

Understanding Women with Autism: Symptom Presentation, Resources, and a Conversation with an Autist

UNM Continuum of Care Fall Training

October 1, 2021
9:00-12:30



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Acknowledgements

Founded in 1889, the University of New Mexico sits on the traditional homelands of the Pueblo of Sandia. The original peoples of New Mexico – Pueblo, Navajo, and Apache – since time immemorial, have deep connections to the land and have made significant contributions to the broader community statewide. We honor the land itself and those who remain stewards of this land throughout the generations and also acknowledge our committed relationship to Indigenous peoples. We gratefully recognize our history.



Who are we?

Elisheva Levin,
PhD

Ann Branscum,
PhD



Tentative Plan for the Day:

Session 1 (9:00-10:30)

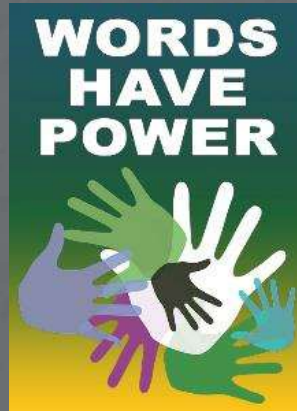
- A. Defining the Language of Autism & Disability
- B. Defining Autism Symptomology
- C. Intersectionality's
- D. Neurodiversity

Session 2 (10:45-12:30)

- A. Adult Resources
- B. An Autist's Experience



Defining the Language of Autism & Disability



A Word about Language

Person First Usage

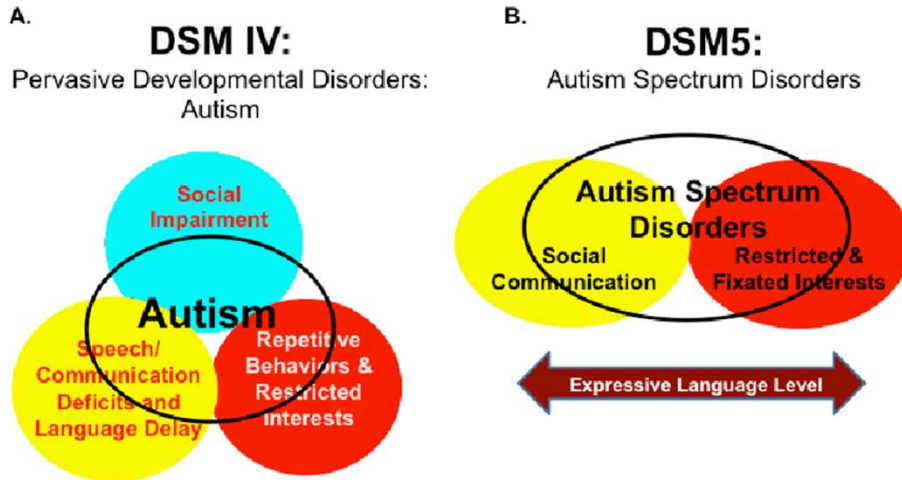
- Literally “person with autism”
- States person ≠ disability
- Implies a diagnosis or difference from the norm
- Refers to supports, treatment, and cure



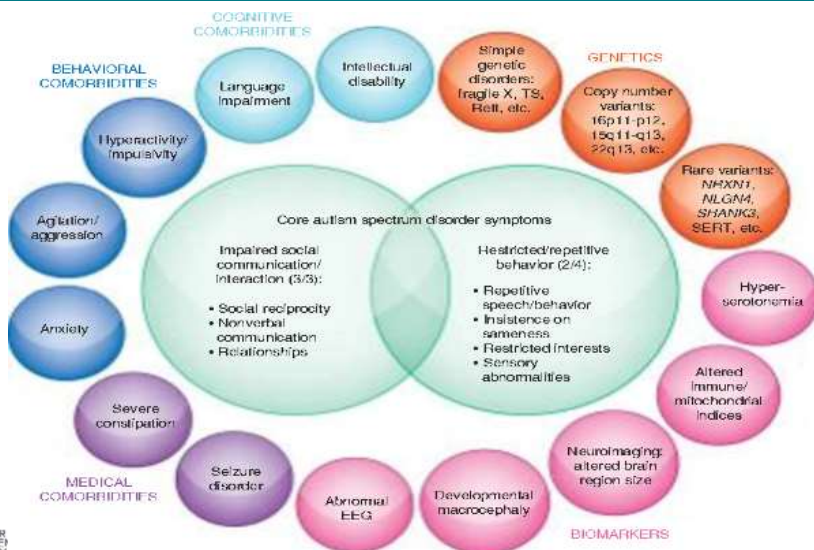
Identity First Usage

- Literally “autistic person”
- States autism ≠ deficit
- Implies neurodiversity is the norm
- Refers to supports and access to citizenship

Autism Spectrum Disorder (DSM-5)



Autism Co-morbidities & Genetics



Published in
Neuropsychopharmacology 2012
Networking in Autism: Leveraging Genetic, Biomarker and Model System Findings in the Search for New Treatments. Veenstra-VanderWeele, R. Blakely

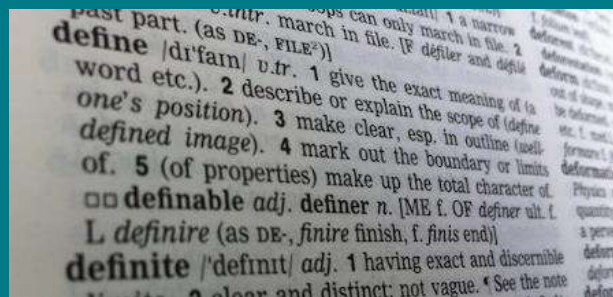


Defining Autism Symptomology

- Basic Definitions
- Female Differences
- Problems with misdiagnosis/no diagnosis
- Masking
- Importance of Mental Health



Basic Definitions





Social communication and social interaction (3 of 3)

- 1. Social-emotional reciprocity.
- 2. **Nonverbal communicative behaviors** used for social interaction.
- 3. **Relationships:** developing, maintaining, and understanding

Stereotyped or repetitive motor movements, use of objects, or speech (2 of 4)

- 1. **Repetitive** movements, use of objects, or speech
- 2. **Routines** or ritualized **patterns** of verbal or nonverbal behavior.
- 3. Intense **interests**
- 4. **Sensory** differences



(APA, 2013)



Early development



Significant impairment



Not better explained by something else

Levels:

- 1: Requiring support
- 2: Requiring substantial support
- 3: Requiring very substantial support



(APA, 2013)

Prevalence Rates: USA

Identified Prevalence of Autism Spectrum Disorder

ADDM Network 2000-2016 Combining Data from All Sites

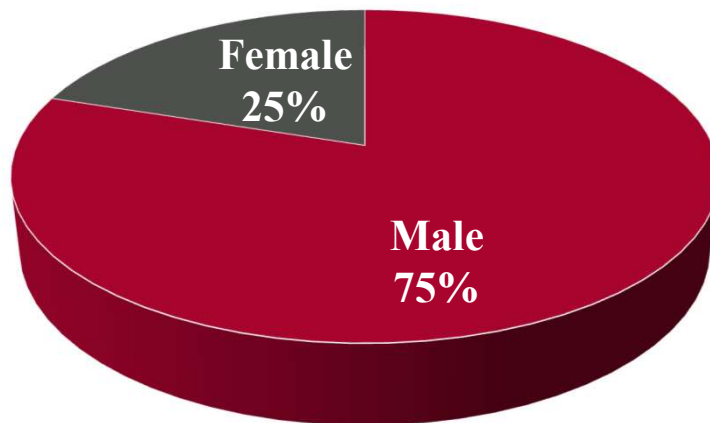
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children...
2000	1992	6	6.7 (4.5-9.9)	1 in 150
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2014	2006	11	16.8 (13.1-29.3)	1 in 59
2016	2008	11	18.5 (18.0-19.1)	1 in 54



<https://www.cdc.gov/ncbddd/autism/data.html>; Maenner et al., 2020

Prevalence Rates: USA, 2016 Data

3.4-4.1:1



<https://www.cdc.gov/ncbddd/autism/data.html>; Maenner et al., 2020



NM CDD Data



Prevalence
Female 23%
Male 77%

ASD Diagnosis
Females (54%)
Males (64%)

Age of Diagnosis
Females: 6.47
Males 6.51

Females More Likely to Be:
AI/AN (19%F, 13%M)
Asian (4%F, 2%M)
Black/AA (5%F, 2%M)
[Hispanic/Latino (54%F, 58%M)]

ID Diagnosis
Females 17%
Males 8%



Female Differences



Are We Missing Females?

Growing concern that females with autism are overlooked in both identification and research.



Are We Missing Females?

- A predictive model (USA) indicated up to 39% more females should be diagnosed with ASD
- Ratio should be about 28% female and 72% male
- Leaky assessment pipeline



Theories

Risk Factors



Biological Risk Factors



Genetic Risk Factors



Social-Cultural Biases



Differences in Symptomology



Camouflaging



(Hull et al., 2020; Jack et al., 2021; Lockwood Estrin et. al., 2020; Robinson et al., 2013)

Related to Research and Assessment

- Most research includes males, not females
- Present differently than males (more about this to come)
- Diagnostic processes less likely to identify females (Loomes et al., 2017; Russell et al., 2011)
 - Especially if have age-level language and IQ
- Norming of diagnostic tools



ASD Screeners Norming Data

Modified Checklist for Autism in Toddlers-Revised with Follow Up (M-CHAT-R/F; Robins et al., 2014) Validation Study

- 7,570 girls (48%),
- 7,793 boys (50%),
- 249 gender unspecified (2%)

Screening Tool for Autism in Toddlers and Young Children (STAT; Stone et. Al., 2000) Preliminary Validation Study

- 48 boys (66%)
- 25 girls (34%)

ASD Assessments Norming Data

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012)

Participants described as having Autism in the validation sample

- Toddler Module: Total N= 182, Females: 24%, Males: 76%
- Module 1: Females 116 (20%), Males 460 (80%)
- Module 2: Females 34 (18%), Males 150 (82%)
- Module 3: Females 17 (13%), Males 112 (87%)
- Module 4: Females 2 (13%), Males 14 (87%)

Childhood Autism Rating Scale, Second Edition (CARS-2; Schopler et al., 2010) Verification Sample

- Standard Version (ST): Female 230 (22%), Male 804 (78%)
- High Functioning (HF): Female 214 (22%); Male 780 (78%)

ASD Assessments Norming Data

Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012)

Standardization Sample

- Preschool
 - Female 120 (49%), male 127 (51%)
- School-age (has sex-based norms)
 - Female 518 (51%), male 493 (49%)
- Adult standardization sample
 - Female 279 (54%), male 323 (46%)

Autism Diagnostic Interview- Revised (ADI-R; Rutter, LeCouteur, & Lord, 2003)

- ADI to ADI-R Study (Lord et al., 1994): 2 females (20%), 8 males (80%)
- ADI-R with 84 preschoolers (Lord et al., 1993): participant sex not reported
- Replication study (Lord et al., 1997): 106 females (25%), 326 males (75%)

Assessment Scale Considerations

- Scales normed by sex:
 - *Social Responsiveness Scale, Second Edition (SRS-2; Constantino & Gruber, 2012)*, school age only
 - Fewer symptoms required for females for significance
 - *Behavior Assessment System for Children (BASC-3; Reynolds & Kamphaus, 2015)*: not ASD specific

Social Communication Skill Differences in Females with ASD on an *ADOS-2* Task

Polish study (Rynkiewisc et al., 2016)

16 girls with ASD, 17 boys

Demonstration task, *ADOS-2* Module 3

Results

Females had more vivid gestures

Females had better communication skills



Sex Differences in Adaptive Behavior and Social Skills Study

- Ratto and colleagues, 2018 Study
- School-age youth diagnosed with ASD without co-occurring ID
- Examined *ADOS/ADOS-2*, *SRS*, and *ADI-R*



Ratto et al., 2018 Study: *ADOS*, 1st and 2nd Editions

Females **less RRBs**
(lower scores on
excessive interests,
small effect size)

Females had **less
directed facial
expressions** (small
effect)

Females out-performed
in **identifying and
sharing emotions with
others** (small effect)

None of the findings survived corrections for multiple comparisons, so overall, performance on the ADOS/ADOS-2 considered similar across sexes.



Ratto et al., 2018 Study: *Autism Diagnostic Interview-Revised (ADI-R; Rutter, et.a., 2003)*

Females
significantly less
likely to meet
ASD criteria

Females with
higher IQs least
likely to meet
ASD criteria



Another *ADI-R* Study (Beggiato et al., 2017)

Range of facial expressions
(reciprocal social interactions domain, girls scored higher than boys)

Imaginative play
(communication impairments domain, where girls have more)

Circumscribed interests (repetitive and stereotyped behaviors domain, less pronounced in girls)

Unusual preoccupations
(repetitive and stereotyped behaviors domain, less pronounced in girls)

Recommendation: apply correction factors to avoid a gender bias in the diagnosis of ASD when using the ADI-R.

Assessment Scale Recommendations

- Clinical judgement/expertise paired with measurement tool information/scores
- May consider borderline results as possibly significant for girls if scale not normed by sex

General Considerations

- May have autism but not a diagnosis and/or may have other diagnoses
- Compare females to same-age, non-autistic females, not to males with ASD
- Females may have fewer externalizing issues
- Think about QUALITY
- More adults seeking diagnosis
- Seek consultation as needed



Social Communication Considerations



Early Development Considerations: Social Communication

Very Important to Consider, No Matter the Age:

- Might have been an early talker, precocious
- More interaction with adults
- One friend
- “Shy”
- Social functioning: “I don’t understand”
- “She was just different”
- Too sensitive, too intense, too much...



Play Behaviors

- Directed play (my way or the highway)
- May have used pretend play but could involve intense fantasies or limited flexibility
- Quality of pretend play:
 - **Scripting from movies/videos**

Play Behaviors

- Interacted with same-age peers or adults
- Interacted with males, females, both?
- Quality:
 - Type of play
 - Following or actually interacting



Social Communication Skill Differences in Females with ASD (Head et al., 2014; Hiller et al., 2014; Kreiser & White, 2014)

- More difficult to maintain long-term friendships or relationships
- Difficulty coping with conflict in social relationships (as compared to males with ASD)
- Differences might be more apparent in early childhood and then again in adolescence
- Larger emotional vocabulary
- Greater awareness and desire for social interaction
- May develop one or two close friends



Conversation

- Consider ability to engage in extended reciprocal interactions
- Variety of conversational topics?
- Consider complexity of inquiries
 - Basic questions
 - Canned questions/responses
- Responses to social bids
- Consider prosody
- Formal speech
- Volunteers too much info (TMI!)



Information Gathering

(Hull et al., 2019; Lai & Szatmari, 2019)

- Ask about masking/camouflaging
 - Purposely mimics peers' social behaviors and interests?
- Ask about different contexts
 - May see less camouflaging or compensation in less-pressured settings
- Assess ability to **maintain** social relationships (Hull et al., 2019)
- Have mismatched interests with others?
- Easier to express self/ideas via writing/art rather than face-to-face interactions?

Information Gathering (Hull et al., 2019; Lai & Szatmari, 2019)

- How are social situations for them?
 - Uncertain?
 - Exhausting (physically, emotionally)?
 - Need alone time to recover?
 - How is social conflict for them?
 - Apologize often?
- Experienced peer rejection and/or bullying?
 - Understand the reason for this?
- Identity and authenticity
 - Able to feel like themselves?
 - Feel as if they are losing track of who they really are?
 - Internal experience different than external presentation
- Ask what they do with their friends
 - Can they engage in these activities alone?
 - Situations have a social buffer (e.g., pet)



RRB Considerations



Early Development Considerations: RRBs

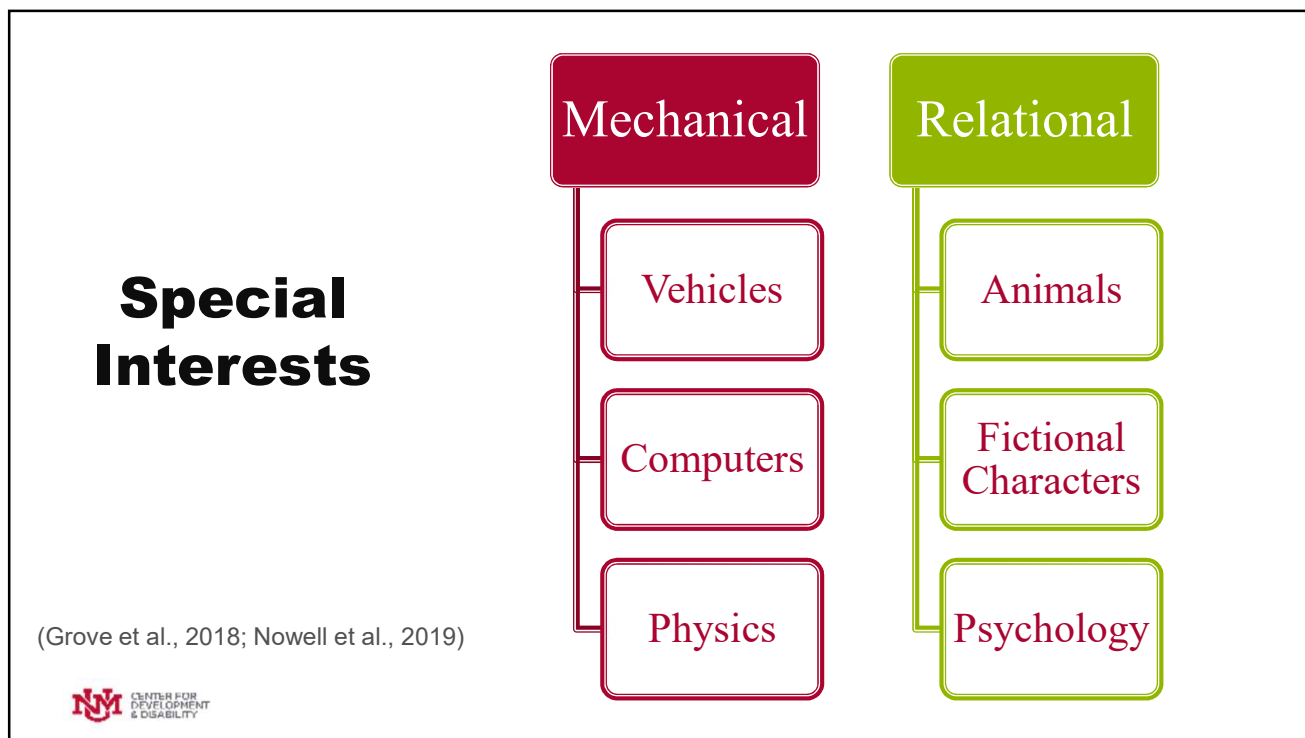
- Might have been hyperlexic
- Epic meltdowns
- Rule-based or routine-based behavior



Restricted Interests Differences

(Hull et al., 2019; Lai & Baron-Cohen, 2015)

- More socially acceptable
 - My Little Pony
 - Justin Bieber
 - Frozen
- But **intensity** and **duration** might be different
- May not talk about interests *ad nauseum* like males
- Tend to be related to people/animals rather than inanimate objects
- Creates fewer difficulties for the family



Motor Mannerisms

- May not display as many motor mannerisms (Mandy et al., 2012; Szatmari et al., 2012)
- Ask about “hidden” (subdued), or context-specific expression

Sensory

- Consider sensory intolerances and related masking
- Consider food sensitivities/preferences
 - **Eating disorder**

Adaptive Skills Considerations



Adaptive Skill Differences

(Lai & Stazmari, 2020; Ratto et al., 2018)

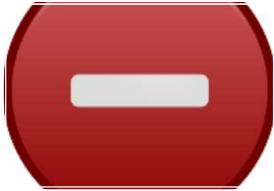
- Important to consider because could impact available supports
- Lower adaptive skills (as compared to same-age females)
- Adaptive skill differences might manifest more in adolescence and early adulthood



Problems with misdiagnosis or no diagnosis



Receiving a Diagnosis



**KNOW
YOURSELF**



Concerns with Under- or Late- Identification (Begeer et al., 2013):

Delays intervention that might have otherwise helped address unique behavioral health and social needs

“I think women tend to be diagnosed in life when they actually push for it themselves...when you’re a child, you don’t realize that you’re anxious and depressed...your education is going to suffer because of that and I think that if I had known, and if people had helped me from earlier on, then life would’ve been a whole lot easier” (Bargiela, Steward, & Mandy, 2016; p. 7).

Concerns with Under- or Late- Identification (Begeer et al., 2013):

Social susceptibility

- Bullying
- Coercion
- Manipulation
- Understanding Consent

I was really badly bullied. Someone spat on me once, while others would react by getting angry. I would respond by saying "that's a violation of the criminal behavior act" or something like that. It was not how people would expect you to react.

Eloise Stark

(<https://www.bbc.com/news/uk-england-51475739>)



Masking



Camouflaging Effect (Hull et al., 2017, 2019)

- Compensating for and masking characteristics of autism
- Used to minimize the appearance of autism-related characteristics in social settings
- Conscious and unconscious
- Females are more likely to use coping strategies to hide or mask ASD behaviors



Adaptive Morphing (Lawson, 2020)

- Means of keeping safe in a world that does not tolerate difference
- Disguise your autism (gender, sexuality, etc.)



Motivations for Camouflaging (Hull et al., 2017)

- Desire to fit in
- Avoid bullying or other negative treatment
- Form connections with others that might be difficult if they presented their authentic self



Camouflaging Examples (Livingston & Happe, 2017)

Mimicking facial expressions

Limit hand flapping

Learning/mimicking social rules or behaviors from books or television shows

Forcing eye contact

Stop talking about an interest

Laugh when others laugh

Using executive function strategies to learn to recognize different facial expressions



How Masking Might Look at School

Compliant

Anxious

Worried

Exhausted

Well-behaved

Socially Lost

Gifted

Perfectionist



The image shows three young women sitting on a blue couch. Each woman is holding a laptop computer in front of her face, completely obscuring her eyes and expression. This visual metaphor represents the concept of 'masking' in a school setting, where individuals hide their true feelings and reactions to fit in or avoid negative consequences.



How Masking Might Look at Work

- Hiding interests and stims
- Reluctance to ask for accommodations
- Saying “yes” to everything asked
- Using social scripts/mimicking others
- Wearing uncomfortable clothing

Hannah Gadsby on the “Comfort Cocoon” She Calls Her Clothes



<https://www.vanityfair.com/style/2021/04/hannah-gadsby-on-the-comfort-cocoon-she-calls-her-clothes>

Tools for Measuring Masking

Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2018)

- Open access: <https://link.springer.com/content/pdf/10.1007/s10803-018-3792-6.pdf>
- 25 item self-report, sample UK population 16+
- Three subscales:
 - Compensation
 - Masking
 - Assimilation



Compensation Checklist (Livingstone et al., 2020)

- Open access: <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-019-0308-y>
- 31 item Compensation Checklist
- Can be completed as a self-report or clinician measure
- Subscale areas:
 - Masking
 - Shallow Compensation
 - Deep Compensation
 - Accommodation

Research | [Open Access](#) | Published: 12 February 2020

Quantifying compensatory strategies in adults with and without diagnosed autism

[Lucy Anne Livingston](#) , [Punit Shah](#), [Victoria Milner](#) & [Francesca Happé](#)

Molecular Autism **11**, Article number: 15 (2020) | [Cite this article](#)

<https://molecularautism.biomedcentral.com/track/pdf/10.1186/s13229-019-0308-y> (open access)

Scroll Down 

Supplementary information

 [Additional file 1. Supplementary materials.](#)

Mental Health



Mental Health (Begeer et al., 2013):

Increased chance of mental health challenges (Hirvikoski et al., 2020; Kovacs & Devlin, 1998):

Anxiety

Increased risk for suicide

Self-harm

Impact of masking

Depression

Eating disorders

Misdiagnosis



The costs of camouflaging autism

Many girls hide their autism, sometimes evading diagnosis well into adulthood. These efforts can help women on the spectrum socially and professionally, but they can also do serious harm.

“Nearly everyone makes small adjustments to fit in better or conform to social norms, but camouflaging calls for constant and elaborate effort. It can help women with autism maintain their relationships and careers, but those gains often come at a heavy cost, including physical exhaustion and extreme anxiety.”



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<https://www.spectrumnews.org/features/deep-dive/costs-camouflaging-autism/>; Russo (2018)

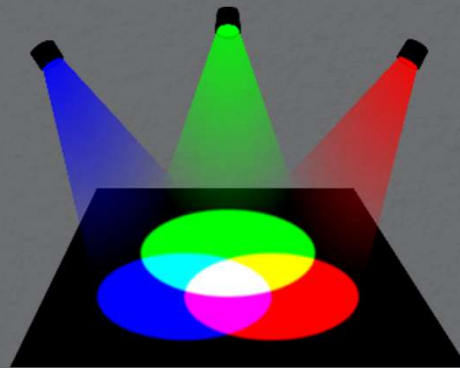
The Spoon Theory

- A metaphor used to describe the amount of mental or physical energy a person has available for daily activities and tasks.
- Developed by Christine Miserandino as a way to express how it felt to have lupus.
- Provides a visual representation of units of energy that a person might have and how chronic disability forces her to plan out her days and actions in advance, so as not to run out of energy, or spoons, before the end of the day

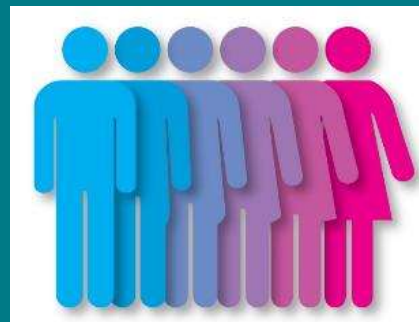


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Intersectionality's



Gender Identity and Autism



Some Terminology



<https://au.reachout.com/articles/the-difference-between-gender-sex-and-sexuality>

Some Terminology



<https://au.reachout.com/articles/the-difference-between-gender-sex-and-sexuality>

Some Gender Identity Terminology

- **Cisgender:** individuals who have a match between the sex they were assigned at birth, their bodies, and their gender identity
- **Gender non-conforming:** an adjective and umbrella term to describe individuals whose gender expression, gender identity, or gender role differs from gender norms associated with their assigned birth sex.
- **Non-binary:** umbrella term used to describe gender that doesn't fit squarely into male or female. Can include people who feel their gender is a mix of both, changes often, is something totally separate, or have no strong sense of gender at all.
- **Genderqueer:** refers to a person whose gender identity falls outside of the gender binary (i.e. identifies with neither or both genders).
- **Gender Dysphoria:** refers to discomfort or distress that is associated with a discrepancy between a person's gender identity and that person's sex assigned at birth (and the associated gender role and/or primary and secondary sex characteristics)
- **Two-spirit:** some Indigenous people use this term to describe an individual that possess both masculine and feminine traits



Gender Diversity Considerations

(Warrier et al., 2020)

Those who do not identify with the sex they were assigned at birth:

Three to six times more likely to have ASD compared to cisgender people

Gender-diverse people more likely to:

*Report ASD traits

*Suspect they have undiagnosed ASD



Gender Dysphoria in Autism

- Less binary about many things
- Less influenced by societal expectations
- Termed “gender defiant” by some (Gilani et al., 2015)
- More likely to have mental health challenges, bullying/victimization, suicidal ideation, worse quality of life (Chang et al., 2021)



Ideas for Providers

- Think carefully about how we ask about gender
- Ask about pronoun preferences
- Have voices of gender diverse people in our communities/ agencies/ advisory boards.
- Include preferred pronouns in emails, Zoom names.

Autistic Gender ID & Relationships



Importance of Connection

- Social connection is a powerful predictor of long-term physical and mental health. Having meaningful friendships impacts our:
 - Cardiovascular system
 - Immune systems
 - Stress responses
 - Sleep
 - Cognitive health
 - Longevity
- Loneliness (a mismatch between desired and actual levels of social connection) is a mortality risk factor, referred to as a toxic emotion by some.
- Loneliness can be under recognized for people with autism



Relationships

- May have fewer friends but friendships can be deep and greatly meaningful
- Some have more male friends
- Friendships can form via shared interests
- Sexual relationships may be impacted by autism (e.g., flirting, understand nuance, understanding how to please their partner sexually)
- May see cautiousness with forming relationships/friendships
 - Don't mistake as disinterest
 - Consider reasons for cautiousness (relational bullying/aggression)



Sexuality, LGBTQ+



Sexuality and Autism

- We tend to treat people with autism like children
- We desexualize those with ASD
- We are uncomfortable talking about sex

But:

- Sexuality is an integral part of being human.
- Love, affection, and sexual intimacy contribute to health relationships and individual well-being
- Sexual health involves a positive and respectful approach to sexuality and sexual relationships, including pleasurable and safe sexual experiences



From the Arc's Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD, 2019)

- People with intellectual disability and/or developmental disabilities, like all people, have **inherent** sexual rights. These rights and needs must be affirmed, defended, and respected.
- Every person has the right to **exercise choices** regarding sexual expression and social relationships. The presence of an intellectual or developmental disability, regardless of severity, does not, in itself, justify loss of rights related to sexuality.
- All people have the right within interpersonal relationships to:
 - Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose
 - Dignity and respect
 - Privacy, confidentiality, and freedom of association.



From the Arc Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD, 2019)

- With respect to sexuality, individuals have a right to:
 - **Sexual expression and education, reflective** of their own cultural, religious and moral values and of social responsibility
 - Individualized **education and information** to encourage informed decision-making, including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases
 - **Protection** from sexual harassment and from physical, sexual, and emotional abuse. With respect to sexuality, individuals have a responsibility to consider the values, rights, and feelings of others.



Gender and sexual minorities

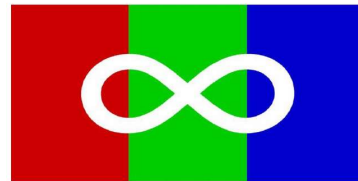
L	G	B	T	T	Q	Q	I	A	A	P
Lesbian A woman who is primarily attracted to women.	Gay A man who is primarily attracted to men; sometimes a broad term for individuals primarily attracted to the same sex.	Bisexual An individual attracted to people of their own and opposite gender.	Transgender A person whose gender identity differs from their assigned sex at birth.	Transexual An outdated term that originated in the medical and psychological communities for people who have permanently changed their gender identity through surgery and hormones.	Queer An umbrella term to be more inclusive of the many identities and variations that make up the LGBTQ+ community.	Questioning The process of exploring and discovering one's own sexual orientation, gender identity and/or gender expression.	Intersex An individual whose sexual anatomy or chromosomes do not fit with the traditional markers of "female" and "male."	Ally Typically a non-queer person who supports and advocates for the queer community; an individual within the LGBTQ+ community can be an ally for another member that identifies differently than them.	Asexual An individual who generally does not feel sexual desire or attraction to any group of people. It is not the same as celibacy and has many sub-groups.	Pansexual A person who experiences sexual, romantic, physical and/or spiritual attraction to members of all gender identities/expressions, not just people who fit into the standard gender binary.



<https://buffer.com/resources/lgbtqia-resources/>

The Double Rainbow

- Autistic and lesbian, gay, bisexual, or transgender
- AKA “dual rainbow” or “twainbow”
- Two separate rainbows; two separate coming out stories



Double Minority

“One of the two main autism symbols, the infinity sign shows strength, potential, and pride. The primary colors are capable of composing all other colors of the rainbow, so it represents the overlap of autism onto every Pride gradient, since those on the spectrum are found in every country, sex, race, religion, and sexual orientation.”

Louis Molnar, founder of Twainbow.org

What Providers Need to Know

Women with disabilities are sexually assaulted or abused at a rate at least **twice** that of the general population of women.

Among adults who have developmental disabilities, as many as 83% of females and 32% of males are victims of sexual assault.



What Providers Need to Know

Sexual minorities were three times more likely to report sexual violence and/or harassment compared to heterosexual people.

Most studies reveal that approximately 50% of transgender people experience sexual violence at some point in their lifetime.



What Providers Need to Know

1 in 8 neurodivergent and LGBTQIA+ Australian young people have attempted suicide in the past year.

1 in 3 have attempted suicide in their lifetime.
Rate is more than twice non-disabled.

Rate is more than twice non-disabled LGBTQIA+ youth and five times as high as youth who do not have a disability and do not identify as LGBTQIA+.



Questions to Ask Yourself

- Am I asking the same information and providing the same information, resources, options, and recommendations I would give a patient without a disability?
- Am I assuming that sex for this patient is the same as sex for a nondisabled person?
- Am I assuming their sexual orientation and gender identity?
- Am I providing accessible and inclusive resources?
- Am I talking to them, or to their parent or support staff?



Questions to Consider Asking the Client

- What is the best way for you to communicate during this appointment?
- Are you sexually active?
- How does your disability impact your sexuality and your experience of sex?
- Do you have a history of assault?
- What makes resources accessible and inclusive for you?



Consent

Teach Consent

- What it is
- When it is needed
- Not just the absence of a no but presence of a yes

Model Consent

- Examples:
 - Before hugging someone;
 - type of hug
 - Pushing their wheelchair

Teach How to Ask for Consent

- What do you want me to do?
- Does this feel good?
- Is this ok?
- Do you want me to stop?
- How's this?

Teach How to Revoke Consent

- Pull away
- Say/sign/write no or stop
- I'm not sure
- Not right now



Resources

- Real Talk Toolkit from Autistic Self Advocacy Network
 - <https://autisticadvocacy.org/wp-content/uploads/2015/12/realtalk-toolkit-v2.pdf>
- Scarleteen: Sex Ed for the Real World
 - <http://www.scarleteen.com/>
- Key Terms and Concepts in Understanding Gender Diversity and Sexual Orientation Among Students, APA
 - <https://www.apa.org/pi/lgbt/programs/safe-supportive/lgbt/key-terms.pdf>



Sensory Differences & Sexuality



Sensory Considerations (Gray et al., 2021)

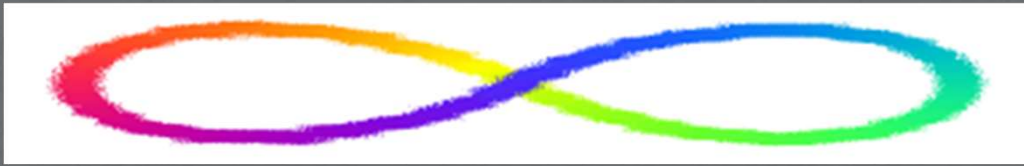
- Sensory differences can impact ability to meet others
 - Often meet others in large social gatherings and this can be overwhelming for many autistic people
- Sensory features sometimes impactful enough that they reduce libido or willingness to engage in sexual activity with others
- Less common sexual sensory fascinations sometimes noted



Sensory Response Patterns (Adapted from Gray et al., 2021)

Code	Description	Examples
Low neurological threshold	Highly sensitive to sensory input during sexual or romantic encounters	Repetitive squeaking of bed might distract
High neurological threshold	Great deal of sensory input needed to meet sensory demands	Increased time needed
Tactile	Sensory experiences related to touch sensations	Over or under sensitivity can impact experience
Auditory, Visual	Hearing and vision sensations	Distracted by environmental sounds and sights
Gustatory	Taste sensations	Kissing- sensitive to partner's taste and/or what they had during their last meal
Olfactory	Smell sensations	Sensitive to body odors or body fluid smells
Proprioceptive	Sensory experiences related to body position or pressure	Preferences related to strength of touch

Thinking about *Neurodiversity*



What is Neurodiversity?

NEURODIVERSITY:

differences in how the human brain works

- **Neurodiversity *IS* a biological fact**
- **Neurodiversity is *NOT* a political or social activist movement**
- **Neurodiversity is *NOT* an individual trait, it varies across Anatomically Modern Humans (Homo sapiens sapiens)**
- **A person different from the dominant standards of “normal” neurocognitive functioning is**

NEURODIVERGENT

Companies now hiring neurodiverse talent:

Developing programs, reform HR to hire needed talent

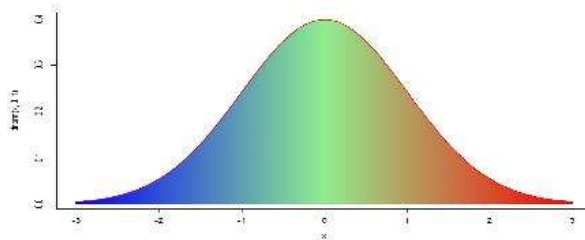
- Team up with experienced government/non-profits
- Include non-interview assessment processes
- Train management & colleagues in what to expect
- Set up support programs
- Tailor methods to manage careers
- Scale and then mainstream the program



Disability as a Social Construction and The Autism Policy Paradigm Shift



The Full House



- The Normal Curve represents the *RANGE* of variation in a continuous trait
- The range of variation represents the *WHOLE* population
- Normal is the *ENTIRE RANGE* of variation of a trait in a given population



Autism Tsunami

- A *TIDAL WAVE* of children diagnosed in large numbers *HITTING THE SHORES* of adulthood
 - The tsunami includes *ADULTS* not yet formally labeled and/or not receiving services
- A tidal wave of individuals with a *DIVERSITY OF NEEDS* overwhelming ASD services in New Mexico

Goehner, 2012

Khan, 2015

Levin, 2017



Policy Paradigm Shift: The Structure of Scientific Revolutions

- Evidential and philosophical *ANOMALIES BUILD* within an established scientific theory
- A *DISCONTINUITY OCCURS* and is documented by a series of critical findings discussed in a series of scientific papers and meetings
- Taken together, these findings establish *A NEW CONCEPTUALIZATION* of the field that shares neither assumptions or vocabularies with the old



Kuhn & Hacking, 2012

The Road to a Policy Paradigm Shift

- A *GAP* in the conceptualization and delivery of ASD services *OPENS*
- ASD community members start to *DREAM* about what *GOOD POLICY* would look like
- Dreams of good policy are solidified in *PLANS TO SHIFT* the *ASD INFRASTRUCTURE*



Levin, 2017

GOAL: ACCESS TO CITIZENSHIP

- Individual Choice
- Remove Systems Barriers
- Dignity Of Risk
- Community Involvement
- Meaningful Work At Market Price & Benefits
- Independence In Living Arrangements, Recreation, & Relationships

Levin, 2017



Adult Resources and Ideas for Supports



Environment Considerations (Parents, Self, Loved Ones, Colleagues)

Support unmasking/authenticity:

- Allow for stimming
- Downtime is important
- Slower pace
- More time for transitions
- Provide comfort items
- Supportive, accommodating environment



Social/Daily Living

- Conversational skills
- Interest groups
- Support within the ASD community
- Safety: teach and protect to avoid victimization
- Self-advocacy (e.g., school or workplace accommodations)

Therapeutic Considerations

- Working with support system on acceptance/love/strengths spotting
- Support related potential psychiatric challenges
- Identity development
- Teaching calming and coping strategies (camouflaging is exhausting!)
- Executive function development (e.g., flexibility)



CDD Evaluation

- UNM Center for Development and Disability (CDD)
 - **ASD testing, children and adults**
- Referrals: self, parent, doctor, school, EI, etc.
- For more information: 505-272-3000



UNM Center for Development and Disability (CDD) Autism Programs

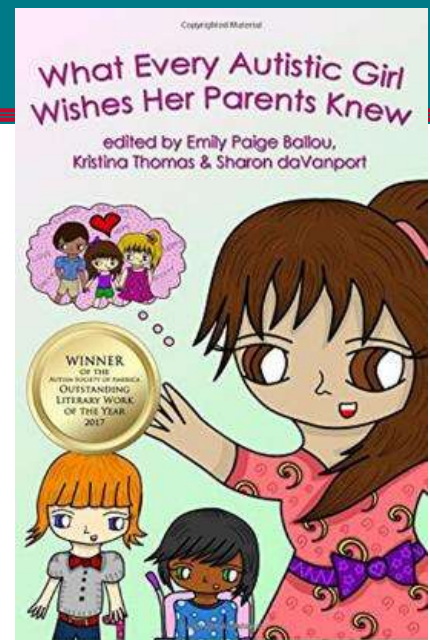
- THRIVE Program
 - Somer Wright, sdwright@salud.unm.edu
- Facing Your Fears
 - Marybeth Graham; mgraham2@salud.unm.edu
- Parent Home Training (PHT)
 - Sylvia Acosta, 505-272-4725; syacosta@salud.unm.edu
- Project ImPACT
 - Sylvia Acosta, 505-272-4725; syacosta@salud.unm.edu
- Autism Family and Provider Team
 - 505-272-1852 or 1-800-270-1861



<https://unmhealth.org/services/development-disabilities/programs/autism-programs/>

Web Resources

- Autistic Women and Nonbinary Network (AWN)
 - <https://awnnetwork.org/>
 - Organization with a mission to provide community, support and resources for Autistic women, girls, nonbinary people, and all others of marginalized genders.



Web Resources

- **Autistic fatigue - a guide for autistic adults**
- <https://www.autism.org.uk/advice-and-guidance/topics/mental-health/autistic-fatigue/autistic-adults>



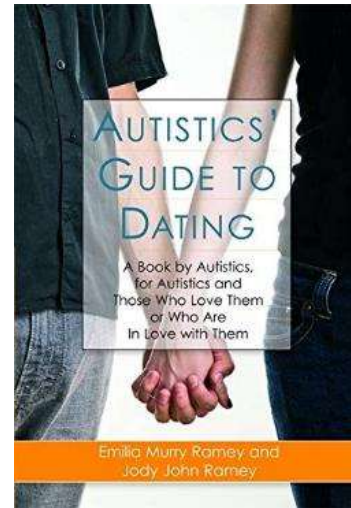
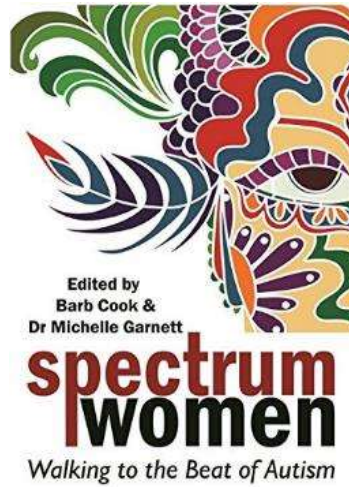
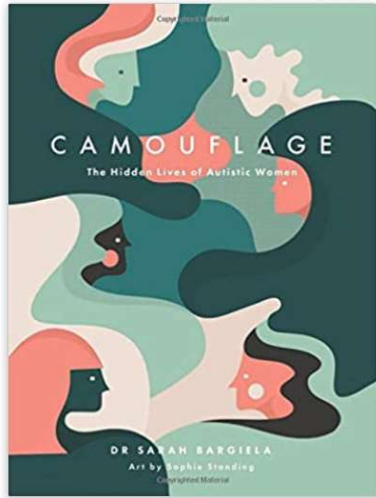
Online Groups

Social Media Groups:

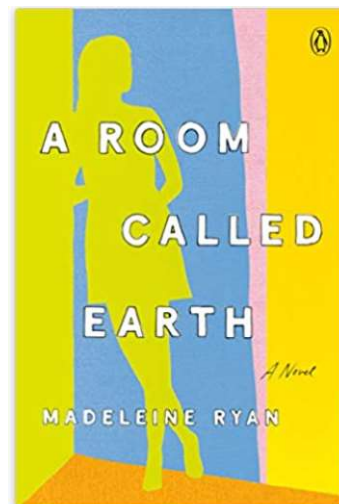
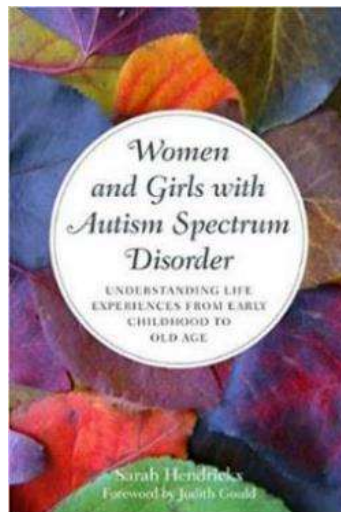
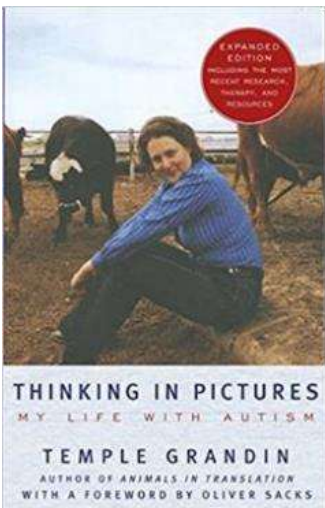
- Autistic Self-Advocacy Network (ASAN)
- Autism Late Diagnosis Support and Education
- Autism and Aspergers Safe Room: A Safe Haven for Women on the Spectrum
- I've been autistic all along?!



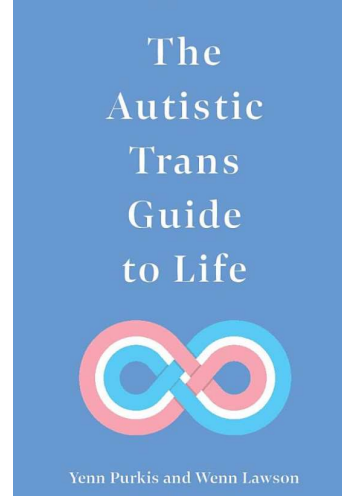
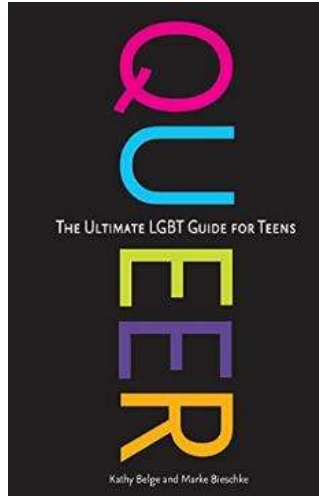
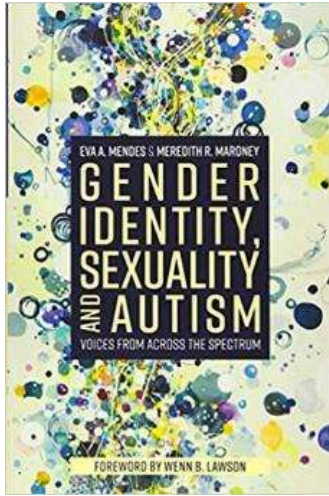
Book Ideas



Book Ideas



Book Ideas



Questions or Comments



An Autist's Experience



Elisheva Levin, PhD, Autist: My Story

Elisheva Levin earned her doctorate in Special Education at the University of New Mexico, specializing in autism and disability policy. Dr. Levin is a post-doctoral faculty member with the UNM School of Medicine at the Center for Development and Disability in the Autism and Other Developmental Disabilities Division. Her interests include rural disability policy, the effect of social constructions of disability on advocacy, and the application of received and chosen social identities on individuals with disability. Dr. Levin resides in Red Hill, New Mexico and is a snowbird riding out COVID in southern Arizona.



Interview with Ann Branscum



Open Q&A: Elisheva & Learners



Questions or Comments



Satisfaction Survey

- <https://www.surveymonkey.com/r/F2QT2ND>



References

- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Attwood, T., Garnett, M. S., & Rynkiewicz, A. (2011). Questionnaire for Autism Spectrum Conditions (Q-ASC) [Measurement instrument].
- Bargiela, S., Steward, R. & Mandy, W. (2016). The Experiences of late-diagnosed women with Autism Spectrum conditions: An investigation of the Female Autism Phenotype. *Journal of Autism and Developmental Disorders*, 46, 3281–3294. <https://doi.org/10.1007/s10803-016-2872-8>
- Barnard-Brak, L., Richman, D. and Almekdash, M.H. (2019), How many girls are we missing in ASD? An examination from a clinic- and community-based sample., *Advances in Autism*, 5(3), 214-224. <https://doi.org/10.1108/AIA-11-2018-0048>
- Begeer, S., Mandell, D., Wijinker-Holmes, B., Venderbosch, S., Rem, D., Stekelenburg, F., & Koot, H. M. (2013). Sex differences in the timing of identification among children and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(5), 1151–1156. <https://doi.org/10.1007/s10803-012-1656-z>
- Beggiato, A., Peyre, H., Maruani, A., Scheid, I., Rastam, M., Amsellem, F., Gillberg, C. I., Leboyer, M., Bourgeron, T., Gillberg, C., & Delorme, R. (2017). Gender differences in autism spectrum disorders: Divergence among specific core symptoms. *Autism research : official journal of the International Society for Autism Research*, 10(4), 680–689. <https://doi.org/10.1002/aur.1715>
- Constantine, J.N., & Gruber, C.P. (2012). *Social Responsiveness Scale, Second Edition (SRS-2)* [Manual]. Torrance, CA: Western Psychological Services.
- Gadsby, H. (2021, April 1). Hannah Gadsby on the “comfort cocoon” she calls her clothes. *Vanity Fair*, www.vanityfair.com
- Gray, S., Kirby, A. V., Graham Holmes, L. (2021). Autistic narratives of sensory features, sexuality, and relationships. *Autism in Adulthood*, 00, 1-9. <https://doi.org/10.1089/aut.2020.0049>
- Grove, R., Hoekstra, R.A., Wierda, M. and Begeer, S. (2018), Special interests and subjective wellbeing in autistic adults. *Autism Research*, 11: 766-775. <https://doi.org/10.1002/aur.1931>



References

- Head, A.M., McGillivray, J.A. & Stokes, M.A. (2014). Gender differences in emotionality and sociability in children with autism spectrum disorders. *Molecular Autism* 5, 19. <https://doi.org/10.1186/2040-2392-5-19>
- Hiller, R. M., Young, R. L., & Weber, N. (2014). Sex differences in autism spectrum disorder based on DSM-5 criteria: evidence from clinician and teacher reporting. *Journal of Abnormal Child Psychology*, 42(8), 1381–1393. <https://doi.org/10.1007/s10802-014-9881-x>
- Hirvikoski, T., Boman, M., Chen, Q., D'Onofrio, B. M., Mittendorfer-Rutz, E., Lichtenstein, P., Bölte, S., & Larsson, H. (2020). Individual risk and familial liability for suicide attempt and suicide in autism: A population-based study. *Psychological Medicine*, 50(9), 1463–1474. <https://doi.org/10.1017/S0033291719001405>
- Hull, L., Lai, M.-C., Baron-Cohen, S., Allison, C., Smith, P., Petrides, K., & Mandy, W. (2020). Gender differences in self-reported camouflaging in autistic and non-autistic adults. *Autism*, 24(2), 352–363. <https://doi.org/10.1177/1362361319864804>
- Hull, L., Mandy, W., Lai, M.C., Baron-Cohen, S., Allison, C., Smith, P., & Petrides, K.V. (2018). Development and Validation of the Camouflaging Autistic Traits Questionnaire (CAT-Q). *Journal of Autism and Developmental Disorders*, 49: 819-833. <https://doi.org/10.1007/s10803-018-3792-6>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on my best normal": Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519–2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Jack, A., Sullivan, C., Aylward, E., Bookheimer, S. Y., Dapretto, M., Gaab, N., Van Horn, J. D., Eilbott, J., Jacokes, Z., Torgerson, C. M., Bernier, R. A., Geschwind, D. H., McPartland, J. C., Nelson, C. A., Webb, S. J., Pelphrey, K. A., Gupta, A. R., & GENDAAR Consortium (2021). A neurogenetic analysis of female autism. *Brain : a journal of neurology*. Advance online publication. <https://doi.org/10.1093/brain/awab064>



References

- Kovacs, M. & Devlin, B. (1998). Internalizing disorders in childhood. *Journal of Child Psychology and Psychiatry*, 39: 47-63. <https://doi.org/10.1111/1469-7610.00303>
- Kreiser, N. L., & White, S. W. (2014). ASD in females: Are we overstating the gender difference in diagnosis?. *Clinical Child and Family Psychology Review*, 17(1), 67–84. <https://doi.org/10.1007/s10567-013-0148-9>
- Lai, M. C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013–1027. [https://doi.org/10.1016/S2215-0366\(15\)00277-1](https://doi.org/10.1016/S2215-0366(15)00277-1)
- Lai, M.C. & Szatmari, P. (2019). Sex and gender impacts on the behavioural presentation and recognition of autism. *Current Opinion in Psychiatry* 33 (1). <https://doi.org/10.1097/YCO.0000000000000575>.
- Livingston, L.A., Shah, P., Milner, V. & Happe, F. (2020). Quantifying compensatory strategies in adults with and without diagnosed autism. *Molecular Autism* 11(15). <https://doi.org/10.1186/s13229-019-0308-y>
- Lockwood Estrin, G., Milner, V., Spain, D., Happe, F., & Colvert, E. (2020). Barriers to Autism Spectrum Disorder diagnosis for young women and girls: A systematic review. *Review Journal of Autism and Developmental Disorders*, . <https://doi.org/10.1007/s40489-020-00225-8>
- Loomes, R., Hull, L., & Mandy, W. (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 and Adolescent Psychiatry*, 56(6), 466–474.
- Lord, C., Luyster, R.J., Gotham, K., & Guthrie, W. (2012). *Autism Diagnostic Observation Schedule1, Second Edition (ADOS-2) [Manual: Modules 1-4]*. Torrance, CA: Western Psychological Services.
- Lord, C., Pickles, A., McLennan, J., Rutter, M., Bregman, J., Folstein, S., Fombonne, E., Leboyer, M., & Minshew, N. (1997) Diagnosing Autism: Analyses of data from the Autism Diagnostic Interview. *Journal of Autism and Developmental Disorders* 27, 501–517. <https://doi.org/10.1023/A:1025873925661>



References

- Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 24(5), 659–685. <https://doi.org/10.1007/BF02172145>
- Lord, C., Storoschuk, S., Rutter, M. and Pickles, A. (1993). Using the ADI-R to diagnose autism in preschool children. *Infant Mental Health Journal*, 14, 234-252. [https://doi.org/10.1002/1097-0355\(199323\)14:3](https://doi.org/10.1002/1097-0355(199323)14:3)
- Maenner, M.J., Shaw K.A., Baio J., et al. (2020). Prevalence of Autism Spectrum Disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveillance Summary*, 69(4):1–12. DOI: <http://dx.doi.org/10.15585/mmwr.ss6904a1<234::AID-IMHJ2280140308>3.0.CO;2-F>
- Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A., & Skuse, D. (2012). Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents. *Journal of Autism and Developmental Disorders*, 42(7), 1304–1313. <https://doi.org/10.1007/s10803-011-1356-0>
- Nowell, S. W., Watson, L. R., Boyd, B., & Klinger, L. G. (2019). Efficacy Study of a Social Communication and Self-Regulation Intervention for School-Age Children With Autism Spectrum Disorder: A Randomized Controlled Trial. *Language, Speech, and Hearing Services in Schools*, 50(3), 416–433. https://doi.org/10.1044/2019_LSHSS-18-0093
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). Having all of your internal resources exhausted beyond measure and being left with no clean-up crew": Defining autistic burnout. *Autism in Adulthood*, 2(2), 132-143. <https://doi.org/10.1089/aut.2019.0079>
- Ratto, A. B., Kenworthy, L., Yerys, B. E., Bascom, J., Wiecekowsky, A. T., White, S. W., Wallace, G. L., Pugliese, C., Schultz, R. T., Ollendick, T. H., Scarpa, A., Seese, S., Register-Brown, K., Martin, A., & Anthony, L. G. (2018). What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills. *Journal of autism and developmental disorders*, 48(5), 1698–1711. <https://doi.org/10.1007/s10803-017-3413-9>



References

- Reynolds, C.R., & Kamphaus, R.W. (2015). *Behavior assessment for children: Third edition. (BASC-3)*. [Assessment Instrument]. Bloomington, MN: Pearson.
- Robins, D. L., Casagrande, K., Barton, M., Chen, C. M., Dumont-Mathieu, T., & Fein, D. (2014). Validation of the modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics*, *133*(1), 37–45. <https://doi.org/10.1542/peds.2013-1813>
- Russell, G., Golding, J., Norwich, B., Emond, A., Ford, T., & Steer, C. (2012). Social and behavioural outcomes in children diagnosed with autism spectrum disorders: A longitudinal cohort study. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, *53*(7), 735–744. <https://doi.org/10.1111/j.1469-7610.2011.02490.x>
- Russo, F. (2018, February 21). The costs of camouflaging Autism. *Spectrum*. www.spectrumnews.org
- Rutter, M., LeCouteur, A., & Lord, C. (2003). *Autism Diagnostic Interview-Revised* [Manual]. Los Angeles, CA: Western Psychological Services.
- Schopler, E., Van Bourgondien, M.E., Wellman, G.J., & Love, S.R. (2010). *Childhood Autism Rating Scale, Second Edition* [Manual]. Los Angeles, CA: Western Psychological Services.
- Szatmari, P., Liu, X. Q., Goldberg, J., Zwaigenbaum, L., Paterson, A. D., Woodbury-Smith, M., Georgiades, S., Duku, E., & Thompson, A. (2012). Sex differences in repetitive stereotyped behaviors in autism: implications for genetic liability. *American Journal of Medical Genetics. Part B, Neuropsychiatric Genetics : The Official Publication of the International Society of Psychiatric Genetics*, *159B*(1), 5–12. <https://doi.org/10.1002/ajmg.b.31238>
- 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>