

# Autism in women - under-diagnosed, under-served and under-represented

Rachel Morgan-Trimmer

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## Abstract

Autism has historically been seen as primarily a male issue, and these attitudes still persist. The result is that autistic women and girls are going undiagnosed. This leads to huge problems with mental illness, inability to access the services and support they need, and significant social and professional issues, such as long-term unemployment. This article looks at some of the specific issues that affect autistic women, and how to address these, so that autistic women and girls can live the fulfilling lives they deserve.

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## About autism

Citation Link

Have you ever accidentally eaten or drank something that was unexpectedly vile? Maybe when you were a kid and you tasted cocoa powder without realising there's no sugar in it. Or perhaps you're at a buffet and help yourself to a dish, only to discover it's mind-blowingly spicy.

It's awful isn't it? You're expecting something so lovely and then this hideous taste fills your mouth and you can't spit it out and don't know what to do.

This happened to my friend when I accidentally put salt in her tea instead of sugar. And to my dad when he first moved to this country and didn't realise orange squash is supposed to be diluted.

So what do we do? We start to be a bit more careful about what we eat or drink. We might even completely avoid some things in case we get another nasty surprise. To this day, my friend is cautious whenever I make her a cup of tea. And my dad never really took to orange squash, even after he learnt how you're supposed to drink it.

What does all this have to do with autism? Well, all the autistic people you know are trying to keep ourselves from such unpleasant experiences. And we all have an internal, unseen set of rules to keep ourselves safe. You might not understand why an autistic person does something, or avoids something, or is acting strange about a particular situation. But it's as if you're offered a food or drink you haven't had before but looks or smells like something that you didn't like. Or it's served by someone you don't trust.

To an outsider, it might look odd. But to an autistic person, our set of rules make perfect sense, even if we can't explain them to anyone else. So when an autistic person says they want one thing one way, and a seemingly similar thing another way, we're not trying to be difficult or weird, we're following a perfectly logical set of rules. But you might not be able to see them.

Here's another question for you. Imagine if you'd just been served a glass of undiluted orange squash, or salty tea, or food so spicy it makes your eyes water. You would probably say you didn't want any more. But what if someone said you were being difficult for not eating or drinking it? Or that you were asking too much if you wanted your squash mixed with water, or to eat something that didn't make your mouth feel as if it was on fire? What do you usually do when someone says you're hard work, or that you're nit-picky, or that you expect everyone to do what you want?

You might argue. You might explain why you feel that way, and why you want things to be different. You might get angry and shout! Or you might get upset and shut down. Some people – especially those who are used to having their feelings invalidated – would just eat the food or drink the drink. Even if it made them uncomfortable, or unhappy, or ill. These people are the ones who don't like to make a fuss. These people are often autistic, and they're often women. And one of the reasons autistic women are suffering – from being under-diagnosed, under-served, and under-represented – is because we don't like to make a fuss.

## **About women**

What sort of people do you imagine when you hear the word “women”?

Do you imagine a range of ages or just women your own age?

Are they fat or thin? Tall or short? Or a mix of different body shapes and sizes?

Do you imagine only women from your own background, or do you picture people of different races, cultures and backgrounds?

All of us are guilty of tribalism to a certain extent. Associating with people like ourselves, thinking of only those people when we're talking or writing about them. But in talking about women and autism, we need to remember what a huge diversity there is. And not just those who we might think of as minorities, such as women of colour, or LGBTQA+ people, but also older women, those from a different socio-economic background, those with fewer opportunities than us, and so on.

When I say “girls” or “women” or “females”, and “boys” or “men” or “males” in this paper, I am talking about how we are treated by others. That means there will be some trans men who were treated as girls when they were little, and some trans women who only were culturally in the ladies' club once other people saw them as women. I'm also talking about non-binary people because they will, at one

time, have been treated as a particular gender. So I use these terms mainly in a social and cultural context, which I believe is more important than any other definition.

I don't think there's an inherent difference between autistic men and women. What there is a difference in, is how society treats and socialises males and females.

Dr Kate Fox, author, poet and comedian

### **Autism in women: under-diagnosed**

There is no argument about the fact there's a [diagnostic gap between boys/men and girls/women](#) when it comes to autism diagnoses.

[1.8% of men are diagnosed autistic, compared to 0.2% of women](#). But how many people are actually autistic but haven't got a diagnosis?

Of course, we don't know.

What's strange is that experts agree there's a diagnostic gap, with males much more likely to be diagnosed than women. But even with that knowledge, official sources still cite males as being more likely to be autistic than females.

For example, [the National Autistic Society estimates that the ratio of male autistics to female is 3:1](#). They don't say how they arrive at this estimate.

The Center for Disease Control in the USA is worse. [They confidently claim that more than 4 times as many males are autistic as females, neglecting to mention that this is a diagnostic ratio, and doesn't necessarily reflect the fact that females are more likely to be undiagnosed.](#)

So why do so many women remain undiagnosed? Most researchers agree – it's because there's a gender bias in diagnosis. The diagnostic criteria are skewed towards males, and stereotypically masculine interests.

When you begin the diagnostic process, you get a form to fill in to see if you might be autistic. These forms are skewed towards traditionally masculine interests and behaviour. In fact, the form used by [the Autism Research Institute in America even uses male pronouns](#). When citing examples, these forms use cars and numbers, including dates and strings of information. Diagnostic forms also refer to "rude" behaviour which is something men tend to get away with a lot more than women, who might learn to be quiet rather than continue to be told they're impolite.

### **Clues to the diagnostic gap**

Autism is "persistent difficulties with social communication and social interaction, restricted and repetitive patterns of behaviours, activities or interests" to the extent that these "limit and impair everyday functioning".

*Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*

Let's look at each of these in turn to see if we can find clues to the reason for the diagnostic gap.

First of all, let's examine "persistent difficulties with social communication and social interaction".

First of all, [a number of studies](#) support the theory that women in general tend to be better at social interaction, possibly because they find it more rewarding. So an autistic woman is potentially more likely to have better social skills than her male counterpart, simply because of her gender.

Women are socially and culturally encouraged to "be nice". We might have difficulties with social communication and interaction, but we're trained out of being "rude" or "inconsiderate" or "blunt", or indeed any type of behaviour that puts our own needs ahead of someone else's. We're told to be polite, to think of others, to consider people's feelings before we speak. And if we're unable to do that, we get punished.

Our punishments might be verbal – we get shouted out for doing something wrong even though we didn't do it on purpose. Or they might be social – people stop spending time with us because they don't like how much we "go on about" our special interests. Or they might be self-inflicted. We don't apply for jobs because we don't think we'll be able to talk to people in the "right" way, or we deliberately isolate ourselves because we can't deal with yet another person making us feel small and stupid. We sit quietly in a group because we don't know what to say, while a man (autistic or not) is happily talking on and on about whatever he likes, unaware or unconcerned that he's boring everyone else.

What's significant about this is that the all-too-common female response is to be quiet. To not make a fuss. And the issue about being quiet is that it's not noticed. We tend not to notice things by their absence, so we don't notice when a woman might not be speaking, or joining in, or putting herself forward.

The second part of the diagnostic criteria is "restricted and repetitive patterns of behaviours, activities or interests".

My theory about why autistic women go unnoticed, is because our interests are productive. This is obviously a generalisation, but experience has taught me that there's a lot of truth in it.

This is what I have seen from male autistics. Obsessive interest in football. Being able to look at a picture of a roundabout and say which A-roads are linked to them. Organising boarding passes from every trip in alphabetised folders. Minecraft. Tinkering about with code. [Winning the World's Strongest Man competition](#).

Now let's see some examples from autistic women. Knitting cardigans for babies you don't even know. Embroidery. User experience research (how people use a product or service). Graphic design. Being brilliant at craft and setting up a craft group so you can teach everyone else. Drawing. Cooking.

That last one is my own autistic special interest. I thought for a long time that I couldn't be autistic because I didn't have a special interest. I thought I had to like trains, or cars, or collecting action figures or something. I never realised that cooking was a special interest, because it's something that most people can do. It's not particularly unusual. And while it might have been a little out of the ordinary to leave pies on my neighbour's doorstep, or make a fancy dinner for everyone who visited, no-one ever told me to stop doing it – because everyone likes free food! And when someone said I was obsessed with food and went "on and on" about it, I just thought I was fat and greedy. I only realised it might be

a bit extreme when people were surprised at how many cookbooks I own – the current figure is around 200.

That women's autistic special interests tend to be productive is not the sole reason they go unnoticed. After all, many autistic men produce great things, and many autistic women have unproductive interests as well. Women's special interests – like my obsession with cooking – tend to be more normal and less extreme. Being the World's Strongest Man is extreme. Having a celebrity crush – and even being quite obsessed with the celebrity – is not considered out of the ordinary, which is why a teenage autistic girl might be seen as simply normal.

Girls display better superficial social skills, better language and communication, less inappropriate special interests and activities, and less aggressive and hyperactive behaviour than boys.

Gillberg & Coleman, 2000

### **The deficit model of diagnosis**

Autism, like many neurodiverse conditions, is defined by a deficit model. It's all "what's wrong with you", not "what are you good at?". As we know, most autistic people are good at certain things, and some are outstanding. With a deficit model, it's more likely that women are going to be under-diagnosed, because it misses what we're good at – which is often communication. It doesn't mean we're less autistic, it means we're better at blending in, being polite and learning what happens when we don't follow the social rules. The attention to detail that autistic people are famous for doesn't just manifest itself in maths, or engineering or IT. It can also manifest in subjects that women tend to be drawn to and excel at – such as languages, literature and craft.

The other aspect that the current diagnostic model misses is the psychological cost. Women tend to be more likely to put others first, regardless of the cost to themselves. People-pleasing is an autistic characteristic that we also find in many women. We don't like what happens when others are displeased with us, so we take steps to keep others happy, even when it comes at great cost to us. Some women are so culturally and socially conditioned to put others first that they never even consider alternatives – people-pleasing is too ingrained.

The social communication element of autism is a key exemplar of the psychological cost of "masking" (hiding or minimising autistic traits). We are quiet but then become frustrated, or we speak bluntly and are shamed, or we nod and smile politely at "banter" even though it exhausts us. This cost of being autistic is something that is initially unseen and even when it appears elsewhere (most commonly in mental illness), it is not always treated with the seriousness it deserves.

We talk a lot about the social impairment being a key diagnostic criterion for autism, but it's not the only one. If the focus in autism diagnosis was on outcomes, rather than characteristics, (such as the mental health issues associated with autism), I predict that we'd automatically see higher diagnostic rates for women.

Again, autistic females are not a problem for other people. If we're tired, it doesn't affect anyone else. If we're sad, or anxious, or isolated, it doesn't really affect anyone else. Our special interests tend to be quiet and have a positive impact on other people.

So autistic women continue to be apparently unproblematic, discouraged from “making a fuss” and, as a result, to be undiagnosed.

### **Autism in women: under-served**

The logical outcome of under-diagnosis of autism in women is that our needs aren’t served.

In my job as a neurodiversity consultant, I offer training on autism (amongst other things) to companies. Many people still don’t see the value of being inclusive to autistics, even though there are countless [studies showing how diverse workplaces make more money](#), and [how autistics in particular tend to be more productive](#). Autistic people, men and women, are still not seen as valuable – we’re often still seen as “special needs” with all that implies. And people don’t invest in what they don’t value.

People also frequently lump neurodiversity and mental illness together, although neurodiverse conditions aren’t mental illnesses. Conditions are seen collectively as “head stuff”, partly as there’s considerable overlap, as demonstrated by the prevalence of autistic people with mental health conditions. The medical establishment is not set up to look for autism in women, so as soon as a woman presents with any “head stuff” they are frequently diagnosed with depression and given a prescription for anti-depressants, and possibly a referral to a therapist, if they’re lucky. Systemically, there’s no incentive or desire to look for the reasons behind the depression, and women who suspect they might be autistic are often dismissed or invalidated.

You find in women’s health, “no available data” comes up a lot. Historically, women’s health has been neglected in research. And the problem is compounded in autism, when people still believe that women are less likely to be autistic than men. The existing research on autism in women uses the word “superficial” a lot. For example, superficial social skills. Superficially coping. It comes back to the issue that autistic women are unproblematic for other people – if they seem to be coping, the problems aren’t apparent. And there’s is often an unwillingness or inability to dig deeper.

### **Autistic women at work**

When it comes to work, autistic women are the victims of “double discrimination”. While [we’re more likely to be in paid work than men](#) (in the UK at least), [the gender pay gap is 15%](#). We get paid less for doing the same work. Both women and autistic people are less likely to speak up and ask for more money or a promotion, so that issue is compounded for people who are both female and autistic.

We also see too few women and autistics in upper management. [There are not enough women on boards](#) and too few autistic people in management. When I was looking at what other people were offering in training autistic managers, all the results were for managers who had autistic team members. The concept that autistic people could be in management wasn’t even something that had crossed people’s minds! Although there are many autistic people who are in senior management, and many more who are entrepreneurs.

## Lack of engagement

The fact that many autistic women have a tendency to be quiet and unproblematic renders us almost invisible. We can't tackle a problem that we don't see, and even though more autistic women are starting to speak up about their late diagnosis, and being clear about what we need, we still find we're facing a double obstacle. The first issue is that we're so used to "not making a fuss" it takes a great deal of energy and going outside our comfort zone to start to ask for things that we want and need. The second is that we are still often dismissed, under-rated and undervalued by others – both as women and as autistic people. Most women will have a memory of being treated as a "silly little girl" by men whose only superior quality was being able to talk louder and with more confidence. And many autistics will recognise only too well that feeling of being thought of as "less than" others – even, in extreme cases, as expendable.

The result of this is that we stop engaging. We don't have the energy nor the thick skin for an argument, or to ask for more, or to assert our boundaries. Job-hopping, for example, is very common amongst autistic people, not only because it's hard for us to find a workplace that fits our needs, but also because we are often underpaid and undervalued, so we have to move jobs to get that promotion we so desperately want – and deserve.

This lack of engagement is not our fault, but it compounds the problem, and leads to the third part of the cycle – under-representation.

## Autism in women: under-represented

Of course, with people still believing autism is a "male condition" and autistic women being denied the resources to speak up, the under-diagnosis and under-serving of autistic women leads to us being under-represented.

First, let's look at research. Women are under-represented in many fields of health - "no available data" comes up a lot when you look for how something affects women. And this holds true for autism research as well. [One meta-analysis](#) found that males were vastly over-represented in intervention studies and while 82% of other studies included both males and females, 17% were male-only compared to a tiny 0.49% which were female-only. This lack of female representation in autism studies is obviously problematic, but when you consider the different presentation of autism in men and women, and the outcomes, the lack of female-only studies becomes even more of an issue.

It's not just research either. The media also focuses more on autistic males than females. For example, a recent [Guardian article featured portraits of autistic people](#). 7 were male, and only 2 were female. If you search Google Images or any stock photo library for "autism" you will get an overwhelming number of pictures of boys. Where women do appear, it's frequently as the mother to an autistic kid. We're relegated to the sidelines, rather than centre stage.

You'll also see a similar issue if you search clothing or other print-on-demand products featuring autism. With a shop that sells shirts and hoodies, they're almost always exclusively in male cuts and sizes. Where women appear, it's often again as a mother, for example, in a slogan like "proud autism mum" or "proud of my autistic son".

The fact that we “cope” (superficially, at least) with our challenges so well is another reason we’re poorly-represented. A person might be familiar with an autistic meltdown, but less familiar with an autistic shutdown, which would be the more socially acceptable way of coping with challenges, and therefore one more likely to be taken by women. While we might have a clear picture of a stereotypical autistic male (glasses, trainspotting, working with computers), the same clear picture doesn’t exist when we try to think what an autistic woman might look like.

This is starting to change, slowly, [with more high-profile women announcing they are autistic](#). It starts to break the stereotype – not just of autistics being mostly male, but also that we can be successful in jobs where stereotypically “female” traits are valued – such as communication, listening and having a keen fashion sense.

But even with this, we’re still dealing with the issue that autistic women are not well-represented in the media, or in other areas, such as research, and that leads to us being under-diagnosed. It’s a vicious circle.

### **Breaking the cycle: diagnosing autistic women**

Let’s look at the under-diagnosis problem first.

What we’ve established is that women approach their doctor with other issues – frequently mental health issues. It has been suggested that any diagnosis of depression or anxiety should come with an automatic screening for neurodiversity. This suggestion will doubtlessly be derided as too difficult, too expensive or unnecessary – as so many interventions for women are. That doesn’t mean it shouldn’t be considered.

Another suggestion would be to screen all children at school for neurodiverse conditions. Currently, parents face long waiting lists and endless battles to get their children diagnosed and supported – and this is compounded for the children who don’t make a fuss. And as we’ve seen, the children not causing a problem for anyone tend to be girls. Resources – be they interventions, money or other support – are focused on the children who are disruptive.

One way I have been trying to address the issue of under-diagnosis, in my own small way, is by presenting a picture of autism to women who might not have seen themselves described like this before. I frequently talk to women who say “I thought I might be autistic, but...” and then give a reason such as “I don’t have a special interest” (they always do but it’s not always obvious). Or they say “I cope quite well” (yet they always have mental health issues). Or they think the fact they have friends automatically disqualifies them from an autism diagnosis. Seeing “real” autistic women, and the variety of autistic presentations that exists, can encourage them to pursue a diagnosis. Understanding the pathway, and that they might have a battle ahead, also helps them to get started.

Clinicians urgently need to tackle the under-diagnosis problem. The most significant impact they can have is by looking at the current diagnostic criteria and examining how these can be re-examined to include the way autistic women present. They could also look at how we might frame questions to get accurate information from autistic women seeking a diagnosis. For example, “do you like trains?” could result in a firm “no”, but you could achieve the same tick on the form with a question like “do you like organising your books by title, author or genre?”.



## **Breaking the cycle: serving autistic women**

With more women being diagnosed, we are able to collectively get our needs met more appropriately. For example, in the workplace, knowing that autism is classified as a disability under the Equality Act 2010 can help employees understand their rights, and the responsibilities of their employers. Connecting and communicating with other autistic women, in places without shame or judgement, can help us get to know ourselves. Many of us have spent so long suppressing our own wants and feelings that we often need help to understand what we need, before we can start asking for accommodations. We frequently also need help valuing ourselves and developing the confidence to assert our boundaries and start living a life built for us, rather than for other people.

Education is key here – with autistic women understanding what they’re entitled to, whether that’s legal protection at work or the right to a referral for a diagnostic assessment. We also need to educate others – not just about what they are required to provide for autistic people, but also why. What would be the outcomes of an inclusive service or workplace? How would this benefit autistic people and, by extension, everyone else? What would each individual personally get out of being inclusive?

Again, researchers and clinicians can also be a significant part of the solution here. Researchers can embrace the concept “nothing about us without us” which means designing studies with the input of autistic women. They can ask questions tailored to women’s lifestyles, interests and behaviours. They can also identify what studies autistic women believe would be helpful, and can design interventions around the needs of autistics of all genders. Above all, they could ensure a representation of autistic women in studies that is at least equal to male participation.

## **Breaking the cycle: representation of autistic women**

Accurate representation is a big part of the education piece.

We can’t hope to educate medical professionals, employers and service providers about autism if we’re still using out-dated male stereotypes. We can put ourselves forward as examples of autistic women, sharing what our lives are like and helping people understand the rich variety of individuals across the autistic spectrum.

Not all of us are willing or able to stand up on a public platform to do this, but we can all help educate individuals in smaller ways. For example, explaining to colleagues that you prefer email to phone, because it makes you less anxious, or telling an events organiser that you will need a quiet room. Every time we do this, we help others understand what an autistic woman looks like, what we want, and what we need.

## **Speaking up**

To address the issues facing autistic women, all of us need to speak up for each other. To explain, to educate, to ask difficult questions about why autistic women aren’t being considered, and why their needs aren’t being met.

But one of the hardest things to do is to speak up for oneself. We all need to believe that we deserve

diagnosis, treatment and representation as much as anyone else. No matter who we are – male or female, autistic or not – we all have value and we all deserve to live the best life we can.

It's time to start making a fuss.

## References

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## Author

**Rachel Morgan-Trimmer** is a neurodiversity consultant. She is a public speaker and trains companies how to include, work with and celebrate people with dyslexia, ADHD and autism.

E-mail: [rachel@sparkleclass.com](mailto:rachel@sparkleclass.com)

URL: <https://sparkleclass.com>

Video of Rachel delivering a version of this paper on YouTube:  
<https://www.youtube.com/watch?v=W1UNQq6EQlo>

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