

Providing sensitive antenatal care for autistic women and birthing people

Summary:

Autistic people face significant disparities in their experiences of healthcare services compared to non-autistic people, with autistic adults reporting lower satisfaction with staff communication, and higher odds of unmet healthcare needs relating to their physical health, mental health, and prescription medications¹. These difficulties are also apparent when accessing perinatal care services. It is essential that we address this ensuring the protected characteristic of disability under the Equality Act (2010) is honoured. In this article, Sophie Rayner, Nicolette Porter and Emilie Edwards discuss how midwives can provide sensitive antenatal care for autistic women and birthing people.

What is autism?

Defining autism

The National Autistic Society defines autism as “a lifelong developmental disability which affects how people communicate and interact with the world”². This definition is broad and the categorisations of ASD are ever-changing. A more inclusive definition would be that autism is a neurodevelopmental **difference** which affects people in many ways, including social skills, sensory processing, and executive functioning. Often autism is described in terms of the person’s perceived functioning, however this notion is largely rejected by autistic communities.

Professional categorisations have also changed: the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) depicted Autistic Disorder alongside other defunct neurodevelopmental disorders, whilst the DSM-V uses the umbrella term of Autism Spectrum Disorders, split into three levels based upon support needs. Previously used terms such as ‘Asperger’s syndrome’ have ceased to be used, although some people may still identify with these diagnoses.

Autism in women

Since its first recognition by Leo Kanner in 1943, autism has often been considered a 'boy's club'. Currently, there is estimated to be at least 2-3 boys diagnosed with autism for every girl³. This is a shifting statistic, as the differences in how autism presents between the sexes are recognised and diagnostic criteria are widened to include women. This has resulted in increasing numbers of women being diagnosed with Autism Spectrum Disorder (ASD), albeit often at an older age⁴ due to their tendency for internalising problems, ability for traditional social skills and the inclination to 'mask' autistic behaviour.

As increasing numbers of women are diagnosed with ASD, we will inevitably see more autistic pregnant women and people entering maternity services. It is key that we learn about autism and adapt our practices to make services accessible to these clients. In this article we will mostly use identity-first language (autistic person), rather than person-first language (person with autism), as this is preferred by most autistic people⁵.

Autism in the perinatal period:

Studies show that autistic people have increased intervention and risk for poorer outcomes in pregnancy including iatrogenic preterm birth, elective caesarean-section, and pre-eclampsia⁶. Further research should be done on the reason for these statistics and best practice to mitigate harm; ensuring a holistic approach is taken.

When learning about ASD as healthcare workers, it is vital to consider common comorbidities that may affect autistic people. Epilepsy affects up to 46% of the autistic population⁷; as the MBRRACE-UK report highlights, people with epilepsy wishing to conceive should receive medication review and counselling, and maternity teams should be aware of risk factors related to epilepsy⁸.

Also commonly comorbid with ASD are mental health disorders; particularly anxiety⁹, depression, obsessive compulsive disorder (OCD)¹⁰, and eating disorders¹¹. It is key for midwives to be aware of mental illness and be able to make the correct referrals. Referral to perinatal mental health teams should be considered for all autistic service users presenting with a history of mental illness. When

screening for mental health conditions, keep in mind that some autistic people suffer with alexithymia (difficulty identifying emotions), and therefore consider other factors such as apathy levels, sleep and eating, alongside self-reported moods¹⁰.

Points for practice:

Article 14 of the European Convention on Human Rights legislates against discrimination and ensures that people are treated with dignity and respect. Reasonable adjustments should be made to guarantee that everyone has access to the same maternity care as per the Equality Act 2010. How can we ensure that autistic women and birthing people feel confident that we will give them reasonable adjustments and adapt to their needs?

Disclosure

Accessibility must extend to disclosure of autism. Many autistic people avoid disclosing their ASD diagnosis to healthcare professionals due to their lack of awareness¹². Many maternity booking questionnaires will ask about mental illness and learning disabilities, but for some, autism doesn't fit into either category. A dedicated question about neurodiversity would benefit this population and those with other neurodevelopmental conditions for example ADHD, dyslexia, and Tourette's syndrome.

Continuity of carer

As research develops, services can begin to adapt to ensure inclusivity for those on the autistic spectrum, however experiences of autistic individuals and current research can dictate recommendations for practice. Fundamentally, the best thing we can do for autistic service users is offer continuity of carer. Ample research shows the benefit of continuity of carer, particularly in improving outcomes seen in autistic mothers such as preterm birth¹³. Autistic people often struggle with change and social communication, so seeing the same midwife will help mitigate some of this stress. This will also allow the named midwife to become aware of the individual triggers, interests and coping strategies of their autistic clients. This is vital in minimising the stress that may be encountered while using perinatal care services.

Communication needs

Top barriers for accessing healthcare for autistic people include communication difficulties with healthcare professionals. Communication barriers could be eased with the use of 'health passports', healthcare education and adaptation of communication methods. Giving rigorous antenatal education on

various potential scenarios can be beneficial, and allowing for detailed birth plans that consider these scenarios. Using different resources such as visual aids, videos and more may help those with different learning needs. Additionally, the importance of advocates for autistic people should be remembered. This person should be included in care planning and allowed free ward visitation during hospital admissions.

Physical and sensory needs

Another barrier for accessing healthcare are physical and sensory difficulties in the healthcare setting¹⁴. Consideration of home visits to avoid sensory processing difficulties, and ensuring accommodations are allowed when hospital cannot be avoided, such as allowing an advocate, quiet side rooms and access to self-soothing items such as noise-cancelling headphones and fidget toys. Routine is important, so anxiety may be minimised with consistent time and venue of appointments, and clear agendas for each contact. Similarly, predictability can prevent distress in autistic people.

It is important to consider that autism is not only a neurocognitive phenomenon, but has important physical and sensorial effects which can lead to overload and subsequently 'meltdowns' or 'shutdowns.' This is particularly important when considering the physiological variations of pregnancy. Nausea or perception of fetal movements may feel particularly intense¹⁵, consequently having a causal effect on bonding and mental health. This is something that maternity professionals can mitigate through education, planning, and informed consent. To allow for the varying learning and additional needs of autistic individuals, a range of resources and learning materials should be used.

Conclusion

If perinatal services fail to adjust to autistic client's needs, this may swiftly become a vulnerable group for disengaging with services.

Whilst there are many ways you can learn about autism and support autistic service users; you don't have to be an autism expert. If you need additional help or advice, there are a plethora of professionals and charities that can offer support; as well as working alongside any professionals the service user may already have contact with.

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