The 'Other' Half of Autism: How Australia fails Neurodivergent Women



From the outside, Elizabeth "Lizzie" Thompson is an effervescent and outgoing university student with an infectiously gung-ho approach to life. A capable and ambitious 21-year-old woman studying creative writing with dreams of becoming an author.

Unrecognisable to the naked eye, however, Lizzie is one of over 40,000 Australian women living with Autism.

Intimidatingly well-spoken, Lizzie is a master's-bound student with a dry wit who supports her studies as a Pilates instructor. Her autism challenges my preconceptions of the condition; it certainly doesn't seem to have a salient effect on her, at least from a superficial distance.

I am seated opposite Lizzie on a dank picnic bench in the courtyard of St Mary's College, at the University of Melbourne, the venue of her choice. Lizzie has called St Mary's home for three years, proudly revealing herself as elected Vice-President of the student body. It is a beautiful, cocooned location.

Our bench is under the diffused canopy of a naked tree. Lizzie points out that the few stubborn autumn leaves that remain still have a golden hue.

It's a cold morning and I am feeling the chill. Originally a self-described 'Brissy girl,' you would not expect Lizzie to be sharing such sentiments with me, yet, as her fellow collegiates walk by, exchanging passing waves in her direction throughout our interview, it quickly becomes apparent – Lizzie is in her element.

This wasn't always the case.

"I always had a suspicion there was something 'off' with me," Lizzie reveals.

"I thought I just wasn't as mature as others – my personality just one that people found off-putting," she continues.

Like many other women, Lizzie's journey to attaining an autism diagnosis was exactly that – a journey.

Growing up, the potential of having autism wasn't even considered a possibility in the mind of Lizzie and her parents, even medical professionals overlooked it, Lizzie disclosed.

This social obliviousness of autism in women is just as ubiquitous in the psychological and medical spheres as well. <u>Autism in women is often misdiagnosed</u> as borderline personality disorder or narcissistic personality disorder.

Several years of searching for an answer and several misdiagnoses later, Lizzie was eventually officially diagnosed with autism at the age of 19. For reference, the average age for diagnosis in Australian boys is <u>between the ages four to six</u>.

When it comes to the broader, male-focused discourse on autism, a lot of labels are thrown around.

It would be all too common for you to hear someone refer to Lizzie as possessing a high-functioning brand of autism, like many other neurodivergent women, or perhaps hear the increasingly trendy and seemingly more nuanced term of 'high-masking.' This compartmentalising of autism is a slippery slope, and a framework I, myself, fell victim to.

"To say high functioning and low functioning can be so reductive," Lizzie corrects me.

"You can't be *a little* bit autistic," she continues.

This is a common misconception concerning female neurodivergence, I am told.

Lizzie cuts to the heart of it: the deeply androcentric nature of autism research and diagnosis in a simple, elegant sentence: "Just about everything that is known about autism is based on pretty antiquated observations on middle-class white boys."

This rings true. Existing research concerning neurodivergence is a case of 'the squeaky wheel getting the oil,' with most research averaging a male-to-female participant ratio of 8:1 <u>according to a recent MIT study.</u>

New research by the Australian Institute of Health and Welfare reveals that <u>men are</u> <u>four times more likely to be diagnosed with autism</u> than women.

Australian psychologist, Dr Robert McCrossin, estimates this number is more likely three girls for every four boys with autism. If this figure is true, over 80,000 Australian women could be living with undiagnosed autism.

This systemic disregard and lack of acknowledgement of neurodivergent women in research does little to mitigate the pressure women feel to meet social expectations, regardless of their neuro-normativity. Rather, it reinforces the implicit bias that autism is a 'men's issue'.

"Low-needs autistic women can often operate with similar levels of social functioning to that of a neurotypical man," says psychologist, Dr Raina Walker, of Mullum Road Clinic.

One of the distinct characteristics of autism in women, Raina tells me, is a difficulty connecting with their peers.

Lizzie's own lived experience reflects this.

"The expectations of girls are different; you can get away with a lot less," Lizzie explains.

"I'm nice to them, I feel like I dress like them, and yet, I just feel like I can't get through to them at all."

This phenomenon is well known in psychological circles and studied under <u>Female</u> <u>Phenotype Theory (FPT)</u> – the idea that, as a coping mechanism, autistic women become skilled at masking traits of autism by imitating social behaviour, leading to less overt or conventional (male) manifestations of autism.

"I think everyone wants to be loved and accepted. You learn very quickly how to behave to get even a smidgen of that," agrees Lizzie.

In some respects, this brand of female neurodivergence is almost a completely distinct condition.

This often-conscious exertion of effort has a more significant toll on the mental health of the individual, however.

"Neurodivergence in women typically involves the internalisation of a lot of negative feelings and confusion, as opposed to being expressed through hyperactivity or impulsivity," Raina explains.

Beyond the lack of representation and social awareness, the systemic overlooking of women with autism has real-world consequences.

"Getting diagnosed is a really expensive and difficult process," Lizzie protests.

For an adult who isn't considered 'high-needs' under the current Medicare system, <u>little</u> <u>financial support is offered</u>. So much so that Lizzie estimates her all-over-the-place journey to a diagnosis came at the cost of up to \$9000.

This is particularly troublesome considering eighty percent of Australian women with autism <u>remain undiagnosed by the time they turn 18</u>, yet the medical consensus supports early diagnosis.

"Diagnosis can be a crucial tool for helping autistic women understand their unique needs and communicate these needs to their peers, functioning to reduce unknown feelings of being inadequate or abnormal," claims Raina.

"For women like Lizzie, a diagnosis offers crucial closure that can boost social and mental health," says Raina from her clinical experience.

But without a wider education and acceptance of how autism affects women differently, many neurodivergent Australian women will stay in the dark.