Gender Fluidity Prism in Diagnosis of Autism Spectrum Disorders

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Abstract

Gender Fluidity Prism in diagnosing Autism Spectrum Disorders aims to show an outline for the need of every clinician to be aware and proactive of the complexity of gender in neurological diagnosis, specifically Autism Spectrum Disorders. To show the requirement of a gender neutral diagnostic tool and the valid need for training in gender neutral understanding in semi structured interviews. To look at conclusions from previous researchers. Results of an anonymous 24hr global survey on this subject and qualitative comments from those who answered to be shared.

Keywords: Asperger’s; Autism; Equality; Females; Gender; Homosexuality; Missed Diagnosis; Misdiagnosis; Prism; Transgender ; Gender Fluid.

1. Introduction

I have worked to promote awareness of differing traits in Autistic females and earlier diagnosis and support after waiting 32 years myself for my Asperger Syndrome diagnosis and having 2 female children diagnosed with an Autism spectrum disorder at 6 and 2 years of age. My aim, by raising acceptance of females on the Autism spectrum is to ensure that my daughters and females like my daughters would not have to endure the vulnerability, misunderstandings and hurdles that Autistic females of the past had to navigate. In the 8 years since eldest daughter’s diagnosis and the journey of research and awareness.

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I noticed that the females who had more stereotypical "male" traits had earlier diagnosis due to more male based diagnostic tools in comparison the Females who had stereotypical "Female" traits. It is suggested by The CDC that the ratio of Autistic males to females is "4–5 times higher among boys than girls, with a prevalence of one in 42 boys compared with one in 189 girls" [2]. However this could well be due to the fact that Females can present very differently, are not as widely understood in clinical practice, therefore less likely to receive a diagnosis and therefore less likely to be statistically counted.

In recent years due to professionals actively training in gender neutral diagnosis tools and experienced, well informed clinicians adapting diagnostic experiences to promote equality, the advances in awareness of the presentation of Autistic females is wider known than ever before. Therefore, meaningful equality in training and practice of diagnosis has been implemented resulting in advantageous consequences for many more on the Autistic Spectrum. This is still ongoing and stills a large and vitally important hurdle to ensure equality for females.

I fear however that, as with any patterns there will still be a group of the Autistic community that will be indirectly excluded from the same early diagnosis and support and that somewhere in the midst of the mass explosion of "Female" traits of Autism, that, Autistic males who present with more "Female " traits will be left not fitting neatly into either “camp” without diagnosis and support. Resulting in a pocket of the Autistic community again subjected to the pattern of vulnerability, health implications and lack of resources. I feel as an Autistic female of past generations who experienced firsthand the consequence of missed or misdiagnosis, a duty to try, in a small way to ensure these experiences will not repeat for Autistic males who present with more stereotypical female Autistic traits "...the real social world is fluid and rapidly changing. We have to process socially relevant information rapidly, spontaneously and on-line, in order to achieve day-to-day social interaction......the absence of spontaneous theory of mind would cause difficulty in social interaction and communication, even in adults with high verbal and cognitive skills" [8].

A recent contact validated the thought process of the complex relationship between gender and equality of diagnosis. The contact came from a Father, Heterosexual, happily married with an adult Autistic son. This male contacted me to say how similar we seemed to be to one another. He had Autistic traits but was not sure he should be diagnosed as autistic. He self-identified as having primarily a male brain with some female tendencies. He believed that all the ambiguities in his profile would make it very difficult for him to get a definitive diagnosis. I thank him for the courage to write to me which in turn gave me the courage to write this paper and conduct a survey. Males are in as much need for gender neutral diagnosis and safeguarding as females.

2. Materials and methods

My own ability to see patterns of human behavior, Reading of previous research as referenced and the construction of an online survey which is free and widely available, is then shared on social media platforms whilst participants identity remains hidden, both from the person conducting survey and in the results.
3. Results

Results of survey shared for 24hr period titled “Feminine Autistic traits in males “4 July 2015.

Quantitative

Answered by

66% Male

28% Female (majority mothers of Autistic sons)

6% Other (gender fluid / Transsexual / Gender ambiguous)

Diagnosis tool they would prefer to be diagnosed by

2% would prefer a male only based diagnostic tool

11% would prefer a female only based diagnostic tool

87% would prefer a gender neutral diagnostic tool

Qualitative comments

“…Many people have A typical traits that are simply traits have been ignored as part of diagnosis “

- Ambigender Survey participant awaiting diagnosis

“I (present) more female, when I finally worked it out is was because I realized I had heightened empathy and then discovered the intense world theory, empathy is thought of being stronger in females.”

– Non diagnosed, Autistic male with Autistic family members, survey participant

"Gender identity should be included in diagnosis rather than being a separate thing, It’s all about education of the people who diagnose. Gender identity is something not all healthcare professionals understand at a care level“

– Autistic, gender neutral survey participant

“…I am more relaxed and contented in the presence of female company as opposed to male company …”

-Diagnosed Autistic Male Survey participant.
“I feel I’m somewhere between female and A gender, I certainly don’t feel fully female “

-Diagnosed Autistic female survey participant.

“(Stereotypes of Autism)... should be more fluid given the number of Autistics who are gender dysmorphic”

-Male, awaiting Diagnosis with Autistic son

“I am more interested in stereotypical male interests…”

-Diagnosed Autistic female survey participant.

“..My interests include complementary therapies and New Age spirituality and I find there are many more women interested in these things than men. I am not interested in sport, cars or typical male pursuits “

-Diagnosed Autistic Male Survey participant.

“Person centered diagnosis which is tailored to the person ...meeting a person with a blank slate...I am genderfluid so that does have an effect on my views and experiences.”

-Diagnosed Autistic Male Survey participant.

“I had not thought of male Aspies exhibiting more typically feminine Aspie traits but it does seem logically possible.”

-Diagnosed Autistic Male Survey participant.

The problem of the complexity of sexuality, gender and neurological diagnosis seems to be that they are all separate elements yet utterly at the core of ones being, identity and a part of what makes them who they are and therefore how they present. It is not enough to suggest that an personal presentation of Autistic traits are not visible due to any combination of the elements of that person, yet it is vital to understand all the elements that make up that person in order to understand them and their traits in practice.

The issue society faces now can be recognized through people who clearly don’t fit the definition, which in fact accounts for many people. In a sense people are living in a world they simply don’t fit into, they are marginalized, and because of these narrow definitions it seems right that they should be. To alter societies views changes must be made and the social constructions of gender that take place on a daily basis must include alternatives to the idolized hegemonic male, and female” [7]. Human nature is complex and diverse and cannot be fully supported by quantitative measures alone. Are our rigid stereotypes of both gender and Autism preventing us from seeing a bigger picture? And a bigger pool of individuals whom are lacking support and lacking diagnosis? Or are the traits in themselves a myth? And the interests in fact a sensory seeking experience? “Feminine interests of many gender dysphoric young boys with ASD concerned soft tissues, glitter, and long hair and could be understood as a preference for specific sensory input typical for ASD.
The majority of the gender dysphoric adolescents with ASD were sexually attracted to partners of the other sex [1]. After being contacted by males who have felt they identified as being Autistic, but without diagnosis this complexity became clear. One Male had visited GP and turned away as they were not considered to “look” Autistic, as can so often be the case for females. This male is Homosexual and I feel that perhaps this was a hurdle as the persona of “what a homosexual “ male presents as and “what a female trait Autistic male “ presents as caused confusion and therefore medical exclusion. Could it be that the gender of a Autistic person is very different not only in it presentation but also in its nature to that of an individual whom is not Autistic? If our very nature is different can we apply non Autistic gender roles in a carbon copy fashion to Autistic experiences?


“The 'extreme male brain' theory suggests that autism spectrum disorder (ASD) is an extreme variant of male intelligence. However, somewhat paradoxically, many individuals with ASD display androgynous physical features regardless of gender….Women with ASD had higher total and bioactive testosterone levels, less feminine facial features and a larger head circumference than female controls. Men in the ASD group were assessed as having less masculine body characteristics and voice quality, and displayed higher (i.e. less masculine) 2D:4D ratios, but similar testosterone levels to controls. Androgynous facial features correlated strongly and positively with autistic traits measured with the Autism-Spectrum Quotient in the total sample. In males and females with ASD dehydroepiandrosterone sulfate did not decrease with age, in contrast to the control group”.

Gender of course is not simply a matter of nature; our gender is also a social construction and fluid not fixed. so over time , and over age an Autistic persons gender roles thus autistic presentation can change , in both timely and late diagnosis this should be taken into account to promote inclusion [5]. “Existing literature makes the significant contribution of drawing our attention to the presence of gender-related concerns in individuals with ASD. However, it is unclear whether the most fruitful way to conceptualize this issue is in terms of comorbidity. A more complex approach that attempts to understand gender in developmental terms is potentially more salient for both research and clinical purposes. Our current understanding about the unique social development of individuals with ASD, which may impact the process of gender identity formation, underlines the need for such an approach. Future work should attempt to explore the development of gender identity in a longitudinal fashion, in order to improve our understanding of the relationship between gender and ASD”.

Just as there are Autisms (plural) there is also a spectrum of gender. When relying on black and white thinking, statistics and quantitative research human experience is often number crunched into figures, which feel safe and reliable yet miss out a wealth of information of the human experience where the pattern of human behavior is all too often replaced with the pattern of numbers. “Taking an appropriate developmental history reveals the possible underlying problem of an ASD with an additional diagnosis or mis-diagnosis” [6]. A long term focus would be to ensure all clinicians have been trained in gender neutral tools and how to interpret the answers of questions to be gender neutral in semi structured interviews.
The contrast of Science and Psychology must compliment, rather than contrast. Whilst big data is a vital need so are qualitative voices, where the patterns of behavior can really only be heard thus learned and understood. How one diagnoses and supports an Autistic person in semi structured interviews is much like a **Prism**, a reflection of the understanding, knowledge and experience of the clinician who diagnosis. The Autism Spectrum is vast and beautifully complexed, Some individuals are easily identified as being Autistic and given a swift diagnosis, support and human rights, however for many individuals their Autism is a prism, the triad of impairments are present, yet it remains transparent until the appropriately trained clinician shines their knowledge and their light onto it, it is only then that the colors and complexity can be seen and understood.

4. Conclusion

Gender Fluidity Prism in Diagnosis of Autism Spectrum Disorders has achieved its aim of hearing qualitative experiences from the Autistic community on this much over looked “loop hole” in diagnosis. It is however vital that larger and wider research is conducted to ensure that this is not a forgotten matter. The Survey for this paper was online for a very small amount of time, if a larger survey was conducted a much wider experience could be shared. There was however a real need to have a survey conducted and to get the “ball rolling” on this subject. Every day an Autistic person goes without self-awareness, support and meaningful diagnosis they are vulnerable, prone to depression, anxiety, confusion and abuse. It is important that when any inequality issue is raised, the duty of raising equality is not solely placed on the hands of over stretched charity bodies. Charities are often firstly formed in infancy by strong members of a community working together to fight for either own or families human rights due to the human rights of the person not being fully fulfilled by existing systems and infrastructure. In the circumstance of inequality comments must be raised with the governing bodies and international bodies, such as MPs, Government, the United Nations and the Human rights offices. Autism in all its shades should have the right to diagnosis as each individual on the Autistic spectrum has a triad of impairment that leads to vast safeguarding issues and vulnerability regardless of the degree of presentation. I feel that all individuals on the Autistic spectrum have the human right to meaningful, timely diagnosis and support and diagnosis to be a right rather than a lottery.

References


