



BREASTFEEDING: THE AUTISTIC EXPERIENCE

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Disclaimer: This article will use the term 'autistic mum/parent' rather than 'mum/parent with autism' as this is the preferred term for the majority of the autistic community. It is what we are!

I became a Mother Supporter ten years ago in 2009 because I was struggling to find the support and information I wanted and needed while breastfeeding my first baby. After nine years, two more breastfed babies and seven years of running my own support group, I

got formal confirmation that I am autistic.

This series of events is more closely linked than it might at first appear.

This article isn't going to explain autism or autistic traits in detail. However, it will be useful to know that breastfeeding has been one of my 'special interests' for eleven years. A special interest is most simply described as a 'very intense hobby'. It is something an autistic person will want to focus on in great depth, involving learning,

Photo: Becks and her family

collecting, researching the subject far beyond what is usually expected from someone.

Broadly speaking, autism is a difference in the way a person experiences, interacts and communicates with the world, compared with the majority of others around them. Autistic women especially are often aware that they are not the same as others around them and they learn to 'mask'. Masking means you have observed the behaviours, actions and interactions of those around you in life and learnt to take on those behaviours, actions and interactions as your own in order to function in the same or similar environments. It is necessary to be aware of masking as a supporter, as it will potentially hide the reality of an autistic mother's experience. Unobservable realities could be both negative (such as pain levels, confusion, sadness, worries and concerns) and positive (the level of knowledge and the level of determination a mum has to reach her breastfeeding and parenting goals).

Why did I become a breastfeeding supporter? Because I wasn't able to access the support options I found when I was a new mum and really needing them, and I didn't know why. I knew I felt different, I knew what I was trying to share as my

parenting experience was different from what other parents were experiencing and sharing with one another. I couldn't call a helpline as I didn't know who would answer or what they'd want to know from me! There were no face to face groups for me to go to and as I wasn't going to any other baby related groups, I wasn't about to be going to a breastfeeding group either because... PEOPLE!!!

Since my diagnosis I have discovered that there are many mums and parents like me, autistic and breastfed/breastfeeding. Now, there is a far greater network of autism support to be found online and through social media than there was back when I was first setting out in parenthood. However, from what I can find from researching, asking others and searching online, there is no specific consideration given to supporting breastfeeding autistic mums and parents.

Initially I approached the 'mainstream' breastfeeding support community and asked "Do you think there needs to be a difference in the way you'd support an autistic mum or parent in breastfeeding? Can you think of anything you'd do differently?" And the response I got back was "why would they be any different to anyone else we would support?"... "we give the same kind of support to everyone"... "labels

don't matter"... "why would we change our approach?"... "everyone can be supported in broadly the same way."

I asked the question to a group of autistic mums on Facebook: "Do you feel that your being autistic needs to be taken into account when seeking, accessing and receiving breastfeeding support?" The answer was a resounding YES! So I set up a Facebook group for autistic breastfeeding mums, and the idea for this article was born as we began to talk about our experiences and how breastfeeding supporters could become more aware of how they can better support an autistic mum.

The following points were put together after various discussions in the Facebook group of autistic breastfeeding mums. The first point is one to **very much** take into consideration! Get a feel for the level of knowledge the person you are supporting already has - it can be validating to the mum seeking support to feel her reading and research has been acknowledged.

Some of these points may be 'obvious' things that you do during your support role anyway but they are included because the group consulted considers them important:

1) The mother seeking support is likely to have researched and become as knowledgeable as the person she is seeking support from! Some, like me, may become a breastfeeding supporter because it made sense to become one while learning everything I could on the subject. Running your own support group is far easier than going to one! You have more control of the environment when you lead.

2) The determination to breastfeed is likely to be VERY high and emotional health more fragile towards suggestions of a problem that may need interventions such as topping up. There can be very black and white feelings: breast milk is good, formula is bad. Be able to back up your support with further research and let mum know this is available for her to read and interpret herself.

3) Be reliable. Communication is even more important than ever. Be where you say you will be at the time you have said you will be there! If you have to change plans, let mum know with as much advance notice as possible. Being early to see mum might not be as welcome as you think, even if she is early to an appointment herself. It may not be that she is happy to be seen early, but that she wants to acclimatise to the surroundings.

Even if you will only be five minutes late, let mum know if at all possible. Make sure you have a way to communicate with mum that she is comfortable with. Don't make a phone call unless it is expected or you know mum is ok with talking on the phone. If you've said you'll send a text or email on a certain day or time, make sure that happens. When prearranged events don't go to plan it can lead to extreme anxiety and distress.

4) High anxiety levels are common with autism, not always about the 'usual and obvious' things. Catastrophic thinking is something we can do at pro level! Does the mum need more or less information about something to be able to feel better?

5) Some autistic parents may interpret support as 'pressure' to HAVE to make breastfeeding work and feel that if they are struggling in any way they need to stop and switch to formula. This response is driven by a strong need for control which is common with autistic parents. However, autistic mums may also want definitive answers to questions. How ideas and options are presented is important. Ask mum if she would prefer for information to be presented as 'what to do' or 'ideas to try'.

6) Sensory processing differences

can sometimes mean that pain and discomfort can be felt far more strongly than average, meaning phrases like "it shouldn't hurt if you're doing it right" could be upsetting to a mum who is hypersensitive to all touch. Senses can also be significantly dulled and so a mum could be unaware of damaging breastfeeding technique if relying on pain alone as a warning. Pain and discomfort may also be described differently, so clear communication to gather information is vital.

7) Sensory overload leading to shutdown or meltdown may present in a similar way to breastfeeding aversion, but it is essential to distinguish between the two and work with mum to explore ways to change the sensory experience. This conversation needs to happen when the overload isn't taking place and any distress has passed. Depending on the nature of the sensory issues things such as changes in baby and mum's positioning, creative clothing or covering hacks for mum or baby, distraction strategies such as stim/fiddle toys for mum can be explored. Temperature changes on exposed skin or the differences between her body temperature and the feeling of baby's body temperature on her skin may also need to be considered.



www.autism.org.uk

8) It has likely taken a lot of energy and courage to make contact with someone to seek support. It may then be that mum seems to be struggling to engage with you for the next step. Be patient and initiate the conversation with a closed question—open questions can feel overwhelming. Check if there is any environmental factor that is hindering communication beyond the obvious distractions. Quiet background noises, flickering light, moving air draughts or moving objects that may not be a problem to you may be painfully obvious to an autistic mum. Do not expect eye contact or physical body language cues, and an autistic person who is masking their struggles may seem ‘happier’ or less stressed than they actually are. Written/drawn communication and notes for future reference can be very useful.

9) Language and phrasing may need to be considered. “Some mums find”, “it has been shown that” and “you might like to try” can feel like vague terms to a more literal thinker and the mum you are

supporting may not realise that you are making a suggestion for them to try. Check that you have been understood. Would a physical list of things to try be helpful?

10) **BE SPECIFIC!** If you don’t want something taken literally, then don’t say it literally. Consider how you are giving information. Visual notes can be helpful to remind a parent which parts of the information you have passed on are guidelines and do not have to be exactly that way, and which parts are ‘need to happen this way’.

It should also be kept in mind that you may support a parent who does not know that they are autistic, but you, from personal or past experience or reading, see some traits that may indicate they communicate differently. It may then be worth keeping the above points in mind when giving support.

Further Information

There is much information to be found online about autism and how autism presents in females. The main autism charity for the UK is The National Autistic Society. Their website (www.autism.org.uk) has lots of general information about autism and links to local organisations in many areas. There are Facebook groups for those who want to better support autistic

people; a recommended group is 'Ask Me, I'm Autistic'. There are also many autistic women who are sharing their experiences by blogs, vlogs and recordings of talks given in a professional role. Sarah Hendrickx is an autistic autism professional who has given many talks and written much about the female autistic experience (see YouTube for some great videos). There is also a channel on YouTube by 'Yo Samdy Sam', she has some great videos around pregnancy and parenting as an

autistic person.

I hope this article will begin to open a wider discussion around the support of autistic mothers, parents and their families as a whole, right from the beginning of pregnancy and beyond.

My hope is that this article will lead to further discussion and communication between autistic families and those who support them in areas that have so far been largely overlooked or unconsidered.

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and inspiring'*



Association of Breastfeeding Mothers

'Thought provoking'

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Philippa Pearson-Glaze - Breastfeeding after surgery

Smita Hanciles - Infant feeding support and mental health

*'Great variety,
great quality'*

The Priory Rooms
Birmingham

more details to follow

*'Passionate speakers,
totally engaging'*