

IMPACT CASE STUDY

Understanding and improving maternity care for people with learning disabilities



Introduction

There are more than 1.5 million people with learning disabilities living in the UK. Yet, despite entitlements to good health and social care service, many experience inequalities in provision in relation to maternity services.

Parents with learning disabilities report a poor experience of maternity care and a lack of reasonable adjustments to meet their individual needs. Midwives report they lack the competence and confidence to recognise and respond to the needs of parents with learning disabilities.

Why was this work needed?

The Together Project, led by Dr Anna Cox at the University of Surrey, brought together parents with learning disabilities, researchers and health and care professionals to find out what good maternity care looks like. The study explored the acceptability, use and perceived impact, of the Together Project Resources, within one NHS Trust, and identified the barriers and facilitators to implementing these resources.

It highlighted the value of working with both experts by experience (people with learning disabilities) and experts by experience (e.g. midwives and learning disability nurse) in developing and evaluating resources to support the delivery of good care.

The study made sure that the voices of parents with learning disabilities were invited and heard. Midwives reported that the resources had a positive impact on their skills and confidence in recognising and supporting parents with learning disabilities, enabling them to reflect on how they deliver care to parents with learning disabilities and how they could do things differently in future.

It also demonstrated the value of multi-disciplinary advisory team, which helped to further modify the resources, to make sure they were relevant and meaningful.

The project resources are available to [download from the project website](#).

What impact did this study make?

As a result of this work:

The resources are being used by midwives and other health care professionals working with maternity services to improve their understanding and awareness of the needs of parents with learning disabilities and identify individual needs and support the reasonable adjustments required to ensure equitable care for people with learning disabilities.

Available to download from the project website, the resources have been downloaded over 800 times by health and social care professionals, academics, and those working in the policy/government/charity sector, mainly in the UK, but also around the world including America, Canada and Australia.

The training has been evaluated by 83 midwifery students and seven people with learning disabilities at the University of Surrey, for the past two years, and the University intends to sustain and spread its delivery.



Student-reported learning disability awareness was significantly higher across all domains post training and sustained at follow up.

They also reported the most notable aspect of training was learning with and from people with learning disabilities.

Additional funding to support dissemination and implementation of the Together Project Resources enabled the project team to share (electronic and hard copies) of the resources with the Head of Midwifery in every maternity unit in England. NHS England (NHSE) also provided additional funding to extend the study to three additional sites.

So far, the resources have been shared with all 119 maternity units and 44 local maternity and neonatal systems (LMNS) in England. Sussex LMNS have implemented it into their personalised care and support plan. Surrey Heartlands Integrated Care System have incorporated the resources into their five-year Perinatal Equity Action Plan. Midwives and other health care professionals in maternity services are using these resources to identify and support individual needs to provide equitable care for people with learning disabilities.

The resources were cited in:

- [Supporting the delivery of good maternity care for parents with learning disabilities](#). Midwifery. Cox A, Parsons T, Watkin S, Gallagher A. (2021).
- [A measure to evaluate parenting interventions: Using inclusive research to modify a tool to measure change in parenting self-efficacy during the antenatal period](#). British Journal of Learning Disabilities. Ip, A., Kendall, S., Jabeen, A., Watkin, S., & Cox, A. (2023).
- [Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England](#). Science Direct Cox A, Ip A, Watkin S, Matuska G, Bunford S, Gallagher A, Taylor C (2024).
- [Learning disability awareness training for undergraduate midwifery students: Multi-method evaluation of a co-produced and co-delivered educational intervention in England](#), Nurse Education Today. Cox A., Tobutt D., Harris J., Watkin S., Eynon C., Matuska G. (2024).
- Included the award-winning book '[Having a Baby](#)' (co-authored by the Dr Cox which cites the Together Project Resources), which won the British Medical Association award for patient information.

Media Coverage

- Guides to good maternity care, Community Living, 4 January 2024

Policy

- Presented to the House of Lords in February 2020, by the Head of Policy at the Florence Nightingale Foundation in a presentation about the real gaps in service provision for people with learning disabilities.
- Cited in the Surrey Heartlands Local Maternity System Five-Year Perinatal Action Plan 2022-2027.

Feedback

- 'Currently filling this in with a woman whom this will benefit greatly. We have nothing like this in our Trust.'
- 'I will share these with consultant midwives across the LMNS.'
- 'The video is really useful as a discussion starter and teaching aid.'
- 'This has been used in our team with a couple of families. The families found it really useful.'
- 'Thank you for sharing. Please consider making a "western" version or sharing with the US Department of Health.'