

Colouring Outside The Lines

Ask The Experts...

This is the first 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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Claire Evans-Williams

Dr Claire Evans-Williams is a Consultant Clinical Psychologist, with specialisms in Adult Mental Health and Autism.

The majority of her career has been spent serving the NHS, which she left in March 2017 to develop a community organisation The Autism Academy UK, officially launched in August 2017.

Claire writes for a range of clinical/academic journals and other online outlets; contributes to academic, clinical, and professional conferences; and provides independent community and in-patient Autism consultation to a number of NHS boards across Scotland. Claire is very proud to have recently become a Trustee of Scottish Women's Autism Network (SWAN) and Editor of Psychological Medicine for MedShr.

In her spare time, Claire surrounds herself with nature and animals, two passions she has maintained since childhood.

Claire received her Autism diagnosis aged 32.

For more information on Claire and to follow her organisation, The Autism Academy UK, join their Facebook page at www.facebook.com/autismacademyuk or if any of the comments have raised questions for you or your family and you would like to make an enquiry, contact us at info@autismac.com

What are the best bits about being autistic?

This is an interesting question. It's like asking me "what are the best bits about being Claire?". I can't speak for all autistic people because we're each so unique. But — I can say that I am extremely driven, motivated, and dedicated to things that interest me — I want to know everything there is to know about a subject. I have a strong work ethic because I keep going until I'm satisfied on my knowledge and understanding of a subject. I would say I'm a natural analyst, and enjoy working with complex information. So as a Clinical Psychologist, these characteristics are a big advantage.

Another advantage is having a visual, pictorial representation of most things in my mind. I can therefore mentally "see" things in my head like a movie clip- this helps me to manipulate information and supports decision making processes.

Another characteristic I share with many autistic people is a strong sense of social justice. Perhaps because I differentiate between "right" and "wrong" in a categorical way? Social justice is a big driver in my life and I feel it is important that I do what I can to ensure all people, animals, and the planet is treated with the respect they deserve.

I also think being autistic has enabled me to be highly creative. Not in an artistic way, but a conceptual and intellectual way. For years I have kept a daily list of "interesting ideas" ranging from research paradigms to household DIY projects! My husband and close friends often tell me I operate at different level to others. Sometimes they refer to this as "Claire's high cloud" thinking, meaning that my thinking constantly operates at a complex conceptual level. I don't chose to think in this way, it's just where my mind is happy being. Thankfully I have a husband, friends and family who are able to pick up and support me implementing the more practical requirements of day-to-day living like what we're having for tea, housework, and shopping!

Did you have an early 'diagnosis'? Did that help? If not, do you think an early 'diagnosis' would have helped?

This is a difficult question. My answer to this question has changed over time, and no doubt will continue to change as I grow older. When I was first diagnosed aged 32, I experienced a range of emotions: happiness and elation that there was a "reason" I was different; irritation and anger that no-body around me when I was little had considered autism; and sadness and despair that I could not turn the clock back to find out if an early diagnosis would have had made any difference to my life. I eventually told myself "why consider what ifs" because the past cannot change.

Speaking purely from my own personal experiences — I think there would have been both positives and negatives to an early diagnosis. But the biggest concern I have about early diagnosis is whether it would have influenced my ability to keep trying and pushing myself to succeed. I may have fallen into the trap of saying "I can't do X because I'm autistic"- particularly as a young obstreperous teenager!

Having said that, I think having an early diagnosis would have helped me understand that despite hating school, I could learn to love education and learning and that specialised topics would be my thing! It may have helped me to separate negative associations with school from education and learning and made it easier for me to motivate myself and participate in learning out-with the school curriculum. So I'd like to have had my diagnosis around the time of 3rd/4th year in high school — the time of picking exam subjects. But ask me again tomorrow — and my opinion may be different!

How can parents help their daughters to understand/accept their 'diagnosis'?

I think the most valuable role of a parent is instilling confidence and self-esteem in a child. Giving a child opportunities to feel good about themselves is a precious gift parents can give that will stay with a child over their lifetime. Teaching children that they are not defective, diseased, or abnormal is a good start- even the word "disorder" in Autistic Spectrum Disorder implicitly signals that autistic children are somehow not good enough. Where possible I avoid using the term disorder, and opt for just using "autism" or "condition".

Role-modelling is an excellent way to teach your child how to love, respect, and accept themselves. Openly and transparently talking about autism with friends and family as a condition which brings, not only challenges, but wonderful, exciting, and unique abilities, characteristics, and talents is simple, but often overshadowed by focusing on the negative. Children learn through what they see, and experience so it's important for parents to model self-compassion, acceptance and respect.

In addition to modelling the behaviour, verbalise your thinking out loud. A basic example of self-compassion could be how you react to regular day-to day occurrences like breaking an object: "I'm not going to get upset at myself for dropping the glass. It was an accident, and I'm very tired" and "when I'm tired I know I drop things" and "I know this is a sign that I need to rest and look after myself". Modelling these behaviours for your children is a great way to teach them how to treat and look after themselves. This will foster the development of their confidence, self-esteem and self-compassion.

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

Peer support is so incredibly powerful. I wonder if your daughter feels alienated from her peers because a diagnosis has confirmed that she is "different" from them? Spending time with another autistic little girl of a similar age may help. It could be that she feels alone, and isolated — spending time with autistic peers will teach her that she is not alone, there are others just like her who see the world in a different way.

Perhaps also spending some time drawing together or googling together — famous people with autism (or who are rumoured to have autism). There are female athletes, actresses — and you could use this knowledge to help her gradually change her perception of what it means to be autistic. If you suspect her unhappiness may even be developing into a depression? Please see your G.P for guidance and support.

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

I think this is a beautiful question from a loving parent. I think the very nature of this question demonstrates your commitment to preventing you impose your views.

It's a sure thing in life that no one is perfect. Perfection does not exist — it's a myth. As a parent all you can do is the best to your ability. Having awareness of the needs of autistic people is paramount. For you this means knowing and loving your daughter. You can advocate for her best by knowing and loving her, and using this to ensure you have her needs met. There maybe times when you get it wrong or make a mistake — as we all do. That is ok. I can tell you with a reasonable degree of certainty that you will (unknowingly) get things wrong from time to time. But given a high level of awareness and appreciation of your daughter's needs this is actually a great thing! Every step of the way on your advocacy journey you will learn new things, and make new discoveries about both yourself and your daughter. I would advise you to embrace the mistakes or errors along the way. They are a wonderful opportunity to learn. Share with your daughter — your thoughts and understanding of her needs. Listen to her. Learn together.

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

If there's one thing my child self could have told my parents it would be — please understand how exhausted and tired I am — but also — please help me to stimulate my mind. I think this must be an incredibly hard balancing act for parents. In fact — it's an incredibly hard balancing act as an autistic adult!

Too little mental stimulation for me is not good. Without a focus on my interests and hobbies, and structured activity I slip into boredom and begin to feel lost. Over a sustained period of time this can have a big knock-on impact to my mood. It feels like my purpose in the world has disappeared and the things that make me happy and keep my mind stimulated are gone. Having said that — the scales can be tipped the other way. Too much activity can lead to stress and eventually burn-out from all the processing. It's very easy for me (and other autistic people) to get too focused on tasks and it can become very difficult to pull yourself out of it. It almost feels like a magnetic attraction between myself and a task. I now know I have to pull myself out of tasks very quickly with a full determination to do so — as I begin to realise I am becoming “hooked” on engaging in a task.

In an ideal world I would have loved for my Mum to have helped me find balance, and this begins with firstly identifying and recognising there is a need for balance in activity — an awareness that your child must begin to learn what their equilibrium is. As a parent you must temporarily turn into a detective! Watching, observing, keeping notes on how your child operates day-to-day. All with the purpose of finding the ideal equilibrium — carefully balancing activity with rest..

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?

At age 15 your daughter is at a stage in her development whereby parents and the family system are less appealing and important compared to establishing peer group relationships. This is a time when children begin to value relationships and experiences external to the family system. It is not unsurprising to hear that she is denying this aspect of herself, because it enables her to shed part of who she is in order to test the waters of “fitting-in” with her peers.

Consider it like this — at this stage in her development school peers are the “in-group” and parents and family are the “out-group”. Teenagers need to test out the belief systems of the family in which they grew up in — and often this means rebelling against or choosing a different belief system than the one you've been raised in. All teenagers go through this.

There are multiple ways you could approach this. Firstly I'd try to establish is it the label, the word “Autism”? Perhaps for her at the moment this conjures negative associations? And perhaps this label also has associations to her younger self as a child? It is possible she wants to detach herself (a more grown-up present self) to the younger child that she was? It may be that “Autism” represents a child with problems and difficulties that she no longer wishes to be attached to? If hearing the word “autistic” upsets her — then don't use it. She knows she is autistic and you do too. It's possible to support her in a different way by focusing on her “needs” and ways to support these needs. I would also (if you haven't already) sit down with her, have a cup of tea and a biscuit and explain to her that you would like to understand why this is upsetting her so much. Explain that you want to be the best Mum you can possibly be, and so you'd like her help to make sense of what she's experiencing. Listen very carefully. Accept what she tells you and emphasise to her that you're there to support her in any way she needs, as her mother. In addition to this, as your daughter develops into a young woman she is transitioning from a child to an adult. Incredibly difficult time for all teenagers, and even more so for autistic teenagers. I think it may be helpful for her to meet some talented, charismatic and inspiring young autistic women. It may be helpful for her to have these experiences as a lynchpin which will help her to re-conceptualise what autistic women look like, what they've achieved, and demonstrate their success in life. In this way she learns experientially that being autistic had positive associations and will provide aspiration and comfort to be her true self.

Was there one thing that made the difference for you? A person, place, therapy, organisation... anything really!

Someone recently told me about a sad story they read in a magazine some years ago. The article was written by an autistic man sharing his experiences of childhood. It was said he wrote about how his weekends were spent travelling up and down the country, attending various appointments with doctors and other health professionals with an attempt to find a “cure” for his “autism”. The autistic man wrote how loving his parents were, and how they desperately wanted to make their son “better”. As you may expect this had a profound impact upon the autistic young man. He spoke of how he never felt “good enough” and it was his view that his parents wanted another child, a different version of who he was. He went on to explain that being autistic is integral to who he is as a person, and by chasing a “cure” to his autism it indicated to him that his parents didn’t want him as their child.

I don’t have children myself. However if my husband and I were blessed with an autistic child I would be extremely cautious about who and what entered their life. I would only allow my child to be surrounded by people who accepted them as a holistic being, embracing both the challenges and wonderful positives integral to who they were. For me — whether it’s an organisation, a therapy, or a place, it comes down to the individual person, and the people involved.

Personally speaking, I think this is the key to positive, meaningful relationships and connections. Relationships like this can foster resilience, self-esteem and confidence in your child, no matter their age or ability. When I was a teenager I frequently visited a neighbour. An older couple, whom happened to be friends and work colleagues of my mum. After tough days at school I’d turn up unannounced at their doorstep with my school uniform on; wild hair, shirt untucked, and school tie undone. I’d be warmly welcomed, given a drink and a snack and then we’d get to work! I’d help Raymond process his photograph stills, we’d talk about the pictures he’d taken, and he’d show me how to operate his camera equipment. After a few hours I’d make my way home feeling positive and good about myself. My mum would ask “had a nice time with Raymond today?” — realising that he’d called my mum to let her know where I was!

The reason for sharing this story is to emphasise that making a connection with another human being is so important to autistic children growing up. It reaffirms to a child they are worthwhile, important, and cared for. It need not be a Therapist or a professional organisation — meaningful and helpful support can be found with neighbours, family friends, or perhaps pets. My best advice is to support and foster relationships with people who accept your child holistically, with all their differences — just as they are. The importance of these relationships in supporting your child to cope with difficulties and challenges, and in enabling growth of self-esteem and confidence is immeasurable.

For those of you who struggle with independence and executive functioning, does it improve after teen years?

Executive Functioning is one of the biggest challenges of my life! For me it happened the other way around — having school, university, parents etc provided a structure and routine in my life. The challenge for me is keeping a balanced structure which requires meticulous planning and organisation. The trouble is, the energy I have to put into planning and organisation can be through the roof. A task that’s suppose to help can end up being a bigger challenge!

Again, speaking only of my personal experience it does not get easier. That’s not to say it becomes more difficult either. I think the challenges associated to executive functioning vary and change over time, with different demands and challenges to overcome.

Simple things can support executive functioning skills like getting into the habit of using a diary system, writing everything down, using colour-coding as a means to prioritise tasks, and phone alarm systems as reminders to execute tasks. Importantly there are factors such as mental health to consider when discussing executive functioning. High levels of stress release hormones into the body which can hinder parts of the brain responsible for executive functioning. So be mindful of anxiety and depression as factors that influence functioning. Again high fatigue levels from intense processing can influence executive functioning. So it’s a complex area to explore. If you think a professional opinion on this may help, then please go to your G.P and explain your concerns. It may be worthwhile exploring any possible factors influencing your child’s executive functioning.

How can I let my daughter know I empathize and support her, without stressing her further?

What soothes your daughter? If you can answer this question confidentially you are on the right track! Music? Video-game? Drawing? Whatever it may be then I suggest you help her learn how to use these to self-soothe and de-compress. So the knack to this is finding a time when she is not in distress. Research shows that when we are emotional and experiencing high levels of distress, we cannot use the rational thinking part of our brain to good effect. So by speaking with her when she is calm, you can engage the thinking part of her brain to make a good plan. One way may be to develop a “menu” of strategies or activities for her to choose from when the time comes. Start by asking her about things that help distract her? Things that help to relax/calm her? Things that excite/motivate her? If she’s unsure about how to answer these questions, you could suggest helping her to explore and try out different things? If a thing works/helps -add it to the self-soothing menu. If it doesn’t help, then move on to try something else. Together, get some nice card and pens (and glitter, stickers or whatever she likes) and write up the menu of options. The next thing to do is jointly develop your plan of action. When she next becomes distressed what is your agreed plan? Do you approach her with the menu and help to facilitate choosing an option? Or is the menu pinned up on her bedroom wall and you leave her to it? When you both agree on the menu and plan, then give it a whirl to see if this is helpful. Again, when she’s calm and relaxed organise a discussion to review how well the plan/menu went. What worked? What didn’t? What do you need to change in your plan/menu for next time? Lots of praise and encouragement when she is calm will encourage continued use, and plenty of space if she needs time to process. Even though you are not directly consoling her through physical touch, or being present to support her, the process of developing this strategy together will speak volumes of your love and desire to support her during the difficult times. (Ps - check out the phone app “virtual hope box” it may be helpful!).

How can parents be sure they are not giving their daughters a complex or being too protective?

My mum was not over-protective. To give you some context I was raised by a single Mum, whom also happened to be a senior member of staff in the primary school I attended. Sometimes you hear adult children of doctors say things like “when I was a kid, unless my head was hanging off I got sent to school” — meaning that the profession of their parent influenced their parenting style and outlook on illness. Similar to this — as a child of a teacher I think there are influences in parenting style and outlook on education and achievement. Looking back I am so proud of my Mum and so thankful for all the support and opportunities she gave me. Education was very important in my family and so I was always pushed to work hard and study. I was rewarded for good exam results, and my family always celebrated any successes I had, no matter how small or seemingly insignificant.

I will admit that as my main role model my Mum was a tough act to follow. I looked up to my Mum and was simultaneously amazed and overwhelmed by my Mum’s professional and personal life achievements. In some respects I occasionally felt alienated from her because I believed her to be so clever, beautiful, and talented compared to myself. My Mum often seemed invincible and I’d often think to myself “I’ll never be able to achieve what she has”. At some level all children want to impress their parents, and make them proud. But — what happens when a child feels that they aren’t able to reach their parents expectations? Importantly this statement holds true irrespective of whether the expectations are real or perceived by the child. I think we must consider not only what parents do, but also what they don’t do or may not be doing enough of. Had my Mum had an inkling of my thoughts at this time, I’m sure she wouldn’t have hesitated to demonstrate her vulnerabilities, the challenges she faced and had overcome, and supported me to re-evaluate perceptions I held about others’ expectations of me. Often many parents believe that they need to engage in perfect parenting, and model excellent coping by showing no vulnerabilities, modelling successes, and protecting their child from experiencing any kind of distress. It is important to teach autistic children that we all have vulnerabilities, experience set-backs and difficult paths on the road to achieving goals, whatever they may be. It is so vitally important that children are exposed to challenging circumstances and experience a degree of distress so that they may learn helpful and appropriate ways to cope. In order to protect children for the future, parents can teach their children experientially how to manage perceptions, expectations, and also ways of coping. The first thing children often do is look to others (particularly parents and in the case of older children, their peers) to learn these valuable and crucial life lessons. After you’ve had a really tough day — model expression of your emotions “Today was hard, and I’m feeling really tired”. Model self-care “I’m going to need some time to recharge and help myself feel better” — and so allow your child to be part of that process if you can? “When I feel like this it helps me feel better when I listen to some music and paint my nails” as an example. Teach your child that you are vulnerable, and have tough days just like her. Invite your child to share the experience of self-care and self-compassion.

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

To answer this question is complex because it is dependent on what developmental stage we are focusing upon. I don't think I could narrow it down to one thing. Unconditional love and acceptance from my family is most probably the foundation to everything else. By acceptance I mean realising my individual potential, talents and characteristics and running with them. Acceptance to encourage and support me in the areas of my life that count, and not re-directing me to pursue activities or studies that were not meaningful to me, or that which made me feel like I had to pretend to be something I was not.

As I have alluded in answering the other questions, meaningful relationships are incredibly important. However this sometimes means accepting that your child (depending on the stage of development) may not need a close relationship with parents all of the time. It's important to recognise that teenagers in particular need space and time to explore outside the family system. This is a time where teenagers compare their own beliefs and aspects of who they are — to see how they fit with the outside world. To find their meaning and place in the world. Supporting and fostering relationships external to the immediate family system is a great way for you to help your child feel loved and wanted. Having said that, a parent supporting this process is a sensitive and tricky task. Your desire to support may be taken as over-involvement and dare I say it “interfering”. Additionally an issue with singular friendships is that they can be risky — placing “all your eggs in one basket” may result in a disappointing outcome. I can only imagine how incredibly hard it must be for parents to see their child in distress, particularly when it is the result of a friendship break-down. When this happens a reliable and consistent unconditional support of a parent is invaluable. Listening, empathising, and supporting. When I was growing up my Mum tried to widen my support network, where I had different interactions and connections with people in a variety of settings. For instance, community art classes, dancing groups, tennis lessons, volunteering for the forestry commission etc. All of these were distinct, separate little networks. In situations where there is a falling-out with a peer, or a breakdown in one of these networks, then there are others to fall back on. This prevents isolation from future social contact with others and opportunities to make connections and form meaningful relationships. I can tell you this — I often hated the idea of going to do these activities! On occasion my mum had a hard time getting me to attend. I'm so glad she persevered because without these experiences the opportunity to learn about myself, gain confidence and self-esteem would have been sparse!

Were you in a mainstream school? Would a school especially for autistic girls have been better for you?

I went to a mainstream school. I did not know I was autistic until completion of my education. I did need support — quite a bit at times. I was lucky enough to have a school teacher for a mother. She gave me a lot of additional time to support my learning at home.

My biggest issue at school was processing both auditory and visual information at the same time. I can do one or the other well. However it becomes really hard doing both for long periods of time — ultimately resulting in fatigue, shutdown, and not being able to take on board important information required for learning. It's taken me years to find strategies and ways of working that suits my learning style. I need more time to process information — but once I've got it- I've got it!

The learning style of autistic children is so varied, but on the whole there are some main features shared by autistic children — such as the need for additional processing time. I think this would have made a huge and impactful difference to me. Not only in improving my ability to learn, but also in developing an understanding of my learning style which would have improved my confidence and self esteem as a child and teenager. I am not against main stream schools. Some mainstream schools are excellent and provide suitable and appropriate supports for autistic children. As you may well know a lot of this comes down to politics and funding which I will not go into here. Personally speaking, I think I would have loved the opportunity to go to a school for autistic girls, assuming that the school had a good reputation for supporting the needs of autistic girls, and providing solid educational and learning opportunities. Education is not merely about the formal curriculum but also the hidden curriculum of learning about life (e.g. Friendship, peer-support, coping etc). Feeling equal to peers, understood by teachers, and cherished as a unique individual is a powerful experience. Find a school that can offer this and it's a winner in my eyes.

How is it best to support our daughters through exam pressures and projects at school?

I think preparation is the key! If you don't feel adequately prepared then this heightens anxiety levels, which subsequently impact upon ability to learn and demonstrate learning. By supporting your child to create a good timetable for revision or a plan to compose a piece of work this may help to settle some anxiety (executive functioning support).

I think that some autistic people also experience a desire for "perfection" in what they do? So I think it's important to discuss the subjectivity of perfection. What does it look like? What would it mean to be perfect? I always say that perfection is a myth that we carry about in our minds. It's a bit like a thirsty exhausted traveler seeing a water oasis in a desert! It's a mirage of our own made-up desires to reach or achieve something.

Reassurance from parents about negative outcomes in exams is important. What's the worst possible scenario? You don't pass the exam- right? If this happens then what's still important and positive in your life? Parents who love you? Having fun with the pet dog? Having a cracking sense of humour? Intelligent? Kind? Here the aim is to contextualise the exam, comparing its importance to other values and goals in life. So important also to tell your child that irrespective of the exam outcome — you think they are wonderful! The result on the exam will not change how you view them. It may also help in this instance to create a "plan B" together. What's the plan if your child doesn't pass? In other circumstances it may be necessary for you to impose breaks from study. Too much studying can be detrimental and lead to increased anxiety and exhaustion. I always find the best way to approach this situation is present them with information about how the brain works — a quick Google will uncover an article or paper on studying efficiency and how the brain cannot process huge chunks of information in short periods of time, particularly when anxiety is lurking in the background. Short breaks built into the study plan are so important. My top tip is — build in sleep breaks! The brain undertakes huge amounts of processing when asleep. I'd wake up refreshed after an hour or so, and the study material I had been learning seemed to stick in my memory more effectively!

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Coming up
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Rose Hughes

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