

Developing a Better Understanding of Autism Spectrum Condition (ACS) in Girls & Women

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Abstract

Today, many girls are women in their late teens or adult years before they are diagnosed accurately with autism. There are several reasons why this still occurs, despite professionals' confidence in assessing and observing them. Perhaps the biggest reason why this happens is because "We reinforce from the youngest of ages that autistics should follow along with the crowd and push away their thoughts and feelings" (Dorsey, n.d.). Some wise people are starting to see the problem with this. Rachel Dorsey, an autistic SLP, wants to help reframe this deficit-based thinking and says, "As with all of our clients, autistic people deserve to be valued for who they are, not what they seem to lack" (Dorsey, et al., 2020). More people need to understand that "Autistic traits are not pathological defects. Furthermore, SLPs can use strength-based approaches, the neurodiversity paradigm, and/or person-and-family centered care (PFCC) to improve self-acceptance, foster their autistic identity, respect their autonomy, and therefore improve their quality of life" (Burton et al., 2020). When therapists fail to do this, they are teaching clients to mask. Girls and women with ASC are proven to be better at copying behaviors of neurotypicals, or in other words, they are better at *masking*. Why should we care? **Masking has been proven to cause mental health issues and suicide in autistic people.** Professionals need to reframe goals, intervention styles, and interactions with autistic clients and their families in order to stop encouraging masking. **Autistic people's lives are on the line.** Masking prevents girls and women from receiving an early diagnosis and in turn, keeps them from accessing appropriate services, support, and resources.

Purpose

- Highlight autistic voices
- Debunk stereotypes
- Discuss what this means for professionals
- Educate audience on why girls often go undiagnosed
- Discuss various approaches (ie. strength-based)
- Inform audience of current, known symptoms of ASC in girls & women
- Discuss the problems autistic people are experiencing

Masking

- Conscious and/or unconscious trauma-based response to being autistic in a neurotypical-designed society; Suppression of personality and autistic traits in favor of acting more neurotypical
- An attempt to appear less autistic to avoid judgment and discrimination
- Many autistic people don't realize how heavily they are masking until the mask is too much and they fall into *burnout*
- Copying others (ie. scripting)
- It's exhausting

"I automatically mimic what other people are doing, what people are saying, how people say things. I went to camps...and I would come back with strong accents, but I can't consciously put on an accent...my way of coping is that I mimic"

- Girls are aware of what they "should do" in social interactions
- Also known as camouflaging
- We reinforce this
- May look like careful observation of peers, reading novels/psychology books, imitating fictional characters, trial and error learning in social situations
- Masking has been proven to cause mental health issues and suicide attempts in autistic people. It also prevents girls and women from receiving an early diagnosis

Underdiagnosis

- Underrepresentation of females in studies
- Girls and women may mask until middle/high school after burnout
- Internalizing feelings/difficulties (mental health) while boys act outwardly with more tantrums
- Stereotypes like: "*Less females have autism. . . People with autism are low-functioning . . . don't have friends or interest in making friends . . . are just shy. . . have severe and overt social communication problems. . . always have savant skills like math and science*"
- Mis-diagnosed with ODD, anxiety, depression, GI probs, eating disorders, intellectual disability, ADHD, multiple personality disorder
- Diagnostic overshadowing
 - Letting prior diagnoses and/or co-morbid diagnosis explain too much
 - High levels of anxiety is a sign

"Four to five years of depression and anxiety treatment...years of talking therapy...and not once did anyone suggest I had anything other than depression."

Conclusions

- Autistic traits are not pathological defects. SLPs can use **strength-based approaches, PFCC, the social model and/or the neurodiversity paradigm** to improve self-acceptance, foster their autistic identity, respect their autonomy, and therefore improve their quality of life; Don't teach masking!
- Discuss masking with clients and do not create or implement goals that teach masking
- Use resources created by people with autism
- Reframe goals
- Do not use the medical model
- Acknowledge, accept, and validate autistic children's current emotions. Don't disregard them.
- Discuss neurodiversity and neurotypicality with all kids

- Stop using functional labels and the term "Asperger's"
- The term autism spectrum condition (ASC) may be used because the term 'disorder' is regarded by some as stigmatizing and the term 'condition' acknowledges both the disability and the differences and strengths in such individuals.
- Have autism on your list of possible diagnosis
 - Can't rule it out because they have neurotypical behaviors too
 - One test is not enough (ask about their subjective experiences, test spontaneous social interactions, ask about friendships etc.)
 - Useful assessments: Social Responsiveness Scale, Autism Spectrum Quotient (AQ), Camouflaging Autistic Traits Questionnaire (CAT-Q), Social Language Development Test

References & Helpful Resources: QR Code

- References
- Symptoms in women and girls with ASC
- Resources for goal writing from an autistic SLP
- Neurodiversity Paradigm, strength-based approaches, and PFCC
- Useful Resources
- Autistic SLPs

