accommodating sensory needs (e.g. wearing headphones to manage noise levels)
  - Improving relations with family
    - Family gives more advanced notice before events
    - Support autonomy
  - Fostering positive sense of identity

Psychoeducation/counseling about autism

- Not deficits/deficiencies, but a difference in how an individuals' brain/nervous system is wired
  - Some things will be easier, e.g. special interests. For some, this might align with a job that one can get paid for. For others, it might not.
  - Some things will be more challenging, e.g. crowded situations requiring social interaction that are overwhelming from sensory standpoint
- Goal is to learn/attune to one's unique nervous system, learning its needs, and how to regulate it
  - Redesign life with sensory needs in mind, seek accommodations when necessary
  - Prepare a sensory kit, access before/during/after stressful experiences
  - Make time for special interests/sensory needs, which helps regulate nervous system
- Find opportunities to unmask, discover one's authentic self, develop positive identity
  - Make friends with other neurodivergent people
  - Recognize that masking may be needed in some situations for safety reasons. Develop awareness/intentionality of when to mask, as well as time to recover
  - Celebrate/cultivate autistic strengths

Managing co-occurring diagnoses for autistic youth and adults

- Co-occurring diagnoses examples: ADHD, mood disorders (depression, bipolar), anxiety disorders (social, generalized, panic), OCD, eating disorders, PTSD, etc.
- Treating one may exacerbate another
  - E.g. Treating ADHD with a stimulant may exacerbate an eating disorder
  - E.g. Treating OCD when considering co-occurring bipolar disorder
- Potential for side effects or different responses
  - Start very low dose, give agency to self-titrate
  - Be aware that responses may differ from expected response
  - Side effects may limit the dose that is tolerated
- Need for collaboration and shared-decision making centering the patient's priorities, values, and agency

Making your practice more neurodiversity-affirming

- Ask about accessibility needs ahead of time
- Ask about communication preferences (e.g. verbal, written)
- Adjust sensory environment, e.g. dim/adjust lights, get rid of overhead harsh lights
- Invite them to do what they need to do to be comfortable, move, stim, not make eye-contact
- Allow access to sensory/fidget toys
- Give heads-up about what to expect during the appointment
- Allow a support person to be there if requested
- Start with interests/passions to engage, if having difficulty with engagement
- Be direct and clear, avoid euphemisms. Open-ended questions might be difficult
- Offer breaks, get permission before talking about challenging topics
- Flexibly convert to telehealth, if unable to make it in-person
- Start medications low and titrate slowly (increased side effects), empower pt to self-titrate (guided)
- Modify psychotherapeutic techniques. Traditional CBT may be less effective. Exposure – may not desensitize. ACT, IFS more helpful
- Reconsider ABA, social skills training
- Check ableist language, use neurodiversity-affirming language

Making your practice more gender-affirming

- Introduce yourself with name/pronouns
- Ask pt what name/pronouns they go by (alone, in front of parents, in EHR)
- Use gender neutral greetings: e.g. folks, friends, y'all, everyone instead of ladies/gentleman, boys/girls,
- Don't use honorifics such as Mr./Mrs./Ms./Mx. unless you know what pt uses
- Don't assume pronouns based on appearance - use name, or they/them
- If you make a mistake, correct yourself quickly and move on. Don't over-apologize and put the trans person in the position of needing to comfort you
- Correct others when they misgender the patient. e.g. "by the way, the patient uses they/them pronouns"

Summary

- Existing “gold standard” autism assessment tools identify only a small subset of autistic folks and more likely miss females, gender-diverse, people of color, high IQ
- People with subclinical autistic traits and who are self-diagnosed show similar problems (and worse suicidality) as formally diagnosed
- Autistic people are more likely to have diverse gender identities and sexual orientations
- Neurodiversity paradigm and social model of disability is another way to view autism, as opposed to the pathology paradigm and medical model of disability
- Autistic people can do really well with the proper supports and are rewarding to work with

Intro to Autism resources

- What is Autism - essay by Nick Walker, PhD, an autistic trans professor of psychology, which is part of a larger book: Neuroqueer Heresies.
  - https://neuroqueer.com/what-is-autism/
- Neurodiversity: Some Basic Terms & Definitions - by Nick Walker, PhD
  - https://neuroqueer.com/neurodiversity-terms-and-definitions/
- Divergent Conversations podcast: Podcast of Megan Neff and Patrick Casale, 2 autistic+ADHD therapists describing their experiences of autism and ADHD. Start with “What is Autism?” Parts 1-4, episodes 48-51 (Apr 5-26, 2024), then check out the other episodes.
  - https://www.divergentpod.com/

- Compiled Autism Resources

Autism resources for clinicians

- Unmasking Autism by Devon Price
- Is this Autism? A guide for Clinicians and Everyone Else & A Companion Guide for Diagnosing
- The Adult Autism Assessment Handbook: A Neurodiversity-Affirming Approach
- Supporting Transgender Autistic Youth and Adults by Finn Gratton, LMFT, LPCC
- Neuroqueer Herressies by Nick Walker
- Neurodivergent Insights
- Divergent Conversations podcast
- Dr. Donna Henderson podcast episode on diagnosing autism in girls and women
- Autism Resources from PACT Coalition
- Finn Gratton's ND-affirming consult group

Autism resources for patients

- Unmasking Autism by Devon Price
  - Devon Price is a trans autistic social psychologist, and also has a number or articles on Medium that may be worth looking at.
  - https://www.penguinrandomhouse.com/books/688819/unmasking-autism-by-devon-price-phd/
- AASPIRE Health Care Toolkit: Excellent for both medical and mental health.
  - https://autismandhealth.org/
- Neuroclastic:
  - https://neuroclastic.com/
- Neurodivergent Insights:
  - Website of an autistic + ADHD psychologist Megan Anna Neff, with helpful diagrams and tools:
  - https://neurodivergentinsights.com/
- Divergent Conversations podcast:
  - Podcast of Megan Neff and Patrick Casale, 2 autistic+ADHD therapists describing their experience of neurodivergence.
  - https://www.divergentpod.com/
- Queer Life Space Neuroqueer group ($15).
  - https://www.queerlifespace.org/group-therapy
- Healthy Relationships on the Autism Spectrum (HEARTS): 18+
  - https://sites.bu.edu/hearts/
- Autistic strengths, skills, interests
  - https://www.frontiersin.org/journals/psychiatry/articles/10.3389/fpsyt.2023.1264516/full

Thank you

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References

- Alhujaili, N., Platt, E., Khalid-Khan, S., & Groll, D. (2022). Comparison of Social Media Use Among Adolescents with Autism Spectrum Disorder and Non-ASD Adolescents. Adolescent Health, Medicine and Therapeutics, Volume 13, 15–21. https://doi.org/10.2147/AHMT.S344591
- Aragon-Guevara, D., Castle, G., Sheridan, E., & Vivanti, G. (2023). The Reach and Accuracy of Information on Autism on TikTok. Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s10803-023-06084-6
- Berger, M. N., Taba, M., Marino, J. L., Lim, M. S. C., & Skinner, S. R. (2022). Social Media Use and Health and Well-being of Lesbian, Gay, Bisexual, Transgender, and Queer Youth: Systematic Review. Journal of Medical Internet Research, 24(9), e38449. https://doi.org/10.2196/38449
- Coyne, S. M., Weinstein, E., Sheppard, J. A., James, S., Gale, M., Van Alfen, M., Ririe, N., Monson, C., Ashby, S., Weston, A., & Banks, K. (2023). Analysis of Social Media Use, Mental Health, and Gender Identity Among US Youths. JAMA Network Open, 6(7), e2324389. https://doi.org/10.1001/jamanetworkopen.2023.24389
- Crompton, C. J., Ropar, D., Evans-Williams, C. V., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. Autism, 24(7), 1704–1712.
- Crompton, C. J., Sharp, M., Axbey, H., Fletcher-Watson, S., Flynn, E. G., & Ropar, D. (2020). Neurotype-Matching, but Not Being Autistic, Influences Self and Observer Ratings of Interpersonal Rapport. Frontiers in Psychology, 11, 586171. https://doi.org/10.3389/fpsyg.2020.586171
- D'Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline. Autism Research, 15(10), 1929–1940. https://doi.org/10.1002/aur.2795
- Gordon, J. D., Whitfield, D. L., Mammadli, T., & Escobar-Viera, C. G. (2023). Social Support–Seeking Strategies on Social Media at the Intersection of Lesbian, Gay, Bisexual, Transgender, and Queer Identity, Race, and Ethnicity: Insights for Intervention From a Qualitative Study. JMIR Formative Research, 7, e51702. https://doi.org/10.2196/51702
- Hanckel, B., & Chandra, S. (2021). Social Media Insights from Sexuality and Gender Diverse Young People During COVID-19. Western Sydney University. https://doi.org/10.26183/KVG0-7S37
- Hartman, D., O'Donnell-Killen, T., Doyle, J. K., Kavanagh, M., Day, A., & Azevedo, J. (2023). The adult autism assessment handbook: A neurodiversity-affirmative approach. Jessica Kingsley Publishers.
- Henderson, D. A., Wayland, S. C., & White, J. (2023). Is this autism? A guide for clinicians and everyone else. Routledge.
- Henderson, D. A., Wayland, S. C., & White, J. (2023). Is this autism? A companion guide for diagnosing. Routledge.
- Hull, L., Petrides, K. V., & Mandy, W. (2020). The Female Autism Phenotype and Camouflaging: A Narrative Review. Review Journal of Autism and Developmental Disorders, 7(4), 306–317. https://doi.org/10.1007/s40489-020-00197-9
- Gratton, F. V. (2020). Supporting transgender autistic youth and adults: A guide for professionals and families. Jessica Kingsley Publishers.
- Hours, C., Recasens, C., & Baleyte, J.-M. (2022). ASD and ADHD Comorbidity: What Are We Talking About? Frontiers in Psychiatry, 13, 837424. https://doi.org/10.3389/fpsyt.2022.837424
- Kahn, N. F., Sequeira, G. M., Reyes, V., Garrison, M. M., Orlich, F., Christakis, D. A., Aye, T., Conard, L. A. E., Dowshen, N., Kazak, A. E., Nahata, L., Nokoff, N. J., Voss, R. V., & Richardson, L. P. (2023). Mental Health of Youth With Autism Spectrum Disorder and Gender Dysphoria. Pediatrics, 152(6), e2023063289. https://doi.org/10.1542/peds.2023-063289

References

- Kuo, L., Perez-Garcia, S., Burke, L., Yamasaki, V., & Le, T. (2022). Performance, Fantasy, or Narrative: LGBTQ+ Asian American Identity Through Kpop Media and Fandom. Journal of Homosexuality, 69(1), 145–168. https://doi.org/10.1080/00918369.2020.1815428
- Kuo, M. H., Orsmond, G. I., Coster, W. J., & Cohn, E. S. (2014). Media use among adolescents with autism spectrum disorder. Autism, 18(8), 914–923. https://doi.org/10.1177/1362361313497832
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. Journal of the American Academy of Child & Adolescent Psychiatry, 56(6), 466–474. https://doi.org/10.1016/j.jaac.2017.03.013
- McCrossin, R. (2022). Finding the True Number of Females with Autistic Spectrum Disorder by Estimating the Biases in Initial Recognition and Clinical Diagnosis. Children, 9(2), 272. https://doi.org/10.3390/children9020272
- McDonald, T. A. M. (2020). Autism Identity and the "Lost Generation": Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum. Autism in Adulthood, 2(1), 13–23. https://doi.org/10.1089/aut.2019.0069
- McQuaid, G., Ratto, A. B., Jack, A., Khuu, A., Smith, J. V., Duane, S., Clawson, A., Lee, N. R., Verbalis, A., Pelphrey, K., Kenworthy, L., Wallace, G., & Strang, J. (2023). Gender, assigned sex at birth, and gender diversity: Windows into diagnostic timing disparities in autism [Preprint]. PsyArXiv. https://doi.org/10.31234/osf.io/kc6ax
- Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem.' Disability & Society, 27(6), 883–887. https://doi.org/10.1080/09687599.2012.710008
- Overton, G. L., Marsà-Sambola, F., Martin, R., & Cavenagh, P. (2023). Understanding the Self-identification of Autism in Adults: A Scoping Review. Review Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s40489-023-00361-x
- Price, D. (2022). Unmasking autism: Discovering the new faces of neurodiversity (First edition). Harmony Books
- Russell, S. T., Pollitt, A. M., Li, G., & Grossman, A. H. (2018). Chosen Name Use Is Linked to Reduced Depressive Symptoms, Suicidal Ideation, and Suicidal Behavior Among Transgender Youth. Journal of Adolescent Health, 63(4), 503–505. https://doi.org/10.1016/j.jadohealth.2018.02.003
- Strang, J. F., Anthony, L. G., Song, A., Lai, M.-C., Knauss, M., Sadikova, E., Graham, E., Zaks, Z., Wimms, H., Willing, L., Call, D., Mancilla, M., Shakin, S., Vilain, E., Kim, D.-Y., Maisashvili, T., Khawaja, A., & Kenworthy, L. (2023). In Addition to Stigma: Cognitive and Autism-Related Predictors of Mental Health in Transgender Adolescents. Journal of Clinical Child & Adolescent Psychology, 52(2), 212–229. https://doi.org/10.1080/15374416.2021.1916940
- Strang, J. F., McClellan, L. S., Li, S., Jack, A. E., Wallace, G. L., McQuaid, G. A., Kenworthy, L., Anthony, L. G., Lai, M.-C., Pelphrey, K. A., Thalberg, A. E., Nelson, E. E., Phan, J. M., Sadikova, E., Fischbach, A. L., Thomas, J., & Vaidya, C. J. (2023). The autism spectrum among transgender youth: Default mode functional connectivity. Cerebral Cortex, 33(11), 6633–6647. https://doi.org/10.1093/cercor/bhac530
- Thomas, T. R., Tener, A. J., Pearlman, A. M., Imborek, K. L., Yang, J. S., & Michaelson, J. J. (2022). Dimensional gender diversity is associated with greater polygenic propensity for cognitive performance and interacts with other genetic factors in predicting health outcomes.
- Van Schalkwyk, G. I., Marin, C. E., Ortiz, M., Rolison, M., Qayyum, Z., McPartland, J. C., Lebowitz, E. R., Volkmar, F. R., & Silverman, W. K. (2017). Social Media Use, Friendship Quality, and the Moderating Role of Anxiety in Adolescents with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 47(9), 2805–2813. https://doi.org/10.1007/s10803-017-3201-6
- Walker, N. (2021). Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities. Autonomous Press.
- Warrier, V., Greenberg, D. M., Weir, E., Buckingham, C., Smith, P., Lai, M.-C., Allison, C., & Baron-Cohen, S. (2020). Elevated rates of autism, other neurodevelopmental and psychiatric diagnoses, and autistic traits in transgender and gender-diverse individuals. Nature Communications, 11(1), 3959. https://doi.org/10.1038/s41467-020-17794-1
- Yeargin-Allsopp, M., Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., & Murphy, C. (2003). Prevalence of Autism in a US Metropolitan Area.