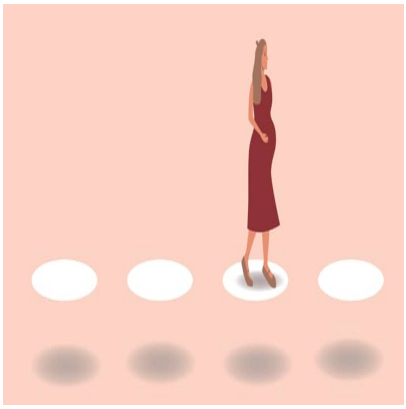

Description

Providing Accessible Healthcare for Autistic Women

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Introduction



This blog accompanies **an article** with the same title which I have written around ideas to enhance maternity care for autistic women. (Published in The Practising Midwife journal February 2023 issue).

Current narratives say autistic women felt isolated, neglected, stigmatised and judged when engaging in maternity care. They felt hospital environments were sensory overloading and caused barriers to accessing care.

With support from the Florence Nightingale Foundation, I created a series of **support plans** to enable care adjustment ideas to flow between women and midwives to lower barriers and change future narratives for autistic women.

Estimated autism prevalence in the UK

Estimations place the number of autistic people in the UK to be around 1-2% of the population (around 700,000) however, this figure is much higher as many girls remain undiagnosed. This is due to male orientated diagnostic tools which were built upon autistic male characteristics and behaviour presentations.[1]

Undiagnosed autistic women

Such undiagnosed, mainly female autists remain hidden through masking or camouflaging their autism as they learn to imitate gestures, body language and use pre-prepared scripts to fit in with others,[2] despite these being difficult skills to

maintain. For undiagnosed women who go on to become mothers, one in five of those with autistic children will be diagnosed themselves in adulthood.[3] This is where we as midwives intersect in the story because autistic women, regardless of when they are diagnosed and recognised, are accessing maternity care.

How autistic women experience maternity care

Current narratives by autistic women describe their pregnancy, birth and postnatal experience as poor. When adapting to motherhood, autistic women feel isolated, neglected, stigmatised and judged.[4] They feel they needed to compare themselves to other mothers, so their parenting ability was not questioned.

However, masking led to feelings of inadequacy, depression and loneliness. In clinic and hospital environments, women experienced sensory overload from the different noises, smells, lights, disruptions and the sheer amount of people which caused them to feel disabled and unable to process information.[5,6,7,8]

For many autistic women the perinatal period can be filled with a fear of losing their children because many of them are referred to social services under the guise of them not being able to care for their babies.[3,4,9]

> This leads many women to decide not disclose their autistic status, meaning they are denied the chance of accessing essential support for their mental wellbeing and transition to motherhood.[4]

Even when women do tell maternity staff they are autistic, they feel unsupported and misunderstood, possibly because they appear less disabled than they are.[10] This means that communication from midwives can be vague, and procedures are not explained in a way that autistic people can understand.[11,12]

Reasonable adjustments

Autistic women felt happier when they had continuity of care from a midwife who could tailor care around their communication and sensory needs, who did not presume them to be of poor intellect function based solely on their autistic status.[13] However, most autistic women are not offered reasonable adjustments due to poor staff autism knowledge[14] which, has been acknowledged by health professionals themselves.[15]

Today, much of the training professionals receive is based around information gleaned from studies based on male participants and stigmatising assumptions that all autistic people struggle in all situations, which is simply not true. Autistic people may struggle with the changes that pregnancy brings not only to their physiology but also to their daily routines and the new environments they now engage in, such as clinics and hospitals.

Why this subject is important to me

I was excited to write an article for The Practising Midwife journal to share the communication/support plans I made a few years ago to support the small changes we can make to the environment to enable accessible care for women.

> My passion for sharing this knowledge and improving maternity services for autistic women stems from me being an autistic woman, a midwife and a mother of an autistic daughter who may access maternity care at some point.

I feel that midwifery is not just a job, it's our identity which is modelled around kindness and wanting to provide excellent support and care to women. We have the potential to change future maternity care experiences for autistic women when we are armed with knowledge of the difficulties some autistic women may face when accessing maternity care and the practical things that may make a difference.

Conclusion

I hope the information I wrote for the article goes some way to initiate collaborative working between autistic women and the healthcare professionals supporting them. I also hope through using the **support plans** as a prompt, appointments are more accessible for autistic women which, may in turn reduce some of the anxiety and stress caused by being in clinical hospital environments.

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Category

1. News & Views

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1. autism
2. maternity care

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