



Where Autism
Professionals Connect

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Women and autism: an interview with Charlene Tait

1. Can you tell us how you first became interested in autism?

Well, my interest in autism spans, I think 26 years now; I started working with what's now Scottish Autism, in 1990, when I was managing and developing a day service for twenty autistic adults, and have been working in the field ever since in a variety of roles, including an academic position for seven years, and then back to Scottish Autism for the post that I have now.

2. Can you tell us about your current work?

I'm Director of Autism Practice and Research for Scottish Autism, and my job really is to look at continuous autism practice improvement, to develop a charitable offering which is [?] support to parents, professionals and autistic people who contact the organisation looking for information, advice. And also, we have the Centre for Practice Innovation, which is really about knowledge management and the generation of knowledge and evidence from the practice perspective, so we have lots of practitioner research work going on around the organisation, as well as developing and maintaining relationships with the wider academic community, so it's a very broad remit that I have with Scottish Autism.

The idea for the women and girl's project really was a development on from what we would call our core Right Click programme; we developed an online support programme for parents and differentiated it across the sort of age groups for parents of very young, probably more newly diagnosed children, teenagers in transition and for parents who are supporting adults at home, and that really came from, we've run an advice line for many years and we got often the same kinds of inquiries, and a kind of feeling of helplessness about the limits of what we could do for people, so, we recognise that there's enormous, you know, sort of repository of information and knowledge in the organisation, so what we decided to do was almost download ourselves, and put this into a programme format that parents could access, and that's proved extremely successful; we've had over a thousand parents access that, and they also have the opportunity to contact an autism advisor if they want to talk things through.

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So we were confident about the model; we knew it could work, and in Scotland we've run a series of impact seminars around autism in conjunction with the Scottish Government, Research Autism and ourselves at Scottish Autism; we funded a very, very comprehensive series of seminars, and that I met Dr Katrina Stewart whose research was with autistic women and girls; I was very inspired by her work and very motivated to have some practical response to the research that she had uncovered because, of course, there were a lot of issues and a lot of challenges that had come up, so we thought what could we do to sort of respond to that? So that was really the catalyst for the development of the women and girl's Right Click, and we were funded by the Scottish government to develop that specifically, and it's been an amazing experience; we've had... really, front and centre to the whole thing has been involvement of autistic women and girls, either through further research focus groups, you know, surveys, questionnaires, to inform the content of the programme, but also as contributors to the programme.

So, the philosophy is, a sort of model of information and inspiration, so there's very practical things there, and there's research materials on there too, but there's a lot of lived experience there, and the idea is that other autistic women can be inspired by the role models that they meet through the programme and recognise that, you know, they too can do anything they want to do in life! They can have a job, they can be mothers, they can have relationships, that their autism isn't a barrier to that if they choose that way, so, this idea of information, inspiration is kind of blended throughout the programme.

3. What difficulties might autistic women and girls face in their lives?

So, of course, autistic women and girls face a lot of the same challenges that non-autistic women and girls face, but the context of issues around social interaction, social communication, and the different thinking and processing style adds to those challenges and difficulties. And so, in terms of things like relationships, employment, education, just accessing everyday...you know, health experiences, these were all things that the women that we engaged with told us were problematic for them. So, there's, I guess, any kind of everyday interaction or everyday activity could be problematic for someone, and so we've taken our time to understand on a more individual level some of the experiences that women have had, but the research showed us that these areas such as getting a diagnosis, you know, in the education system, the health system, in employment, in relationships, all of these things were stressful and anxiety-provoking and challenging for the women that we worked with.

4. What advice would you give women who are having difficulties?

I think that we recognise that diagnosis is an issue in autism, per se, there's a lot of late diagnosis still goes on and, when you work in the field for a long time, that's quite baffling as to why that would be. I think that some of the... research around the presentation of autistic women does make it a bit more challenging because practitioners often have a bit of a tunnel vision about what autism might be and even people who are very experienced can sometimes find it hard to recognise some more, I wouldn't say mild, but more subtle presentations of autism.

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So I think that if a woman is concerned that they might be on the spectrum, I think the first thing is to equip yourself to really understand what autism is and really figure out what way it might be impacting on you, and it might be useful to find other individuals who might support you.

Here in Scotland, we have something called SWAN: the Scottish Women's Autism Network, and that's really a place where autistic women can come together and Katrina Stewart who did the research for the women and girl's programmes are one of the founders of that organisation, and I know that they get a lot of women in that position who come and say "I think I might," or "I've just been diagnosed," and so I think to find someone who can have empathy and understanding for you, and who might be willing to, you know, support you by going to appointments or by being an advocate or helping you assert yourself around the diagnosis.

So I think it's a challenge, because there's a lack of really good services for adult diagnosis in Scotland, but I think that that is about our job to educate the community a bit more about the very, very broad presentation of autism, but my advice would be to try and make either virtual or real connections with women who might have that empathy and understanding and help you through that process, or to contact organisations like ours who might be able to support you and direct you around that.

5. What advice would you give professionals working with autistic girls and women?

I think that the advice that I would give is to not to have your autism goggles on and just think that autism is this one kind of, you know, form of presentation, and to recognise that the impact of social communication, social interaction can be very, very varied, and actually the thinking and processing issues in autism are really pronounced, I think, in many individuals, obviously. So I think that professionals need to take some responsibility for broadening and deepening their knowledge of autism; I think we suffer a little bit from the one hour awareness raising on autism and people think they know autism. So I think it's to sort of maybe have a bit of understanding of "you don't know what you don't know" and I think that the biggest thing is to actually believe people who come to you for support if they're experiencing sensory overload or having difficulties; they're not making that up, believe them and trust their own knowledge of themselves, and meet them with a little bit of acceptance and understanding and recognise that the deficit is actually yours in terms of your knowledge and understanding and not the person. The person knows themselves, knows themselves quite well and is asking for their help so be prepared to do a little bit more work to make that happen for them.