

Peer mentoring for autistic women and girls: an interview with Dr Catriona Stewart

1. Can you tell us a bit about your background?

I live and work in Scotland. I am mother to two absolutely fabulous, young, grown-up children. I founded SWAN, Scottish Women's Autism Network, in 2012, on the back of my PhD, which focused on girls with Asperger's syndrome and anxiety. And I first realised that autism was something that personally affected me while I was studying for my PhD, so several years after I started studying autism in the first place.

And that's had some impact, as you might imagine, over the years. And I work as an advisor with Scottish Autism. They originally employed me to help them develop the online resource for women and girls, the Right Click programme, which was great fun.

2. Can you tell us about SWAN, and why it was set up?

So I set SWAN up in 2012, in response to what I'd found in my PhD study, which was on girls, Asperger's girls, and anxiety, And it's really apparent that a lot of autistic girls struggle to access their education. I don't like using the term school refusal, because it sounds like the girls are refusing their education, when in fact, what's happening is insurmountable barriers are being put in place to prevent them accessing their education.

So that's one of the things I found in my PhD study, was the school environment itself was really quite toxic to them. The other thing was, of course, I realised that girls grew up. And not only was I realising there were a lot more girls in society than we were thinking at the time, or that other people were thinking at the time, I should say, but obviously girls grow up, so there were going to be autistic women in society who might be not aware they were autistic.

But I was beginning to meet women who had spent a lifetime just getting on with their lives, and obviously no diagnosis, but were beginning to realise that perhaps they might be autistic, either because they were having some kind of crisis in their lives, or sometimes because their own children had been diagnosed, and things began to slot into place for them.

So SWAN was really set up as a response to that realisation, to support women at any stage of their understanding about their own autistic identity, to provide support, and also to build on the knowledge base, because there was so little information about girls and women at that point.

So it's a way of actually building on that information. My own research was very much based on the principle of trying to facilitate the authentic voice of the autistic girls who took part

in my study. So SWAN's really an extension of that. It's actually making autistic women and girls visible, but also allowing them to speak and to be heard in whatever way they communicate.

3. What impact does the lack of appropriate support have on autistic women and girls?

I think the biggest thing absolutely fundamental to the lack of awareness initially, in terms of autistic females, is a lack of self-identity. Even by the time a girl's eight, nine, 10, 11, 12, there'll have been huge efforts to pretend to be normal, as Liane Holliday Willey would've said, to mask and masquerade, fit in.

And if you spend, and then for women like myself, for example, spend a lifetime not knowing that I was autistic, you're basically in the process of self-denial the whole time, and it's a survival strategy. Masking is essentially a survival strategy, but the consequence of that is a core lack of self-identity.

Who are you? Poor self-esteem, because you don't see yourself as being acceptable or okay. It can sometimes be very hard to feel that you're ever being listened to because of the communication issues. A lot of autistic people, as we know, they're quite intellectually very capable but emotionally a lot younger than your years. So there's that kind of real discrepancy.

And so what I'm really saying is that basically, the development of poor mental health. But it's also that sense of self that will impact on every single aspect of their lives as they go through their life cycle. The choices they make, the relationships they have, the potential for being able to get into appropriate employment, their decisions around do they have have children, do they not have children? So self-identity and mental health I think's the biggest thing, really.

4. Can you tell us about SWAN's pilot peer mentoring project?

So it's very exciting. We're right in the middle of it, at the moment. The mentors have just been through a programme of really very rich and varied kind of forms of training and experiential learning, and they've just been paired up with their mentees.

It's been modelled very much as a co-production, so although, obviously, we had a programme of training and the whole process all the way through, we've encouraged, and we've listened, and we've responded to feedback all the way along. We wanted the mentors to very much feel that this was their programme, that it wasn't just something that's being imposed on them.

And that's been really, really interesting, and I think we've all learned an enormous amount, but again, it goes back to that idea of maybe empowering autistic people to feel that they can take charge of their own self development, rather than just right, this is what you have

to do. It's an extension of what SWAN does already, which is get women in touch with each other and give them that sense of self-identity and confidence and relational experiences and community.

5. What outcomes do you expect to see from the pilot?

We had certain kind of general headings that we were kinda building this around, and it was to do with things I've mentioned before, like self-identity and esteem and confidence and citizenship. But it's obviously very much about the personalised self-development of each individual. So it's as much about the process as it is about any specific outcomes. But I have to say, we're already seeing an enormous shift in some of the women taking part.

6. Can you tell us about the importance of the project being designed and facilitated by autistic women?

As I usually do when I've got something kind of big coming up, I ask the questions to the Network. So the Wedge, which is the inner admin group for the SWAN, I asked them what do you think about these questions? And they were so excited that they were being asked about the importance of peer support for autistic women. And it was just really lovely, the responses. So I'm wondering if you mind if I could just read out a couple of the responses, 'cause actually, they sum them up themselves. So this was from Rony, who's the Project Coordinator.

"I would like you to include the importance of the empowerment through community aspect of what we do. Forming a positive autistic identity is crucial to well-being, and to me, it is a cornerstone of life for autistic women and girls. I feel empowered through peer support and through finding my tribe, and this experience has been transformational in my life. The real pleasure comes from being able to witness this incredible transformation in others."

Sorry, I'm getting emotional, 'cause it's fantastic. And then Marian, who's one of the people that runs the Aberdeen group, said,

"For me, better mental health and self-acceptance are huge. When we feel better about ourselves, we're more able to contribute to society, less prone to burnout, over-analysing social interactions, hitting crisis points. And we can only do that with improved access to assessment and diagnosis. We need to know who we are".

So that sums it up, I think.

7. What are your hopes or ambitions for SWAN and for autistic women and girls?

For SWAN, I would like to see it just continuing to grow, and I would like to see it being sustainable in the sense that I would like to see it funded. And we're having fantastic support from Scottish Autism and other partners like Forestry Commission, but it would be

great to have SWAN actually seriously funded on its own, because we could do so much more.

The potential is huge. I'd like to see it reaching some of the communities, the people that we're not getting to at the moment. So areas of multiple deprivation, black and minority ethnic communities, rural communities in Scotland, Highlands and Islands. So basically, for SWAN just to do more of what it's doing already, just to watching it grow and continue. I'd also like to see that kind of peer support and mentoring available to all autistic people, not just girls and women. In terms of girls and women, greater equity and just ability to access all the things that most people take for granted that they should be able to access.

So being able to access their education, being able to access employment if that's what they want, being able to feel supported if they want to have a family. I want to see better autism understanding services. So we talk about being autism aware, but actually, we do know people are a lot more aware of autism, but we also know that that doesn't necessarily mean they understand autism.

So not necessarily more autism-specific services, but more autism understanding services. So I'm talking about things like mental health services, maternity services, social services, all that kind of thing. I think, just to round up, for girls and women, I want them to be able to have the same opportunity to be happy and healthy and achieve their best potential, in the same ways as we want everyone else to.