

Exploring how health inequalities can be addressed through autism training and understanding in maternity services

Diane Fox



ORIGINAL

Background

The national strategy for autistic children, young people and adults: 2021 to 2026 (Department of Health and Social Care (DHSC) 2021) outlines the UK government's commitment to improving services. The strategy advises that all health care professionals and students require mandatory training on autism in order to improve care outcomes and address health inequalities. This includes acknowledging the difficulties autistic people can have accessing health care, coping with interaction with medical staff and coping with health care environments. Also, there is an appreciation that the waiting times for diagnosis can take many years due to service provision and funding constraints in some areas.

Increasing the understanding and knowledge of maternity staff is crucial to ensuring equality and improving care outcomes. Is there a strategy in your maternity provision to support women with neurodiversity or mandatory training for staff? I have worked with the Royal College of Midwives (RCM) to create an i-learn module on autism and pregnancy — available on the RCM website. The next steps would be to create Autism Leads and in-house training through co-production using women's voices and experiences.

What is autism?

One in 100 people in the UK are on the autism spectrum, known as having autism spectrum condition (ASC) (National Autistic Society (NAS) 2022).

Some people have a diagnosis and support, while others are undiagnosed with no support in place. Women are less likely to be diagnosed as they may 'mask' or hide their needs during childhood and adulthood to try to 'fit in'. This may lead to women having little support in place to deal with the challenges of daily tasks and responsibilities. This can lead to social, educational, economic, physiological,

psychological and emotional and health inequalities. Pregnancy, childbirth and motherhood can be a real challenge for these women (Pohl et al 2020).

Why is autism important to midwifery?

According to recent research by McCrossin (2022) 80 per cent of autistic women are not diagnosed by the time they turn 18, therefore many women in pregnancy may not have a diagnosis or support in place. Consequently, they may have an increased risk of health inequality and poorer outcomes in pregnancy. The presentation of autism can be very complex with a plethora of co-occurring conditions apparent. Therefore, these women should be considered as vulnerable even if a diagnosis is not in place.

Under the Equality Act (2010) and Autism Act (2009) midwives have a duty of care to ensure reasonable adjustments should be made to improve care provision. Midwives should also recognise it can be difficult to assess women with hidden disabilities. Autism can run in families, so women with autistic children or relatives may have a higher chance of also being autistic.

Use of language

Language is personal to each woman; if unsure, always ask. Some women may prefer ‘person-first’ language (for example, ‘person with autism’) and some may prefer ‘identity-first’ language (for example, ‘autistic person’).

Kenny et al (2016) found that there was preference for ‘autistic’ as opposed to ‘a person with autism’. However, this is not always the case and each person should be taken on a one-to-one basis and asked their preference.

It is also worth noting that current terminology is autism/autistic spectrum, autism spectrum condition (ASC), and neurodiversity. This supersedes previous language, such as Asperger’s Syndrome and autism spectrum disability/disorder, an evolution from the use of ‘deficit-based language’. However, again, each individual will have personal preferences and may prefer these terms due to the common practice at their time of diagnosis.

Challenges autistic women may encounter

Each woman is different and should be allowed to discuss in detail her needs and adaptations during pregnancy, birth and motherhood. However, research shows some issues may be:

Sensory issues

Women may have lots of sensory issues; this can manifest as hyper- and hypo-sensitivity. This presentation can be complex and overwhelming and needs careful discussion with the woman (Samuel et al 2022). For example, an autistic woman may be sensitive to sounds, smells, light, tastes, touch, speech, personal space, pain, eye contact, breathing, clothing, bedding, heat and cold.

Social understanding and interaction

Women may have difficulty understanding small talk; jokes; social norms; facial expressions; tone of voice; taking turns to talk; understanding and following instructions; taking in lots of information at once; making decisions quickly — but also, may need lots of information and time to plan. Women may have difficulty regulating behaviour and emotions; similarly they may not always be able to articulate feelings, desires and needs fully. Also, women may not have full awareness of bodily functions such as a lead up to sensory bodily functions, bowel and bladder function and pain, and postpartum bleeding, for example.

Extreme anxiety

Women may be very anxious in new places and meeting new people; may be anxious about changes in routine and unexpected events; may need lots of information and time to plan decisions and events; may need partners or family members present to feel safe. Childbirth can be extremely overwhelming for these women (Taylor 2014). If things become overwhelming this may result in a ‘shutdown’ or ‘meltdown’; which can be very scary and exhausting. Lots of time, space and privacy will be needed to recover.

Some women may cope by non-attendance and non-compliance with medical care, behaviour driven by a heightened sense of extreme anxiety. Consequently, this can lead to women becoming extremely anxious throughout pregnancy and motherhood with the increased risk of experiencing health inequalities (Samuel et al 2022).

Co-occurring conditions and complex presentation

Clinical presentation can be very complex and may need input from the multi-professional team including: general practitioners (GPs), health visitors, social workers, Early Help teams, school support for existing children, support workers, physiotherapists, speech and language teams, disability nurses, neurologists, gastrointestinal specialists, endocrinologists, psychologists, perinatal teams, midwife leads for mental health, vulnerable women, domestic abuse and substance abuse, psychiatric inpatient units, mother and baby units, domestic abuse advocates, police, probation services, prison services.

One person may need input from all these services therefore it is not only important to build awareness and guidelines for supporting women with autism, but also paramount to create links and a multidisciplinary approach to improving care provision.

Table 1. Risks with higher prevalence for women with autism compared to non-autistic women

Heavy periods
Pre-diabetes/diabetes types 1 and 2
Premenstrual syndrome (PMS)
Polycystic ovary syndrome (PCOS)
Hypertension
Thyroid disorders
Autoimmune disorders
Obesity
Epilepsy
Cancers (especially hormone-related)
Congenital adrenal hyperplasia (CAH)
Cholesterol imbalance
Cardiac arrhythmia

Sources: Ingudomnukul et al 2007, Simantov et al 2022.

Table 2. Increased prevalence of co-occurring conditions

Condition
Learning issues
Dyslexia, dyscalculia, dysgraphia, dyspraxia
Sensory processing issues
Attention deficit hyperactivity disorder (ADHD)
Obsessive compulsive disorder (OCD)
Connective tissue disorders
Ehlers-Danlos syndrome
Hypermobility
Eating disorders/anorexia
Non-binary/gender fluid
Fragile X
Fibromyalgia

Sources: Bush et al 2021, Hampton et al 2021, Warrier & Baron-Cohen 2021, Hampton et al 2022, Samuel et al 2022.

Table 3. Care outcomes for autistic women (increased prevalence)

Outcome
Lower segment caesarean section (LSCS)
Preterm labour and birth
Mental health (post-traumatic stress disorder (PTSD), postnatal depression, anxiety, suicide)
Non-compliance with care/treatment
Social services intervention
Substance abuse
Domestic abuse
Exploitation, physical and sexual abuse

Source: Warrier & Baron-Cohen 2021.

How can midwives help?

How to help using the SPELL framework, as advocated by the National Autistic Society (NAS 2021):

Table 4. SPELL framework

Issues to consider	Plan of care	Care provision in labour
STRUCTURE	Having a predictable routine and environment can help an autistic person feel calm, safe and in control	Continuity of carer Clear path and management of expectations and process Able to do a hospital visit prior to labour to manage expectations
POSITIVE	Be positive, kind and understanding without bias — especially in new situations and challenges	Support the woman's decisions and explain procedures Take her lead Avoid direct language and chose wording carefully
EMPATHY	Use empathy to communicate to reduce anxiety and distress	'Tell me what you need to make it OK' Be accepting of behaviour that may be needed
LOW AROUSAL	Low sensory environment may help reduce anxiety	Low lights, sounds, no small talk
LINKS	Help create and maintain links to a support network — family, friends and professionals	Ensure the woman has support with family and friends May need extra support to adjust to parenthood Ensure clear links and updates are in place with GPs and health visitors prior to discharge

The way forward

Moving forward the challenge is to raise autism awareness, understanding and acceptance in health care settings. This can be addressed by autism training for midwives and student midwives and all health care professionals.

Linking possible care outcomes to care provision is crucial to understand the extra support these vulnerable women need with empathy and compassion. This highlights the need for the development of guidelines and creating Autism Leads to improve care provision. Lastly, more research is needed to help provide more information and evidence-based practice for the future.

Author

Diane Fox (RM). Email: diane.fox4@nhs.net

Diane has been a midwife for 16 years and is currently studying for a Masters in Education. She is autistic and carer for her autistic child. She is a member of NHS Experience and NHS Improvement (NHSE/I) Midlands Autism Expert by Experience Focus Group.

Diane has a specialist interest in promoting understanding and acceptance of autism in midwifery to improve care provision. In 2021 she collaborated with the RCM to develop an i-learn module on autism and pregnancy. In 2022 she presented at the RCM Research and Education Conference.

Please contact Diane if you require any further information or training for your organisation.

RCM i-learn module on Autism and Pregnancy:

<https://www.ilearn.rcm.org.uk>

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Fox D. MIDIRS Midwifery Digest, vol 32, no 3, September 2022, pp 279-282.

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