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Streeter, Holly


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University of Plymouth

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Families who experience neurodiversity: understanding and improving their encounters of maternity care

Holly Streeter¹

¹Safeguarding Support Midwife. Royal Cornwall Hospitals NHS Trust, TRURO, TR1 3LJ, UK.
Email: holly.streeter@nhs.net

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Background

Fifteen percent of the population are neurodiverse (ADHD Aware, 2023) Maternity care should be equal and equitable for all (NHS England and Improvement, 2021) and personalised around each pregnant person’s unique circumstances (NHS England, 2016) including those who identify within the neurodiverse community. Maternity services should be continuously improving and desire to promote a positive birth experience that applies to all (Leinweber et al., 2022), including those who identify as neurodiverse. Maternity staff may feel reluctant to provide confident care to autistic women. This could be due to a lack of experience, awareness, or a minimal level of available training (Henry, 2023). Midwives should be supported to provide equitable and accessible maternity care to families who experience neurodiversity.

Review of the evidence

Literature was reviewed from CINAHL, EMBASE, British Nursing Index and the Cochrane Library. Only full text articles, in the English language from the past five years were included. Three different search concepts were used and then repeated for each database. Duplicates were manually removed, titles and abstracts screened for relevance and the remaining full text articles then reviewed. Supplementary searches were also undertaken from relevant associated references and previous knowledge base.

The literature reviewed begins to show an understanding of autistic women’s experiences within the perinatal period. Describing the barriers autistic people may have to accessing appropriate maternity care (Grant, 2022, Hampton et al., 2022.) and that there is a limited understanding of the parenting experiences of autistic people (Dugdale et al., 2021). The evidence base suggests no understanding of the effects of autism and broader neurodiversity amongst the wider family unit when receiving maternity care.

Project plan

This project will adopt the JBI Evidence Implementation Model (Porritt et al., 2020). Stakeholders from maternity services will be identified to support the project for their

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insight and knowledge. A retrospective audit of pregnant people over the last five years, who identify autism or neurodiversity at their pregnancy booking, will be undertaken to inform the scope of change. The service change project will take the form of introducing evidence-based guidance to support maternity staff when caring for the pregnant person and their family. Longer-term evaluation and research of the intervention is planned. This would include formal use of a patient and public involvement group to ensure ongoing relevance and effectiveness in practice (Ocloo and Matthews, 2016).

References


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