AIMS For a better birth...

Doulas Supporting Neurodivergent Birth

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By Victoria White

Neurodiversity is the concept that all people vary in terms of human brain function and cognition, including how emotions are experienced, sociability, attention and learning. It refers to the brain diversity of all people, but the term 'neurodivergence'[1] is often used to describe people who have neurodevelopmental differences including autism, ADHD, dyslexia, dyspraxia, dyscalculia, Tourette's and more.

It is estimated that 15-20% of people are neurodivergent.[2] Many neurodivergent people, diagnosed or not, will have support needs around multiple themes which may include sensory processing, communication, executive functioning and mental health. When we think about perinatal experiences in relation to these themes, we find that many elements of pregnancy, birth and the postnatal period can throw up several challenges for a neurodivergent birthing person. It is important to keep in mind when discussing these challenges, that no two neurodivergent people, or their experiences, will be the same.

It is well documented that many neurodivergent people experience sensory processing challenges.[3] This happens when the brain experiences difficulties receiving information from the senses, filtering and discriminating between it, and responding to that information in an effective way. Extra information can make it through to conscious awareness, which can be distracting or at worst totally overwhelming, even

causing pain and/or a fight, flight or freeze response.

The senses are bombarded during pregnancy, birth and the postnatal period. For example, the bright lighting, loud noises and unfamiliar smells within a clinical setting, the mess of early parenthood, and the sensory experience of breastfeeding or chestfeeding. This intensity is not just limited to the five most commonly talked about senses; sight, sound, touch, taste and smell. There is also proprioception, which is a sense of spatial awareness, and the vestibular sense, which is our experience of balance. As our body changes so much during pregnancy, and then again following birth, these senses can be impacted.

Interoception is the sensory system that tells us what is going on inside our body, and includes things like thirst, hunger, tiredness and a need to use the toilet. Again, these are all things that many people report experiencing differently during pregnancy, birth and postnatally. People who experience challenges with interoception may find they are amplified during this time.

Neurodivergent people often have communication styles that differ from their neurotypical peers (the term for people who are not neurodivergent). There is no right or wrong style of communication, but being aware of some of the areas of difference can be helpful for everyone. And efforts need to be made by both neurodivergent people and neurotypical people to understand and bridge the gaps.

Executive dysfunction: a condition widely associated with many neurodevelopmental conditions, is typically understood to include a range of behaviours and traits such as impulsivity, problems prioritising, disorganisation, time management issues and difficulty focusing. Awareness of some of these challenges experienced by neurodivergent people is important, but we also need to be aware of our own judgement and the judgement of others in relation to these traits. For example, executive dysfunction can mistakenly be interpreted as laziness or a lack of interest.

Anxiety can be one of the biggest challenges of neurodivergence. The anxiety does not stem from being neurodivergent in itself, but from the different ways that neurodivergent people need to function in a world that is tailored to neurotypical needs. In addition, the perinatal experience itself can be stressful right from the point of trying to conceive, due to an inability to control the situation. In order to help manage feelings of anxiety, people may exhibit routine and repetitive behaviours, such as stimming (self-stimulatory behaviours). Routines may be helpful because they are predictable, feelsafe and help people to feel in control.

Knowing what to expect and how to manage things is often crucial to neurodivergent people experiencing anxiety. Rigid thinking about what is going to happen during pregnancy, what labour will be like, what life with a newborn will be like etc., can lead to distress if things turn out to be different. Real, honest truths are therefore important, but supporting people to become comfortable with an element of uncertainty is also key.

Ultimately, we need to be able to meet people where they are at, free of judgement and assumptions, and support their individual needs. This is where the role of a doula, supporting both the neurodivergent birthing person and those providing that person with clinical care, can make a huge difference. Doulas

provide continuous practical and emotional support for families during pregnancy, birth and the postnatal period. They perform a non-clinical support role and signpost their clients to quality information and resources in support of informed decision-making.

One of the key benefits of doula support is continuity. Doulas may start working with families at any time, but most commonly a doula hired to support a labour and birth will spend time building rapport and getting to know their clients antenatally; and they may also work within the home providing support during the early weeks of life with a newborn. This continuity allows the development of meaningful relationships, understanding and trust. This can be reassuring for a neurodivergent birthing person, particularly if it is not possible to access that same level of continuity within their maternity service. Doulas can also provide continuous support during labour and birth, which research has found[4] is beneficial for birthing people and their babies.

With the development of trust and understanding within the relationship, comes an awareness of an individual's needs. A doula can get to know a neurodivergent person's support needs around communication, sensory processing and executive functioning. They can also directly facilitate communication by supporting the accessibility of the information shared, by acting as an advocate, or by attending appointments that can then be debriefed and discussed with their client afterwards. They can support neurodivergent birthing people to reduce sensory stressors in their environment and facilitate experiences where sensory seeking may provide regulation. Many people who are sensory seeking may have a sensory 'menu' that they use for self-regulation, including fidgets, weighted blankets and movement.

Doulas can also support executive functioning if required; examples include compiling a directory of useful contacts, providing an appointment reminder service, and providing maps and photos to help with navigating facilities and facial recognition. Not every neurodivergent birthing person will need all these things - these are examples of what individualised support might look like. It is important to avoid making assumptions about what help is needed, and to explore this individually with each client.

Birth and postnatal planning is always important, but it can be particularly useful for neurodivergent people and can include additional planning for how to manage cognitive and sensory input. A birth plan with images may be particularly useful for visual thinkers, and a doula can support the planning process.

A doula with an understanding of someone's neurodivergence can also be aware of the important role that masking plays. When a neurodivergent person has to change their behaviours to be more 'socially acceptable' in our society, this process is called masking. Females are particularly good at this as they tend to be more socially motivated. Many people will feel that there is a perceived way of being pregnant, how to do birth, and how to parent. They may then feel shame and embarrassment if their reality differs from these expectations. It may also be difficult for healthcare professionals and others to understand a birthing person's support needs, if they are masking their neurodivergence. A doula who has had time to develop a relationship with their client may be able to see when this is happening and support the neurodivergent person to communicate their needs with their care providers.

We know that with the right support and understanding, it is possible to have a neurodivergent-friendly pregnancy, birth and postnatal period. With an estimated 15-20% of the population being neurodivergent, improved awareness and understanding of neurodivergent support needs perinatally is essential. Doula support can undoubtedly play an important role in meeting individual needs and communicating them with the clinical professions. The result of this type of personalised support for neurodivergent birthing people is that anxiety is ultimately lowered, mental health outcomes are improved, and families have a positive start to their lives together without a foundation of trauma.

As a doula I became concerned about the lack of awareness of neurodivergence and formed an organisation called ND Birth. My goal is to facilitate improved access to doula support for all neurodivergent birthing people who feel they would benefit from it. If you would like to be involved in the work we are doing please visit www.ndbirth.com. For more information on this topic you can also access the fantastic resources of the Maternity Autism Research Group (maternityautismresearchgroup.co.uk), the wonderful work of Diane Fox, Specialist Autism Midwife (dianefox.uk) and listen to The Neurodivergent Birth Podcast (you can listen directly at ndbirth.com), where our aim is to promote awareness and understanding of perinatal neurodivergent experiences in order to improve support.

Author Bio: Victoria is a birth and postnatal doula who supports families through pregnancy, birth and beyond. She believes birthing people have the right to a positive birth and postnatal experience, and that this can be achieved with the help of consistent and compassionate support. She offers support both in person in Aberdeen, Scotland, and online anywhere in the world. She is also a trained Traumatic Birth Recovery 3 Step Rewind Practitioner, and Perinatal Emotional Health and Wellbeing Practitioner. She is the mum of two girls, one of whom is autistic, and is passionate about improving support for neurodivergent people perinatally, which led her to creating the organisation 'Neurodivergent Birth' and The Neurodivergent Birth Podcast.

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1 Resnick A. (2023) What Does It Mean to Be Neurodivergent?

https://www.verywellmind.com/what-is-neurodivergence-and-what-does-it-mean-to-be-neurodivergent-5196627

2 ADHD Aware (2022) Neurodevelopmental Conditions

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3 UK Parliament (2023) Neurodiverse Connection – Written evidence (ALN0075)
https://committees.parliament.uk/writtenevidence/118957/pdf/

4 DoulaUK Evidence in support of doulas. https://doula.org.uk/research/