

# Girls and Autism

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**Lynne Malcolm:** Hi, Lynne Malcolm with you for *All in the Mind*. Today, girls and women on the autism spectrum; are they slipping through the net?

**Temple Grandin [archival]:** My name is Temple Grandin. I'm not like other people. You know, you never get cured of autism, but what you do is you learn more and more things. When I was a little kid I was very autistic, non-verbal, rocking. That's the kind of kid they just put away in institutions. But I had a speech teacher that worked really hard with me, and I can't emphasise enough the importance of young children getting early intervention. You got a two-year-old or three-year-old with no speech, don't wait.

**Francesca Happé:** One of the best known women with autism is Temple Grandin, and she is an extraordinarily brilliant woman who has I think several degrees and PhDs and designs livestock facilities. And she talks about her ability to visualise the whole of a livestock facility in her head before she even begins to draw the blueprints. And also she talks about her empathy for animals, her ability to see the world as if she was one of the cattle that's going to have to go through this livestock facility and to notice the little shiny things that might scare them or disturb them and so on.

How is she representative of women with autism? Well, she's highly, highly intelligent, she talks about her ability to compensate and to cope, and she also interestingly talks about having made great progress even later in life. So she said at one point that her brain switched on aged 50. So a very important message that it's not just children with autism, it's adults and older adults too with autism.

**Lynne Malcolm:** That's Francesca Happé, Professor of Cognitive Neuroscience at the Institute of Psychiatry in London, and she's also president of the International Society for Autism Research.

Apart from a few notable exceptions such as the inspiring Temple Grandin, autism or ASD is most often thought of as a male disorder. However, Francesca Happé explains that the statistics tell only part of the story.

**Francesca Happé:** The general prevalence suggests that about four times as many males as females get an autism diagnosis, and this varies across the spectrum. So the proportions are higher in high functioning or more subtle forms of autism, and more even at the lower end of the spectrum where there is also intellectual impairment.

**Lynne Malcolm:** So what's the level of understanding of women with ASD generally?

**Francesca Happé:** I think we know very, very little really about how autism presents in girls and women. There are some studies, but the main problem is that the studies start in a clinic. And so you can see there is a circularity. If we are missing women and girls with

autism because we are not good at recognising them, then studying those we do spot isn't going to tell us very much about the ones we miss.

**Lynne Malcolm:** Dr Janine Manjiviona is a clinical psychologist in Melbourne with 20 years experience of diagnosing girls on the autism spectrum.

**Janine Manjiviona:** They are being both underdiagnosed I think and misdiagnosed. And when you historically have a look at the whole history of autism, originally in Kanner's descriptions, they were largely focused on males. And Hans Asperger's clinical cases were all male. So across the epidemiological studies throughout the world that provide sex ratios, gender differences are always apparent, and females never outnumber the males, and the reasons for that are not always clear but I think it's plausible that underdiagnosis of females may contribute.

**Lynne Malcolm:** Janine Manjiviona.

Research is emerging that one of the reasons that ASD in females may be missed by clinicians is that it looks different in girls than it does in boys. Girls may be better at covering up the more obvious characteristics of autism.

**Francesca Happé:** Some of the differences are that we think the social difficulties in some girls with autism may be less obvious. Some women with autism describe a strategy of copying somebody. They pick somebody in their class or their workplace and they just copy everything about that person, how they dress, how they act, how they talk, and that kind of masking strategy we don't see very much in boys and men with autism.

If you looked at the research on women with autism, most of the work suggests that women with autism may be more impaired and more often have intellectual difficulties and be hit harder by autism, but I suspect that's because the subtler cases are missed by our diagnostic system.

**Lynne Malcolm:** So why do you think girls often do go undiagnosed?

**Francesca Happé:** It's interesting question, why we might miss girls with autism, because on the face of it you might think that our expectations of social functioning are even higher for girls than for boys, and so maybe we should be more alert to these difficulties. I think there are a lot of reasons why we might miss autism in women. One is diagnostic overshadowing or diagnostic substitution were, for example, a girl who has eating disorders, when that's picked up as an eating disorder they don't ask any more questions about what else might be different about this young woman. So a girl with autism who has an eating disorder may just be diagnosed with an eating disorder.

I think it's also likely that girls show their autism in a different way, and a way that our diagnostic system isn't ready for. So an example would be that when a clinician is deciding if a child has autism, they will look for rigid and repetitive behaviour, which might include unusual special interests. A boy with autism might have a fascination with electricity pylons and know all the facts about electricity pylons, and the clinician is going to go, aha, that's sounds pretty odd to me. But a girl with autism might be fascinated by a particular pop

group, and she learns all the facts about them, and when she says her interest is this pop group, the clinician thinks, well, that's pretty normal. So unless he digs deeper and finds out actually she has no interest in going to hear them perform or even listening to their music, she just collects the facts, then otherwise the clinician is going to be fooled into thinking, okay, this isn't autism.

**Lynne Malcolm:** Professor Francesca Happé.

Because ASD can be missed in girls, they often don't discover it till later in their lives.

Hannah Belcher had been seeing therapists throughout her adolescence because of her struggles with her psychological health. And a diagnosis of ASD in her early twenties came as a bit of a shock.

**Hannah Belcher:** I was 23 and I was in art therapy and I'd had a lot of therapy before this that hadn't worked, things like CBT, that got to a point with me where they'd realised that I was really avoidant and quite blocked. She finally said to me, 'I think you've got Asperger's.' I'd never considered it before, it was a real shock. And I went through a whole process of accepting it, denying it, being angry about it, before I got officially diagnosed.

**Lynne Malcolm:** Why do you think it was unnoticed?

**Hannah Belcher:** I think the main problem was that my symptoms weren't as obvious as they are in males. So things like eye contact I was perfectly okay with, I actually count out my eye contact, so it was never really a problem. And I think doctors just saw my anxiety and just saw that as the main diagnosis without really considering why is that there. I think they saw that as the challenging behaviour problem and not what was underlying it.

**Lynne Malcolm:** So, looking back, what were your symptoms?

**Hannah Belcher:** I had a lot of problems with anxiety, social anxiety in particular, talking to people. So when I started school I found that I just was too anxious to speak so I just couldn't form my words, I couldn't think of what to say to people, and it just became like a really big anxiety problem for me where the more people pressured me, the harder it was to speak. So I dropped out of school when I was 14 because that all became too much for me. But the ones I never really paid attention to, things like sensory problems, I'm quite sensitive to noise and colour and smells and things like that.

**Lynne Malcolm:** And you were also obsessed with music?

**Hannah Belcher:** Yes, I still am a little bit, in a kind of typical autistic obsessional way. I just listen to the same song over and over again, and I still do that now, if I get a song I like it's just on repeat constantly until I get sick of it.

**Lynne Malcolm:** And what about your relationship to food?

**Hannah Belcher:** I was a very picky eater. I think that was my main problem when I was a child. It had to be in a certain way, it had to be cut in a certain way, put on the plate in a

certain way. There was only certain items I would eat and I would just eat them continually until I got sick of them and I'd move onto the next thing. I'm still like that a little bit now but slightly better.

**Lynne Malcolm:** And what did he think was going on for yourself before you were diagnosed?

**Hannah Belcher:** I thought it was anxiety problems as well. I never considered autism really. I studied it and I still had never considered that I could have autism because my view of autism was also quite male stereotypical.

**Lynne Malcolm:** Hannah Belcher thinks that girls and women with autism mask their symptoms because of the social pressure on them as they are growing up. They're taught to be polite, and socially adaptable and they become very good at what she calls social mimicking. She's so passionate about this topic that she's doing a PhD in psychology at Anglia Ruskin University in Cambridge. She's conducting an online survey to improve the diagnosis for females with ASD.

**Hannah Belcher:** So my research is with Dr Steven Stagg, and we're looking at the number of females that have been undiagnosed with autism possibly, and also looking at if their social mimicking has anything to do with this, whether those females that are better at socially mimicking are being hidden more, and what role that has to play with misdiagnosis as well with other mental health conditions.

**Lynne Malcolm:** And what are the results that you're seeing?

**Hannah Belcher:** At the moment it's quite early stages, we haven't really got anything just yet. I've had a lot of females come forward, all saying the same thing, you know, 'I had this problem, I think I'm autistic, I socially mimic really well,' just loads of them seemed to have this same problem.

**Lynne Malcolm:** So do you think we need different diagnostic measures for testing autism in girls and boys?

**Hannah Belcher:** I think it's probably important to look at the social adaptations they are making alongside what we already have. So I think something like the social mimicking scale I've come up with, something like that to go alongside the diagnosis, to say, okay, this female is slightly below the threshold for diagnosis but she does score highly on social mimicking, so we have to take that into account, that she could be hiding a lot of her symptoms.

**Lynne Malcolm:** Hannah Belcher believes that females with ASD present differently because of socialisation.

However, there's growing suspicion that the underlying biology of autism in males and females may also be quite distinct.

Professor Francesca Happé at King's College London studies ASD using brain imaging studies and genetics.

**Francesca Happé:** I think there are probably both biological differences and social and cultural reasons why we may not be very good at picking up autism in girls. One of the explanations for the unbalanced ratio, why more girls might be affected, is what's called the female protective effect. So we've done some work that suggest that girls who have autism have been hit harder or have a larger genetic dose than boys with autism, and you can tell this because if you look at their brothers and sisters, the brothers and sisters of girls with autism are more likely to have autism or some traits of autism than the brothers and sisters of boys with autism. So that's suggesting there's a bigger genetic hit for those girls with autism than for boys with autism.

**Lynne Malcolm:** So from a biological perspective, why might females be protected against autism?

**Francesca Happé:** In general, males are more affected by all neurodevelopmental disorders. So there are more males than females with ADHD, attention deficit hyperactivity disorder, with dyslexia, with dyspraxia or clumsiness. It seems that the male developing foetus takes a longer time in a vulnerable stage and so may be more susceptible to all kinds of things. However, the ratio in autism is even higher than in those other cases. We don't know why exactly that is. Simon Baron-Cohen has a theory that it's about exposure to testosterone in utero, predisposing the male brain to the autistic pattern. That's a very interesting theory. There are other theories as well. The answer is at the moment we don't know.

**Lynne Malcolm:** So one theory I think you might have been referring to, it is called the extreme male brain theory. Tell me about that theory.

**Francesca Happé:** So Simon Baron-Cohen has the theory of the extreme male brain, which suggests that all of us have a balance between our ability to understand other people, which he calls empathising, and our ability to understand non-social systems, he calls systemising. And he says in a male brain the systemising is highly developed and the empathising is less good, and that autism can be thought of as a very extreme version of this where social understanding is really very problematic and poor, but understanding of non-social systems can be extremely good.

**Lynne Malcolm:** So what do you think of this theory?

**Francesca Happé:** I think it's interesting. I don't fully agree with it. I think that, for example, empathising that Simon Baron-Cohen talks about is actually made up of lots of different abilities, some of which are quite intact in autism, like the ability to empathise with somebody's emotional state or care if somebody is hurt. People with autism have no problem with that. And on the other hand knowing what somebody else is thinking, which is very difficult for people with autism. So I think empathising in Simon's theory really mashes together a whole lot of things that are quite distinct. And I think it's not clear in his theory whether empathising and systemising are in trade-off, so if you are good at one you have to be bad at the other or whether they are really separate dimensions, which some of our

work would suggest the non-social assets in autism and the social difficulties in autism are really quite separable and distinct and actually have distinct genetic underpinnings.

**Lynne Malcolm:** Francesca Happé.

It's *All in the Mind* with me, Lynne Malcolm, on RN, Radio Australia and online.

We're hearing about the distinct experience of girls and women with autism spectrum disorder. Because they can present differently, they're often not recognised as having ASD, and can be misdiagnosed.

Donna Rigoni has two children, Ayla and Bailey, both with a diagnosis of ASD. Her daughter Ayla is now 5 years old.

**Donna Rigoni:** When she was about 2 ½ I noticed lots of little things with the way she was playing. She would organise her toys, she wouldn't let anyone touch her toys, it had to be in a certain way. And then with her language she would repeat the same thing over and over. So if we were driving somewhere and she'd see a pattern on the wall she would repeat that every time we drove past that same place. So lots of repetitive information she was giving me.

**Lynne Malcolm:** So when you are noticing her behaviours, what made you think that they were part of the autism spectrum disorder?

**Donna Rigoni:** Well, I also have a son who was diagnosed before her, so just following things that he was doing as well, stuff like the sensory issues, walking on her tippy-toes, hands over her ears when there was a loud noise, so even vacuuming was hurtful for her. Things like dressing and washing was all just too traumatic for Ayla, she would adjust scream that I was hurting her every time I'd dry her and wash her. So just putting the play, the language, the sensory problems all together, and it just screamed ASD to me.

**Lynne Malcolm:** So you have a son with ASD as well?

**Donna Rigoni:** Yes.

**Lynne Malcolm:** And what are the differences in the way they behave and the way they present?

**Donna Rigoni:** It's huge. Ayla's a lot calmer and she talks to me more about her feelings, like she'll say to me, 'Mum, what does that mean? Mum, why is that person looking like that?' Meaning their face expressions. She shuts down when she is overwhelmed, whereas my son will have a meltdown when he is overwhelmed. So he is very loud. He's a bit more angry, sounds a bit more abrupt than her. And even her interests, for my son it's technology, downloads, anything to do with wi-fi and technology interests him, where her interest is animals, horses in particular, dogs, it just seems an interest that more children tend to go to than to what my son's interest was or is. But definitely Bailey was easier to pick.

**Lynne Malcolm:** Donna Rigoni.

Clinical psychologist Janine Manjiviona diagnosed Donna's daughter Ayla with ASD. She emphasises how important it is to gather comprehensive information from multiple contexts when they're being assessed, to prevent girls from slipping under the radar.

She says that there are a number of other conditions which can overlap with ASD, and girls are most often diagnosed when they hit puberty.

**Janine Manjiviona:** Well, I think it's at that time when their difficulties become more obvious. Often they are on the periphery of social groups. The girls have often learned their social skills by intellect, not necessarily intuitively or instinctively. Teenage girls are very socially demanding on each other, and the girls with ASD can be marginalised, teased and bullied. And up until then the difficulties may be masked due to a veneer of coping.

**Lynne Malcolm:** There's discussion in the literature, and you've seen this too in your practice I think, that there is a crossover between the symptoms of ASD and eating disorders such as anorexia nervosa with girls. Can you tell us about that?

**Janine Manjiviona:** Yes, anorexia is one of the conditions that overlaps with ASD. It's not the only condition and there's lots of comorbidity issues with ASD, but controlling weight can be a way of fitting in, looking right, it can be part of an attempt to gain social acceptance. And I guess another reason might be that when girls hit puberty, many of them have trouble coping with the changes in their body and feelings, menstruation, breast development and so on, and they can develop anorexia as a way of coping. They don't like highlighting their femaleness, and many of them prefer to have a somewhat androgynous look.

They've told me too in my clinical discussions with them that they don't really want to grow up. 'I don't want to grow up,' they say, 'I don't want to have children, I just want to stay home with mum and dad and my brothers and sisters.' So I think it's related in part to that whole issue of change and anxiety.

**Lynne Malcolm:** Psychologist Janine Manjiviona offers therapy to girls and women with ASD to help them deal with their concept of themselves and the anxiety associated with that.

She also referred Donna Rigoni and her five-year-old daughter Ayla to a therapy program called Social Thinking at Spectrum Services in Melbourne. It's designed to help prevent anxiety developing later.

**Donna Rigoni:** So she's in a small group of three children which are at the similar level to her on the spectrum. She has been taught things like whole-body listening, so how to listen properly, so learning to stay still, looking at the person who is talking so they know that you are listening. Also we are working on having Ayla's body in the group. She knows that if she is sitting with the group, other people in the group know that she is listening and willing to contribute. If her body is out of the group than the other children in the group will think, oh, Ayla is not really wanting to contribute. So she has used that at school this year. She actually says to her teacher, 'I'm putting my body in the group.' So she is using a lot of the language that she is being taught.

A big one that Ayla's doing at the moment is learning a strategy called the group plan, and what it is is she has to follow what everyone else is doing within the group. So this shows that they are thinking of each other, that Ayla understands that if she is following the group plan, everyone is happy, and they can work together constructively. If she is not in the group plan and wants to do her own thing, well, it might make others unhappy. And this has really helped with things like birthday parties.

We went to a birthday party recently and it was something that Ayla was a little bit stressed about the night before. But the lady in charge of the party explained what they were doing, and I said to Ayla, 'Don't worry Ayla, just follow the group plan.' She said, 'Mum, I know, I'm following the group plan, it's all good.' So she was able to use that in her everyday life. So that has really helped.

She has also learned a phrase called 'words are bumping', and so she knows that if someone is trying to talk on top of her or interrupt, she'll say, 'Hang on, stop, words are bumping, I need to finish what I'm saying.' So this has all been from the speech therapy that she's doing.

We're also doing a lot on thinking thoughts and feeling feelings. So Ayla has been taught that you think with your brain and you feel with your heart. She understands that people have thinking bubbles above their brain. She knows you can't see it but she knows that if they are looking at something, they would probably be thinking about that thing, and that has been really helpful because there are days where Ayla has upset me, and I'll say to her, 'You're hurting my heart, Ayla.' And she'll go, 'Oh, okay.' And so she gets that.

And there'll be times when she'll come home and she'll pick up something and say, 'Mum, what am I thinking about?' And she'll hold something and look at it really intensely, and I'll go, 'You're thinking about having a drink.' And she goes, 'Yeah, that's right!' And then she'll make me look at something and say, 'What are you thinking about?' And we play games like that. So all of that stuff has been an incredible help for Ayla, which is stuff that my son didn't have because he was diagnosed later. So I think the earlier girls are diagnosed, you can give them so much more help. And what I'm hoping is by the time Ayla gets to puberty we will be prepared. So it won't be so stressful, and hopefully she won't be so anxious.

**Lynne Malcolm:** Donna Rigoni.

Hannah Belcher wasn't diagnosed with ASD until she was 23 years old, and she feels it's really important to get the right diagnosis to prevent inappropriate treatment.

**Hannah Belcher:** Things like depression, anxiety, OCD and borderline personality disorder are really common misdiagnoses for females with autism, and people don't tend to look at the root of them. So with OCD I say that someone with OCD may have to turn a light switch on and off a certain number of times because they feel like something bad will happen, whereas someone with autism may do that and it's quite a soothing mechanism. And I think with girls in particular this has been misconstrued as a different disorder overall. I think that's the main problem with the misdiagnosis.

**Lynne Malcolm:** Does that apply to you and behaviours that you display?

**Hannah Belcher:** I certainly had some OCD traits when I was younger, hand washing in particular, and I do things now that are quite obsessive, movements and things like that, which are more for me soothing than they are obsessive. I don't feel like something bad will happen if I don't clink my fingers a certain number of times, it's a soothing kind of stimming mechanism for me.

**Lynne Malcolm:** It just makes you feel better?

**Hannah Belcher:** Yes, which certainly if my psychiatrist saw me doing it he'd think, okay, OCD, but...

**Lynne Malcolm:** Even your psychiatrist doesn't really understand that?

**Hannah Belcher:** I think it's a general problem with psychiatrists, that they aren't given a thorough training on autism. So the view they have is also quite stereotypically male, so it's still a challenge getting through to the doctors that there is a difference.

**Lynne Malcolm:** What would you like to see in the future? Where are you going to take your research?

**Hannah Belcher:** I want to see better diagnosis for females overall, I want to see more females being picked up earlier in their lives when they can get the support at school that they need, and just more awareness about the issue. I had an article out recently and I got accused of sexism and all sorts because the issue is so unknown and so unheard of that it's quite difficult to get the message out there. Certainly I think it's a definite gap in our understanding of autism that needs to be addressed.

**Lynne Malcolm:** Hannah Belcher.

**Francesca Happé:** Certainly for the families where there isn't a diagnosis of autism in particular, if your daughter has lifelong social and communication problems, if they don't get on with others in the way that you would expect and they find it hard to know if other people are joking or being sarcastic or telling a lie, if they are socially vulnerable, then you might think about whether this is autism, even though it doesn't fit the stereotype of autism, it doesn't look like *Rain Man* or one of the portrayals of male autism in the media.

**Lynne Malcolm:** And Francesca Happé suggests that further study into the gender differences seen in autism may help our overall knowledge of the autism spectrum disorder.

**Francesca Happé:** I think a lot of researchers believe that if we understood why more males than females are affected with autism we would have a better understanding potentially of either the genetic or environmental influences on autism. So, for example, if Simon Baron-Cohen is right and it's to do with foetal testosterone in utero, then we might have a handle on the mechanisms of brain development that are different in autism. And I suppose the point of all of the genetic work that is going on around the world is to understand the

mechanisms in order to improve outcome, to make outcome for people with autism the very best that it can be.

**Lynne Malcolm:** In the course of her work Francesca Happé has formed friendships with many women with autism and she's struck by the diversity of their experience.

**Francesca Happé:** Some of my friends with autism will say, 'If I could take a pill tomorrow and wake up without autism I would do it instantly because my autism makes me so frightened of the world and so unable to go out and do the things I want to do that I hate having autism.' And then I have other friends, women with autism, who say, 'Autism is who I am and what I am and I wouldn't change it. It is me.'

Interestingly I have some friends with autism who have transitioned genders from being a woman to being a man and feel much, much more comfortable as a man, which is interesting, and I learn a lot from talking to them. And other women with autism who go and speak about their experiences and are such gifted orators, so funny, so poised on stage, that people really doubt that they even have autism. But then if you could see that same woman trembling at the thought of having to buy a ticket at the train station or having to brush past a dog in the railway carriage to get to her seat, you see this ability of some women with autism to mask their difficulties. But how much it affects their everyday life and how brave they are to struggle to live in our neurotypical world.

**Lynne Malcolm:** Francesca Happé, Professor of Cognitive Neuroscience at King's College London.

Further information related to today's program can be found on the *All in the Mind* website, it's easy to navigate your way there from the RN home page.

Thanks to producer Diane Dean and sound engineer Luke Purse. I'm Lynne Malcolm. Great to have your company, see you next week.

## Guests

Francesca Happe

Professor of Cognitive Neuroscience, Institute of Psychiatry, London

President of the International Society for Autism research

[University Profile](#)

Janine Manjiviona

Dr. Janine Manjiviona, clinical psychologist

Hannah Belcher

PhD student, Anglia Ruskin University, Cambridge

[University profile](#)

Donna Rigoni

Mother of girl with autism spectrum disorder