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

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Special Edition

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

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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

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

- ADHD Aware (2023) 'What is ADHD? / What is Neurodiversity', Available at: <https://adhdaware.org.uk/what-is-adhd/neurodiversity-and-other-conditions/> (Accessed, 07 February 2023).
- Grant, A. (2022) 'Breaking barriers', *Midwives*, 25, pp. 36–38.
- Dugdale, A., Thompson, A., Leedham, A., Beail, N. and Freeth, M. (2021) 'Intense connection and love: The experiences of autistic mothers', *Autism*, 25(7), pp. 1973–1984. DOI <https://doi.org/10.1177/13623613211005987>
- NHS England and NHS Improvement (2021) 'Equity and equality: Guidance for local maternity systems', Available at: <https://www.england.nhs.uk/wp-content/uploads/2021/09/C0734-equity-and-equality-guidance-for-local-maternity-systems.pdf> (Accessed 18 February 2023).
- Hampton, S., Allison, C., Aydin, E., Baron-Cohen, B. and Holt, R. (2022) 'Autistic mothers' perinatal well-being and parenting styles', *Autism*, 26(7), pp. 1805–1820. DOI: <https://doi.org/10.1177/13623613211065544>
- Henry, K. (2023) 'Providing accessible healthcare for autistic women', *Practising Midwife*, 26(2), pp. 37–41. DOI: <https://doi.org/10.55975/VGTY3495>
- Leinweber, J., Fontein\_Kuipers, Y., Karlsdottir, S.I., Ekstrom-Bergstron, A., Nilsson, C., Stramrood, C. and Thompson, G. (2022) 'Developing a woman-centered, inclusive definition of positive childbirth experiences: A discussion paper', *Birth* [Preprint]. DOI: <https://doi.org/10.1111/birt.12666> .
- NHS England (2016) 'National Maternity Review: Better Births Improving outcomes of maternity services in England A Five Year Forward View for maternity care', Available <https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf> (Accessed 18 February 2023).
- Ocloo, J. and Matthews, R. (2016) 'From tokenism to empowerment: progressing patient and public involvement in healthcare improvement', *BMJ Quality and Safety*, 25(8), pp. 626–32.
- Porritt, K., McArthur, A., Lockwood, C., Munn, Z. (2020) *JBI Handbook for Evidence Implementation*. Available at <https://implementationmanual.jbi.global> (Accessed 18 February 2023).
- Woodman, J., Simon, A., Hauari, H. and Gilbert, R. (2020) 'A scoping review of "think-family" approaches in healthcare settings', *Journal of Public Health (United Kingdom)*, pp. 21–37. DOI <https://doi.org/10.1093/pubmed/fdy210> .



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