

A feasibility study exploring the acceptability and perceived impact of Together Project resources, co-produced to support the delivery of good maternity care for people with learning disabilities.



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Introduction

People with learning disabilities deserve good care and to be treated with respect. However, they often experience discrimination, disadvantage and disrespect, most particularly, when they embark on the journey to become parents. Evidence reveals that people with learning disabilities who are pregnant, and who become parents, have poor experiences, poor outcomes and are more likely to have their children taken into care than those without learning disabilities. Midwives have reported feeling ill-prepared and unsupported to provide the care parents with learning disabilities need and prefer.

The Together Project, which brought together parents with learning disabilities, researchers and health and social care professionals, aimed to improve support for parents with learning disabilities within maternity services. In phase 1 (funded by Health Education England), a Toolkit was prepared to support professionals, which focused on: identifying need; preparing for parenthood; and supporting the journey to baby and beyond. A Maternity Passport was also developed, to be completed with and held by the parent themselves, to support sensitivity to individual needs and preferences. Phase 1 of the Together Project enabled the team to develop and revise the Toolkit and Maternity Passport, in response to initial feedback from professionals. An article reporting phase 1 can be found at <https://doi.org/10.1016/j.midw.2021.103073>. The following summary report focuses on phase 2 of the Together Project (funded by Health Education England and the National Institute for Health and Care Research), implementing and evaluating the resources in maternity services.

Research questions

1. Is it feasible to implement and evaluate the Together Project resources in maternity services?
2. How do midwives and parents with learning disabilities perceive the Together Project resources to impact on maternity care?

Aim

The aim of phase 2 of the Together Project was to inform the future design and evaluation of the Together Project resources – Toolkit and Maternity Passport – by determining their acceptability and perceived impact within local (South East England) maternity systems.

Objectives

1. To trial recruitment procedures;
2. To determine recruitment rates;
3. To trial data collection procedures;

4. To collect and analyse the views of participating midwives regarding acceptability of the Together Project resources and their impact on the care they deliver to parents with learning disabilities;
5. To collect and analyse the views of parents with learning disabilities regarding acceptability of the Maternity Passport and its impact on experience of maternity care;
6. To invite feedback on the Maternity Passport and its impact on experience of maternity care provision from key stakeholders who come into contact with the Maternity Passport as part of this study (family/informal carers or other health and social care professionals supporting a parent with learning disabilities).

Ethical Considerations

Accessible Participant Information Sheets and consent forms enabled a meaningful informed consent process. The overall conduct of the project was informed by the Together Project values: **Trust**; **Open-mindedness**; **Gentleness**; **Enablement**; **Time**; **Humility**; **Equality**; and **Respect**. This study was reviewed by Camden & Kings Cross Research Ethics Committee (IRAS Project ID: 296218).

Research Design

This was a qualitative feasibility study which involved online interviews and an online survey employing open ended questions.

Setting

Four NHS Trusts across Kent, Surrey, Sussex and Wessex took part in the study. These four Trusts included six hospitals with maternity services, which varied in their use of electronic (BadgerNet or EuroKing) or handheld maternity notes.

Participants

Parents with learning disabilities and midwives were invited to take part in the study from participating NHS Trusts. Midwives were invited to take part in the study if they were over the age of 18; a midwife at a participating trust; and if they thought they may be supporting a parent with learning disabilities. Parents with learning disabilities were invited to participate if they were registered or identified as having learning disabilities/a pregnant person whose partner was registered or identified as having learning disabilities/a partner of a pregnant person who was registered or identified as having learning disabilities; over the age of 18 years; under the care of maternity services within a participating NHS trust; and judged to have the capacity to consent to the study.

Recruitment

A project midwife was funded within each Trust to support recruitment. Midwives contacted the project midwife with details of any parent under their care who they thought may have learning disabilities, the project midwife then contacted the parent to tell them about the Together Project and use respectful questioning to determine if they were eligible. The Project Midwife received training from the Together Project team on how to sensitively ask whether someone has a learning disability. They used their Mental Capacity Act training to judge whether each parent had the capacity to consent to the study. The project midwife then emailed information on the Together Project to the midwife, inviting them to take part. The project midwife at each site kept anonymised recruitment records to inform recruitment rate calculations.

Data collection

Semi-structured interviews with midwives and parents were carried out remotely via Zoom, MS Teams or telephone at the end of the implementation period. The topic guide was informed by the Consolidated Framework for Implementation Research (CFIR) with a particular focus on domain IV (Individuals Domain) which is based on the COM-B model of behaviour change. A link to a brief online survey (using Qualtrics) was included at the back of the Maternity Passport to collect feedback from anyone who came into contact with the Maternity Passport as part of this study (family/informal carers or other health and social care professionals supporting a parent with learning disabilities). Feedback was sought on the content, format, and usefulness of the Maternity Passport.

Data analysis

Qualitative data was analysed using thematic analysis and data was managed on QRS NVivo 12 software. Themes were constructed from the interview data and mapped onto the Consolidated Framework for Implementation Research (CFIR, see <https://cfirguide.org/>). Barriers and facilitators to implementation of the Together Project resources were mapped onto the five domains of the framework: innovation; setting (combining outer and inner domains); individuals; and implementation process. Responses to open ended questions were considered alongside interview data from midwives and parents to inform improvements to the Maternity Passport.

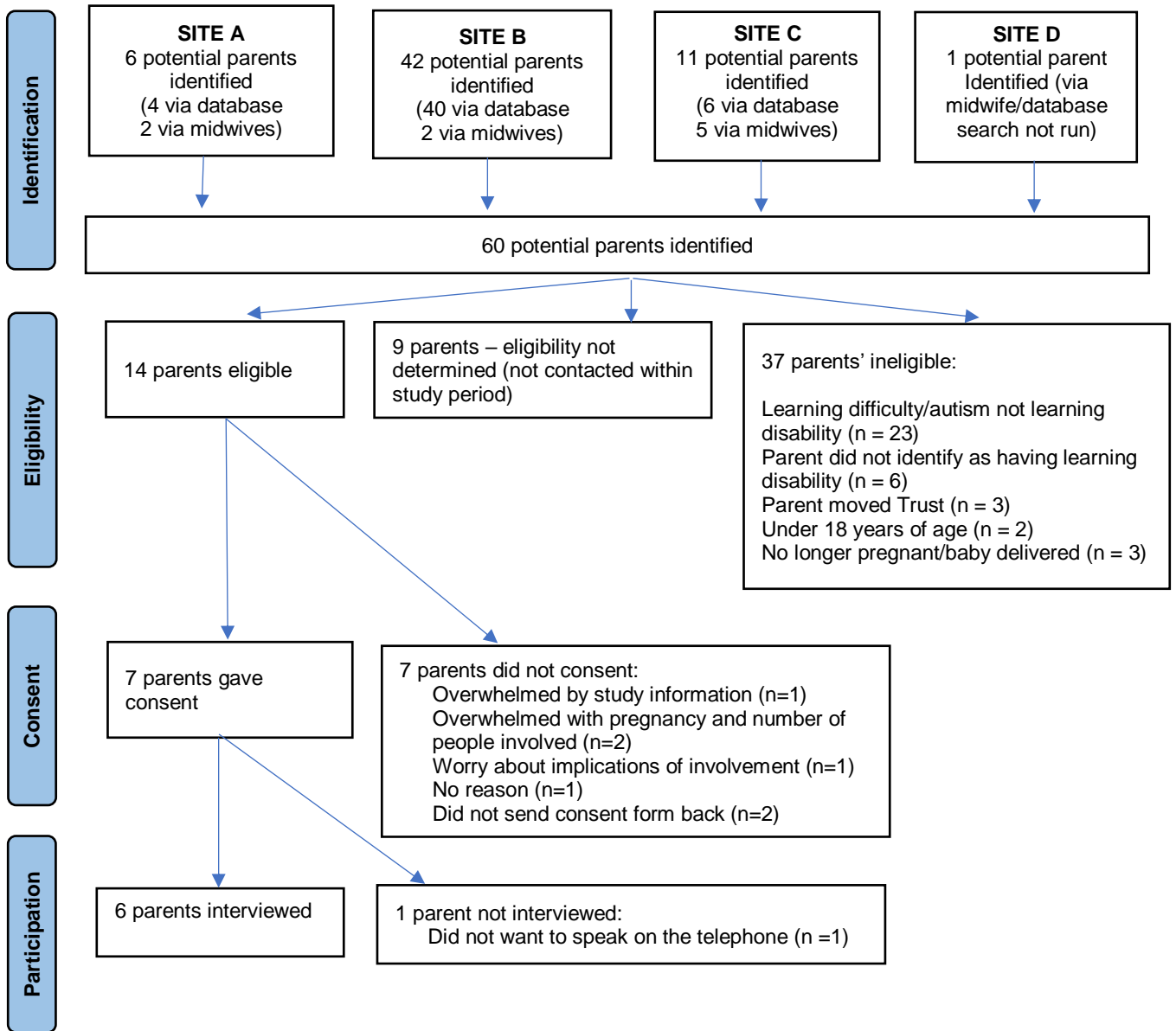
Findings

Interviews were conducted with 6 parents with learning disabilities who experienced maternity care using the Together Project resources at one of three participating NHS Trusts in the South East of England (all white British, female and in their second or third trimester); two of whom took part in a follow-up interview when they reached their third trimester; and 17 interviews were conducted with midwives (seven community, nine specialist and one student midwife) who worked at one of four NHS Trusts in the South East of England. The online survey (employing open ended questions, relating to the Maternity Passport specifically), had five responses from parents with learning disabilities (n=2); family members (n=2); and a social care professional. Findings are presented below within subsections considering feasibility and impact, in line with the research questions for this phase of the Together Project.

Is it feasible to implement and evaluate the Together Project resources in maternity services?

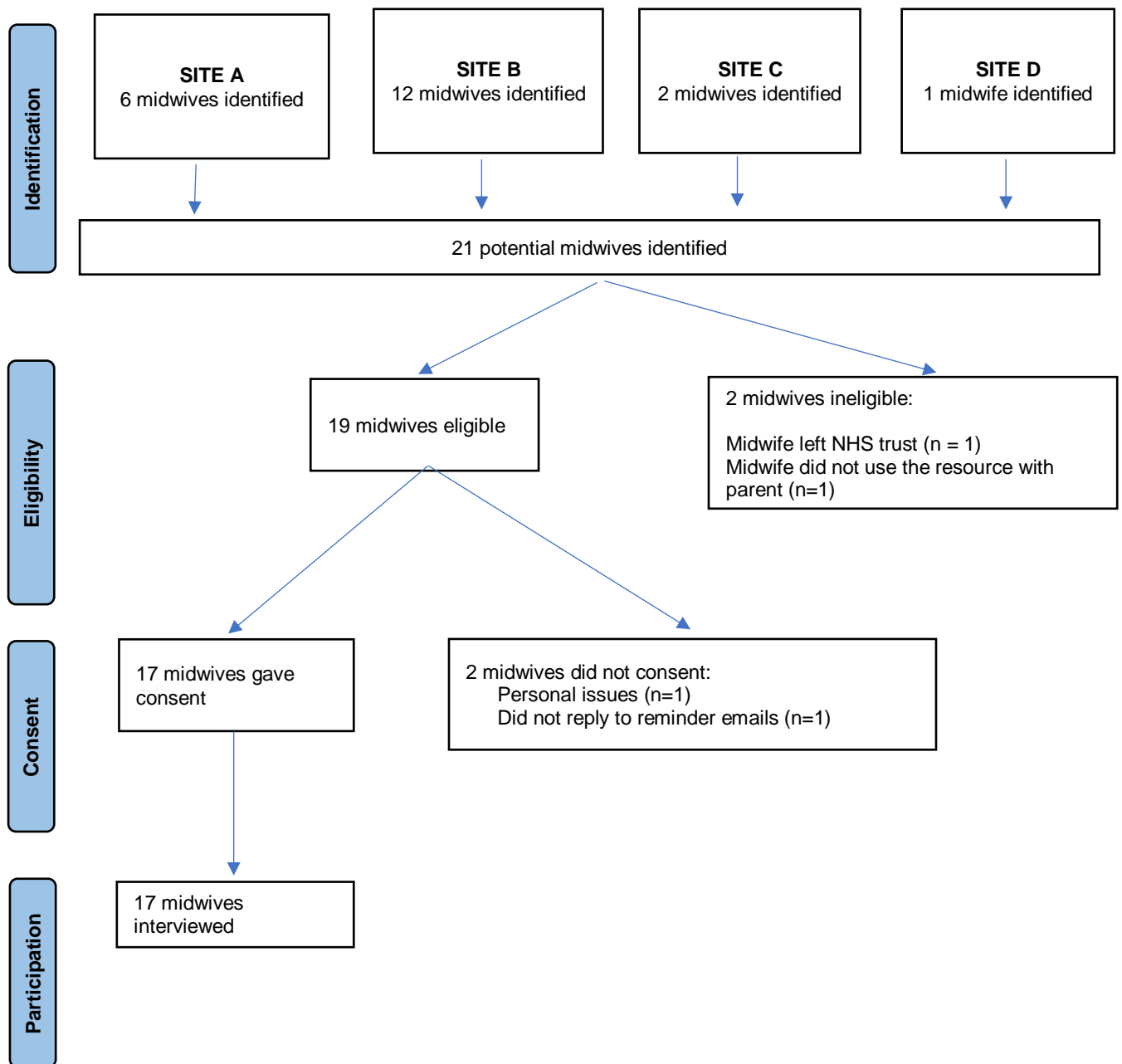
Recruitment rates to phase 2 of the Together Project were recorded to consider the feasibility of implementing and evaluating the resources. Recruitment periods across the four participating NHS Trusts ranged from 22 weeks (Site D) to 34 weeks (site A). During the recruitment period, 9,566 pregnant women were booked in. Of these women and their partners, 60 parents (6.3%) were identified as potentially eligible for the Together Project (50 identified via maternity database and 10 via their midwife). Of the 60 parents identified as potentially eligible, 29 parents (48%) did not identify as having a learning disability, three parents had moved to a different trust, two parents were under 18 years old, and three parents were no longer pregnant. The eligibility of nine parents was not determined within the study period. Of the 14 parents who were confirmed to be eligible, seven parents (50%) gave informed consent, and six parents were interviewed. Reasons for not wanting to take part were provided by five parents, these included feeling overwhelmed by study information (n=1), not wanting to speak on the telephone (n=1), feeling overwhelmed with pregnancy and number of people involved (n=2), and worry about implications of involvement (n=1). Figure 1 presents the recruitment of parents within the four participating NHS trusts and their journey to interview, or not, with reasons.

Figure 1: Recruitment of parents with learning disabilities



A total of 21 midwives self-identified as supporting a parent who may have learning disabilities across the four NHS trusts, and 17 midwives (81%) were interviewed. Reasons why midwives were not eligible or did not consent: moving trust (n=1), not having used the Together Project resources (n=1), no response (n=1), or personal reasons preventing them from taking part (n=1). Figure 2 presents the recruitment of midwives within the four participating NHS trusts and their journey to interview, or not, with reasons.

Figure 2: Recruitment of midwives



How do midwives and parents with learning disabilities perceive the Together Project resources to impact on maternity care?

Themes constructed from the qualitative data are presented within the domains of the CIFR.

Themes mapped onto the *innovation domain* focused on perceptions of the Together Project resources themselves. Parents and midwives felt that the resources were accessible in terms of both content and format, the language used was considered to be ‘nice and simple’ and the paper format of the Maternity Passport was preferable to electronic records. However, they made recommendations for refinements to the design of the resources. Midwives requested that the Together Toolkit was shortened in length and accompanied by specific training, and parents felt that the Maternity Passport should be more colourful and personalised.

The *setting domain* focused on perceptions of barriers to the implementation of the Together Project resources within local maternity and neonatal systems. These barriers included: time pressures within busy clinics (exacerbated by the pandemic), a lack of resources and training to support utilisation of the Together Project resources, a digital system which proved ineffective in supporting identification of people with learning disabilities, and unutilised support from learning disability specialists. However, the use of the Together Project resources was facilitated by the NHS’s commitment to individualised care for everybody, including people with learning disabilities.

Themes mapped onto the *individuals domain* – focused on characteristics of the innovation deliverers (midwives) and innovation recipients (parents-to-be with learning disabilities) – suggested that midwives were motivated to use the resources to improve interprofessional relationships and the care that they provided; and to empower parents and give them a sense of control. However, midwives were demotivated to implement the resources by their perceptions of the capability of parents-to-be with learning disabilities; (mis)conceptions of duplication between the Together Project resources and existing maternity records, and their discomfort discussing learning disabilities. Midwives felt opportunities to engage with maternity passports were missed as parents often forgot to bring it with them; they highlighted the importance of building trust in order to use the resources effectively, due to issues around stigma; and reflected on their need to improve their capability to identify which parents may have a learning disability. Parents reporting feeling motivated to use the Maternity Passport as it helped them to feel organised, but they required a network of support to enable them to engage effectively with the Maternity Passport. Due to often complex lives, parents reported that they kept forgetting to take the Maternity Passport to appointments.

The *implementation process domain* – focused on perceptions of the process of implementing the Together Project resources - highlighted how the project midwives valued the training received as part of their role on the Together Project, they valued time, patience, and advocacy for successful implementation of the Together Project resources. Both midwives and parents recommended broadening the focus of the Maternity Passport to include those who need additional support and not only those who identify or have a diagnosis of learning disabilities.

Overall, recruitment rates and qualitative feedback from interviews with parents with learning disabilities and midwives demonstrated that it is feasible and acceptable to implement Together Project resources (Toolkit and Maternity Passport). Challenges to implementing the resources mainly focused on the local maternity and neonatal systems, highlighting the need for midwives to benefit from the necessary training, resources, maternity databases, and specialist support to facilitate and supplement the use of the Together Project resources. The need for, and implementation of the Together Project resources is supported by NHS commitment to personalised care in maternity services. NHS guidance on Personalised Care and Support Planning, directs Local Maternity Systems to offer every pregnant person in England a Personalised Care and Support Plan, the Together Project aligns with this guidance, providing resources to support midwives in providing accessible and individualised care for parents with learning disabilities.

Recommendations

- Local Maternity Systems should consider the Maternity Passport as an accessible version of a Personalised Care and Support Plan, for those who prefer a paper-based and easy-read document, in line with NHS guidance;
- Local maternity and neonatal systems should offer maternity specific learning disability awareness training which includes the Together Project resources;
- Links between learning disability nurses and midwives need to be forged and supported within NHS Trusts;
- Maternity specific learning disability awareness training should be incorporated within undergraduate training programmes to ensure midwives deliver good maternity care to this population from the start of their practice;
- Digital maternity systems should be reviewed with experts by profession and experts by experience to ensure that systems lead midwives to accurately and respectfully ascertain and record the needs of the parents they support.

Conclusion

Phase 2 of the Together Project was successful in identifying the barriers and facilitators to implementing resources to support person-centred maternity care for parents with learning disabilities. It has highlighted the value of working with both experts by experience (people with learning disabilities) and experts by profession (e.g. midwives and learning disability nurses) in developing and evaluating resources to support the delivery of good care for people with learning disabilities. It has also demonstrated the value of a multi-disciplinary advisory team (including Elfrida Society Parent's Project) which helped to further modify the resources, ensuring the refined innovative resources are relevant and meaningful to the population they intend to benefit. Overall, this second phase of the project supports the acceptability and value of Together Project resources in ensuring the voices of parents with learning disabilities are invited and heard during their journey to baby and beyond. Midwives reported that the Together Project 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 the future.

Next steps

Following on from the findings of phase 2 of the Together Project, we are developing three additional resources to further support improvements in maternity care for people with learning disabilities:

- An educational film based on learning from the Together Project to support midwives in recognising which parents may have a learning disability;
- Co-produced learning disability awareness training for midwifery students, co-delivered to second year students at the University of Surrey and evaluated for impact;
- An accessible outcome measure to evaluate parenting programmes for people with learning disabilities, to ensure that the support delivered to people with learning disabilities when they are expecting a baby, continues to be evaluated and improved. This will be an amended version of the Tool to Measure Parenting Self-Efficacy in the antenatal period (TOPSE- ante-natal, see <https://www.topse.org.uk/site/topse/>).