

# Colouring Outside The Lines

## Ask The Experts...

This is the fourth in a series of Ask The Experts publications designed to connect parents of autistic girls with autistic women.

As parents of autistic girls, members of Colouring Outside The Lines were asked what questions they would like to ask autistic women in order to help them support their daughters as effectively as possible. As a group, we strongly believe that by connecting our daughters with the autistic community, especially autistic females, we can ensure that their future is bright and their minds inspired.

Our first group of experts have kindly agreed to respond to various questions about school, support, diagnosis, relationships & careers.

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### Cat Stewart

I have been involved in autism for over 15 years, gained my MSc in 2004 and completed my PhD, a qualitative study of experiences of girls with AS and anxiety, in 2010.

I was a member of the Autistic Advisory Panel to the National Autism Project 2014-17 and am currently helping to develop its extended project, the National Autistic Taskforce.

In 2012 I co-founded the peer-support charity, SWAN: Scottish Women's Autism Network which I chair. SWAN has run 4 ground-breaking conference and learning events at 2015-17, and was involved in consultations for SIGN and the NES autism training framework; SWAN leaflets are included in the RCGP Autism Toolbox. SWAN was shortlisted for a National Diversity Award in 2016.

I deliver presentations and training for autistic people, practitioners, parents and special interest groups including: NAS Women & Girls conference (London), the IV International Conference on Advancement in Women's Studies, Toronto, and Meeting of Minds, Copenhagen 2017. I have been a NAS Professional awards judge for 2 years.

I have contributed 2 book chapters for a forthcoming compendium of writings by autistic women and have a contract with Jessica Kingsley to write a book on women and autism.

In 2015 charity Scottish Autism was given funding for the development of an online resource, the Right Click for Women and girls, which was based on my research and for which I was academic consultant. I currently work full-time for Scottish Autism as an advisor.

What are the best bits about being autistic?

My very able brain; my logic; my creativity; my ability to 'think outside the box'; my love of the natural environment and music.

How/when would you like to have been told you were autistic

Receiving a diagnosis young in the context of the 70's might not have been particularly helpful. Knowing from very young in a positive context would be best, I think.

My daughter was recently diagnosed but she seems so unhappy - what can I do to help my daughter embrace her 'diagnosis'?

She sees her diagnosis as being the thing that makes her 'different' and it sounds as if being different for her right now is a major problem, so the diagnosis isn't the problem, it's how she perceives that impacting on her and her life. It has to be seen in the light of something that brings positives as well as negatives.

What could your parents have done better to support you when growing up?

Recognised me as an individual who had a right to be 'different'; not been as sexist; been more affectionate.

My 15 year old has previously spoken very positively about her autism, but now she seems to be hating being autistic - how can I help?

I would look at it the other way about and ask what it is that is causing her to be so negative about it.

How best do I advocate for my autistic child whilst making sure I'm not also (unknowingly) imposing my own NT view on to her?

Keep asking her and keep listening.

## What, above all else made the difference for your child?

Promoting her strengths, building on her interests and abilities and advocating for her when she needed support for things that challenged; my daughter is a gifted musician so I supported her taking that as far as she wanted.

## How can we be sure we aren't being too protective?

I think you do need to let your children take on challenges, make mistakes, push themselves. Don't tell her she 'can't', unless there really is a very good reason to do so. Support her taking (managed) risks and trying things.

Don't let her use her autism as a reason for not trying, not doing, not making an effort. But also of course teach her to know when to say 'no', to assert her needs and to look after herself...difficult balance

## What is one thing that positively affected your self worth and made you feel wanted and loved?

Life experience teaching that the only person who would ever love me the way I needed was - me, I have to care for myself as an adult cos no one else is going to.

## What is the best way to be supportive to a girl who hates being hugged?

Just tell her you are there whenever she wants/needs you.

## Do you know where there are good sex and relationships resources?

Scottish Autism's Right Click for women and girls is going to be posting a series of sex-education videos up soon.

## What are the key things parents can do to support their autistic daughters as they go through their teenage years?

Love her! Remember that while her intellectual brain may well be maturing at the same rate as her peers or possibly even be advanced, emotionally she's likely to be 'younger' than her age; this is going to cause huge challenges for her socially as well as emotionally. She may have difficulties with her academic work too, for all sorts of reasons, from anxiety or difficulties in being organised or in focussing. She may well start to be anxious about her future, as she sees her achievements and place in her social world not matching her abilities; she may find peers she had as friends start to puzzle or annoy her, or that she is excluded from things. Reassure her - even while you are worried yourself; put the emphasis on what she CAN do, not what she can't; support her pursuing her interests, from astrophysics, to make-up, art, to music etc. Teach her about safety and self-esteem, especially self-esteem!

Do you know of resources about alcohol and how it may affect someone on the spectrum?

See Sarah Hendrickx' book on alcohol and also Jeanette Purkis.

How do you deal with stress and pressure/demands so you can be both functional and happy in a working environment?

It is challenging and entails ensuring a balance of work and time off; finding a sympathetic working environment that supports a bit of flexible working helps or self-employment.

Did anyone ever suggest you should restrict your ambitions because you are autistic?

It is suggested, I know that but as I didn't know, I wasn't restricted. I did crash though through exhaustion, a couple of times in my life.

If I had the self-knowledge combined with encouragement to work to my strengths and abilities, I might have got my PhD much, much earlier.

HUGE THANKS to our first Ask The Experts panel.



Claire Evans-Williams



Sarah Hendrickx



Rose Hughes



Cat Stewart

More Ask The Experts coming soon...

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