AIMS For a better birth...

Revisiting pregnancy and birth through an autistic lens

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Sarah Fisher looks back on her journeys to motherhood with new autistic insight, reflecting on the importance of having trust in herself and her care providers.



By Sarah Fisher

Like many autistic mothers, it is only since having my children that I have learnt I'm autistic. My eldest is now nine and my twins, five. What I describe as 'my autistic epiphany' triggered me to re-examine all sorts of events and experiences through a new autistic lens, not least, my births and perinatal journeys.[1] Looking back there were clues that I'm autistic, many relating to my natural instincts and trust-related issues. My body clearly always knew, even before my mind caught on.

Trusting my pregnant body and intuition

The start of both of my antenatal journeys was marred by overwhelming and debilitating nausea that didn't ease until later in the second trimester. I've since learnt that hyperemesis gravidarum (HG) can be 'dry', but due to the lack of regular vomiting my condition went largely undiagnosed. There's evidence to suggest that autistic women are particularly prone to HG.[2,] Despite being unaware I was autistic or conscious of the extent of my sensory sensitivities, I knew I had a good sense of smell, which was

heightened in pregnancy and which I felt was a factor aggravating my nausea.

During the nauseous months my diet was extremely limited in sharp contrast to my usual healthy and diverse pescatarian diet. It was hard to find much at all that I could stomach. After a few attempts of forcing down something nutritious backfired, I learnt to trust when and what my body was allowing me to eat - even when the only liquid I could manage was diet coke and the only fruit to pass my lips was banana - albeit only with custard, a childhood comfort food. Thankfully, once the nausea eased, I went through a ravenous stage that I interpreted as being compensatory and was more than happy to indulge.

Another early indication that my instincts were trustworthy included that feeling of 'being pregnant'. This feeling kicked in very early, before women can usually feel it. I was on holiday when I realised I was pregnant the second time. Knowing that I had only a matter of days before the all-encompassing nausea, I wanted to run home and frantically battle my to-do list. Despite words of encouragement that 'every pregnancy is different', I knew that the nausea would be the same, and I was right.

Likewise, when I started sensing movements weeks before most pregnant women do, I was met with disbelief. Yet as the tiny sensations grew in frequency and intensity, my suspicions were confirmed. I can understand this now because with my autism comes hypersensitivity, including to my own bodily sensations. Less easily explained, my predictions about the sex of my babies turned out to be accurate. These days I have more trust in my intuition. I am more attuned to inner thoughts and feelings and this attunement has bestowed on me a sense of power. Armed with my new autistic self-understanding I have more self-trust and confidence.

That trust and confidence would have been useful, especially the first time around. New parents often feel bombarded and overwhelmed by multiple sources of contradictory information, advice and opinions. I'd worked as a researcher for NCT, which helped, but had I known I was autistic I would have been more comfortable with differences in opinion and less bothered by unwanted advice and interference.

My instincts during pregnancy now make even more sense. As my due date approached, or the induction date for my twins, I felt an even stronger need to make my world smaller by withdrawing from contact and retreating further into myself. Hoping for physiological births, I wanted to remain calm and confident by avoiding any interactions that might be overstimulating and intrusive.

I even found well-meaning friendly messages extremely irksome. I had no desire to be with or hear from anyone other than a few trusted people who I would seek out if I wanted to. I just wanted to be left to it. I imagine my family felt frustrated and hurt at times, given they naturally wanted to be kept informed. Now I've insight into my interaction and communication preferences, I feel more able to explain and justify them, and find they're better respected in return. But how sensible I was wanting to block out the outside world, both before and during labour.

When I went into labour in my first pregnancy, my partner and I didn't tell anyone because I didn't want the distraction and stress of update requests. When our son was born I regretted the news being shared so soon. Even just a couple of hours of peace and quiet after the birth with just the three of us would have

been precious. Knowing it's time you can never get back, we enjoyed some beautiful 'golden hours' after the birth of our twins. This skin-to-skin time helped to get breastfeeding established.

Establishing trust with health professionals

I wasn't fortunate enough to have continuity of carer throughout my pregnancies. I hardly saw any midwives or obstetricians more than once, which led to deepened feelings of anxiety, stress and uncertainty. This was particularly challenging in my twin pregnancy as I was planning and hoping for a physiological twin birth.[3] During that pregnancy my mental health was poor. Like many autistic women, I was prone to anxiety. When our planned second and final child turned out to be twins, I knew that being a mum to three would be overwhelming. This unexpected news triggered great anxiety, spiralling into depression.

Had I known I was autistic, providing a continuity of care team would have been a 'reasonable adjustment' that I would have requested.[4, 5] Continuity of carer is known to be an important factor for building trusting relationships between autistic women and health professionals and improving women's overall maternity care experiences.[5] I would have greatly benefited from developing a trusting relationship with my care providers, assuming they were kind, flexible and accommodating of my needs and communication preferences. Reducing the number of health professionals I communicated with, and ideally, having someone to advocate on my behalf, would have saved stress and time all round.

As a service-user I'm interested in the evidence-base and rationale underlying any decisions or courses of action. I have many questions, a need for detail, and like to do things in my own way and my own time. If that is respected it usually works out well. I've always been conscious that I can seem inflexible, demanding or difficult. But now I understand why. These are not simply desires but autistic needs. Continuous, trusting relationships with healthcare professionals are more likely to deliver care that meets my specific, autistic needs, including my need for a sense of autonomy and to come to my own informed decisions.

I'm not someone who responds well to false assurances or having my feelings dismissed. I experienced this regularly when I expressed upset or reservations about twins, only to be told it was a 'blessing.' Continuity would have helped my mental health and reduced the number of times I had to share difficult feelings, and help those caring for me avoid saying things that, although well-intended, made me feel worse.

Concerns about that and involving yet another person in my care meant I didn't access mental health support. I was fortunate however, to find and have the continuous support of Jane Denton, then Director of the Multiple Births Foundation,[6] based at my chosen hospital. She provided the sensitive and emotional support and consistency that I was lacking from my care providers, accompanying me along my antenatal twin journey, mentally, and sometimes physically, at hospital appointments.

Trust and the birth environment

I need to feel informed and prepared with reliable information and at no time was this more evident than

in pregnancy. Already more informed than most, I did a lot more reading and research to inform my decision-making about where and how I wanted to give birth. I had a strong desire for a calm and less intrusive birth environment, which I now realise was rooted in my sensory needs. I formulated birth plans that set out preferences. Looking at these now, it's interesting that the requests I made are common adjustments favoured by autistic pregnant women, such as avoiding unnecessary interruptions, and low light and noise levels. Being given full information and explanations about my care and opportunities to discuss any changes was also important.

These preferences are also common hypnobirthing suggestions, known to help the production of the hormone oxytocin that brings on contractions and helps you stay calm.[7] It pleases me to know that my autistic instincts and needs also made sense from a biological perspective. I'd practised hypnobirthing religiously during both pregnancies, which I found helped increase my confidence and trust in my ability to give birth, and to stay relatively calm.

In my first pregnancy I opted for the standalone Edgware Birth Centre where I believed I would feel more relaxed. When my 12 week scan put my due date forward by five days it was very stressful. I was sure of my ovulation and conception date and I had more faith in my own calculated date than the one from the scan. This was significant because if overdue by a certain number of days (according to the scan date), the birth centre referred you to the obstetric unit, and I don't cope well with uncertainty or changes to plans.

As it happened, I was sent straight there anyway, because labour started with the release of meconium stained waters. Suddenly being deemed higher risk was stressful, as was the more medicalised care and environment that I'd sought to avoid. This wasn't helped by the increased monitoring due to the meconium, nor by the largely unflexible care I received from the array of staff who came and went who I'd not previously met.

My pleas to turn down the bright lights mostly fell on deaf ears. My request to turn down the CTG[8] volume which I found distracting and stress-inducing wasn't permitted, even with a midwife sitting observing it. Despite requesting minimum disturbances and for questions to be put to my partner (also covered in the birth plan we kept handing out), this was largely ignored. If I'd have known I was autistic I could have been all the more guided by my intuition and assertive about my needs, and I hope they would have been more accommodating in return.

As well as the noise of the CTG being problematic, the seemingly constant need for readjustment of the sensor pads and straps drove me crazy. Not liking fuss and being fiddled with, I just wanted to be left alone and feel my labour would have 'progressed' better if I had been. Doing what I could to block it all out, I resorted to labouring in an eye mask and fleeing to the toilet to hide, only to be retrieved.

Fast forward to my twin pregnancy, I chose a different NHS Trust, but my preference for the along-side birth centre wasn't permitted and so I was bound for the obstetric-unit once more. However, my previous poor experience of a hospital birth - not only the environment but also the feeling of being frightened and coerced into things rather than having genuine discussions and involvement in decision-making - only made me more determined to birth in a way I trusted was right for myself and my babies.

The more complex twin pregnancy made this somewhat trickier, but given my anxiety, all the more important.

Labour commenced when I was at 38+3, the time I trusted was right for induction rather than the 37 weeks suggested. Thankfully, despite the gruelling journey I'd had to formulate my birth preferences, and not having met any of the health professionals there that day, the care I received was far better. They seemed gentler and took my requests more seriously, perhaps due to my clear anxiety and vulnerability. Knowing that I'd not had a good experience at a different hospital, there seemed to be a genuine desire by my carers at Queen Charlotte's hospital to give me a positive experience, and this resulted in my wonderful twin births.

Trust in labour

The trusting relationships I formed with two midwives were key to my positive twin birth experiences.[9] Firstly, consultant midwife Arezou Rezvani, who I approached at 34 weeks when I was struggling to get clarity and support in relation to my birth options. She enabled me to exercise choice, and was seemingly unrattled by my desire for great detail and autonomy. As some of my preferences were contrary to the multiple pregnancy guidelines, she spoke with senior consultants and, following a healthy 35 week scan, she briefed the necessary staff, and added my preferences to my file to prevent obstacles on the day. Secondly, Laura Forster, a wonderful midwife with whom I soon felt confident and at ease, and therefore more grounded. Looking back, I feel this trust was reciprocated in terms of the way she enabled me to labour and behave in my way. Despite limited experience with twins, she was warm, encouraging, respectful of my choices and worked confidently to achieve them. She remained consistently nearby sitting quietly and unobtrusively rather than popping in and out which I'd have found disruptive.

I wonder if I'm the only woman who prefers and finds it easier to cope with intense, established labour? I found all the uncertainty and fiddling with me that I associate with early labour very stressful, so welcomed stronger contractions which made it easier to focus, go into myself and block out my surroundings. Reflecting on the primal, stripped-back person I became in labour, did being autistic exacerbate my sense of this, or mean I was more able to go there?

Yet some sensory sensitivities couldn't be blocked out... When birthing my first twin, I swiftly banished my partner from my side when I smelt coffee on his breath and thought I'd vomit. This autistic clue had eluded me until I heard strong aversions to coffee on the labour ward mentioned in a Maternity Autism Research Group (MARG) webinar.[10] I've also joined the dots between my autism and the lip balm I insisted my partner apply for me in between every contraction during the pushing stage with my oldest son. I can't bear having dry lips or hands but at least my rapid consumption of lip balm and hand cream is now explainable as a sensory thing.

On the subject of support from my partner, it amuses me to recall the suggestion in antenatal classes that your partner massages your back to ease labour discomfort. I couldn't bear to be touched, unsurprisingly given that uninvited touch bothers me at normal times when I'm focusing on or distracted with something. Yet I can't imagine having coped in labour without my partner's trusted presence which I

wanted and needed. Albeit mostly at a distance and following orders!

My autistic births

As my awareness of what being autistic means for me has deepened, so has my understanding of strange and disconcerting labour experiences. At times during the most intense moments, I felt like a completely different person. In this intense state of being I was far less aware of others, their presence was confusing, and I was more likely to take things literally. Despite being blunt myself, I was extremely sensitive to the words of others, especially during my first child's birth when I had contact with more health professionals and felt less at ease.

This unnerving alien-like feeling was something that kept puzzling me. My autistic awakening has completed the puzzle, for I believe that the physical intensity and altered state of my mind I experienced during labour revealed my true autistic self, stripping me of over 40 years of learning, conditioning and masking. I was reminded of myself as a child, before I'd learnt that all words are not literal, and when I understood others less.

I don't doubt that in active labour women become more raw and inward-facing, regardless of neurodiversity. Without being able to experience and compare birth as a neurotypical person I've questioned my autistic interpretation, and wondered if Entonox played a role. But there have been other times during moments of physical and mental intensity that I've had similar, although less extreme, feelings. Many in the postnatal period, and other situations involving great stress, sleep deprivation or over-stimulation. These states, for want of a better way of explaining it, make me feel 'more autistic', by which I mean my sensory sensitivities and communication differences are heightened and daily life is more challenging.

Minutes after my first son was born I asked the midwife what he weighed, and she replied by asking how she was supposed to have weighed him when she'd been with me all the time. Despite having only had gas and air, I was disoriented and felt strongly criticised by that small remark. I also felt shamed by the tone of another response she made. The tone of what is said can be more important than the words. My older, wiser self might have been more patient or at least have felt less chastised by the sensed criticism, but my feelings at the time remind me of childhood experiences and feelings. I mentioned these comments to my partner some time afterwards and he was surprised they bothered me. Yet nine years on these fleeting interactions and words replay in my mind when thinking about my first moments of motherhood. I hate to imagine how traumatised I'd feel had I been spoken to more harshly.

While all women are vulnerable in this way in labour, I wonder if being autistic left me more so. You can forget some details about what happened and when, but not how you were made to feel. On paper my first and twin births wouldn't look dissimilar. What was missing from the first was the trust established with a gentle, respectful and considerate midwife who was consistently there for me. Her flexibility, good communication and kind words made so much difference. This type of personalised and accommodating maternity care from health professionals with whom women have had the opportunity to get to know and trust, seems fundamental to understanding and meeting autistic women's needs, but would of course

greatly benefit all women, irrespective of neurodiversity.

Author Bio: Sarah is a mum of three, including twins. She is a women's health advocate and Patient and Public Involvement Leader for health research.

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1 This article focuses predominantly on my birth experiences. For more autistic reflections on my antenatal and postnatal experiences see: Fisher, S. (2024) Navigating pregnancy, birth and early parenthood as an autistic mum. Available at: https://www.ndbirth.com/post/navigating-pregnancy-birth-and-early-parenthood-as-an-autistic-mum-sarah-fisher

2 Hampton, S., Man, J., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2023). A qualitative exploration of autistic mothers' experiences I: Pregnancy experiences. Autism, 27(5), 1271-1282. https://doi.org/10.1177/13623613221132435

3 I've written about my twin birth journey. See: Fisher, S. (2023) A quest for a physiological twin birth. *The Practising Midwife*, 26 (11), pp.31-34. Available at: https://www.all4maternity.com/a-quest-for-a-physiological-twin-birth/

4 Henry, K. (2023) Providing Accessible Healthcare for Autistic Women. *The Practising Midwife*, 26 (02), pp. 37-41.

5 Fox, D (2022). 'Supporting autistic pregnant people', National Autistic Society. https://www.autism.org.uk/advice-and-guidance/professional-practice/pregnant-autistic

6 The Multiple Births Foundation corroborated with Birmingham City University to establish the Elizabeth Bryan Multiple Births Centre. For more info see: https://www.bcu.ac.uk/health-sciences/research/centre-for-social-care-health-and-related-research/research-clusters/ebmbc

7 Howell, M. (2009) Effective Birth Preparation: Your guide to a better birth. Surrey: Intuition Un Ltd.

8 Editor's note: CTG stands for cardiotocograph. A CTG machine records the baby's heartbeat on a paper printout and this makes a beeping noise.

9 Editor's note: The two midwives who provided Sarah with such excellent support are mentioned by name with their permission.

10 The Maternity Autism Research Group (MARG) is an Autistic-led collective of health professionals and researchers working together to improve care for Autistic women and people.

https://www.maternityautismresearchgroup.co.uk/